
Factors contributing to stress among parents of children with autism

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ABSTRACT

Numerous autistics have behavior repertoires that might be predicted to have an impact on the family. The proposed study was designed to gauge the different factors contributing to stress among parents of children with autism between the ages of 3-14 years. Study was carried out at five institutions of Lahore on a purposively selected sample of eighty parents (both fathers & mothers) of forty children with autism.

A self prepared structured interview schedule named as Parental Stress Catalog (PSC) was used for collecting information from the parents. Descriptive statistical measures as well as independent samples t-test was used to analyze the collected data. Percentages, means and SDs of the responses, regarding different factors contributing to parental stress were found. T-test was applied to verify the differences between mothers' and fathers' responses.

Results revealed a considerable amount of stress among parents of children with autism. There were various factors (psychological, social, educational, financial and future concern) identified which caused stress in parents having children with autism but future concern of the child was a factor in which parents experienced more stress than other factors. The study also revealed that mothers suffered more stress than fathers; they consequently require special attention and counseling services from professionals.

Keywords: autism, parenting, stress

INTRODUCTION:

Autism is a disability related to communication carried out with others and the way it affects surroundings. Apart from the moderately effected ones others may need special support. Moreover, they are sensitive to smell, taste and other senses (The National Autistic Society, 2014).

Grosso, (2012) described that parents of children with autism are as different as their children so their lives are full of stressors. Parenting demands enhance and consequently there is an increased nervous tension and load on parents (Sabih & Sajid, 2008). Resultantly, they suffer from a lot of stress and anxiety (Hasting & Johnsons, 2001; Tarakheshwar & Pargament, 2001, Gray, 2002; & Sivberg, 2002). This scenario has made the context of parental stress, a contemporary focus of research. Taking care of a child with autism can prove to be a life-changing experience for parents. Not only can they be found struggling to accept their lost dreams but also, a gain in sense of coherence can be witnessed through which they accept the change in their priorities and values (King, Zwaigenbaum et al., 2006).

Altiere and Kluge, (2009) concluded that parents of children with autism have

disorientation that is an outcome of the reaction of defeat and obliteration happening after knowing that their child has autism. Though, numerous parents are anxious to bring forth their resources in the direction of help their child with autism needs, sometimes in every possible way.

According to Anderson, (2010) parents turn out to be physically and mentally drained and expressively exhausted because of certain issues and behaviors concerning their child with autism (Dunn et al., 2001). They experience powerlessness, aggravation, annoyance, distress, feelings of insufficiency, guiltiness and breakdown (Higgins et al., 2005).

The primary factor as concluded by Fleischmann, (2005) causing stress and anxiety in parents having children with autism is their child's condition. Moreover as Dixon, (2009) and Anderson, (2010) discovered, in addition to taking stress, many parents become frustrated and may undergo clinical depression or sadness.

In Pakistan, Autism has come under the limelight only in recent years. However, the word is still unheard by the majority of the population. This puts the parents of children with autism into a dilemma as very little information is available about the various health and educational facilities available for children with autism. Parents of

these children face stress in their daily lives contributed by many factors like lack of health, educational and other facilities etc. There are not only few avenues for parents of children with autism to refer to but also these services are mostly concentrated in big cities of the country. This study explored a relatively new horizon with respect to Pakistan. It is imperative that autism organizations and doctors should recognize the potential issue of parental stress. Moreover, they must teach the families as well as community the ways to tackle with those factors which contribute to parental stress.

OBJECTIVES

The study was conducted to achieve the following objectives:

- To find out the psychological and social factors contributing to stress among parents of children with autism.
- To find out the educational and financial factors contributing to stress among parents of children with autism.
- To find out the factors related to future concern of a child with autism contributing to parental stress.
- To find out whether mothers of children with autism experience more stress than fathers.

METHODOLOGY

The research design of this study was descriptive in nature and a survey was carried out for this purpose.

Population and Survey Sample

The population for the study was parents of children with autism. A sample of eighty parents (both fathers & mothers) of forty children (between the ages of 3-14 years) diagnosed with autism was purposely selected from five institutions (dealing with children with autism) of Lahore to gauge the different factors contributing to stress among parents of children with autism.

