



TO STUDY STRESS AND PSYCHOLOGICAL WELL-BEING IN MOTHER OF INTELLECTUALLY DISABLED CHILDREN IN RURAL AREA: A CROSS SECTIONAL OBSERVATION STUDY

Psychiatry

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ABSTRACT

Introduction: Intellectual and developmental disability (IDD) is a developmental impairment that has no known treatment. Children with intellectual disabilities are typically abandoned and excluded from society as a whole. The wellbeing of a family is influenced by the mental and physical health of the parents, especially the women who are the centre of the family. They are the ones who must deal with issues related to their child's disability, such as delayed development, a higher incidence of child psychopathology, behavioural issues, and decisions about whether to seek out-of-home care for the child and therapeutic services while simultaneously maintaining the household. current study was conducted to determine stress and psychological well-being in mother of intellectually disabled children **Materials and Methods:** Present cross-sectional prospective study was conducted on 50 Caregiver mothers of intellectual disability (ID) child from rural area to determine their stress and psychological well-being. Children were classified into mild (IQ-55 to 79), moderate (IQ 35 to 54) and severe (IQ 20 to 35) intellectual disability (ID) based on IQ. Stress was assessed by Perceived Stress Scale (PSS) and wellbeing by psychological wellbeing scale. **Observations and Results:** PSS score low (0 to 13), Moderate (14 to 26) and High (27 to 40) was found in 18 (36 %), 18 (36 %) and 14 (28 %) cases respectively. Result was statistically significant ($P=0.032$). PWB score Very Low (50 to 58), Low (58 to 83), Moderate (83 to 217), High (217 to 242) and Very High (242 to 250) was found in 7 (14 %), 9 (18 %), 11 (22 %), 11 (22 %) and 12(24 %) cases respectively. Result was statistically significant ($P=0.034$) **Conclusion:** Parents of intellectually disabled children should engage in therapies including psychotherapy, relaxation, and stress-reduction strategies to improve their psychological health. Proper counselling services also assist the parent in leading a healthy life and in maintaining their psychological health

KEYWORDS

Intellectual disability (ID)

INTRODUCTION

The arrival of a child alters the structure and dynamics of the household and fosters a hedonistic environment for everyone, especially the parents. The ideal expansion and expression of a marriage is having children. Pregnant parents typically have an ideal conception of their child; the difference between the dream child and the actual child may be the source of bad attitudes and parenting stress^{1,2}. When a child misses developmental milestones, parents who were hoping for a "healthy newborn" go through a grieving process. When parents learn their child is special, they frequently experience astonishment, sorrow, guilt, wrath, sadness, and anxiety. Parents' responses to their child's impairment vary greatly throughout this period of shock, sadness, and organization. Due to the stigmatizing effects of the labelling process, sufferer children and their families experience a wide range of issues, including psychological, financial, mental, and social isolation because these kids are typically thought of as "mad" or "insane" because of their subnormal intellectual functioning^{3,4,5}.

Youngsters that develop and learn more slowly than typical children who struggle to function in their personal and social life without any support are typically referred to as having an intellectual disability. Children all across the world experience intellectual disabilities, which are characterized by limits in cognitive functioning and adaptive behavior, and rates are projected to rise as more children survive due to better medical treatment^{6,7}. According to estimates, children in underdeveloped nations are disproportionately likely to have intellectual disabilities. There are more than 15 percent of children in India who have intellectual disabilities, according to the 2011 Census. Intellectual and developmental disability (IDD) is a developmental impairment that has no known treatment. Children with intellectual disabilities are typically abandoned and excluded from society as a whole. Hayman (1990)¹⁰ defined psychological wellbeing as a mental condition characterized by pleasant feelings of good health, exhilaration, high self-esteem and confidence, and it often associated with regular physical activity.

