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Adjustment Problems among Mothers of Children with and without Autism Spectrum Disorder

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The present study compared adjustment problems in mothers of children with Autism Spectrum Disorder (ASD) with mothers having normal children. 132 mothers (122 mother from main study and 10 mothers from pilot study) of children with ASD (Clinical group, n=66) and mothers with normal children (Normal group, n= 66) were included in study. Mothers of ASD children were recruited from six different institutions for mentally challenged children. Mothers of normal children were taken from six mainstream schools. Data was collected by administering a Demographic Questionnaire, Bell's Adjustment Inventory and Self Report Questionnaires. A Cross Sectional Research Design was used. Descriptive statistics, Independent sample t-test was used to analyze the data. Results showed that mothers of children with ASD reported greater Emotional Adjustment Problems, Health Adjustment Problems, and Social Adjustment Problems as compared to normal group. Conversely, there was no difference in mothers on Home Adjustment. These findings have implications for intervention with mothers of children with ASD. Future studies need to focus on maternal counseling that would help in decreasing their adjustment difficulties.

Keywords: Adjustment problems; Autism Spectrum Disorder, mothers.

A disability does not only affect the person but it also affects all family members in different domains (Crnic, Friedrich, & Greenberg, 1983). Rearing a handicapped child can be very difficult as with the manifestations of Autism parents get progressively confused and apprehensive about the uncertain future of their children. The communication of the diagnosis of a disabled child usually becomes a traumatic event for the family (Symon, 2001).

Bristol, Gallagher and Holt (1993) reported that personal difficulties reported by mothers of children with Autism include: increased stress; poor physical health; depression; excessive time demands; parental burnout; and concerns about their child's dependency, effect on family life, and future psychosocial problems. There is a dearth of

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empirical literature in Pakistan describing adjustment problems in parents of children with Autism Spectrum Disorder. In a developing country like Pakistan, children with developmental delay have traditionally been the sole responsibility of mothers; therefore having such a child is of great challenge to the mental health of the mother. It often requires a reorientation and reevaluation of the family goals, responsibilities and relationships. Considering the mental health of the mothers could be adversely affected while taking care of children with ASD, the present study was planned to discover the adjustment problems of mothers of children with ASD.

Adjustment is an umbrella term and often used as a synonym for accommodation and adaptation. Kulshrestha (1979) explained that the adjustment process is a way in which the individual attempts to deal with stress, tensions, conflicts etc and meet his or her needs. In this process, the individual also makes effort to maintain harmonious relationships with the environment.

Families having a child with autism have reported the greatest levels of stress (Boyd, 2002). Care giver encounter different pressures in the course of everyday living; and often they try to handle them to their best ability. When these pressures seriously affect one's coping resources, they lead to maladjusted behaviors (Davison, Neale, & Kring, 2001).

Adjustment problems refer to maladaptive reactions to a stressful situation occurring soon after the onset of the stressor. The individual fails to adjust properly to new stressful condition of life. Stress results from simultaneous occurrence of two or more incompatible needs or motives (Morgan, 1987). The parenting stress and adjustment problems experienced by the parents depends on some objective and subjective factors, including severity of the disability, parents' appraisal of the situation, and their coping resources (Dyson 1997). Allik, Larsson, and Smedje (2006) have suggested that the mothers of children with Asperger Disorder have poorer physical and mental health than mothers of normal children.

There is a dire need for researchers to explore the experiences regarding adjustment problems of families engaged in educational interventions for autism so that mothers of children with ASD can adopt effective coping mechanisms and manage maladjustment experienced during difficult parenting (Hastings et al., 2005).

The aim of the present study is to highlight maternal home adjustment, health adjustment, social adjustment and emotional adjustment of mothers of children with ASD. The care giver's adjustment problems are important to rule out because they affect not only the parent's well being but also its outcome. Studying maternal Adjustment problems among mothers of children with Pervasive Developmental Disorders (PDDs) is incredibly important because the literature on childhood Autism Spectrum Disorder clearly indicates that there is limited research available on many aspects of the topic. For instance, there is relatively little research that focuses explicitly on adjustment problems in families of children with autism (Hastings, Kovshoff, Brown, Ward, Espinosa &

Remington, 2005) or on the social impact upon families of having a child with an Autism Spectrum Disorder (Higgins, Bailey & Pearce, 2005). Therefore, there is a dire need for researchers to explore the experiences regarding adjustments problems of families engaged in educational interventions for autism (Hastings & Johnson, 2001). Therapeutic program can be designed on the basis of findings in order to reduce and prevent adjustment problems and enhancing psychological wellbeing. Therefore the present study aimed to examine adjustment problems of mothers of children having Autism spectrum disorder.

