

STRESS AMONG PARENTS OF CHILDREN WITH INTELLECTUAL DISABILITY

Raj Kumari Gupta*, Harpreet Kaur**

ABSTRACT

The present study examines stress among parents of children with intellectual disability. 102 parents formed the sample of this study, 30 of whom had children without disability. A stress assessment test with internal validity of 0.608 was utilised. This test has two parts: physical and mental, former with 19 items and latter with 21 items. T test was applied to check differences in stress, gender differences, and differences in mental and physical stress. Results show that, most parents of children with intellectual disability experience stress, physical and mental stress are significantly correlated, gender differences in stress experienced occur only in the mental area, and parents have higher mental stress score as compared to physical stress.

INTRODUCTION

Diagnosis of intellectual disability in a child provokes a period of disequilibrium followed eventually by an adjustment to life with or without undue stress. There are various stresses which emerge and reemerge over time. Discrepancies between expectations and the performance of the developmentally disabled child continue bringing feelings of grief (1).

A parent shows a series of reactions after knowing that their child is disabled. These include shock, denial, guilt, sorrow, rejection and acceptance. Questions like 'why me?' 'How can it be?' keep arising without answers. Some of them undergo tremendous guilt feelings, experience deep sorrow, have strong under expectations of achievement, may have unrealistic goals, may want to escape form reactions and ultimately turn to accept the child (2). All this can affect different parents differently. Their physical and mental health may actually suffer or they perceive it to suffer. Wikler (1) mentions that tremendous amount of stress chronically affects their lives.

Farber (3) found that initial stress in parents appears to be sex-linked which shifted with time. Mothers of intellectually disabled children and neurotic children undergo more stressful experience than mothers of chronically ill or normal children. According to Faber (4), jealousy and resentment may develop in siblings if the disabled child requires most of his parent's attention, leaving short tempers and impatience for the others.

Jani (5) in a study examined the social problems related to the presence of a intellectually disabled child. Results indicate that parental feelings were marked by anxiety about future. Also, negative effects towards other siblings, psychological stress, decreased interaction with neighbors and relatives, misunderstandings within family and economic loss were significant facts associated with presence of a child with intellectual disability in the family.

Dupont (6) found in a review of a four year caseload of a small community mental health centre, that the community mental health services often had a policy of not providing services to persons with intellectual disability.

Loeb (7) has expressed that parents of intellectually disabled children face many special stresses. They have little opportunity to explore their own needs and difficulties.

Fishman et al.(8) in their study examined the role of parenting stress and parental depression and marital intimacy among parents of disabled children and developmentally normal children. Results showed that mothers and fathers of autistic children significantly showed greater stress and depression as well as marital intimacy than mothers and fathers of children with Down Syndrome.

Heller et al. (9) found that in comparison with fathers of intellectually disabled children, mothers spent more time providing care, offered more types of support and perceived more caregiving burden. The behavior and health of the children had a greater impact on mothers than on fathers.

Peshawaria et al (10) stated that there were gender differences in facilitating and inhibiting factors that affect coping in parents of children with intellectual disability in India. Mothers are under more pressure to balance childcare needs and household chores. Physical support was a relief to them.

Seshadri et al (11) reported a direct relationship between the degree of perceived burden, social emotional burden, disruption of family routine and disturbance in family interactions for women with intellectually disabled children rather than men.

Hedov et al. (12) studied self perceived health in Swedish parents of children with Down Syndrome (DS). They found mothers of children with DS had significantly lower, less favorable scores on self perceived health than did the fathers of DS children and control group.

Shin and Crittenden (13) in their study provided explanations for well being of Korean and American mothers of children with intellectual disability. Causes of stress for the American mothers was specific to the individual variables. For Korean mothers, cultural values that carry social influence were strongly associated with their experience of stress.

Laurvick et al. (14) while working on physical and mental health of mothers caring for a child with Rett Syndrome found that factors positively related with better mental health were the following: the mother working full time or part-time outside the home, the child not having a fracture in last two years, less reporting of facial stereotypes and involuntary facial movements, being in a well adjusted marriage and low stress scores.

Kermanshahi et al. (15) in their study on perceptions of lives with children with intellectual disability found six major themes: challenging the process of acceptance, painful emotional reactions, the interrelatedness of mother's health and child's well being, struggles to deal with oneself or the child, inadequate support from the family and the community, and the anxiety related to child's uncertain future.

Studies in literature indicate that parents of children with intellectual disability, more specially the mothers, would have high stress and low health scores. On the other hand, Mahoney (16) documented some positive effects. He found that the disabled child can have an integrative effect by focusing the family's energy in a concerned, loving manner, thereby minimizing some of the other day to day problems. Some parents expressed a new appreciation for life and ordinary things they used to take for granted.

