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A Cross-Sectional and Comparative Study of Caregiver Burden of Primary Caregivers of Mentally Retarded Subjects Attending Tertiary Care Hospital (IMH) and Rehabilitation Centre (SWEEKAR)

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Abstract:

There are multiple problems of having a mentally retarded child in the family. Having a mentally retarded child poses a significant risk to physical and emotional well being of parents. This study was undertaken to assess the caregiver burden of primary caregivers of mentally retarded (MR) subjects who are attending mental hospital and compared with primary caregivers of MR subjects attending rehabilitation centre. Method: It is a cross-sectional and comparative study where primary caregivers 30 each in both groups were selected by random sampling and assessed on Zarit burden scale (ZBI). Modified kuppup swamy scale was used to assess socioeconomic status. Diagnosis of MR was done on basis of ICD-10 diagnostic criteria and Intelligent Quotient (IQ) assessment was done on Bhatia battery. Results: A total of 60 caregivers (30 each in IMH and Sweekar) were studied. The mean ZBI scores were 37.03 with SD 5.99 for IMH and 23.33 with SD 5.52 for Sweekar group. The caregivers of IMH were matched with sweekar for age, gender and religion. The caregiver burden was associated with severity of MR in IMH (p value 0.046012) and sweekar group (p value 0.0458), the caregiver burden was also associated with duration of care giving in IMH group (p value 0.03726). Burden was inversely proportional to education of caregivers in sweekar group (p value 0.033599). Conclusion: Mean ZBI scores were more in IMH group than sweekar group. Factors associated with caregiver burden are severity of MR, duration of care giving and education of caregiver. Recommendations: Counseling for caregivers given at different stages of development, with emphasis on regular follow-ups is being recommended for effective management of MR.

Keywords: Caregiver burden, mental retardation, primary caregiver and Zarit burden scale.

1. Introduction

Mental retardation is a highly disabling condition. According to American association of mental deficiency- Mental retardation (MR) can be defined as significantly sub average general intellectual functioning resulting or association with concurrent impairment in adaptive behavior and is manifested during developmental period.⁽¹⁾ The prevalence of MR in India varies from 0.22%-3.7%.⁽²⁾ There is much evidence that family members experience a wide range of emotions in response to a diagnosis of MR including denial, shock, anger, grief, guilt, embarrassment, depression, withdrawal, ambivalence and fear of stigma.⁽³⁾ Burden can be defined as the presence of problems, difficulties or adverse effects caused by a child with mental retardation, which are likely to affect the family functioning.⁽⁴⁾ Primary caregiver refers to a person who spends most of time in care-giving contact with ill member. Caregiver may be the patient's close relative, parents or sibling who is an adult staying with the patient and takes prime responsibility of care.⁽⁵⁾

There are multiple problems of having a mentally retarded child in the family such as additional financial burdens for treating child's condition dealing with child's problematic behavior and social stigma associated with disabilities.⁽⁶⁾ Parents of children with MR often experience more physical symptoms, negative affect and poorer psychological wellbeing than parents of normal children without disabilities.⁽⁷⁾ A recent study found 12% of GAD and 50.5% of MDD among caregivers of children and adolescents with MR.⁽⁸⁾ Family income may be reduced because care giving responsibilities make it difficult for both parents to work outside home. An added area of concern for some families is difficulty managing family relationships,⁽⁹⁾ high rates of divorce, marital

breakdown,⁽¹⁰⁾ difficulty in maintaining and satisfying social networks.⁽¹¹⁾ Parents will be in a state of continuous strain in securing adequate services for their child, obtaining information about services and dealing with professionals.⁽¹²⁾

2. Indian Studies

An Indian study by Thiyam Karan Singh found that parents having a mentally challenged child in the family is not a burden, but they are willing to see the situation more positively and overcome the situation more gracefully.⁽²⁾ Majority of mothers rated overall burden to be moderate to severe. The mothers of mentally handicapped children reported higher burden than those of physically handicapped children. When comparing burden perceived by mothers of handicapped boys and girls it was found that more effect on mental health of mothers was reported by mothers of female children.⁽¹³⁾ Study by Sen on difficulties experienced by families with disabled children found that mothers felt severe sadness and they indicated that after having a disabled child their social life, working life and family relationships got affected.⁽¹⁴⁾ In another comparative study on caregiver burden of children with mental retardation and normal children, mothers of children with MR showed more burden than mothers of normal children.⁽¹⁵⁾ Study by Gathwala on family burden in mentally handicapped children found that burden was significantly associated with low socioeconomic status and poor physical health of caregivers.⁽¹⁶⁾ In a country like India where care provided for MR is mainly home based and alternate support systems such as day care centers, weekend care and special schools are meager, the burden of care can be enormous. Not much work has been done to assess the impact of MR on caregiver burden. Thus this study was taken up with the following aims and objectives.

