

# A Study to Assess the Knowledge, Perceived Challenges, and Coping Strategies on Home Care Management Among Caregivers of Mentally Ill Patients with the View to Evaluate the Effectiveness of an Information Booklet on the Knowledge of Home Care Management in a Selected Hospital of Delhi

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## ABSTRACT

**The objectives of the study were:** To assess the knowledge, perceived challenges, and coping strategies of caregivers on home care management of mentally ill patients, to seek association between knowledge and demographic variables and previous knowledge of home care, to develop and evaluate the effectiveness of an information booklet on the knowledge on home care management. to determine the correlation between knowledge and perceived challenges.

**Materials And Methods:** This study was carried out in two phases in which the assessment of knowledge on home care, perceived challenges and coping strategies was done in phase-I and evaluation of the effectiveness of information booklet on home care management was done in phase-II. The sample were 100 caregivers of mentally ill patients in phase-I and 37 caregivers in phase-II. The sampling technique was purposive for both the phases. The tool used were structured knowledge questionnaire, rating scale and standardized brief COPE for coping strategies.

**Results:** Major findings of the study revealed 63% of caregivers of mentally ill patients had good level of knowledge. It was found that majority of the caregivers e.g., 68% of mentally ill patients were having moderately perceived challenges. Most of the caregivers of mentally ill patients used problem focused coping style. There was a positive correlation between knowledge and perceived challenges. Based on the findings in Phase-I the information booklet on home care management was developed. The development of informational booklet on home care management was effective to increase the knowledge of the caregivers.

**Keywords:** [Home Care Management, Perceived Challenges, Caregivers of mentally ill patients]

## INTRODUCTION

Besides the wide prevalence of mental disorders, common people are unaware of the facts related to mental illnesses. It is widely seen that people hold a negative

belief about mental illness thinking mental illnesses are dangerous, unpredictable, and are not curable. Some people believe that mental illnesses are caused by supernatural power, excessive worrying,

black magic, curse, or evil spirit. Therefore, they prefer religious remedies, non-professional medical help, or alternative medicines for treatment.<sup>[1]</sup>

Mental illness may causeway of psychological problems like diminished quality of life of family members as well as an increased social distance for patient and family. Coping mechanisms for dealing with mentally ill patients differ from one family to another for a variety of reasons. Psychiatric professionals often view the relatives of a patient as people of support because they can act as informants regarding the patient and they can act as co-therapists at home. The relatives should be in an ideal social and mental state.<sup>[2]</sup>

**Mokwena. K.E., Ngoveni. A. 2020** had undertaken a study to find out the challenges of providing home care for a family member with serious chronic mental illness. Globally there are fewer resources for the treatment and the condition are worsen in the low- and middle-income countries. The analysis of the study suggested that caring for patients with serious mental illness at home is difficult, unbearable, and this is due to many situations where family members had to face violence, safety concerns, financial difficulties, and emotional disturbances, etc.<sup>[3]</sup>

In India, 90% of psychiatric patient lives with their family. The family caregiver has numerous roles in the care of the patient including day-to-day care, supervising medications, follow-up, and financial needs. The caregivers also bear with the behavioural disturbances in patient. Therefore, experience considerable stress and burden and need help to cope with it.<sup>[4]</sup>

One of the most effective ways to positively affect attitudes is to deliver relevant messages that will resonate with target audiences, encourage the public to recognize, acknowledge and disclose their problems or those of family members and provide information that will help the people.

## **MATERIALS & METHODS**

After obtaining administrative approval the tools were administered to caregivers of mentally ill patients. The study was done in two phases by descriptive survey and experimental design. The tool used in phase -I were structured knowledge questionnaire, rating scale on perceived challenges and standardized brief COPE for coping strategies among the caregivers of mentally ill patients. Based on the findings in Phase-I the information booklet on home care management was developed. In phase-II, effectiveness of the information booklet was checked. Sample size was 100 and 37 for phase -I and II respectively and purposive technique was used.

## **STATISTICAL ANALYSIS**

The obtained data was tabulated and analysed using both descriptive and inferential statistics. Data was represented in frequency, percentage, mean, chi-square and t-value.