Instruments

A self prepared structured interview schedule named as Parental Stress Catalog (PSC) was used for data collection. After preparing the structured interview schedule it was being reviewed by a team of psychologists for ensuring the validity of the scale. Cronbach alpha reliability was calculated to be 0.87 indicating strong internal consistency for this scale.

Procedure

The researcher collected information from all centers and institutions dealing with children with autism in Lahore, and shortlisted five institutions which had the maximum number of children with autism for the study. Permission was taken from management of each institution. Parents were contacted through administration in order to collect data. They were explained the purpose of the research and a written consent was taken from them before the start of data collection. Parents willing participated in the research.

RESULTS

Data was entered to the grid sheet of SPSS, version 17. Descriptive statistical measures as well as independent samples t-test were conducted to analyze the data..

Table 1 reveals that there was significant difference between the responses of mothers and fathers regarding their feeling of being emotionally drained worrisome and apprehensive about having a child with autism, grief concerning the loss of the life style that they expected to have for themselves. Moreover, depression for not being able to determine their child's needs. It shows that (42.5%) respondent fathers whereas (90%) respondents mothers had extreme worries about having a child with autism, only (12.5%) respondent fathers whereas (62%) mothers had extreme grief regarding the loss of the lifestyle. (67.5%) fathers to some extent whereas (67%) mothers had extreme depression for not being able to determine their child's needs, and (52.5%) fathers while (50%) mothers to some extent become annoyed on not identifying their child's need (Table 1).

It also indicates that (60%) respondent fathers to some extent and (55%) mothers extremely felt hopeless, (60%) fathers to some extent and (72%) mothers felt extremely apprehensive, (55%) fathers to some extent whereas (67%) mothers felt extremely emotionally drained when their child did not respond to their love and affection and they had to work extra hard for their child (Table 1).

Table 2 concludes that most of the respondent fathers (65%) and mothers (75%) felt that their life was not as they anticipated so they experienced a lot of stress.

Table1: Percentage, mean and SD of responses, regarding psychological factors contributing to parental stress (n = 80) because of their child with autism.

Statements	Subjects	Extreme	To Some extent	Not very much	Never	Mean	SD	t-(78)
Worry about having a child with autism	Mothers	90	10	0	0	2.9	0.09	12.3***
	Fathers	42.5	57.5	0	0	2.4	0.24	
Grief concerning the loss of the life style	Mothers	62	30	7	0	2.5	0.45	6.8***
	Fathers	12.5	57.5	27.5	2.5	1.8	0.46	
Depression, for not being able to determine child's needs	Mothers	67	27	2	2.5	2.6	0.53	5.7***
	Fathers	15	67.5	15	2.5	2.0	0.40	
Annoyance, on not identifying child's need	Mothers	37	50	12	0	2.2	0.48	0.8
	Fathers	32.5	52.5	10	5	2.1	0.61	
Feeling of despair, when the child doesn't respond to their love & affection	Mothers	55	30	7	7.5	2.3	0.84	1.73
	Fathers	22.5	60	7.5	10	2.0	0.70	
Feeling emotionally drained	Mothers	67	27	2	2.5	2.6	0.53	2.7***
	Fathers	37.5	55	5	2.5	2.3	0.45	
Apprehensions of having a child with autism	Mothers	72	22	5	0	2.7	0.39	5.5.***
	Fathers	32.5	60	5	2.5	2.2	0.42	

Note: Options are coded as Never=0, Not very much=1, To some extent=2, Extreme=3

Table 2. Respondents' perception regarding their life style that they expected (n = 80)

Statement	Subjects	Exactly	Moderately	Only	Minimum.	No	Mean	SD	t-78)
Expected life style	Mothers	0	12.5	10	2.5	75	4.40	1.11	1.1
	Fathers	0	22.5	12.5	0	65	4.1	1.31	

Note: Options are coded as No=1, Minimum = 2, only =3, moderately=4, exactly = 5

Table 3: Respondents who become wild in annoyance due to their child with autism (n = 80).

