

# Impact of Autism Spectrum Disorder on Family

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## ABSTRACT

**Background:** Autism is a complex syndrome which consists of a set of developmental and behavioral features. Children with autism face different challenges in family and as well as society.

**Aim:** The aim of this study was to find out the impact of autism impact on family. Method: A narrative review was done to conduct this study.

**Findings:** Autism has a persistent impact on the family, economic status, sibling and considerably modifies the lifestyle of each member of the family.

**Conclusion:** This study strongly found that whole family members are affected by the condition of children with Autism.

**Keywords:** Autism; Maternal impact; Impact on father; Sibling impact; Impact on financial status

## BACKGROUND

Autism spectrum disorders (ASD) is a gathering of neurological disorders with severe developmental disability that create problems with thinking, feeling, language and interaction with others. This is a lifelong developmental disability that limit social, educational, occupational and other important demands in every stage of life. Now a days ASD is becoming more prevalent in society and it affects more in males than females. Overall ASD prevalence estimates varied from 5.7 to 21.9 per 1,000 children aged 8 years in United States [1].

The World Health Organization estimated that 0.76% of the world's children had ASD in 2010 but there is lack of evidence in low- and middle-income countries [2]. The Autistic children's welfare foundation estimated that there are approximately 3,00,000 children are affected by ASD in Bangladesh and boys one in every 94 and for girl one in 150 affected by autism in Bangladesh [3].

The literature did not find any specific neuropathologic feature which has yet been documented. The neuroimaging findings suggested in case of children with autism an increased brain volume is predominately a function of increased white matter volume [4].

Diagnosis of Autism is very difficult because there is no definite medical test. In this circumstance the professional chooses the

assessments and diagnostic tools. The American Psychiatric Association released the fifth edition of its Diagnostic and Statistical Manual of Mental Disorders (DSM-5) in 2013. It is now the standard reference that healthcare providers use to diagnose mental and behavioral conditions, including autism. The ICD-10 is the most commonly-used diagnostic manual in the UK. The DSM and ICD-10 criteria both create the foundation for diagnostic tool of Autism. Screening for ASD, the Centers for the Disease Control and Prevention (CDC) set up a visit at the age of 18 months and 24 months towards professionals [5].

The risk of Autism is associated with several factors. Systematic reviews and meta-analyses suggested more than 20 individual, familial, pre-, peri- and neonatal factors are meeting evidence for ASD risk [6-9].

The parental ages are one of responsible risk factor for developing ASD. Older aged mother and also father are responsible for having children with this disorder [10]. ASD is associated with first born baby. A study stated that firstborn children had a higher increased risk of autism [11]. Research suggested that ASD may be caused by genetic and or environmental factors [12]. The authors detailed that accurate cause of autism is still unknown but there is a significant association between vaccines and autism spectrum disorder [13]. Another study found that no relationship between vaccines and

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ASD [14]. Some of parents with autism believed that autism is caused by both of biological and environmental factors [15].

Children with ASD show elevated levels of behaviour problems than children with other developmental disorders [16]. ASD can visible in a variety of symptoms in childhood, youth and adolescent. The features are including atypical eye contact, hyperactivity, repetitive body motions such as rocking or hand flapping. The symptoms of ASD can vary from mild to severe and especially found repetitive and stereotyped behaviors [17].

Having a child with Autism the impact on various aspects of family lives are affected including housekeeping, finances, emotional and mental health of parents, marital relationships, physical health of family members, limiting the response to the needs of other children within the family, poor sibling relationships, relationships with extended family, friends and neighbors and in recreation and leisure activities [18]. A study shows that Children with autism face a variety of challenge that can significantly negatively impact on parent and family functioning [19]. Also, it can create significant stress throughout all family members. Thus, social and communication deficits effect on total family members. Emotionally and financially the families of autistic children become exhausted. ASD can evidently have a potential impact on the child and the functioning of whole family [20]. In a research it is found that parents of children with ASD have more divorce rate than parents who do not have a child with a developmental disability [21].

Children with autism are identified as problems on mothers' anxiety and depression [22]. The relationship between stress and behavior problems of children with Autism are appears to be reciprocally related such that elevated child behavioral problems lead to increases in parental stress. Parenting stress is not only an increase in behavior problems it also has an adverse effect on the outcomes of behavioral interventions [23]. There are some important factors which are associated with parental stress in children with autism, including feelings of loss of personal control, absence of spousal support, informal and professional support. Adjustments to the reality of the child's condition, housing and finance are some of the other factors that influence parental stress [24].

