MOTHERS OF CHILDREN WITH DEVELOPMENTAL DISABILITIES: AN ANALYSIS OF PSYCHOPATHOLOGY

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ABSTRACT

Objective: To compare the psychopathology in mothers of autistic children with mothers of mentally retarded children.

Design: Cross section study.

Place and duration of study: This study was carried out on mothers of children studying in special schools across Mumbai, India from January 2006 to January 2009.

Subject and Methods: 300 mothers each of children with mental retardation were rated on the Beck Depression Scale, Toronto Alexithymia Scale, State-Trait Anxiety Inventory and Symptom Checklist-90 Revised. The data was tabulated and statistically analysed.

Results: Mothers of autistic children had significantly greater depression than mothers of mentally retarded children ($p = 0.0481$). Anxiety state and trait scores were significantly higher in these groups though psychopathological anxiety was absent ($p = 0.0057$, $p = 0.0002$). Mothers of mental retarded children had greater alexithymia scores and a significant majority of them had alexithymia of a pathological nature ($p = 0.0001$). They also had higher somatization scores on the SCL-90 ($p = 0.031$) while autistic mothers reflected greater anxiety ($p = 0.0016$) and general symptomatology index scores ($p = 0.0021$).

Conclusion: The psychopathology in mothers of children with developmental disabilities warrants attention in any program designed to treat children with autism and mental retardation.

Key Words: Developmental disabilities, Psychopathology, Autistic children.

INTRODUCTION

The birth of a disabled child induces complex feelings in both the parents. There is denial, shock, aggression, unhappiness and even lack of acceptance[1]. Many a times, mothers even refuse screening for disabilities in the antenatal period as they would not wish this reality to dawn upon them[2]. Feelings of guilt, depression, anxiety are all part of the adjustment process and though some of the mothers adjust well, psychopathology remains rampant among the others[3-4].

Many disabled children are on medications for long periods and visit specialists from different medical specialties in addition to speech and occupational therapy. The cost of this is often borne by parents only adding to their woes each time[5]. In India particularly the cost of medical treatments are borne by the patient as there is no government support or health schemes like in the US and UK. A child with developmental disabilities may visit a psychiatrist, neurologist, pediatrician, occupational therapist, physiotherapist, special educator and speech therapist. The cost of all therapies and medical opinions are borne by the parents. This often puts a large financial burden on the family especially if from the lower socio-economic strata.

Mothers of children with intellectual disabilities have been proven to experience higher levels of stress and depression than their spouses[6-8]. It has been noted that mothers of autistic children show an increased anxiety with respect to the poor social relatedness, delayed speech development, hyperactivity, behavioural problems and lack of eye contact in their children[9-11]. Mothers of autistic children are also more introverted and neurotic than other mothers. They have also been proven to be more frustrated, oversensitive and stern than other mothers[12]. Studies have also presented that 33-53% of mothers with disabled children have depressive symptoms[13] and on comparing mothers of children with Down's syndrome and autism, it is found that the mothers of autistic children were more distressed and also have limited social support[14]. The present study is based on a similar study conducted in Turkey where psychopathology in mothers of mentally retarded children were compared with mothers of autistic children[15].

There are epidemiological studies on mental retardation and autism in India, but there is relatively little data on the psychopathology of mothers that rear these children. Today the roles of men and women in families are being redefined. Mothers and fathers are being studied more often in various fields of medicine.

We aim to throw light on the psychopathology of the Indian mother that has to bring up a disabled child.

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The aim of this study was to compare the psychopathology in mothers of autistic children with mothers of mentally retarded children. In our regular clinical work involving support groups and individual therapy with these mothers we had observed a diverse presentation of psychopathology across mothers of children with mental retardation and autism. Hence rather than use a control group with normal mainstream children we decided to compare the two groups and see what difference emerged. There have been many studies comparing mothers of children with developmental disabilities to mothers of normal school going children but few that compares mothers within the disabilities. Hence we had the impetus to move in this direction.

