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Psychosocial issues of siblings of children with autism spectrum disorder

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Abstract

The aim of this systematic review was to identify extend to which the siblings of children with Autism spectrum disorder were facing psychosocial problems. The review also attempts to understand research carried out in this area so far. Methods: Electronic databases were reviewed in order to critically appraise the 14 articles relevant to the topic. Results: The following variables were considered in this review- Coping, adjustment, issues in relationship, quality of life, and behavioural problems. Conclusion: A need was identified for more rigorous empirical research in this area, which incorporates larger samples and uses randomised design studies to test study efficacy appropriately.

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INTRODUCTION

Autism is a group of neurodevelopmental disorders, collectively called autism spectrum disorder (ASD). Autism is characterized by a variety of behavioural deficits such as impaired social interaction, problems with verbal and nonverbal communication, unusual, repetitive, or severely limited activities and interests. The ASD's include Autistic disorder, Asperger's syndrome, childhood disintegrative disorder, and pervasive developmental disorder not otherwise specified (usually referred to as PDD-NOS). Global prevalence of autism and other pervasive developmental disorders was 62/10 000 (Elsabbagh M 2012). Research studies focused on families of children with developmental disabilities have often been designed to consider evidence 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 consequence of having a brother or sister with ASD. These include: Isolation or resentment, loneliness, Confusion, distress or embarrassment at the way in which ASD manifests itself in the affected sibling.

For the past 14 years, disability researchers have begun to recognize the importance of studying non-affected siblings. This is a crucial development, as it is known fact that having a brother or sister with a disability can significantly impact upon siblings. For siblings of children with ASD there can be additional challenges, such as learning to cope or adjust with associated stereotyped and difficult behaviors. Given the often "invisible" nature of the disability, children may also encounter negative reactions to their sibling from the public and peers (Roeyers & Mycke 1995). Most psychosocial research in the domain of developmental disability remains focused on patients and parents, with a particular lack of attention paid to siblings. This lack of focus has been conceptualised as reflecting the siblings 'potentially side lined position in the family during the illness process (Houtzager et al 1999). Not only it is important to increase understanding of how such issues affect well siblings, but it could be considered of equal importance to find out how this understanding translates into practical and therapeutic support for these children. It is hoped that the result and synthesis of the existing studies can be used as a reference or a lead for the future researches in this filed. Objectives of this systematic review are to:

- i) Identify the extent to which psychosocial issues of siblings of Children with autism spectrum disorder have been researched.
- ii) Provide an overview of studies in this area to date, including information about: objectives; settings; methodological characteristics; outcome variables selected and the measures used to assess them

iii) Identify any further research needs in this area.

Method

Data Sources and Search Strategy

In this review psychosocial studies were operationalized as those which reported issues pertaining to the “coping, adjustment, issues in relationship, quality of life, and behavioural problems”. The databases searched were PubMed, EBSCO, Google scholar, PsychNET, Scopus. Searches were conducted regularly between January to September 2014. The decision on which databases for research were chosen was purely based on the areas of psychiatry, psychology, and social sciences. Cross references were also used to obtain relevant literature. The key words for search were brothers, sisters, autism, issues, psycho social problems, coping adjustment, sibling relationship, behaviour problem and quality of life. Articles published from 2000 to 2014 were collected on the basis of objectives and variables of the study.

Study selection (inclusion and exclusion criteria)

All references generated through the search were screened against specified inclusion and exclusion criteria. Sample size was not included as inclusion or exclusion criteria as the paucity of research in this area. Initial decisions regarding the suitability of papers for inclusion were made after reading the titles and abstracts of the articles which was identified using the search strategy mentioned above. These articles were further scrutinised against the criteria and a final decision regarding inclusion was derived. Reference lists were hand -picked for relevant articles and assessed in the same way.

Studies were included in the review if they satisfied the following inclusion criteria:

(1) Articles in English language, (2) typically developing sibling aged 0-18 years of a child diagnosed with autism spectrum disorder (3) both qualitative and quantitative studies dealing with psycho- social aspects of siblings of child with autism spectrum disorder (4) Studies published from January 2000 to August 2014.

Studies were not included if they met any of the following exclusion criteria: (1) published before 2000, (2) unpublished dissertations, thesis, case studies, literature reviews, discussion papers, secondary sources or papers aimed only at developing a measure, (3) studies designed generically for families with no-sibling specific content, (4) Studies which included only adult typically developing siblings.

