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Original research article

A comparative study of mental health in caregivers of mental retardation and autism children

[1]Manoj Kumar P, [2]Dasika Sree Keerthi, [3]Asha Mounika Datla

[1,2]Associate Professor, Department of Psychiatry, Ayaan Institute of Medical Sciences, Moinabad, Telangana, India

[3]Assistant Professor, Department of Psychiatry, Government Medical College, Jagtial, Telangana, India

Corresponding Author: Manoj Kumar P

Abstract

Autism and Intellectual disability have significant impact on family members. Both are associated with poor communication, academic and social skills that make the child more dependent on the caregiver than the normal child.so we aimed at assessing mental health of caregivers of Mental Retardation and Autism children using GHQ-28. Our study showed that Mental health of these caregivers has significantly affected (p<0.05). Mental health of Caregivers of MR is more affected than that of Autism. Among the individual domains somatic symptoms, anxiety domain, social dysfunction and severe depression domain all are higher in MR care givers than AD group. Mothers of all the children showed features of Anxiety and Depression. And anxiety more than depression. Further mothers need more help than fathers. Skills training to the caregivers can help them to deal effectively with the children with such disabled children.

Keywords: Mental retardation (MR), autism, GHQ, caregiver

Introduction

The lived experience of parents with children diagnosed with autism spectrum disorder is an important area of study, as quantitative research has indicated higher rates of mental disorders in this population compared to parents of typically developing children (Corcoran *et al*., 2015). Parents of children with autism face a unique set of challenges, including difficulties obtaining an ASD diagnosis, resistance to the diagnosis, and a lack of accessible services relative to their needs. (Nicholas *et al*., 2020)

The arrival of a child with disabilities can be a profoundly distressing and devastating experience for a family (Children Born with Disabilities: How Families Respond, 2023). The realization that the expected healthy child they had anticipated for months never materialized can lead to feelings of grief and loss. Similarly, parents of children with chronic health issues are at risk of emotional strain and difficulty adjusting to the demands of caring for a child with special needs (Vitulano, 2003). There is substantial evidence that family members grapple with a range of emotions when faced with the diagnosis of such disabilities, including mental retardation and autism.

Mental Retardation: Mental retardation is a condition of arrested or incomplete development of the mind, characterized by impairment of skills manifested during the developmental period, which contribute to the overall level of intelligence. Mental retardation is divided into four degrees of severity; mild (50-70 IQ), moderate (35-49), severe (20-34) and profound [less than 20] (King *et al*., n.d). Research has found that the degree of disability affects the family's level of stress and adaptation (Gath, 2005) (Soedjatmiko *et al*., 2016).

Autism: A pervasive developmental disorder defined by the presence of abnormal and/or impaired development that manifest before the age of 3 years, and by the characteristic type of abnormal functioning in all three areas of social interaction, communication, and restricted, repetitive behavior (Carr & LeBlanc, 2007).

Autism and Intellectual disability have significant impact on family members. Both are associated with poor communication, academic and social skills that make the child more dependent on the caregiver than the normal child.

Providing care for a dependent individual can be a highly stressful endeavor, potentially posing risks to the caregiver's psychological well-being. A **Caregiver** is an individual, paid or unpaid, who assists another person with impairments in their activities of daily living (Zarit *et al*., 2016). Research indicates that caregivers often experience depression, utilize maladaptive coping strategies, and express concerns

