



A COMPARATIVE STUDY OF PSYCHIATRY MORBIDITY AMONG CAREGIVERS (MOTHERS) OF INTELLECTUAL DISABLED CHILDREN.

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ABSTRACT

Background: Intellectual disability (ID) is a highly disabling and permanent condition which can trigger a different psychological response in parents. The birth of a Intellectually disabled child produces feelings in mother and other family members which are in complex nature.

Aims and Objectives: To find the socio demographic variables and psychological impact (i.e. Quality of life [QOL], Social Support, Depression and Anxiety) on mothers of children with ID.

Materials and Methods: A cross sectional comparative study was conducted with a total of 120 participants. Out of it 60 were diagnosed as (Intellectual disability) ID and rest 60 were normal children. The data were collected in a special Pro forma, and mothers of these patients were evaluated with Hamilton Rating Scale for Depression (HAM-D), Hamilton Anxiety Rating scale (HAM-A) for anxiety, World Health Organization QOL-BREF (WHOQOL-BREF) for QOL and Multidimensional scale of Perceived social support (MSPSS) to assess the level of perceived social support. Data was analyzed using SPSS version 21. Frequency table, percentages, means and standard deviation (SD) and t-test were used.

Result: The results of t-test revealed statistically significant differences ($p < .01$) in the level of anxiety, depression, quality of life and social support in both groups of mothers. The mean age of patients with ID was 10 years and mean intelligence quotient was 47.93.

Conclusion: The anxiety and depression in mothers of ID children in the present study are much greater than mother of normal children. The mother of ID children perceived less social support and low quality of life as compare to mothers of normal children. These factors among mothers of ID children may help health professionals in identifying mothers at risk. Regular screening of mothers of ID children should be included in the protocol for intervention/therapy or other management.

KEYWORDS : Anxiety, Depression, QOL, Social Support, Caregivers, Children with intellectual disabled.

INTRODUCTION

Intellectual disability (ID) formerly known as mental retardation is not a disease but a condition, characterized by significant limitations in both in adaptive behavior like practical skills, social and conceptual) and intellectual functioning like problem solving, reasoning and learning. The onset of Intellectual disability (ID) should be before the age of 18 years.[1] The causes can be a range of genetic and environmental factors that lead to a combination of social and cognitive impairments.[2] ID is a highly disabling and permanent condition. The birth of a Intellectually disabled child produces feelings in mother and other family members which are in complex nature. Rearing, a child with ID, is an perpetual process that affects parents and other family members.[3,4] especially in India and particular in Kashmir mothers are more responsible for the education, caring and rearing of children with ID than fathers. However raising a child with ID is a significant role of both parents. [5,6]

Hence, it is considered that the main caregivers for children with ID are mothers.[8] A mother expects her child to be born healthy but diagnosis of a child as disabled takes a heavy toll on her happiness and well-being. Such a diagnosis can precipitate a range of psychological responses in a mother thereby constituting a crisis for mothers and demanding extraordinary psychological adjustment. Nurturing an ID child is lifelong and time consuming, the mothers reported that they were emotionally and physically exhausted and felt socially isolated.[9] Compared with mothers of children with normal development, mothers of children with ID have lower family functioning, a higher caregiver burden, and a lower sense of coherence.[10]

Parents often have needs during this time that are not addressed by professionals because of the exclusive focus on the child during the

evaluation. The 35%–53% of mothers of children with disability have symptoms of depression suggested by studies in many countries on parents with intellectually disabled child.[11] Singhi et al.[12] concluded in his study “India on psychosocial problems faced by parent and family members” that parents of disabled children face severe economic problems, distractions in family activity schedule, problems in social interaction, and marital disadjustment, and also higher neurotic condition. Hedove et al.[13] reported that the presence of a family member with Down’s syndrome might have a negative impact on maternal quality of life (QOL). (14,15)

However, there are a few studies done in India particularly in Jammu and Kashmir, thus the present study attempts to examine the level of anxiety and depression and QOL in mothers with intellectually disabled children. This study also tries to establish whether psychological problems are more prominent in the mothers with intellectually disabled children than mothers with normal children. So that mothers of ID children may help by health professionals in identifying mothers at risk and for further intervention/therapy or other management.

Materials and Methods

The research design employed was descriptive, cross sectional and comparative study.

Study setting

The study was conducted in the Psychiatry Outpatient Department of Tertiary Care Hospital, SKIMS Medical College & Hospital Bemina, Srinagar. It is a teaching institute with an attached tertiary care hospital facility and the hospital is centrally located with representation from all districts of Kashmir division of state of Jammu and Kashmir with all the specialties under one roof. The study was approved from ethical

community of Sheri-Kashmir Institute of Medical Sciences, Srinagar.