Hypotheses

1. There is likely to be significant difference in parental stress between mothers of PDD children and mothers of normal children.
2. There is likely to be significant difference in home adjustment problems between mothers of PDD children and mothers of normal children.
3. There is likely to be significant difference in emotional adjustment problems between mothers of PDD children and mothers of normal children.
4. There is likely to be significant difference in social adjustment problems between mothers of PDD children and mothers of normal children.

Method

Participants

The present study included a purposive sample of 132 mothers of children with ASD (Clinical group, n=66) and mothers of normal children (Normal group, n= 66). Mothers of ASD children with mean age of 33 (SD =4.79) were recruited from six different institutions for mentally challenged children, namely: Centre of Mentally and Physically Affected Special Students (n=8); Autism Institute of Pakistan (n=10); The Dimensions (n=7); Govt. Shadab Training Institute for Special Education (n=2); The Rising Sun (n=24) and Amin Mukhtab (n=15). The age range of children was between 3 to 12 years (M = 7.68, SD = 2.60).

The Normal group was matched on the age, religious inclination, education, marital status and occupation of the mothers of the clinical group. Both groups were comparable on the gender of the child. A sample of 66 mothers (M = 33.07, SD = 5.41) of normal children were recruited through six different normal schools namely: Qurban and Surraya Trust, Government Elementary School for Boys; Government High School for Girls; Iqra Model High school; Shaheen Institue; Mumtaz Public High School and Pasha Model High School. Mothers in both the groups were the main care providers at home and were educated at least up till middle (8th grade). The age range of children was between 3 to 12 years (M = 7.54, SD = 2.21).

Measures

Bell's adjustment inventory. This 140 item inventory was developed by Bell (1934) comprises of five subscales namely: Occupational Adjustment, Home Adjustment, Health Adjustment, Social Adjustment and Emotional Adjustment. The Occupational

Adjustment subscale was not used in the present study because all the mothers were housewives. High score refers to poor adjustment in specific areas. The reliability for the specific areas and total adjustment ranges from 0.75 to 0.95 by test-retest method and from 0.80 to 0.89 by odd-even method. Its validity is 0.785. An adapted Urdu version of Bell's Adjustment Inventory was used (Sheikh, Kausar, & Tabassum, 1994).

Demographic questionnaire. A self developed demographic questionnaire was used which included information regarding: Age; education; occupation; family monthly income; religion; family system; and history of psychiatric illness, number of children with ASD in the family, birth order, age and gender of the child.

Self report questionnaire. This self developed questionnaire comprised of five questions, which covered five different dimensions including, how they felt while filling in the questionnaire, the difficulty level they faced in understandability of language, length of questionnaire, time taken and their own suggestions or recommendations.

Procedure

Pilot study. For pilot study, five mothers of children with and without ASD were assessed in the pilot study. The age of the children ranged from three to twelve years with sample drawn through two institutions of mentally challenged children and two schools of normal children. Firstly, written permissions were taken from the principals of institutions of mentally challenged children and schools of normal children.

The school administration helped the researcher in approaching the mothers of the children. Secondly, the rationale and procedure of the study was explained to the participants. They were assured about the confidentiality of their identities, and the information provided, and assurance was also provided that the information given by them would be solely used for research purposes. Thirdly, written consent was obtained from each participant. Finally, participants were administered Bell's Adjustment Inventory, Demographic Questionnaire and Self Report Questionnaire. The purpose of the pilot study was to check for the comprehension of questions and time taken in filling in the questionnaire. Individual administration was carried out in a single sitting. A self report questionnaire was used to take feedback from the participants. Most of the participants appreciated the concept, and found the questionnaires interesting and easy to comprehend.