3. Aims and Objectives

1. To study and compare socio demo graphic profile of primary caregivers in IMH and Sweekar.
2. To study and compare caregiver burden of primary caregivers of mentally retarded subjects attending Institute of mental health and those attending Sweekar academy of rehabilitation sciences.
3. To study the correlation between severity of MR and caregiver burden.
4. To study clinical profile of MR subjects in both settings.

4. Study Setting

For the Government hospital sample Institute of Mental Health, Erragadda, Hyderabad, Telangana state was taken up. Rehabilitation sample was collected from Sweekar Upkar rehab center, Secunderabad, Telangana state, 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, behavioural problems and for certification purposes. The purpose of the 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. This camp is organized by the 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. Sweekar Academy of Rehabilitation Sciences is an organization providing Rehabilitation, Speech therapy, Psychiatric management, Behavioral modification, Sensory integration for Downs syndrome, IQ assessment and Special education for mentally retarded subjects. It also provides home based management for caregivers. Its services are nominally paid. Caregivers of MR subjects attending Sweekar who met inclusion criteria were included in the study.

- SIZE OF SAMPLE: 30 Primary caregivers from each group.
- STUDY PERIOD: 23/02/2015 to 23/03/2015.
- STUDY DESIGN: Cross sectional and comparative study.

4.1. Inclusion Criteria

- For caregivers:
 - 1) Age 18-45yrs.
 - 2) Who gave consent and cooperative?
 - 3) Living with MR subjects for more than one year.
- For MR subjects:
 - 1) Mild, Moderate and Severe MR.
 - 2) Attending rehabilitation centre for more than 6 months (for rehab sample).
 - 3) Do not have psychosis, behavioral problems requiring admission.

4.2. Exclusion Criteria

- For caregivers:
 - 1) Who did not give consent.
 - 2) Substance dependence.
 - 3) Severe uncontrolled medical illness.
 - 4) Previously diagnosed psychiatric disorders in caregivers.
 - 5) Single, divorced, separated parent.

- For MR subjects:
 - 1) With psychosis requiring admission in to hospital.
 - 2) Profound MR.

4.3. Procedure

Diagnosis of MR was made as per ICD-10 diagnostic criteria and IQ levels were assessed with Bhatia battery. Study subjects were randomly selected, those who met inclusion criteria were explained about the study. Informed consent from the study subjects (primary caregivers) was obtained before conducting the interview. Those who gave consent were entered on intake proforma. This included age, gender, marital status, education, socioeconomic status, type of family, duration of illness, duration of care giving and relationship to patient. Caregiver burden was assessed by Zarit caregiver burden scale. Modified Kuppu swamy scale was used to assess socioeconomic status. Socio demographic data of mentally retarded subjects also were recorded. Prior permission was obtained from authorities of rehabilitation center and hospital before conducting the study.

5. Rating Scales Used in This Study

International classification of diseases (ICD-10) ⁽¹⁷⁾: diagnosis of MR was made as per ICD-10.

Bhatia battery ⁽¹⁸⁾: Among all tests C.M. Bhatia's performance battery is the best test available for assessing MR. It has five sub tests- Koh's block design test, Alexander pass along test, pattern drawing test, immediate memory test, picture construction test. It provides two scores- performance and verbal quotient. Its average gives IQ.

Modified Kuppuswamy scale ⁽¹⁹⁾: It is a composite scale of education, occupation of head of the family, along with monthly income of the family which yields a score of 3-29. This scale classifies the study population in to high, middle and low socioeconomic status.

Zarit burden scale ⁽²⁰⁾: developed by Steven H Zarit to assess the level of burden experienced by the principal caregivers of older persons with dementia and disabled persons. It has got 22 items scores ranging from 0-88, 0-20-no to mild burden, 21-40-mild to moderate burden, more than 40 severe burden. A burden score 24-26 can be used for identifying caregivers at risk of depression.

Mental retardation has been classified in to four categories based on severity as mild IQ-50 to 69; Moderate IQ-35 to 49; severe IQ-20-34; Profound IQ-less than 20. Disability as per Go is 50% for mild, 75% for moderate; 90% for severe; 100% for profound. ⁽²¹⁾

6. Statistical Analysis

Data has been analyzed using SPSS version 17 of windows. Intragroup data are described as means and percentages. Zarit burden scores were represented using pie charts. Sociodemographic data was represented using bar charts and chisquare tests. Statistical significance was set at 0.05.

