To Study the Relationship between Level of Stress and Coping Strategies among Parents of Mentally Retarded and Autistic Children

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ABSTRACT

Background: Stress generally refers to two things: the psychological perception of pressure, on the one hand, and the body's response to it, on the other, which involves multiple systems, from metabolism to muscles to memory. Through hormonal signaling, the perception of danger sets off an automatic response system, known as the fight-or-flight response, that prepares all animals to meet a challenge or flee from it. A stressful event —whether an external phenomenon like the sudden appearance of a snake on your path or an internal event like fear of losing your job when the boss yells at you—triggers a cascade of hormones, including adrenaline and cortisol, that surge through the body, speeding heartbeat and the circulation of blood, mobilizing fat and sugar for fast energy, focusing attention, preparing muscles for action, and more. It generally takes some time for the body to calm down after the stress response has been triggered. Syle (1975) According to the World Health Organization (1994), approximately 156 million people or 3 percent of the world's population have mental retardation. Coping has been defined as problem solving efforts made by an individual when the demands of a given situation tax adaptive resources (Lazarus et al., 1974; Pearlin & Schooler, 1978).

Objective: To Study the relationship between level of stress and coping strategies among parents of mentally retarded and autistic children.

Methodology: A sample of 70 parents i.e. 35 parents of mentally retarded children (18 fathers and 17 mothers ) and 35 parents of autistic children were taken from different institutions of Raipur (SAMWEDNA, ASHA DEEP & KOPALWANI ) and Chandigarh (PRYAAAS) who were fulfilling the inclusion and exclusion criteria were selected for the present study. The tools used for assessing the variables are Socio Demographic Data Sheet (Self made), The Cope Scale (Carver et al., 1989) and Parental stress scale (Berry and Jones, 1995).

Result: This study

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revealed that correlation between coping and parental stress in which significantly negative correlation was found in acceptance and turning to religion with parental stress.

Keywords: Parental stress, coping strategies, Mentally Retarded & Autistic Children.

Stress generally refers to two things: the psychological perception of pressure, on the one hand, and the body's response to it, on the other, which involves multiple systems, from metabolism to muscles to memory. Through hormonal signaling, the perception of danger sets off an automatic response system, known as the fight-or-flight response, that prepares all animals to meet a challenge or flee from it. A stressful event —whether an external phenomenon like the sudden appearance of a snake on your path or an internal event like fear of losing your job when the boss yells at you—triggers a cascade of hormones, including adrenaline and cortisol, that surge through the body, speeding heartbeat and the circulation of blood, mobilizing fat and sugar for fast energy, focusing attention, preparing muscles for action, and more. It generally takes some time for the body to calm down after the stress response has been triggered. Syle (1975) defined a model, dividing stress into eustress and distress. Where stress enhances function (physical or mental, such as through strength training or challenging work), it may be considered eustress. Persistent stress that is not resolved through coping or adaptation, deemed distress, may lead to anxiety or withdrawal (depression) behavior.

The term, “developmental disabilities,” [i.e., severe chronic conditions that are due to mental and/or physical impairments with an age of onset prior to age 22] “Intellectual disabilities/Mental Retardation”, “physical disabilities”, and “autism” are terms that are used in India and are subsumed our use of the term developmental disabilities (Center for Disease Control and Prevention, 2004). Mental retardation is one of the most prevalent developmental disabilities. Mental retardation, mental deficiency, mental sub normality and mental handicap, developmental disability or delay are the terms used to refer to the same condition. The terms used in the past such as amentia, idiocy, feeble minded, moron, imbecile and oligophrenia are now obsolete. According to the World Health Organization (1994), Coping has been defined as problem solving efforts made by an individual when the demands of a given situation tax adaptive resources (Lazarus et al., 1974; Pearlin & Schooler, 1978).Dumas et al. 1991; Abbeduto et al. 2004; Warfield 2005). Studies reported that Mothers of children with developmental disabilities reported significantly higher levels of stress and assigned more negative child characteristics than mothers of children without disabilities (Emerson 2003; Neece and Baker, 2008). However, fathers of children with disabilities, in comparison to mothers, have higher levels of stress associated with the child’s communication abilities (Frey et al., 1989) and in their feelings of attachment to the child (Beckman, 1991; Krauss, 1993). approximately 156 million people or 3 percent of the world's population have mental retardation. Studies report the prevalence of autism to be anywhere from about 5 cases in every 10,000 individuals (American Psychiatric Association, 2000) to 60 cases in every 10,000 children 18 years old or younger.
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(Fombonne, 2003). Morgan (1988) considered autism to be the most severe childhood behavioral disorder with the most complex developmental pattern. Personal coping refers to efforts made by an individual acting as his or her own resource, rather than seeking support, assistance or validation from the social environment.