## **RESULT**

### **Phase-I**

#### **Section I: Description of the sample characteristics.**

- Majority (39%) caregivers of mentally ill patient were from age group 26-35 years.
- When coming to gender most of the sample were from male gender (58%).
- Considering the educational level of the caregivers of mentally ill patient majority (33%) of them were from secondary school.
- For the occupation majority were from private sector (46%)
- Majority that is (39%) of the family were having an income of less than 10,000.
- As per the data, majority (68%) of the caregivers were married.
- Regarding the type of family majority (84%) were from nuclear family.

- Majority (91%) belongs to Hindu religion.
- As far as relationship with the patient was considered, majority (26%) were parents.
- Regarding the length of stay with the patient with mental illness, majority of caregivers were (71%) from more than 2 years.
- Data revealed that majority (96%)

caregivers were having no previous knowledge regarding home care.

**Section II: Findings related to the knowledge of the caregivers of mentally illpatient.**

**Frequency and Percentage Distribution of Knowledge of the Caregivers of Mentally Ill Patients**

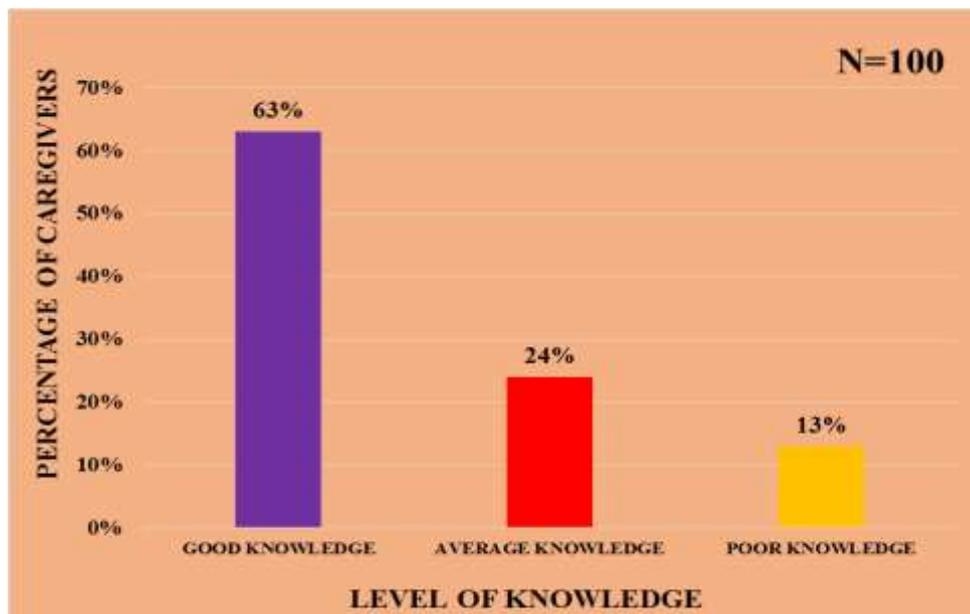


Figure No. 1.1: Bar Diagram Showing Level of Knowledge Distribution of Caregivers of Mentally Ill Patients.

Figure No. 1.1 revealed that majority of the caregivers of mentally ill patients were having good level of knowledge that is (63%) followed by average knowledge (24%) and poor knowledge (13%) level of knowledge.

