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**Research Article**

# A Cross Sectional Study of Caregiver Burden and Psychiatric Morbidity in Primary Caregivers of Mentally Retarded Subjects

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**Abstract:** Caregivers experience a multidimensional range of problems, often associated with their care giving role. It is important to identify these areas of burden and provide necessary support. This cross sectional study was taken up to determine the prevalence of psychiatric morbidity and burden among primary care givers of mentally retarded (MR) subjects. Sixty diagnosed MR subjects and their primary care givers who met inclusion criteria were recruited in to the study. Primary care givers were assessed on Zarit Burden scale, GHQ-12, MINI, and Modified Kuppuswamy scale. Sociodemographic details were entered on intake proforma. Mental retardation was diagnosed as per ICD-10, IQ assessment was done as per Bhatia battery. Majority of primary care givers were mothers and expressed mild burden. The prevalence of psychiatric morbidity as per MINI was 28.6% (25% Depression, 2.4% Alcohol abuse and 1.2% GAD). As burden increased psychiatric morbidity also increased but the association was not significant (p value= 0.097557). 50% reported physical illness. There was statistically significant association between physical illness and burden (p value =0.00001). There was a negative correlation between care giver burden and IQ (p value=0.000169). There was a weak positive correlation between GHQ and burden (p value=0.752313). Medical services offered to mentally retarded should therefore move from individual to family level. Government should look in to need for starting interventions directed towards caregivers.
**Keywords:** Care giver burden, Mental retardation, ZBI.

## INTRODUCTION

Mental retardation (MR) is defined as a disability characterized remarkably by low intellectual functioning, IQ<70 in conjunction with significant limitations in adaptive functioning [1]. Worldwide prevalence of MR has been reported to be as high as 2.3% [2] and in India it has been reported to be around 2% for mild MR and 0.5% severe MR [3]. In national sample survey of 2004, 94 people per 1,00,000 were reported to be mentally retarded [4]. Care giver burden is defined as a multidimensional response to physical, psychological, emotional, social and financial stressors usually associated with the experiences of caring [5]. Burden of care has two components: subjective and objective burden [6]. Objective burden includes measurable effects such as economic burden, care givers loss of work, social and leisure activities, house hold disruptions such as child care, restrictions on relationships within and outside the family etc. Subjective burden includes mainly the psychological sufferings of the caregivers themselves such as depression, hatred, uncertainty, guilt, shame and embarrassment etc [7].

Parents experience enormous physical and emotional burden while caring for a child with disability [8]. Primary care giver who is closest to person with MR bears the brunt of their disability. As the child grows up and disability becomes quite noticeable, parents face embarrassing situations enhancing stigma. Poor performances of the MR persons with disability are needed to be compensated by caregivers. It leads to unavoidable stress and psychological trauma among the caregivers. Caregiver burden impoverishes the physical, psychological, emotional and functional health of the care givers [9]. Care giving burden often reflects caregiver's perceived level of distress, demands and the pressure associated with care giving responsibilities, roles and tasks [10]. Caregivers reported social strain, ill health and disrupted family life [11].

Researchers have revealed that psychiatric morbidities such as depression and anxiety are common among mothers of MR children. Different studies on parents of children with disabilities have suggested that

35-53% mothers of children with disabilities have symptoms of depression [12-16]. Caregivers experience depression, burden, less social support and less coping than non caregivers [17].

A study conducted comparing African American parents of disabled children and African American peers with non disabled children found that care givers with disabled children reported more health conditions like arthritis and diabetes than non care givers [18].

Care giving was found to be associated with experiencing subjective gains and satisfaction [19]. Researchers have concluded that as MR subjects symptoms improved, associated care giver stress also reduced [20]. This is relevant because negative consequences of burden on care givers may harm their care giving effectiveness whereas experiencing subjective gains and satisfaction may enhance their care giving ability.

This study was taken up because we have observed problems in taking care of such children by their families as they routinely come into our contact when they visit our Psychiatric OPD for certificate (disability) and treatment of co morbidities like epilepsy, MR with behavioral problems and psychosis.

