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Stress and Family Burden in Mothers of Children with Disabilities

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Abstract

The present study was designed to assess and compare parenting stress and family burden in mothers of children with disabilities and children without disability. For this purpose, a multi group design was adopted which consisted of five groups of mothers viz. mothers of children with mental disability, mothers of children with both mental and physical disability, mothers of children with physical disability, mothers of deaf and dumb children and mothers of children without disability. Parenting stress index and family burden scale were administered on 125 mothers of children with disabilities and without disability (25mothers in each group), selected from three districts of Haryana state. For statistical analysis, t- test, simple analysis of variance and Duncan's post hoc test were used. Results revealed that mothers of children with both mental and physical disability and mothers of children with mental disability scored significantly higher level of parenting stress and family burden compared to mothers of children with physical disability, mothers of deaf and dumb children, and mothers of children without disability.

Key words: Parenting stress, Family burden, mothers of children with disabilities

Introduction

Disability can be defined by the manifestation of physical and mental limitation within a specific social or environmental context. The World health organization[1] has defined disability as any restriction or lack of ability to perform an activity in the manner or within the range considered normal for a human being. Child with disability means a child who deviates from a normal child in mental or physical characteristics to such an extent that he requires special education and related services.Latson[2] states that parents deal with inherent chronic stress of parenting. Parents usually take pride in their children's achievements but are easily hurt by their children's failures. Parents experience so much worry about the safety and development of their children.

The childhood period can be a stressful time for all parents; however parents of children with disabilities may experience specific sources of stress associated with child's disability and families' concern. Parents of children with disability exhibit a great amount of stress which may include stress related to the child's characteristics, particularly behavioural problems, inadequate support and long term care. Additional sources of stress may include parental conflict associated with caring for their child with disability, lack of financial and social support, and alteration in family's lifestyle and leisure activities due to care giving responsibilities.

Majority of studies on parenting stress and family burden associated with raising a disabled child have focused on mothers. Mothers face more stress as compared to fathers because mothers bear disproportionate share of responsibilities in raising their disabled child. In their study, Rodrigue, Morgan, & Geffken[3] reported that mothers of disabled children experience greater parenting stress and lower parenting competency as compared to mothers of children without disability. Veisson[4] also reported that mothers show significantly more negative emotional states and

more depressive symptoms. Beckman[5] compared parental stress in 54 mothers and 54 fathers of children with disabilities with the parental stress of equal number of mothers and fathers of normal children. Mothers generally reported more stress in parent domain than fathers, but both parents experienced high level of stress in child domain. Parents of disabled children reported greater amount of parenting stress than parents of normal children.

Asberg, Vogel, and Bowers[6] investigated the correlates of parenting stress in parents of deaf children. About 17% of the sample scored higher than the clinical cut off on the parenting stress index; however, the average PSI score (mean = 72.71, SD = 15.84) was not statistically different from the normative sample. Rodriguez and Murphy[7] examined parenting stress and abuse potential in mothers of children with developmental disabilities. Results revealed significant parenting stress which was strongly correlated with abuse potential, particularly stress related to parental attributes. Khamis[8] examined the contribution of various factors to parental stress and psychological distress among parents of children with mental retardation and found that the age of the child was significantly related to parents' feeling of distress and parental stress was less when the child was older. While, high level of child dysfunction was associated with more psychiatric symptomlogy.

Ross, Blanc, & McNeil[9] reported that parents of disabled children show more burden in giving care to their disabled child. Child's caregiving represents an additional role to the family and requires that caregivers consider child's need as a priority, putting their own need second place. Maurin and Boyd[10] said that the concept of family burden includes two aspects, first is "objective burden" of daily assistance activities, financial impact, behaviour supervision and disruption of family routine and second is "subjective burden" of worries about the patients and feelings of being disturbed by caregiving activities. Family caregivers suffer from a high level of burden. In his study, Sloper[11] reported that all families of children with disabilities face vastly increased costs and many needed medical services such as assessment, treatment, and equipment are not covered under public health policies.