7. Results

Majority of caregivers in both groups were females (72.6% vs 85.8%). 90% of caregivers from IMH, 62% from sweekar group were aged between 35-44years. Most of them were Hindus in both groups (78% vs80%). 60% of IMH and 96.66% of sweekar belonged to urban area. There were more of nuclear families in both groups (56% vs82.5%), Low socioeconomic class was predominant in IMH group, lower middle was more in sweekar group. Unskilled labourers (60%) were more in IMH group whereas in sweekar group, 60% were housewives.

7.1. Socio-Demographic Data of Caregivers Attending IMH & Sweekar

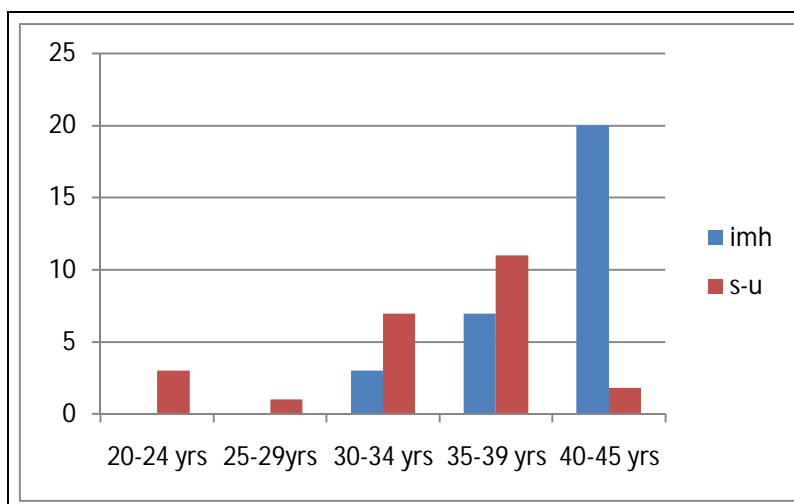


Figure 1

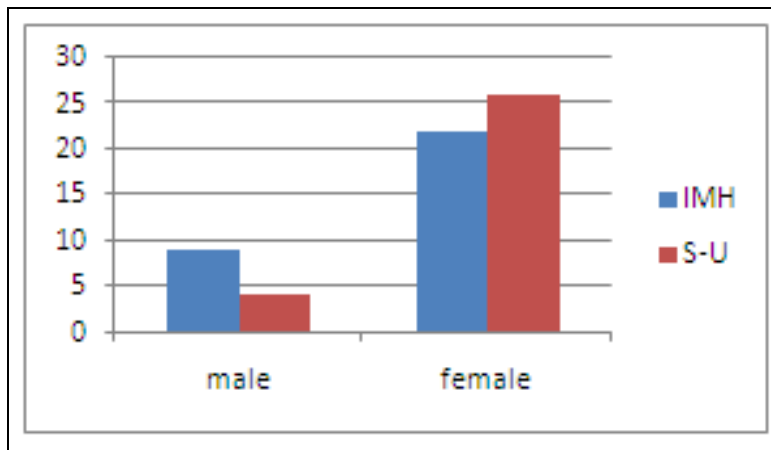


Figure 2

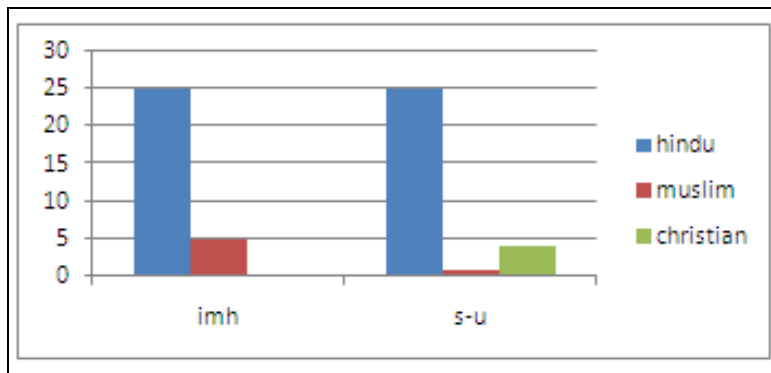


Figure 3

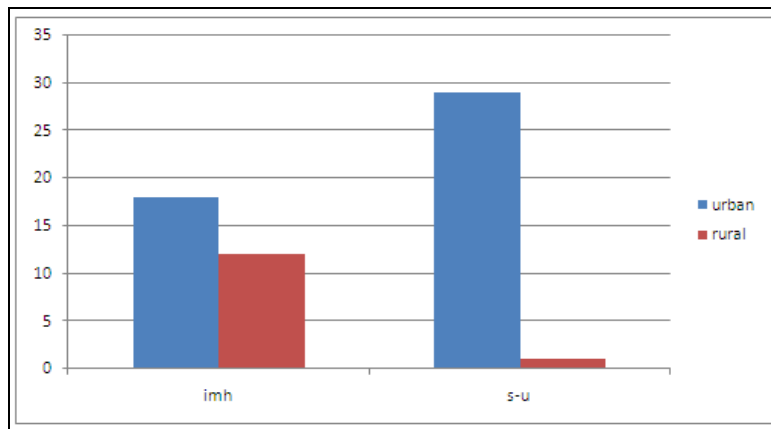


Figure 4

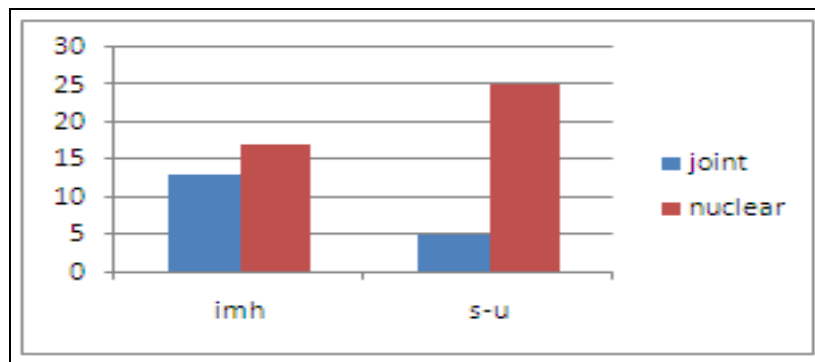


Figure 5

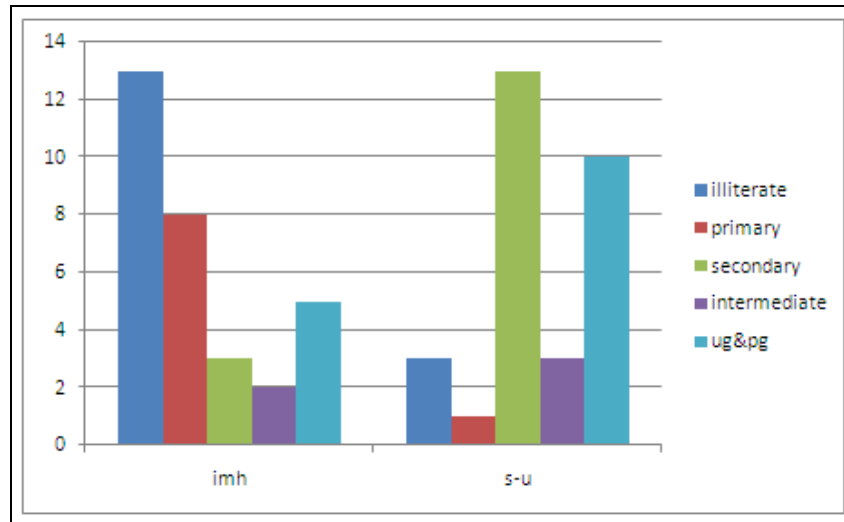


Figure 6

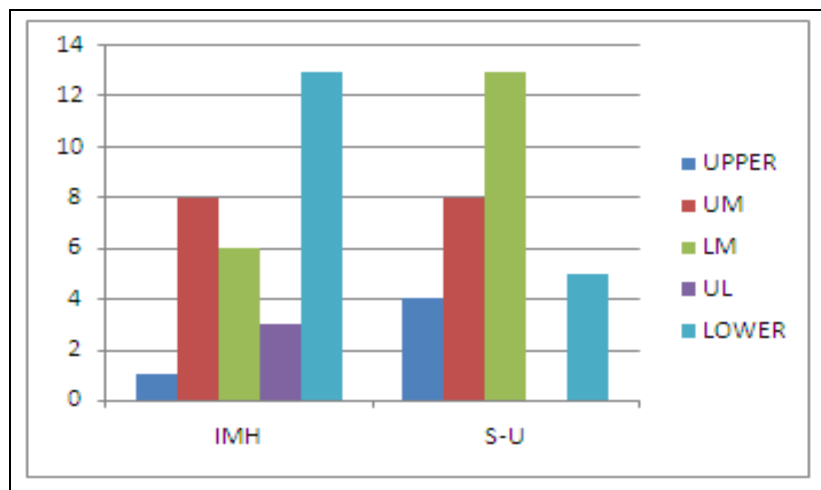


Figure 7

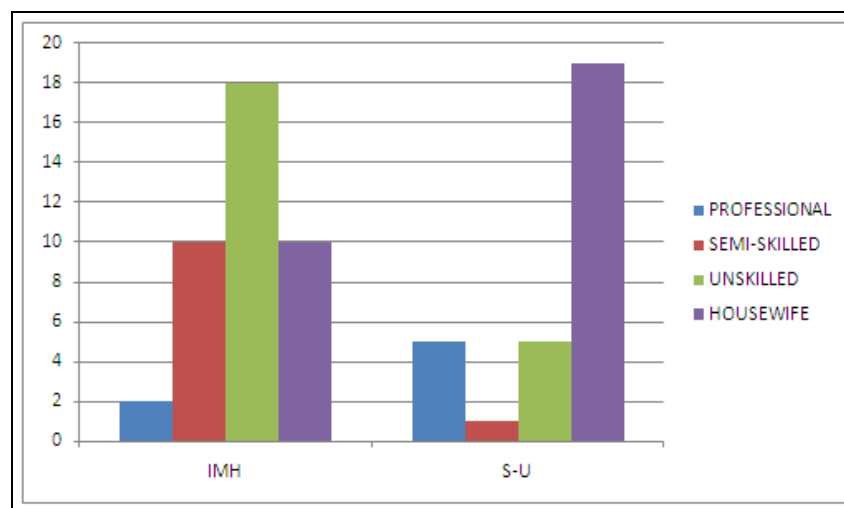


Figure 8

