Original article

Stress among Parents of Children with Mental Retardation

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Abstract

Mental retardation is one of the most prevalent developmental disabilities of the children globally. Family is the main source of support for those disable children in any society. Parents experience enormous physical and mental stress to tackle the mentally retarded children. This present comparative cross-sectional study tried to compare difference of mental and physical stress between the parents of children with mental retardation and the parents of children with no mental retardation. It included 220 parents, 110 of whom had children with mental retardation and another 110 parents of children with no mental retardation. To assess stress, A Quick Stress Assessment Test (QSAT) (Vaz, 1995) was used, which comprised two parts: physical and mental, former with 19 items and latter with 21 items. Data were collected with a self-administered questionnaire and analyzed by using SPSS software. To check differences of stress scores and gender differences of stress,'t' test and '?^{2}' tests were applied as required. The study revealed that the parents of children with mental retardation (PCMR) shared significantly greater stress score (34.27) than the parents of children with no mental retardation (PCNR) (21.66), [$t_{(218)}$= 2.63, p=0.001]. Mental stress score was significantly higher among PCMR (33.57) than the PCNR (26.46) [$t_{(218)}$= 3.87; p=0.002] while physical stress score was insignificantly higher among PCMR (20.43) than the PCNR (18.66). Majority of the parents with mentally retarded children (71.4% mothers and 67.5% fathers) had higher mental stress than physical stress [?$^{2}_{(1)}$=2243, p=0.024]. Mothers had significantly higher mental stress score than the fathers of mentally retarded children ['t'$_{(109)}$, p=0.025]. Special measures like early diagnosis, prompt treatment and counseling for mental and physical stress of the parents along with provision of need based rehabilitation services for the mentally retarded children at different levels to reduce the stress burden of their parents.

Key Words: Stress, Parents, Children, Mental Retardation

Introduction

Mental retardation is a major intellectual disability among condition worldwide. Around 1-4% of the world population may have some level of mental retardation[1]. The magnitude of mental retardation is highest in developing countries primarily due to environmental, nutritional, disease burden and poverty[2]. Every parent feels a sense of self worth at the same time they pass through a level of stress in the process of rearing up of children. Mental stress is radically higher among parents of children with mental retardation [3].

Discrepancies between expectations and the performance of the mentally retarded child continue bringing feelings of grief[4]. A parent shows a series of reactions after knowing that their child is with mental retardation. These include shock, denial, guilt, sorrow, rejection and acceptance. 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. Physical and mental stress may chronically affect their lives[5].

Farber found that initial stress in parents appears to be sex-linked which shifted with time. Mothers of mentally disabled children undergo more stressful experience than mothers of chronically ill or normal children[6,7]. Related social problems revealed that parental feelings were marked by anxiety about future along with negative effects towards other sib-

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lings, psychological stress, decreased interaction with neighbors and relatives, misunderstandings within family and economic loss[8,9]. Parents of children with mental retardation face many special stresses like little opportunity to explore their own needs and difficulties and depression[10,11]. The behavior and health of the children had a greater impact on mothers than on fathers. Peshawaria et al stated that there were gender differences in facilitating and inhibiting factors that affect coping in parents of children with mental retardation. Mothers are under more pressure to balance child care needs and household chores[12].

Different studies revealed direct relationship between the degree of perceived burden, social and emotional burden, disruption of family routine and disturbance in family interactions for women with mentally disabled children rather than men[13-15]. Physical and mental stress of mothers for caring mentally disable children pose huge burden to their productivity and work performances[16]. Study on perceptions of lives with children with mental retardation 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 mental retardation, more specially the mothers, would have high stress and low health scores[17,18].

In developing countries like Bangladesh, the situation is worse where majority of the families are already living with different constrains with scarcity of resources and little access to appropriate health care services. Parents especially the women are the gravest victims of mental and physical stress[19] who have to bear major responsibility of their children. The study was designed to compare the physical and mental stress of the parents of children with mental retardation with the stresses of the parents of the children without mental retardation. The study findings will contribute to formulate specific measures to ensure active participation of the parents of the children with mental retardation in child rearing and development activities by reducing their physical and mental stresses.

