

# Stress in Parents of Children with Intellectual Disability



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## Abstract

Parenting is a challenging process. Having a child with intellectual disability is even more challenging. The present study aims to explore the Perceived stress of mothers and fathers having intellectually disabled children. Section I of FISC MR was administered on a sample of 100 parents (50 mothers and 50 fathers) attending the Out Patient Department of District Mental Health Unit of National Rural Health Mission (N.R.H.M.) at District hospital Faizabad. Results obtained highlights the Gender differences in perceived stress among parents of children with intellectual disability in terms of daily care stress, family emotional stress, and social stress. However for financial stress the analysis presents a mixed picture, as, for mothers the financial stress is in terms of financial burden however it was husband's responsibility to manage financial requirements whereas for fathers it's in terms of exhausted savings with financial burden.

**Keywords:** Intellectually Disabled, FISC MR.

## Introduction

Birth of a child after marriage, makes a couple psychologically complete and socially respected; child birth gives totality to the couple (Mane 1990). The birth of an intellectually disabled child disturbs the family equilibrium leading to stress and problems (Narayan 1993).

Stress is being considered by current researchers as an inevitable, normal experience that is felt when an individual is unsure to meet the demands of environment. According to (Patnaik, 2014) stress is "a negative emotional experience accompanied by predictable biochemical, physiological, cognitive, and behavioural changes that are directed either towards altering the stressful event or accommodating to its effects".

Parenting stress is a normative part of the parenting role (Crnic & Greenberg, 1990), as life style is changing, parenting is becoming more difficult day by day. It becomes manifold difficult when it comes to that of a disabled child. An intellectually disabled child leads to a variety of stressors and stress reactions related to the child's disability (Orr, et.al., 1993).

Intellectual Disability is a disorder with onset during the developmental period that includes both intellectual and adaptive functioning deficits in conceptual, social, and practical domains. (APA 2013, DSM-5)

In the country like India, the care for individuals with disability is mostly undertaken by the family members. However with the changing scenario like, changes in social structures (for eg. disintegration of joint families ) and economic systems (eg inflation, unemployment, etc) the stress of caring for a child with intellectual disability have increased and took its toll upon the parents of such children.

## Review of Literature

Many studies, both in India and abroad have demonstrated that parents of a child with an intellectual disability (ID) are likely to experience significantly higher levels of parenting stress than parents of nondisabled children (Gupta & kaur 2010, Upadhyaya and Havalappanavar 2008; Kumar 2008; Roach et al.1999 )

However studies focusing on the impact of parent's gender presented a mixed picture. Large chunk of studies suggest that mothers feel heightened amount of stress in comparison to fathers. (Chouhan et al. 2016, Azeem. et al 2013, Upadhyaya and Havalappanavar 2008 , Blacher et al 2005; Saloviita et al 2003; Singer, 2006, Heller et al ,1997). Studies in a variant direction contend that there is no significant difference between both parents (mothers and fathers) on the level of stress, though studies pertaining to this are very few in number. Contrary on the above findings, some studies report that fathers experience more stress as they have fewer outlets for their stress than do mothers (Cummings 1976).

Here a need is generated to assess the parental stress in caring for children with intellectual disability, and also to explore, who experience more stress, mother of intellectually disabled child or father of intellectually disabled child.

**Methodology**

**Aim of the Study**

The study aims to explore the Perceived stress of mothers and fathers having intellectually disabled children.

**Research Design**

An ex post facto research that is exploratory in orientation and Descriptive in nature.

**Sample**

Sample of the present study was 100 parents (50 mothers and 50 fathers) of intellectually disabled children who fulfil the selection criteria of the study. The method of sample selection was purposive sampling. The data was collected from the Out Patient Department of District Mental Health Programme Unit of District hospital Faizabad.

**Selection Criteria of the Sample**

**Inclusion Criteria**

Only those parents were included who were living together along with the child. Parents who have no psychiatric or chronic physical illness were included in the study. Further educational status and occupation of parents was also taken care of viz: those parents were included who had studied up to class 10<sup>th</sup> or above and mothers who were housewife.