		IMH(n=30)	SWEEKAR(n=30)	Chi square	p value
AGE	15-24	0(0%)	3(10%)	3.2909	0.1929
	25-34	3(10%)	8(26.64%)		(NS)
	35-45	27(90%)	19(63.36%)		
GENDER	FEMALE	22(73.36%)	26(86.68%)	1.6667	0.196
	MALE	8(26.64%)	4(13.32%)		(NS)
RELIGION	HINDU	25(83.35%)	24(80%)	0.113	0.73
	MUSLIM	5(16.65%)	2(6.68%)		(NS)
	CHRISTIAN	0(0%)	4(13.32%)		
DOMICILE	RURAL	12(40%)	1(3.33%)	11.882	0*
	URBAN	18(60%)	29(96.66%)		(SIG)
FAMILY	JOINT	13(42.29%)	5(16.65%)	5.07	0.02*
	NUCLEAR	17(57.71%)	25(83.35%)		(SIG)
SES	U	1(3.33%)	4(13.32%)	9.9789	0.04*
	UM	8(26.64%)	8(26.64%)		(SIG)
	LM	6(20%)	13(63.29%)		
	UL	3(10%)	2(6.68%)		
	L	12(40%)	3(10%)		
OCCUPATION	PROFE	2(6.68%)	5(16.65%)	10.17	0.01*
	SSK	2(6.68%)	1(3.33%)		(SIG)
	USK	16(52.28%)	5(16.65%)		
	HW	10(33%)	19(63.27%)		
EDUCATION	ILLITRATE	13(43.29%)	3(10%)	20.716	0*
	PRIMARY	8(26.64%)	1(3.33%)		
	SECONDARY	3(10%)	13(43.29%)		
	INTER	2(6.66%)	3(10%)		
	UG/PG	4(13.32g%)	10(33.33%)		

Table 1: showing socio demographic factors of caregivers attending IMH and SWEEKAR

The association between age, gender, marital status and religion was not statistically significant across the two groups, indicating that both groups were matched for above factors. Whereas the association between domicile, family type, socioeconomic status (SES) and education was statistically significant indicating that both groups were not matched. (Table 1)

Caregiver burden(ZBI)	IMH(n=30)	Sweekar(n=30)	Chisquare value	P value
Mild	13(43.32%)	18(60%)	3.0792	0.214
Moderate	9(29.99%)	9(30%)		(NS)
severe	8(26.64%)	3(10%)		

Table 2: showing caregiver burden by ZBI across the two groups (IMH and SWEEKAR):

In IMH 43.32% of caregivers reported mild burden, 29.99% moderate and 26.64% severe burden. In Sweekar 60% reported mild burden, 30% moderate and 10% severe burden. The association between caregiver burden and place of study was not statistically significant (Table 2). In both groups all caregivers (100%) reported burden, not even a single caregiver reported that they did not have burden. The mean ZBI scores were 37.03 SD 5.99 for IMH and 23.33 SD 5.52 for Sweekar