Statement	Subjects	Always	Mostly	Sometimes	Never	Mean	SD	t-(78)
Those who become wild in annoyance	Mothers	5	35	50	10	1.4	0.53	1.2
	Fathers	15	45	22.5	17.5	1.6	0.89	

Note: Options are coded as Never=0, Sometime=1, Mostly=2, Always=3

Table 4: Percentage, mean and SD of responses, regarding social factors contributing to parental stress (n = 80) because of their child with autism.

Statements	Subjects	Extreme %	To some extent %	not very much %	Never %	Mean	SD	t-(78)
Respondents' stress because their child lack in appropriate play	Mothers	80	20	0	0	2.8	0.40	3.8***
	Fathers	45	45	7.5	2.5	2.3	0.72	
Feeling of frustration when their schedule times doesn't successful	Mothers	42	42	12	2.5	2.2	0.81	1.2
	Fathers	20	55	25	0	2.0	0.67	
Respondents' toothlessness when their household shores become effected	Mothers	45	52	0	2.5	2.4	0.65	5.1***
	Fathers	10	45	40	5	1.6	0.73	
Sorrow due to limited interactions with their relatives	Mothers	30	40	20	10	1.9	0.94	1.8
	Fathers	10	50	17.5	22.5	1.5	0.95	

Note: Options are coded as Never=0, Not very much=1, To some extent=2, Extreme=3

Table 5: Percentage, mean and SD of responses, regarding social factors contributing to parental stress (n = 80) because of their child with autism.

Statements	Subjects	Always %	Mostly %	Someti mes %	Do not Know	Never %	Mean	SD	t-(78)
Mismanagement of their house hold chores	Mothers	15	57.5	27.5	0	0	1.9	0.64	3.1**
	Fathers	7.5	30	52.5	0	10	1.4	0.76	
Frequency of the respondents regarding the effect on their marital life	Mothers	7.5	50	27.5	0	15	1.5	0.84	0.5
	Fathers	12.5	25	47.5	0	15	1.4	0.88	
Negligence of the rights of their other children	Mothers	80	20	0	0	0	2.8	0.40	6.4***
	Fathers	20	55	25	0	0	2.0	0.67	
Retort of their other children	Mothers	15	57.5	27.5	0	0	1.9	0.64	2.01*
	Fathers	37	50	12	0	0	2.2	0.69	
Effect on their daily activities	Mothers	52.5	32.5	12.5	0	2.5	2.4	0.79	5.7***
	Fathers	2.5	45	50	0	2.5	1.5	0.59	
Minimum get together with their friends	Mothers	47.5	35	12.5	0	5	2.3	0.86	4.7***
	Fathers	10	30	45	0	15	1.4	0.85	
Relatives avoidance	Mothers	2.5	27.5	47.5	0	22.5	1.1	0.77	1.1
	Fathers	2.5	15	52.5	5	25	0.9	0.73	
Uncomfortableness	Mothers	30	37.5	22.5	0	10	1.9	0.95	2.7*
	Fathers	12.5	27.5	35	0	25	1.3	0.97	
Take child into community	Mothers	7.5	52.5	35	0	5	1.6	0.70	1.2
	Fathers	17.5	42.5	37.5	0	2.5	1.8	0.77	
Embarrassment while taking their child outside the home	Mothers	7.5	50	32.5	0	10	1.6	0.77	1.1
	Fathers	2.5	50	35	0	12.5	1.4	0.74	

Note: Options are coded as Never=0, Sometimes=1, Mostly=2, Always=3, do not know=not considered

Table 6: Percentage, mean and SD of responses, regarding educational factors contributing to parental stress (n = 80) because of their child with autism

Statements	Subjects	all of them %	most of them %	few of them %	do not know %	not of them %	Mean	SD	t-(78)
Respondents' information regarding country's special educational policies	Mothers	2.5	12.5	62.5	15	7.5	1.0	0.67	1.5
	Fathers	0	2.5	72.5	20	5	0.8	0.47	
Respondents contentment from the services provided by their child's school	Mothers	0	15	62.5	2.5	20	0.9	0.61	0.7
	Fathers	2.5	12.5	65	0	20	1.0	0.65	

Note: Options are coded as not of them=0, few of them=1, most of them=2, all of them=3, do not know=not considered

Table7: Percentage, mean and SD of responses, regarding financial factors contributing to parental stress (n = 80) because of their child with autism.