The wellbeing of a family is influenced by the mental and physical health of the parents, especially the women who are the center of the family. They are the ones who must deal with issues related to their child's disability, such as delayed development, a higher incidence of child psychopathology, behavioral issues, and decisions about whether to seek out-of-home care for the child and therapeutic services while

simultaneously maintaining the household¹¹. Intellectually disabled Children need good care and education in order to take their places in society. These needs are provided primarily by the family, especially by the mothers. Therefore, it is important to determine the difficulties that a mother encounters during the education and care of a disabled child. With this perspective the current study was conducted to determine stress and psychological well-being in mother of intellectually disabled children

MATERIAL AND METHODS

Present study will be conducted after approval by institutional ethics committee. 50 Caregiver mothers from rural area coming to psychiatry OPD for obtaining disability certificates of their intellectually disabled child will be enrolled in this study after taking informed consent of participation. Children between age group (5 to 18) assessed by Clinical psychologist for their intellectual disability (ID) and are classified into mild (IQ-55 to 79), moderate (IQ 35 to 54). and severe (IQ 20 to 35) based on IQ. Mother with age more than 18 years and having formal school education will be assessed by two standardized instruments perceived stress scale and psychological well-being scale to study the stress felt by the mother and the psychological wellbeing by mother respectively.

Inclusion criteria

Selection criteria for caregivers

1. Mother staying with child for more than 5 years
1. Children age more than 5 years
2. Already diagnosed with intellectual disability

Exclusion criteria

1. Mother with intellectual disability
2. Caregivers not willing to give consent
3. Mother with known case of psychosis

Tools Used: Following tools were used in the study

A. Perceived stress scale¹²:

The Perceived Stress Scale (PSS) is the most widely used psychological instrument for measuring the perception of stress. It is a measure of the degree to which situations in one's life are appraised as stressful. Items were designed to tap how unpredictable, uncontrollable, and overloaded respondents find their lives. The scale

also includes a number of direct queries about current levels of experienced stress. The PSS was designed for use in community samples with at least a junior high school education. The items are easy to understand, and the response alternatives are simple to grasp. Moreover, the questions are of a general nature and hence are relatively free of content specific to any subpopulation group. The questions in the PSS ask about feelings and thoughts during the last month. In each case, respondents are asked how often they felt a certain way. Individual scores on the PSS can range from 0 to 40 with higher scores indicating higher perceived stress. Scores ranging from 0-13 would be considered low stress. Scores ranging from 14-26 would be considered moderate stress. Scores ranging from 27-40 would be considered high perceived stress.

B. Psychological well being¹³:

This scale was developed using Likert technique. suggestion was invited from the expert from the different fields such as psychology, sociology and psychiatry. Reliability of the scale was determined by test- retest method and internal consistency method. This scale consists of 50 question which are divided into five domains are satisfaction, efficiency, sociability, mental health and inter personal relationship. This scale consists of fifty statements. All statement is of positive manner. 5 marks to strongly agree, 4 mark to agree, 3 marks to undecided, 2 mark to disagree, 1 mark to strongly disagree. The sum of mark obtained for the entire scale. Higher the score more is the well-being.

Statistical analysis

Statistical analysis was performed using SPSS software, version 20. Data are expressed as number of cases & percentage N (%). χ^2 -test was used to study correlation between two variables. P value less than 0.05 is considered as Statistically significant.

RESULT

In present study out of total 50 cases child with mild intellectual disability (ID) were 22 (44 %), moderate intellectual disability (ID) was 18 (36%) and severe intellectual disability (ID) were 10 (20 %). Child who came with age between 11 to 18 years were maximum having mild intellectual disability (ID) 14 (28 %) whereas 5 to 10 years age group children showed mainly moderate and severe intellectual disability (ID) (11 (22 %) and 7 (14 %) respectively). No statistical correlation was found for two variables ($P=0.131$). Total boy children were 27 (54 %) and girl child's were 23 (46 %). Maximum boys showed mild ID 13 (26 %) whereas maximum girl child showed moderate ID 10 (20 %). No statistical correlation was found for two variables ($P=0.595$). In 29 (58 %) children birth order was first out of which maximum showed mild ID 13 (26 %). No statistical correlation was found for two variables ($P=0.964$) (**Table 1**). In 20 (40 %) cases it was first child and in rest 30 (60 %) it was second or more in order. Out of total mother 42 (84 %) were unemployed and 48 (96 %) had only ≤ 10 th/12th education (**Table 2**). PSS score low (0 to 13), Moderate (14 to 26) and High (27 to 40) was found in 18 (36 %), 18 (36 %) and 14 (28 %) cases respectively. Result was statistically significant ($P=0.032$). (**Table 3**). PWB score Very Low (50 to 58), Low (58 to 83), Moderate (83 to 217), High (217 to 242) and Very High (242 to 250) was found in 7 (14 %), 9 (18 %), 11 (22 %), 11 (22 %) and 12 (24 %) cases respectively. Result was statistically significant ($P=0.034$). (**Table 4**).

