Relationship between Parental Stress and Coping Strategies among Parents with Autistic Children

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Abstract

The present study explored the relationship between parental stress and coping strategies among parents with autistic children. The sample consisted of total 120 parents (60 fathers, 60 mothers of diagnosed 60 children with Autism) collected through purposive sampling. The study was an exploratory study and used co-relational research design. The study investigated all the possible relationships among variables and demographic variables. Results showed significant correlations between stress and coping strategies. Those parents who relied more on active avoidance coping, reported lower levels of stress as compared to those who relied on problem-focused coping strategies. Fathers scored significantly low on stress than mothers. Data showed significant differences in parental stress and coping strategies with the increasing age of the children. Gender differences were also explored which suggested that parents with boy-child had comparatively higher levels of stress than parents with girl-child.

Keywords: Parental Stress, Coping Strategies, Autism, Special Education, Educational Psychology.

Introduction

Raising a child with a disability is difficult for any family to cope with, but research suggests that raising a child with autism causes more stress and has a greater impact on parental mental health than raising a child with any another developmental disabilities (Dunn et al.,2001; Sanders and Morgan, 1997). Parents of children with autism experience greater risks to their health and psychosocial adjustment than parents of typically developing children, and report higher levels of stress (Baker, Brookman and Stahmer, 2005). Individuals with an autism spectrum disorder display three core characteristics: qualitative impairments in social interaction, deficits in communication, and repetitive and stereotyped patterns of behavior (American Psychiatric Association, 2000). The aforementioned impairments can range from mild to severe and may manifest through a variety of symptoms. While not required to receive a diagnosis, many individuals of autism also shows cognitive impairments that place them below the cutoff for intellectual disability.

Parental Stress and Coping with Autism

'Many traits of autism exacerbate the most challenging aspects of parenting any child' (Siegel, 1997) and is important therefore, to acknowledge the potential impact that parental stress may have on the management of a child's autism (Lecavalier, Leone and Wiltz 2006). There is a vast hidden costs to livelihood health in regard to the stress and sleeplessness that are frequently experienced by parents that are caring for a child with autism (Loynes, 2001). Mothers, in particular, are considered to be at a higher risk mental health problems and it is thought that stress is a key factor in this (Piven and Palmer, 1999). Furthermore, it has been noted that these costs to psychological health of an individual. Also, it can often have a far-reaching impact on relationships. Anecdotally, it is widely accepted that families with an autistic child are more vulnerable to marital breakdown (Loynes, 2001).

Additionally, research into families under stress has shown that a link exists between relationship breakdown and poor physical and mental health, which may have further implications for the quality of family relationships. In her conclusions Loynes (2001) recommended that families with autistic children be provided with more emotional and practical support, and that professionals in various fields can be made more aware of the strains that caring for a child with autism can have on relationships.

'Stress and family adaptation appear to differ considerably as the child develops through the various stages of life that is: infancy, childhood, adolescence and into adulthood. It is dubious that parenting stress changes to a great extent as the child ages, but parents' experiences of stress changes over time' (Hastings et al., 2005a). It is important to highlight that it is not inevitably the child with autism who acts as the source of stress in the family, there may be external stressors, such as lack of appropriate services, or insufficient special education provision (Sivberg, 2002). In addition to this some parents have identified indirect effects of their child's autism, such as: the loss of free time for relaxing, the impact on family doings and spontaneity, safety concerns and fear of their child hurting themselves or others, as contributing to their stress (Hutton and Carron, 2005). Nevertheless, some authors (e.g. Hastings and Brown, 2002) have reported that behavior problems are the most significant predictors of parental stress in children with disabilities.

It is known from the very nature of the symptoms of autism that it is common for children to exhibit behaviors that are difficult to understand and manage. Indeed, a study in recent past reported that behavior problems were more associated with stress than any of the other child/caregiver characteristics measured, with conduct problems and lack of pro-social behaviors being the most strongly associated with increased stress in caregivers (Lecavalier et al., 2006). This was supported by Osborne and Reed (2008), who reported that not only did autistic severity contribute majorly to levels of parenting stress, but so did the child's age at diagnosis, with younger age at diagnosis being equated with greater levels of current parenting stress. Duarte, Bordin, Yazigi and Mooney (2005) also reported that having a child with autism is the main factor in mothers presenting with stress. However, they recognized some maternal personality characteristics which added to increased levels of stress in the mothers. These included: the mother indicating little expression of emotion, low

interest in people, being an older mother, or having a younger child. Nonetheless, it appears that for some mothers the experience of having a child with autism is relatively more stressful than for others.