**Mean, Median and standard deviation of the knowledge**

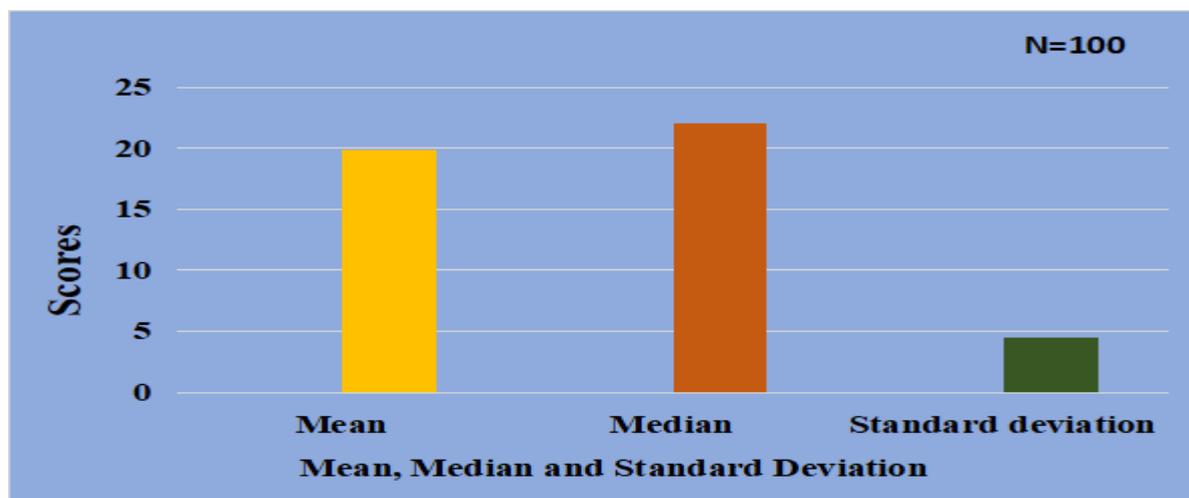


Figure No. 1.2: Bar Diagram Showing Mean, Median and Standard Deviation of Caregivers of Mentally Ill Patients

Figure No. 1.2 shows that the mean of the caregivers of mentally ill patient is 19.87, the median came out to be 22 and the standard deviation resulted in 4.54.

### Frequency and Percentage Distribution of Aspects of Knowledge of Caregivers of Mentally Ill Patients

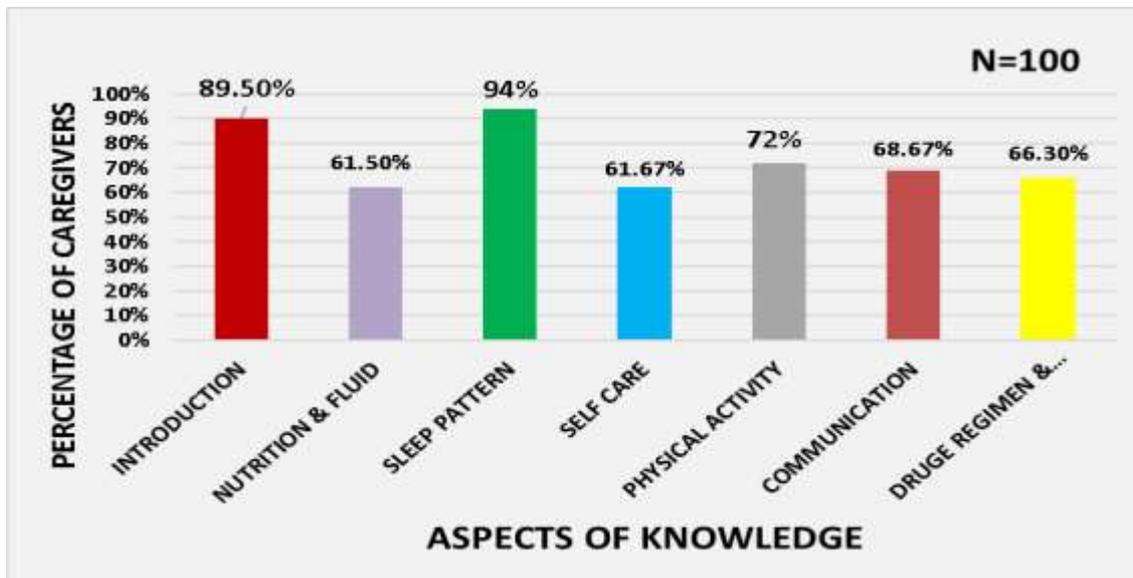


Figure No. 1.3: Bar Diagram Showing Aspects of Knowledge Caregivers of Mentally Ill Patients

Figure No. 1.3 shows that as reported by the caregivers of mentally ill patients, the caregivers were having least knowledge regarding the nutrition and fluid i. e 61.50%. The caregivers of mentally ill patients were having most percentage of knowledge of sleep-pattern (94%) followed by introduction (89.50%), communication (68.67%), drug regimen and follow-up.