SUBJECT AND METHODS

Subjects – The study subjects were mothers of children between the ages of 8 – 12 years with autism and mental retardation that were attending special schools in Mumbai. The mothers were those whose children were in special schools across Mumbai and met our inclusion criteria. The study was conducted over a three year period from Jan 2006 to Jan 2009 and no exact sample size was calculated. The schools that the author visits has around 1000 mothers each of children with mental retardation and autism – hence an arbitrary sample size of 300 in each group was decided upon. The study was a cross sectional one. A total of 600 mothers were analyzed. 300 mothers having children with autism & 300 having children with mental retardation were selected for the study on the following criteria.

The Children – These children were those that had been diagnosed at least a year before as having Autistic Disorder or Moderate or Severe Mental Retardation and presently satisfied the Diagnostic and Statistical Manual for Psychiatric Disorders – IV (DSM-IV) for the same[16]. The diagnosis was made by the psychiatrist who was treating the child.

Severity of Disability in the children – The Children Autism Rating Scale (CARS)[17] was administered to the children prior to the study and mothers of children with a score between 34 and 52 reflecting moderate to severe autism were selected for the study. This scale is the only autism scale validated in an Asian population[18]. The IQs of the children with mental retardation was rated by the Wechsler Children Intelligence Scale – Revised (WISC-R). Mothers of children with moderate or severe mental retardation were selected for the study. The IQs of children with autism were assessed by a clinical psychologist using WISC-R and children with IQ above 70 were chosen for the study. This was done as the presence of mental retardation in the autism group could confound our findings.

Inclusion criteria for the mothers

1. Age group 18-50 years.
2. They never suffered from a psychiatric disorder in the past and never took any psychiatric medication in their lifetime (assessed via history and clinical evaluation).
3. Non-consanguinous marriage.
4. They were residing in the same place of residence since the past 5 years.
5. They had only one child with developmental disability (mental retardation or autism).
6. They were all staying with their husband.
7. They did not suffer from any medical illness or physical disability.

Inclusion Criteria for the Children

1. Age group 8-12 years.
2. They were diagnosed with autism or mental retardation by their treating doctor at least 6 months prior to the study.
3. They had no physical disability / visual or hearing impairment

SCALES USED

The study was performed in a cross sectional manner.

Age, education history, occupation and other relevant data were recorded in the data form. Mothers were clinically interviewed using the following scales –

1. **Beck Depression Inventory (BDI)** – evaluates depression and its emotional, cognitive and motivational components with 21 items. Scores range from 0-63 where 10-15 reflects mild depression, 16-23 reflects moderate depression and 24-63 reflects severe depression[19-20].
2. **State Trait Anxiety Inventory (STAI)** – is a self report scale that evaluates anxiety state and anxiety trait separately with questions of 20 items each. Scores range from 20-80 where a score greater than 60 signifies overanxiety[21].
3. **Toronto Alexithymia Scale (TAS)** – is a self report scale that assesses alexithymia with 26 items. Scores of 11 or over confirm alexithymia while those of less than 11 rule it out. It has been used in a wide variety of settings and cultures and is the only scale used widely in the Asian population[22-23].
4. **Symptom Checklist -90 (SCL-90)** – This is a self report scale that has been widely used in the normal as well as distressed populations. 90 items are divided into 9 subscales that include Somatization, Obsessive Compulsive, Interpersonal Sensitivity, Depression, Anxiety, Anger-Hostility, Phobia, Paranoia and Psychoticism. The scales have a lickert type scale of distress from 0 to 4. Scores are defined as General Symptom Index (GSI) with higher scores representing more psychopathology. Scores on each scale from 0 to 0.99 are nor-

mal while scores over 1 represent psychopathology[24].

SPSS statistical software package was used for the data analysis. Chi square test and Student t test were used in the analysis. A value of $p < 0.05$ was considered significant. The entire statistical analysis was done by a qualified bio-statistician.

RESULTS & DISCUSSION

As shown in table 1, the two groups did not differ in socio-demographic data and were well matched in all regards. Majority of mothers in both groups were graduates. This could probably be due to the fact that only the educated mothers understood the need of such of a study and consented for the same. Another factor is that in India only parents who are earning well can afford special education due to the high fees and hence parents whose children attend special schools are often well educated and well placed.