Moreover, Parents who belong to urban class and nuclear family were included. Those parents were included who have children up to 12 years of age. The level of intellectual disability was taken care of, that is those parents were selected who have children with mild to moderate level of intellectual disability. Children with no severe physical disorder or condition requiring priority medical management or any Co-morbid Psychiatric Disorder were included for the study.

**Exclusion Criteria**

Those parents were excluded who were not staying with the child or were separated / divorced. Parents having any psychiatric or chronic physical illness were excluded from the present study. Those parents were excluded whose educational qualification was less than class 10<sup>th</sup> and mothers who were employed. Moreover, Parents who belong to rural class and joint or extended family were excluded. Parents who have children more than 12 years of age were excluded. The level of intellectual disability was taken care of, that is those parents were excluded who have children with severe to profound level of intellectual disability. Parents of children with severe physical disorder or condition requiring priority medical management or any Co-morbid Psychiatric Disorder were excluded.

**Characteristics of the Sample**

Major characteristics of the sample of the study are depicted in the figure below:-

**Table 1: Depicting the Characteristics of the Sample of Present Study**

| S.No | Socio Demographic Variable                                | Fathers (Males) N=50 | Mothers (Females) N=50 |
|------|---|----------------------|------------------------|
| 1    | <b>Age</b>  |                      |                        |
|      | Range   | 26 to 35 years       | 25 to 35 years         |
|      | Mean  | 31.48                | 29.92                  |
|      | Standard Deviation  | 2.52                 | 3.08                   |
| 2    | <b>Education</b>  |                      |                        |
|      | Intermediate  | 26%                  | 56%                    |
|      | Graduate  | 50%                  | 30%                    |
|      | Post-Graduate   | 24%                  | 14%                    |
| 3    | <b>Occupation</b>   |                      |                        |
|      | Housewives  | 0%                   | 100%                   |
|      | Self Employed   | 38%                  | 0%                     |
|      | Job   | 46%                  | 0%                     |
|      | Unorganized sector<br>Mechanic/<br>Carpenter/Labourer etc | 16%                  | 0%                     |
| 4    | <b>Religion</b>   |                      |                        |
|      | Hindu   | 70%                  |                        |
|      | Muslim  | 30%                  |                        |

From the above table it could be seen the mean age of fathers was 31.48 with a range of 26 to 35 years and standard deviation of 2.52. The mean age of mothers was 29.92 with range of 25 to 35 years and standard deviation of 3.08. Regarding educational status, majority of fathers were Graduate (50%), whereas majority of mothers were intermediate (56%). Analyzing the occupation of the sample it was seen that (46%) of fathers were in job, (38%) were self employed and (16%) were in unorganized sector whereas (100%) of the mothers were housewife's. Further (70%) of the parents were Hindu and (30 %) were Muslim.

**Measures Used**

Informed consent form, Semi structured Performa for socio - demographic details and clinical variables, Family Interview for stress and coping in mental Retardation (FISC-MR) (Girimaji et al 1999)

Family Interview for stress and coping in mental Retardation (FISC-MR) Developed by Satish Chandra Girimaji, Shobha Srinath , Shekhar Seshadri & D.K. Subba Krishna . (1999) was used to assess perceived stress among parents of children with intellectual disability. It is a standardized tool for Indian samples with a reasonable degree of reliability and validity; the coefficients of measures of reliability were

between 0.36 to 0.9. The coefficients of validity measures were between 0.51 and 0.63. English version of tool is available so it was translated to hindi using back translation method. .

#### Procedure

Patients whose parents met the selection criteria were taken up for the study. Rapport was established and a written consent was taken. Confidentiality was ensured. The data was collected by face to face structured interview. Parents were thanked for their cooperation. Analysis and interpretation of generated data was done using qualitative analysis.