Materials and Methods

The study was planned with the hypothesis that, i) Parents of Children with Mental Retardation (PCMR) will experience significantly greater stress as compared to Parents of Children without Mental Retardation (PCNR), ii) Parents of children with mental retardation will experience significantly greater mental stress than physical stress, iii) Mothers of children with mental retardation will experience significantly greater stress than the fathers. This comparative cross-sectional study was conducted during January to June 2009 among conveniently selected 220 parents of whom 110 were Parents of Children with Mental Retardation (PCMR) and the rest 110 were the Parents of Children with no Mental Retardation (PCNR). The PCMR were selected from the Kalyani Special School, Bangladesh Protibondi Foundation, Mirpur and Malibag Branch and School for Intellectually Disabled, SWID, Bangladesh, Eskaton and Dhanmondi Branch. On the contrary, the PCNR were also selected from Manarat International School, Dhaka and Mohammadpur Preparatory Higher Secondary School, Dhaka. All the participants were selected conveniently considering specific inclusion and exclusion criteria.

Inclusion criteria

- Parents of children with mental retardation (PCMR) must have alive mentally retarded (diagnosed by specialist) children.
- Parents who provided informed written consent.
- Parents who could read and write in Bengali without any assistance.
- Parents aged >18 years.
- Parents irrespective of sex.

Exclusion criteria

- Seriously sick parents.
- Psychologically instable parents who could not response to the interview.
- Parents who had no willingness to participate.

Tool:

A Quick Stress Assessment Test (QSAT)[20] was used in the study, which comprised 40 items, 19 in perceptions on physical aspect and 21 in mental aspect. There were 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. 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=0.608: p<0.01). A score two or more in an area was time to start dealing with stress[20].

Data Collection Procedure

Data were collected from individual participant by obtaining informed written consent. They were assured that data would be kept confidential and be used only for research purposes. Both group of parents were administered the QSAT individually. Bengali version of the questionnaire (QSAT) was used to collect data. At the beginning, the participants were explained about the objectives and procedure of the study followed by instructions regarding the contents and way of fill up of the questionnaire were given to the individual participant. Parents were reached in the morning, when they accompanied the children to the schools. Data were attempted to collect form the parents especially when they waited for a certain period in front of the respective schools to bring their children home. Each participant was given separate questionnaire to fill up and it was taken 30-45 minutes to complete the self-administered interview.

Statistical Analysis

After scoring all the responses, data on mental and physical stress were analyzed separately. PCMR group was compared with PCNR group. Mean difference of stress score was subjected to't' test and gender difference of stress was subjected to "?2 test.

Ethical Issues

Informed written consent was taken form the parents prior to data collection. The parents were informed about their right to withdraw from the study at any stage or to restrict their data from analysis. Privacy was maintained during data collection and confidentiality of data was maintained strictly.

Results

Distribution of the Participants

The study included total 220 parents, of whom 110 parents had mentally retarded children and the rest 110 parents had children without mental retardation. Among 110 parents of children with mental retardation, 70 (63.6%) were mothers and 40 (36.4%) were fathers. On the contrary, among 110 parents of children without mental retardation, 42 (38.2%) were fathers and 68 (61.8%) were mothers. The age range of children was 8 to 16 years.

Background variables of the Parents

The study showed that mean age was a little higher (34.8±6.4 years) among the parents of children with mental retardation (PCMR) than the mean age (34.3±5.6 years) of the parents of children without mental retardation (PCNR). Majority (28.33%) of the PCMR were graduates followed by higher secondary (26.58%), secondary (24.17%) and masters (16.66%). On the contrary, major part (36.67%) of the PCNR had secondary followed by 25.55% had higher secondary, 18.42% were graduates and 10.98% were maters. It was found that majority (41.33%) of the PCMR were service holders followed by housewives (32.12%), businessmen (24.29%) and students (2.26%). On the other hand, majority (43.56%) of the PCNR were housewives followed by service holders (27.24%), businessmen (22.87%) and students (6.33%). Average monthly income was higher (Tk.24,567±2237.32) in PCMR group than in the PCNR group (Tk.18,725±2435.16). Majority (56.34%) of the PCMR had nuclear family while majority (57.35%) of the PCNR had joint family, which is depicted in Table-I.