**Aims and Objectives**

- To study the burden experienced by primary care givers of MR subjects.
- To study the prevalence and nature of psychiatric morbidity experienced by primary care givers.
- To study the association between burden and psychiatric morbidity.
- To study the prevalence of physical illness in primary care givers of MR subjects and its association with burden.

## MATERIALS AND METHODS

**Type of study:** A cross sectional study.

**Type of sample:** Sample was collected from Institute Of Mental Health, Hyderabad, Telangana State.

**Study period:** The study was conducted from 22nd January to 22nd March 2015.

**Inclusion criteria**

For care givers:

- Age between 15-45yrs.
- Who gave consent and cooperative.
- Living with MR subjects for more than one year.
- Do not have serious medical illness
- Do not have previously diagnosed psychiatric disorder.

For MR subjects:

- Mild, moderate and severe MR.
- Do not have psychosis, behavioral problems requiring admission.

**Exclusion criteria**

For care givers:

- Who did not give consent.
- Substance dependence.
- Single, divorced, and separated parent.

For MR subjects:

- With psychosis requiring admission in to hospital.
- Profound MR.

## METHODOLOGY

As per ICD-10 [21] Sixty MR subjects and their primary care givers who met inclusion criteria were included in to the study. Informed consent was obtained from all primary care givers before conducting study. Objective data regarding demographic details of primary care givers were entered on intake proforma. They were assessed on Zarit Burden interview for burden [22] GHQ [23], was given to all primary caregivers. Those who scored more than two on GHQ were given MINI [24] to document psychiatric morbidity. Modified Kuppuswamy scale [25] was used to assess socioeconomic status. For assessing medical morbidities in care givers qualitative information like prescriptions, test reports as well as their own explanations were taken in to account. IQ assessment of MR subjects was done using Bhatia battery [26] by clinical psychologist. Prior permission was obtained from authorities of hospital before conducting study.

Institute of mental health (IMH) is a 600 bedded tertiary care hospital situated in Hyderabad city of Telangana State; its beneficiaries are from neighboring states like Andhra Pradesh, Karnataka and Maharashtra. Mentally retarded patients are brought here for treatment of co morbidities like epilepsy, psychosis, behavioral problems and for certification purposes. The purpose of certificate is to get railway concession and pension for mentally retarded. SADAREM (Software for Assessment of Disabled for Access Rehabilitation and Empowerment) camps are held periodically in IMH for issue of disability certificate to MR subjects for getting social welfare benefits like pension. These camps are organized by Social welfare department, government of Telangana. Caregivers of MR subjects attending camps and OPD for treatment who met inclusion criteria were included in the study.

Rating scales used in the study:

**ICD-10 [21]:** International classification of diseases 10th edition was used to diagnose mental retardation.

**Zarit Burden Interview (ZBI) [22]:** ZBI developed by Steven H Zarit is a self administered questionnaire to

assess the level of burden experienced by the principal caregivers of older persons with dementia and disabled persons. It has got 22 items with a five item response set ranging from "never", " nearly always", scores ranging from 0-88.0-20 - no to mild burden, 21-40-mild to moderate, >40-severe burden. The ZBI includes factors most frequently described by caregivers as problematic, such as their physical and psychological health, finances, social life and the relationship with the patient.

**GHQ-12 [23]:** General health questionnaire used in this study is a 12-item version was used to screen for psychiatric morbidity in the caregivers. Each item is accompanied by four responses typically "not at all", "no more than usual", "rather more than usual" and "much more than usual."Scores are assigned using a binary method 0, 1, 2.

**MINI [24]:** MINI international neuropsychiatry interview is a structured diagnostic interview developed by Sheehan for diagnosing psychiatric disorders as per DSM-IV and ICD-10 diagnostic criteria.

**Modified kuppuswamy scale [25]:** is the most widely used scale for assessing socioeconomic status. It classifies the study population in to high, middle, low socioeconomic status.

**Bhatia battery [26]:** It has five subtests (1) Kohs block design test, (2) Alexander pass along test, (3) Pattern drawing test, (4) immediate memory test and (5) picture construction test. It provides two scores-performance quotient, verbal quotient averaged together we get IQ of child.

