Psychological Well-Being and Parental Concern of Children with Autism

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ABSTRACT:

Background: Autism spectrum disorder (ASD) is a disability that affects three main areas, communication skills, social interaction and behavior patterns. It has been observed that parents of the children with ASD suffer more stress than parents of a child with any other disability and it increases the negative psychological outcomes on parents especially on mothers. Children and families living with ASD face many social, economic and emotional challenges.

Objectives: The current study tried to explore the indicators of stress levels within ASD families, as well as to examine the effects and to what extent, with a child with ASD has on the family. The present study offers quantitative research method in an attempt to obtain a complete origin of stress, depression and fear in parents of children with autism & the consequences for the family.

Methodology: This cross sectional survey has been used to measure the psychological well-being and parental concerns of children aged between 24 months to 10 years diagnosed with ASD as per DSM IV (diagnostic and Statistical Manual IV) were recruited. Samples were drawn through purposive sampling technique. Forty children of different institutes of special needs were selected as sample population. The parental concerns of children with autism were measured through a self developed questionnaire and another questionnaire DASS (Depression, Stress and anxiety scale) is used to measure the level of depression, stress and anxiety among parents of children with autism.

Results: The findings of the present study show that the parents of ASD children had increased level of stress, anxiety & depression measured by DASS. The key indicators were assumed to be financial constraints, lack of facilities, and lack of professionals, family pressure and social acceptance.

Conclusion: The mothers of the children on autism spectrum are more depressed, anxious and stressed due to financial constraints, lack of facilities, lack of professionals, social and family pressure as compared to the fathers of children on autism spectrum.

Keywords: Autism Spectrum Disorder, Disability Psychological Well-being, Depression, Anxiety, Stress, Cross Sectional (JRCRS 2013; 1(1): 21-27

INTRODUCTION:

Autism spectrum disorder (ASD) is a disability that affects three main areas, communication skills (about a third to a half of individuals with autism does not develop enough natural speech to meet their daily communication needs), social interaction (people with autism have social impairments and often lack the intuition about others that many people take for granted) and

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behavior patterns (repetitive movement, such as hand flapping, head rolling or body rocking) [1]. It has been observed that parents of a child with ASD suffer more stress than parents of a child with any other disability and it increases the negative psychological outcomes on parents especially on mothers. Children and families living with ASD face many social, economic and emotional challenges[2-3]. According to Dominick and Rutgers studies, it has been observed and parents report that they experience complex feelings like shock, denial, depression and anxiety at the birth of a disabled child4-5. Parents take an additional amount of time for acceptance and adjustment phase and some parents develop more severe symptoms due to economic instability and lack of health and educational resources. After that diagnostic confusion, behavioural and health problems, and feeling of loneliness in parents also add to these hardships6-7. As there is an increase in the severity of the disability, the child become more dependent on parents and parental responsibilities increase, resulting in parental anxiety and stress.

According to different researches, it has been observed that autism is differentiated by other disorders in three areas, including mutual social interaction, communication and repeated stereotyped patterns of interest and behaviour8-9. These are known as the triad of impairments (autism association NSW). A child with autism may show frequent and ritual practices, hand spinning, or running in circles, exaggerated fear, inflicted injury, temper tantrums and eat and sleep disturbances mechanism 10-11.

In different studies it has been analyzed that autism has a strong genetic basis, although the genetics of autism are complex and it is unclear whether ASD is explained more by rare mutations with major effects, or by the interaction of multiple genes rare common genetic variants12-13. The complexity arises from the interactions between multiple genes, environmental and epigenetic factors that do not change DNA, but are inherited and affect gene expression14. Studies of twins suggest that heritability is 0.7 for autism and as high as 0.9 for TEA, and siblings with autism are approximately 25 times more likely to be autistic then general population. However, most mutations that increase the risk of autism have not been identified. Typically, autism cannot be traced to a Mendelian (single gene) mutation or single abnormal chromosome, and none of the genetic syndromes associated with autism spectrum disorders[15-16]. Several genes have been located in many candidates, with only small effects attributable to a particular gene. The large number of people with autism affected family members may result from spontaneous deletions or duplications in genetic material during meiosis [17]. Therefore, a substantial fraction of autism cases may be attributable to genetic causes that are highly heritable but not inherited so the mutation that causes autism is not present in the genome of the parents[18].

