

The stress of the parents of the intellectually disabled children in Goa

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ABSTRACT

This paper is an assessment of the stress borne by the parents who have intellectually disabled children. We have used cross-sectional descriptive method for the study. Through Stratified Random Sampling method six special schools are selected. The sample size of the parents is 116. To assess the stress, we use Dr Satish Girimaji's schedule, namely "Family Interview for Stress and Coping in Mental Retardation" (FISC – MR). With the help of the guide and other experts in the field, a stress questionnaire is prepared based on FISC – MR and tested for validity and reliability. The study shows the following results. Of the 116 parents, 12 have mild stress, 53 moderate, 47 severe and 4 have profound stress. The stress scores have the mean value of 53.57, median 54, mode 39, and the standard deviation 17.95. Parents stress scores are derived from 4 different subsections. They are Daily care stress, emotional stress, family stress and social stress. Among these Daily Care stress has the highest mean (16.90). The 't' test and ANOVA are the statistical tools used. ANOVA results based on parents' age, religion, income, birth order of the child and number of children - have the p value greater than the alpha level 0.05. This indicates that there is no statistically significant difference in the stress level of the parents with respect to these variables. For the education level of the parents, the p value 0.09, though not very significant, yet close to 0.05, shows that education does play a role. Among the variables, Occupation of the parents and the age of the child have the p value lesser than the alpha level (0.05), indicating that they do make significant difference in the stress level of the parents. The t test results indicate that there is no significant difference in the marital status, location and the type of family. Regarding the gender of the child, the p value (0.049) is lesser than .05. It indicates that there is a significant difference in the stress level of the parents who have an intellectually disabled female child as compared to the parents of the male child. Thus, it is evident that these parents go through enormous stress in caring for their special child.

Keywords: *Stress, Parents, Intellectual Disability, Children, Goa*

The birth of a child is a beautiful and significant moment in the family. Parents have different dreams and hopes for their children. An intellectually disabled child is an unsuitable

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vehicle for fulfilling such parental hopes. Parents are immediately saddened in knowing that their child will not reach the career goals they had envisioned for them. (Azeem, Dogar, Shah, & Cheema, 2013) The critical factor is that unlike other diseases, intellectual disability is a permanent condition.

In the families in which there are intellectually disabled children the demands and responsibilities are manifold. Parents need to identify the intensity of the problem of the child and meet his or her needs accordingly. As the child grows older problems become complex and parents need to reinvent strategies to meet the needs of the child and this adds to the ongoing stress. They feel helpless since powerlessness to change what is happening is very difficult to accept (Smith, 2003).

Whenever the parents are found with their intellectually disabled children, they quickly become an attraction and cause of sympathy. Many people who have normal children do not really understand the chaos and burden of those who have intellectually disabled children. The disabilities of the children usher range of effects on the parents. Walsh, Mulder, & Tudor (2013) showed that an overprotective parenting style moderated the relationship between pain and parent stress. Olsson & Hwang (2001) found that the prevalence of parental depression was closely related to the differences in child characteristics. Rao & Beidel (2009) indicated that the parents of children with high functioning autism experienced significantly more parenting stress.

Zablotsky, Bradshaw, & Stuart (2013) in their study realized that if the stress was left unmanaged, high stress levels could lead to the development of depressive symptomatology. Morya, Agarwal, Upadhyaya, & Sharma (2015) showed that families with intellectually disabled children with IQ less than 50 experienced significantly higher stress. When they do not find adequate social support, which is a common mode of coping, stress intensifies.