In Bangladesh there is limited existing study on this topic which represents a picture of current condition. In these circumstances a study is needed for understanding about ASD impact on family. It is hoped that this study may explore the experiences of family on Autism in order to better understand how to approach service delivery, to empower families, to provide educational support and also may help for professionals. The aim of the study was to find out the impact of Autism on family.

## METHODOLOGY

### Study Design

A narrative review was done to conduct this study.

### Selection Criteria

The selection criteria were:

- 1) The studies considered only children with ASD;
- 2) On the date from 1990 to February 2017;
- 3) Consider only children not adult and exclusion criteria was other neurological disorders.

## DISCUSSION

The aim of this study was to find out the impact of Autism in family. The impact affects not only on parents but also on siblings and interpersonal interaction between family members [25]. It is indicated that families are experienced in both positive and negative impact of having a child with Autism [26].

### AUTISM IMPACT ON PARENT

Parenting stress is the experience of distress or discomfort that results from demands associated with the role of parenting [27].

Parental stress is an important predictor for intervention outcomes in children with ASD like lower levels of developmental improvement in behavioural interventions, including decreased development of language, communication and other adaptive behaviours [28].

A systematic review of 10 studies it was indicated that ASD can strongly influence on family dynamics, resulting in caregiver overload, especially in mothers [29]. In another study it is resulted that high levels of distress have been found in up to 70% of mothers and 40% of fathers of severely disabled children [30]. A study indicated that other family member of children with autism also faces depression [31]. It was also investigated that having a child with an ASD also can affect other areas of family functioning [32].

### MATERNAL STRESS

Stress is a natural practice and is related to parenting. This stress also associated with household tasks of caring for a child and it is related to ASD and other developmental disorder [33]. Stigma also plays an important role for mother's depression [34]. It has been showed that though mothers are involved in care of their child all the time so they are facing more challenges than fathers [35]. In another study concluded that reducing difficult behavior in children with ASD may improve the relationship between parent and child [36].

A study was conducted on parental stress in families of children with autism and other developmental disabilities. This was a cross-sectional study. 50 families of children with autism and 50 families of children with other developmental disabilities were selected for this study. Different type of outcome measures used like; Parenting Stress Index Short Form, Gastrointestinal Questionnaire, Child Sleep Habits Questionnaire. Parental stress was significantly higher for the autism group and for non-Hispanic and US mothers [37]. There was link between mother's loneliness, social support and depressive symptoms in children with autism [38]. A study indicated that the risk of maternal depression increases with the degree of impairment of autism [39]. In another study the authors found that mothers of autistic children had difficulty in pursuing their professional careers due to excessive time demand for caring the child [40].

The level of stress of mothers in children with autism was considered. This study proved that higher rates of depression were reported by mothers of the teenage girls [41]. Another review of studies found parents of a child with ASD had decreased parenting efficacy, increased parenting stress, and an increase in mental and physical health problems compared with parents' children with other developmental disorders in high income countries [42]. Another study recorded that there are no differences in the level of stress, coping mechanisms and the level of support comparing

parents of children with ASD [43]. Parent especially mother is getting embarrassed who do not understand the condition of autism and its symptoms. Mother of children with autism faces loss of the relationships between family members due to the time consuming, task of caring for their child family and friends [44].

One study found that parents of children with autism had higher levels of maternal depression and lower social support than parents of children without autism because the mother of children with autism are more time engaged in child caring and maintaining the household and no time for leisure activity [45,46]. One study reported that if Autism child is improved in adaptive functioning ultimately increased maternal wellbeing [47]. But another study showed that no association between parental stress and adaptive skills [48].

## THE STRESS OF FATHER

The fathers of children with autism are suppressing their feelings most of the time at the cost of anger [49]. One study confirmed that any child disabilities have a greater impact upon the mother than the father [50]. The association between gender and stress levels was examined. This study revealed that mothers reported higher stress levels than fathers [51]. Another study has found similar result [52]. In addition, it is parents of children with ASD have significantly higher divorce rates than families of children without disabilities [21]. In a study it is indicated that due to having children with autism stressful life events are very common like divorce, separation, moving home, the death of a family member, economic, job, or legal problems that decreases family functioning [53].

