

Impact of autistic children on family



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In recent study the attention has been drawn towards the impact of autistic children on the family. Autism refers to neurodevelopment disorder as identified at early age of 3 years old and characterized by considerable social interaction and communication impairment, unusual and repetitive and stereotyped behaviors. Parents of autistic children face great and unending challenges due to slow mental development of the child. These challenges are in the form of stress other negative psychological outcomes. Parenting autistic child places extra stressors on parent related to social and behavioral difficulty of the child. In addition, the challenges are increased with the caring and lack of community understanding about the disorder.

Many studies have reported that there are growing complaints about psychological distress, anxiety and depression amongst the parents of autistic children. A comparative study suggests that this ratio of depression and anxiety is more in the parent of autistic children than the parents of developing children. Additionally, in several other studies of parents of autistic children, the children's aggressive behavior and their violent conduct were most strongly related to parent stress, rather than other symptoms of autism such as severe developmental delay, and adaptive skills (Schieve et al, 2007; pp. 115).

Besides, a child with the symptoms of autism causes his family to suffer from different levels of distress; the distress is high level of mental, emotional and financial distress (Estes et al, 2009; Abstract). A child with autism suffers from rigorous deficit in imagination, shared social interactions, communication, and restricted or unusual behavioral that adversely affect the entire life not only of child but also of family such as daily living

activities, school life, relationship with family and with peer groups (Hulya Bilgin & Leyla Kucuk, 2010; Problem Statement).

Family is the basic and important unit in any society; and children are central part of family institution that also makes it a dynamic institution with changes led by children. The existence of a child in a family changes the role of parents. If child is with new and abnormal conditions it makes the entire family to adopt a different and change attitude. The new attitude of parents aims to deal with the complications that occur due to child with autism ((Hulya Bilgin & Leyla Kucuk, 2010; pp. 92, Introduction). However, every new born baby needs some time to adjust to new circumstances but a child with disability and especially Autistic child can cause difficult situation due to unusual social behavior and difficulty in communicating in the society. The adjustment of such child can put the parents at the risk of poor mental health resulting from mental, emotional and financial stress (Hulya Bilgin & Leyla Kucuk, 2010; pp. 92, Introduction, paragraph 2).

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In many cases parents have to be involved in caring the children with lifelong autism disorder and in mostly cases parents are the victims of the children's behavior and unprogressive attitude. Parents and siblings of such child have to go through a time of explanation of the autistic child's behavior (Ghanizadeh, Alishahi & Ashkani, 2009; pp. 478). According to other studies, justifying the behavior of autistic children is definitely not an easy job to do and it rather triggers to their stress. Moreover, explanation and justification for the abnormal behavior of autistic child makes the family feel inferior.

Parents, as a primary caregiver, have to endeavor to spend much time to make a balance between the demands of autistic children and other non-autistic children.

Studies have indicated that treatment and education of children with autism makes the parents tired and depressed and this depression surely affect their personal and professional behavior. The fulfillment of autistic children's needs usually requires a good margin of time for which they have to sacrifice their social contacts with the other member so family, relative, and community. As a result of physical aggression of children, parents have to suffer from physical trauma. In many cases, it is observed that despite the proper attention by parents and treatment support, autistic children preserve their performance and behavior problems and the understanding and awareness of community members about Autism is limited and they do not realize the severity of the problem due to which parents are more anxious to justify the behavior of their children. As a result of negative effects of having autistic children parents are more worried and shows over concerned related to their children's behavior. However, there are control groups in communities for their children's learning problems and there are many facilities to provide the children with yet there are problems related to behavior of community's members. In most cases parents have to teach, train and frequently communicate with their children and there is counseling help required for regulating the deficits in different areas of the problem (Ghanizadeh, Alishahi & Ashkani, 2009; pp. 478). A survey has indicated that parents' level of frustration and stress is higher about the provision of education to autistic children; moreover, for parents of autistic children, it is

excessively difficult to acquire appropriate educational provision for their children compared with children with other disabilities (Parsons, Lewis & Ellins, 2009; pp. 37).