Coping Strategies

Parents have been found to use a variety of coping strategies in addition to social support, including: use of service agencies, social withdrawal, religion, normalization, individualism and activism. However, no one coping strategy has been identified as more successful than another, and families have reported varying the strategies they used according to the particular problem. That said use of service agencies and family support seemed to be the most successful strategy for a substantial number of parents (Gray, 1994; Gray, 2006). Parents have also described an important coping strategy as planning ahead, anticipating difficulties that may arise in a given situation, and devising a response that could be implemented if necessary. Another common coping strategy was to take life one day at a time and deal with problems as they arose. Parents felt that it was not realistic to plan for every eventuality because life was too full of unexpected events (Gray, 2003; Hutton and Carron, 2005). Previous research has indicated that there may be a negative relationship between level of strain on the family system and level of coping (Sivberg, 2002), with the suggestion that it is important for parents of children with autism to identify and employ a range of adaptive coping strategies. Sivberg (2002) reported that, relative to families of normally developing children, parents of children with autism scored higher on use of the avoidant coping behaviors of distance and escape. However, although these are generally considered to be maladaptive, these strategies can be functional in certain situations. For example, distancing oneself from the autism following diagnosis may act as a protective mechanism in the early stages of adapting to the reality of the situation.

In contrast, Higgins et al., (2005) identified self-esteem, optimism and spousal support as the three main coping strategies employed by the primary caregivers in their study. Other parents have described that they often coped by separating themselves to spend time with their developmentally normal children as well as their child with autism, although they acknowledged that this tended to have a negative impact on the family as a coherent unit. It has also been reported that cognitive coping strategies such as adjusted expectations, living in the present and appreciation of 'little things' are effective for some parents (Glass, 2001).

Gray (2006) sought to investigate how families' use of coping strategies changed over time, and found that parents followed up from his 1994 study cited using far fewer coping strategies 12 years later. This may be a positive reflection of an improvement in their child's symptoms, and consequently a reduced degree of emotional distress for the parents because their child was easier to live with. Reduced use of coping strategies may also reflect the increased age of their child and the parents being relatively further forward in the adaptation process than they were at the time of the previous study. Gray (2006) found that parents' use of treatment services had declined as a coping strategy, but again this may be a reflection of their child's increased age, and possibly also reduced availability of services for the parents in his sample. Over time the parents in Gray's study reported increased use of emotion-focused coping strategies, which included the adoption of more philosophical attitudes and emotional responses to difficulties.

Gender Differences in Parental Stress and Coping

Another area worthy of consideration is the differential experiences of stress and coping within the family unit of the child who has autism. To date, most research has focused on mothers, with some acknowledgement of fathers. Even when both parents have been included in a research study, for the most part they have been considered independently of one another. However, the reality that 'family members do not all experience similar effects as a result of being a relative of a child with autism', and the fact that research has tended to focus on the autistic child as the source of stress in the family has recently been recognized (Hastings et al., 2005b). It has therefore been proposed that a systemic conceptualization might be more appropriate as this would recognize the probability that family members all affect one another. Gray (2003) reported that the most striking difference between parents in his study was the perceived personal impact of the child's autism. With regard to mothers, he found that they were more likely to cite an effect of their child's autism on their emotional well-being. Fathers generally reported that their child's autism affected them indirectly, via the stress experienced by their partners. Fathers were therefore most likely to see themselves as a source of support for their partners in times of increased stress.

Further investigation of gender differences has found that while mothers may report more difficulties than fathers, there was no difference between parents in reported levels of stress (Hastings et al., 2005b). For mothers, a strong positive relationship between their stress and their child's behavior problems was found, with no apparent effect of adaptive behavior or severity of autism symptoms on stress. There was also some effect of their partner's depression. However, in the case of fathers, the relationship with the child's characteristics did not hold, and paternal stress was found to be positively predicted only by their partner's depression. It seems possible then that there may be some interaction between parents' mental health states. However, the mechanisms by which these influences might work require further exploration. With regard to the finding that mothers are more affected by their child's behavior problems, one potential explanation put forward by Hastings et al., (2005b) is simply that mothers are typically more involved in the care of their child with autism. A second explanation suggested is that the difference might be due to fathers employing different coping strategies to manage their child's difficult behavior, which are more adaptive in reducing their stress. One study has reported that mothers tended to describe more use of practical coping strategies such as engaging their child in a therapeutic regime, and keeping the child with autism separated from their siblings. In contrast, fathers more often described keeping their child busy when they were at home and going to work as their most common coping strategies (Gray, 2003). Going to work was considered important by fathers as it created a role for them that was separate from the family's domestic life and, in some cases, fathers acknowledged that work allowed them to reduce the amount of time they spent with their autistic child.