METHODOLOGY

Sample
A sample of 70 parents i.e. 35 parents of mentally retarded children (18 fathers and 17 mothers ) and 35 parents of autistic children were taken from different institutions of Raipur (Samwedna, Asha Deep & Kopalwani) and Chandigarh (PRYAAS) who were fulfilling the inclusion and exclusion criteria were selected for the present study.

Inclusion criteria
- Parents of children in the age range of 3 – 18 years
- When both parents were alive.
- Only those parents who gave consent.

Exclusion criteria
- Single or divorced parents.
- Parents with any history of psychiatric /chronic physical illness.
- Parents not consenting and cooperating for the study

Tools Used
1. Socio Demographic Data sheet
A self made semi-structured data sheet especially designed for the study. Demographic sheet contains Information regarding subject’s age, gender, number of siblings, birth order, place of birth, nature of delivery, and clinical details such as diagnosis, duration of illness and severity of problem, parent’s age, educational qualification, monthly income, number of children, and family history of psychiatric illness.

2. Parental stress scale (Berry and Jones, 1995)
The scale was used for the assessment of parental stress for both mothers and fathers and for parents of children with and without clinical problems. PSS is a self-report scale that contains 18 items representing pleasure or positive themes of parenthood (emotional benefits, self-enrichment, and personal development) and negative components (demands on resources, opportunity costs and restrictions). Respondents are asked to agree or disagree with items in terms of their typical relationship with their child or children and to rate each item on a five-point scale: (1) strongly disagree, (2) disagree, (3) undecided, (4) agree and (5) strongly agree. The 8 positive items are reverse scored so that possible scores on the scale can range between
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18-90. Higher scores on the scale indicate greater stress. The Parental Stress Scale demonstrated satisfactory levels of internal reliability (.83), and test-retest reliability (.81).

3. The Cope Scale (Carver et al., 1989):
This scale was used to measure the coping strategies used by parents with clinical problems. It contains 14 items self reported inventory that measures 14 dispositional coping strategies (styles) used across stress situations. Each item is rated on a 4-point scale with values identified as 1, “I usually don’t do this at all;” 2, “I usually do this a little bit;” 3, “I usually do this a medium amount;” and 4, “I usually do this a lot.” First five items of the scale assess problem focused coping, four assess emotional focused coping and last five assess dysfunctional coping. The discrimination validity of the coping styles with regard to a wide range of personality traits has been demonstrated (Carver et al., 1989). Overall scale showed acceptable internal consistencies that ranged between $r = 60$ and $r = .96$ with the exception of the scale distraction (Mental disengagement) (Cronbach’s $r = .50$) (Volrath et al., 2003).

Procedure
The authorities of the institutions of Chandigarh (U.T) and Raipur (C.G) were contacted and consent for the study was taken from them. Then the data for the study was collected through personal contact with the parents of mentally retarded and autistic children, who were already diagnosed by the Clinical psychologists, Psychiatrists and/or Pediatrician and were fulfilling the inclusion and exclusion criteria. After developing a good rapport with the parents their socio demographic and clinical details were collected. The parental stress scale was administered to find out their stress level and Cope scale was administered to measure their coping strategies.

Obtained scores were analyzed with Statistical Package for Social Sciences (SPSS – 11.5). Descriptive statistics, Chi square and t-test were applied.

RESULTS
In the present study parents was given measures of stress Level. Obtained responses were analyzed using statistical techniques. The results are given below.

Table 1, Demographic variables of Parents with autistic and mentally retarded children.