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about their diminished quality of life (Schulz & Sherwood, 2008). Evaluating the health status of primary caregivers is crucial for developing interventions aimed at the rehabilitation of children with disabilities.
Mental health is a state of well-being in which an individual realizes his or her own abilities, can cope with the normal stresses of life, can work productively and is able to make a contribution to his or her community (Developmental Disabilities-Disease and Mortality in Sub-Saharan Africa, 2023). Mental health problems encompass a wide range of disorders that affect mood, thinking and behavior.
In this positive sense, mental health is the foundation for individual well-being and the effective functioning of a community Priority should be given to prevention and promotion in the field of mental health (Herrman & Moodie, n.d). Literature indicates that the level of communication ability, specific cognitive or sensory impairments, sex, and age of the patient may be relevant to the mental health of the caregiver (Peng *et al*., 2020).
In this positive context, mental health serves as the foundation for individual well-being and the effective functioning of a community. Accordingly, priority should be given to prevention and promotion strategies within the realm of mental health. (Schulz & Sherwood, 2008) The existing literature suggests that factors such as the level of communication ability, specific cognitive or sensory impairments, sex, and age of the patient may be relevant to the mental health of the caregiver.

Aims and Objectives
Aim
To compare mental health in care givers of children with mental retardation and autism.

Patients and Methods
Study Design: This is a cross-sectional study to measure the mental health in caregivers of children with mental retardation and autism.

Area of Study: Care givers of children presenting to outpatient department.

Sample Size: Care givers of 40 children diagnosed to have mental retardation, 40 children diagnosed to have autism.

Inclusion Criteria
For Caregivers
1. Caregivers of children diagnosed to have mental retardation and autism.
2. Males and females aged between 18 and 60 yrs.
3. Those who have given informed consent.

For children
1. Diagnosed to have mental retardation or autism according to ICD-10 criteria.
2. Males and females aged between 3 and 17 years of age.

Exclusion Criteria
For Caregivers
1. Those with organic psychosis or mental retardation
2. Those who have previously diagnosed to have any other mental illness
3. Those who did not give consent
4. Those who are aged less than 18 yrs. and more than 60 yrs.

For Children
1. Those who have been aged less than 3yrs and more than 17 yrs.
2. Children with hearing impairment, visual impairment, motor impairment, speech impairment.
3. Children with epilepsy and any other significant medical illness.

Null Hypothesis
1. No significant psychopathology detected in caregivers of mental retardation and autism children.

Procedure
Caregivers of children attending the outpatient department and diagnosed with mental retardation or autism, who meet the inclusion and exclusion criteria, were enrolled in the study. After obtaining informed consent, sociodemographic details were collected using an intake proforma, and the GHQ-28 was administered to the caregivers.

Statistical Analysis
- Descriptive statistics depicting numbers-frequency averages-mean median and dispersion-standard

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deviation, standard error, quartiles.
- Graphical displays include bar diagrams, histograms, scatter plot, pie diagrams.
- Tests of comparison for discrete variables-chi square test.
- Tests of comparison for continuous variables-independent student's t-test and ANOVA.
- Tests of association include Pearson's product moment correlation test and Spearman's rank correlation test.

Tools

Administered in the study:

1. Semi structured proforma.
2. **GHQ 28:** The GHQ-28 was developed by Goldberg in 1978.Developed as a screening tool to detect those likely to have or to be at risk of developing psychiatric disorders, the GHQ-28 is a 28-item measure of emotional distress in medical settings. Through factor analysis, the GHQ-28 has been divided into four subscales. These are: somatic symptoms (items 1-7); anxiety/insomnia (items 8-14); social dysfunction (items 15-21), and severe depression (items 22-28) (Goldberg *et al*. 1979).
3. **Informed consent**

Results

A total of 80 caregivers were interviewed. Out of which 40 were of children with mental retardation and 40 were of children with autism.

Sociodemographic profile of the sample

A total of 80 caregivers, 40 Grp A (of mental retardation children) and 40 Grp B(of Autism children) were interviewed.