In terms of emotional coping strategies, Hastings et al., (2005a) reported that fathers were more likely to describe trying to suppress their feelings, whilst mothers were more likely to report that they vented their emotions, expressed a greater variety of emotions, and used social support as a means of dealing with these emotions. It was found that mothers used both active avoidance and problem-focused coping strategies more

frequently than fathers, with the former being related to increased levels of stress and mental health problems. Hastings et al., (2005a) proposed that a disruption in marital support due to depression in one partner may account for the finding that maternal and paternal depression predicts the partner's stress. Fathers rarely cited any additional strategies to those already discussed.

In summary, it seems probable that mothers and fathers in families of children with autism uses different coping strategies in accordance with the gender roles that they adopt. One could speculate that it appears to be the case that, in line with the general population, traditional gender roles are adopted in these families: mothers become the primary caregiver and, if they do work outside the home, it is on a part-time basis, whereas fathers take on the role of main breadwinner. Mothers are therefore spending more time with their autistic child and as a consequence they are likely to be required to adopt various coping strategies in order to effectively manage this. In contrast, fathers may have less time with their autistic child and so are perhaps not required to employ the same level of coping strategies. When interpreting the findings on stress and coping, it is important to consider whether mothers and fathers may also interpret their child's autism differently (Gray, 2003). Furthermore, an examination of the degree to which the experience of stress is affected by factors external to the family may further help to explain differences in the coping approaches used by mothers and fathers. It is somewhat difficult to draw firm conclusions from the research on coping due to the variation in measures used by studies in quantifying variables such as coping strategies and level of family strain.

Objectives

The study was done with the following objectives:

1. To explore the relationship between coping strategies and psychological well-being among parents with autistic children.
2. To associate the coping strategies and psychological well-being of parents with autistic children.
3. To find the difference in coping strategies and psychological well-being of fathers and mothers with autistic children.
4. To investigate the impact of child gender and age with coping strategies and psychological well-being.

Sample Distribution

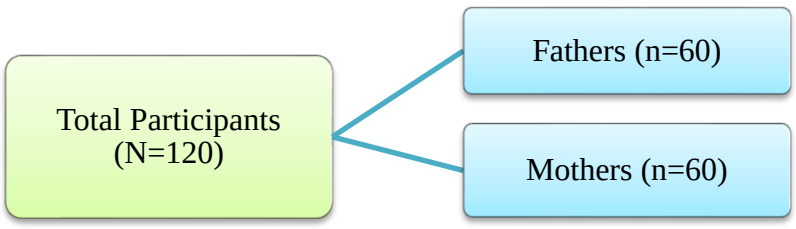

Figure 1: Total Sample Size

The sample that has been taken for this study was comprised of 120 parents (Fathers=60 & Mothers= 60) of identified 60 children with Autism. The age of parents fall from 25-56 years. The age range of children was 4-18 years. The children were separated into two groups due to the difference in their age range, i.e. younger children 4-9 and older children 10-18. Children selected had both parents alive. The sample was purposively taken from different special schools in Jaipur city.

Measures Used

1. **Parental Stress Scale (PSS)**

Parental Stress Scale, originally developed by Berry & Jones (1995), was used to measure parental stress. It is a self-report measure that contains 18 items representing pleasure or constructive refrains of parenthood comprising emotional welfares, self-enrichment, personal development and negative constituents such as demands on possessions, prospect costs and limitations. Respondents were asked to agree or disagree with items in lieu of their distinctive relationship with their child or children and to rate each item on a five-point scale: strongly disagree (1) disagree (2), undecided (3) agree (4) strongly agree (5). The 8 positive items were contrary scored so that possible scores on the scale ranged from18 to 90. Score on all the items was summed to get a total score. Higher scores on the scale specify greater stress and low scores indicates minor scores. The scale is proposed to be used for the valuation of parental stress for both mothers and fathers and for parents of children with and without clinical problems. The Parental Stress Scale confirmed acceptable levels of internal reliability (.83) and test re-test reliability (.81). The scale demonstrated satisfactory convergent validity with various measures of stress, emotion and role satisfaction, including perceived stress, work/family stress, emotion, loneliness, anxiety, guilt, marital satisfaction, marital commitment, job satisfaction and social support. Discriminant analyses verified the capability of the scale to discriminate between parents of typically developing children and parents of children with both developmental and behavioral problems.

