

Original Research Article

A study to assess the degree of depression among parents of mentally challenged children

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ABSTRACT

Background: Raising a mentally challenged child is a challenging and exhausting task. Families can easily become overwhelmed by the process of finding and funding appropriate services. They are faced with the stress of continually witnessing their loved one's struggles to complete everyday tasks, social interactions and education. They must live with the knowledge that there is no end to these struggles.

Methods: The study was descriptive study to assess the degree of depression. 200 parents of mentally challenged children in different special educational institutions of Jammu and Kashmir were chosen by convenient sampling method and data was collected with the help of questionnaire (modified becks depression inventory II).

Results: Findings of the study revealed that majority 9 (4.5%) were normal, 63 (31.5%) had mild depression, 92 (46%) parents had moderate depression and 36 (18%) of parents had severe depression. Significant association was found between relationship with child ($p < 0.005$), religion ($p < 0.001$), education ($p < 0.001$), occupation ($p < 0.00$), monthly family income ($p < 0.000$) and the degree of depression among parents of mentally challenged children.

Conclusions: This study revealed that majority of the parents of mentally challenged children were having moderate depression.

Keywords: Assess, Depression, Parents, Mentally challenged children, Jammu and Kashmir

INTRODUCTION

Depression is a significant contributor to the global burden of disease and affects people in all communities across the world. Depression is estimated to affect 350 million people. The World mental health survey conducted in 17 countries found that on average about 1 in 20 people reported having an episode of depression.¹ By 2025 depression will be the second leading cause of world disability.²

We all have our everyday disappointments and suffering, significant losses is a part of human life cycle. These disappointments and losses bring about emotional blues and bouts of sadness from time to time. Depression is only rendered pathological when it interferes with

personal, social and occupational functioning of the individual and individual is rendered incapable of fulfilling his own need thus fostering dependence on others. The degree of depression is assessed by the extent of impairment in these domains. Some people suffer from pathological depression under mild stress while others need strong precipitating factors to elect the symptoms of depression. This is due to certain factors like premorbid personality, available defense mechanisms, available family support and social support system. The people who have extroverted premorbid personality, strong defense mechanisms, strong family dynamics and work in a structured environment are less likely to suffer from depression than people who have poor premorbid personality, weak defense mechanism, dysfunctional family dynamics and work in an

unstructured environment. Many family members may feel alienated from other families and friends who do not live with mentally challenged child on a daily basis and therefore cannot truly appreciate what it involves.³

Parenting is one of the most challenging jobs an individual will ever face. Raising children can be stressful at times, but also very rewarding. Becoming the parent of a child who has a disability is a time of great stress and change.⁴ Parents who have children with disabilities report higher amounts of physical, emotional, psychological and financial demands; however the extent of stress depends upon a number of variables that were first introduced in family stress theory and identified in Hill's ABCX family crisis model.⁵

The parents may have a feeling that the present condition of the child is because of something they did or did not do and blame themselves for the present condition of the child. The self-blame turns into guilt and guilt is expressed by self-directed anger (anger turned inwards) which is Freud's view of depression. Often, parents get offended with their doctors or the professionals who disclose the diagnosis to them. They do a lot of doctor shopping hoping someone will say that their child is normal. They may get a feeling that the doctors, whom they have trusted so much, have failed them and also, they may feel that they should have recognized the problem sooner. The reactions of shock and disappointment make the parents struggle. They find that their support systems fail because they feel the other family members and friends are also struggling to cope with their feelings and become vulnerable and starts reacting to the advice and comments given by friends, relatives, and experts.⁶ Many family members may feel alienated from other families and friends who do not live with mentally challenged child on a daily basis and therefore cannot truly appreciate what it involves.

All these factors contribute to disparity expressed as hopelessness, helplessness and worthlessness classically exhibited in pathological depression.

Jan (2008) conducted a study for disabled children in Jammu and Kashmir. This study aimed at identifying school dropout rate among disabled children and signifying dissemination of education for their sustainable development. For the purpose, secondary data was obtained from the Jammu and Kashmir state in India, comprising all identifying disabled children in age group of 6-14 years. The results indicated that there were more disabled boys in Jammu and Kashmir than girls in the age group of 6-14 years. Disabled children generally suffered orthopedic complications. The number of disabled children attending formal school of education was very less, especially in case of disabled girls. The number of disabled children attending school in the age group 11-14 years was less than disabled children attending school in age group of 6-11 years. Though legislature provided equal and special rights and schemes for disabled

children, yet its proper implementation was far from its goal. The study suggested specific teaching methods and facilities for disabled children with effective implementation of schemes and services for them.⁷

Understanding the parents attitude was important because it impinged upon and interacts with the child.