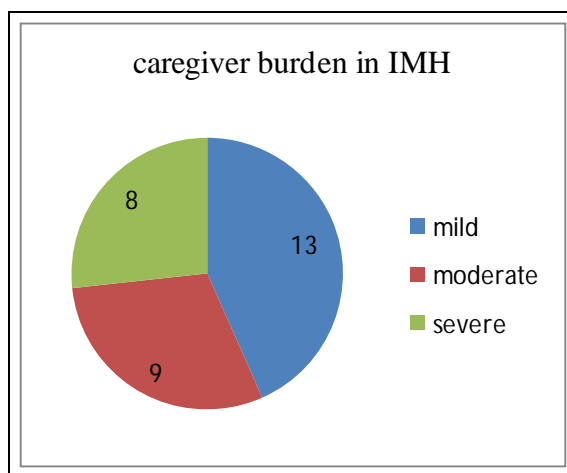


Figure 9: IMH: Mild-43.329%; Moderate-29.99%; Severe-26.664%

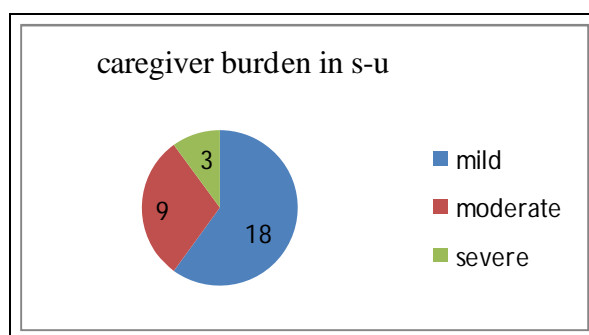


Figure 10: Sweekar: Mild-60%; Moderate-30%; Severe-10%

Severity of MR	Mild CG burden(n=13)	moderate (n=9)	Severe(n=8)	Chisquare value	P value
Mild MR(n=11)	9(89.91%)	1(5.04%)	1(5.04%)	9.6886	0.046012* (SIG)
Moderate MR(n=11)	3(29.97%)	4(39.96%)	4(39.96%)		
Severe MR(n=8)	1(12.5%)	4(50%)	3(37.5%)		

Table 3: showing association between caregiver burden and severity of MR(IMH):

89.91% of mild MR subject’s caregiver reported mild burden, 50% of severe MR subject’s caregiver reported moderate burden. The association between caregiver burden and severity of MR was statistically significant (p value =0.046012). (Table 3).

Severity of MR	Mild CG burden(n=18)	moderate (n=9)	Severe(n=3)	Chisquare value	P value
Mild MR(n=17)	14(82.32%)	2(11.8%)	1(5.88%)	9.66	0.0458* (SIG)
Moderate MR(n=9)	3(33.33%)	5(55.55%)	1(11.11%)		
Severe MR(n=4)	1(25%)	2(50%)	1(25%)		

Table 4: showing association between caregiver burden and severity of MR (SWEEKAR):

82.32% of caregivers with mild mentally retarded subjects reported mild burden, 50% of caregiver with severely retarded subjects reported severe burden. The association between caregiver burden and severity of MR is statistically significant (p value 0.0458). (Table 4).

Duration of care giving	Mild CG burden(n=13)	moderate (n=9)	Severe(n=8)	Chisquare value	P value
<10hrs	11(61.05%)	5(27.55%)	2(11.4%)	6.5797	0.03726* (SIG)
>10hrs	2(20%)	4(30%)	6(50%)		
Total	13	9	8		

Table 5: showing association between caregiver burden and duration of care giving (IMH):

The association between caregiver burden and duration of care giving in IMH subjects was statistically significant (p.value 0.03726). (Table 5)

Education of caregiver	Mild CG burden(n=18)	moderate (n=9)	Severe(n=3)	Chisquare value	P value
Illiterate(n=3)	1(33.4%)	0	2(66.55%)	16.682	0.033597*
Primary(n=1)	1(100%)	0	0		(SIG)
Secondary(n=13)	8(61.52%)	5(38.48%)	0		
Inter (n=3)	1(33.33%)	1(33.33%)	1(33.33)		
UG and PG(n=10)	7(70%)	3(30%)	0		

Table 6: showing association between caregiver burden and education of caregiver (SWEEKAR):

70% of caregivers with graduation and post graduation in Sweekar group reported mild burden, 66% of illiterate care givers reported sever burden. The association between caregiver burden and education was statistically significant (p value 0.033597). (Table 6)

Most of the MR subjects in the study belonged to age group of 5-15years (66.6%). There were more male MR subjects in both groups (60% vs 72.6%). All the subjects in both groups were unmarried and unemployed. The mean age at which subjects were diagnosed with MR was 6years for sweekar group, 10years for IMH group. In IMH group percentage of subjects with mild and moderate MR were 36.6% each, 26.6% were severe. Subjects in the sweekar group were attending special school for more than one year, subjects in IMH group dropped out after attending school for 2-3years. Most common type of co morbidity of MR was seizures, were more in IMH group (60%) than sweekar group (33.3%). Co morbidities were present in 80% of MR subjects in both groups. Family history of MR was present in 10% of subjects in both groups.