Caring for a disabled child may impose direct costs on family for medical care, transportation, parental labour-market activity, and other health care needs. If a child requires exceptional level of care from parent, the parent might reduce hours of work or leave the job to meet the child's need. Families caring for disabled children are likely to experience more material hardship and economic insecurity (Meyers, Lukemeyers, & Smeeding[12]). Angold et al[13] on the basis of their study reported that about 10.7% of the parents in general population experienced parental burden. Child's symptomology and level of impairment, and parental mental health problems were the significant predictors of parental burden in parents.

Luescher et al[14] reported that the degree of parental burden depends more on the parents' coping skills and the level of family functioning rather than on the degree of the child's impairment. Schene[15] linked objective and subjective burden experienced by the family in the socio cultural perspective. He also postulated about the role of coping, attribution style and social skills etc. for the understanding of burden of caregivers. The mere presence of disabled person in family need long term adjustments among the other family members and particularly the caregivers. In these circumstances the burden of care becomes an important variable in the context of home management of disabled person.

Objectives:

1. To assess and compare parenting stress in mothers of children with disabilities and children without disability.
2. To assess and compare family burden in mothers of children with disabilities and children without disability.

Hypotheses:

1. Mothers of children with disabilities would score higher on parenting stress than mothers of children without disability.
2. Mothers of children with disabilities would score higher on family burden than mothers of children without disability.

Method

Design:

To fulfil the objectives of the study a multi group design was used. There were five groups of mothers. There were 25 mothers in each of the five groups viz. Children with mental disability, children with both mental and physical disability, children with physical disability, deaf and dumb children and children without disability.

Sample:

In present study, 125 mothers of children with disabilities and children without disability were selected from three districts of Haryana state (India) on the basis of non random sampling.

Tools:

Parenting stress index:

Parenting stress index developed by Abidin[16] was used. It consists of 36 items. Respondents are required to choose one of the five response alternatives for each statement. The alternatives are 'strongly agree', 'agree', 'undecided',' disagree', and 'strongly disagree'. The scores ranged from 36-180.In addition to the total scores it yields three more scores viz. Parental distress, parent- child dysfunctional interaction and difficult child. The correlation coefficient between the first and second set of scores were .63 for the child domain, .91 for the parent child domain and .96 for the total stress score. The Hindi version of this scale was administered. The test-retest reliability was .83.

Family burden scale:

For measuring family burden a structured interview schedule developed by Pai and Kapur[17] was used. The scale assesses both the subjective and objective burden. The total burden score can be obtained by adding the rating of the24 items and may range from 0 to 48. The cronbach alpha was .90.convergent validity was shown by significant positive correlation (r= .78) between the objective and subjective burden scores. The coefficient of correlation between Hindi and English version was .73.

Procedure:

All the mothers included in sample were contacted personally. After establishing rapport both measures were administered. The testing process was liberal in the sense that rest was given when desired by the respondents. The family burden was assessed by personally interviewing each respondent. The obtained data were analyzed by using t-test, simple analysis of variance and Duncan's post hoc test.

Results

To compare parenting stress and family burden in mothers of children with disabilities and children without disability, simple analysis of variance was done, and for significant mean comparison post hoc Duncan's test was applied.

Table 1 shows that the mean parenting distress scores of mothers of children in different groups differ significantly ($F= 95.24$, $df=4,120$, $P< .01$). Post-hoc Duncan's test revealed that mothers of children without disability

scored significantly less (mean= 31.84, SD= 8.93) on parenting distress compared to mothers of children with disability. Mothers of children with both mental and physical disability scored significantly higher (mean = 56.68, SD=1.95) on parenting distress. Mothers of children in other groups did not differ significantly in their scores on parenting distress.

On parent child dysfunctional interaction, mothers of children with both mental and physical disability scored highest mean score which is 56.2 with SD of 2.75. Mean scores of mothers of children in different groups differed significantly (F=36.73, df=4,120, P<.01). Duncan's test revealed that mothers of children without disability scored (mean= 34.60, SD=10.82) significantly less than mothers of children with disabilities. Mothers of children with physical disability (mean= 49.16, SD=8.53) and mothers of deaf and dumb children (mean= 50.60, SD= 4.86) did not differ significantly from each other. However, both groups of mothers scored significantly less than mothers of children with mental disability (mean= 54.28, SD= 5.04) and mothers of children with both mental and physical disability.