Table 1: Sociodemographic Data of both Groups

Data	Autism mothers (N = 300)	Mental Retardation mothers (N = 300)
Age		
< 30 years	174 (58%)	156 (52%)
> 31 years	126 (42%)	144 (48%)
Education		
Primary	12 (4%)	12 (4%)
Secondary	18 (6%)	18 (6%)
Graduates & above	270 (90%)	270 (90%)
Occupational Status		
Employed	36 (12%)	24 (8%)
Unemployed	264 (88%)	276 (92)%
Religion		
Hindus	216 (72%)	234 (78%)
Muslims	84 (28%)	66 (22%)

Depression scores - When assessing the scores on the Beck Depression Inventory (BDI) (Table 2), the scores were divided into mild, moderate and severe depression. It was seen that a majority of mothers with autistic children had moderate to severe depression compared to the mothers of children with mental retardation who had more of mild to moderate depression ($p = 0.0481$). Autism mothers also had significantly higher depression scores compared to the mental retardation group ($p = 0.0035$).

Anxiety scores - On assessing the anxiety levels (Table 3), it was noted that mothers of autistic children had significantly higher scores on both state anxiety ($p = 0.0057$) and trait anxiety scales ($p = 0.0002$). Thus autistic mothers experienced anxiety both at the time of their assessment which was ongoing (state anxiety) and in addition had anxiety as an integral part of their personality (trait anxiety).

Alexithymia scores - On assessment of alexithymia it was found that in contrast to the previous scales, mothers of children with mental retardation had significantly greater scores on alexithymia ($p = 0.0001$) and a greater number of mothers having retarded children demonstrated the presence of alexithymia ($p = 0.0383$).

General Psychopathology scores - On comparing the scores on the SCL-90 scales of psychopathology (table 5), it was noted that mothers of children with mental retardation had significantly greater scores on the somatization subscale ($p = 0.0031$). This is consistent with

Table 2: Scores and Profiles on the Beck Depression Inventory (BDI)

Data	Autism mothers	Mentalr etardation mothers		p Value
BDI DEPRESSION LEVELS	**N = 300**			
NORMAL	36 (12%)	72 (24%)	$X^2 = 8.422$(df = 3)	***0.0481****
MILD	72 (24%)	120 (40%)		
MODERATE	108 (36%)	72 (24%)		
SEVERE	84 (28%)	36 (12%)		
	MEAN ± SD			
BDISCORES	16.8 ± 8.3	12.3 ± 7.2	t = 2.9938	***0.0035****

* significant.

(For Depression levels Chi Square test was used).

(For BDI Scores Student t test was used).

Table 3: Scores And Ratios of Anxiety on the State Trait Anxiety Inventory (STAI)

Data	Autism Mothers (N = 300)	Mental Retardation Mothers (N = 300)		p Values
SCORES	***Mean ± SD***			
STATE ANXIETY SCORE	46.3 ± 8.2	42.2 ± 6.1	t = 2.8285	***0.0057****
TRAIT ANXIETY SCORE	48.1 ± 6.2	43.1 ± 7.2	t = 3.8349	***0.0002****
RATIOS	***(N = 300)***			
STATE ANXIETY NORMAL	204 (68%)	192 (64%)	X^2 = 0.047(df = 1)	0.8331 NS
STATE ANXIETY PRESENT	96 (32%)	108 (36%)		
TRAIT ANXIETY NORMAL	180 (60%)	198 (66%)	X^2 = 0.174(df = 1)	0.6777 NS
TRAIT ANXIETY PRESENT	120 (40%)	102 (34%)		

* significant. NS – not significant.
(For the STAI scores Student t test was used).
(For the STAI ratios Chi square test was used).

Table 4: Scores and Ratios on the Toronto Alexithymia Scale (TAS)

Data	Autism Mothers	Mental Retardation Mothers		p Values
SCORES	***Mean ± SD***			
TAS SCORES	9.2 ± 4.1	12.3 ± 3.2	t = 4.2444	***0.0001****
RATIOS	***(N = 300)***			
NORMAL SCORES	222 (74%)	156 (52%)	X^2 = 4.291(df = 1)	***0.0383****
ALEXITHYMIA PRESENT	78 (26%)	144 (48%)		

* significant.
(For the TAS scores student t test was used in the assessment).
(For the TAS ratios Chi Square test was used in the assessment).