Statements	Subjects	Extre me %	To some extent %	Not very much %	Never %	Mean	SD	t-(78)
Frequency of the respondents regarding their feeling of toothless, when their financial resources don't allow them to fulfill all the basic needs of their child	Mothers	40	35	20	5	2.1	0.89	2.1*
	Fathers	15	50	27.5	7.5	1.7	0.81	

Note: Options are coded as Never=0, Not very much=1, To some extent=2, Extreme=3

Table 8: Percentage, mean and SD of responses, regarding financial factors contributing to parental stress (n = 80) because of their child with autism

Statements	Subjects	Always %	Mostly %	Someti mes %	Never %	Mean	SD	t-(78)
Respondents' consent of financial resources to get all possible special educational services for their children with autism	Mothers	5	25	52.5	17.5	1.2	0.77	0
	Fathers	7.5	30	37.5	25	1.2	0.90	
Consent of financial resources to fulfill all the basic needs of their child	Mothers	7.5	45	42.5	5	1.6	0.71	0.6
	Fathers	2.5	47.5	45	5	1.5	0.63	

Note: Options are coded as Never=0, Sometimes=1, Mostly=2, Always=3

Table 9: Percentage, mean and SD of responses about future concerns (n = 80)

Statements	Subjects	Extreme %	to some extent %	not very much %	Never %	Mean	SD	t-(78)
Frequency of parental stress regarding their child's future care giving	Mothers	80	17.5	2.5	0	2.8	0.47	2.1*
	Fathers	57.5	32.5	7.5	2.5	2.5	0.74	

Note: Options are coded as Never=0, Not very much=1, To some extent=2, Extreme=3

Table 3 shows that (45%) respondent fathers mostly, and (50%) mothers sometimes become wild in annoyance because of their child with autism.

Table 4 indicates the significant difference among the responses of parents regarding their stress when their child did not follow their schedules successfully. (42%) of the both respondent fathers and mothers had extreme frustration, when they were not able to follow their schedules successfully. It was also found that 45% of both fathers and mothers felt extremely helpless when their household chores were affected because of their child, half of the (50%) fathers and (40%) to some extent felt sorrow due to limited interactions with their relatives.

Table 5 shows a significant difference among the responses of parents regarding the mismanagement of their house hold shores. Results shows that 30% fathers and 57.5% mothers mostly held their child with autism responsible for the mismanagement of their house hold shores, (47.5%) respondent fathers sometimes and 50% mothers mostly felt that their marital life was affected because of their child with autism, (55%) of fathers mostly felt whereas 80% mothers always felt that the rights of their other children were affected, and when it happened there other children react badly. Resultantly they feel stress (Table 5).

Results shows that (50%) fathers sometimes whereas 52.5% mothers always felt that their daily activities were affected, 45% of the fathers stated that they sometimes while 47.5% mothers always had minimum get together with their friends, (52.5%) fathers and 47.5% mothers reported that their relatives sometimes avoid coming to their residence because of their child so they experience stress (Table 5).

Results indicates that 27.5% fathers mostly and 30% mothers always felt uncomfortable being in a get together with their relatives, (42.5%) of the respondent fathers and 52.5% mother mostly took their child into community i.e. shopping malls and (50%) of both fathers and mothers mostly, felt embarrassed to take their child outside the home (Table 5).

Results reveals that most of the respondents both fathers and mothers thought that they were not fully aware of the country's special educational policies. (72.5%) of fathers and 62.5% mothers thought that they knew only few of them. Results divulge that not even a single respondent was fully satisfied from the services provided by their child's school. (65%) fathers and 62.5% mothers were

satisfied from few of the services provided by their child's school (Table 6).

Results shows that there was significant difference among the responses of parents regarding their feeling of toothless when their financial resources don't allow them to fulfill all the basic needs of their child (Table 7).