On the study done on Perception and attitude, Ashum & Singhal (2004) noted that disability was still viewed in terms of a tragedy in India. Many consider it is to be a curse from God for the sins committed by their ancestors or themselves. People respond to a tragedy as they perceive it. Their attitude towards their children also affects accordingly. In India, family bears the main burden of caring for such children unlike in the developed world. The family members, particularly parents, are more affected by the condition (Singh, Indla, & Indla, 2008). It affects also the siblings and the relationship among the family members. The main reason why raising a child with intellectual disability is stressful is because it requires an intensive physical engagement as well as coping with emotional reactions to the child's condition. Some parents begin to blame themselves for the condition of their child. This self-blame gradually leads to guilt feeling. Many go through period of confusion. Different economic pressures also put a lot of strain on the parents. Due to lack of social links many go through phases of isolation and bewilderment. (Boromand, Narimani, & Mosazadeh, 2014). We undertook this study in order to understand the actual difficulties faced by the parents of those children who have intellectual disabilities and how we can help them find ways to cope with their stress constructively.

METHODOLOGY

Sample

We used the cross-sectional descriptive method to obtain the stress scores of the parents who have intellectually disabled children. The study sample is chosen from among the parents from the state of Goa, whose children are the day scholars in the special schools.

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We selected six special schools through *Stratified Random sample*. Of these six schools the sample comprises of 116 parents who are parents of the intellectually disabled children enrolled therein as day scholars.

Inclusion criteria (Delimitation)

1. Parents of Intellectually disabled children who are admitted in special schools in Goa.
2. Parents whose children are between the ages of 3 to 15.
3. Parents whose children are day scholars in special schools.

Exclusion criteria

1. Parents who have chronic physical illness.
2. Parents who have mental illness.

Instruments

In order to assess the impact of stress, we prepared the questionnaire based on Dr Girimaji's "Family Interview for Stress and Coping in Mental Retardation, (FISC-MR). (Girimaji, Srinath, Seshadri, & Subba Krishna, 1999). We got the written permission from the Dr Girimaji to utilize the instrument. The stress questionnaire has twenty-eight items. In order to check the reliability of the scale "test – retest reliability" test is used. To check the validity of the questionnaire, content validity is used.

Data Analysis

Descriptive analysis is used to understand the behavior of the data which includes Mean, Median, Mode, SD, percentages etc. for the categorization of stress in their subscales and later also for the comparisons according to the variables. These values determine the basic behavior of the scores along with the averages in different categories which help in understanding and comparing the stress level based on different attributes.

Analysis of variance – single factor and student's t-test are used to determine for any statistical difference in stress level based on different variables. All tests are carried out at 95% confidence level. Thus, in all cases the p value is compared with the alpha level 0.05 to indicate if the results are statistically significant.

Objectives

1. To determine the areas in which the parents of intellectually disabled children experience stress.
2. To document the relation between stress and various socio-demographic variables.
3. To ascertain the nature of stress experienced by the parents of intellectually disabled children.

RESULTS & DISCUSSION

Table 1. The measures of stress and their values

S. No	Measures	Values
1.	Mean	53.57
2.	Median	54
3.	Mode	39
4.	Standard Deviation	17.95
5.	Maximum possible score	112

The above table shows that mean and median are very close values. Mode value is 39. The SD value is 17.95. From the total of 28 questions (28x4) the maximum possible score is 112. The above values suggest that the scores are normally distributed.

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Comparison and discussion on Stress scores in relation to the selected Variables

The Parents of the intellectually disabled children have unique stress, which differs from parent to parent because each person is unique. Keeping this in mind, we studied the stress scores of the parents in relation to twelve variables. The selected variables of the parents are: Age, Education, Marital Status, occupation, domicile, religion, monthly income and type of family. The selected variables of the children are: Age, sex, Birth order and total number of children.

There are 116 parents. Their total mean value is 53.53 and SD 17.95.

Table 2: Socio-demographic variables with their range, number, mean and SD.