A study points out that parents of autistic children are more likely to score high in the aggravation range (55%) than the parents of non-autistic but slow developmental problem children and parents with special health care needs children without any developmental problem. On the other hand, the proportion of parents with high aggravation within the autism group is 66% for those parents whose children are in need of special services and 28% for those whose child did not. Study has indicated that parents of autistic children who recently need special service are more likely to score high aggravation than the parent of those children with autism who are without recent special service needs (Schieve et al, 2007; pp. 114).

Studies examining psychosocial adjustment of family with autistic children such as family functioning, marital satisfactions, as well as social support in families of children with autism disorder defer similarly questionable results. Some other result shows the presence of increased family distress, lack of marital satisfaction and inappropriate social support while others indicate that the functioning of such families with autistic children is not greater problem than the marital satisfaction and social support (L. M. Lach et al. 2009; pp. 608).

Studies examining the parents' mental status during diagnostic and planning processes proved that during the diagnostic and planning processes parents have extremely stressful time as statutory diagnosis is extraordinary time

consuming, moreover there is very little participation of parents offered in care and education plans. Parents stress and depression related to child treatment and education process including development change over time but level of stress is always stable but prevalence of depression can vary on the base of different characteristics of child (M. B. Olsson & C. P. Hwang, 2002; pp. 549).

Family lives stressful life since their child is diagnosed with autism because many autistic children are not born with any symptoms or indication such as physical, behavioral adjustment, and intellectual abnormalities, and after the diagnosis they experience shock, denial, and pessimism (Hulya Bilgin & Leyla Kucuk, 2010; pp. 97, paragraph: discussion).

Different coping strategies are suggested for families and especially for mothers in order to give a better care to the child. Among coping strategies, harmony and unity is observed as source for few mothers. According to another study, informal support of family, friends and community members are, however, nonprofessional but effective and there is significantly reduced depression in parents of autistic children (Hulya Bilgin & Leyla Kucuk, 2010; pp. 98, paragraph 1).

A study was performed to analyze reasons of parents stress, the findings of result reported that 39 % of respondents, though a little of population, expressed stress as a result of mainstream educational provision for their children with ASD. However, education provision has always been stressful issue for parents and dissatisfaction that extends to staff and school, is more regarded as another cause of stress in parents of autistic children. On the

other hand, the willingness of the school to give importance to the complaints and views of parents and positive and flexible response to the child's needs and parents' satisfaction is also correlated with decreased stress. However, many of parents showed satisfaction about the education provision are also found distress and depressed (S. Parsons et al. 2009, pp. 38, paragraph 3).

The impact of having a child with autism on the family can be terrific, having plan ahead for trips, not having enough time alone to rest, and planning vacations and fun impossible.

A study has performed an analysis to realize the experience of family and parents after the diagnosis and how they react in different phase. This is quite a truth that parents can never be ready to hear that their boy or girl is diagnosed with the disorder of autism that is considered as untreatable and possibly will last till the end of life moreover will require many changes in life style and care for from the child's family. Family usually goes through different phases such as at first shock and disbelief, grief, disorganization and despair and reorganization. However, the first reaction of family members is different from other family and individuals and lives through these phases differently, and some go back to first phases for a time. (Elder & D'Alessandro, 2009; pp. 241, paragraph: " It's Been So Hard to Accept that Our Son has Autism. Is There Anything that Can Help?"). During the first phase family is in the state of shock and disbelief and parents of diagnosed child often show denial of the fact; they suspect that something terrible has happened with their child they do not want to believe in that. At this stage parents are so stressed and they make different opinions. The level of

