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Research Article

Knowledge and Perceived Challenges of Home Care Management Among Caregivers of Mentally Ill Patients in a Selected Psychiatric Hospital of Srinagar with a View to Develop a Pamphlet

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ABSTRACT

Background : The study was conducted with the aim of assessing the knowledge and perceived challenges of home care management among caregivers of mentally ill patients so that informational aid in the form of a pamphlet could be prepared to incredibly improve their knowledge regarding home care management of mentally ill patients in order to help them grow efficiently.

Objective: To assess caregivers' knowledge and challenges in home care for mentally ill patients. To determine the relationship between knowledge and caregiving challenges for mentally ill patients. To examine the association between knowledge, challenges, and caregivers' socio-demographic variables.

Material and Methods: A quantitative descriptive research was conducted at IMHANS, Srinagar, Kashmir, with 80 samples selected via non-probability purposive sampling. Data was collected using a self-structured interview and the "Zarit Burden Interview" scale, then analyzed using descriptive and inferential statistics.

Results: The study found 91.2% had good knowledge, 5.0% average, and 3.8% poor. Moderate to severe burden affected 56.2%, mild to moderate 35.0%, severe 5.0%, and no to mild 3.8%. A strong positive correlation existed between knowledge and caregiving challenges ($r = 0.809$, $p < 0.001$). Significant associations were found with education ($p = 0.002$) and income ($p = 0.014$); challenges also correlated with income ($p = 0.046$).

Conclusion: Despite good knowledge, caregivers faced moderate to severe burdens. Knowledge didn't reduce caregiving challenges. The study suggests organizing health camps, teaching programs, and providing informational aids to enhance caregivers' knowledge of home care management.

Keywords: Knowledge, Perceived Challenges, Caregivers, Mentally Ill Patients, Home Care

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Introduction

Mental illness is “collectively all diagnosable mental disorders” or “health conditions that are characterised by alterations in thinking, mood, or behaviour (or some combination thereof) associated with distress and or impaired functioning”.[1] Mental illness and disorders represent a significant global public health challenge, causing considerable morbidity and mortality worldwide. There are more than 200 classified forms of mental illness. Some of the more common disorders are depression, bipolar disorder, dementia, schizophrenia, anxiety disorders, etc.[2]

Around 1 in every 8 people, or 970 million people, currently suffer from such conditions, placing mental disorders among the leading causes of ill health and disability worldwide. Mental disorders can have a profound impact on individuals, families, and communities, contributing to a reduced quality of life.[3]

A global analysis of the burden of disease attributed to mental disorders estimated that mental disorders accounted for 32.4% of years lived with disability (YLDs) and 13% of disability-adjusted life years (DALYs) in 2016, instead of the earlier estimates suggesting 21.2% of YLDs and 7.1% of DALYs.[4] In 2019, a study of the burden of mental and substance use disorders around the globe found that mental disorders accounted for the largest proportion of DALYs (56.7%), followed by neurological disorders (28.6%) and substance use disorders (14.7%).[5]

During the last decades, many epidemiological studies conducted in India have highlighted the prevalence rate of mental disorders between 5.82% and 7.3%, which shows that the prevalence of major mental disorders is almost the same all over the world. The prevalence reported from these studies is 65 per 1000 in India; one in eleven people suffers from mental illness.[6]

The caregiver plays a key role in caring for the mentally ill patient. Caregivers handle the day-to-day needs of the patients, monitoring their mental state, identifying the early signs of illness, relapse, and deterioration, and helping patients access health care services. When meeting the needs of the patient, caregivers may face the behavioural disturbances of the ill patient and can also be targets of the patient’s abusive or violent behaviour.[7]

The management of the patient at home has assumed greater importance as a result of the shift of patients from the hospital to the community. The process of caring at home often takes a long time and places heavy challenges on the family. Caregivers need good knowledge about disease, coping skills, care at home, and social support. Knowledge of family members regarding home care management of mentally ill patients at home can reduce symptoms, improve medication compliance, prevent relapses in patients, and reduce stress and challenges for family members who are involved in patient care.[8]

