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**THE IMPACT OF AUTISM ON FAMILY WITH AUTISTIC
CHILD**¹Dr Zeeshan Aslam, ²Dr Faisal Rasheed¹Nishtar Medical University, Multan, Pakistan.²Medical Officer, DHQ Hospital Jauharabad, Khushab, Pakistan.**Article Received:** May 2021**Accepted:** May 2021**Published:** June 2021**Abstract:**

Autism spectrum disorders (ASD) refers to a group of neurological disorders associated with a severe developmental disability and cause difficulties with communicating, thinking, and interacting with others. As a result, this condition results in difficulties meeting social, educational, occupational, and other important demands throughout one's entire life. Males are disproportionately affected by autism spectrum disorder (ASD), which is becoming more prevalent today. Estimates of ASD prevalence in the US ranged from 5.7 to 21.9 per 1,000 children aged eight years, according to the source. Autism is a very complicated disorder. A wide range of studies indicate that families with children face various challenges. It is one of these problems. Stress that parents endure because of an autistic child influences the family's well-being as a whole. The findings from this study showed that family involvement in the lives of children with ASD cannot be overemphasised. An easy way to help everyone in the family is to improve familial support, marriages, and social involvement. Parents of children with autism spectrum disorder may discover that they benefit from receiving supportive and positive social support. Increasing the adaptability of family members who are related to autistic children may benefit both parents, particularly the mother.

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BACKGROUND:

Autism spectrum disorders (ASD) are a term that refers to a group of neurological disorders that are associated with a severe developmental disability and cause difficulties with thinking, feeling, communicating, and interacting with other people. As a result, an individual who has this condition will have difficulty meeting social, educational, occupational, and other important demands throughout his or her entire life. Males are disproportionately affected by autism spectrum disorder (ASD), which is becoming more prevalent today. ASD prevalence estimates in the United States ranged from 5.7 to 21.9 per 1,000 children aged eight years, depending on the source.

According to the World Health Organization, 0.76 percent of the world's children were diagnosed with an autism spectrum disorder in 2010, but there is a paucity of evidence in low- and middle-income countries to support this figure. For example, ASD affects approximately 3,000,000 children in Bangladesh, according to the Autistic Children's Welfare Foundation, with boys accounting for one in every 94 cases and girls accounting for one in every 150 cases.

No specific neuropathologic feature has been identified in the literature to distinguish this disease from others like it. However, according to the findings of neuroimaging studies, increased brain volume in children with autism is primarily due to increased white matter volume in the brain.

Because there is no conclusive medical test for autism, making a definitive diagnosis is extremely difficult. Typically, the professional determine which assessments and diagnostic tools will be used in this situation. DSM-5, or the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition, was published by the American Psychiatric Association in 2013 and is the most recent edition. It is now the gold standard for healthcare providers to diagnose mental and behavioral disorders, including autism spectrum disorders. In the United Kingdom, the International Classification of Diseases, Tenth Revision (ICD-10) is the most frequently used diagnostic manual. It is hoped that by using the DSM and ICD-10 criteria, we will develop diagnostic tools for autism. To screen for autism spectrum disorder (ASD), the Centers for Disease Control and Prevention (CDC) recommended that children between the ages of 18 and 24 months visit a professional.

A large number of risk factors for autism have been discovered. According to the findings of numerous systematic reviews and meta-analyses, there are over

20 individuals, familial, prenatal, perinatal, and neonatal risk factors for ASD.

One of the risk factors for developing autism spectrum disorder is the age of the parents. It is believed that both mothers and fathers over the age of 50 are responsible for the birth of children with this condition. The birth of a first child is associated with the development of ASD. According to one study, children born first had a higher risk of developing autism than other children. According to research, autism spectrum disorder (ASD) may be caused by genetic and environmental factors. However, while the precise cause of autism is still unknown, the authors assert that vaccines are strongly associated with an autism spectrum disorder. Another study found no evidence of a connection between vaccines and autism. Parents of children with autism believe that the disorder is caused by both biological and environmental factors, which they believe are intertwined.