understanding the disorder is more likely to observe positive by fathers than mothers and the level of taking the diagnosis is different in both of them. But still mothers are the primary caretakers of such child rather than fathers who are mainly responsible for financial support. In phase two, parents experience grief and anger; as they begin to understand the term of diagnosis and its implications they usually express intense grief and sorry. Mothers are observed as the most vulnerable at this stage because they think of their future distorted as unable to get married and go to college. Most of the parents express their grief through anger. In phase three, family starts to believe their life out of control as a result of disorganization and despair. Families usually relate their feeling of despair with the perception of their lives as “ out of control”. During the treatment and other medical services parents are observed as overwhelmed with their feelings. Families immediately after the diagnosis find it important to save additional employment and longer working hours to pay for the expenses of autism treatments. At first the stress that family experience is the familial and marital stress, especially at the second stage. At this stage they need support and assistance in both having effective coping strategies and making important social support and respite care. In fourth phase, parents learn to cope up their conditions but some degree of chaos usually remain, however, families who have successfully gone through the first three phases of shock and disbelief and mourning often succeed to change their lifestyle and future perspective as they go thorough to fourth phase that refers to re organization (Elder & D'Alessandro, 2009; pp. 242, paragraph: Grief Process).

Though care giving is a normal duty of parents, with high level of care required by autistic child having long term functional disabilities is surely a burdensome effect the normal lives of parents including physical, mental and social. Other studies have reported that being primary caregivers, the primary health of parents is rather important in terms of child's health and care. If parents of such child continue to show chronic medical conditions it can adversely affect the child's health quality. According to other study, with the presence of an autistic child there are negative effects on the family members but this effect is much worse on parents because they are the most vulnerable group who stay close to the child having practically the entire burden of family care for their severely autistic child. In the process of treatment and cure of such child parents are the most important factors for improving the functioning of child, and the health related problem with parents can affect the developmental process. According to the recent study on rehabilitation and therapy of children with autism reported that in order to gain unity in all aspects of the autistic child's life, parents are considered as a very important character in the rehabilitation process of child.

For parents to become capable of caring their child with autism and contribute to the quality of the rehabilitation process of child, they must be of good health themselves, because this care uses great psychological and physical efforts. Therefore, protecting good health and well-being of parents is a prerequisite for the most favorable care for the child. Poor caregiver health can surely contribute to repeated hospitalizations placements for children with constant conditions (Benjak, Mavrinac & Å imetin, 2009; pp. 404, paragraph: 3). In addition, differences in maternal and paternal coping

strategies and positive awareness can be a chief element in marital discord (K. W. Phelps et al. 2009; pp. 138, paragraph: discussion). It is considered important to monitor the levels of stress constantly while paying attention to both mothers and fathers. These areas of fortification lead to the probability for professionals develop the strengths of caregivers during dealing with the overwhelming stress that they experience (K. W. Phelps et al. 2009; pp. 139, paragraph: 2). There has been primarily focus on the coping strategies of the parents with autistic child. There are different coping strategies that families shared for coping with many difficult situations and all of the families shared same levels of rejection by their other members of family, friends, and strangers in the community (Hutton & Caron, 2005; pp. 181, paragraph: Family's Coping Ability paragraph 2 & 3).

Autistic Children and Effects on Mothers as a primary Caregiver

Caregivers play a vital role in the care giving and a central part of the lives of children with autism. The health conditions of caregivers are interrelated with the health of autistic children. The health of caregivers is particularly important because there has been a decided shift toward community-based rehabilitation of children with autism. Community Base Rehabilitation identifies the caregivers as partners in the provision of care and the principles of family-centered care rooted in health policy and accepted by health and social services agencies offering services to children with autism and their families, aims to maximize the opportunities for social inclusion. Since caregivers are an instrumental partner taking active participation in affecting the nature and direction of care process of autistic children. Evidence shows that caregivers have impact physical and psychological of

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the children with autism. This impact is regarded as psychological and physical stress caused by caring a child with communication and social problems (L. M. Lach et al. 2009; pp. 608).