**Table 2: Showing Results of Qualitative Analyses of the Areas of Perceived Stress (Section-I FISC-MR)**

| Area                    | Mother  | Father   |
|-------------------------|---|--|
| Daily Care Stress       | High care demand- 39%<br>No time for self-25%<br>lack of support-17%<br>Adequately manage- 12%<br>Professional sacrifice-7%                             | Wife cooperation -42%<br>less time for family- 21%<br>family complains-16%<br>Occasional stress/ interference-16%<br>Disinterested-5%    |
| Family Emotional Stress | Psychological/ physical complaints-30%<br>Blaming Self/ God- 25%<br>Family Related Stress- 18%<br>Marital maladjustments- 18%<br>Supportive husband- 9% | Supportive family- 37%<br>Blaming- Spouse/ God- 30%<br>Disappointment- 13%<br>Family Problems-12%<br>Physical /Psychological problems-8% |
| Social Stress           | Decreased social life -42%<br>Embarrassment -27%<br>Adjustment problems-23%<br>Confidence in Child-8%   | Embarrassment - 37%<br>Good Social relations- 29%<br>Social Gathering without family-21%<br>Confidence in child/ family-13%              |
| Financial Stress        | Financial burden- 42%<br>Husband's responsibility-27%<br>Received financial support-16%<br>savings exhausted-15%  | Exhausted savings- 34%<br>Financial burden-26%<br>Anxious towards loan-24%<br>Received financial support-16%                             |

#### Daily Care Stress

This is the first area of Perceived Stress. According to FISC-MR Daily care stress is taken as that kind of parental stress which occurs during the caring task of their disabled child Content analysis of obtained responses brought to fore five response categories for mothers and five for fathers.

As depicted in table 2 mothers' highest responses category that emerged was "high care demand" (39%). This category reflects that majority of mothers during child care task, felt to be very demanding throughout the day. The verbatims in this category were "हर वक्त इनपे नजर रखनी पड़ती है इनकी सब जिम्मेदारी हमें ही देखनी है. सब काम छोड़कर इनको ही देखना पड़ता है दिनभर इतना काम होता है कुछ और तो कर ही नहीं पाते है ।"The next response category that emerged was "no time for self" (25%). It denotes the mothers have no time for self. The verbatim in this category is "बच्चो और परिवार वालो में इतना समय निकल जाता है. खुद के लिए समय ही नहीं है ।"Last three categories which emerged were "lack of support" (17%), "adequately manage" (12%) and "professional sacrifice" (7%).

When same information was tapped for fathers, majority of fathers fell in "wife's cooperation"

#### Analysis

The qualitative data generated on FISC –MR Section I was analyzed. Content analysis was done and percentages were computed.

#### Results and Interpretation:

In the present study, the stress experienced by the parents of intellectually disabled children has been explored with the help of FISC-MR (section-I). Data obtained on this section has been analyzed for both parents (mothers and fathers) separately on the four main areas of this tool which are daily care stress, family emotional stress, social stress and financial stress.(as depicted in the table below.

(42%) category. Verbatim in this was "वाइफ सब कर लेती है, मिलके सब हो जाता है ।"Next (21%) of fathers reported that they had "less time for family". Responses in this category were "ऑफिस का काम ही इतना ज्यादा होता है घर के लिए टाइम नहीं निकल पता है । घर आते है तो थके रहते है समय नहीं मिल पाता ।"Last three categories were "family complaint" (16%) , "occasional stress/interference" (16%) and "disinterested" (5%)

Analysis indicates gender differences in terms of daily care stress. For mothers the task of daily care is of high care demands, with no time for self, lack of support and mothers had to sacrifice their career for the same. For fathers the task of caring the child is hugely covered by wife's support, further they have less time for family due to office responsibilities and have reported that the family complaints also for the same. However fathers do feel occasional stress regarding the caring of child but a few of the fathers reported to be disinterested in terms of daily care needs of the child.

The picture emerged portrays the typical Indian stereotype of parents where mothers are expected to give extra inputs for upbringing the child and fathers play a small role in daily child care task compared with that of mothers. A probable reason

could be that women tend to spend many more hours than men on family and household chores. This finding is corroborated by (Upadhyaya and Havalappanavar 2008) who reported that in the area of care mothers report higher stress in comparison to fathers. (Seth 1979) also reported that 83% of mothers perceived care stress with respect of disabled children.