Table 1: Distribution of cases according to child demographics

Sr No.	Characteristic	Mild ID 22 (44 %)	Moderate ID 18 (36 %)	Severe ID 10 (20 %)	Total 50 (100 %)	Chi square	P value
1	Child Age (Years) a. 5 to 10 b. 11 to 18	8 (16 %) 14 (28 %)	11 (22 %) 7 (14 %)	7 (14 %) 3 (6 %)	26 (52 %) 24 (48 %)	4.0517	0.131
2	Child Gender a. Girl b. Boy	9 (18 %) 13 (26 %)	10 (20 %) 8 (16 %)	4 (8 %) 6 (12 %)	23 (46 %) 27 (54 %)	1.0361	0.595
3	Birth order a. First b. Second or More	13 (26 %) 9 (18 %)	10 (20 %) 8 (16 %)	6 (12 %) 4 (8 %)	29 (58 %) 21 (42 %)	0.0713	0.964

Table 2: Distribution of cases according to mothers' characteristics

Sr No.	Characteristic	Mild ID 22 (44 %)	Moderate ID 18 (36 %)	Severe ID 10 (20 %)	Total 50 (100 %)	Chi square	P value
1	Number of children 1 2 or more	8 (16 %) 14 (28 %)	8 (16 %) 10 (20 %)	4 (8 %) 6 (12 %)	20 (40 %) 30 (60 %)	0.2694	0.873
2	Employment Employed Unemployed	6 (12 %) 16 (32 %)	2 (4 %) 16 (32 %)	0 (0 %) 10 (20 %)	8 (16 %) 42 (84 %)	4.305	0.116
3	Education ≤ 10 th /12th Graduate	21 (42 %) 1 (2 %)	18 (36 %) 0 (0 %)	9 (18 %) 1 (2 %)	48 (96 %) 2 (4 %)	1.7045	0.426

Table 3: Distribution of cases according to Perceived Stress Scale (PSS)

Sr No.	PSS Score	Mild ID 22 (44 %)	Moderate ID 18 (36 %)	Severe ID 10 (20 %)	Total 50 (100 %)	Chi square	P value
1	Low (0 to 13)	12 (24 %)	5 (10 %)	1 (2 %)	18 (36 %)	10.4922	0.032
2	Moderate (14 to 26)	6 (12 %)	9 (18 %)	3 (6 %)	18 (36 %)		
3	High (27 to 40)	4 (8 %)	4 (8 %)	6 (12 %)	14 (28 %)		

Table 4: Distribution of cases according to psychological wellbeing (PWB)

Sr No.	PWB Score	Mild ID 22 (44 %)	Moderate ID 18 (36 %)	Severe ID 10 (20 %)	Total 50 (100 %)	Chi square	P value
1	Very Low (50 to 58)	1 (2 %)	2 (4 %)	4 (8 %)	7 (14 %)	16.5923	0.034
2	Low (58 to 83)	2 (4 %)	5 (10 %)	2 (4 %)	9 (18 %)		
3	Moderate (83 to 217)	3 (6 %)	6 (12 %)	2 (4 %)	11 (22 %)		
4	High (217 to 242)	7 (14 %)	3 (6 %)	1 (2 %)	11 (22 %)		
5	Very High (242 to 250)	9 (18 %)	2 (4 %)	1 (2 %)	12 (24 %)		