Variables	Range	Number of Parents	Mean	SD
Age	21-30	15	59.33	17.82
	31-40	38	55.18	17.94
	41-50	46	51.91	17.85
	51-60	17	49.35	18.28
Education	Illiterate	17	51.06	16.59
	Primary	48	52.27	18.16
	Pre university	21	61.81	17.15
	Graduation	24	48.79	15.44
Marital Status	PG/Professional	6	61.33	25.58
	Single/widow/div	5	58.6	20.29
	Living together	111	53.34	17.91
Occupation	Unskilled worker	3	34.33	8.50
	Business	6	39	12.49
	Service	24	54.54	17.56
	Home maker	83	55.04	17.97
Area	Rural	69	55.16	17.52
	Urban	47	51.23	18.52
Religion	Hindu	54	55.07	18.32
	Christian	47	53.53	17.66
	Muslim	15	48.27	17.73
Monthly Income	Below 5000	35	53.14	18.86
	5001-10000	45	55.84	17.24
	10001 and above	36	51.14	18.08
Type of family	Nuclear	94	52.77	18.27
	Joint	22	57	16.51
Age of the child	Below 5	6	63.67	15.67
	6 to 10	41	59.39	17.85
	11 to 15	69	49.23	17.06
Gender of the child	Male	74	51.5	17.89
	Female	42	57.21	17.69
Birth Order	First	71	52.79	18.44
	Between	13	47.08	16.16
	Last	32	57.94	16.97
Total no of children	One	28	58.79	20.08
	Two	48	52.60	18.19
	Three	28	49.39	15.18
	Four	12	55	16.78

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Stress in relation to the Age of the parents

In the table above the highest mean (59.33) is for those of the age group of 21 -30. Interestingly, the table also shows that as the mothers' age increases the stress mean score decreases. Analysis of Variance – single factor is utilized to determine the stress level based on age of the parents. The obtained P-value is 0.37 is greater than the alpha level (0.05) and it indicates that though there is a difference as per the age, it is not statistically significant.

This is in line with the study done by Al-Qaisy (2012). He selected a sample of 235 mothers of children with intellectual disability from Al-Amal center for disability. He found that the age of the mothers had no relation to the stress experienced by them. However, Rezendes & Scarpa (2011) found a small positive relationship between the maternal age and level of stress, suggesting that older mothers were reporting higher levels of stress. The typical development of independence is often impeded in special children and thus the child's caregiving needs and demands did not decrease over time.

Stress in relation to the Educational level

In Table 2 we see the education level of the parents and their corresponding stress scores. Through ANOVA the obtained p-value is 0.09 which is close to the alpha level (0.05). It shows that education does play a role, even though not statistically significant. Kumar (2008) in his study found a significant difference in the mean psychological stress score of the parents who had studied PUC and those who had not. Those parents with better qualification levels had low stress scores and higher coping scores. The advantage for the educated parents was that they were far more aware of the condition and knowledgeable about the professional help available for them. They attended many seminars and workshops which enhanced their coping strategies.

Stress in relation to the Marital Status

Of the 116 parents who formed the sample of the research, 111 are living together. Only 5 are without their spouse who have higher mean (58.6) than the ones who live together. When *Student's t-test: Two-Sample Assuming Equal Variances* is utilized, the obtained p value is 0.26 which is greater than the alpha level of significance (.05). This indicates that there is no significant difference in the stress experienced by parents based on their marital status. Gohel et al. (2011) in his study opined that families with intellectually disabled child need additional help. This would help them to avoid making families with handicaps into handicapped families. Mbugua and others stated that the married caregivers had statistically significant higher levels of risk of depression than the singles, divorced, or separated because in the African culture, intellectual disability is associated with stigma and, hence, the risk of higher levels of depression among the married. Nearly half (44.7%) of the depressed caregivers were married. (Mbugua, Kuria, & Ndeti, 2011)

Stress in relation to the Occupation

The above table shows that 83 parents are homemakers. Most of these parents have no choice but to do the household chores and look after their children, while their spouse works outside. The mean value of those at home is highest at 55.04. In the ANOVA test the P value is .043 which was lesser than the alpha level (.05). This suggests that there is a significant difference. Gohel et al., (2011) had done a study on psychosocial impact on the Parents of intellectually disabled children in Anand District. There they found that unemployed fathers had significantly (P value – 0.04) more negatively affected relationship than the rest of the fathers. However, Gupta, Mehrotra, & Mehrotra (2012) in their study, asserted that Parents engaged in more lucrative and prestigious occupations had more stress than parents engaged

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in less prestigious and lucrative occupations, due to impaired sense of competence, restrictions placed on other life roles, marital conflict, lack of social support and depression.