### Section III: Findings related to the perceived challenges of the caregivers of mentally ill patient.

#### Frequency and Percentage Distribution of Perceived Challenges by Caregivers of Mentally Ill Patient

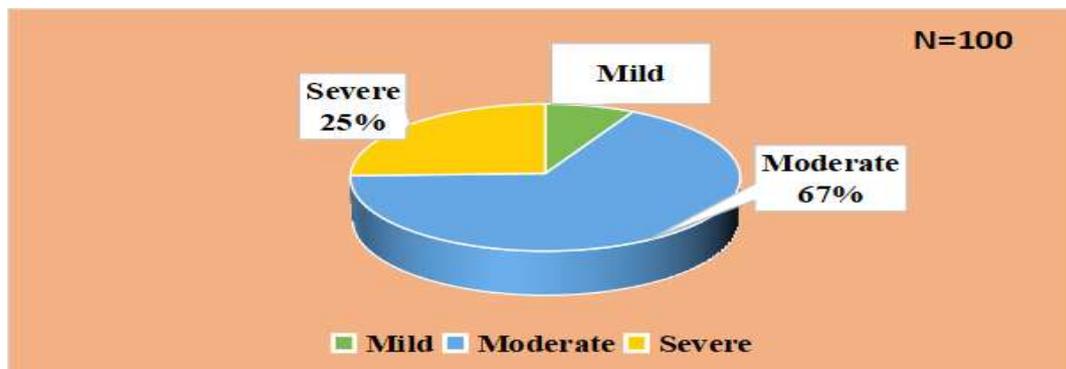


Figure No. 1.4 Pie Diagram Showing Category of Perceived Challenges of Caregivers of Mentally Ill Patients.

Figure No. 1.4 as reported majority of the caregivers of mentally ill patients were facing moderately perceived challenges with 68% followed by 26 % caregivers of

mentally ill patients were severely perceived and 8% caregivers of mentally ill patients were having mild perceived challenges.

**Section IV: Findings related to the coping strategies of the caregivers of the mentally ill patient.**

**Mean Overarching Coping Styles of Coping Strategies of Caregivers**

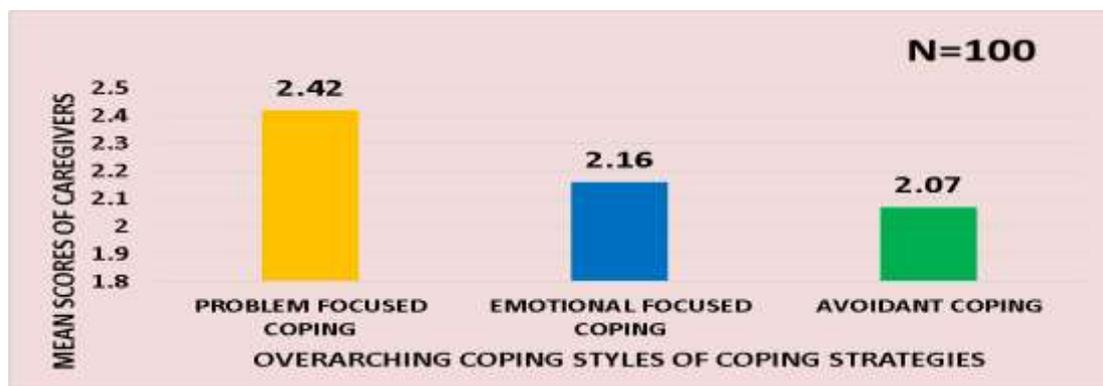


Figure No. 1.5: Bar Diagram Showing Mean of Caregivers of Mentally Ill Patient According to Overarching Coping Styles.

Figure No. 1.5 shows that the majority of caregivers of mentally ill patients used problem focused coping as coping style. Least used coping style was reported as avoidant coping style as a coping strategy.

