

A Study to Assess the Parenting Stress and the Related Factors among Parents of Differently Abled Children in Selected Special Schools of Kolkata

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Abstract: ***Background:** An overwhelming majority of differently abled children especially with ID have traditionally cared for in their families. Parents are the central and most important link in the care, education and supervision of child with disability hence they undergo enormous amount of physical and psychological issues related to child care and very little work has been done in this regards. **Objectives:** The study was conducted to assess the parenting stress, identify the related factors affecting and association of parental stress with identified factors and selected demographic variables. **Study Design:** A cross-sectional study. **Materials and Methods:** Research was conducted among differently abled children from 5-18 years of age in 5 selected special schools of Kolkata using parental stress scale by berry berry and a self- structured questionnaire. **Results:** Parents of differently abled children experienced (48.7%) severe to (47.3%) moderate stress with mean score 67.48 ± 5.444 and 54.21 ± 4.157 respectively, while caring the child. The identified factors contributing to parental stress were extra inputs for care, altered social life, worry & disturbed behaviour of child. **Conclusions:** The findings of the study revealed that parents experienced severe as well as moderate parental stress, irrespective of gender. The primary responsibility of caring the child was often fulfilled by the mothers hence they were more stressed than the fathers.*

Keywords: parenting stress, differently abled children

1. Introduction

Children are the greatest gift of God to humanity. Every parent builds up a lot of dreams for the child to be born. A good parent and child relationships are vital for the development of children. When an individual becomes a parent they opt for all the roles of parenthood and the lesson associated with it, they even feel that their personal life is over as they have to devote maximum time parenting the child. Every time they experience those dour parts of parenthood, they feel exhausted & stressed. This leads to resentment as they end up taking care of the child instead of doing what they really want to do¹

The scenario gets much worsened when a child is born with a disability. The parents undergoes a number of reactions such as anger, guilt, rejection, isolation² resulting in "stress" not only as the result of child-rearing but also due to their social and environmental circumstances, responsibilities and everyday life.³ The situation becomes much more challenging for the parent when they discover that their child is intellectually disabled or has a developmental disability. According to ICD-10, ID is a condition of "arrested or incomplete development of the mind" and characterized by impaired developmental skills that contribute to the overall level of intelligence.⁴ Studies have shown that parents of disabled children develop psychological issues while child care.⁵ Many studies have been similar in reporting that there are several parental factors which may interfere with the parent-child relationship and increase the risk for parental stress, which in-turn result in low confidence in parenting abilities, low perceived attachment with the child, health problems, depression and anxiety among parents.⁶

Caring for such children is found to be physical as well as mentally tasking job for the parents, which becomes worse depending on the type of disability, resulting in a compromised quality of life of the parents.⁷ Baker et.al

(2002) quotes that severity of the child's behavioral problems is one of the strongest predictors of parental stress.⁸

2. Aims and Objectives

Study aimed at assessing the parenting stress and the related factors among parents of differently abled children.

2.1 Objectives

- 1) To assess the parenting stress among the parents of differently abled children.
- 2) To identify the factors related to parenting stress among the parents of differently abled children.
- 3) To find out the association between parenting stress and factors affecting parenting stress.
- 4) To find out the association between parenting stress and selected demographic variables among the parents of differently abled children.

3. Materials and Methods

Study setting: the study was conducted in selected 5 special schools of Kolkata, which provided formal education and training to differently abled children. These school are operated by non-governmental organizations.

Sample selection: Parents having intellectually disabled children of 5-18 years of age diagnosed according to ICD 10 by a visiting doctor, counsellor and a psychologist. An informed consent for the study was taken and one or both parents having psychiatric illness or major Med/ Surg disease were excluded. A sample of 150 patients was selected for the study. Parent of the child were interviewed for assessing parenting stress using parenting stress scale (PSS) and related factors of contributing to parenting stress were identified using a self-structured questionnaire. The

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data collected was pooled, tabulated and subjected to statistical analysis. Chi-square tests were used wherever appropriate.

4. Results

Socio-demographic variables of the study population

It was found in the study population that more than half (54.7%) of the parents were in the age group of 31-40 yrs, while a few (10%) were in the age group of 51-60 yrs. Most of the participants were female (77.7%). Half of the respondents (51.3%) were graduate while almost a quarter of them (22.4%) only completed their primary education. Majority (60.7%) of the respondents were housewives, almost one fourth (24%) were pvt/self- employed, almost one tenth (8.7%) were govt employee and only few (6.7%) of respondents were unemployed. Almost half (49.3%) of the participants belonged to nuclear family, less than one third (32.7%) belonged to joint family.