Main Study. In the main study, same procedure was followed as in the pilot study. Although, 78 mothers of children with ASD were approached through school authorities, only 61 mothers completed the questionnaires. After collecting data of clinical group, two class intervals of equal interval of age of mother and child and education of the mother were made to collect data of mothers in normal group to control for confounding variables (see table 1). Furthermore, normal group was also matched on religion, occupation and marital status of the mothers with the clinical group. All the mothers were Muslims, married and housewives, both groups were also made comparable on the

gender of the children. There were 57 boys and nine girls in each group. Participants took 35 to 45 minutes to complete the questionnaires in a single sitting. The present study took ten months to complete.

Results

Independent sample t- test is calculated to find out the difference on adjustment problems of mother of children with ASD and the mothers of normal children (N = 132) as measured by Bell's Adjustment Inventory. Out of 132 mothers, 122 mothers were recruited for main study and 10 for pilot study. Descriptive statistics are also used to calculate Mean, Standard Deviation, Frequency, Percentage etc.

Table 1

Frequency of Number of Children in Clinical and Normal Groups, their Age as well as their Mother's Education and Age.

Age of the child in years	Years of education in years	Age of the mother	Groups	
			<u>Clinical</u> <i>F</i>	<u>NORMAL</u> <i>F</i>
3-8	7-12	25-35	7	7
3-8	7-12	35-45	4	4
3-8	12-17	25-35	16	16
3-8	12-17	35-45	5	5
8-13	7-12	25-35	8	8
8-13	7-12	35-45	2	2
8-13	12-17	25-35	7	7
8-13	12-17	35-45	17	17

Note. Class intervals are counted by excluding the upper limits.

Table 2

Independent Sample t-test for Home Adjustment, Emotional Adjustment, Health Adjustment, Social Adjustment Scales of Bell's Adjustment Inventory of Mothers with ASD Children and Mothers with Normal Children (N= 132).

Variables	Clinical group		Normal group		t	Cohen's d
	M	SD	M	SD		
Health Adjustment	14.05	4.01	11.33	1.93	4.94**	0.86
Social Adjustment	16.17	3.97	11.80	3.12	7.01**	1.22
Home Adjustment	15.36	3.9	14.89	3.41	0.73	0.12
Emotional Adjustment	16.03	4.01	10.73	1.97	9.62**	1.67

Note: **= $p < .01$

The above table shows that mothers of ASD children face more health adjustment problems as compared to normal group. Moreover, mothers of ASD children reported more social adjustment problems than normal group. Furthermore, mothers of PDD children reported more emotional adjustment problems than normal group. Therefore, results of independent sample t-test revealed the value of t as being significant for both health and social adjustment problems.

Analysis shows that the value of t is insignificant for home adjustment problems. That is there is no difference between mothers of children with ASD children and normal children on home adjustment problems. They are experiencing equal levels of home adjustment problems. Consequently, the hypothesis was partially accepted.

Discussion

The results of independent sample t-test revealed that the value of t (refer to table 1) of the present study showed significant differences on Social, Health, and emotional adjustment problems.

The fact that more social adjustment problems were reported by mothers of children with ASD children than by mothers of normal children indicates that the social isolation experienced by families of autistic children can be severe. Isolation may occur for a variety of reasons and leave parents lonely and depressed (Pearlin, Mullan, Semple, & Skaff, 1990) with a negative self-concept (Pearlin, Lieberman, Menaghan, & Mullan, 1981). Many parents have a difficult time socializing with parents of normal children,

and some of them cannot identify themselves with social circle around them. As the child with autism grows older and the difference between his/her peers becomes more obvious, parents might feel more isolated. Friendships may dissolve as caretakers abandon hobbies and outside interests. Another possible reason may be that parents of autistic children hold the opinion that their child has negative characteristics and therefore, as Gallagher and colleagues (1993) reported, experience more feelings of stigmatization (as cited in Gray, 1993). Mothers of autistic children may be at increased risk for psychosocial difficulties because of the scarcity of professional resources, unrelieved parental responsibilities, parental loneliness and isolation, and their child's slow progress (Bishop, Richler, Cain, & Lord, 2007).