The present study was planned with the hypothesis that, a) Parents of Children with Intellectual Disability (PCID) will experience significantly greater stress as compared to Parents of Children with No Disability (PCND), b) Parents of children with intellectual disability will

experience significantly greater mental stress than physical stress, c) Mothers of Children with Intellectual Disability(MCID) will experience significantly greater stress than fathers.

METHODOLOGY

Descriptive research method was employed in this study.

Sample

102 subjects formed the sample of this study. Three schools meant for children with intellectual disability were chosen. Within a school, parents of children were chosen randomly. These schools were from Chandigarh, Jalandhar and Ludhiana in India. Three schools for regular children from Patiala were taken on convenient sampling basis. 30 parents had children with no disability (17 fathers and 13 mothers). 65 parents had children with intellectual disability (30 mothers and 35 fathers). 7 couples filled the questionnaires together, hence those data had to be dropped. The age group of children was 9 to 15 years.

Tool

A Quick Stress Assessment Test (QSAT) (Vaz, 1995) was used in this study. It comprises 40 items, 19 in perceptions on physical aspect and 21 in mental aspect. There are three options in each item: Y, if answer applied more than once a week, S, if it occurred every month, N, if it occurred less frequently than once a month. Maximum possible score in case of mental area was 38 and in case of physical it was 42. A score of 2, 1 & 0 were given to Y, S & N respectively.

Content validity was established by expert opinion. Internal validity was established by present authors by inter-correlations of two parts of the test ($r = .608$; $p < .01$).

A score two or more in an area is time to start dealing with stress (17).

Procedure

Data were collected in two stages. Firstly parents of children with no disability and an equal number of parents of children with intellectual disability were administered the QSAT individually. They were assured that data would be kept confidential and be used only for

research purposes. Secondly, additional parents of children with intellectual disability were taken to study gender differences.

Data analysis

After scoring all the responses, data of the mental and physical health were analysed separately. PCID group was compared with PCN group. Gender differences within PCID group were subjected to t-test.

RESULTS

Most subjects showed higher mental stress than physical stress (65 subjects out of 95). Three subjects showed equal score in both areas. 27 subjects showed higher physical stress than mental stress. Six subjects showed no stress in mental area (all from PCN category). Two subjects showed no stress in physical area (one each from PCID and PCN groups). One subject (PCN) showed no stress at all. Highest score in physical area was 38 and in mental area it was 42.

Descriptive data on stress scores is depicted in Table I.

Table 1. Lowest and highest scores in various categories

| GROUP | AREA | SCORES | VALUE |
|--------------|-------------|---------------|--------------|
| PCID | Mental | Lowest | 0 |
| | | Highest | 32 |
| | physical | Lowest | 2 |
| | | highest | 40 |
| PCN | Mental | Lowest | 0 |
| | | highest | 26 |
| | Physical | lowest | 0 |
| | | highest | 36 |

Table 1 shows that highest stress score is higher in case of PCID group in both mental and physical areas than in PCN group and lowest score is lower in PCN group than in PCID group. Table II depicts the frequencies of parents in various conditions.

Table 2. Frequencies of parents in various conditions

| CONDITION | MCN N=13 | FCN N=17 | MCID N=30 | FCID N=35 |
|---------------------------------|---------------------|---------------------|----------------------|----------------------|
| Mental stress > physical stress | 7 | 6 | 21 | 31 |
| Mental stress = physical stress | 0 | 1 | 1 | 1 |
| Mental stress < physical stress | 6 | 10 | 8 | 3 |

In the group with disabled children, in majority of subjects, mental stress is higher than physical stress. Very few subjects have equal scores in both areas. Higher number of subjects have higher physical stress in the group without disabled children. This suggests that the stress of having a child with disability manifests itself more in mental area than in physical area.

Table 3. Statistics for comparison among PCID & PCN groups on total stress.

| GROUP | N | MEAN | SD | T- RATIO |
|--------------|----------|-------------|-----------|---|
| PCID | 30 | 32.16 | 10.80 | 2.46 |
| PCN | 30 | 20.50 | 05.00 | Significant at .01 Level for directional hypothesis |

When the two groups of parents were compared, it was found that mean and variability of the group with disabled children was higher than the other group. The mean difference, when subjected to t-test for independent means yielded a significant t ratio ($t = 2.46$; $p < .01$). This shows that PCID group experiences far greater stress than the PCN group. This confirms hypothesis no 1. This finding is supported by other studies (1,7,12). When data of mothers and fathers was analysed, the picture which emerged is presented in Table 4.