Need For The Study

Caring for a relative with a serious mental illness often places a heavy burden on the caregiver’s shoulders. The problems, difficulties, or adverse events that affect the lives of caregivers are the most powerful predictors of psychological distress in caregivers.[9] Being a caregiver can cause disruption and limitations to their daily lives in aspects such as personal freedom, reduced leisure time, missing work, challenges in interpersonal relationships with others (coworkers, friends, and family), as well as induce feelings of shame, guilt, and worry.[10]

Literature reveals that approximately 60-70 million Indians suffer from severe and chronic mental disorders.[11] WHO stated that schizophrenia, depression, dementia, substance-related disorders, and other mental disorders make up 13% of the global disease burden, surpassing both cardiovascular disease and cancer. By 2030, depression will be the second-highest cause of disease burden in middle-income countries and the third-highest in low-income countries.[12] Even the World Health Organization (WHO) estimates that 1 in 4 families will have at least one member suffering from a mental disorder.[11]

One study (2017) found that 45% of Kashmir’s adult population (1.8 million) was suffering from some form of mental distress. There is a high prevalence of depression (41%), anxiety (26%), and post-traumatic stress disorder (19%), and (47%) have experienced some sort of trauma. Another study (2019) found that the prevalence of childhood disorders was 22- 27% (aged 8–14 years). A retrospective study (2012) on suicide recorded an increase of more than 250% in the number of suicide attempts between 1994 and 2012. The results of these studies reflect that there has been a phenomenal increase in psychiatric morbidity over the past 18 years.[13]

A descriptive study was conducted by Deepa et al. to assess the knowledge, perceived challenges, and coping strategies on home care management among 100 caregivers of mentally ill patients in a selected psychiatric hospital in Delhi. The findings of the study revealed that the majority (63%) of caregivers of mentally ill patients had a good level of knowledge, followed by an average level of knowledge (24%), and a poor level of knowledge (13%), respectively. Also, the majority of the caregivers were facing moderately perceived challenges (68%) followed by 26% who were facing severely perceived challenges, and 8% of caregivers were having mild perceived challenges.[14]

Based on the literature and the investigator’s clinical experience, it is evident that the caregivers of mentally ill patients face challenges in providing care to them. Despite the fact that knowledge can play a pivotal role in improving outcomes, there is a dearth of studies in the literature, especially in mental health and psychiatric nursing in Jammu and Kashmir. Hence, the investigator felt the need to conduct the study on the knowledge and perceived challenges of home care management among caregivers of mentally ill patients.

Materials and Methods

A quantitative research approach was used for the present study with a descriptive research design. Permission was obtained from the concerned authorities to conduct the final study.

Ethical clearance was obtained from the Institutional Ethics Committee (IEC) to conduct the study using the non-probability purposive sampling technique to select 80 caregivers in the outpatient and inpatient departments of IMHANS (Institute of Mental Health and Neurosciences), Srinagar, Kashmir. Data were collected by the researchers themselves using a self-structured interview schedule and Zarit Burden Interview scale from July 13 to August 6, 2023.

Sample Size Estimation

To observe the mean knowledge score of 66.70 ± 15.11 with a relative precision of 10% and a 95% confidence level, the sample size required was approximately 80.[15]

The reliability of the self-structured interview schedule regarding home care management among caregivers of mentally ill patients was determined by Cronbach's alpha reliability test. It was found to be 0.778, and the reliability of the 'Zarit Burden interview' scale was already determined by Cronbach's alpha reliability test, and it was found to be 0.93; the intra-class correlation coefficient for the test-retest reliability of the Zarit burden score was 0.89 (N = 149).

The pilot study was conducted on 10% of the total sample, i.e., 8 caregivers of mentally ill patients, to estimate the feasibility of the study.

A "self-structured interview schedule and Zarit Burden Interview scale" were administered to assess the knowledge and perceived challenges of home care management among caregivers of mentally ill patients.

Assessment of knowledge scores was categorised into various levels based on the scale developed by Sawant in his study on knowledge assessment among caregivers towards mental illness.[16] Knowledge score of less than 33% indicates poor knowledge, 33–66% indicates average knowledge and > 66% indicates good knowledge.