Compared to other developmental disorders, children with autism spectrum disorder (ASD) have more behavioral difficulties. Autism spectrum disorder (ASD) can manifest itself in various ways during childhood, adolescence, and the early stages of adulthood. However, the following characteristics are atypical eye contact, hyperactivity, and repetitive body movements such as rocking or hand flapping. Autism spectrum disorder (ASD) symptoms can range from mild to severe, and they are most commonly associated with repetitive and stereotyped behaviors. Housekeeping, finances, parents' emotional and mental health, marital relationships, and the physical health of family members are all negatively impacted by having an autistic child. Other negative effects include poor sibling relationships, relationships with extended family, friends, neighbors, and participation in recreational and leisure activities negatively impacted by having an autistic child. According to a study, children with autism experience a wide range of difficulties that can harm the functioning of their parents and families. Additionally, it has the potential to cause significant stress for all members of the family. A family's social and communication deficits as a result of this affect the entire group. Families with autistic children become emotionally and financially drained as a result of their condition. Autism spectrum disorder (ASD) can impact both the child and the family's functioning. Researchers have discovered that compared to parents of children without developmental disabilities, the divorce rate for parents of children with ASD is higher.

The anxiety and depression that mothers experience when their children have autism are well documented. In children with Autism Spectrum Disorder, stress and behavioral problems appear to be mutually reinforcing because increased child behavioral problems result in increased parental stress. Behavioral problems are exacerbated when parents are stressed, and the outcomes of behavioral interventions are negatively affected as a result, according to a new study. Parents of children with autism are stressed for a variety of reasons, some of which are significant. These include a sense of loss of control, the absence of spousal support, and informal and professional support. Other factors contributing to parental stress include adjusting to the child's condition and housing and financial considerations for the family.

The lack of existing research on this subject in Bangladesh has resulted in a lack of information that provides a snapshot of current conditions. In these circumstances, a study is required to understand better the impact of ASD on the family members involved. Ultimately, it is hoped that this study will delve into the experiences of families affected by autism to understand better how to approach service delivery while also empowering families, providing educational support, and providing guidance to professionals. Therefore, one of the study's goals was to determine the impact of autism on children and their families.

Pre-diagnosis

Parental stress begins when parents are unable to comprehend their child's challenging behaviors and communication issues (Duarte, Bordin, Yazigi, & Mooney, 2005; Montes & Halterman, 2007; Myers, Mackintosh, & Goin-Kochel, 2009; Silva & Schalock, 2012). Families with higher levels of education and affluent socio-economic backgrounds are more likely to recognize and seek professional help when their children exhibit unusual developmental patterns (Harstad, Huntington, Bacic, & Barbaresi, 2013; Mandell et al., 2010; Mandell et al., 2009; Rosenberg, Landa, Law, Stuart, & Law, 2011; Valicenti-McDermott, Hottinger, Seijo, & Shulman, 2012). In search of answers, many parents spend years hopping from one health care provider to the next, only to become increasingly concerned about their child's delayed development and bizarre repetitive behavior patterns (Altiere & von Kluge, 2009a; Braddock & Twyman, 2014; Dabrowska & Pisula, 2010; Moh & Magiati, 2012; Mooney, Gray, & Tonge, 2006; Nealy, O'Hare, Powers, & Swick Most of the time, health care providers blame a child's behavior on poor parenting and dismiss parental concerns (Altiere & von Kluge,

2009b; Nealy et al., 2012; Silva & Schalock, 2012). Early diagnosis and intervention are critical because early intervention is associated with improved social and communication outcomes, improved brain function, and a reduction in the need for costly services as the child grows and develops (Butter, Wynn, & Mulick, 2003; Dawson et al., 2012; Gray, 2006; Vismara & Rogers, 2010).