7.2. Sociodemographic Data of MR Subjects Attending IMH & Sweekar

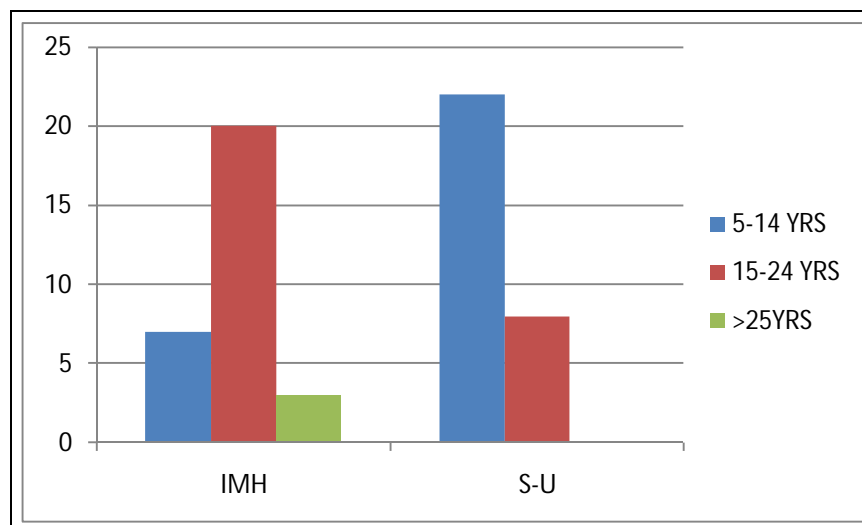


Figure 11

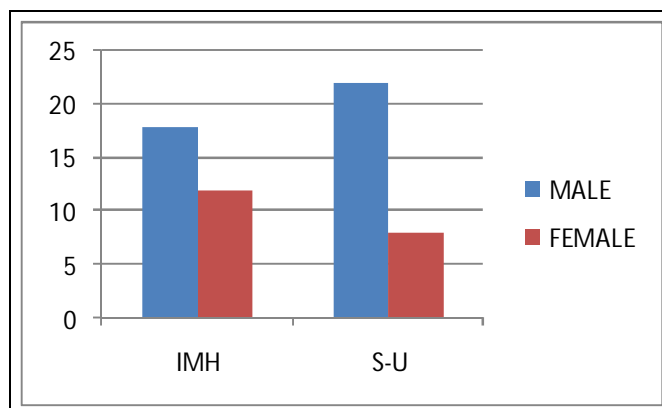


Figure 12

8. Discussion

The socio demographic factors of the present study showed that more than two-thirds of primary care givers were females(mothers) in IMH and sweekar group, only third were males(fathers).This is in line with study by Galila shawky, Mobolaji u Dada.⁽²²⁾ Awadalla stated in his study that mothers in the family usually has the responsibility of care giving their mentally retarded children.⁽²³⁾ More than 90%of caregivers were in the age of 35-45years in both groups. This is in agreement with Seltzer study⁽²⁴⁾ Regarding education, two-fifths of primary caregivers were illiterates in IMH group which is in congruence with Schulze and Angermeyer⁽²⁵⁾ who stated that parents had low education level. In sweekar group illiterates were only one-tenth, more than one third had graduate and postgraduate education. This is in accordance with Scorgie,⁽²⁶⁾ who found that there were more educated caregivers in their study. More than two-thirds of primary caregivers belonged to nuclear families in both groups. This is in accordance with study by Sethi.⁽²⁷⁾ There were more caregivers from low socioeconomic status in IMH group in line with study by another Indian author Kaur.⁽²⁸⁾ There were more of middle socioeconomic status in sweekar group. In both groups all primary caregivers reported burden, however there was difference in severity. In IMH group more of caregivers expressed severe burden, in sweekar group more caregivers expressed mild burden. Burden was present in 100% of primary caregivers irrespective of the fact whether their children received special education or not, this calls for need to address the caregiver burden by providing them counseling. This estimate of burden is higher than burden estimated by Indian studies which indicated minimal to moderate burden, reason for this may be our study assessed burden in primary caregiver only, whereas study by Kaur⁽²⁸⁾ assessed burden of whole family. Burden will be more on primary caregiver than on whole family, this might have made the difference. Caregiver burden increased proportionately with MR severity, with primary caregivers of mild MR subjects expressed mild burden, caregivers of severe MR severe burden in both groups.(p value=0.046012), (p value=0.0458) This type of positive correlation between caregiver burden and severity of MR was also seen in study by Sethi⁽²⁷⁾ which concluded that caregivers of severe to profound MR children had high level of stress and burden. In IMH group primary caregiver burden was also associated with duration of caregiving. Caregivers who are involved in caregiving more than 10 hours reported severe burden, those with less than 10hours reported mild burden.(p value=0.03726) Similar positive correlations between caregiver burden and duration of caregiving was found in study by Y O Oshodi.⁽²⁹⁾