Assessment of perceived challenge scores was categorised into various levels based on the scoring criteria of the "Zarit Burden Interview" scale already prepared by Zarit SH in 1980. Perceived challenge score of 0–21 indicates no to mild burden, a score of 21–40 indicates mild to moderate burden, a score of 41–60 indicates moderate to severe burden, and a score of > 61 or 61–88 indicates severe burden.

All data collected were coded and organised before entry. Data were entered in the Statistical Package for Social Sciences (SPSS) version 27.0 and analysed by using descriptive statistics (frequency, percentage, mean, and standard deviation) to describe the extent of knowledge and perceived challenges.

Inferential statistics (Pearson's correlation coefficient) were used to find out the relationship between knowledge and perceived challenges and chi-square (χ^2) test was used to find out the association between knowledge and perceived challenges with their selected socio-demographic variables.

Results and Discussion

Findings Related to Socio-Demographic Variables

Table 1 showed that about half (55.0%) of study subjects belonged to the age group of 20-35 years. Almost two-thirds (66.2%) were males. Regarding educational qualifications, one-third (32.5%) had secondary educational qualifications. About one-third (37.5%) of study subjects were unemployed. Almost one-third (31.3%) had a family income of Rs 10,000 to 20,000/month. The maximum number of study subjects (65.0%) belonged to the nuclear family. The maximum number of study subjects (72.5%) belonged to rural areas. About one-quarter (26.3%) had a relationship with the patient as a child. Over one-quarter (28.8%) of study subjects had 6 months to 2 years as the duration of the caregiver's role. A similar study was conducted by Jack-Ide and Amegheme[17] (n = 50). Findings showed that almost two-thirds (62%) were female. Those in the age range of 34–49 (60%) accounted for the majority of the participants. Regarding educational qualification, two-thirds of study subjects (66%) had primary education, one-fifth (22%) had completed secondary education, only (12%) had a tertiary education, almost half (44%) were public servants, one-third (34%) were self-employed, a small percentage (12%) were farmers, 10% were students, and over half (28%) were parents. Another similar study was conducted by Walke et al. (N = 320).[18] Findings showed that the majority of the caregivers were in the productive age group of 31-50 years (55.6%), 63.6% were female, 33.4% had completed their education up to university level, 40.3% had a family income in the range of INR 5001-10,000, 41.9% provided care for mentally ill dependents for a period of 1–2 years, and 30% were the spouses of those who were mentally ill individuals. About half of them worked. Also, another similar study was conducted by Koshy (n = 80).[11] Findings showed that the majority (87.5%) of caregivers belonged to nuclear families, 75% were providing care from 6 months to 5 years, 61.3% of caregivers were residing in rural areas, and 48.75 % of caregivers were parents.

Findings Related to Knowledge Scores

The majority of study subjects (91.2%) had good knowledge, whereas a small percentage (5.0%) had average knowledge and only (3.8%) had poor knowledge (Figure 1). The mean knowledge score was 31.35 with an SD of ± 4.99 (Table 2). Similar results were conveyed from a study conducted by Deepa et al. (N = 100).[14] Findings of the study revealed that the majority (63%) of caregivers of mentally ill patients had a good level of knowledge, followed by an average knowledge level (24%), and a poor knowledge level (13%). The mean ± SD of the knowledge sore of study subjects was 19.87 ± 4.54.

Findings Related to Perceived Challenge Scores

About half (56.2%) of study subjects faced moderate to severe burden, one-third (35.0%) faced mild to moderate burden, a small percent (5.0%) faced severe burden, and 3.8% faced no to mild burden (Figure 2). The mean score of perceived challenges was 42.76 with an SD of 10.67 (Table 3). A similar study was conducted by Chothe (N = 184).[19] The results showed that mild burden accounted for 41.8%, moderate burden for 52.2%, and severe burden for 6%. The highest burden was seen in financial issues. The mean ± SD of the level of burden was 32.50 ± 14.40.