**Section V: Finding related to the relationship between knowledge and demographic characteristics**

Table No. 1.1: Chi- Square Value Showing Association between Level of Knowledge and Demographic Variables. N=100

DEMOGRAPHIC DATA		LEVEL OF KNOWLEDGE			ASSOCIATION WITH LEVEL OF KNOWLEDGE				
Variables	Option	Poor	Average	Good	Chi-Test	P value	df	Table value	Result
	26-35	7	4	27					
	36-45	2	10	21					
	46-55	1	1	6					
	56-Above	1	0	0					
Gender	Male	8	16	34	1.22 7	0.541	2	5.991	Not significant
	Female	5	8	29					
Educational level	Can read and write (Hindi or English)	1	0	11	10.8 85	0.208	8	15.507	Not significant
	Primary	2	2	12					
	Secondary	6	10	16					
	Higher secondary	3	11	18					
	Graduated	1	1	6					
	Post graduate	0	0	0					
Occupation	Housewife	4	1	16	9.16 7	0.328	8	15.507	Not significant
	Unemployed	1	6	8					
	Government sec.	1	0	3					
	Private sector	6	13	27					
	Others	1	4	9					
Income per month	<10,000	5	8	26	1.60 2	0.952	6	12.592	Not significant
	10,001-20,000	3	6	12					
	20,000-30,000	3	8	20					
	20,000-30,000	3	8	20					
	>30,001	2	2	5					
Marital status	Unmarried	2	9	18	2.79 6	0.592	4	9.488	Not significant
	Married	11	14	43					
	Separated/divorced	0	0	0					
	Widow/ widower	0	1	2					
Type of family	Nuclear family	13	20	51	3.74 1	0.442	4	9.488	Not Significant
	Joint family	0	3	11					

	Single parent	0	1	1					
Religion	Hindu	12	22	57	0.61	0.970	2	5.991	Not Significant
	Muslim	1	2	6					
	Christian	0	0	0					
	Others	0	0	0					
Relationship with the patient	Parent	5	6	16	6.167	0.628	8	15.507	Not Significant
	Spouse	3	5	14					
	children	4	5	14					
	Sibling	1	7	11					
	Others	0	1	8					
Family history of mental illness	Yes	0	0	4	2.447	0.294	2	5.991	Not Significant
	No	13	24	59					
Length of stay with mental illness	Less than 6 months	1	1	6	5.120	0.529	6	12.592	Not Significant
	6 months-1 year	1	0	1					
	1-2 years	2	9	16					
	More than 2 years	9	14	40					

The data presented in Table no. 1.5 shows the computed chi-square values between knowledge scores of caregivers with selected variables, the computed chi-square values of selected variables like gender (1.227), educational level (10.885) occupation (9.167), income per month (in rupees) (1.602), marital status (2.796), type of family (3.741), religion (0.61), relationship with the patient (6.167), family history of mental illness (2.447), length of stay with mental illness (5.120), Previous knowledge of home care (0.639) are statistically insignificant and only age (18.055) was found to be statistically significant at 0.05 level of significance.

## Phase-II

### Section-VI: Description of Characteristics

- Majority 32.43% of the caregivers of mentally ill patients were from the age group 36-45 years followed by (29.73%) and 18-25 years and 25-36 years.
- Most of the study participants, (64.86%) were males
- Most of them were having secondary educational level (43.24%) followed by (37.84%) higher secondary, (10.81%) primary and (5.41%) graduate.
- Majority, (51.35%) participants were from private sector followed by (18.92%) unemployed, (13.51%) housewife and others and (2.70%) government sector.
- Majority of the (35.14 %) participants were having income of less than 10000

followed by (29.73%) from 20,001-30,000, (24.32%) from 10,001-20,000 and (10.82%) more than 30,001.

- Most of them were (67.57%) married followed by (29.73%) unmarried, (20.70%) widow/widower and no participant were separated/divorced.
- Majority (89.19%) of them were from nuclear family, (8.11%) were from joint family and (2.70%) were single parent.
- Majority (91.89%) were Hindu, (8.11%) from Muslim and no participant was from Christian or other religion.
- Majority of the participants were (29.73%) were parents of the patient followed by (24.62%) children, (21.62%) were spouse and siblings and (2.70%) were from the other relationship with the patient.
- Most of the participants (100%) were not having family history of mental illness.
- Majority of the participants (67.57%) were having more than 2 years of length with mental illness followed by (32.43%) were having 1-2 years of length with mental illness.
- Most of the participants (97.30%) were not having previous knowledge of the home care and (2.70%) were having previous knowledge of home care.

### Section VII: Finding related to the effectiveness of information booklet on knowledge scores of caregivers of mentally ill patients regarding home care management.

Figure No. 1.6: Frequency polygon diagram showing Pre-test and Post-test knowledge scores of caregivers according to class interval.