Parent Response to Diagnosis

After receiving an ASD diagnosis, parents may experience feelings of confusion, denial (Altiere & von Kluge, 2009a), and decision-making uncertainty (Stuart & McGrew, 2009), depending on the severity of the child's symptoms (Stuart & McGrew, 2009), among other things (Nealy et al., 2012). Many parents are concerned that they are not doing enough to assist their children in their studies (Lutz, Patterson, & Klein, 2012). Parents' feelings of failure are exacerbated by the associated feelings of guilt and disappointment at not being able to "fix" the situation (Dunn et al., 2001; Nealy et al., 2012; Neely-Barnes, Hall, Roberts, & Graff, 2011). A variety of aspects of parents' lives change, including their relationships with family and friends, daily routines, and hopes and dreams for their children in the future (Altiere & von Kluge, 2009a; Dale, Jahoda, & Knott, 2006). Ludlow and colleagues (2011) found that the requirement for continuous care and supervision is a significant source of stress for parents of children with a wide range of symptom severity; however, the association between stress and symptom severity was inconsistent. Stress levels were lower for parents of children with milder symptoms in one study (Moh & Magiati, 2012), but they increased as the child's functionality improved, according to another (Sukhodolsky et al., 2008). Additionally, stress was found to diminish over time as a result of adaptation (Bekhet et al. 2012), comprehension and acceptance (Dabrowska & Pisula, 2010), and the establishment of consistent daily routines (Dabrowska et al. 2010). (Gray, 2006). Parents are also stressed out by worries about the future of their children. The future independence and safety of their children are a source of concern for parents of higher functioning children (Dabrowska & Pisula, 2010; Hill-Chapman, Herzog, & Madura, 2013; Ingersoll & Hambrick, 2011; Jones et al., 2013), whereas the future care of their children is a source of concern for parents of lower functioning children (Dabrowska & Pisula, 2010; Hill-Chapman, Herzog (Lutz et al., 2012).

Post-diagnosis

Seeking Services and Communication with Health Care Providers

The difficulty in locating and managing post-diagnosis parent struggles and balancing autism services only exacerbates the situation (Altiere & von Kluge, 2009a; Gray, 2006; Ludlow et al., 2011; Meadan, Halle, & Ebata, 2010; Nealy et al., 2012). Finding healthcare providers who are helpful, knowledgeable, qualified to assess ASD, and understand the difficulties associated with caring for a child with ASD can be difficult to come by, especially in rural areas (Brown et al., 2010; Nealy et al., 2012; Silva & Schalock, 2012). However, while parents from all backgrounds have expressed marginalization and neglect, parents of color attribute this to racial discrimination (Altiere & von Kluge, 2009a; Gray, 2006). Parents who can form a collaborative relationship with a health care provider who is willing and able to share appropriate evidence-based information report a higher level of satisfaction with their child's health care experience as well as a lower level of anxiety (Altiere & von Kluge, 2009a; Meadan et al., 2010; Moh & Magiati, 2012; Rivard, Lepine, Mercier, & Morin, 2015). On the other hand, healthcare providers rarely share pertinent information about a child's situation with other healthcare team members, and they rarely communicate research findings to the parents of those children (Altiere & von Kluge, 2009a; Silva & Schalock, 2012).

Educational Needs and Communication with Educators

Parents face a similar set of challenges in the educational system as children. School participation is impaired by challenging behaviors, which expose the child to other judgment and criticism from teachers who are unfamiliar with the characteristics of ASD or the difficulties that the family is experiencing (Ludlow, 2011; Silva & Schalock, 2012; Walsh, Mudder, & Tudor, 2013; Ludlow et al., 2011; Walsh, Mudder, and Tudor, 2013). (Dillenburger, Keenan, Gallagher, & McElhinney, 2004; Myers, Mackintosh, & Goin-Kochel, 2009). Parents of children with autism spectrum disorder (ASD), particularly those of African-American and Hispanic descent, face significant challenges in gaining access to educational resources and planning instructional education (Harstad et al., 2013; Valicenti-McDermott et al., 2012).

Disturbing patterns of behavior Many studies have identified "challenging behaviors" as the primary source of stress; however, only one study has focused exclusively on these behaviors, identifying physical and emotional aggression, destruction, and self-injury as the primary sources of stress in participants (Fodstad, Rojahn, & Matson, 2012). Additional difficulties include tantrums and meltdowns (Ludlow