MATERIALS AND METHODS:

A cross sectional survey was employed to identify the key areas of concern within families and parents of ASD children. To measure the patient's stress, anxiety and depression a scale of 42 items is used. The DASS 42 is a validated design and consists of three self-support scales designed to measure the negative emotional states of depression, anxiety and stress and mental status of the parents, all assessed by a scoring system of Lovibond. A self-developed questionnaire will be used to check the parental concerns of autistic children which cause depression, anxiety and stress in parents.

Parents of children aged between 24 months to 10 years diagnosed with ASD as per DSM IV Criteria-American Psychiatric Association (American Psychiatric Association, 1994), who had shown interest in participating were recruited, an exclusion criterion included any known

existing mental issues of parents. Sample will be drawn through purposive sampling technique. 40 children of different institutes of special needs will be selected as a sample population.

This study comprises of three phases: Development of questionnaire, administration of questionnaire and analysis of results. In the first phase of the study, a questionnaire of parental concern of autistic children has been formed by using different dimensions (Lack of facilities, Lack of professionals, Financial constraints, Single parents, Family pressure/acceptance (in laws), Social acceptance, Depression of parents specially mothers, Marital relationship. Another questionnaire (DASS 42) is also used to measure the depression, anxiety and stress of parents. In the second phase of the study, questionnaire is administered on the selected sample, after taking their verbal consensus. The participants were asked to follow the instructions.

In the third phase of the present study, statistical analysis was performed using SPSS (Version 17.0, SPSS Inc. Chicago, USA). Frequencies and percentage of parents' response were calculated to find out the parental concerns of children on autism spectrum. The result of the study has been shown in the form of tables and graphs.

Table 1:

	Lack of facilities	**Lack of professionals**	**Financial constraints**	**Family pressure/acceptance**	**Social acceptance**
F	9	8	12	6	5
%	22.5	20	30	15	12.5

The Percentage of DASS in males and female are listed in Table 2 shows the percentage of depression, anxiety and stress of parents. It is observed that the mothers are more anxious, depressed and stressed due to an autistic child. It is also observed that 27% fathers are normal. They didn't show depression, anxiety and stress while having a child with autism.

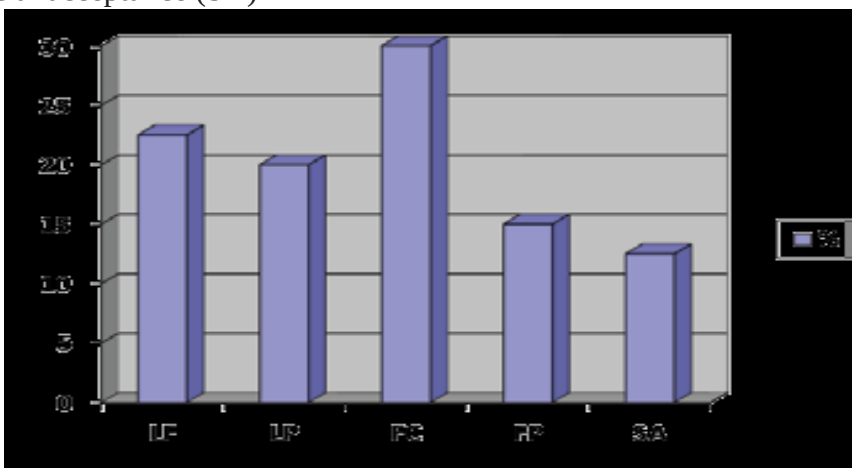
Table 2:

	Depression	**Anxiety**	**Stress**
Fathers	25%	29%	19%
Mothers	38%	35%	27%

The graph-1 shows that the parents faced financial difficulties when they have a child on autism spectrum. Lack of facilities and lack of professional is 2nd and 3rd major concern of parents respectively. While the parents also report that family pressure and social acceptance is also a major concern of them when they have a child on autism spectrum**.**

Graph 1:

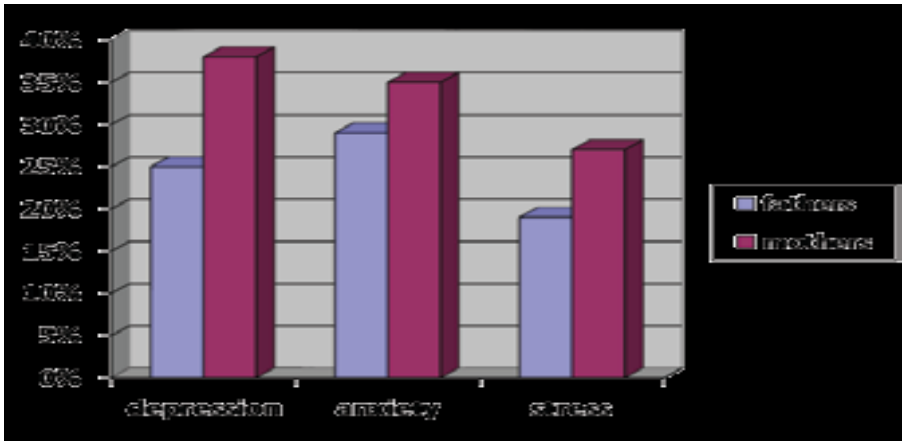
Graph shows the percentage of parents and their response on different variables:
Lack of facilities (LF), lack of professionals (LP), financial constraints (FC), family pressure (FP), social acceptance (SA)



The graphical representation in graph-2 shows the difference between the depression, anxiety and stress of the fathers and mothers. According to the data shown in graph, mothers are more depressed, anxious and stressed as compared to the fathers of the children on autism spectrum.

Graph 2:

Difference between depression, stress and anxiety of mothers and fathers with a child on autism spectrum



DISCUSSION:

The result of the present study shows that financial constraints are one of the major concerns of parent of children on autism spectrum. To have children with autism in our society can be both challenging and straining on a family as a whole. The highest percentage of parents identifying a child with disability but not getting help is due to financial constraints. Living in a society where lack of education and awareness results in people having large size families 19-20. With one such family having a child on the autism spectrum, it becomes next to impossible to cater to the needs of a child. Since such children not only need extra attention of the parents but also need special schooling, teachers and therapists.

According to the study of Kogan MD, et.al it has been confirmed that the financial constraints are a major concern of parents of the children on autism spectrum 21-22.

According to present study lack of facilities for the children with special needs specifically on autism spectrum is the second major concern of the parents 23. Some parents do not make the best possible effort to get their child the help he or she needs due to the lack of facilities and staff to adequately address the needs with autism spectrum disorder. Another reason for these parents not receiving sufficient help for their children is because of the lack of professionals in the particular field24-25. Professionals who deal with such disorders are specifically qualified and trained. They are trained to identify the developmental disorder, and establish a treatment program for the child, while keeping in mind the degree to which the child is affected by the autism spectrum disorder. A number of parents do not get their children the help required due to family pressure26-27. Family pressures are of many different types. Mostly it is because parents

are made to rethink about spending their family resources as the parents are not only responsible for the well-being of their one child but the other family members. In our society mother's feel more anxious as compared to the fathers because they face difficulty in managing the basic needs of other family members and in laws consider them responsible for the child on autism spectrum [28]. There is some evidence from researches which show that family pressure is also an important source of anxiety and depression in mothers of children on autism spectrum. Jo Bromley has studied the psychological well-being of parents and the results of his study indicate that mothers feel more depressed and anxious due to the family pressure and lack of family support[29].

Another reason is social acceptance, which sadly still plays a vital role in the parents' decision to attend to their child special needs. Children with disability are still not accepted in our society. They are treated differently and they are considered as a burden on the family[30-31].

The results of the present study also show that the mothers' level of anxiousness, depression and stress is more than that of the fathers. The few reasons for that being the case are because the mother has a whole different relationship with the child, as it stays nine months in a mother's womb. A mother's affiliation with the child is thus different and more profound. Another reason for her to feel more depressed is because she can foresee the number of difficulties and hardships the child would have to go through its life [32]. She can imagine the discrimination the child would face. The lack of social acceptance the child would have to endure and how he or she would not be able to enjoy and experience the many stages of human experience, like accomplishments, friendship, love, marriage etc. As in different studies it has been confirmed that the mothers feel more depression, anxiety and stress as compared to the fathers[33].

David and William conducted a study in 1992 and the result of their study shows that women feel more stressed as compared to the men in Australian society when they have a child on autism spectrum, the systematic analysis of Richard P. et.al also shows that the mothers feel more depressed and stressed due to the family pressure and social acceptance when they have a child on autism spectrum. The results of Jo Bromley's study indicated that more than half of the mothers tested positive for significant psychological distress and this was associated with low levels of family support and education of children with higher levels of challenging behaviors [34-35].

CONCLUSION:

The mothers of the children on autism spectrum are more depressed, anxious and stressed due to the financial constraints, lack of facilities, lack of professionals, social and family pressure as compared to the fathers of the children on autism spectrum.

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