Findings Related to the Correlation Between Knowledge and Perceived Challenges of Home Care Management among Caregivers of Mentally Ill Patients

Table 4 and Figure 3 revealed that there was a highly significant positive correlation between knowledge and the perceived challenges of home care management among caregivers of mentally ill patients ($r = 0.809$, $p < 0.001$). A similar study was conducted by Deepa et al.[14] Findings showed that there was a positive correlation between knowledge and perceived challenges ($p \leq 0.05$). Another similar study was conducted by Khalil et al. (N = 150).[20] Findings showed that there was a negative correlation reported between the participant's knowledge and their attitude at $p \geq 0.5$, while a positive correlation was conveyed between the respondent's knowledge and the family burden scale at $p \geq 0.5$.

Findings Related to the Association Between Knowledge and Perceived Challenge Scores of Home Care Management Among Caregivers of Mentally Ill Patients with their Selected Socio-Demographic Variables (age in Years, Gender, Educational Status, Occupation, Family Monthly Income, Type of Family, Type of Residence, Relationship with the Patient and, Duration of the Caregiver's Role)

Table 5 depicted that there was a statistically significant association between the knowledge scores of study subjects and their socio-demographic variables like educational status ($p = 0.002$) and family monthly income ($p = 0.014$). There was no significant association found between the knowledge scores of study subjects and other socio-demographic variables like age in years ($p = 0.204$), gender ($p = 0.085$), occupation ($p = 0.678$), type of family ($p = 0.664$), type of residence ($p = 0.443$), relationship with the patient ($p = 0.266$) and duration of the caregiver's role ($p = 0.361$). A similar research study was conducted by Sunitha et al. (N = 110).[21] Findings showed that demographic variables such as caregivers' educational status and place of residence had a statistically significant association with the level of knowledge regarding schizophrenia among caregivers at $p < 0.01$ and $p < 0.05$ levels, respectively. The other demographic variables like age, gender, type of family, occupation, economic status, relationship with the patient, and length of stay with the patient, had not shown a statistically significant association with the level of knowledge regarding schizophrenia among caregivers. Table 6 depicted that there was a statistically significant association between the perceived challenge scores of study subjects and family monthly income ($p = 0.046$). There was no significant association found between the perceived challenge scores of study subjects and other socio-demographic variables like age in years ($p = 0.283$), gender ($p = 0.171$), educational status ($p = 0.123$), occupation ($p = 0.560$), type of family ($p = 0.854$), type of residence ($p = 0.901$), relationship with the patient ($p = 0.129$) and duration of the caregiver's role ($p = 0.094$). Similar results were conveyed from a study conducted by Koshy[11] (N = 80). Findings showed that there was no significant association between perceived challenges and demographic variables like age of the caregiver ($p = 0.09$), gender ($p = 0.41$), educational status ($p = 0.56$), type of family ($p = 0.32$), type of residence ($p = 0.81$), relationship with the patient ($p = 0.05$), and duration of the caregiver's role ($p = 0.05$) at $p < 0.05$.

Table 1.Frequency and Percentage Distribution of Study Subjects According to Their Selected Socio-Demographic Variables

(N = 80)

Variables	Categories	Frequency	Percentage
Age of the caregiver (years)	< 20	3	3.8
	20–35	44	55.0
	36–50	28	35.0
	51–65	4	5.0
	> 65	1	1.2

Gender	Male	53	66.2
	Female	27	33.8
Educational status	Primary school	17	21.3
	Secondary	26	32.5
	Higher secondary	14	17.4
	Graduate and above	23	28.8
Occupation	Government or private employee	16	20.0
	Self-employed	24	30.0
	Unemployed	30	37.5
	Student	10	12.5
Family monthly income (in rupees)	< 10,000	15	18.7
	10,000–20,000	25	31.3
	21,000–30,000	20	25.0
	> 30,000	20	25.0
Type of family	Nuclear	52	65.0
	Joint	20	25.0
	Extended	8	10.0
Type of residence	Rural	58	72.5
	Urban	22	27.5
Relationship with the patient	Parent	18	22.5
	Spouse	13	16.3
	Sibling	19	23.7
	Child	21	26.3
	Any other	9	11.2
Duration of the caregiver’s role	6 months–2 years	23	28.8
	2–4 years	22	27.4
	4–6 years	18	22.4
	> 6 years	17	21.4

Table 2.Mean, Standard Deviation, and Mean Percentage of Study Subjects According to Their Knowledge Scores

Descriptive Statistics	Mean ± SD	Mean Percentage
Knowledge score	31.35 ± 4.99	87.08