et al., 2011; Bearss, Johnson, Handen, Smith, and Scahill, 2013), bold and inappropriate statements made to others or in public, verbal or physical perseveration, tuning out, repetitive movements, and poor body control, as well as unusual responses to sensory stimuli. Although judgment and criticism from others regarding these issues are significant sources of stress, only one study in this review examined the experiences and responses of parents to these situations (Nealy et al., 2012). Another issue contributing to chronic fatigue in the parent and the exacerbation of behavioral problems in the child has disrupted sleeping patterns. The constant vigilance and care required (Giallo, Wood, Jellett, and Porter, 2013; Moss & Howlin, 2009; Montes & Halterman, 2007; Silva & Schalock, 2012), the child's tantrums, and the social impact of the child's challenging behaviors can appear to be endless and exhausting (Giallo, Wood, Jellett, and Porter, 2013; Moss & Howlin, 2009; Monte (Ludlow et al., 2011; Myers, Mackintosh, & Goin-Kochel, 2009). While strategies for improving sleep onset are effective (Malow et al., 2014), more research is needed to improve the quality of other aspects of sleep. For parents of children with autism spectrum disorder (ASD), managing their child's diet, nutrition, and weight presents a unique challenge, especially when added to an already difficult daily routine (Curtin, Jojic, & Bandini, 2014). In addition to being predisposed to obesity as a result of the use of certain pharmaceuticals (Aghaeinejad, Djafarian, Mahmoudi, and Maskooni, 2013; Evans et al., 2012), autistic children are also predisposed to poor motor development (BroderFingert, Brazauskas, Lindgren, Iannuzzi, & Van Cleave, 2014; Curtin et al., 2014; Zuckerman e (Gillette-Dreyer et al., 2015). Several children with autism spectrum disorder (ASD) also have an obsession with high-calorie foods (Aghaeinejad et al., 2013; Evans et al., 2012). Many other parents struggle to keep their child at a healthy weight because of their child's hypersensitivity to food textures, odors, and the picky eating that goes along with it (Zobel-Lachiusa, Andrianopoulos, Mailloux, & Cermak, 2015). Food as a motivator for behavioral changes contributes to unhealthy eating habits (Center for Autism Research, 2014).

Stigma

The ongoing negative stigma associated with autism spectrum disorders adds to the stress experienced by parents of children with ASD (Altiere & von Kluge, 2009a; Lutz et al., 2012). Public meltdowns are referred to as the "shopping experience" by parents. They are associated with onlookers who are critical of the situation and disparage remarks about the parents' poor parenting (Neely-Barnes et al., 2011, p. 213).

Because autism spectrum disorder (ASD) is an invisible disability with no readily identifiable physical characteristics to explain inappropriate comments and behaviors, parents believe they are being judged more harshly (Myers, Mackintosh, & Goin-Kochel, 2009). Parents acknowledge that they have been negatively confrontational on occasion, corroborating the critic's assessment of their poor parenting abilities. Nealy et al. (2012) report that some parents admit to picking their battles with their children and frequently choosing to ignore the offender, while others tend to isolate themselves and their child in order not to face criticism or embarrassment (Dabrowska & Pisula, 2010; Dunn et al., 2001; Ekas & Whitman, 2011; Ludlow et al., 2011; Lutz et al., 2012; Woodgate, Ateah, & Secco, 2008).

Marginalization, Victimization, and Bullying

ASD children are frequently excluded from birthday parties, are the last to be selected for sports teams, and are forced to eat lunch alone regularly (Foden & Anderson, 2012). Parents must engage in strategies that increase their child's knowledge of social skills, increase the likelihood of their child improving friendships, and develop fundamental strategies for preventing bullying situations from developing (Laugeson, Frankel, Mogil, & Dillon, 2009). Victimization and bullying are more likely to occur in a child who has difficulty with social interaction and comprehension of verbal and nonverbal communication, as well as with academics (Hebron, 2014; Schroeder et al., 2014). Children with ASD are bullied by their peers and siblings at a rate of 65–75 percent, compared to 20–35 percent of typically developing peers (Carter, Marintez-Pedraza, and Gray, 2009; Foden & Anderson, 2012; Hebron & Humphrey, 2014; Little, 2002; Schroeder et al., 2014; van Roekel, Scholte, and Didden, 2010); and 47 percent of parents report that their child is bullied (von Roekel et al., 2010).

Autism Impact on Parent

In the context of parenting, *stress* is defined as the sensation of distress or discomfort brought on by the demands of the parental role.

Family stress is a significant predictor of intervention outcomes in children with autism spectrum disorder (ASD), including lower levels of developmental improvement in behavioral interventions and lower levels of developmental improvement in areas such as language, communication, and other adaptive behavior development.