**Statistical analysis:**

Data has been analyzed using SPSS version 17 of windows. Intra group data are described as means and percentages. ZBI were represented using pie charts. Pearson's correlation test was used to test correlation between variables. Chi square tests are used to test significance. Statistical significance was set at 0.05.

## RESULTS AND DISCUSSION

**Burden in primary care givers**

In our study 83.3% of primary care givers were females, among them mothers accounted for 96%, 1% aunts, and 3% grandmothers. This highlights the challenges faced by mothers. All primary care givers expressed burden (100%) as per ZBI. 51.46% of primary care givers expressed mild burden, 29.88% moderate burden, and 18.26% severe burden. This findings are in accordance with studies by Indian authors like Kuldeep Singh [27], Sethi [28] and Upadhyaya [29] who reported that parents of children with MR particularly mothers (primary caregivers) experience high level of burden. The possible reasons for this could be (a) Mothers spend more time with children while caring for them. (b) Most mothers were homemakers, lost employment by compulsion for taking care of MR subjects. (c) They were restricted to home and did not have time for themselves.

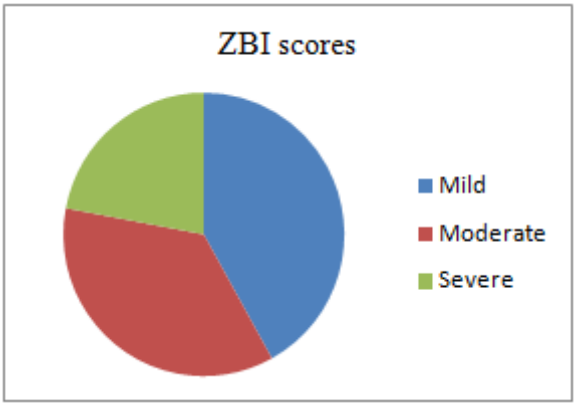


**Fig. 1: Pie chart showing burden scores of primary care givers of MR subjects**

Mild burden-31(51.46%); Moderate-18(29.88%); Severe-11(18.26%)

**Psychiatric morbidity in primary care givers**

The prevalence of psychiatric morbidity as per MINI among primary care givers of MR subjects in our study was found to be 28.6%. Of these 25% were found to have depression, 2.4%alcoholabuse, 1.2% GAD. The prevalence seems to be slightly less than study by Emerson [12], which reported 35%. Indian study by Nagarkar [30] estimated depression in mothers of MR children as 85%. High prevalence in Nagarkar' study may because they included those who already have been diagnosed with psychiatric illness, whereas our study excluded caregivers who have diagnosed mental illness. That's why our study reported lesser prevalence. The prevalence of psychiatric morbidities were slightly higher in Swedish [13], Turkish [14], Asian British [15], British [12] and Quatar [16] study ranging from 35-53%. The difference may be due to (a) Different rating scales and their psychometric properties, (b) Differences in the age group of MR subjects (c) Setting of the study (d) Geographical variables like culture, financial status and (e) Health care delivery. Whatever said and done psychiatric morbidity is a matter of concern and needs to be addressed.

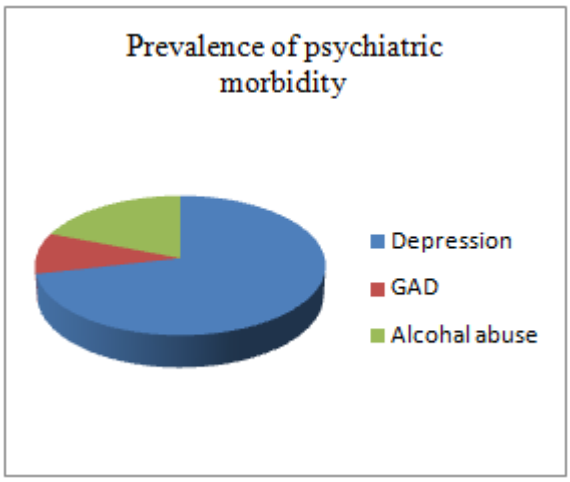


**Fig. 2: Pie chart showing prevalence of psychiatric morbidity in primary care givers of MR subjects**

Depression-15 (71.40%); Alcohol abuse-4 (19.08%); GAD (Generalized anxiety disorder)-2 (19.08%)