DISCUSSION

Present cross-sectional prospective study was conducted on 50 Caregiver mothers of intellectual disability (ID) child from rural area to determine their stress and psychological wellbeing. Children were classified into mild (IQ-55 to 79), moderate (IQ 35 to 54) and severe (IQ 20 to 35) intellectual disability (ID) based on IQ. Stress was assessed by Perceived Stress Scale (PSS) and wellbeing by psychological wellbeing scale developed using Likert technique. Results obtained consisted of 22 (44 %) children with mild intellectual disability (ID), 18 (36%) with moderate intellectual disability (ID) and 10 (20 %) with severe intellectual disability (ID). PSS score low (0 to 13), Moderate (14 to 26) and High (27 to 40) was found in 18 (36 %), 18 (36 %) and 14 (28 %) cases respectively. Result was statistically significant ($P=0.032$). PWB score Very Low (50 to 58), Low (58 to 83), Moderate (83 to 217), High (217 to 242) and Very High (242 to 250) was found in 7 (14 %), 9 (18 %), 11 (22 %), 11 (22 %) and 12 (24 %) cases respectively.

Result was statistically significant ($P=0.034$). In similar study performed by Charles Masulani Mwale et al (2018)¹⁴ 70/170 (41.2%) of parents of children with intellectual disabilities reported psychological distress. In both a univariate and multivariate analysis, it was found that the location of one's residence ($P=0.05$), low socioeconomic status ($P=0.05$), knowledge of the child's disability ($P=0.05$), lack of confidence in managing the disabled child ($P=0.05$), increased perceived burden of care ($P=0.05$), and not having access to psychological support ($P=0.05$) significantly predicted psychological distress among parents of disabled children. They came to the

conclusion that parents of intellectually impaired children in Malawi experience a significant amount of psychological suffering. Malawi desperately needs psychosocial interventions to assist parents of children with intellectual disabilities. **Feizi A et al (2014)**¹⁵ found that Mothers of children with sensory-motor mental and chronic physical problems experience more stress than mothers of children with psychological disorders ($P < 0.05$). Mothers of children with psychological illnesses had a lower stress score than the other two groups. Additionally, there was a statistically significant difference in the parent-child dysfunctional relationship score between mothers of children with chronic medical difficulties and moms of children with psychiatric disorders ($P 0.01$). Mothers of children with sensory-motor mental problems who had a different number of children showed a significant difference in their levels of stress ($P 0.05$); mothers of children with chronic physical problems who had a different level of education also showed a significant difference in their levels of parenting stress ($P 0.05$). They concluded that due to high level of parenting stress among our studied samples, special education and early intervention are needed for parents in our study population in order to deepening their diagnostic knowledge and professional consultation on stress management. **S. Parameswari et al (2012)**¹⁶ study findings convey that more than half of the parents do not have good mental health due to their multiple responsibilities. The family members of children with intellectual and developmental disabilities should be taught stress reduction and relaxation strategies to help the parents of such children with mental health issues. Psychotherapy is one therapy that can help parents of children with such conditions. **J. M. Cramm et al (2011)**¹⁷ found that parental stress and the child's depressive feelings strongly affected psychological well-being. Additionally, they discovered a connection between restricted caregiver social activities and parental stress. Support services should treat depressive symptoms in children with intellectual impairments, promote caregivers' social engagement, and lessen stress in order to maintain caregivers' mental health.

Children with intellectual disability (ID) are mostly cared by their parents. They have experienced both highs and lows, and they have witnessed both the best and worst times. It's critical for parents to keep in mind that there is no one perfect approach to raise a child. They should be aware that it's okay to ask for assistance and make use of the resources available to them, whether they come from the professional or larger family members. To have a strong marriage that can endure, parents must make time for one another satisfying the children's requirements. Teachers and experts can offer helpful knowledge and strategies for overcoming the difficulties that parents encounter. Exchange of information can be facilitated by those who are also caring for children with intellectual disability (ID).