According to a systematic review of ten studies, autism spectrum disorder (ASD) can significantly impact family dynamics, resulting in caregiver exhaustion, which is particularly prevalent among mothers. According to the findings of another study, up to 70 percent of mothers and 40 percent of fathers of severely disabled children experience significant emotional distress. According to one study, other members of a child's family who have autism suffer from depression. The presence of an ASD child can also impact other aspects of family functioning, as discovered in this study.

Maternal Stress

Stress is an unavoidable aspect of being a parent. Stress is also associated with household tasks associated with child care, linked to autism spectrum disorder (ASD) and other developmental disorders. The stigma associated with being a mother also plays a significant role in her depression. Even though mothers are constantly involved in their children's upbringing, they face more difficulties than fathers in this regard. According to the findings of another study, reducing challenging behavior in children with ASD may aid in the improvement of the parent-child relationship.

Parents of children with autism or other developmental disabilities were asked to study parental stress in their homes. The nature of this investigation was cross-sectional. Approximately 50 families with children diagnosed with autism participated in this study, and an additional 50 families with children diagnosed with other developmental disabilities. Many different outcome measures were used in this study, including the Parenting Stress Index Short Form, the Gastrointestinal Questionnaire, and the Questionnaire on Child Sleep Habits. Moms from non-Hispanic backgrounds and mothers from the United States reported significantly higher levels of parental stress than the general population. In addition, there was a link between mothers' loneliness, social support, and depressive symptoms in children with autism. According to one study, the risk of maternal depression increases in direct proportion to the severity of the child's autism disorder. Another study discovered that mothers of autistic children found it difficult to pursue professional careers because their children's excessive time demands interfered with their ability to do so.

It was decided to take into account the level of stress experienced by mothers of autistic children. According to the findings of this study, mothers of teenage girls experience higher rates of depression. In

addition, researchers discovered that parents of children with ASD had lower parenting efficacy, higher levels of parenting stress, and more mental and physical health problems than parents of children with other developmental disorders in high-income countries, according to a review of studies. According to another study, parents of children with ASD and non-parents were found to have no differences in their stress levels, coping mechanisms, or level of support. Parents, particularly mothers, are embarrassed when people who do not understand autism and its symptoms approach them with their children. In addition, women who have children with autism are at risk of losing family relationships due to the demanding task of caring for their children's extended family and friends.

According to the findings, mothers of children with autism are more likely than mothers of children without autism to suffer from maternal depression and have lower levels of social support. This is because mothers of children with autism spend more time caring for their children and maintaining the household, leaving little time for leisure activities. According to one study, when the adaptive functioning of an autistic child is improved, maternal well-being is improved as well. Another study, on the other hand, found no link between parental stress and children's adaptive abilities.

Paternal Stress

In order to protect their children from autism, fathers of autistic children frequently suppress their emotions, especially their anger. According to one study, any disability experienced by a child has a greater impact on the mother than on the father. Therefore, we looked into the relationship between gender and levels of stress in the participants. According to the findings of this study, mothers reported higher levels of stress than fathers. Another study discovered results that were similar to the first. Additionally, parents of children with ASD have a significantly higher divorce rate than parents of children who do not have disabilities. According to a study, stressful life events such as divorce, separation, relocation, the death of a family member, economic, job, or legal difficulties all contribute to decreased family functioning by interfering with communicating effectively.

Sibling Impact

According to the findings of the research, children with ASD have a mixed effect on their siblings. Several studies have been conducted on children with autism, finding a positive effect and finding a negative

effect. In addition, a second study discovered mixed (both positive and negative) findings.

When it came to most siblings and cousins of children with autism spectrum disorders, they interfered in all aspects of their lives, including their vocational, marital, and family planning opportunities. Another study confirmed that siblings who have an autistic brother or sister report feelings of embarrassment or shame resulting from having a brother or sister with autism. It was also reported that 84 percent of siblings aged 8-15 reported that their brother or sister with autism was aggressive toward them when interacting with them during play.