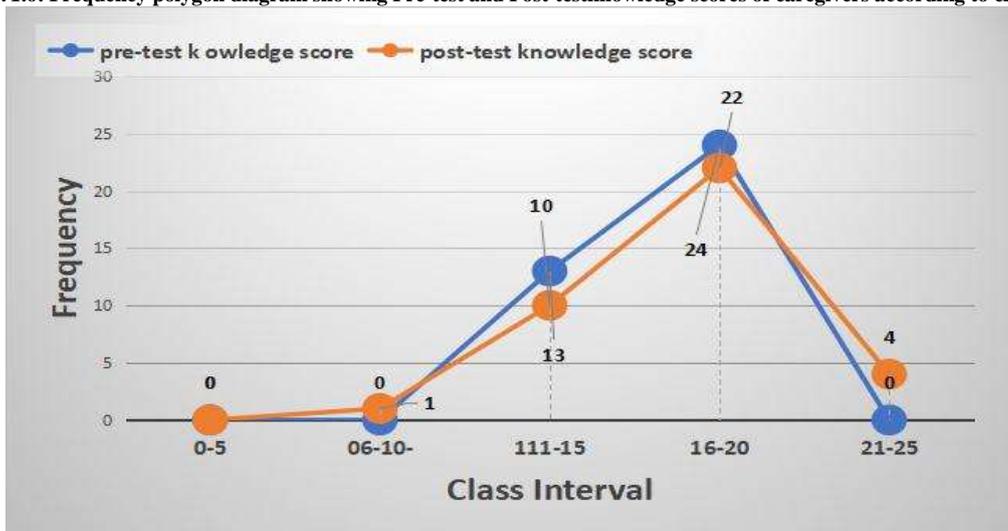


Figure no. 1.6 shows the pre-test knowledge scores of caregivers of mentally ill patients regarding home care management according to the class intervals of the scores. The frequency interval of knowledge score started from 0-5 and highest pre-test test knowledge frequency was 24 in the class interval 11-15, whereas post-test knowledge frequency score was 22 in the class interval

16-20. The comparison between the pre-test and post-test knowledge scores of caregivers was plotted in the form of frequency polygon in the figure no. 1.6

**Frequency distribution of pre-test and post-test knowledge scores according to scoring criteria.**

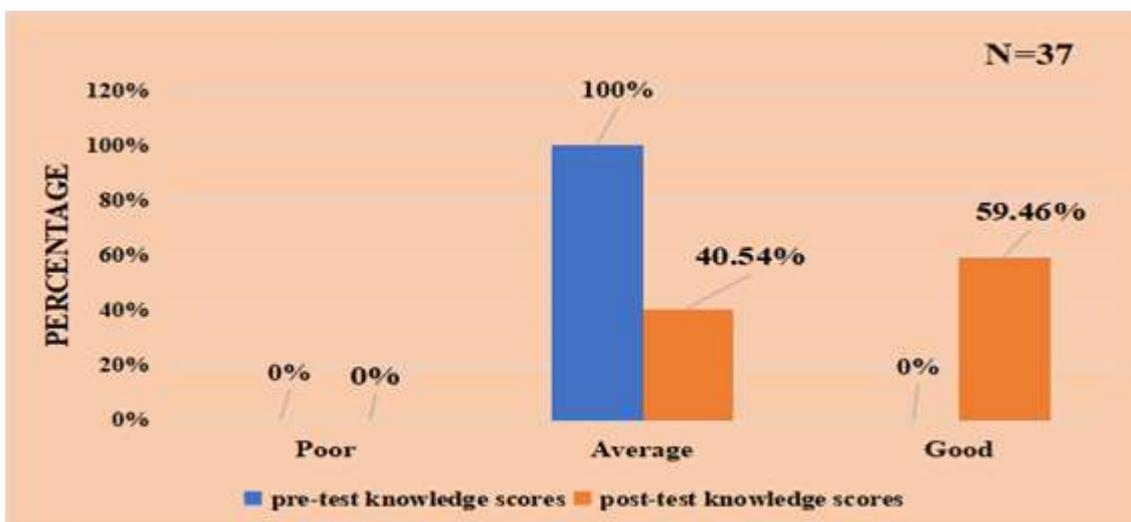


Figure No. 1.7: Bar Diagram Showing Percentage Distribution of Pre-Test and Post-Test Knowledge Scores of Caregivers of Mentally Ill Patient.