On difficult child component, mean scores of mothers of children with disabilities and mothers of children without disability differed significantly (F=62.57, df =4,120, P<.01). Post-hoc Duncan's test revealed that mothers of children without disability scored (mean= 31.36, SD= 11.75) significantly less than mothers of children with disabilities. Mothers of children with physical disability scored (mean= 51.12, SD= 4.63) significantly less than mothers of children with mental disability (mean= 54.36, SD= 2.75) and mothers of children with both mental and physical disability (mean=55.48, SD=3.01).

Further, on total parenting stress, mean scores of mothers of children in different groups differed significantly (F=97.81, df =4,120, P<.01). Post-hoc Duncan's test revealed that mothers of children without disability scored significantly less (Mean=97.80, SD=27.66) than mothers of children with disability. Mothers of children with physical disability (mean=152.56, SD=10.07) and mothers of deaf and dumb children (mean=157.52, SD=9.17) scored significantly less than mothers of children with mental disability (mean=163.32, SD= 8.40) and mothers of children with both mental and physical disability (mean= 168.36, SD= 5.16).

Table 2 shows that mean scores of mothers in different groups differ significantly (F=12.10, df=4,120, P<.01) on economic burden scale. Duncan's test revealed that mothers of children without disability perceived significantly less economic burden (mean=1.04, SD=1.74) compared to mothers of children with different disabilities. Mothers of children with mental disability (mean=5.12, SD=2.60) experienced significantly higher level of economic burden than mothers of children with physical disability (mean=3.48, SD=2.70). Other groups did not differ significantly from each other.

On perceived obstacles in daily living activity, mothers of children in different groups differed significantly (F=71.33, df=4,120, P<.01). Duncan's test revealed that mothers of children without disability perceived less obstacles in daily living activity (mean=2.76, SD=1.45) compared to mothers of children with different disabilities. Mothers of children with physical disability scored (mean=5.40, SD=1.7) significantly less than mothers of children with mental disability (mean=7.84, SD=.55), mothers of deaf and dumb children (mean=6.08, SD=1.22) and mothers of mentally with physically disabled children (mean=7.76, SD=.83). Mothers of deaf and dumb children scored significantly less than mothers of children with mental disability and mothers of mentally and physically disabled children.

On disruption in family interaction, mothers of children in different groups differed significantly (F=126.79, df=4,120, P<.01). Duncan's test revealed that mothers of children without disability scored (mean=1.84, SD=1.28) significantly less than mothers of children with disabilities. Mothers of deaf and dumb children scored (mean=5.28,

SD=1.40) significantly less than mothers of children with mental disability (mean=7.84, SD=.62), mother of children with both mental and physical disability (mean=7.92, SD=.40) and mothers of children with physical disability (mean=6.40, SD=1.41).

In case of effect on others mental and physical health, mean scores of mothers of children in different groups differed significantly (F=5.83, df=4,120, P<.01). Duncan's test revealed that mothers of mentally with physically disabled children scored significantly higher (mean=5.76, SD=2.61) than other groups of mothers. Mothers of children without disability scored (mean=2.80, SD=1.60) significantly less than mothers of children with disability.

Further, on total family burden, the mean scores of mothers of children in different groups differed significantly (F=66.21, df=4,120, P<.81). Duncan's test revealed that mothers of children without disability scored (mean=8.44, SD=4.30) significantly less than mothers of children with different disabilities. However, mothers of children with different disabilities did not differ significantly with each other in their scores on total family burden.

Discussion

The present study was intended to assess and compare the parenting stress and family burden in mothers of differently disabled and children without disability. These findings are consistent with our first hypothesis, mothers of children with different disabilities and children without disability differed significantly on all components of parenting stress index. Duncan's post hoc test demonstrated that the mothers of children having both disabilities i.e. mental disability with physical disability were significantly higher on almost all the components of parenting stress index. Secondly, mothers of children with mental disability were also found to have higher level of parenting stress compared to parents of physically disabled, deaf and dumb children and children without disability. It may be because of the fact that the children with mental disability and children with mental and physical disability require great amount of time and effort for parenting and caregiving. Moreover, the physically disabled and deaf and dumb children have better comprehension and ability to follow instruction and learning compared to the mentally disabled. Our finding coincide with the study of Donovan[18] who reported that mothers of adolescents, who were autistic, previewed greater level of family stress than the mothers of mentally retarded children, as autistic child requires more attention and care. Results found by Keller and Hong[19] that children's demandingness and neediness for care was related more to maternal stress, and child's acceptability was related more to parental stress also supports our finding.