**Association between primary caregiver burden and psychiatric morbidity**

76.69% of primary caregivers who expressed mild burden did not have psychiatric morbidity, 23.31%of caregivers with mild burden had psychiatric morbidity. Similarly 58.4% with severe burden had psychiatric morbidity, 41.6% did not have psychiatric morbidity. But the association between caregiver burden and psychiatric morbidity was not significant.(p value=0.097557) (Table 1)

**Table 1: Showing association between caregiver burden and psychiatric morbidity**

| Primary care giver burden | With psychiatric morbidity(n=21) | Without psychiatric morbidity(n=39) | Chisquare value | p value |
|---|---|---|---|---|
| Mild(n=31) | 7(23.31%) | 24(76.69%) | 4.6546 | 0.097557 |
| Moderate(n=18) | 8(44.4%) | 10(55.55%) | | (NS) |
| Severe(n=11) | 6(58.4%) | 5(41.61%) | | |
| Total | 21 | 39 | | |

There were more caregivers with psychiatric morbidity in severe burden group and more without psychiatric morbidity in mild burden group. The reason for this could be caregivers with mild burden did not have psychiatric morbidity or may be those with psychiatric morbidity might have perceived severe burden because of their cognitive distortions which are typical of depression. There might be a bidirectional relationship in that, care givers with psychiatric morbidity might find caring for a MR person burdensome, while the burden of caring for a MR person could also precipitate psychiatric illness.

**Prevalence of physical morbidity**

50% of primary care givers reported physical problems, of which 30% reported arthritis, 26.74% reported hypertension, 23.26% reported thyroid problem, and 20% reported diabetes. This is in line with U.S studies [31] in which researchers found various associated medical conditions like hypertension, diabetes, and thyroid problems in mothers of children with intellectual disability. The reason may be mothers of children with intellectual disability may be spending more time in care giving and may not have time to exercise and take care of their health. This leads to obesity. They also experience increased levels of stress. Obesity and increased levels of stress triggers physical illness in those who are predisposed. In a latest retrospective cohort study in Australia [32], researchers found that mothers of children with intellectual disability had more than twice risk of death, due to cancer, cardiovascular diseases and misadventures like homicide and suicide. These increased hazards may be related to increased stress of rearing child with disabilities.

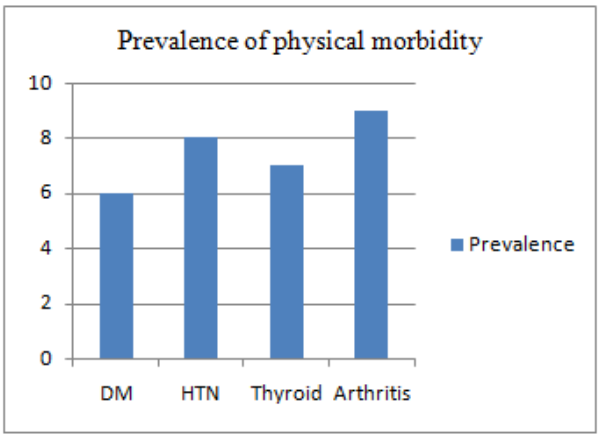


**Fig. 3: Graph showing prevalence of physical morbidity among primary care givers of mentally retarded subjects**

DM (Diabetes mellitus)-6 (20%); HTN (Hypertension) -8 (26.74%); Thyroid problem-7 (23.26%) and Arthritis-9 (30%)

**Association between primary care giver burden and physical illness**

In mild burden group 80.625% reported no physical illness, 91.97% of care givers with severe burden had physical problems. The association between burden and physical problems is statistically significant

(p value= 0.00001). (Table 2) As burden increased physical problem also increased and vice versa. Burden is taking toll on physical and mental health of care givers.