Stress in relation to the Domicile

The table 2 shows the mean scores of the rural parents as 55.16 and the mean value of the urban parents is 51.23. Rural parents go through slightly more stress in comparison to the urban parents. It is because people in the urban areas have easy access to the special education institutions and they also have easy access to the medical facilities, in the event of emergencies. Easy conveyance in the cities could also contribute to the lesser stress of the parents in the urban domiciles in comparison to those in the rural areas. However, it is not statistically significant.

The *Student's t-test: Two-Sample Assuming Equal Variances* confirms it. The p value (0.12 for one-tail) is higher than 0.05 (alpha level). It indicates that there is no significant difference in the stress experienced by the parents of rural and urban areas.

Stress in relation to the Religion

In the study done on 116 parents, the mean scores are highest for Hindu group (55.07) followed by Christian parents who have the mean score of 53.53 and the Muslim parents have the mean score of 48.27. All the three mean scores are very close to each other.

Analysis of Variance – single factor tool is used to determine the stress level based on Religion of the parent. The obtained p value is 0.43. Since the p value (0.43) is higher than 0.05, it indicates that there is no significant difference in the stress experienced by parents based on their religious affiliations.

Stress in relation to the Monthly income

In our research 45 parents belong to the middle-income group (5001-10000Rs) with a mean value of 55.84 which is above the mean of other two groups as is observed in table 2. The obtained ANOVA p value is 0.50 which is higher than 0.05. It indicates that is no significant difference in stress experienced by parents.

Poverty adds burden to the woes of the parents. Shortage of resources, including food, medication, durable medical equipment, and apparel can add to the stress of raising children with disabilities. In conditions of poverty, a child with a disability is regarded as a burden and an object of charity without rights, rather than as an unfortunate child. (Gupta et al., 2012) Upadhyaya & Havalappanavar (2008) assessed fathers and mothers of 628 intellectually disabled individuals for their perceived stress. It was noticed by them that more than one intellectually disabled children in the family; lower age of the intellectually disabled individual and parents; and lower income of the family were associated with higher stress.

Stress in relation to the Type of the family

Of the total 116 parents, 94 have nuclear families with the mean score of 52.77 and the rest 22 joint families have mean stress score of 57. Through *t-test* the obtained p value is 0.16 which is greater than the alpha level of significance 0.05. This shows that though there is a difference it is not statistically significant.

In the study done by Gupta et al., (2012) many parents reported receiving little support from their extended families in taking care of their child.. Instead of being a help, sometimes the larger size of the family, can add to the stress of the parent. However it differed from another

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study. Gray & Holden (1992) reported the results of a study done on the Australian sample of parents who had children with autism. The study revealed that Parents with larger families reported lower scores of anger.

Stress in relation to the Age of the child

In the table above, 6 parents have children below the age of five with the highest mean value of 63.67. It indicates that younger the children, greater the stress. Probably as the children get older parents begin to cope better with the stress they face. The obtained p value through ANOVA is 0.005 which is lower than 0.05. It indicates that there is significant difference in the stress level based on the age of the child.

Gray & Holden (1992) confirmed the fact that Parents with older children reported lower scores of anger. In another study, the parents of young children who were below 4 years, high initial levels of parenting stress resulted in less subsequent self-perceived involvement, and poorer communication, with the child. (Osborne & Reed, 2010) Davis and Carter discovered associations between child behavior and parenting stress. They examined mothers and fathers of 54 toddlers with Autism Spectrum Disorder (mean age = 26.9 months). Parents reported elevated parenting stress. (Davis & Carter, 2008)