Table-I: Background Variables of the Parents

Attribute	Finding	
	PCMR	PCNR
Mean(±SD) age	34.8 (±6.4) years	34.3 (±5.6) years
Education	Primary: 4.26%, Secondary: 24.17%, Higher Secondary: 26.58%, Graduate: 28.33%, Masters: 16.66%.	Primary: 8.38%, Secondary: 36.67%, Higher Secondary: 25.55%, Graduate: 18.42%, Masters: 10.98%.
Occupation	House wife: 32.12%, Service:41.33%, Business: 24.29%, Student: 2.26%	House wife: 43.56%, Service: 27.24%, Business: 22.87%, Student: 6.33%
Average monthly family income	Tk.24,567/- (±2237.32)	Tk.18,725/-(±2435.16)
Average number of children	3.2 (±2.6)	2.4 (±2.2)
Type of family	Nuclear: 56.34%. Joint: 43.66%	Nuclear: 52.65%. Joint: 57.35%

The study revealed that the parents of children with mental retardation (PCMR) experienced significantly greater stress (mean score 34.27) than the parents of children with no mental retardation (PCNR) (mean score 21.66) with t ratio [$t_{(218)}$= 2.63, p=0.001]. Regarding mental stress, PCMR shared significantly higher stress score (33.57) than the PCNR (26.46) with a significant t ratio [$t_{(218)}$= 3.87; p=0.002]. On the contrary, physical stress was insignificantly higher among PCMR (20.43) than the PCNR (18.66), which is presented in Table II.

Table-II: Stress score between parents of children with mental retardation (PCMR) & parents of children with no mental retardation (PCNR)

Stress	Group	N	Mean Score	SD	't' test		
					't' value	df	p
Mental	PCMR	110	33.57	13.22	3.87	218	**0.002**
	PCNR	110	26.46	7.56			
Physical	PCMR	110	20.43	8.43	1.23	218	0.24
	PCNR	110	18.66	9.86			
Total	PCMR	110	34.27	12.52	2.63	218	**0.001**
	PCNR	110	21.66	05.46			

Among the parents with mentally retarded children, majority (71.4% mothers and 67.5% fathers) had higher mental stress than physical stress [?$^{2}_{(1)}$=22 43, p=0.024]. Very few subjects had equal scores in both areas. On the contrary, in the group with mentally normal children, higher number of 55.0% fathers and 35.3% mothers had higher physical stress while 58.8% mothers and 37.5% fathers had higher mental stress without statistical significance, which is depicted in the Table-III.

Table -III: Distribution of stress by gender of the parents

Condition	PCNR		PCMR		Significance Level (χ^2 test)
	Mothers f (%)	Fathers f (%)	Mothers f (%)	Fathers f (%)	
Mental stress > physical stress	40 (58.8)	15 (37.5)	50 (71.4)	27 (67.5)	[$\chi^2_{(1)}$=22 43, **p=0.024]**
Mental stress = physical stress	04 (5.9)	03 (7.5)	04 (5.7)	02 (5.0)	[$\chi^2_{(1)}$=3.21, p=0.62]
Mental stress < physical stress	24 (35.3)	22 (55.0)	16 (22.9)	11 (27.5)	[$\chi^2_{(1)}$=2.63, p=0.53]
Total	68 (100.0)	42 (100.0)	70 (100.0)	40 (100.0)	[$\chi^2_{(1)}$=2.26, p=0.46]

The study depicted that the stress score was significantly higher in mental area in both mothers (18.13) and fathers (15.47) than the stress in physical area, which were 14.83 and 14.86 for mothers and fathers respectively. Mental stress score was significantly higher among MCMR group than the FCMR group ['t'$_{(109)}$, p=0.025]. Data were indicative of insignificant differences in total stress and physical stress among fathers and mothers but they differed significantly in mental stress with mothers scoring higher group ['t'$_{(109)}$, p=0.042], which is focused in Table-IV.

Table-IV: Physical and mental stress between father (FCMR) and mother (MCMR) of children with mental retardation

Group	Stress	Mean Score	SD	Comparison	T-Ratio	Significance Level	
						df	P value
MCMR	Total	31.56	12.47	Total Stress in MCMR & FCMR	0.226	109	0.341
	Physical	14.83	06.23	Physical Stress in MCMR & FCMR	0.002	109	0.362
	Mental	18.13	07.88	Mental Stress in MCMR & FCMR	0.608	109	0.042
FCMR	Total	34.27	11.17	Physical & Mental Stress in MCMR	0.140	109	0.223
	Physical	14.86	05.19	Physical Stress in MCMR	0.126	109	0.087
	Mental	15.47	08.16	Mental Stress in MCMR	1.987	109	0.025