Objective

The objective was to assess the level of depression among parents of mentally challenged children.

METHODS

A descriptive research approach was adopted for current study. Study participants were recruited from 6 special educational institutions of Jammu and Kashmir (learning edge Munawarabad Srinagar, Chotay Taray foundation Barzulla Srinagar, Shafaqat special school Bemina Srinagar, Zeeba Aapa institute of inclusive education Bijbehera Anantnag, Rotary inner wheel home Channi Jammu and Jiger institute Gangyal Jammu) whose children were enrolled there and who fulfilled the inclusion criteria. 200 parents of mentally challenged children were selected by convenient sampling technique. Data was collected by modified Becks depression scale II. Ethical permission was obtained from Institutional Ethical committee. A structured questionnaire was used to get baseline data on sociodemographic variables of child and parent. Data was collected by modified Becks depression scale II created by Aaron Beck first published in 1961 and revised in 1996.⁸ The tool was sent to 15 experts from the field of nursing, medicine, psychiatry and psychology. The experts were requested to provide feedback regarding adequacy and relevance of the content. In the present study, reliability of the tool was estimated as 0.98, so the tool was found reliable to collect the data. Informed written consent of the participants was taken and if the participants were illiterate, the consent was read out and impression of thumb was taken from participants in front of the member of that special educational institute. Data was collected within the time period of 4 months from February 2021 to June 2021. The exclusion criteria for the study was parents of mentally challenged children who were not present at the time of study; who were not willing to participate in the study; and who were on antidepressant drugs.

RESULTS

Section A

Part I: Analysis of socio demographic and attribute variables of mentally challenged children and parents of mentally challenged children

Table 1 shows frequency and percentage distribution of socio demographic and attribute variables of mentally

challenged children and parents of mentally challenged children.

Out of 200 children there were 70 (35%) with mild mental retardation, 87 (43.5%) with moderate mental retardation, 32 (16%) were with severe mental retardation and 11 (5.5%) with profound retardation. There were 22 (11%) children without any associated conditions, 21 (10.5%) had autism, 22 (11%) had ADHD, 25 (12.5%) had Down's syndrome and 110 (55%) has other conditions like blindness, deafness, dumbness, motor

impairment. Among 200 samples of mentally challenged children, 3 were below 6 years of age making 1.5%, 90 were in the age group of 6-10 years making 45%, 68 were in the age group of 11-15 years making 34% and 39 were above 16 years of age making 19.5%. On analysis, out of 200 mentally challenged children it was found that 108 (54%) were males and 92 (46%) were females. On interpretation of birth order out of 200 children, majority of the children 91 (45.5%) were second born, 80 (40%) were first born, 25 (12.5%) were third and 4 (2%) were fourth born.

Table 1: Frequency and percentage distribution of socio demographic and attribute variable of mentally challenged children and parents of mentally challenged children.

S. No.	Demographic variables	Frequency (n=200)	Percent
1.	Degree of mental retardation		
	Mild	70	35.0
	Moderate	87	43.5
	Severe	32	16.0
2.	Profound	11	5.5
	Associated condition		
	Autism	21	10.5
	ADHD	22	11.0
	Down's syndrome	25	12.5
3.	Others	110	55.0
	Nil	22	11.0
	Age of the child (years)		
	<6	3	1.5
	6-10	90	45.0
4.	11-15	68	34.0
	>16	39	19.5
	Sex		
	Male	108	54.0
5.	Female	92	46.0
	Birth order of child		
	First	80	40.0
	Second	91	45.5
	Third	25	12.5
6.	Fourth	4	2.0
	Parent relationship		
	Father	73	36.5
7.	Mother	127	63.5
	Age of the parent (years)		
	Below 30	1	0.5
	31-35	13	6.5
	36-40	55	27.5
8.	Above 40	131	65.5
	Religion		
	Muslim	42	21.0
	Hindu	153	76.5
9.	Sikh	5	2.5
	Education		
	Illiterate	55	27.5
	Primary	45	22.5
	Middle	10	5.0
Secondary	59	29.5	

Continued.

S. No.	Demographic variables	Frequency (n=200)	Percent
	Hr. secondary	9	4.5
	Graduate	17	8.5
	PG and Above	5	2.5
10.	Occupation		
	Employed	30	15.0
	Self-employed	66	33.0
	Unemployed	104	52.0
11.	Monthly family income (rupees)		
	Less than 10,000	114	57.0
	10,000-15,000	48	24.0
	More than 15,000	38	19.0
12.	Family type		
	Nuclear	135	67.5
	Joint	58	29.0
	Extended	7	3.5
13.	Family h/o MR		
	Yes	14	7.0
	No	186	93.0
14.	Consanguinity of marriage		
	Yes	19	9.5
	No	181	90.5
15.	Habitat		
	Rural	108	54
	Urban	92	46

Table 2: Describes the degree of depression among the parents of mentally challenged children.