Different studies have indicated that caregivers of children with autism are at the higher risk of stress than the caregivers of non-autistic children. Moreover, researches have focused on the mental status of primary caregiver especially on mothers (K. W. Phelps et al. 2009; pp. 134). Many studies about the effects of having autistic children on family has reported that parents and especially mothers are at the highest risk of depression and this psychological stress is caused by tedious demand of raising such child. Moreover depression and stress results in poor mental health (Hulya Bilgin & Leyla Kucuk, 2010; pp. 93). According to another study, mothers of children with autism are at the higher risk of stress than mothers with non-autistic child. The reason explained is that mothers experience stress while caring for their child and demand of parenting an autistic child that is really hectic cause mothers having mental stress. Moreover, parents feel great financial and emotional burden and also experience physical and psychological stress (Hulya Bilgin & Leyla Kucuk, 2010; pp. 93).

Different studies explain the stresses as a result of changes that a family has to adopt after learning about the autism diagnosis and these changes alter their life preferences causing them stress. The stress that affect the parents of autistic child are categorized into six general categories: (a) the Symptomatology of child such as aggression and violent behavior, (b) extra expenditure for treatment and education of child as financial burden, (c) the shortage of medical facilities and expert support, (d) the shortage of

informal/ spousal support, (e) the therapeutic effect of medical and educational interventions and (f) augmented burden of care and the risk of stigmatization (Hulya Bilgin & Leyla Kucuk, 2010; pp. 93).

The mental stresses affect the integrity and well being of parents because they need to give psychosocial and instrumental support, along with the subjective societal consideration and acceptance of the child's condition. Because mothers has to come across all major challenges in raising autistic child both at home and in the society, she is more affected by these adjustments than fathers. This could be justified as cultural phenomena as well where mothers are more responsible for the care and development of a child than fathers. In many societies, mothers are primary caregivers of such child; while fathers are responsible for financial responsibilities (Hulya Bilgin & Leyla Kucuk, 2010; pp. 93). The challenges and adjustment related to autistic children does not only affect the parents, but also the siblings, educators and health professionals.

The relationship of mother and child is also affected due to less severe maladaptive behaviors and less social impairments of the child with autism. In this regard, mother and child's relationship is affected when care giving is not meeting the greater requirements of autistic child. Moreover, mother's feeling is related to the quality of their lives. Those mothers who have difficulties in family integrity and consistency show higher levels of depressive symptoms and anxiety (Ghanizadeh, Alishahi & Ashkani, 2009; pp. 479).

Decision making about the choice of school, methods of education and rehabilitation courses are considered as an essential part of caring of caregivers. Mothers, as a primary caregivers have psychological burden of taking these decisions and sometimes she has to take these decision on her own. Due to lack of cooperation from medical health providers and nurses it becomes very difficult for mothers to take such important decision and bear the higher strain of responsibility. Previous studies have suggested that mothers from lower socio-economic background have very limited coping strategy to deal with their feelings of stress and suffer from higher stress. With a long time spent with autistic child, the mental status of mothers turn out to be negative and the greater the level of strain felt by them. On the other hand, mothers have reported that they do have any channel of acquiring the appropriate information help regarding handling the care of autistic children by physicians, social workers and nurses (Tsai & Wang, 2009; pp. 545).

Effects of Autistic Children on Siblings

Siblings have always been center attention of researchers who are engaged in identifying the effects of autism on family. Siblings also bear the results of having an autistic sister or brother in family because they are the first childhood partner. During childhood, social engagements, communication and behavioral adjustment amongst the siblings determines the mental health and effects on the other siblings due to autistic siblings. Since the relationship of siblings last longer due to its roots into earlier days of childhood, its effects are also unique and long lasting. Different researchers have indicated that on the basis of strong ties amongst siblings there is

immense possibility of being affected by autistic brother or sister. However, they explain the reasons of such effects as a result of combine and mutual experiences of emotional and other development. Besides, regardless of mental and developmental problem siblings share comfort and sense of belonging. Moreover, being first social partner the intimacy among siblings is obvious.