	MR (N=40) Grp A	**Autism (N=40)** Grp B
Caregiver		
Age (Mean ± SD)	37.43±11.043	37.45±6.389
Gender (male)	47.5%	30%
Gender (female)	52.5%	70%
Marital status		
Married	87.5%	92.5%
Widowed	10%	2.5%
Divorced	2.5%	5%
Children		
Age (Mean ± SD)	7.98±2.597	9.15±2.445
Gender (male)	62.5%	65%
Gender (female)	37.5%	35%
Severity of illness		
Mild	32.5%	45%
Moderate	37.5%	45%
Severe	27.5%	0
Profound	2.5%	10%

Sociodemographic profile of the MR grp

The mean age of the caregivers in the mental retardation group was 37.43 ± 11.043 years. Among them, 47.5% were male and 52.5% were female. The majority of the caregivers, 87.5%, were married, while 10% were widowed, and 2.5% were divorced. The mean age of the children in this group was 7.98 ± 2.597 years, with 62.5% being male and 37.5% female. In terms of the severity of mental retardation, 32.5% were mildly affected, 37.5% were moderately affected, 27.5% were severely affected, and 2.5% were profoundly affected.

Sociodemographic profile of the Autism grp

The mean age of caregivers was 37.45 ± 6.389 years. Among them, 30% were male and 70% were female. The marital status of the caregivers was as follows: 92.5% married, 2.5% widowed, and 5% divorced. The mean age of the children was 9.15 ± 2.445 years. Of the children, 65% were male and 37.5% were female. The severity of illness among the children was as follows: 45% mild, 45% moderate, 0% severe, and 10% profound.

GHQ Score: The means of total GHQ score for caregivers of children with MR was 31.90 ± 6.364 and of autism was 27.73 ± 5.675.(TABLE 2) Means for individual domains of GHQ were compared among the 3 groups shown in TABLE 3. For the MR group the individual mean in somatic symptoms was 10.10 ± 1.614, anxiety/insomnia was 6.15 ± 1.777, social dysfunction was 9.17 ± 1.583 and severe depression was 6.48 ± 1.587. For the autism group mean in somatic symptoms was 9.25 ± 1.354, anxiety/insomnia

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was 5.20 ± 1.588, social dysfunction was 8.23 ± 1.330 and severe depression was 5.05 ± 1.552.

Table 2: Total GHQ Score

Diagnosis	Mean	Std. Deviation	% of Total N
Normal	10.05	3.651	33.3%
MR	31.90	6.364	33.3%
AUTISM	27.73	5.675	33.3%
Total	23.22	10.892	100.0%

Table 3: Diagnosis *Domains of GHQ

Diagnosis		Somatic Symptoms	Anxiety/Insomnia	Social Dysfunction	Severe Depression
MR	Mean	10.10	6.15	9.17	6.48
	Std. Deviation	1.614	1.777	1.583	1.585
	% of Total N	33.3%	33.3%	33.3%	33.3%
AUTISM	Mean	9.25	5.20	8.23	5.05
	Std. Deviation	1.354	1.588	1.330	1.552
	% of Total N	33.3%	33.3%	33.3%	33.3%
Total	Mean	7.38	4.60	6.78	4.47
	Std. Deviation	3.588	2.136	3.058	2.387
	% of Total N	100.0%	100.0%	100.0%	100.0%

The ANOVA for the above means found significant variance between the groups for somatic symptoms [F (2,117) = 289.630, p (0.000)], anxiety/insomnia [F (2, 117) = 69.850, p (0.000)], social dysfunction [F (= 258.280), p (0.000)] and severe depression [F (=110.786), p (0.000)] (TABLE 4)
Correlation between gender of caregiver and total GHQ score was done. In mothers total GHQ score was found to be on higher score. (TABLE 5)

Table 4: ANOVA Domains of GHQ Table

			Sum of Squares	df	Mean Square	F	Sig.
Somatic Symptoms * Diagnosis	Between Groups	(Combined)	1274.867	2	637.433	289.630	.000
	Within Groups		257.500	117	2.201		
	Total		1532.367	119			
Anxiety/Insomnia * Diagnosis	Between Groups	(Combined)	295.400	2	147.700	69.850	.000
	Within Groups		247.400	117	2.115		
	Total		542.800	119			
Social Dysfunction * Diagnosis	Between Groups	(Combined)	907.400	2	453.700	258.280	.000
	Within Groups		205.525	117	1.757		
	Total		1112.925	119			
Severe Depression * Diagnosis	Between Groups	(Combined)	443.617	2	221.808	110.786	.000
	Within Groups		234.250	117	2.002		
	Total		677.867	119			