Stress in relation to the Gender of the child

In our study we find that the parents with female children have stress mean value 57.21 which is higher than those with male children (51.5). Higher parenting stress in parents of girls is due to the fear of abuse and neglect. In the *Student's t-test* the p value 0.049 is lesser than .05 (alpha level). It indicates that the stress level of the parents who have female child is significantly higher in comparison to the parents of the male child. This is in conformity with the study done by Gupta, Mehrotra & Mehrotra (2012). They used the short form of the Parenting Stress Index and a few open ended questions to a convenience sample of sixty-six patient families in New Delhi and Faridabad. Among the variables, they found that the female sex of the child was associated with higher stress. Al-Qaisy (2012) chose a sample of 235 mothers who had children with such disability. The results, however, indicated that mothers' stress did not differ with gender of the intellectually disabled children.

Stress in relation to the Birth order

In this study, of the 116 parents 71 parents have their first child with intellectual disability with the mean score of 52.79. The 32 parents who have their last child with intellectual disability show slightly higher mean value of 57.94. The other 13 parents show the mean value of 47.08.

Analysis of Variance – single factor is utilized to determine the stress level based on the birth order of the child. The obtained p value (0.15) is higher than the alpha level 0.05. It indicates that there is no significant difference in stress experienced by parents based on the birth order of the child.

Stress in relation to the Total number of children

Among 116 parents 28 parents have only one child and that single child is intellectually disabled. Understandably these parents go through highest stress as indicated by the mean score of 58.79. Then next group of parents are with two children. They are 48 in number. Their stress score mean is 52.60. There are 28 parents who have three children. Their mean score is 49.39. The remaining 12 parents have four children. These mothers show the mean score of fifty five.

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The obtained p value (0.25) though ANOVA is greater than the alpha level 0.05. It indicates that even though there is a difference in stress experienced by the parents based on the number of children, it is not statistically significant.

Discussion on the Stress score measures in their subscales: Mean, SD and Percentage

Stress is part and parcel of life. There are various factors both internal and external that contribute to stress. In this research, Parents stress scores are divided into 4 different subsections. They are daily care stress, emotional stress, family stress and social stress.

Table 3. Categories of Stress and their measures

Categories of Stress	Number of Parents	Number of items	Mean	SD	Score Range
1. Daily Care Stress	116	9	16.90	6.07	0 – 36
2. Emotional Stress	116	5	9.43	3.41	0 – 20
3. Family Stress	116	7	13.48	5.12	0 – 28
4. Social Stress	116	7	13.76	4.98	0 – 28
Total	116	28	53.57	17.95	0 - 112

Discussion on Daily Care stress

Daily care stress category has 9 items, with each item score ranging from 0 – 4. The maximum possible score of the 9 items is 36. Daily care stress questions include items like extra care needed, tantrums, excessive demands, constant vigilance, fussy attitude, medical and other expenses, dependence, sleeplessness of the special child etc., which affect the stress level of the parent.

In the studies done on the psychological and physical health of the parents, Raina et al. (2005) discovered that parents were strongly influenced by child behaviour and caregiving demands. Child behaviour problems were an important predictor of caregiver psychological well-being. Of all things, it was caregiving demands which contributed directly to both the psychological and the physical health of the caregivers. According to Karasavvidis et al. (2011) the parents' stress was coming from their inability to adapt to the everyday care demands of their child.

Discussion on Emotional stress

Emotional stress category includes items like sadness, anxiety, worry, hopelessness, resentment, worthlessness, tension, blame game, evil wish etc, which affect the stress of the parent. Emotional stress score has the mean value of 9.43. The standard deviation value of Emotional stress is 3.41.

Very often parents' fear of the unknown dominates over the known. Therefore, in order to cope with stress emotional stability is vital. The study was conducted by Ganjiwale, Ganjiwale, Sharma, & Mishra (2016) to assess the quality of life of the caregivers and the utilization of coping strategies when they have children with physical as well as mental handicaps, in Anand, Gujarat. The main coping style used by the caregivers was active emotional coping. Ketelaar, Volman, Gorter, & Vermeer (2008) in their study discovered that maladaptive behaviour did significantly contribute to parental stress scores for the parent domain subscales attachment, relationship with spouse, depression, and, in particular, sense of competence.