#### **Family Emotional Stress**

This is the second area of stress which explores the feeling of parents that occurs after having a intellectually disabled children, for eg, internal suffering, worries, and disappointments. It is also possible that it might affect their family relationships. The content analysis of obtained responses fell under 5 categories for mothers and 5 categories for fathers

As seen in table 2, majority of mothers responses included "psychological/physical complaints" (30%). Verbatim in this category were like "सच तो यही है की मेरे बाद क्या होगा इसका सोच सोच के रात भर नींद नहीं आती है, घबराहट होती है, इतनी चिंता रहती है की सर में दर्द होने लगता है।" Similar findings were reported by (Kazak 1987) who reported that mothers of children with intellectual disability have problem in sleeping and need more medical assistance. Further, (25%) of mother's responses depicted "blaming to self / god", verbatim were "हमारी ही गलती है, जो ऐसा बच्चा पैदा किये है। भगवान् पता नहीं किस जनम का बदला ले रहे है।" (18%) of the responses were "family related stress", verbatim were like "परिवार के लोग केवल ताना मरना जानते है, बच्चे को लेकर ससुराल के लोगो के साथ मनमुटाव रहता है।" lastly (18%) of the responses depicted "marital maladjustments" and (9%) of the responses were denoting husband's support related to child with intellectual disability.

Now moving to the fathers' responses, majority of fathers responses indicated that the fathers get support from wife and other family members regarding the child with intellectual disability, as (37%) of fathers responses fell in the category of "supportive family", with verbatim like "बच्चे की देखभाल बीवी की मदद से आसान है, हाँ मिल जाती है घरवालों की मदद जब भी जरूरत पड़ती है।" Further, (30%) of fathers responses denoted "blaming to spouse / god" verbatim included "इन्होने तीन बार कुल देवी का प्रसाद नहीं खाया था इसीलिए ये सब हुआ, हमारी अम्मा बताई है।" Moreover (13%) expressed "disappointments" related to child. The verbatim in this category were "इसके बारे में सोच कर बहुत दुःख होता है, सारी उम्मीदें टूट गयी है, भगवान् दुःशमन को भी ऐसा बच्चा ना दें।" and 12% of the responses fell in the category of family problems.

The overall picture of family emotional stress depicts that mothers have more psychological/physical problems than fathers. Further Mothers blamed themselves and god for child's problems and fathers also blamed the mothers for the same.

Mothers faced family related problems and marital maladjustments however for fathers there was more of support available from mother and other family member's. Studies have also indicated that having a child with mental retardation can have negative impact on the parent's marriage. (Murphy 1982, Featherstone 1980).

#### **Social Stress**

This is the third area of stress. The Content analysis on obtained responses elicited four response categories for mothers and four for fathers.

Table 2 shows that majority of the mothers responses fell in the category of "decreased social life" with (42%) of statements falling in this category. Verbatim depicting it is "मैं इसे बाहर नहीं जाने देती, मैं खुद भी इसलिए कई जगह नहीं जाती". "Embarrassment" due to child's condition was emerged as the second category with (27%) of mother's responses. "बुरा तो लगता ही है, शर्म भी महसूस होती है जब लोग हसते है इसका मजाक उड़ाते है।" Moreover, (23%) of mothers stated that they have "adjustment problems in society" and (8%) of the mothers responses fell in the category of "confidence in child".

On the contrary, majority of father's responses fell in the category of "embarrassment / shame" (37%) "शर्म तो आएगी ही ये बताने में की मेरा बच्चा ऐसा है" further (29%) of the fathers responses fell in the category of "good social relations", and (21%) of the responses indicated that the fathers attend social gatherings without the child or family as this emerged as the third response category. Lastly (13%) of the father's Responses fell in the category of "confidence in child and family".