Duration of disability, age of diagnosis and level of retardation of differently abled children

Duration of disability among the age group was found to be (37.3%) among > 10 yrs and 6-10 yrs respectively, and a quarter (25.3%) of them were found disabled for the past 1-5 years. Majority of them (95.3%) were diagnosed with ID between 0-5 years, and only few (4.7%) were diagnosed between 6-10 years of age. Almost half of the children (42.7%) were having autism, more than one third (35.3%) had Downs Syndrome along with ID.

Differently abled child according to gender, age and number of siblings

Majority (71.3%) of differently abled children were males and (28.7%) were female. 37.3% of children belonged to the age group of 6-10 yrs, 36.7% belonged to 11-15 yrs and only (5.3%) belonged to the age group less than 5 years. 41.3% of children were single child in the family.

Parental stress score

Majority (48.7%) of parents had severe parental stress (mean score 67.48 ± 5.444), 47.3% had moderate parental stress (mean score 54.21 ± 4.157) whereas only 4% of parents had mild parental stress (mean score is 37.17 ± 1.602) which reveals mild parental stress.

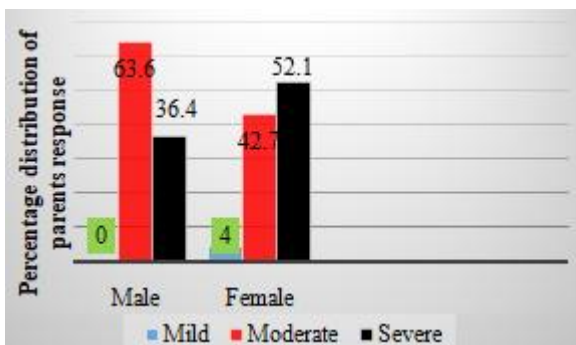


Figure 1: Distribution of parental stress according to gender

Fig 1.shows that out of 33 males, majority (63.6%) was moderately stressed, out of which 36.4% experienced severe parental stress. Among 117 females 52.1% experienced

severe parental stress and only 4% experienced mild parental stress.

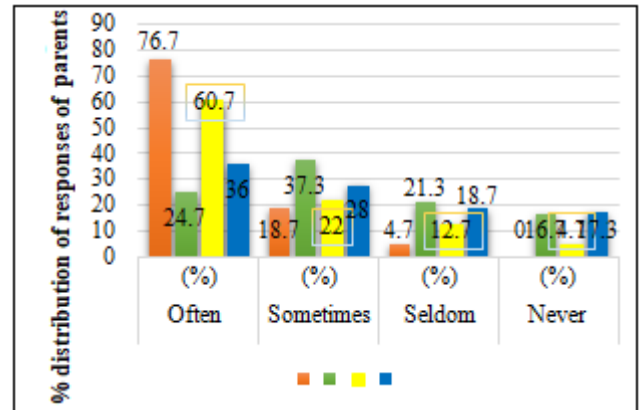


Figure 2: Distribution of Factors Affecting Parenting Stress

Fig 2. reveals that majority (76.7%) of parents reported need for extra inputs of care very often to take care of the child, more than one third (37.3%) expressed that they were not getting adequate leisure time for themselves, majority of the parents (60.7%) were often tensed due to the dependency need of the child by performing his/her daily activities, more than one third of parents (36%) often felt uncomfortable due to uncontrolled and attention seeking behaviour of the child.

Family emotional stress

It was found that more than half of parents (54%) never had any marital problems, however more than one tenth (13.3%) had marital issues. Maximum parents (70%) often worry about the child's condition.

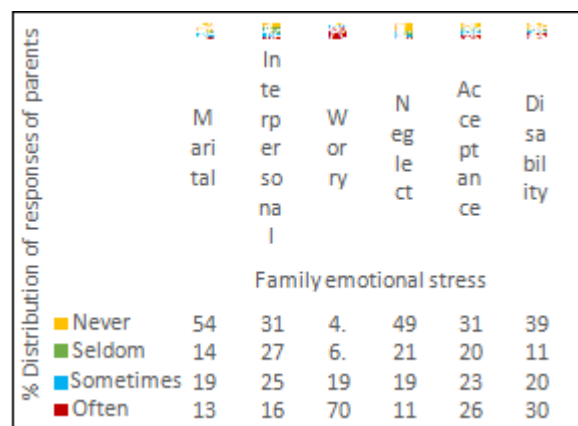


Figure 3: Family emotional stress

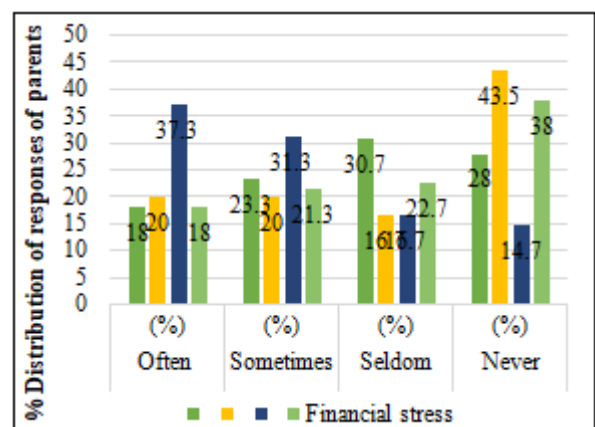


Figure 4: Social Stress

Fig 3. shows that 18% often felt socially embarrassed to take the child for outing or visiting other relatives. More parents (43.5%) were often offered physical help, while only one fifth of parents (20%) often felt that they were not offered adequate physical help from relatives or friends to take care of the child. Many parents (37.3%) often experienced difficulty due to the child's inability to adapt, while less than one sixth of parents (14.7%) felt the opposite.