Different researches on the topic of effects of autistic child on siblings in the general population points out that relationship of sibling show essential consistency throughout childhood and they share personal, interpersonal and ecological influence on each other. Additionally these effects reflect the life course of siblings. Studies have shown that in the presence of an autistic child not only relationship of siblings is affected but also mental and social conditions of siblings. Other study shows that statistically there was considerable but minor impact on the psychological functioning of siblings due to presence of an autistic child; moreover these psychological conditions are defined as depression, anxiety and behavioral adjustment. However, these effects are different at different stages of life but these effects are regarded as negative effects (Orsmond, & Seltzer, 2007; pp. 313-314).

The major reasons why researchers studying the effects of autistic child on other siblings are that siblings play an important role in the communication process of autistic child and the presence of autistic child can negatively affect the communication learning process of siblings. Moreover, siblings always have a stressful life conditions due to autistic sibling; because temperament profile have included lower positive effects and higher negative effects on the siblings of autistic child than non-autistic child.

However, child with mild symptoms and less behavioral problem show more positive effect and rather share the activities with siblings. A child with severe symptoms of autism has long lasting social and behavioral adjustment problem that last with old age of life. There is negative type of mix feelings found in siblings such as of sorry, precocious responsibility and involving in frightening behaviors. More apparently, siblings are embarrassed and experience loneliness, guilt and anger. This influence is therefore not only on the parents of the child but also on the siblings and the relationship among the family members (Buys, 2003; pp. 3 & 5).

The adverse effects of autistic child on siblings also affect the relationship of siblings with their friends and other social unit. There is also risk of having change moral behavioral problem. As a result of communication and social interaction problem there is little intimacy and nurturance among them but this can be coped up by the higher support of parents and conversely it can cause negative relationship among siblings. Therefore different studies have stressed upon the need of training such parents to help siblings to cope up (Ghanizadeh, Alishahi & Ashkani, 2009; pp. 478-479).

Social, Emotional and Financial Impact of Autistic Children on Family

Much research has been done focusing on the families issues related to autistic child. The specific area of interest of these researches was the impact of autistic child on the family members. Throughout the researches, it has been identified that the experience of parents in relation to caring an autistic child is unique and experience challenges in the same regard. The family system plays an important role in the developmental of child and if

the child is with autism, their responsibility and role in the environment doubles. The way the functioning of family affects the child; the development of child affects the functioning of family (Altieri & Kluge, 2009; pp. 83-84, paragraph: introduction 2 paragraph). It has been indicated in different researches that the developmental and intervention process of child with autism affects the health of parents. Study indicates that parents of children with autism suffer from poor health that includes physical and mental; therefore, literature suggests preserving good health of parents and well-being as a precondition for the care for children with autism (Benjak et al, 2009; pp. 403. Paragraph: conclusion). The impacts of having autistic children cause parents to go through uncountable functional problems as well as extra burden. Different studies have provided evidence for high growth rate in the physical, mental, social, financial aspects of parents and the effect of autistic child on parents conversely affects the child (Konstantarcas, 1991; pp. 358, paragraph 1).

The American Academy of Pediatrics has explained the importance of the health of parents with autistic child to take a better care; according to them, because family is the most significant part of child's life, they are responsible for the healthcare and well being of child; moreover, the ultimate health of a child is related with the physical, mental and emotional health of parents.

It is found in the data received by NSCH about functional status of families of children with autism that parents of autistic child are obliged to care the child due to inappropriate and difficult provision of child care arrangement. As a result of strict schedule with the child care giving parents have very little opportunity to find employment option. In this regard, it is found more

difficult caring toddler or infants because they have higher rates of medical problems and illness that require parental attention (Blanchard et al, 2006; pp. 1209, paragraph: Family and Community Functioning). On the contrary, researches were found that suggested the well functioning family can have a balance level of flexibility in adjustment. This balance can be maintained by acquiring different resources such as social care support and new coping techniques, there are evidences of families which successfully coped up with problem (Altiere & Kluge, 2009; pp. 84, paragraph: 2).