Discussion on Family stress

Family stress category has items such as neglect of others in the family, differences with the spouse, differences with family members regarding the care and disciplining of the child, rudeness of others in the family, avoidance, scolding etc.

According to Gupta and Kaur, the situation and relationships in the family either reduce or increase stress. Negative effects towards other siblings, 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. (Gupta & Kaur, 2010) Koo (2017) conducted his study on the parents who had intellectually disabled children mainly to gauge their stress and coping, in the Kyoung-in area. The fathers who had intellectually disabled children differed on the stress experienced. It depended on health status, cohesiveness, support and satisfaction experienced with their spouse. In another study, Gohel and others noted that the parents required to devote more time to intellectually disabled child than normal child and that would create bad impact on the siblings. 54% parents felt that they were giving less time to siblings. (Gohel et al., 2011)

Discussion on Social stress

Social stress category has items like accusations, house arrest, ostracizing, uneasiness in the midst of friends and relatives, apprehensiveness, comparisons and restrictions etc., which affect the parents. Parents who have intellectually disabled children require mutual support from spouse, family and friends. Chourasiya and others had done a cross-sectional study in special schools of a city of central India. It was done to gauge the stress perceived by families of intellectually disabled children. They evaluated stress in different sub areas. In area of social life stress sub scale of altered social life and social embarrassment 48 and 49 families respectively reported nil effect on them, while 5 families had persistent apprehension leading to child being frequently kept away from social situation. (Chourasiya, Baghel, Kale, & Verma, 2018)

CONCLUSION

This study provided us with new information and a few leads in some areas of stress.

Attitude matters most.

Even though parents of the intellectually disabled children go through enormous stress, some parents have composed demeanor, while there are a few who find apparently little problems, unmanageable. It shows that it is not the disability but the attitude towards the disability that matters.

Caring demands time.

We discovered that many parents have to be alert throughout so as to protect the child from self-harm, harming others and destroying things. Even in the nights they are not able to rest adequately, since their child is very fussy and demanding. Even in dire needs some parents cannot entrust their child to the care of anyone, even for a day, since others do not know to manage.

Bewilderment encountered by parents

Most unfortunate thing is that the parents do not understand what is happening to them. They have done everything possible for the welfare of their child. They have frequented many religious centers. They have recourse to many healers. Sadly, many return back disappointed. Some are going through depression.

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Lack of interest in socializing

Because of their child's condition, parents have lost interest in social gatherings and functions. Suspicious looks and unending questions hurled by the people force these parents remain mostly indoors. They have stopped inviting friends, relatives and neighbours.

Resentment and misunderstanding

They are angry with their situation in life. They feel that no one, not even their spouse understands their plight. They also have differences with their spouse pertaining to the care and medication of their special child.

Financial burden on the family

Special diet, medicines, appliances, training, etc., add to the expenses. Since many parents are homemakers, they depend on their spouse for sustenance.

Ignorance and misattribution

We discovered that some are superstitious. In their confusion, they have arrived at their own unscientific conclusions regarding their child's disability. They feel guilty and blame themselves for their child's condition and for giving birth to such a child. The parents also give wrong spiritual connotation to their situation and consider it to be a punishment from God for their misdeeds. It is attributed also to the ancestral curse.

Apathy of the neighbours

We learnt that many parents are pained at the insensitivity of their neighbours. There are instances when neighbours have restricted their children from playing with the special child, citing the reason of contagion. Even when they travel with their child, people often stare at the parents as if they had committed some crime. People's ruthless comments and remarks have hurt the parents most.

Fear of the unknown

The parents have many concerns and fears. The worst fear of the parents is regarding the care of their child after they have gone from this world. 'Who will look after my child once I die?' is the constant agonizing query.

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Conflict of Interest

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