Table 5: Scores on the Symptom Checklist – 90 (SCL-90)

SCL-90 Scales	Autism Mothers	Mental Retardation Mothers	t Value	p Values
	Mean ± SD			
SOMATIZATION	0.77 ± 0.41	1.13 ± 0.73	3.0404	***0.0031****
OBSESSIVE COMPULSIVE	0.71 ± 0.42	0.83 ± 0.38	1.1215	0.2647
INTERPERSONALSENSITIVITY	1.09 ± 0.65	1.04 ± 0.47	0.7071	0.4812
DEPRESSION	1.22 ± 0.71	0.99 ± 0.64	1.8478	0.0677
ANXIETY	0.95 ± 0.61	0.64 ± 0.36	3.2549	***0.0016****
ANGER HOSTILITY	0.45 ± 0.39	0.53 ± 0.43	0.7054	0.4822
PHOBIC ANXIETY	1.02 ± 0.75	0.93 ± 0.52	0.8498	0.3975
PARANOIA	0.68 ± 0.41	0.61 ± 0.47	0.8869	0.3773
PSYCHOTICISM	0.51 ± 0.37	0.59 ± 0.45	1.0529	0.2950
GENERALSYMPTOMATIC INDEX	0.97 ± 0.48	0.67 ± 0.36	3.1589	***0.0021****

* significant.

(Student t test used for statistical analysis).

Table 6: Ratios of the Scales on SCL-90

Scale		Autism Mothers (N = 50)	Mental Retardation Mothers (N = 50)	Statistics (df = 1)
SOMATIZATION	***NORMAL***	222 (74%)	156 (52%)	$X^2 = 4.290$
	PSYCHOPATH.	78 (26%)	144 (48%)	***p = 0.0383****
OBSESSIVE COMPULSIVE	***NORMAL***	240 (80%)	252 (84%)	$X^2 = 0.068$
	PSYCHOPATH.	60 (20%)	48 16%)	p = 0.7946 NS
INTERPERSON SENSITIVITY	***NORMAL***	216 (72%)	198 (66%)	$X^2 = 0.187$
	PSYCHOPATH.	84 (28%)	102 (34%)	p = 0.6654 NS
DEPRESSION	***NORMAL***	168 (56%)	210 (70%)	$X^2 = 1.544$
	PSYCHOPATH.	132 (44%)	90 (30%)	p = 0.2140 NS
ANXIETY	***NORMAL***	162 (54%)	234 (78%)	$X^2 = 5.392$
	PSYCHOPATH.	138 (46%)	66 (22%)	***p = 0.0202****
ANGER HOSTILITY	***NORMAL***	204 (68%)	228 (76%)	$X^2 = 0.446$
	PSYCHOPATH.	96 (32%)	72 (24%)	p = 0.5040 NS
PHOBIC ANXIETY	***NORMAL***	204 (68%)	228 (76%)	$X^2 = 0.446$
	PSYCHOPATH.	96 (32%)	72 (24%)	p = 0.5040
PARANOIA	***NORMAL***	258 (86%)	264 (88%)	$X^2 = 0.088$
	PSYCHOPATH.	42 (14%)	36 (12%)	p = 0.7662 NS
PSYCHOTICISM	***NORMAL***	276 (92%)	270 (90%)	$X^2 = 0.122$
	PSYCHOPATH.	24 (8%)	30 (10%)	p = 0.7268 NS
GENERAL SYMPTOMATIC INDEX (GSI)	***NORMAL***	210 (70%)	228 (76%)	$X^2 = 0.206$
	PSYCHOPATH.	90 (30%)	72 (24%)	p = 0.6524 NS

NS – not significant
* - significant.
(Chi square test used for the statistical analysis).

the high degree of alexithymia depicted by these mothers. Inability to express their emotions with lower scores on the depression and anxiety scales leads often leads to increased presence of somatic symptoms. Mothers of autistic children had significantly higher scores on the anxiety subscale ($p = 0.0016$) and also had significantly greater scores on the general symptomatic index ($p = 0.0021$).

On assessing the ratio of the scales on SCL-90, it was noted that significantly greater number of mothers of children with mental retardation had psychopathological scores on the somatization subscale ($p = 0.0383$). It was also seen that significantly greater number of mothers from the autism groups had psychopathological anxiety scores ($p = 0.0202$). However there was no significant difference in the number of mothers exhibiting abnormal scores on the general symptomatic index (GSI).