Discussion

This specific comparative cross-sectional study was conducted to compare physical and mental stress between the parents of children with mental retardation and parents with no mental retardation. The study was conducted among 220 parents including 110 parents of mentally retarded children and the rest 110 parents of children without mental retardation. Among 110 parents of children with mental retardation, 70 (63.6%) were mothers and 40 (36.4%) were fathers. On the contrary, among 110 parents of children without mental retardation, 42 (38.2%) were fathers and 68 (61.8%) were mothers. The age range of children was 8 to 16 years. In this regard, the study conducted by Gupta RK et all found the age range of the children of 9-15 years.[21] This variation may be explained by the facts that the study place of this current study was different from the study of Gupta RK, which was conducted in India.

The study found that the mean age was a little higher (34.8±6.4 years) among the parents of children with mental retardation (PCMR) than the mean age (34.3±5.6 years) of the parents of children without mental retardation (PCNR). This variation could be due to selection of the participants conveniently from selected schools of Dhaka city. Regarding educational qualification of the parents, majority (28.33%) of the PCMR were graduates followed by higher secondary (26.58%), secondary (24.17%) and masters (16.66%). On the contrary, major part (36.67%) of the PCNR had secondary followed by 25.55% had higher secondary, 18.42% were graduates and 10.98% were maters. This findings reflect that majority of parents of mentally retarded children had higher education in comparison to the parents of the parents of children with no mental retardation. Regarding occupation of the parents, it was found that majority (41.33%) of the PCMR were service holders followed by housewives (32.12%), businessmen (24.29%) and students (2.26%). On the other hand, majority (43.56%) of the PCNR were housewives followed by service holders (27.24%), businessmen (22.87%) and students (6.33%). Average monthly income was higher (Tk.24,567±2237.32) in PCMR group than in the PCNR group (Tk.18,725±2435.16). Majority (56.34%) of the PCMR had nuclear family while majority (57.35%) of the PCNR had joint family.

Similar findings were revealed by the study conducted Laurvick CL where significant association was revealed between mental retardation of the children and maternal determinants like age, education, occupation[16]. Theses findings of the study can be justified by the logics that majority of the educated and service employed parents specially the mothers of the mentally retarded children could not pay adequate attention and care to their offspring during pregnancy and early childhood, which may precipitate or enhance the factors responsible mental retardation of their children.

The study showed that parents of children with mental retardation (PCMR) group experienced significantly greater mental stress score than the parents of children without mental retardation (PCNR) group and similar finding g was revealed by the study conducted Gupta RK in India where parents of mentally

disabled children shared greater stress score than the parents of mentally normal children.

The study depicted that the parents of children with mental retardation (PCMR) experienced significantly greater stress (34.27) than the parents of children with no mental retardation (PCNR) (21.66) with t ratio [$t_{(218)}$= 2.63, p=0.001]. Regarding mental stress, PCMR shared significantly higher stress score (33.57) than the PCNR (26.46) with a significant t ratio [$t_{(218)}$= 3.87; p=0.002] and the picture is focused in the table-II. It confirmed the first hypothesis. This finding is supported by other studies conducted by Wikler et all[4], Loeb et all[10] and Hedov et all[14] where all the study the findings showed that parents of mentally retarded or disabled children shared greater mental stress than the parents of children with no mental retardation who incurred 31.23, 33.42 and 32.63 stress scores respectively.

On the basis of analysis of data considering gender of the parent i.e. mothers and fathers, the study depicted that the stress scores were higher in mental area than physical area in both mothers (18.13) and fathers (15.47), which is depicted in table-III. This confirmed hypothesis (ii) partially. However, physical stress was slightly less among women as compared to men, but this difference was not statistically significant. This finding supported the finding revealed by the study of Gupta RK et all which showed that parents shared more mental stress than physical stress.[21]

Mental stress score was significantly higher among MCMR group than the FCMR group ('t' test, $p<0.05$), which is focused in table-4. This confirmed hypothesis no (iii). This showed that mental health suffers more, particularly in the case of women. This finding is in consonance with the findings of Peshawaria[12], Hedov et, al[14], Seshadri et al[13] Fahmida et al[22],who indicated that it is the women who were more affected, in coping with stresses of a child with mental retardation.