Although no significant differences were found in any domain of parenting stress among mothers of physically disabled and deaf and dumb children. But they scored significantly higher on all domains of parenting stress than mothers of children without disability. These results are consistent with the recent study of Dogan[20] who reported that parents of children with hearing loss, especially the mothers, perceived greater level of stress and were at risk of developing psychiatric symptoms. In their study, Oelofsen and Richardson[21] reported higher level of parenting stress, weaker sense of coherence and poor health among parents of children with disability than parents of normal children.

In case of family burden, results revealed that mothers of children with mental disability reported significantly higher economic burden and obstacle in daily living and mothers of children with mental and physical disability reported significantly higher disruption in family interaction and effect on other's health. However, significant group comparison by post hoc Duncan test demonstrated no significant difference between mothers of children with mental disability and mother of children with mental and physical disability. These results are similar to the findings of Gathwala and Gupta[22] who identified family burden in parents of mentally handicapped children.

Severest burden was obtained in the domain of effect on physical health of other family members followed by burden of family leisure and effect on family interaction. In their study Mugno, Ruta, D'Arrigo, & Mazzone[23] also found higher level of perceive burden in parents of children with cerebral palsy with mental retardation than those with parents of normal children. Child with special health care needs profoundly affects a family's economic stability.

Conclusion

These findings suggest that mothers of children having both physical and mental disability suffer from significantly higher amount of stress and family burden. It appears that incompetency in taking care of these disabled children increases stress and family burden on mothers. Therefore, special parent training programs should be provided to these mothers to make them effective and competent in their parenting services and to help them control the behaviour difficulties of their children which will in turn decrease their stress and family burden.

References

1. World Health Organisation. Document A29/inf doci/1, Geneva, Switzerland, 1976.
2. Latson S R. Preventing Parent Burn Out: Model for Teaching Effective Coping Strategies to Parents of Children with Learning Disabilities. Learning Disabilities Association of America, 1995.
3. Rodrigue J R, Morgan S B, Geffken G. Families of autistic children: Psychological functioning of mothers. Journal of Clinical Child Psychology, 1990; 19(4): 371–379.
4. Veisson M. Depression symptoms and emotional states of parents of disabled and non disabled children. Social behaviour and personality: An international journal ,1999; 27(1), Quarterly.
5. Beckman P J. Comparison of mothers' and fathers' perceptions of the effect of young children with and without disabilities. American Journal of Mental Retardation, 1991; 95(5): 585-595.
6. Asberg K, Vogel J, Bowers C. Exploring correlates and predictors of stress in parents of deaf children: Implications of perceived social support and mode of communication. Journal of Child and Family Studies, 2008; 17(4): 486-499.
7. Rodriguez C M and Murphy L. Parenting stress and abuse potential in mothers of children with developmental disabilities. Child Maltreatment, 1997; 2(3): 245-251.
8. Khamis V. Psychological distress among parents of children with mental retardation in the United Arab Emirates. Social Science Medicine, 2007; 64(4): 850-7.
9. Ross C N, Blanc H, and McNeil C B. Parenting stress in mothers of younger and older children with behaviour problems: Implications for early intervention. West Virginia Journal of Psychological Research and Practice, 1996; 5: 33-39.
10. Maurin J T and Boyd C B. Burden of mental illness on the family: A critical review. Archives of Psychiatric Nursing, 1990; 4(2): 99–107.
11. Sloper P. Models of service support for parents of disabled children. What do we know? What do we need to know? Child: Care, Health & Development, 1999; 25(2): 85-99.
12. Meyers M, Lukemeyers A and Smeeding T. The cost of caring: childhood disability and poor families. Social Service Review, 1998; 72(2): 209-223.
13. Angold A, Messer S C, Stangl D, et al. Perceived parental burden and service use for child and adolescent psychiatric disorders. American Journal of Public Health, 1998; 88(1): 75-80.