Table 3.Mean, Standard Deviation, and Mean Percentage of Study Subjects According to Their Perceived Challenges Scores

(N = 80)

Descriptive Statistics	Mean ± SD	Mean Percentage
Perceived challenges score	42.76 ± 10.67	48.59

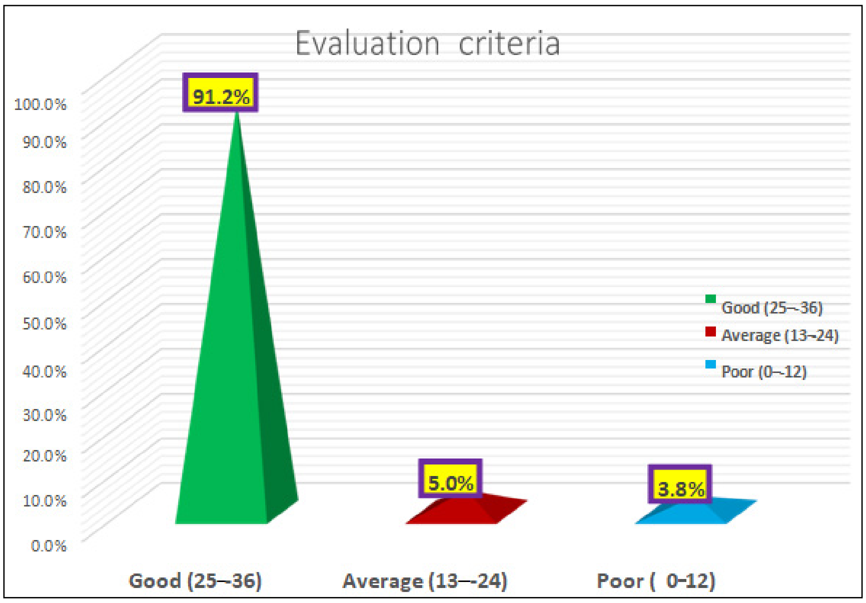

Figure 1.Percentage Distribution of Study Subjects According to Their Knowledge Score

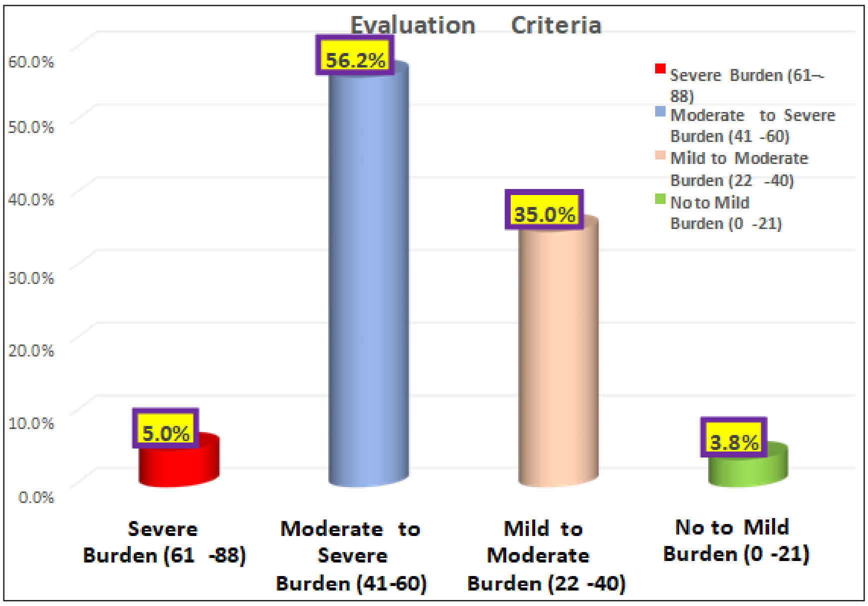

Figure 2.Percentage Distribution of Study Subjects According to Their Perceived Challenge Score

Table 4.Correlation Between Knowledge and Perceived Challenge Scores of Study Subjects

(N = 80)

Pearson's Correlation	Correlation	
	Knowledge	Perceived Challenges
Mean	31.35	42.7625
SD	4.989	10.673
Correlation	0.809	
Table value	0.220	
p value	< 0.001***	
Result	Highly significant	