Search Terms for psychosocial issues

The key words for search were brothers, sisters, sibling, autism spectrum disorders, issues, psycho social problems, coping adjustment, sibling relationship, behaviour problem, quality of life.

Data synthesis

Due to the heterogeneity of included studies in terms of research aims, design, variables, and outcome measures used, a meta-analysis was not appropriate. Data was therefore synthesised from a qualitative perspective.

Details of included and excluded studies

Electronic searches using this strategy produced 2832 results, of which 501 were duplicates. The remaining 2331 titles and abstracts were screened for eligibility, 2305 were excluded for not meeting the inclusion criteria. The remaining 26 full papers were accessed and of these, 8 studies were on psychosocial intervention and 4 studies focused on needs of Siblings of children with autism spectrum disorder, which were further screened for studies on psychosocial issues of typically developing siblings with a brother or sister with autism spectrum disorder. In the final stage, 14 articles were included for this systematic descriptive review.

Results

Fourteen studies met our selection criteria and were reviewed in this study. Finally study variables were grouped into two themes: 1) Quality of life, 2) Sibling relationship, Behavioural, emotional, and social adjustment.

Quality of life: Only two studies were found in the area of sibling’s quality of life. Under this, first study is (Adriana and Claudia 2005) quantitative study to evaluate the Quality of Life (QoL) among siblings of autistic children. In this, researcher compared the quality of life of siblings of autistic children and as a control group, siblings of children with speech disorder. Adriana and Claudia have observed that worst quality of life is among siblings of autistic children. This study has shown that the quality of life was compromised in children by the presence of an autistic sibling and even worse than that of siblings of children with speech disorders. Second study by Moyson and Roeyers (2011) is a qualitative study to investigate how siblings of children with autism spectrum disorder describe and define their quality of life. Nine domains of quality of life of siblings emerged from this study, They are, Forbearance: The typical symptoms like bizarre, aggressive, or annoying behaviour of a brother or sister with ASD can be hard to bear. Mutual understanding: it was important that if the child with ASD were able to speak, so they could talk with each other and understand. Joint activities: siblings were happy to do things with their brother or sister with ASD. Private time: normal siblings indicated their need for "private time" to do things without their

brothers and to do things one-on-one with their parents and having a place of their own at home. Trust in well-being: g. Sibling well-being is dependent on the well-being of the child with ASD. Normal siblings were strongly concerned about the welfare of their brothers or sisters with ASD. Acceptance: normal sibling's acceptance has mainly three stages; in the first stage siblings will just listen the message, in the second stage they go along with it, and in the third stage siblings resign themselves to their special situation and even begin to consider it as "normal". Exchanging experiences: It is important for siblings of children with ASD to meet others with the same experience to share and listen to others stories. Social support: most of the participants indicated the need for support especially from parents and non-partial treatment for all children. Last theme is dealing with the outside world: the invisibility of ASD, for the outside world (i.e., friends, neighbours) often does not know (or is not allowed to know) that the child has ASD. Participants in this study appreciated the fact that the outside world was not always aware of their family situation. Moyson and Roeyers found that siblings of children with ASD can define their quality of life, the unique characteristics of ASD give the siblings' experience a highly personal interpretation, and that the Sibling quality of life concept can be used to support siblings of children with ASD.

Behavioral, emotional, and social adjustment :The review found 12 studies on sibling relationship, Behavioral, emotional, and social adjustment of the siblings of children with Autism Spectrum Disorder (ASD).The current review found that the most common difficulties experienced by siblings of children with ASD in the dyad are related to aggressive behaviors and syndrome-specific behaviors. Review indicated that siblings of children with ASD are at an increased risk of developing internalizing behavior problems.

First study by Ross & Cuskelly(2006), mainly focused on to find out commonly experienced stressors by the siblings of children with ASD, different coping Strategies used by siblings of children with ASD children to deal with these stressors and their knowledge about their sibling's illness. Study concluded that Siblings of children with ASD are at increased risk of developing internalising behaviour problems. Aggressive behaviour was the most commonly reported interaction problem and anger was the usual response. The most common coping strategies used in response to aggression were emotional regulation and wishful thinking. Neither coping strategies, nor knowledge of ASD were associated with adjustment.