2. **Brief COPE**

The Brief COPE initially established by Carver (1997) and interpreted into Urdu by Akhtar (2005), was used to categorize the coping strategies used by parents. Brief COPE is a briefer form of COPE Inventory (Carver, 1989) consisted of 28 items categorized into 14 subscales (Self distraction, Active coping, Denial, Substance abuse, Use of emotional support, Use of instrumental support, Behavioral disengagement, Venting, Positive reframing, Planning, humor, Acceptance, Religion, Self-blame). Items are arranged in a 4-point Likert format (1=Never, 2= Very less, 3= Sometimes, and 4= A lot). Item No. 1 and 19 pertains to “Self-distraction” subscale, Item No. 2 and 7 pertains to “Active coping” subscale. Item No.3 and 8 pertains to “Denial” subscale. Unit No. 5 and 15 pertains to “Use of emotional support”. Unit No. 10 and 23 pertains to “Use of instrumental support” subscale. Item No. 6 and 16 pertains to “Behavioral disengagement” subscale. Items No. 9 and 21 pertains to “Venting” subscale. Unit No. 12 and 17 pertains to “Positive reframing” subscale. Item No 14 and 25 pertains to “Planning” subscale. Unit

No. 18 and 28 pertains to "Humor" subscale. Unit No. 20 and 24 pertains to "Acceptance" subscale. Unit No. 22 and 27 pertains to "Religious" subscale. Unit No. 13 and 26 pertains to "Self-blame" subscale. The substances are summed for each subsection separately to get a total score on all 14 categories.

In the current investigation, structure of Hastings et al. (2005) for Brief COPE (Carver, 1997) was used. He reported four subscales for Brief COPE namely: Active avoidance coping, Problem-Focused coping, Positive coping and Religious/Denial coping. Problem-focused coping included all the items from the original Brief COPE, subscales for Planning, Active coping, Seeking instrumental social support, and one item each from the Acceptance and Emotional social support scales (12, 15, 17, 18, 20, 24, and 28). Active avoidance coping include all of the items from the original Brief COPE subscales for the substance use, Behavioral disengagement, Self-blame, Venting of emotions, and one item from the Distraction scale (item no. 1, 4, 6, 9, 11, 13, 16, 19, 21, 26). Religious/Denial coping is a varied factor that included all the Brief COPE items for religious coping and denial (3, 8, 22, 27). Positive coping includes all items of Brief COPE of active coping, use of emotional support, planning, and use of instrumental support (2, 7, 5, 10, 15, 14, and 25). The items are summed for each subscale separately to get a total score on all 4 categories. The high score on each subscale indicates more use of that specific coping strategy and low score indicates less use of that coping strategy.

Results and Discussion

The results of the study are as follows.

Table 3.1: Correlation between Scores on Subscales of Brief COPE and Parental Stress Scale (N=120)

	Stress
Active Avoidance Coping	**0.598****
Problem Focused Coping	**-0.242****
Positive Coping	**-0.227****
Denial/ Religious Coping	-0.010

*****p<.05 and ** p <.01, ***p<.001

Table 3.1 shows correlation between Brief COPE subscales and stress. Problem-focused coping was negatively associated with stress (r= -0.242). The greater the problem-focused coping, lower the levels of depression, anxiety and stress indicating a higher levels of psychological well-being. Results also indicated significant correlation of active avoidance and positive coping with stress. Religious/Denial coping was negatively associated with stress but no significant correlation was found between religious/denial coping and stress. The probable reason for the same could be that parents on an average does not know how to handle situations and

also are not aware of the repercussions of their behavior on the child. It is important to make parents aware of the varied behaviors of their child and how can they cope with the situation in an effective manner.

Table 3.2: Mean, Standard Deviation & t-value of Fathers and Mothers on the Scores on Indicators of Brief COPE (N=120)

Sub Scale	Fathers (n=60)		Mothers (n=60)		*t*	*P*
	M	**SD**	**M**	**SD**		
Active Avoidance	17.86	4.75	20.33	5.07	**2.760****	0.03
Problem-focused	23.34	4.21	11.26	4.66	**1.383***	0.02
Positive coping	13.60	2.82	14.18	2.59	1.232	0.09
Religious/Denial	11.77	1.73	11.89	1.81	.397	0.06
Sub Scale	**Fathers (n=60)**		**Mothers (n=60)**		***t***	***P***
	M	SD	M	SD		
Stress	44.30	8.31	46.90	7.66	2.804**	0.01

df= 118 , *p<.05,**p<.01

Table 3.2 presented gender differences in the mean scores of fathers and mothers on the subscales of Brief COPE. Significant gender differences were found on “Active Avoidance Coping” (t=2.760, df= 118, p<.01) and “Problem-focused Coping” (t=1.383, df= 118, p<.05). Active avoidance coping was high in mothers as compared to fathers. Whereas, Problem focused coping was high in fathers as compared to mothers. Mothers are considered as prime caregiver of the child, who is with the child 24*7 and thus, the bond between child and a mother is inseparable. This leads to over possessiveness for the child that is one reason why mothers are not able to use much of problem focused coping style in comparison to fathers.