14. Luescher L J, Dede E D, Gitten C J, et al. Parental burden, coping, and family functioning in primary caregivers of children with joubert syndrome. Journal of Child Neurology, 1999; 14: 642-648
15. Schene A H. Objective and subjective dimensions of family burden. Toward an integrative framework for research. Social Psychiatry and Psychiatric Epidemiology, 1990; 25(6): 289–297.
16. Abidin R R. Parenting stress index: professional manual (3rd. Ed) Odessa, FL: Psychological assessment Resources, Inc. 1995.
17. Pai S, Kapur R L. Burden on the family of a psychiatric patient: Development of an interview schedule. British Journal of Psychiatry, 1981; 138 (4): 332–338.
18. Donovan A M. Family stress and ways of coping with adolescents who have handicaps: Maternal perceptions. American Journal of Mental Retardation, 1988; 92(6): 502-509.
19. Keller D and Hong A S. Maternal and paternal stress in families with school-aged children with disabilities. American journal on orthopedically psychiatry, 2004; 74: 337-48.
20. Dogan M. Comparison of parents of children with and without hearing loss in terms of stress, depression, and trait anxiety. International journal of early childhood special education, 2010; 2(3): 247-253.
21. Oelofsen N and Richardson P. Sense of coherence and parenting stress in mothers and fathers of preschool children with developmental disability. Journal of Intellectual &Developmental Disability, 2006; 31(1): 1-12.
22. Gathwala G and Gupta S. Family burden in mentally handicapped children. Indian journal of community medicine, 2004; 29(4): 188-189.
23. Mugno D, Ruta L, D'Arrigo V G et al. Impairment of quality of life in parents of children and adolescents with pervasive developmental disorder. Health and Quality of Life Outcomes, 2007; 5(22)

Table1: Parenting stress in mothers of children with different disabilities and children without disability

	Mothers of children with										
variables	**Mental Disability**		**Mental and physical Disability**		**Physical Disability**		**Deaf and dumb**		**Children without disability**		
	Mean	**SD**	**Mean**	**SD**	**mean**	**SD**	**Mean**	**SD**	**mean**	**SD**	**F-value**
Parenting distress	54.68^{bc}	4.27	56.68^{c}	1.95	52.28^{b}	5.35	54.32^{bc}	2.68	31.84^{a}	10.55	95.24^{**}
Dysfunctional interaction	54.28^{c}	5.04	56.20^{c}	2.75	49.16^{b}	8.53	50.60^{b}	4.86	34.60^{a}	10.82	36.73^{**}
Difficult child	54.36^{c}	2.75	55.48^{c}	3.01	51.12^{b}	4.63	52.60^{bc}	4.81	31.36^{a}	11.75	62.58^{**}
Total scores	163.32^{cd}	8.40	168.36^{d}	5.16	152.56^{b}	10.07	157.52^{bc}	9.17	97.80^{a}	27.66	97.81^{**}

*significant at.05 level, **significant at.01 level

Subscripts a, b, c, d, ab, cd etc. shows Duncan's post hoc test for significant mean comparison

Table2: Family burden in mothers of children with different disabilities and children without disability

	Mothers of children with										
variables	**Mental disability**		**Mental and physical disability**		**Physical Disability**		**Deaf and dumb**		**Children without disability**		
	mean	**SD**	**Mean**	**SD**	**Mean**	**SD**	**mean**	**SD**	**mean**	**SD**	**F-value**
Economic burden	5.12^{c}	2.60	4.48^{bc}	2.18	3.48^{b}	2.70	4.08^{bc}	1.77	1.04^{a}	1.74	12.10^{**}
Obstacle in Daily living activity	7.84^{d}	.55	7.76^{d}	.83	5.40^{b}	1.7	6.08^{c}	1.22	2.76^{a}	1.45	71.34^{**}
Disruption in Family interaction	7.84^{d}	.62	7.92^{d}	.40	6.40^{c}	1.41	5.28^{b}	1.40	1.84^{a}	1.28	126.79^{**}
Effect on other's health	4.12^{b}	2.93	5.76^{c}	2.61	3.40^{ab}	2.44	3.28^{ab}	2.15	2.80^{a}	1.60	5.83^{**}
Total score	24.92^{c}	4.92	25.92^{c}	3.92	18.68^{b}	3.80	18.72^{b}	4.35	8.44^{a}	4.30	66.21^{**}