Sample

A total of 120 sample was taken, out of 120 participants were 60 mothers (Group A) with children of mild to severe level of ID diagnosis of the intellectual disability was done by consultant psychiatrist along with clinical psychologist as per DSM-5 [16] and 60 mothers with healthy children (Group B). Mothers staying with the children since their birth were selected using purposive sampling technique from the outpatient department (OPD) of Psychiatry SKIMS Medical College & Hospital Bemina Srinagar, Jammu and Kashmir. For the control group B, mothers staying with their children since their birth were selected from local area. This group was matched for age, educational qualification, duration of stay with child, family type, no history of past psychiatric illness, and no physical disability. Mothers with previous psychiatric history, more than one child with any form of disability, and mothers of children aged more than 18 years were excluded.

Tools

All the respondents of both the groups was interviewed and assessed separately.

Hamilton Rating Scale for Depression (HAM-D)[17] was administered to determine the level of depression. HAM-D is a 17 items version scale is on 3-point and 5-point likert type scale scored from 0 to 2 and 0 to 4. For 17-item version, a score of 0-7 is considered to be normal while a score of 20 or higher is usually required for entry into a clinical trial.

Results

Table 1: Socio demographic characteristics of mothers and their children with intellectual disability.

Mother (n=60)		Children (n=60)	
Age in years		Age in years	
Mean (SD)	35 years (SD 7.0)	Mean (SD)	10 years (SD 5.0)
Range	25-40 Years	Range	4-16 years
Education	f (%)	Gender	f (%)
Illiterate	33 (55)	Boys	39 (65)
Educated	27 (45)	Girls	21 (35)
Family Income		Domicile	
Poorer income section (Up to Rs 10000/month)	35 (58.3)	Urban	20 (33.33)
Average income section (Rs 10000-30000/month)	22 (36.66)	Rural	40(66.66)
(Good income section Rs30000 and above)	3 (5)	IQ level	
Marital Status		Average	47.93
Married	59 (98.33)	Mild ID	30 (50)
Divorced	1 (1.66)	Moderate ID	23 (38.33)
Family System		Severe ID	6 (10)
Nuclear	51 (85)	No. of Siblings	
Joint	9 (15)	One or two siblings	37 (61.66)
		Three siblings	17 (28.33)
		Four siblings	5 (8.33)
		Five siblings	1 (1.66)

The table 1 shows the socio demographic variables of the study population. The said table of the current study reported that the mean age of mothers with ID children was found to be 35 years (SD 7.0). Most of the mothers with ID children were found illiterate 55% and 45% were educated. The average age of study population (child with ID) was around 10 years (SD 5.0) with age range from 4 to 16 years. Out of 60 study sample 35% were girls and 65% were boys with 66.66% belongs to rural and 33.33% belongs to urban domicile. The average IQ was found to be around 47.93 was measured with help of intelligence test by clinical psychologist. Half of the study sample i.e 50% had mild ID while 38.33% were moderate ID and 10% were severe ID. Having one or two sibling was found 61.66%, 28.33% had 3 siblings, 8.33% had four siblings and 1.66% had 5 siblings.

Most of the mother 58.33% with ID children were belongs to poorer section, 36.66% had average income section and only 5% had good income section. Out of 60 sample of mother with ID children 98.33% were married and 1.66% were divorced however 85% had nuclear and 15% had joint family system.

Hamilton Anxiety Rating scale (HAM-A)[18] to assess the anxiety, The scale consists of 14 items, each defined by a series of symptoms, and measures both psychic anxiety (mental agitation and psychological distress) and somatic anxiety (physical complaints related to anxiety). The HAM-A is on 4-point likert type scale. Each item is scored on a scale of 0 (not present) to 4(severe), with a total score range of 0-56, where <17 indicates mild severity, 18-24 mild to moderate severity and 25-30 moderate to severe.

World Health Organization QOL-BREF (WHOQOL-BREF) for assessment of QOL.[19] The WHO Quality of Life Scale-Brief (WHOQOL-Brief), is a subset of 26 items taken from the WHOQOL-100. Which measures the physical health, psychological health, social relationships, and environment domains. The scale is 5-point likert type scale, scoring from 1 to 5 but 3 items that is item no 3, 4 and 26 are scored in reserved.

Multidimensional scale of Perceived social support (MSPSS) (20) scale was used to measure perceptions of support for 3 sources: family, friends and a significant other. This scale is 12 items with 4 items for each subscale. The scale is 7-point likert scale 1 as very strongly disagree and 7 as very strongly agree.