Degree of depression	Frequency (n=200)	Percent	Mean
Normal	9	4.5	4.67
Mild	63	31.5	15.95
Moderate	92	46	25.32
Severe	36	18	37.11

Table 3: Item analysis of study subjects.

Item in modified Beck's depression inventory (with score)	Frequency (n=200)	Percent
Sadness		
0	12	6
1	76	38
2	90	45
3	22	11
Pessimism		
0	9	4.5
1	123	61.5
2	59	29.5
3	9	4.5
Loss of pleasure		
0	6	3
1	149	74.5
2	41	20.5
3	4	2
Guilty feeling		
0	66	33

Continued.

Item in modified Beck's depression inventory (with score)	Frequency (n=200)	Percent
1	95	47.5
2	37	18.5
3	2	1
Daily care		
0	7	3.5
1	135	67.5
2	53	26.5
3	5	2.5
Personal distress		
0	12	6
1	97	48.5
2	71	35.5
3	20	10
Crying		
0	26	13
1	132	66
2	39	19.5
3	3	1.5
Loss of interest		
0	13	6.5
1	150	75
2	29	14.5
3	8	4
Indecisiveness		
0	14	7
1	139	69.5
2	45	22.5
3	2	1
Worthlessness		
0	28	14
1	138	69
2	31	15.5
3	3	1.5
Loss of energy		
0	26	13
1	154	77
2	17	8.5
3	3	1.5
Sleep pattern		
0	57	28.5
1	106	53
2	35	17.5
3	2	1
Appetite		
0	68	34
1	109	54.5
2	17	8.5
3	6	3
Concentration		
0	10	5
1	133	66.5
2	56	28
3	1	0.5

Continued.

Item in modified Beck's depression inventory (with score)	Frequency (n=200)	Percent
Fatigue		
0	15	7.5
1	133	66.5
2	50	25
3	2	1
Loss of interest in sex		
0	27	13.5
1	130	65
2	36	18
3	7	3.5
Neglect of others		
0	31	15.5
1	137	68.5
2	28	14
3	4	2
Disturbed behaviour		
0	12	6
1	148	74
2	35	17.5
3	5	2.5
Marital problems		
0	26	13
1	130	65
2	41	20.5
3	3	1.5
Altered social life		
0	21	10.5
1	148	74
2	28	14
3	3	1.5
Suicidal thoughts		
0	87	43.5
1	103	51.5
2	10	5
3	0	0

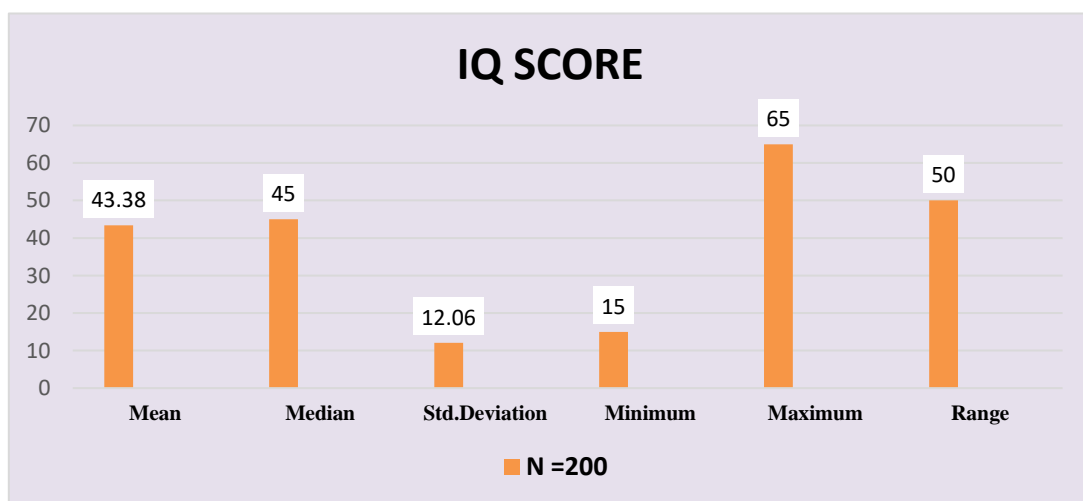


Figure 1: Column diagram shows description of IQ score; mean was 43.38; median was 45, SD was 12.06996, minimum was 15, maximum was 65 and range was 50.

Out of 200 parents, 127 (63.5%) were mothers and 73 (36.5%) were fathers.