Figure no. 1.7 shows that the frequency of scores in pre-test under average category was (100%) which was reduced to (40.54%) in post-test. The frequency under good category was increased from (0%) to (59.46%). This suggests that majority of caregivers score under good category after

the information booklet which indicates a considerable gain in knowledge of caregivers regarding home care management.

### Mean, Median, Standard Deviation of Pre-Test and Post-Test knowledge scores of caregivers

Table No. 1.2 Mean, Median, Standard Deviation of Pre-Test and Post-Test Knowledge Scores of Caregivers, N=37

S. No.	Test	Mean	Median	Standard Deviation
1.	Pre-Test	11.24	11	1.52
2.	Post-Test	17	17	1.49

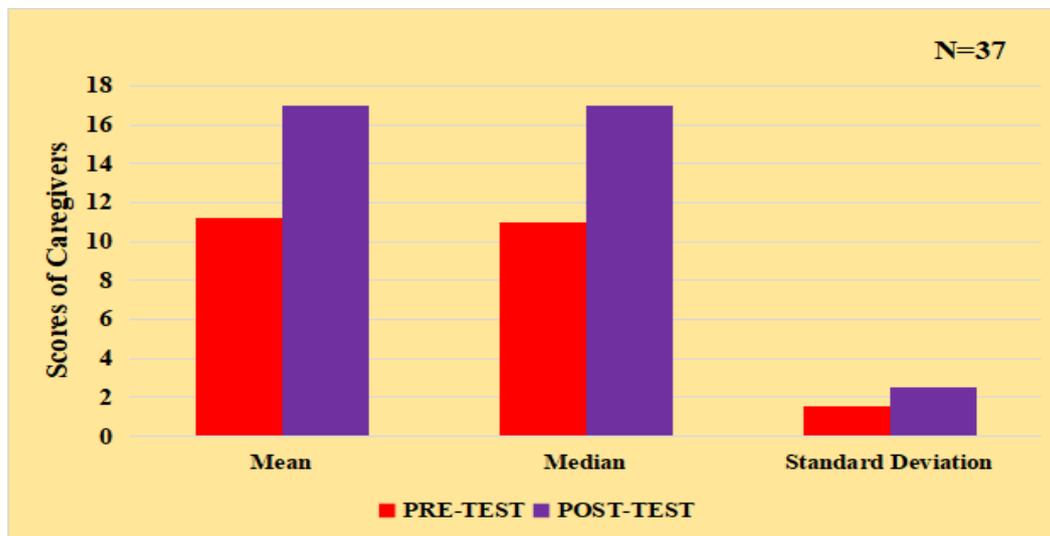


Figure No. 1.8: Bar diagram showing Mean, Median and Standard Deviation of Pre-test and Post-test knowledge scores of caregivers of mentally ill patient.

The data presented in Table No. 1.2 and Figure no. 1.8 shows that the mean post-test knowledge scores of caregivers calculated regarding home care management (17) is higher than the mean pre-test knowledge scores (11.24). The post-test median score of knowledge of caregivers regarding home care management (17) is higher than the median of pre-test knowledge scores (11). The data further shows that the median for the pre-test was (11) whereas for the post-test was (17), which both are closer to the pre-test (11.24) and post-test mean (17) indicating a fairly normal probability curve, which means all the measures of central tendency coincide at the center of the distribution to a great extent. The standard deviation of the post-test knowledge scores was (1.49) which was lower than the standard deviation of pre-test knowledge scores (1.52), suggest an equal and homogenous grasping of knowledge after administration of information booklet.

### Computing “t” value to find out the significance of mean, difference between pre-test and post-test knowledge scores of

### the caregivers on home care management.

Table No. 1.3 Mean, Median Difference, Standard Error of Mean Difference from Pre-test to Post-test knowledge scores of caregivers and “t” value on home care management. N=37

Knowledge test	Mean	Mean difference	SE <sub>MD</sub>	“t” value
Pre-Test	11.24	5.76	0.34	*16.99
Post-Test	17			

\*t value for df (36) level =2.021 P<0.05=significant 0.05 level

The data presented in table no. 1.3 shows that the mean post-test knowledge score (17) is higher than the mean of (11.24) pre-test knowledge scores of caregivers on home care management. The obtained mean difference (5.76) between pre-test and post-test knowledge scores of caregivers was found to be statistically significant with “t” value of 16.99 for the degree of freedom (36) at 0.05 level of significance. Thus, it shows that the obtained mean difference was true difference and not by chance.