Statistical analysis

Data was coded and entered into a master chart. Data was analyzed with the help of SPSS 21. Frequency table, percentages, means and standard deviation (SD) and t-test were used.

Table 2: Summary results of t-test showing the difference between mothers of ID children and mothers of normal children on Perceived Social Support, Quality of life, Depression and anxiety (N=120).

Variables	Group	N	Mean	Std. Deviation	t- value	Cohen's d
Perceived Social Support	Mother of ID Children	60	15.78	3.82	8.57**	1.71
	Mother of normal children	60	21.98	3.38		
Quality of Life	Mother of ID Children	60	12.28	3.59	2.75**	0.55
	Mother of normal children	60	14.56	4.61		
Depression	Mother of ID children	60	30.98	2.81	3.03**	0.80
	Mother of normal children	60	27.22	4.67		

Anxiety	Mother of ID children	60	21.48	3.18	5.38**	1.07
	Mother of normal children	60	17.14	4.21		

** Significant at 0.01 significance level

Cohen's d value, ≤ 0.20 is a small effect size, 0.50 is a moderate effect size and ≥ 0.80 is a large effect size (Cohen, 1992)

The table 2 shows that there was a significant difference between mothers of ID children and mothers of normal children on perceived social support, quality of life, depression and anxiety at 0.01 level of significance with the cohen's d value ≥ 0.80 indicating large effect size, expect quality of life with cohen's d value 0.55 indicating moderate effect size. The mean of perceived social support and quality of life are higher in mother of normal children than mother of ID children, which means mother of normal children are having more perceived social support and quality of life than Mother of ID children. However the mean of depression and anxiety are higher in mother of ID children than mother of normal children, which indicates mother of ID children are having more depression and anxiety than mother of normal children.

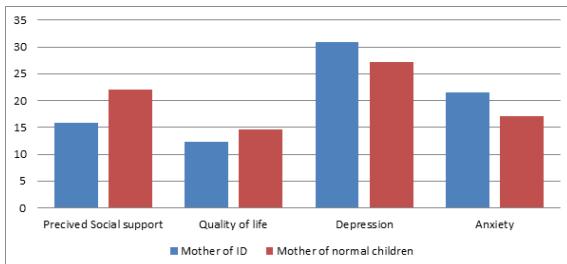


Figure 1: Graphical presentation of mean difference between mothers of ID children and mothers of normal children on Perceived Social Support, Quality of life, Depression and anxiety.

Discussion

The current research was designed to determine the psychological distress of mothers of intellectually disabled and non-disabled children. Research aimed to investigate how child intellectual disability affects mother's psychological wellbeing and makes them more prone to feel depression and anxiety. This comparative study aimed to investigate and compare the prevalence of anxiety and depression in a sample made up of two groups. Results of the current study show that mothers of children with intellectual disability have reported the higher level of anxiety and depressive symptoms. These results were reported by other researches which have explored anxiety and depression in parents of disabled and non-disabled children. Lakshmi, N., and Jabeen, Z. (21) found that parents of visually impaired children experienced more anxiety and depression than the parents of normal children. Depressive symptoms were more frequent in mothers of mentally challenged children than general population.

Similar findings were highlighted by Bumini et al.[22] they found that mild to moderate level of depression and higher anxiety in the mothers. Zigmond and Snaith [23] conducted a study which shows that parents caring for intellectually disabled children had much higher levels of depressive symptomatology than parents of typically developed children. In a study done in Turkey, Firat et al. (24) reported high rates of depression in mothers of children with autism (72.5%) and in mothers of children with mental retardation (44.7%).

In respect to QOL on physical, psychological, social relationship, and environment domains, the findings of the current study indicate significant difference between both groups. Our study found that mothers of children with ID had significantly decreased QOL as compared to the mothers with healthy children. [25,26] they conducted study on health-related QOL in parents of children with Down's syndrome using the WHOQOL-BREF and found that parents scored lower on environmental domain, which encompasses opportunities for recreation. Lin et al.[27] also examined the differences between caregivers of children and adolescents with ID than the general population, and their results show the mean these mean scores were lower than the general population.

Limitations and Suggestions

The present study bore some limitations:

1. It is a small scaled study related to just 60 mothers with ID children these findings thus cannot be generalized to all population.
2. Current research has been restricted to responses to questionnaires. It is recommended that in future qualitative methods of data collection may be employed to get the better understanding of the baseline factors affecting mother mental health.

