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Research Article

# AUTISM: A PSYCHOLOGICAL CHALLENGE FOR THE PATIENT AND THE FAMILY

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# **Abstract:**

Objectives: Research was aimed at the comparison of the self-concept in the sibling of the children having autism with the normal children siblings in the perspective of the psychological well-being of the mothers. Study Design: Comparative cross-sectional research study. Place and Duration: Research was completed from October, 2011 to March, 2013 in the various children institutes of Lahore dealing with the children having autism. Method: These children were diagnosed autism in the institutes that cater the special requirements of the children; various children were included in the research after they meet the criteria. Siblings with counterparts were evaluated for self-concept and the assessment of the mothers was carried out in the perspective of psychological well-being. Results: Research observed that typical children sibling self-concept was poorer in comparison to the normal children siblings in terms of autism. Children's mothers with autism were more depressed in comparison to the mothers of the normal children. Poor self-concept was associated with the autism in the child and it was a significant predicator for behavioral mal-adjustment, popularity, scholastic status, satisfaction and happiness related sibling's self-concept. Conclusion: Difference in the sibling's self-concept in the 2 groups was attributed to the autism present in the children.

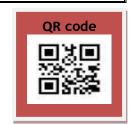
**Keywords:** Autism, Siblings, Self-Concept and Mothers psychological well-being.

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# **INTRODUCTION:**

The key concept of the personality of a child is associated with his/her perception that is formed with the interactivity of the environment and exposure to the society. Pleasant experiences of the family, bond of parents and children and positive interaction of the sibling with the nature for nurturing. However, in the presence of any disability in the children upsets the family system and everybody has concerns about the disabled child. Our research points out that positive self-concept indicates the social relationship, psychological health and life compatibility in terms of events to keep an individual distant from the difficulties of the behavior. A negative perception of the sense of guilt and self-concept may lead to depression and social isolation.

Mental stress of the family increases in the presence of a child with autism and because of the inadequate parenting the poor self-concept also builds up. Children face adjustment issues as the mothers have increased issues of distress and less interaction with the child because of the mall-adjustment of the child. Mothers experiencing increased emotional distress also reflect negative and disengaged parenting. There is a developmental perspective of the maternal distress on the overall development of the child is reflected through research studies in less number. In a setting like Pakistan a disabled child faces many issues and whole family suffers because of these issues of the child. Less research work has been done in these aspects in the setting of an under-developed country like Pakistan. American Autism Society maintains that autism is present in 4 children out of 100, it is also indicated that situation is even worse in countries like Pakistan. According to the Daily Dawn (2015), in Pakistan the total number of children with autism may have reached 350,000. It directly shows that huge number of families are living a distressed life. This issue has been ignored since long. A deep research in this regard is the need of the hour and we did this little effort for the assessment of the objective of the research, we carried out a comparative cross-sectional research that was aimed at the comparison of the selfconcept in the sibling of the children having autism with the normal children siblings in the perspective of the psychological well-being of the mothers.

#### **METHODOLOGY:**

Research was aimed at the comparison of the self-concept in the sibling of the children having autism with the normal children siblings in the perspective of the psychological well-being of the mothers. Comparative cross-sectional research study. Research was completed from October, 2011 to March, 2013 in the various children institutes of Lahore dealing with

the children having autism. These children were diagnosed autism in the institutes that cater the special requirements of the children: various children were included in the research after they meet the criteria. Siblings with counterparts were evaluated for selfconcept and the assessment of the mothers was carried out in the perspective of psychological well-being. A total of 310 children were selected for the research sample and they were divided in 2 groups as children having autism, siblings and mothers and second groups consisted of normal children. Children were shortlisted on the basis of their gender, age, birth order, mothers and educational institution. Criteria was the children with 4 years of total age and having at least a typical sibling in the age group of 6 - 20 years. In second group the criteria were matching the sibling as in Group-I. To minimize external factors that may have an impact on the self-concept, in the children having autism and also had a typical sibling but had another sibling having some kind of other disability, having the same parents or may be of the divorced couples, or having parent with a lethal ailment were not included in the research study. Various sources were used for the data collection. We made contact with the affected families through schools of special education, city hospitals and clinics. Sampling method employed was snowball sampling and also consulted online groups of the autism children and their families. At first, demographic data was collected including gender, birth order, age, siblings number and age, health status, ordinal position, parents matrimonial age and position, professions and educational background. Data analysis reflected that majority of the autism cases were male with a proportion of (75.8%) and mean age was calculated as (8.28) years. However, majority of typical siblings (61.3%) were females and majority was aged than child having autism (70.96%).