Second study from Pilowsky et al (2004) has examined social and emotional adjustment of siblings of children with autism. This study found that siblings of children with autism are for the most part surprisingly well adjusted compared to siblings of children with autism. These findings are still in dilemma due to the low number of the siblings of individuals with ASD that fell into the clinical diagnostic range on a number of behavioural adjustment measures.

Third study by Hastings (2007), this study, compared adjustment for the siblings of children with autism, Down syndrome, and mental retardation was assessed. Study showed that the sibling adjustment did not appear to be related to the behaviour problems of the children with developmental disabilities over time and there were no significant differences in the behavioural adjustment of siblings of children with disabilities across three different etiology groups: autism, Down syndrome, and mixed etiology mental retardation.

Fourth study (Tomney et al 2012) was focused on to find out the possible relation between externalizing behaviours and internalizing symptoms in children with an ASD and externalizing, internalizing symptoms and social problems in their typically developing siblings. Study concluded that typically developing sibling of children with ASD may not be at any greater risk of maladjustment when it compared with typically developing sibling and it is highly related to parental distress.

In the fifth study Kaminsky and Dewey (2002) compared psychosocial adjustment of siblings of children with ASD, Down syndrome and Typically Developing sibling groups. They reported that low levels of loneliness, high level of social support and adjustment in siblings of children with ASD.

Sixth study, (Quintero and McIntyre 2010) investigated siblings, - social, behavioral, academic and maternal well-being in families with and without autism spectrum disorder (ASD). Quintero and McIntyre found there were no significant differences in older siblings' - social, behavioral, and academic adjustment in families with or without a child with ASD and Sibling behavioral adjustment was, significantly related to maternal well-being. Mothers of children with autism report are more daily hassles, life stress, and depression than mothers without a child with ASD.

Seventh study, (Benson& Karlof 2008) examined the social, emotional, and behavioural adjustment of siblings living with a brother or sister with autism to partially control genetic vulnerability factors which faced by siblings of children with autism. Benson& Karlof clearly distinguished between siblings who have a pre-existing clinical diagnosis from those who do not. Findings suggest that siblings of children with autism without a diagnosed disability or disorder are not at increased risk for psychosocial difficulties compared to children in the general population. Psychosocial wellbeing of a sibling can be impacted if they are affected with any behavioural problems which are added by a poor quality of family environment.

Eighth study, (Rao & Beidel 2009) investigated the impact of children with high-functioning autism (HFa) on parental stress, sibling adjustment, and family functioning. Rao & Beidel concluded that families with children with autism has increased levels of stress, impaired or restricted family functioning and reported higher level of internalizing problem behaviours among their siblings of children with autism.

Ninth study, (Gialloetal 2011) reported significantly more emotional and behavioural problems in siblings of ASD than a normative sample, the majority of siblings reported overall good mental health within the normal range on all SDQ subscales. Small portion of siblings with ASD are at risk or in the clinical range for hyperactivity-inattention, conduct, peer problems, emotional symptoms and prosocial behaviour. Socio-demographic and disability characteristics were not associated with mental health difficulties.

Tenth study by Macks and Reeve (2007) compared the psychosocial and emotional adjustment of siblings of children with autism and siblings of non-disabled children. Compared to the siblings of non-disabled children, the results indicated that siblings of children with autism appeared to have a more positive self-concept like positive view of overall personal characteristics, their behaviour, intelligence, scholastic performance, and anxiety. Demographic characteristics (socioeconomic status, birth order, and gender) are more likely to impact a sibling of a child with autism than a sibling of a non-disabled child.

Eleventh study, (Hastings 2003) investigated behavioural adjustment of siblings of children with autism. This study shows that siblings of children with autism having poorer adjustment compared to a normative sample. The maternal stress and behavioural problems of the child with autism did not add significantly to the prediction of sibling adjustment.

Last study, (Kaminsky and Dewey 2001) assessed sibling relationships of children with autism compared to children with Down syndrome and siblings of normally developing children. When both the groups were compared, Kaminsky and Dewey found that siblings of children with autism reported less intimacy and less nurturance by referring their sibling with autism. Sibling relationships also differentiated siblings of children with Down syndrome from siblings of children with autism and siblings of normally developing children. Siblings of children with Down syndrome tend to be more prosocial towards their sibling than siblings of normally developing children and siblings of children with autism.