DISCUSSION

A majority of the mothers in both groups were unemployed. It has been noted in previous studies that employed mothers of disabled children perceive less stress in comparison to unemployed mothers and that employment may also serve as a buffer in their depression[25]. Employed mothers usually have an outlet in the form of their job which allows them personal growth in some other area. In our clinical evaluation and work with these mothers we have seen mothers who are employed are better adjusted than those who are unemployed.

The findings on the Beck Depression Inventory is in keeping with studies in the past where it has been found that mothers of autistic children are more likely to have severe depression[26]. It is also known that depression in mothers of retarded children have more of mild depression and at times may be below the clinical cut off criteria[27-28]. It is noted in longitudinal studies that depression lasts longer and resolves much slower in mothers with autistic children[29].

Mothers of autistic children are more hypersensitive, anxious, tense and excited easily in situations compared to mothers of normal children[12,30]. Mothers of autistic children had higher scores in both state anxiety as

well as trait anxiety. Despite autistic mothers having higher scores, a majority of mothers from both groups did not exceed the cut off scores for anxiety state. Amongst those that exceeded the cut off scores, equal numbers in both groups had the presence of an anxiety trait and anxiety state. It has been noted that anxiety is prevalent in parents of children with disabilities though it may be in the form of individual symptoms and worries about the future rather than a full blown picture where a psychiatric diagnosis may be made[31].

Mothers of children with mental retardation reflected greater scores on the alexithymia subscales than mothers of children with autism. Alexithymia when introduced first was thought to be seen in individuals predisposed to developing a psychosomatic disorder such as hypertension or bronchial asthma. It is stated that patients with alexithymia are those who do not express their emotions clearly and often present with somatic symptoms, mild to moderate anxiety and depression with atypical features[32]. The mothers of mentally retarded children in our study express a similar clinical picture that probably warrants a further exploration and understanding. Alexithymia is today considered a personality trait present in an individual irrespective of actual situational stressors, but one that may influence the response to a stressor[33]. Alexithymia is considered to be an integral part of both depression and anxiety states[34-35].

Our scores on the SCL-90 are consistent with studies mentioned previously[30-31]. It also depicts the finding that mothers with autistic children have global psychopathology or psychiatric symptomatology that may be greater than mothers of children with mental retardation.

It was worthwhile noting that a large number of mothers from both groups had normal scores on the GSI. This indicates that though psychiatric symptomatology may be rampant amongst mothers of autistic and mental retarded children, they may often present as a symptom cluster or isolated symptoms that at times may not be enough to warrant a psychiatric diagnosis. It has been noted in the past that subsyndromal psychiatric disorders are often seen in this population[36-37].

LIMITATIONS

The present study is limited to a fixed population of just 300 subjects. Larger studies that encompass various cultures and settings are needed if these findings are to be replicated. The psychopathology in our study was assessed cross-sectionally. Longitudinal studies on psychopathology are needed to see if the pattern of psychopathology is static or changes over times as growth and development of children with autism and mental retardation ensue. The psychopathology in our study was not correlated with respect to child and maternal variables or to family structure and marital adjustment. We aimed to present that pattern of psychopathology that exists on the whole in mothers having children with either autism or mental retardation and to compare the two groups. The group of children with autism may have included children with borderline mental retardation that was not ruled out and this thus may have affected our results on psychopathology in their parents but not to a large extent shown by the significant differences found between the groups.

CONCLUSIONS

Psychiatric problems are common in mothers of both autistic and mentally retarded children, though they may often present as symptoms, in a subsyndromal manner and may not always help us ascertain a clear diagnosis. The alexithymia and somatic symptomatology in mothers of mentally retarded children along with the anxiety of mothers that have autistic children demands our attention and it is essential that we pay attention to the same in our day to day clinical practice when we treat this population. We have not compared the mothers in our study to a normal group, hence it is difficult to comment whether they have a greater psychopathology than the normal population.

Along with the child, psychological well being of the mother is the must in the difficult task of bringing up a child with developmental disabilities. Centres for the treatment of autism and mental retardation need to focus further on strategies to help mothers overcome these problems as well as enhance psychological support probably through regular clinical assessment and support groups for these 'special' parents.

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