Compared to the general population, siblings of autistic individuals are genetically predisposed to cognitive and social difficulties and linguistic and learning difficulties. The presence of a sibling with ASD alters the course of normal life cycle events. Loneliness and social difficulties among siblings of children with autism have been reported to be particularly high among these siblings. According to one study, loneliness is associated with a lack of social support from one's circle of friends. One study, on the other hand, discovered that having an autistic sibling had no negative consequences. Siblings of children with ASD are more likely than other siblings to experience difficulties adjusting to their new environment.

Financial Impact

Children with Autism Spectrum Disorder hurt the family's lifestyle and socioeconomic standing. According to one study, children with autism spectrum disorders (ASD) suffer significant annual income losses, and a second study confirmed that caring for children with ASD is an expensive endeavor. In the case of an autistic child, the family's weekly out-of-pocket expenses totaled approximately \$120 and were directly related to the education and care of their child, ultimately affecting the family's financial well-being. Low-income caregivers bear an unequal share of the financial burden as a result of their monthly out-of-pocket expenses. It demonstrated the monetary cost of autism spectrum disorder.

By a recent study, families of children with ASD bear a disproportionately large financial responsibility. According to the findings of this study, mothers of children with ASD earn 35% less (\$7189) than mothers of children with another health condition and 56% less (\$14 755) than mothers of children without a health condition. According to the findings of a study, they were found to be associated with a decreased likelihood of living in a higher-income household.

Autism in childhood is associated with a significant annual income loss for the family's household. In this study, the parents of 11 684 children were recruited through a national survey. It was discovered that 131 children had been diagnosed with autism spectrum disorder, and 2775 children had been diagnosed with another disability.

Social Impact

Autism harms one's ability to form and maintain interpersonal relationships. Among the symptoms of autism are difficulties in communicating, interacting with others, behaving, showing interest, and a lack of social skills. Children with autism spectrum disorders and their families face a variety of difficulties. The battle begins at a young age and continues for the rest of one's life. Several other issues, including personal, professional, marital, and financial issues, are intertwined.

Moreover, these issues manifest themselves in a broader social setting. In addition to parents, autism impacts the entire family, including the marital system, the parental system, the sibling system, and the extended family system. Due to parental refusal to allow their child to participate in family programs, community activities, or social activities, this has occurred.

Students with autism spectrum disorders (ASD) may find it difficult to function in a school environment because of their limited comprehension of social situations. For example, children with autism spectrum disorders frequently exhibit rigid and limited play patterns, and they are unable to communicate their desires and capacities for play and form friendships or form peer groups with other children.

Interventions for children with autism are required to reduce parental stress and other negative effects on the family and function properly in society. The family can benefit from a wide range of types of support. These include respite care, professional parent training, and treatment, as well as self-help groups. One study on the impact of respite care on children with developmental delays concluded in 2001 that, while ensuring respite care benefits parental stress reduction and increased coping abilities, no studies have yet demonstrated that respite care is appropriate for children with ASD (autism spectrum disorder). Teacher training appropriate for students with autism spectrum disorders is a predictor of successful behavior management. Social workers may emphasize a client's strengths to avoid judging or blaming the client for his or her shortcomings. Aiding clients in

becoming more aware of their accomplishments and strengths as a result of this process. In addition, social workers can identify the influences of a client's family on that client's life.

This review has some limitations, as you will see below. To begin, this research looked into the various effects of autism on families and their members. Selecting a specific impact of autism on the family will draw attention to that impact more effectively. Second, first and foremost, this review assesses the limited evidence that they are not as strong as they appear in their hierarchy. Third, studies are chosen at random, and since 2010, there has been little new research on this topic to support the claims. As a result, additional investigation in this area is required.

CONCLUSION:

Autism is a multifaceted disorder that manifests itself in a variety of ways. The findings of various studies indicate that families with children are faced with a variety of difficulties. Maternal stress is one of these factors. The stress that parents experience due to having an autistic child is critical because it impacts the entire family's quality of life. In this study's findings, it was discovered that the importance of family involvement in the lives of children with ASD could not be overstated. It is possible to reduce the impact on all family members by addressing familial support, marital relationships, and participation in social activities. When it comes to stress reduction, parents of children with autism spectrum disorder may find that receiving positive and supportive social support is beneficial. In addition, increasing the adaptability of other family members of autistic children may benefit both the parents, particularly the mother, and the children with autism spectrum disorders.

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