**Table 2: Showing association between burden and physical morbidity**

| Burden | With physical morbidity(n=30) | Without physical morbidity(n=30) | Chi square value | p value |
|---|---|---|---|---|
| Mild(n=31) | 6(19.375%) | 25(80.625%) | 24.5644 | 0.00001* |
| Moderate(n=18) | 14(77.7%) | 4(22.2%) | | (SIG) |
| Severe(n=11) | 10(91.91%) | 1(9.09%) | | |
| Total | 30 | 30 | | |

**Correlation between primary care giver burden and severity of MR**

Current study found negative correlation between burden (ZBI scores) and IQ. As IQ increased burden decreases. (r value=0.467) That means caregiver burden increases with increase in severity of MR. Correlation was statistically significant with (p value=0.000169). This is in line with study by Sethi [28], which says that caregiver burden increases with increase in severity of MR.

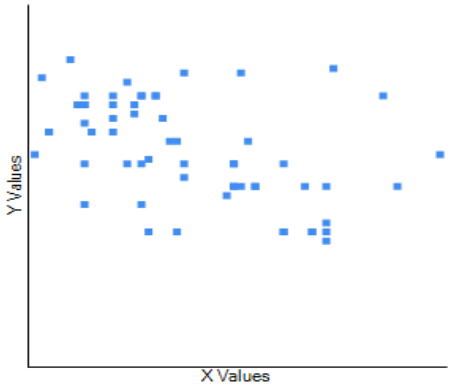


**Fig. 4: Graph showing correlation between burden and IQ**

**Correlation between primary care giver burden and GHQ**

Our study also found weakly positive correlation between Zarit burden scores and GHQ (r value=0.0416), however the association was not significant (p value=0.752313).

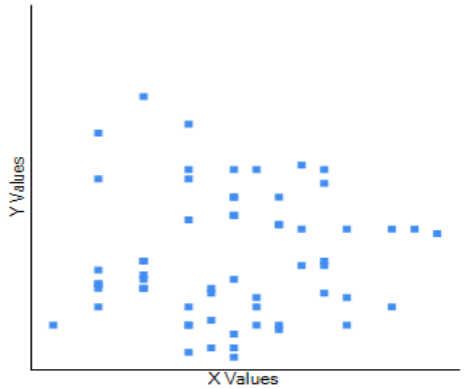


**Fig. 5: Graph showing correlation between burden and GHQ**

**Severity of MR in MR subjects**

Current study found 46.66% subjects with mild MR, 33.33% had moderate MR, 20% had severe MR. This is in line with study by Nagarkar [30] study, which reported 58% mild, 30% moderate and 18% severe.

**CONCLUSION**

- Majority of MR subjects had mothers as primary caregivers (98%). Most of them reported mild burden (51.46%) followed by moderate (27.88%) and severe (18.26%).
- The percentage of psychiatric morbidity was found to be 28.6% of which 25% were found to have depression, 2.4% alcohol abuse, and 1.2% GAD.
- As burden increased, psychiatric morbidity also increased, but the association was not significant (p value=0.097557)
- 50% reported physical illness. There was statistically significant association between physical illness and burden. (p value=0.00001)
- Statistically significant association between caregiver burden and IQ indicating that as burden increases with increase in severity of MR (p value=0.000169).This implies that MR person with more impairment is likely to require more assistance from the caregiver in terms of activities of daily living and as such may impose greater burden on care giver. These care givers require more support in order to lessen the burden of care giving. This will prevent development of psychiatric morbidity in care giver. Child health services need to make arrangements for attending caregivers who develop mental health problems in the process of care giving. In a resource poor setting like India this challenge can be enormous.
- Our study found weakly positive correlation between burden and GHQ. (p value= 0.752313)

**Drawbacks of the study**

- Size of sample is small.
- (Social support was not assessed which might have influenced the results.

**Recommendations for future research**

Medical services offered to the mentally retarded persons should move from individual level to

family level especially towards mothers who are primary care givers.

There is dire need for interventions from government to look in to care giver burden and should start family based schemes and programs for MR children. A number of welfare programs have been started for mentally retarded individuals but primary care givers have been ignored. Interventions should be directed towards caregivers. This will go a long way in welfare of MR individuals.

The ongoing development and evaluation of appropriate interventions for caregivers of mentally retarded persons remain important challenge to mental health professionals.

Special schooling needs to be encouraged for MR persons as most of them were deprived of schooling.

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