The major findings of this study were that parents of children with mental retardation experienced stress. However, all the subjects experienced higher level of mental stress than physical stress and women shared more mental stress than their counterpart men. Generalizations from this study are cautioned, due to the small volume of data and convenient selections of schools.

References

1. World Health Organization (WHO). Ageing and intellectual disabilities - improving longevity and promoting healthy ageing: Summative report. Geneva, Switzerland: WHO, 2000:26-28.
2. Fujiura G, Park HJ, Rutkowsk-Kmitta V. Disability statistics in the developing world: A reflection on the meaning of our numbers. *J Appl Res.* Intellect. Disabil. 2005; **18:** 295-304. http://dx.doi.org/10.1111/j.1468-3148.2005.00268.x
3. Friedrich WN, Freidrich WL. Psychosocial assets of parents of handicapped and non-handicapped children. *Am J Ment.* Deficiency 1981; **85:** 551-553.
4. Wikler L. Chronic Stresses of Families of Mentally Retarded Children. *Family Relations* April 1981; **30**(2): 281-288. http://dx.doi.org/10.2307/584142
5. Berdine WH, Blackhurst AE. An Introduction to Special Education, US: Little Brown and Company. 1985; 618-625.
6. 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). http://dx.doi.org/10.2307/1165524
7. Faber B. Family organization and Parent - Child communication: parents & siblings of retarded child. *Monograph of society research and child development* 1963; **28**(91).
8. Jani MC. Social impact of a mentally retarded child in family. Dissertation, Diploma in Medical and Social Psychology. Bangalore University, India; 1997.
9. Dupont H. Community mental health centers and services for the Mentally Retarded. *Comm. Ment. Health J. Springer, Netherlands.* March 1967; **3**(1).
10. 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* 1979; **5**(3): 177-188.
11. Fishman SN, Woff LC, Non S. Marital intimacy in parents of exceptional children. *Can. J of Psychiatry* 1989; **37**(6): 519-525.
12. Peshawaria R, Menon DK, Ganguly R, Roy S, Rajan Pillay PRS, & Gupta SA. Study of facilitators and inhibitors that effect coping in parents of children with mental retardation in India. Asia *Pacific Disab. Rehab. J* 1998; **9**(1).
13. Seshadri MK, Verma SK, Prashad R. Impact of mental retardation of child on the family in India. *J Clin. Psychology* 2000; 473-498.
14. Hedov G, Anneren G, Wikblad K. Self perceived health in Swedish parents of children with Down's syndrome. Quality of life research. May 2000; 9(4). http://dx.doi.org/10.1023/A:1008910527481 PMid:11131934
15. Shin YJ, Crittenden KS. Well being of mothers of children with mental retardation: An evaluation of the double ABCX model in a cross cultural context. *Asia J of Soc. Psychology* 2003; **6**(3): 171-184. http://dx.doi.org/10.1542/peds.2006-0439 PMid:16966392
16. Laurvick CL, Msall ME, Silburn S, Bower C, Klerk N, Leonard H. Physical and mental health of mothers caring for a child with Rett Syndrome. *Pediatrics* Sept 2006; **118** (4): e1152 - e1164.
17. Karmanshahi SM, Vanaki Z, Ahmadi F, Kazemnezad A, Mordoeh E, Azadfalah P. Iranian mothers' perceptions of their lives with children with mental retardation: A preliminary phenomenological investigation. *J of Develop. and Physic. Disabil.* 2008; ISSN, DOI 10.1007/S 10882-008-9099-3.
18. Mahoney SC. Observations concerning counseling with parents of mentally retarded children. *Am J Ment.* Deficiency 1958; **63:** 81-86.
19. Sen B. Health and poverty in the context of country development strategy: A case study on Bangladesh. Macro-economics. Health and Development 1997; Series no. 26. Geneva: WHO.
20. Vaz A. Quick Stress Assessment Test. Unpublished scale to assess stress, Dept of Education Management, SNDT. Women's University, Mumbai, India 1995.
21. Gupta RK, Kaur H. Stress among Parents of Children with Intellectual Disability. *Asia Pacific Disab. Rehab. J* 2010; **21**(2): 119-126.
22. A Fahmida, MA Wahab, MM Rahman. Pattern of psychiatric morbidity among the patients admitted in a private psychiatric clinic. Bangladesh *Journal of Medical Science* 2009;.**8**(1): 23-28. doi: 10.3329/bjms.v8i1.3186.