Table 5: Correlations Gender of caregiver * Total GHQ Score

			Gender of Caregiver	Total GHQ Score
Spearman's rho	Gender of Caregiver	Correlation Coefficient	1.000	-.182*
		Sig. (2-tailed)	.	.046
		N	120	120
	Total GHQ Score	Correlation Coefficient	-.182*	1.000
		Sig. (2-tailed)	.046	.
		N	120	120

Discussion

In our study, the mean age of caregivers was 37.45±6.389 (Autism grp), 37.43±11.043 (MR grp). Among them, percentage of females was more than males in both groups. Caregivers are mostly married in both groups. The mean age of children was 7.98±2.597 (MR grp), 37.45±6.389 (Autism grp).

The study found that caregivers of children with mental retardation had higher total GHQ scores (31.90 ± 6.364) compared to caregivers of children with autism (27.73 ± 5.675), indicating a greater impact on their mental health. This contrasts with a study in Qatar, which reported higher psychiatric morbidity among mothers of children with autism spectrum disorder (41.2%) compared to mothers of children with Down syndrome (31%).

For the MR group, the individual mean scores on the GHQ subscales were: somatic symptoms (10.10 ± 1.614), anxiety/insomnia (6.15 ± 1.777), social dysfunction (9.17 ± 1.583), and severe depression (6.48 ± 1.587). In the autism group, the mean scores were: somatic symptoms (9.25 ± 1.354), anxiety/insomnia (5.20 ± 1.588), social dysfunction (8.23 ± 1.330), and severe depression (5.05 ± 1.552), indicating that

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the impact on mental health in all domains was greater for the MR group.

In contrast, a previous study found that mothers of children with autism experienced higher levels of somatic symptoms, anxiety/insomnia, and social dysfunction compared to mothers of children with Down syndrome and intellectual disability (Ansari *et al*., 2018). Another study reported that 52% of mothers of children with developmental disabilities experienced psychological problems, with mothers of children with intellectual disability exhibiting the highest prevalence. (O'Keeffe & O'Hara, 2008)

The ANOVA analysis showed significant differences between the groups for the four GHQ subscales: somatic symptoms, anxiety/insomnia, social dysfunction, and severe depression.

Caregivers of children with mental retardation displayed poorer mental health compared to caregivers of children with autism. Mothers in both groups showed higher levels of depression than fathers. Mothers of children with MR had lower physical health, more impairment in social relationships, poorer psychological state, and worse perception of their environment. The severity and duration of the child's illness positively correlated with the caregiver's mental health outcomes, indicating that more severe and longer-lasting conditions led to worse mental health.

Marital status did not significantly impact the number of mothers with elevated depression scores in the autism group, but single mothers in both groups had more highly elevated depression scores than mothers living with partners. (Nagarkar *et al*., 2014). In the MR group, married caregivers had a significantly higher risk of depression, likely due to the stigma associated with intellectual disability in the African culture.

The type of family living arrangement, whether nuclear or joint, was significantly correlated with mental health scores. Nuclear families, likely due to urbanization in India, had an effect on coping that impacted parents' mental health. Joint families with elderly support were associated with better mental health.

Socioeconomic status was not correlated with mental health scores in the expected way, potentially due to bias in self-reporting of income, a key factor in the Kuppuswamy scale used to assess socioeconomic status. Future studies should use a scale less reliant on income alone.

Limitations

The study was cross-sectional that did not include the impact of child's severity and optimism on parental quality-of-life overtime. Future study may employ longitudinal design to test and confirm existing causal pathways within the period of time. The sample size was relatively small and the study was carried out in a single setting.

Implications

The caregivers of persons with MR and autism should also be consulted and considered while planning and providing various intervention services for them. Further mothers need more help than fathers. Skills training to the caregivers can help them to deal effectively with the children with such disabled children.

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