Table 4. Data on total stress, physical and mental stress with regard to gender

| GROUP | TYPE OF STRESS | MEAN | SD | COMPARISONS | T-RATIO | SIGNIFICANCE LEVEL |
|-------------------------------------|----------------|--------|--------|-----------------------------------|---------|--------------------|
| Mothers of children with disability | Total | 30.64 | 11.555 | Total stress in MCMR & FCMR | .926 | - |
| | Physical | 14.83 | 05.475 | Physical stress in MCMR & FCMR | .00211 | - |
| | Mental | 18.13 | 07.270 | Mental stress in MCMR & FCMR | .608 | .05 |
| Fathers of children with disability | Total | 33.16 | 10.200 | Physical & mental stress in Men | .140 | - |
| | Physical | 14.857 | 04.687 | Physical & mental stress in Women | 1.987 | .025 |
| | Mental | 15.07 | 07.680 | | | |

Data shows that the mean stress scores are higher in mental area than physical area in both mothers and fathers and so is variability. Data are indicative of insignificant differences in total stress and physical stress among mothers and fathers. However, they differ significantly in mental stress with mothers scoring higher. This confirms hypothesis II partially. This finding is in consonance with the findings of Peshawaria (10), Hedov et, al.(12) and Seshadri et al (11) who indicated that it is the women who are more affected, in coping with stresses of a child with intellectual disability. However, their physical stress is slightly less as compared to men, but this difference is not significant.

Mental stress in women is significantly higher than physical stress as indicated in Table 4. This confirms hypothesis no III. This shows that mental health suffers more, particularly in the case of women.

The major findings of this study are that parents of children with intellectual disability experience stress. However, all the subjects experience higher level of mental stress than physical stress. Generalisations from this study are cautioned, due to the small volume of data and convenient selections of schools.

*Address for correspondence
3379, Sector 35-D, Chandigarh. U.T. - 160022, India

ACKNOWLEDGEMENT

Thanks to Ms Harpreet Kaur, for collecting data and reviewing part of the literature for this study and Dr Nisha Duggal for collecting some part of the data.

REFERENCES

1. Wikler L. *Chronic stresses of families of mentally Retarded Children*. Family relations April 1981; 30(2):281-288.
2. Berdine W H and Blackhurst A E. *An introduction to Special Education*, US: little Brown and Company. 1985 ; 618-625.
3. Farber B. *Family organization in crisis maintenance of integration in families with several mentally retarded child*. Monograph of society Research and child development 1960, 25(1).
4. Faber B. *Family organization and Parent – Child communication: parents & siblings of a retarded child*. Monograph of society research and child development 1963; 28 (whole no. 91).
5. Jani MC. *Social a mentally retarded child in family*. Dissertation Diploma in Medical and Social Psychology. Bangalore University 1967.
6. Dupont H. *Community mental health centres and services for the Mentally Retarded*. Community Mental Health Journal. Springer, Netherlands. March 1967; 3 (1).
7. Loeb RC. *Group Therapy for parents of mentally retarded children in Attwood, T. The crydon workshop for the parents of severely handicapped School age children*. Child: Care, Health and development; 5(3): 1979177-188.
8. Fishman S N. Woff L C. and Non S. *Marital intimacy in parents of exceptional children*. Canadian journal of Psychiatry 1989; 37(6): 519-5257.
9. Heller T, Hsieh K, and Rowitz L. *Maternal and Paternal caregiving of persons with mental retardation across the life span*. Family relations 1997; 46 (4): 407-115.
10. Peshawaria R, Menon D K, Ganguly R, Roy S, Rajan Pillay P R S, & Gupta S. *A study of Facilitators and Inhibitors that effect coping in parents of children with mental retardation in India*. Asia Pacific Disability Rehabilitation Journal 1998; 9(1).
11. Seshadri M K, Verma S K, and Prashad. *Impact of mental retardation of child on the family in India*. Journal of Clinical Psychology 2000; 473-498.
12. Hedov G, Anneren G, and Wikblad K. *Self perceived health in Swedish parents of children with Down's syndrome*. Quality of life research. May 2000; 9(4).
13. Shin Y J, and Crittenden K S. *Well being of mothers of children with mental retardation : An evaluation of the double ABCX model in a cross cultural context*. Asian Journal of Social Psychology 2003; 6(3): 171-184.

14. Laurvick CL, Msall M E, Silburn S, Bower C, Klerk N de, Leonard H. ***Physical and Mental Health of Mothers caring for a child with Rett syndrome.*** Pediatrics Sept 2006; 118 (4): e 1152 –e1164.
15. Karmanshahi S M, Vanaki Z, Ahmadi F, Kazemnezad A, Mordoeh E and Azadfalah P. ***Iranian Mothers' perceptions of their lives with children with mental retardation: A preliminary Phenomenological Investigation.*** Journal of Developmental and Physical Disabilities 2008; ISSN, DOI 10.1007/S 10882-008-9099-3.
16. . Mahoney S C. ***Observations Concerning Counseling with parents of mentally retarded children.*** American Journal of Mental deficiency 1958; 63: 81-86.
17. Vaz A. ***Quick Stress Assessment Test.*** Unpublished scale to assess stress, Dept of Education Management, S.N.D.T. Women's University, Mumbai, India 1995.