### DISCUSSION

The result of the present study revealed that identification of caregivers having different level of knowledge was done. Majority of the caregivers of mentally ill patients were having good knowledge that is 63 (63%)

followed by average knowledge 24 (24%) and poor knowledge 13 (13%). The findings were similar with the study done by **Kumar D, Kumar P, Singh A. R et al (2012)**.<sup>[5]</sup> They revealed that key informants were found to be more aware about the disease and care. The findings also suggested that there was a growing awareness about mental illness even in general population and the people were being more receptive with the mentally ill people. The present study also show disagreement with the present study conducted by **Gabra. R.H, Ebrahim O.S, Osman D.M.M et al (2020)** <sup>[6]</sup>, a cross-sectional study was conducted among the 425 main family caregivers of mentally ill patients at Assiut University Hospital. It was revealed by the results that caregivers had low scores of the knowledge.

In the present study it was found that sample were having (68%) of moderately perceived challenges whereas other caregivers of mentally ill patient have (26%) severe and (08%) mild perceived challenges. The results came in agreement with the study conducted by **Mokwena K.E, Ngoveni A (2020)** <sup>[3]</sup>, an explorative qualitative study was conducted in South Africa. The findings revealed that caring for patients with serious mental illness at home is difficult, sometimes unbearable, because the families have to deal with violence perpetrated by the patients, safety concerns, financial difficulties and emotional turmoil. The findings were also supported by the study conducted by **S. Sachin, Venkatesan S, Ravindra H. N (2014)** <sup>[7]</sup> to assess the family burden among 60 family caregivers of mentally ill clients in Gujrat. The results showed that 16(26.7%) were not experiencing the burden, 27 (45%) experienced mild burden, 8 (13.3%) experienced moderate burden and 9(15%) experienced severeburden.

The present study showed that the caregivers of mentally ill patient use overarching coping styles of the coping strategies. The mean of the caregivers of mentally ill patients who used problem

focused coping is 2.42 whereas other coping style like emotional focused coping and avoidant coping have mean as 2.15 and 2.07 respectively. The result comes in agreement with the study conducted by **Sun F, Kosberg K, Kaufman A. V (2010)** <sup>[8]</sup> a study was conducted to assess the coping styles by which family caregivers living in rural areas of Alabama deal with the demands of caring for an older relative with dementia. Data were obtained from a sample of 141 caregivers through the random-digit dialling telephone survey. Two coping styles were Avoidance coping appeared to moderate the effects of caregiver health on caregiver burden. Another study came in support conducted by **Azman. A, Singh P.S.J, Sulaiman J (2017)** <sup>[9]</sup> a qualitative study with an aim at identifying and analysing the coping strategies adopted by the family caregivers in dealing with their mentally ill family members. The study findings identified an array of coping strategies used by the family caregivers, including religious coping, emotional coping, acceptance, becoming engaged in leisure activities, and the use of traditional healing to help them cope with their mentally ill members.

#### **LIMITATION**

The present study is limited to the 100 samples selected from the selected hospital, thus posing a restriction to make a broader generalization. Investigator had faced difficulty in getting permission for conducting the study. Some tools used for the data collection had to be developed by the researcher as no standard tool was found. The present study is limited to the family members who is accompanying patient at the time of visit to the hospital.

#### **CONCLUSION**

There was good level of knowledge on home care management among the caregivers. There was a positive correlation between the knowledge and perceived challenges. The informational booklet was

found to be effective on home care management. Written informational material in the form of informational booklet was an effective method of teaching the caregivers regarding the home care management. The findings of the study indicate that informational booklet prepared by the investigator was effective in increase and significant gain in knowledge regarding home care management.

### **Declaration by Authors**

**Ethical Approval:** Approved

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**Conflict of Interest:** The authors declare no conflict of interest.

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