Results indicate that 15% of the fathers and 40% mothers felt extremely helpless when their financial resources did not allow them to fulfill all the basic needs of their child, 37.5% fathers and 52.5% mothers sometimes felt that their financial resources permit them to get all possible special educational services for their children with autism (Table 7 & 8). Results divulge (57.5%) fathers and (80%) mothers had extreme stress regarding their child's future care giving (Table 9).

DISCUSSION

The proposed study was designed to assess the different factors contributing to stress among parents of children with autism. A child with autism represents a steady source of stress on parents. Parents of these children undergo chronic psychosomatic pressure and this pressure may boost up due to several factors. Stress of rearing a child with autism can be overwhelming for parents.

Several results highlighted higher stress ratings on mothers as compared to fathers. Mothers were more at risk to negative outcomes than fathers. This may be because Pakistani culture usually expects males to muzzle their emotions in public. Women, however, are considered to be more emotional in response to stressful events. Also, due to the cultural understanding of prime responsibility of child care lying with mothers, they face additional challenges and stress if their child has autism. Thus, differences in stress level due to variation in gender confirm the gender role socialization of emotions.

This study reveals that (42.5%) respondent fathers whereas (90%) respondent mothers had extreme worries about having a child with autism. A poem titled "Before I go to sleep..." by Meyer, (2000) exemplifies parental grief which supports the findings of present study. Parents should not feel themselves extremely different and unaccompanied. Autism is found to be more prevalent than people assume so. With an acceptance of reality, parents can face the frontal difficulties in a better way.

Present study shows that (62%) respondent mothers whereas (12.5%) respondent fathers had extreme grief concerning the loss of the lifestyle that they expected to have for their child as well as for themselves and their family. These findings are consistent with the findings of Worthington, 1994. Grief is a poignant ache which arises from a result of loss and becomes a factor of colossal distress. The key is to contact with community health centers, converse with spouse and other parents who have children with autism and are in a similar situation. Consequently, parents can gain some emotional support and information.

Raising a child with autism is really a difficult task bestowed upon parents. Present study exemplifies that (67.5%) fathers to some extent whereas (67%) mothers had extreme depression for not being able to determine their child's needs. It happens because most of the time an child with autism is not able to express his/her basic needs. Contrary to the above mentioned findings Hutton & Caron, (2005) in their research found that many parents demonstrated the experience of raising a child diagnosed with autism as being hopeful and positive. Parents of these children should realize that if they yearn to see their child with autism as normal as possible, they must be careful about themselves. They must endeavor to come out of their stressful situation, seek to remain normal and should never think negatively.

Table indicates that (52.5%) fathers and (50%) mothers to some extent become annoyed on not identifying their child's need. Children with autism can't state even their basic wants so their parents just play a conjecturing game to identify their child's wants. But when they can't discover their child's wants they feel frustrated. A study by Horowitz (2004) supports the findings of the present study.

Bringing up a child with autism is very hard. It has been found in the present study that (60%) respondent fathers to some extent and (55%) mothers extremely felt hopeless, (60%) fathers to some extent and (72%) mothers felt extreme apprehension, (55%) fathers to some extent whereas (67%) mothers felt extremely emotionally drained when their child does not respond to their love and affection and they have to work extra hard for their child.

One of the most common factors causing stress is related to the future care giving of the child with autism. Parents think that they provide extra

support and care to their child with autism. They become worried when they imagine the life of their child without them. This thing becomes a source of stress for them that who will take care of their child after their death.

CONCLUSION

Current study reveals that being the parent of a child with autism represents a dynamic and complex process. It is concluded that there are various factors (psychological, social, educational, financial and future concern) which cause stress in parents having children with autism. It is further concluded that future concern of the child is a factor in which parents experience more stress than other factors. Rearing a child with autism has an unfavorable impact on parental psychosomatic functioning.

It is concluded that there is a considerable amount of stress among parents of children with autism. Results also indicate that mothers of these children undergo more stress and are more vulnerable to unenthusiastic outcomes than fathers. Rearing a child with autism can be a life-changing experience.

The present study guide to another important region of research and that is to find out those factors which can be helpful to decrease parental stress. There must be additional investigation concerning impact of developmental disabilities on parents as well as their psychological health problems, which will have clinical significance pro therapeutic intervention amid susceptible parents and families.

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