CONCLUSION

Parents of intellectually disabled children should engage in therapies including psychotherapy, relaxation, and stress-reduction strategies to improve their psychological health. Additionally applicable to the parents and other family members of children with intellectual disabilities, referral services can help them have fulfilling lives. Because of referral services, parents are able to better assist their children. Parents of children with intellectual and developmental disabilities support their child in receiving ongoing special training and rehabilitation based on the motivations and supports from family members and other relatives. This also helps the parents to have hope and confidence in their child's development. Proper counselling services also assist the parent in leading a healthy life and in maintaining their psychological health

REFERENCES

1. J. S. Greenberg, M. M Seltzer and J. R. Greenley. Maternal and paternal care giving of persons with mental retardation across the lifespan. *Family Relations*, 1993, 46, 407–15.
2. H. B. Miltiades, and R. Pruchno. Mothers of adults with developmental disability: change over time. *American Journal on Mental Retardation*, 2001, 106, 548–61.
3. M. Friedrich and F. Friedrich. *Recent Advances and Practices*: University Press, Cambridge, 1981, pp-343–52.
4. F. Vermaes. Mental health services for people with intellectual disability: a conceptual framework. *Journal of Intellectual Disability Research*, 2008, 44, 97–107.
5. C. K. Rastogi. Attitude of parents towards their mentally retarded children. *Indian journal of psychiatry*, 1981, 23(3), 206.
6. Schalock RL, Luckasson RA, Shogren KA. The renaming of mental retardation: understanding the change to the term intellectual disability. *Intellect Dev Disabil*. 2007;45(2):116–24.
7. Dave D, Mittal S, Tiwari D, Parmar M, Gedani S, Patel V. Study of anxiety and depression in caregivers of intellectually disabled children. *J Res Med Dent Sci*. 2017;2(1):8–13.
8. Zaman SS, Khan NZ, Islam S. Validity of the ten question for screening serious childhood disability: results from urban Bangladesh. *Int J Epidemiol*. 1992;19(3):613–20.
9. Census of India (2011). Census of Indian 2011 data on disability retrieved from <https://index.php/disability-register/census-2011-disability-data.html>
10. M. Olsson and C. Hwang. Depression in mothers and fathers of children with intellectual disability. *J Intellect Disabil Res*, 2001, 45, 535–543.
11. G. Llewellyn and D. McConnell. You have to prove yourself all the time: People with learning disabilities as parents. In G. Grant, P. Goward, M. Richardson and P. Ramcharan (Eds.), *Learning disability: A life cycle approach to valuing people*. Finland: WS Bookwell, 2005, pp. 441–467.
12. Lakhan R, Ekundayo OT, Shahbazi M. An estimation of the prevalence of intellectual disabilities and its association with age in rural and urban populations in India. *Journal of neurosciences in rural practice*. 2015 Oct;6(04):523–8.
13. Cohen S, Kamarck T, Mermelstein R. Perceived stress scale. *Measuring stress: A guide for health and social scientists*. 1994;10(2):1–2.
14. Charles Masulani-Mwale, Felix Kauye, Melissa Gladstone3 and Don Mathanga. Prevalence of psychological distress among parents of children with intellectual disabilities in Malawi. *BMC Psychiatry* (2018) 18:146
15. Feizi A, Najmi B, Salesi A, Choram M, Hoveidafar R. Parenting stress among mothers of children with different physical, mental, and psychological problems. *J Res Med Sci* 2014;19:145–52.
16. S. Parameswari&Dr.J.O.Jeryda Gnanajane Eljo. A Study on Psychological Well Being among the Parents of Children with Intellectual and Developmental Disabilities". *Journal Of Humanities And Social Science (IOSR-JHSS)* 2012; 2279-0845.
17. J. M. Cramm and A. P. Nieboer. Psychological well-being of caregivers of children with intellectual disabilities: Using parental stress as a mediating factor. *Journal of Intellectual Disabilities* 2011; 15(2) 101–113