## SIBLING IMPACT

The literature investigated that the impact of children with ASD on siblings is mixed [54]. Some studies found positive and some of related studies indicated negative impact in children with autism. Another study also indicated mixed (positive and negative) results [55].

The most of brothers and sisters of children with ASDs interfered in total life cycle like vocational, marital, and family planning [56]. Another study confirmed that siblings are reporting the negative impact of having a brother/sister with autism is feelings of embarrassment or shame. In this it is also reported that in siblings ages 8-15, 84% reported aggression produced by their brother/sister with autism when they are trying to interact with them during playing [54].

The siblings of persons with autism have greater genetic vulnerability for cognitive, social, linguistic and learning difficulties than the general population [57]. Having a brother or sister with an ASD does alter normative life cycle events. It has been reported that the siblings of children with autism have high levels of loneliness and problems with peers [56]. A study found loneliness to be related to a lack of social support from friends [58]. But one study found that no adverse effects of having a sibling with autism [59]. Siblings of children with ASD are facing at an increased risk of adjustment problems [60].

## FINANCIAL IMPACT

The impact of children with Autism affect negatively on the family's life style and their socioeconomic status [61]. In a study it showed that childhood autism is associated with a large loss of annual household income and another study also confirmed that

caring for children with ASD is a costly matter [62,63]. In case of autism child weekly out of pocket costs approximately to \$120 that was directly related to the education and care of their child with autism and finally impact on economic status of family [64]. The low-income caregivers suffer an uneven burden because of monthly out of pocket expenses [65]. It showed that the economic burden associated with ASD [66].

A study showed that Families of children with ASD face significant economic burden. In this study also revealed that mothers of children with ASD earn an average of 35 % (\$7189) less than the mothers of children with another health limitation and 56% (\$14 755) less than the mothers of children with no health limitation [67]. A study showed that there were associated with decreased odds of living in a higher income household. Childhood autism is linked with a large loss of annual household income. Parents of 11 684 children enrolled in this study by a national survey. There were 131 children with ASD and 2775 children with other disabilities [62].

## SOCIAL IMPACT

Autism is interfering in interpersonal relationships. The symptoms of autism consist of communication, socialization, behavioural and interest impairments, as well as minimal social skills [68]. The families of children with autism and their families are facing various types of challenges. The challenge starts early and it lasts a lifetime. It is associated with other problems such as personal, professional, marital, and financial. These problems occur across a wider social context. Autism is not only effect on parents but also the entire family is involved including; the marital system, the parental system, the sibling system, and the extended family system [69]. It is due to parents not sending their child out into any family program, the community to play or for social participation [70].

Students with ASD their functioning in a school environment can be complicated through their limited understanding of social situations [71]. Children with autism usually have rigid and limited play patterns are unable to share their desires and capacities for play, make a friendship, and develop a peer-group [72].

To reduce parental stress and other impact on family and functioning interventions for children with autism is needed. Different type of supports like respite care, parent training by professionals, treatment and self-help groups can contribute to positive impact on the family. In 2001 a meta-analysis was done on the impact of respite care for children with developmental delay concluded that ensuring respite care is helpful for reduction in parental stress and an increase in coping abilities but no study has not been yet shown that respite care is appropriate for children with ASD [73]. Appropriate teacher training is an indicator for effective behaviour management in students with ASD [74]. Social work professionals may focus on client strengths which prevents the social work professional from judging or blaming the client. Thus, help to clients become more aware of their successes and strengths. Social work professionals are also able to identify family influences on the individual client [75].

In this review there are some limitations. Firstly, in this study it was considered various impact of autism on family. If select specific impact of autism on family it will be more emphasized. Secondly, in this review limited evidence is evaluated in which they are not so strong in their hierarchy. Thirdly, studies are selected randomly and after 2010 it is found limited research evidence on this issue. So future studies are required in this field.

## CONCLUSION

Autism is a complex disorder that has wide range of symptoms. It is seemed that from various studies families with children face various type of challenges. Among them maternal stress is one of them. The Parental stress of having mother of autism child is very important because it is interfering in the quality of life of the entire family. The results of this study found about family impact in children with ASD is emphasized Addressing familial support, marital relationships and participating in social activities may reduce the impact that is affected by all family members. Positive and supportive social support may beneficial for the reductions in stress for parents of children with autism spectrum disorder. Enhancing flexibility among other family members of children with autism may be beneficial for both the parents especially mother and the children.

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