In the 2<sup>nd</sup> step children having autism and their siblings were shortlisted on the basis of the set criteria. Autism severity was evaluated with the help of CARS (Childhood Autism Rating Scale), it is basically a fifteen item tool for the intensity evaluation of the autism through behavior and observation. Self-concept was measured through Piers-Harris Self-Concept scale in the siblings. This scale consists of 60 items which present a total assessment about the perception of an individual through satisfaction, happiness, popularity, physical appearance, behavioral adjustment and attributes. DASS (Depression, Anxiety and Stress Scale) was used for the measurement of the maternal stress through frequency, intensity and negative Approval was secured before emotions. employment of these tools from the participants.

At 3<sup>rd</sup> step counterparts were included in the research for the collection of data in Group-II to match

characteristics of the siblings with Group-I for the assessment of the self-concept through Piers-Harris scale of self-concept. Mother were assessed for depression, stress and anxiety with the help of DASS.

#### **RESULTS:**

Both the groups were processed through rigorous and repeated analysis for the difference finding to analyze the data for reliability through Cronbach alpha scales. Self-concept was compared through Sample T-test in the siblings of children having autism with the siblings of those children which were normal, Pearson Product Coefficient Correlation was employed for the assessment of the association among the hierarchical regression and variables of the self-concept prediction in the siblings of children having autism.

Our research indicated about the self-concept of siblings of children having autism that it was considerably poor than of the typical children. Siblings

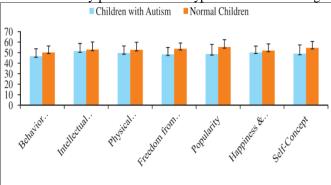


FIGURE-1: COMPARISON OF SELF CONCEPT OF SIBLINGS OF CHILDREN WITH AUTISM (N=62) WITH SIBLINGS OF NORMAL CHILDREN (N=62)

of children diagnosed with autism presented significant poor result in terms of behavioral adjustment; attributes and physical appearance and self-concept popularity. Figure-I represents the depression and anxiety comparison of both the groups as more depression and anxiety was present in the Group-I. Same was the case with the mothers as mothers of the children with autism were more depressed as shown in Figure-II.

A poor conduct adjustment, discontentment and unhappiness was reflected by the family's distress and anxiety in the families having autism cases. Self-concept had also a link with the school status and intellect that can be noticed through mother's depression. Level of the anxiety in the mothers and number of the siblings was considered as an important depression predictor as shown in Table-I, Figure-III and IV.

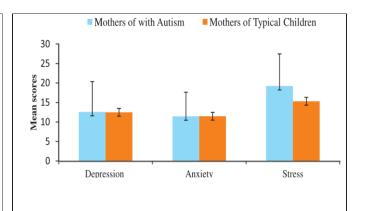


FIGURE-2: DIFFERENCE IN MATERNAL DEPRESSION,
ANXIETY AND STRESS OF AUTISTIC AND TYPICAL CHILDREN (N=62)

TABLE - I: SUMMARY OF HIERARCHICAL REGRESSION ANALYSIS PREDICTING BEHAVIORAL ADJUSTMENT (SELF CONCEPT) OF SIBLINGS FROM MATERNAL DISTRESS (N=62)

		havior		Intellectual and			Freedom from Anxiety			Happiness and		
	Adjustment			School Status			,			Satisfaction		
Predictors	В	SE B	в	В	SE B	в	В	SE B	в	В	SE B	в
Constant	12.58	2.29		15.98	2.36		13.158	2.048		10.33	1.37	
Mother's Age	01	.04	01	09	.04	- .21*	-0.08	0.04	-0.21*	03	.02	14
Mothers' Education	04	.11	04	02	.11	02	0.03	0.09	0.03	05	.06	09
Working Mothers/Non Working	36	.55	06	54	.57	09	-0.38	0.49	-0.07	.13	.33	.04
No. of Siblings	.02	.23	.01	.34	.23	.14	0.46	0.20	0.21*	.13	.13	.10
Maternal Depression	.06	.10	.16	12	.11	33	-0.06	0.09	-0.17	.05	.06	.22
Maternal Anxiety	19	.09	- .47*	13	.09	31	-0.05	0.08	-0.12	10	.05	44
Maternal Stress	02	.06	07	.08	.06	.23	-0.01	0.05	-0.04	03	.03	19
Presence of child with Autism	86	.45	19	-1.01	.46	.21*	-2.12	0.40	0.47***	34	.27	13
Mother's Depression*Autism	01	.12	10	.02	.12	.04	-0.05	0.11	-0.12	11	.07	42
Mother's Anxiety*Autism	.28	.11	.54*	.15	.11	.26	0.13	0.10	0.24	.16	.07	.52*
Mother's Stress*Autism	06	.08	15	05	.08	12	0.003	0.10	-0.01	.05	.07	.23
R <sup>2</sup>	1.00	.15*			.21	.12	0.000	.31	0.01		.12*	1.23
F for change in R <sup>2</sup>		3.36			1.17			.65			2.82	