Association of parenting stress with the selected demographic variable

The study couldn't elicit any significant association of parental stress with the selected socio demographic factors.

Table 1 (a): Association between parenting stress and factors affecting parenting stress, n=150

Factors related to Social and financial stress	Unstandardized Coefficients	Standardized Coefficients	t	p value
	B	Beta		
Altered social life	2.082	0.249	1.547	0.006
Lack of physical help	1.053	0.140	0.890	0.119
Lack of Adaptability	-0.644	-0.076	1.751	0.413
Financial stress	0.597	0.076	2.773	0.375

$p < 0.050$ at 95.0% Confidence Interval

Table 1 (a) depicts significant relationship between parental stress and altered social life with a p value 0.006 at 0.05 level of significance. Lack of physical help, lack of adaptability and financial stress however, did not show any statistical significance with parental stress.

Table 1 (b) Association between parenting stress and factors affecting parenting stress, n=150

Factors related to daily care stress	Unstandardized Coefficients	Standardized Coefficients	t	p value
	B	Beta		
Extra inputs for care	-3.913	-0.239	8.389	0.004
Leisure time	1.257	0.144	2.969	0.107
Dependency need of child	1.665	0.164	2.477	0.082
Disturbed behaviour of child	-1.516	-0.187	0.821	0.028

$p < 0.050$ at 95.0% Confidence Interval

Table 1 (b) depicts significant relationship between parental stress and extra inputs for care, with a p value 0.004 at 0.05 level of significance also the disturbed behavior of the child as significant relationship with parental stress.

Table 1 (c): Association between parenting stress and factors affecting parenting stress, n=150

Factors related to family emotional stress	Unstandardized Coefficients	Standardized Coefficients	t	p value
	B	Beta		
Neglect of others	0.751	0.088	1.625	0.353
Marital problems	1.151	0.145	0.932	0.131
Interpersonal Problems	-1.140	-0.137	1.519	0.124
Worry	2.274	0.208	1.570	0.014
Acceptance by family members	0.171	0.023	2.223	0.801
Disability of the child	0.642	0.092	0.253	0.318

Table 1 (c) depicts significant relationship between parental stress and worry about future of the child with a p value 0.014 at 0.05 level of significance. Neglect of others, marital and interpersonal problems, acceptance by family members and disability of the child did not show statistical relationship with parental stress.

5. Discussion

The present cross sectional descriptive study was conducted among 150 parents of differently abled children studying at selected special schools of Kolkata. On analysing the characteristics of the differently abled children majority were found to be male (71.3%) children and most of them (37.3%) were in the age group of 6-10 yrs and no significant association was found between the child's age and parental stress. The findings of the present study were supported by Ganjiwale D et al, (2016) who found 65% were 6-12 years of age with 83 male child and 33 female child with ID.⁷ Many previous studies also uniformly reported the prevalence of ID in males than females.^{21,54,71,80} The prevalence of ID among females may be underreported due to the stigma associated with it.

Intellectual disabilities gets unnoticed at birth and remains undiagnosed until a child enters the school. The developmental disability are unrecognized by the parents due to their unawareness regarding growth and development of a children and more so if it is their first child.⁷ Majority (95.3%) of children in the present study were diagnosed as ID between 0-5 years and it was found that most of (37.3%) the children were disabled for more than 10 years. Present study also showed no significant association between parental stress and child's level of retardation.

It was observed in the present study that mothers (77.7%) outnumbered the fathers (22.3%) this may be due to the Indian concept of mothers taking primary responsibility in the care of the child. This results is also supported by Lovisotto R et al, (2015) who found that 80% of respondents were mothers and only 20% were fathers.⁵³ Similar observation was seen in other studies also.^{45,69} In the present study could not established significant association between gender of parents and parental stress however, Kamaruddin K, Mamat N (2015) revealed that there was significant association between genders of parents and parental stress.³¹ Among mothers 71.4% experienced high level of stress compared to fathers may be due to high expectations on mothers regarding child care by the Indian society.⁵²