Physical Impact of Autistic Child on Family

Since majority of autistic children with their families and family including parents and siblings is the only caregiver. High level of responsibility and mental stress affects the physical health of the family members. Another study has pointed out that parents have mental distress due to burden and stress of responsibility and this potentially undermine the physical health of the parents of these children with autism (Allik, Larsson & Smedje, 2006; pp. 2, paragraph: 1-4). There is much data about parents adverse physical health related to parents having child with mental impairment or autism. Furthermore, little data has been found on the quality life related to health care in parents with autistic children. Family members especially mothers and fathers feel exhaust of physical functions, such as exhaustion and tiredness in mothers and fathers. A follow up study made to comprehend the physical health of parents with autistic children, the result of study was not different from previous result and parents of autistic child showed poorer physical health (Allik, Larsson & Smedje, 2006; pp. 2, paragraph: 1-4).

Similarly, other study has found rates of physical health problems in mothers caring for their children with autism.

Mental Impact of Autistic Child on Family

Different studies have indicated that the rate of stress is higher in the parents with autistic children than the parents with non-autistic children. Parents while parenting an autistic child have associatively mental stress, blame and sense of devaluation. Many parents reported that they often experienced feeling of extreme anger, guilt, depression, and anxiety and these feelings ultimately expressed in psychosomatic problems. A follow up study made to understand the effects of mental health of parents with autism, however, the result found was not different from the previous and parents of autistic child were found to have poorer mental health with elevated levels of depressive symptoms. A study performed to assess the stress level between mother and father of autistic child and comparatively they were found with similar levels of perceived stress and impaired health (Allik, Larsson & Smedje, 2006; pp. 2, paragraph: 1-4). Other two studies have reported that improved adaptive functioning in children is concerned with increased maternal wellbeing (Estes et al, 2009; pp. 377, paragraph: 2). Another cross cultural study examined the impact of bringing up autistic child on mothers reported that primary caregivers like mothers experienced increased stress when caring for their child and this stress impact their physical and mental health. Family tends to have negative feelings and is pessimist about the future of the child. Moreover, other independent research study has emphasized that higher stress in family is associated with more severe autism symptoms of child. It is studies that disabilities in

parents are often physically prominent, which makes them socially isolated to the present medical and behavioral problems. The reason is explained by researchers as many parents of autistic children adjust their priorities more strongly toward the requirements of their child. Additionally to the basic stressor of the disease itself, secondly stressors take place in key life areas (Hulya Bilgin & Leyla Kucuk, 2010; pp. 93). Mothers of autistic child always believe that their future is connected with their child therefore such child improves majorly such as recovery from leading a normal life. Consequently, parents of such children must need to have practical approach and expectations with balanced hope about the developmental progress of their children (Hulya Bilgin & Leyla Kucuk, 2010; pp. 97, paragraph: discussion).

Living with children who has atypical development and symptoms of autism definitely requires mental and emotional strength in facing difficulty, adversity, danger, or temptation courageously. Therefore, parents need moral social support from both formal and informal support systems to promote efficient coping methods (Hulya Bilgin & Leyla Kucuk, 2010; pp. 93).

Social Impact of Autistic Child on Family

The presence of a child with autism means burden of responsibilities as there are numerous therapeutic sessions from the diagnoses till the inception of interventions, selection of education school and education method, behavioral and social adjustment problem, all these problems involve the parent with care giving activities. A study has explored that an autistic child with chronic problems may cause the diminished family functions by more absent from school, less participation in social activity. As a result of this,

parents have to experience more difficulty with childcare, parenting skills and employment (Blanchard et al, 2006; pp. 1202-03, paragraph: conclusions). A study has found that the majority of children with autism