*Note.* \*p < .05, \*\*p < .01, \*\*\*p < .001

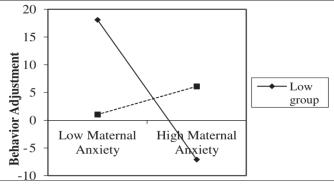


FIGURE-3: MATERNAL ANXIETY EXPLAINING BEHAVIORAL ADJUSTMENT OF SIBLINGS OF CHILDREN WITH AUTISM AND SIBLINGS OF TYPICAL CHILDREN. (N=62)

# **DISCUSSION:**

Our research found that dissatisfaction in the siblings of children having autism was more in comparison to the siblings of normal children in terms of self-concept. An adaptation of unsatisfactory behavior; expression of negative opinions in the physical attributes and appearance; dissatisfaction in the experience and popularity caused anxiety in the autism cases. Mellor also found the same outcomes in his research when he compared both the groups in terms of self-concept. Few earlier studies also opine the same results in the global perspective. Contrarily, there is an increased positive self-concept in siblings of children having illnesses and

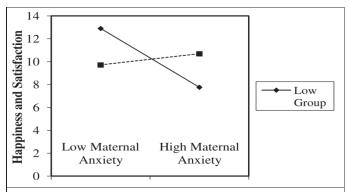


FIGURE-4: MATERNAL ANXIETY
EXPLAINING HAPPINESS
AND SATISFACTION OF SIBLINGS OF
CHILDREN WITH
AUTISM AND SIBLINGS OF TYPICAL
CHILDREN. (N=62)

disabilities, which are contrary to our research as they concluded about the siblings of children having autism that they presented an optimistic view in the conduct, academic performance and intellect and less anxiety was reflected in those cases. An overall personal experience about the characteristics was positive when it was compared with the siblings of normal children. However, a research view also suggests no variation in the children developmental challenges in control and normal cases in terms of self-concept. This difference in both the research studies may be attributed to the family and cultural differences. Children with autism are challenge for the families as they need to overcome

other responsibilities and preoccupations in the household routine, which also affects the social fabric of the families. Another fact is that lower-esteem can be the result of the offensive remarks. In a country like ours the environment around a child also plays a vital role about the self-concept. For instance, looks and physical appearances may distort the overall appearance of the children. In our research repeated feature was the welcoming and better appearance of the child having autism that may have caused the dejection and poor rate of self-concept. Although, these cases act as introvert and they are reluctant in developing friendships. They consider it the basic cause of their loneliness and fail to adjust that decreases their popularity. A mother's analysis reflects about the mothers that in the autism cases and in the normal cases there is no difference in terms of depression and anxiety, which is again contrary to the previous results. It also indicates the mother's depression level in autism cases including disabilities of the intellect. However, in the light of earlier research mothers of the children having autism are under stress more than the normal cases. According to our research, incidence of the children having autism and mother's age are important forecasters of poor self-concept and behavioral adjustment, anxiety and academic performance among siblings. Another predictor is maternal age for scholastic self-concept type. With the growing age of the mother the scholastic performance and other related incidence of self-concept also decreases among siblings, it also affects behavioral adjustment and it can be said that an increase in maternal anxiety, maladjustment increases. In the same way, higher rate of depression and mother's age causes lower scholastic status and scores about liberty by anxiety for siblings and majority of children are also affected in terms of liberty from anxiety type of self-concept. With an increased count of children, freedom from anxiety decreased. Autism in the children caused poor selfconcept and poor popularity that resulted in the shape of unhappiness and dissatisfaction.

Scarce literature is available on the topic in Pakistan; therefore, our study becomes an important contribution on this subject. However, more probes and investigations can be made in this regard for the solution of the problem in Pakistani setting. There is a huge lack of institutional support, physical support, illiteracy, poor level of parent's awareness and most of all the attached stigma of being disable increases the problems and their remedial action for the children having autism brings for the families and siblings.

# **CONCLUSION:**

Research concludes that dissatisfaction in the siblings of children having autism was more in comparison to the siblings of normal children in terms of self-concept. An adaptation of unsatisfactory behavior; expression of negative opinions in the physical attributes and appearance; dissatisfaction in the experience and popularity caused anxiety in the autism cases. Difference in the sibling's self-concept in the 2 groups was attributed to the autism present in the children.

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