Majority 131 (65.5%) were above 40 years of age, 1 (0.5%) belong to the age group of below 30 years, 13 (6.5%) were in the age group of 31-35 years, 55 (27.5%) were in the age group of 36-40 years. Out of 200 parents of mentally challenged children in majority 153 (76.5%) belonged to Muslim religion, 42 (21%) were Hindus and only 5 (2.5%) belonged to Sikh religion. With respect to the parents education, out of 200, 55 (27.5%) were illiterate, 45 (22.5%) were educated up to primary level, 10 (5%) were middle pass, 59 (29.5%) were educated up to secondary level, 9 (4.5%) were educated up to higher secondary level, 17 (8.5%) were graduates and 5 (2.5%) were PG and above. Majority 104 (52%) were unemployed 30 (15%) were employed and 66 (33%) were self-employed. Out of 200 parents of mentally challenged children 114 (57%) had a family income of less than 10000 per month, 48 (24%) had a family income of 10000-15000 and 38 (19%) had a family income of more than 15000 per month.

135 (63.5%) belonged to nuclear family, 58 (29%) belonged to joint family and 7 (3.5%) belonged to extended family. Out of 200 parents 14 (7%) had a family history of mental retardation and 186 (93%) had not a family history of mental retardation. 19 (9.5%) were having consanguinous marriage and 181 (90.5%) were not having consanguinous marriage. 108 (54%) were living in rural areas and 92 (46%).

Section B: Degree of depression observed among the Parents of mentally challenged children

Part II : Description of IQ score

Table 2 shows frequency and percentage distribution of degree of depression graded according to modified Becks depression inventory II scale and grading the total score into categories of normal/mild/moderate/severe.

Out of 200 parents, 9 (4.5%) were normal with the mean value of 4.67, 63 (31.5%) had mild depression with the mean value 15.95, there were 92 (46%) parents with moderate depression and the mean value was 25.32 and 36 (18%) of parents had severe depression with the mean value 37.11.

Depression graded according to individual items in modified Becks depression inventory II scale and grading them according to scores in individual items (from 0-4).

DISCUSSION

Out of 200 parents of mentally challenged children 9 (4.5%) were normal, 63 (31.5%) had mild depression, there were 92 (46%) parents with moderate depression and 36 (18%) of parents had severe depression. This

revealed that majority of the parents of mentally challenged children were having moderate depression.

These findings of the study were also supported by the study conducted by Dorathi 2019 to assess the anxiety and depression level of working women having mentally retarded children. The findings of the study revealed that 34% of mothers had mild depression, 52% had moderate depression and 14% had severe depression.⁹

Zhou et al 2019 to investigate the emotional problems (depressive and anxiety symptoms) of mothers of children with autism spectrum disorder (ASD) and explore the role of the mother's socioeconomic status (SES) and the core symptoms of the child on the mother's emotional problems. Of the mothers studied, 72.5% and 80.2% had depressive and anxiety symptoms, respectively and 67.1% suffered from both symptoms.¹⁰

Azeem et al 2013 conducted a cross-sectional study in Pakistan to assess the level of anxiety, depression and both anxiety and depression together among parents of children with intellectual disability (ID). 198 parents of 100 children with the diagnosis of ID participated in study. It was found that 89% had depression.¹¹

The findings of the study were also supported by a study conducted by Ergun et al 2012 on 168 mothers with mental retardation at Turkey, 64 (38.1%) said they experienced sadness, 72 (42.9%) anger and 32 (19.1%) felt lonely. As many as 92 (54.8%) mothers were blamed by their in-laws for the disability in their respective children.¹²

Limitations

The study was limited to parents of mentally challenged children who were willing to participate in the study; sample size of 200 and period 4 months.

CONCLUSION

The results of the study concluded that out of 200 parents (4.5%) were normal, 63 (31.5%) had mild depression, there were 92 (46%) parents with moderate depression and 36(18%) of parents had severe depression. This reveals that majority of the parents of mentally challenged children were having moderate depression.

Significant association was found between relationship with child ($p<0.005$), religion ($p<0.001$), education ($p<0.001$), occupation ($p<0.00$), monthly family income ($p<0.000$) and the degree of depression among parents of mentally challenged children while as no association was found between parents age group, type of family, family history of mental retardation, consanguinity of marriage, habitat and the degree of depression among parents of mentally challenged children ($p>0.05$). Nurses working in the community and hospitals play a vital role in spreading health awareness. The nursing personnel during her

health education programmes in different wards can impart knowledge regarding depression. The importance of research in nursing is to build the body of knowledge. The findings of the present study serve as the basis for the professionals and students to conduct further studies on depression and different coping interventions used.

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Ethical approval: The study was approved by the Institutional Ethics Committee

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