The overall findings reveals that mothers feel more social stress as their social life is decreased due to the birth of the child, they feel embarrassed and have problems adjusting in society however for fathers having an intellectually disabled child is associated majorly with embarrassment yet they have good social relations as they choose to attend social gatherings without child/ family. Supporting the findings of the study, (Narayan 1979) also reported that the presence of a child with intellectual disability can cause social isolation.

#### **Financial Stress**

Financial stress is defined as the subjective, unpleasant feeling that one is unable to meet financial demands, afford the necessities of life, and have sufficient funds for the living. In this present study, it was taken as financial difficulties because of this child's condition. The obtained responses were carefully content analyzed and four response categories for mother and four for father were elicited. Analysis done reveals that maximum responses (42%) of mothers were in "financial burden" category. Verbatim depicting it is. "पैसे की बहुत दिक्कत है, इनके इलाज में कोई कमी नहीं रखे, बड़े से बड़े डॉक्टर को दिखाया है, इन सब में पैसा तो लगता ही है" however, (27%) of the responses of mothers fell in the category of "husbands responsibility", they considered earning

and taking care of expenses were majorly the responsibility of husband. verbatim of this category included "हाँ खर्चा बहुत है पर पैसे रुपये की जिम्मेदारी इनकी है, ये ही देखते हैं ये सब ." Lastly, (16%) and (15%) of the responses were in the category of "received financial support" and "exhausted savings" respectively.

Analysis of fathers responses it was found, majority of fathers (34%) fell in the "exhausted savings" category. Responses in this category were "अपनी सारी बचा इनके इलाज में लगा दी है, पैसे की तो दिक्कत है" Next responses category that was obtained was "financial burden" (26%) responses like "इतनी मेहगाई में ऐसे बच्चे के कारण बहुत दिक्कत है, खर्चा चलना मुश्किल हो जाता है" fell in this category. Further, "anxious towards loans" (24%). and "received financial support" (16%) were the last two categories which emerged from the responses of the parents.

The findings thus indicate a mixed picture, where both parents experienced financial stresses however, for fathers the financial stress was perceived in terms of exhausted savings with financial burden however, for mothers it is in terms of financial burden and husbands responsibility.

Catering to the financial needs of the disabled child is a great burden for any family. The presence of the child with Intellectual disability can cause financial hardships for families by increasing the family's consumptive demands and decreasing its productive capacity (Turnbull, et.al., 1990, Londsdale 1978, Kaslow and Cooper 1978).

### Conclusion

The present study highlights the Gender differences in perceived stress among parents of children with intellectual disability.

Gender differences were noted in terms of daily care stress of parent's. For mothers the task of daily care is of high care demands, with no time for self, lack of support and mothers had to sacrifice their career for the same. However for fathers the task of caring the child is hugely covered by wife's support, further they have less time for family due to office responsibilities

In terms of family emotional stress, mothers had more psychological/ physical problems than fathers. Further Mothers blamed themselves and god for child's problems and fathers also blamed the mothers for the same. Mothers faced family related problems and marital maladjustments however for fathers there was more of support available from mother and other family members.

Analysis of social stress reveals that mothers feel more social stress as their social life is decreased due to the birth of the child, they feel embarrassed and have problems adjusting in society however for fathers having an intellectually disabled child is associated majorly with embarrassment and they have good social relations as they choose to attend social gatherings without child/ family.

In terms of financial stress the analysis presents a mixed picture, where both parents experienced financial stresses however, it was more

for fathers. As, for mothers it's in terms of financial burden and husbands responsibility whereas for fathers it's in terms of exhausted savings with financial burden.

Hence, this study indicates that parents of intellectually disabled children and especially mothers require adequate intervention and support to reduce their stress. Interventions aimed at reducing daily care stress, enhancing emotional and social support would be beneficial in this regard.

### Implications and Suggestions

The study is a step towards understanding the stress experienced by parents of children with intellectual disability. It could be suggested that professionals when diagnosing a child with intellectual disability must consider for the adequate assessment and management of stresses of parents, such steps would be beneficial not only for the parents but in long term also for the child with disability, as parents with adequately managed stress would be more able to take care of the child with disability.

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