The results also indicated that more health adjustment problems were faced by mothers of children with ASD than normal children. Previous literature showed that hectic schedules and unusual meal planned around the child may lead to vitamin and mineral deficiencies, and sleep deprivation that may further result in difficulties in concentrating, memory impairment, and other health complications in parents of ASD children (Rodrigue, Morgan, & Geffken, 1990). Findings of study of Allik, Larsson, and Smedje (2006) also supported the hypothesis who suggested that the mothers of children with Asperger Disorder (sub category of ASD) have more health related problems as compared to the controls indicating poorer physical and mental health. In the Asperger Disorder, maternal health was related to behavioral problems such as hyperactivity and conduct problems in the child.

Furthermore the findings of the analysis indicated the mothers of children with ASD reported more emotional adjustment problems as compared to mothers of normal children. Mothers of ASD children experience emotional adjustment problems as when the diagnosis of the disabled child is made by a clinician following the assessment and screening, the parents may have feelings of fear, rejection or shock. If the parents are not given some hope, they may have a severe grief reaction (Lainhart, 1999). Another possible explanation could be that the diagnosis of the child, which is a developmental disorder, is sometimes considered as the death of the expected normal child. Most of the parents of developmentally delayed children experience the mourning process but the stage progression and/or the length of the stages may be based on individual differences (Seligman, 1985).

Having a child with ASD may cause emotional distress in mothers that begins before the diagnosis and continues throughout life. Parents and other family members of children with ASD often feel alone, isolated, and ignored before receiving a diagnosis for their child. Upon learning that their child may be autistic, emotions may fluctuate between the reliefs of finally knowing what is wrong, to the despair that the child suffers from a disability with no known cure. When the diagnosis got confirmed then the family of the child experience confusion, guilt, anger, depression, and resentment (Valman, 1981, as cited in Shapiro, 1983). Anger and guilt can be devastating to marriages and other family relationships if not dealt properly.

The analysis showed an insignificant difference on home adjustment between the two groups of parents. This indicates that mothers are experiencing an equal amount of home adjustment problems. Yau and Li-Tsang (1999) proposed that despite the fact that the birth of a child with developmental disability may impose extra demands on the parents, some adaptive and successful functioning can also occur in these families. However, this has not received enough attention, similarly, Byrne and Cunningham (1985) claimed that, the assumption that psychological impairment is an inevitable consequence for the families of handicapped children, has turned to an overgeneralization. According to Shapiro (1983) parents are troubled about the tendency of the professionals to put too much emphasis on the negative aspects of the experience, and underestimate their capacity of adjustment. Greenberg et al. (1994, cited in Schwartz & Gidron, 2002) proposed that caring for a mentally ill child has led some parents to personal growth and self awareness. They reported that, parents feel more tolerant, stronger, and less judgmental. It was also found that the divorce rate among parents of autistic children were significantly lower than the average of the population (Akerley, 1984, as cited in Rodrigue, Morgan, & Geffken, 1990).

Studies that have considered both the beneficial and the deleterious effects on families of disabled children have suggested that responses can range from positive adjustment to distressed maladaptation (Seligman, 1985). Indeed, it seems that families can fluctuate through periods of strength and weakness depending on the situational context and that subsystem within a family unit can respond differentially to the presence of a handicapped member (Seltzer, Abbeduto, Krauss, Greenberg, & Swe 2004). The present study results support the findings of the earlier researchers partially. The mothers of ASD children might have adequate home adjustment due to their personal growth and self awareness. They may have felt their self as tolerant, stronger, and less judgmental as the mothers of normal children. Though three adjustment variables showed significant differences between the two sets of parents, lack of difference on home adjustment partially supports the conjecture.

Limitations and Suggestions

The findings of this study needs to be interpreted with caution in view that the present study is an exploratory one and has few limitations. Some participants in this study were volunteers and most of the mothers of children were associated with organizations or support group, through which they were recruited. Persons who volunteer for studies or who belong to support groups may have fewer adjustment problems than persons who do not volunteer for research. Positive growth as a result of an adversity was not measured in the present study. Future study is needs to address positive growth in the mother of children with ASD. The present findings have clear implications for the clinicians. The results seem to indicate that there is a need to properly assess adjustment problems experienced by these parents and include interventions to help them. Behavioral management and special education programs can be recommended to mothers who are experiencing such adjustment problems. In the long run, the present researchers believe

that health professionals need to focus on supportive therapy for these parents.

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