| Variables            | Groups                          |          |          |          |          |
|----------------------|---------------------------------|----------|----------|----------|----------|
|                      | Autism (N=35)                   | Mental retardation (N=35) |          |          | t-value  |
|                      | M  | SD   | M     | SD   |          |          |
| Age                  |    |       |       |       |          |          |
| M                    | 33.11 | 5.05 | 35.37 | 4.89 | 1.89     |          |
| f                    |    |       |       |       |          |          |
| %                    |    |       |       |       |          |          |
| Informants           |          |          |          |          | χ² value |
| Father               | 18  | 51.4% | 18    | 51.4% |          | .000     |
| Mother               | 17  | 48.6% | 17    | 48.6% |          |          |
| Education            |          |          |          |          |          |
| Illiterate           | 7   | 20%    | 3     | 8.6%  |          |          |
| Up to 8th class      | 9   | 25.7%  | 8     | 22.9% |          |          |
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| Variables                      | Groups                                      | M    | SD   | M    | SD   | t-value |
|--------------------------------|---------------------------------------------|------|------|------|------|---------|
|                                | Autism (N=35)                               |      |      | Mental retardation (N=35) |      |         |
| Up to 12th class              | Graduate                                    | 3    | 8.6% | 4    | 11.4%| 2.94    |
|                               | Post graduate & above                       | 11   | 31.4%| 11   | 31.4%|         |
|                               |                                             | 5    | 14.3%| 9    | 25.7%|         |
| Monthly Income:               |                                              |      |      |      |      |         |
| (Rs.)                         | Less than 2500                              | 16   | 45.7%| 8    | 22.9%| 7.54    |
|                               | 2500 to 5000                               | 8    | 22.9%| 5    | 14.3%|         |
|                               | 5000 to 10,000                             | 5    | 14.3%| 7    | 20.0%|         |
|                               | 10,000 & above                             | 6    | 17.1%| 15   | 42.9%|         |
|                                |                                              |      |      |      |      |         |
|                                | Total number of children in family          | 1.42 | 0.50 | 1.88 | 0.79 | 2.874  |

*p < .05 and **p < .01.

Table 1 represents demographic variables of parents of autistic and mentally retarded children, no significant differences were found in both the groups with respect to age, informants, education, monthly income and total number of children. Most of the parents were educated up to graduation (40%) in both the groups. Majority of the parents of autistic children earned less than Rs. 2500 (45.7%) monthly and parents of mentally retarded children earned more than Rs. 10,000 (42.9%) monthly. Mean of total number of children was 1.42 in autism group and 1.88 in mental retardation group.

Table 2, Demographic and clinical variables of autistic and mentally retarded children.

| Variables                  | Groups                                      | M    | SD   | F    | %    | M    | SD   | F    | %    | χ²/t-value |
|---------------------------|---------------------------------------------|------|------|------|------|------|------|------|------|------------|
| Age                       | Autism (N=35)                               | 8.37 | 3.36 | 10.85| 3.56 | 3.00 |      |      |      |            |
| Sex:                      | Male                                        | 25   | 71.4%| 20   | 57.1%| 1.55 |      |      |      |            |
|                           | Female                                      | 10   | 28.6%| 15   | 42.9%|      |      |      |      |            |
| Birth order in family     | 1.34 | 0.48 | 1.51 | 0.61 | 1.30 |      |      |      |      |            |
| Place of birth            | Home                                        | 16   | 45.7%| 14   | 40%  | 0.23 |      |      |      |            |
|                           | Hospital                                    | 19   | 54.3%| 21   | 60%  |      |      |      |      |            |
| Nature of delivery        | Caesarian                                   | 18   | 51.4%| 16   | 45.7%| 1.14 |      |      |      |            |
|                           | Normal                                      | 17   | 48.6%| 18   | 51.4%|      |      |      |      |            |
|                           | Others                                      | 0    | 0     | 1    | 2.9% |      |      |      |      |            |
| Duration of diagnosis in  | years                                       | 3.91 | 2.29 | 4.28 | 2.98 | 0.58 |      |      |      |            |

*p < .05 and **p < .01.
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Table 2 represents demographic and clinical variables of autistic and mentally retarded children with no significant differences. Average age in autism group was 8.37 (Mean) (SD = 3.36) and in mental retardation group 10.85 (Mean) (SD = 3.56). Most of the children were male in both the groups, 71.4% males in autism group and 57.1% males in mental retardation group respectively. Majority of the children were born in hospital in both the groups (54.3%) in autism group and (60%) in mental retardation group. Most of the children were caesarian delivered (51.4%) in autism group but 51.4% children were normally delivered, (45.7%) children were caesarian delivered and 2.9% children were delivered through other means in mental retardation group. Mean age of duration of diagnosis in autism group was 3.91 and 4.28 in mental retardation group.

Table 3 Frequency and percentage levels of Mental retardation.

| Levels of Mental retardation       | Frequency | Percentage (%) |
|----------------------------------|-----------|----------------|
| Mild Mental retardation          | 15        | 42.9%          |
| Moderate Mental retardation      | 12        | 34.3%          |
| Severe Mental retardation        | 6         | 17.1%          |
| Profound Mental retardation      | 2         | 5.7%           |

Table 3 represents frequency and percentage of levels of mental retardation. Most of the children were having mild level of mental retardation (42.9%) followed by Moderate (34.3%), Severe (17.1%) and Profound (5.7%) level of mental retardation.