Table 3.3: Mean, Standard Deviation & t-value of Fathers and Mothers on the Scores Parental Stress Scale (N=120)

df=118,*p<.05,**p<.01

Table 3.3 shows differences in the mean scores of mothers and fathers of autistic children in relation to parental stress scale.

Significant difference was observed in stress. The findings revealed that mothers of autistic children have higher level of stress as compared to fathers. As mentioned above, mothers are relatively close to their child in comparison to fathers. Also, most of the fathers are working and have people to share their problems with.

Whereas, mothers are generally at home and are not well acquainted as to what is happening around and their major area of concern is the child.

Table 3.4: Mean, SD, and t-value of Parents of Younger and Older Children on the Scores on Parental Stress (N=120)

Sub Scale	Parents with Older Child (n=64)		Parents with Younger Child (n=56)		*t*	*p*
	M	**SD**	**M**	**SD**		
Stress	**49.38**	**6.93**	**46.13**	**9.26**	**2.013****	**0.01**

df=118,*p<.05,**p<.001

Table 3.4 showed differences in mean scores of parents having Younger and Older children on subscale of parental stress. Significant differences were found. The findings suggested that parents having younger children showed higher levels of stress as compared to parents having older children. The mean score of younger children were higher than the means scores of older children on the variable of stress. For any parent their dream is to see their child grow better and stronger, the stress levels of parents with younger children are higher because they are probably newly diagnosed and still have not accepted the specialty of their child.

Table 3.5: Mean, S.D, and t-value of Parents of Boy-Child and Girl-child on the Scores on Parental stress scale (N=120)

Sub Scale	Parents with Boy Child (n=60)		Parents with Girl Child (n=60)		*t*	*p*
	M	SD	M	SD		
Stress	45.81	7.39	50.00	8.34	2.05**	0.01

df =118, *p<.05, **p<.01

Table 3.5 showed differences in mean scores of parents having boy-child and girl-child on parental stress parameter. The findings suggested that parents having girl-child had comparatively higher levels of stress than parents having boy-child. Though, India is developing in many aspects, difference between a male child and a female child is still evident. Parents of female child has various issues and the top issue is marriage of their daughter followed with how will she survive without us. Such issues, creates a havoc in the mind of the parents that leads to stress.

Table 3.6: Mean, Standard Deviation and t-value of Younger and Older Children on the Scores on Brief COPE

Sub Scale	Parents Older children (n=64)		Parents Younger Children (n=56)		*t*	*p*
	M	**SD**	**M**	**SD**		
Active Avoidance	11.66	3.15	10.33	4.86	2.120**	0.03
Problem Focused	13.31	2.11	31.26	4.99	1.763*	0.02
Positive Coping	23.00	2.22	24.18	3.52	1.782	0.07
Religious/ Denial	10.66	3.54	11.89	1.81	0.397	0.08

df=118,*p<.05,**p<.001

Table 3.6 presented gender differences in the mean scores of parents having older and younger children on the subscales of Brief COPE. Significant gender differences were found on "Active Avoidance Coping" (t=2.120, df= 118, p<.01) and "Problem-focused Coping" (t=1.763, df= 118, p<.05). Problem solving coping strategy was used by parents with younger children than parents with older children. Since the parents are newly diagnosed and want the best for their children they are exploring all the possibilities that can treat their child in an effective way. Thus, the use of problem-focused style is significantly higher in parents of younger children than in older children.

Conclusion

It was concluded from the study that:

- Fathers had greater well-being as compared to mothers.
- While making comparison between mothers and fathers, it was found that fathers reported more use of problem-focused coping than mothers as their frequently employed coping strategy was active avoidance.
- Parents of older children reported higher levels of stress as compared to parents of younger children.
- Problem-focused coping was significantly correlated with overall well-being of the parents.

Implication of the Study

Such studies can help counsellors, extension workers and special educators etc. to work in favor of parents, educate them about the neurological disorder so that they can deal effectively with the child and help them become self-sufficient and self-reliant. Furthermore, the study can help as a base in formulation an intervention programme for the parents. Study can be replicated taking in account various specialties like Down Syndrome, Fragile X, Rett's Syndrome etc.

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