REFERENCES

1. Luckasson R, Borthwick-Duffy S, Buntinx WHE, Coulter DL, Craig EM, Reeve A, et al. mental retardation: definition, classification, and systems of support. 10th ed. Washington, DC: American Association on Mental Retardation; 2002.
2. American Association on Intellectual and Developmental Disabilities. Overview of Intellectual Disability: Definition, Classifications and Systems of support. Washington: American Association on Intellectual and Developmental Disabilities; 2010.
3. Gupta A, Singh N. Positive perceptions of parents of children with disabilities. Asia Pac Disabil Rehabil J 2004;15:22-35.
4. Hassall R, Rose J, McDonald J. Parenting stress in mothers of children with an intellectual disability: The effects of parental cognitions in relation to child characteristics and family support. J Intellect Disabil Res 2005;49:405-18.
5. Kumari V. Parental involvement and expectations in promoting social and personal skills of mentally challenged children [dissertation]. Dharwad, India: Dharwad University; 2009.
6. Roach MA, Orsmond GI, Barratt MS. Mothers and fathers of children with Down syndrome: Parental stress and involvement in childcare. Am J Ment Retard 1999;104:422-36.
7. Guolaugsdottir S. The experience of mothers of children with autism: A hermeneutic phenomenological study [dissertation]. London, UK: The Royal College of Nursing Institute; 2002.
8. Manor-Binyamini I. Mothers of children with developmental disorders in the bedouin community in Israel: Family functioning, caregiver burden, and coping abilities. J Autism Dev Disord 2011;41:610-7.
9. Li-Tsang CW, Yau MK, Yuen HK. Success in parenting children with developmental disabilities: Some characteristics, attitudes, and adaptive coping skills. Br J Dev Disabil 2001;47:61-71.
10. Emerson E. Mothers of children and adolescents with intellectual disability: Social and economic situation, mental health status, and the self-assessed social and psychological impact of the child's difficulties. J Intellect Disabil Res 2003;47(Pt 4-5):385-99.
11. Marsh DT. Families and mental retardation: New directions in professional practice. New York: Greenwood Publishing Group; 1992.
12. Singhi PD, Goyal L, Pershad D, Singhi S, Walia BN. Psychosocial problems in families of disabled children. British Journal Med Psychol. 1990;63:173-82.
13. Hedov G, Annerén G, Wikblad K. Swedish parents of children with Down's syndrome. Scand J Caring Sci. 2002;16:424-30.
14. Brummell BH, Babiyak MA, Siegler IC, Vitaliano PP, Ballard EL, Gwyther LP, et al. Associations among perceptions of social support, negative affect, and quality of sleep in caregivers and noncaregivers. Health Psychol. 2006;25:220-5.
15. Gray DE, Holden WJ. Psycho-social well-being among parents of children with autism. Australia and New Zealand Journal of Developmental Disabilities. 1992;18:83-93.
16. American Psychiatric Association. (2013). Diagnostic and statistical manual of mental disorders(5th ed.). Arlington, VA: Author.
17. Hamilton M. A rating scale for depression. J Neuro Neurosurg Psychiatry 1960;23:56-62.
18. Hamilton M. The assessment of anxiety states by rating. Br J Med Psychol 1959; 32:50-55.
19. World Health Organization. Division of Mental Health. WHOQOLBREF – introduction, administration, scoring and generic version of the assessment: field trial version, December 1996. Geneva: WHO; 1996.
20. Zimet GD, Dahlem NW, Zimet SG, Farley GK. The multidimensional scale of perceived social support. Journal of Personality Assessment 1988;52:30-41.
21. Lakshmi, N., and Jabeen, Z. A study on parental anxiety among visually impaired and normal children. Indian Streams Research Journal, 2012; 113: 193 – 196.
22. Bumini G, Gunal A, Tukel S. Anxiety, depression and quality of life in mother of disability children. Sdu Tip Fak Derg. 2008;15:6-11.
23. Zigmond AS, Snaith RP. The hospital anxiety and depression scale. Acta Psychiatr Scand. 1983;67:361-70.
24. Firat S., Diler, R., Avci, A., & Seydaoglu, G. (2002). Comparison of psychopathology in the mothers of autistic and mentally retarded children. Journal of Korean Medical Science, 17, 679-685.
25. Barnett WS, Boyce GC. Effects of children with Down syndrome on parents' activities. Am J Ment Retard. 1995;100:115-27.
26. Oliveira Ede F, Limongi SC. Quality of life of parents/caregivers of children and adolescents with Down syndrome. J Soc Bras Fonacaudiol. 2011;23:321-7.
27. Lin JD, Hu J, Yen CF, Hsu SW, Lin LP, Loh CH, et al. Quality of life in caregivers of children and adolescents with intellectual disabilities: use of WHOQOL-BREF survey. Res Dev Disabil. 2009;30:1448-58.