In sweekar group mild caregiver burden was more in caregivers who were well educated ,severe burden was more among illiterates.(p value=0.0359) This finding is in congruence with studies by Indian investigators like Majumdar⁽³⁰⁾ and Western investigators like Beckham,⁽³¹⁾ where in family's education had an inverse relationship with burden it can be elaborated that educated caregivers had a chance to clarify their doubts and expand their horizons with internet, TV, posters and handouts. Illiterates lack such exposure, this was also emphasized by Narmada,⁽³²⁾ who mentioned that educated mothers have good interaction and tolerance towards their child's behavior, better understanding of nature of illness, how to manage mentally retarded children and hence experience mild burden. Education is probably therapeutic because it reduces burden and increases awareness.⁽³³⁾

The findings of more male MR subjects with, age group 5-15yrs predominantly, age at which diagnosis of MR was made are in line with Indian study by Nagarkar.⁽³⁴⁾ The reason for delay in diagnosis of MR may be due to lack of awareness of parents and family members may be psychological factors like denial.

9. Conclusion

Multiple factors seem to be responsible for burden experienced by caregivers. Our study found severity of MR, duration of care giving, illiteracy were associated with burden, The age at which MR was diagnosed was little late, more so delayed in subjects attending IMH. Delayed diagnosis may be the cause for MR subjects not attending rehab centre.

9.1. Draw Backs of Our Study

1. Primary caregivers were matched for age, gender and religion only, not for Education and socioeconomic status.
2. Social support was not assessed.
3. Size of sample is small and could not be generalized to population.

9.2. Recommendation for Future Research

1. Continuous health education and counseling programs are necessary to improve parents awareness towards care of their mentally retarded children.
2. Counseling should be multi staged at birth, after 2yrs, at school entry, during puberty. This will aid early diagnosis of MR.
3. Medical services offered to the mentally retarded child should move from individual level to family level,
4. Especially towards mothers who are main care takers.
5. Counseling services, treatment and regular screening of mothers of mentally retarded should be included in the protocol of management of MR.
6. Special schooling for mentally retarded needs to be encouraged.
 - Source of Support: Nil.
 - Conflict of Interest: Nil

9.3. Acknowledgements

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ANNEXURE

Intake Proforma

1. Proforma for Caregiver

- Registration number:
- Age:
- Gender:
- Education:
- Marital status:
- Employment:
- Religion:
- Socioeconomic status:
- Type of family:
- Domicile:
- Relationship to patient:
- Duration of care giving:
- Nursing care required: Yes: No:
- Diagnosed as mental retardation how many years back:
- Attending rehabilitation since how long: if any..
- Family history of mental retardation:
- Attitude towards having mentally retarded child:
 - God's gift:
 - Fate/curse:
 - Medical model: consanguinity/fever/infections during pregnancy/
 - Increased maternal age:
- Medical problems in caregivers:

2. Proforma for Mentally Retarded Subjects

- Age:
- Gender:
- Cause of mental retardation(MR): congenital:
 - Acquired:
- Severity of MR: Mild
 - Moderate:
 - Severe:
- Percentage of disability:
- Comorbidities associated:
 - Behavioural problems:
 - Psychosis:
 - Autism:
 - Epilepsy:
 - Cardiac problems:
 - Others:
- MR child born out of consanguinity:
 - Yes:
 - No:

3. Abbreviations

- IMH: Institute of Mental Health
- S-U: Sweekar Upkar
- U: Upper
- UM: Upper Middle
- LM: Lower Middle
- UL: Upper Lower
- L: Lower
- Ug: under graduate
- Pg: post graduate
- PROFE: Professional
- SSK: Semiskilled
- USK: Unskilled
- HW: House Wife
- CG burden: Caregiver burden
- GAD: Generalized Anxiety Disorder
- MDD: Major Depressive Disorder
- OPD: Out Patient Department.