The results of the present study shows that stress is an inevitable phenomenon in the life of parent with differently abled children, evaluation of stress based on parental stress scale score revealed that parents of differently disabled children suffered significant amount of stress, less than half (48.7%) of parents experienced severe parental stress with mean score 67.48 ± 5.444 , almost equal number (47.3%) of parents experienced moderate parental stress with mean score 54.21 ± 4.157 , whereas only (4%) of parents experienced mild parental stress with mean score 37.17 ± 1.602 . The finding suggest that rearing a differently abled child is a challenging job, and in the bargain to keep a balance and control over life process the parents feels

stressed. This is supported by findings of Shyam R, Kavita & Govil D (2014) who found that mothers of children with both mental and physical disability scored significantly higher level of parenting stress than mothers of children with physical disability.^{34,35,37,38}

The study results revealed that out of 33 fathers, majority (63.6%) were moderately stressed and 36.4% were severely stressed. Whereas, among 117 mothers 52.1% experienced severe parental stress and 42.7% experienced moderate stress. It is correlating with the findings of Sethi S, Bhargava SC, Dhiman V (2007) who identified that among the parents with MR, 71.4% mothers and 67.5% fathers had higher mental stress than physical stress [$t(21) = 22.43, p = 0.024$]. Mothers had significantly higher mental stress score than the fathers of mentally retarded children [$t(109), p = 0.025$].⁶¹ The present study findings are consistent with other studies too.¹⁸

Findings in the present study revealed that 76.7% of the parents had to put extra inputs of care very often in meeting the daily care demands of the child. It was also brought out in the study that there exist a positive relationship between parental stress and extra input of care. Similar findings were revealed by Karasavvidis S et al (2011) that parents had to spend considerable time caring for the child.⁷⁰ The findings are also consistent with the findings of other researchers.³⁹ Kawa MH, Shafi H (2013) who found a significant positive correlation in parental stress with daily care stress. The parent has to devote extra time and effort caring for a disabled child as they have to help the child in ADL, manage their behaviour and remain with them so that they do not hurt themselves.³⁸

The present study showed behaviour of the child as a strongest predictor of parental stress 36% of parents are in the opinion that they often felt uncomfortable and child demanded lot of attention. A significant association was also established between behaviour of child and parental stress. The results are consistent with study by Karasavvidis S et al (2011) who showed that behavioural problems of the disabled children have a direct effect on the parental stress.^{42,63,70} Multiple studies examining the relationship between child behaviour problems and parenting stress among children with and without developmental delays have shown that the effect between these two variables is bidirectional.⁷¹

The parents spend their maximum time caring and managing difficult behaviour it was found that more than one third of parents (37.3%) felt that they were not getting adequate leisure time, same findings were depicted by Hartley SL et al (2011) in which high level of childcare responsibilities resulted the parents to restrict their time for participating in enjoyable leisure activities. This was supported by many studies.^{38, 49}

On assessing the dependency need of child it was found that majority of the parents (60.7%) were often tensed due to the dependency need of the child in performing his/her daily activities, which caused them to be tied up to the child. Same findings are observed by Kawa MH, Shafi H (2013) also.³⁸

The disability of the child is a concern for the parents, they worry about the child's future, and care. In the present study results shows that majority of parents (70%) reported that they often worry about the child's condition and which is positively association with parental stress. This results corresponds to the study by Kamaruddin K et al (2015) who revealed that the parents of mentally retarded children are always anxious related to safety and future perspectives of the child.³¹ Other researchers in the same field also showed similar findings.⁴⁷ Results were found to be consistent with Shyam R, Govil D (2014) study who examined the social problems related to the presence of an intellectually disabled child and revealed noticeable anxiety about future of the child.^{37,74} Contrary to the present findings Susan L, Shalini F & Sahayaraj R (2013) shows that there exist no significant association between levels of stress and parents plan for child's future.⁶⁹

6. Conclusion

The present cross section descriptive explored parental stress and the related factors among disabled children and found that they experience moderate to severe parental stress while meeting the needs of the children. There are few factors such as extra input of care, altered social life, worrying about child condition and disturbed behavior of the child, significantly contributed to stress among the parents. The current evidences also support the above findings.

The findings of the study revealed that parents experienced severe as well as moderate parental stress, irrespective of gender. There was a statistically significant correlation between factors such as extra time spend on care, altered social life due to child care, constant worry related to child's disability and disturbed behavior of the child. The study also observed that the selected socio demographic variables were not associated with parental stress.

The primary responsibility of caring the child was often fulfilled by the mothers hence they were more stressed than the fathers. The findings of the study can be utilized in various domains of nursing practice, research, education and administration. Providing high level of tangible support to these mothers in terms of physical help and non- tangible support by the community in terms of education, treatment facilities to enhance the cognitive skills of the child can significantly reduce parental stress. The study emphasizes the need to identify such parents and help in developing positive coping to reduce the possibility of psychological issues in these parents

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