Table 4. Correlation between coping strategies and parental stress.

| Coping strategies                        | Parental stress |
|-----------------------------------------|-----------------|
| Active coping                           | 0.172           |
| Planning                                | 0.045           |
| Suppression of competing activities     | 0.127           |
| Restraint coping                        | 0.030           |
| Seeking social support for instrumental reasons | 0.175      |
| Seeking social support for emotional reasons | 0.242     |
| Positive reinterpretation and growth    | 0.135           |
| Acceptance                              | -.409*          |
| Turning to religion                     | -.355*          |
| Focus on and venting of emotions        | 0.069           |
| Denial                                  | 0.176           |
| Behavioural disengagement               | 0.202           |
| Mental disengagement                    | 0.283           |
| Alcohol drug disengagement              | 0.102           |

*p<.05
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Table 4 represents correlation between coping and parental stress. Significantly negative correlation was found in acceptance and turning to religion with parental stress.

DISCUSSION

The present study was taken with the aim and purpose to study the stress level among the parents of mentally retarded and autistic children. Average age of parents of autistic children was 33.11 years and that of parents of mentally retarded was 35.37 years. Majority of the parents were educated up to graduation (31.4%) in both the groups and only (14.3%) parents of autistic children and (25.7%) parents of mentally retarded children were post graduate and above. Most of the parents were having monthly income less than Rs.2500 in autism group (45.7%) and more than Rs. 10,000/- in mental retardation group (42.9%). Mean of total number of children in the family in autism group was (M = 1.42) and (M = 1.88) in mental retardation group.

Regarding the children mean age in autism group was 8.37 years and 10.85 years in mental retardation group. Most of the children were male in the groups, 71.4% males and only 28.6% females in autism group and 57.1 % males and 42.9 % females in mental retardation group respectively. With respect to the overall percentage of male children with disabilities among the families within this sample, current estimates of the number of male to female children with autism range between 3 to 1 and 4 to 1 and these gender differences are fairly consistent across ethnicities (Centers for Disease Control and Prevention, 2009). Majority of the children were born in hospital in both the groups .Most of the children were caesarian delivered (51.4 %) in autism group and (51.4%) children were normal delivered than (45.7 %) children were caesarian and only 2.9 % children were delivered through others specifically, vacuum pump in mental retardation group. Mean age of duration of diagnosis in autism group was 3.91 and 4.28 in mental retardation group.

Table 4 represents the relationship between levels of stress and coping strategies. It was seen that except acceptance and turning to religion, all coping strategies were having positive relationship with parental stress and there were no significant relationship between them, whereas, acceptance and turning to religion were having significant negative relationship with parental stress. This finding is supported by earlier findings of Bristol (1984) and Wang, et al (2010) which found that families with a child with disability were more likely to emphasize strong moral and/or religious standards for coping than were families without a child with disability. Parents of children with disability were less likely to engage in social and recreational activities. The reason behind this in Indian context, may be parents give much more importance to religion as a coping strategy to deal with their stress (Tarakeshwar & Kenneth, 2001). Acceptance is considered to be a positive coping style and once parents accept autism and mental retardation as a disability, essential steps may be taken to deal with this problem and in the current study most parents were aware of patient’s illness.
SUMMARY AND CONCLUSION
The aim of the present study was to study the relationship between level of stress and coping strategies among parents of mentally retarded and autistic children. For this purpose, 35 parents of mentally retarded and 35 parents of autistic children were selected from institutes of Mental retardation and Autism of Raipur and Chandigarh. The tools used were Socio demographic data sheet, Parental stress scale and the Cope scale.

This study revealed that significant level of relationship was found between coping strategies and parental stress was found.

It adds to the literature available on the psychiatric / psychological co morbidity present in parents of autistic and mentally retarded children, coping strategies used by the parents. This study focuses the need of intervention, psycho-education, psychotherapies and psychiatric treatment to reduce the stress level and enhance the coping strategies in the parents of disabled children. The data from these studies can be used to develop gender, diagnosis and treatment specific programs to reduce psychiatric co morbidity and produce effective coping strategies in the parents of disabled children. The present findings are relevant to the clinical and counseling psychology professionals.

Limitations
Limitations of this study are as follows:
- Small sample used in the present study limit the generalization of present findings.
- Male female ratio in the children group was unequal.

Future Directions
- The sample size can be increased for generalizing the results.
- Other groups of disability can also be focused upon.

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