Discussion

The present systematic review aimed to identify the extent to which psychosocial issues of siblings of Children with autism spectrum disorder have been researched. Current study focused on Quality of life, Sibling relationship, Behavioural, emotional, and social adjustment of siblings of children with autism. Current review results are matching to the findings of previous reviews (Meadan (2010); Beyer (2009); Green (2013) that growing up with sibling with autism can have both positive and negative effect on typically developing sibling. Our review included both qualitative and quantitative data where in the qualitative data (Rao & Beidel (2009); Moyson & Roeyers (2011) looked up on sibling's experience, stressors, their adjustment and coping patterns. On the other hand, quantitative data aimed to compare psychosocial adjustment of siblings of children with autism to other groups of disability and typically developing siblings (Adriana and Claudia (2005), Pilowsky et al (2004); Hastings (2006); Tomeny et al (2011); Kaminsky and Dewey (2002); Giallo et al (2011). All the above studies provided mixed results like having a brother or sister with autism is neither a risk nor protective factor for maladjustment among typically developing siblings.

Age range of siblings of children involved in this review is 3 years to 18 years. Most of the participants were from a wide range of age like from childhood to adolescent (Pilowsky et al (2004); Hastings (2006); Tomeny et al (2011); Kaminsky and Dewey (2002); Macks and Reeve (2007); Hastings (2003) and it leads to confounding findings. Sibling's role, understanding and expectations about other family members will be different in each life cycle. Hence, including children and adolescents in same study for assessing different variables like adjustment and coping will not provide the actual findings. Sibling relationship is one of the very important aspects in every body's life. In each life stage siblings play important role. However, siblings of children with autism in childhood may not understand behaviour of their siblings because of invisible nature of autism which will in turn affect their relationship. The siblings in their adolescent stage may encounter social embarrassments due to their understanding about the illness and friendship. It is therefore important to study both group independently.

There is only one quantitative study (Adriana and Claudia 2005) which looks up on the quality of life of sibling of children with autism. Participants were pre-adolescent age group. In this study physical and psychological dependence were considered as the most important factors to assess the quality of life in childhood. Similar to the findings of psychosocial adjustment studies, (Bensona, & Karlof (2008); Giallo et al (2011) this study also bring out that quality of life of sibling of children with autism impaired. Moyson and Roeyers (2011) qualitatively investigated how

siblings of children with autism spectrum disorder describe and define their quality of life. Moyson and Roeyers reported that siblings of children with ASD can define their quality of life. This finding is not supporting the result of previous study (Adriana and Claudia 2005), mainly because of other socio demographic variables associated with the same.

Majority of studies focused on other psychosocial variables as siblings coping, adjustment, and issues in sibling relationship, and behavioural problems showing a tendency that siblings of children with autism has poor adjustment and high level of internalizing problems (Ross and Cuskelly(2006); Benson & Karlof (2008); Rao & Beidel (2009) Giallo et al (2011) Hastings (2003) Kaminsky and Dewey (2001). At the same time some other studies (Macks and Reeve (2007); Kaminsky and Dewey (2002); Tomeny et al (2011); Pilowsky et al (2004) reported that having a sibling with an ASD is neither a risk nor protective factor for maladjustment in typically-developing siblings. Another interesting finding is that the presence of a child with autism appears to enhance the psychosocial and emotional development of non-disabled siblings when demographic risk factors are limited (Macks and Reeve 2007). The above all findings are leading to the fact that invisibility nature of autism contributes many stress and other issues to siblings. Inconsistency in results in this review is throwing the light to the need for future studies with controlled confounding socio demographic variables.

Conclusion

According to family system theory each family member plays an important role in every family system. Siblings are important aspect of the family system were each one will have an effect on other's growth and development. The take-home message of this systematic review is that siblings of children with autism are undergoing some amount of psychosocial issues with regards to their sibling's invisible nature of illness. Most of the studies which are reviewed in this article were having many methodological limitations like a small sample size, multiple diagnoses, wide age range etc. All these shortcomings are pointing towards to the difficulty of generalizing the findings and the importance of future research in this area with the control of confounding variables. Findings quoted in this review reflect the fact that no two families or situations are exactly the same. Factors such as the severity of ASD in the affected child, availability of social support, socio-economic status, degree of family cohesion, parental well-being, and individual character traits are all likely to play a role in determining outcomes for the typical children of families affected by ASD. A need was identified for more rigorous empirical research in this area which incorporates larger samples and uses randomised control design studies to test intervention efficacy appropriately.

Conflict of Interests

There are no conflicts of interest. All three authors are responsible for the writing and content of this paper.

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