*** $p < 0.001$ highly significant

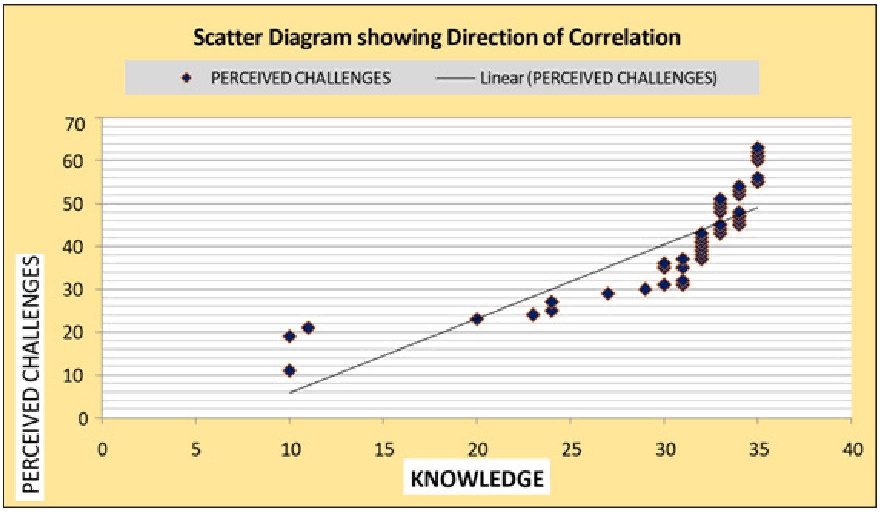

Figure 3.Correlation Between Knowledge and Perceived Challenges

Table 5.Association of Knowledge Scores of Study Subjects With Their Selected Socio-Demographic Variables

(N = 80)

Variables	Categories	Good	Average	Poor	Chi-Square Test (χ2)	df	p Value	Result
		n	n	n				
Age of the caregiver (years)	< 20	3	0	0	10.965	8	0.204	NS
	20–35	43	1	0				
	36–50	23	3	2				
	51–65	3	0	1				
	> 65	1	0	0				
Gender	Male	51	1	1	4.924	2	0.085	NS
	Female	22	3	2				
Educational status	Primary school	11	3	3	20.862	6	0.002*	S
	Secondary	26	0	0				
-	Higher secondary	13	1	0	-	-	-	-
	Graduate and above	23	0	0				
Occupation	Government or private Employee	16	0	0	3.991	6	0.678	NS
	Self-employed	21	2	1				
	Unemployed	26	2	2				
	Student	10	0	0				
Family monthly income (in rupees)	< 10,000	11	1	3	15.894	6	0.014*	S
	10,000–20,000	24	1	0				
	21,000–30,000	20	0	0				
	> 30,000	18	2	0				
Type of family	Nuclear family	47	3	2	2.394	4	0.664	NS
	Joint family	19	0	1				
	Extended family	7	1	0				

Type of residence	Rural	52	4	2	1.627	2	0.443	NS
	Urban	21	0	1				
Relationship with the patient	Parent	15	1	2	9.988	8	0.266	NS
	Spouse	10	2	1				
	Sibling	18	1	0				
	Child	21	0	0				
	Any other	9	0	0				
Duration of the caregiver's role	6 months–2 years	19	2	2	6.585	6	0.361	NS
	2–4 years	20	2	0				
	4–6 years	17	0	1				
	> 6 years	17	0	0				

*Significance at 0.05 level, S: Significant, NS: Non-significant

Table 6.Association of Perceived Challenge Scores of Study Subjects With Their Selected Socio-Demographic Variables

(N = 80)

Variables	Categories	Burden Server	Server Burden Moderate	Moderate Burden To Mi Id	Burden Mi Id To No	Chi-Square Test (χ2)	df	p Value	Result
		(f)	(f)	(f)	(f)				
Age of the caregiver (years)	< 20	0	1	2	0	14.283	12	0.283	NS
	20–35	4	24	16	0				
	36–50	0	16	10	2				
	51–65	0	3	0	1				
	> 65	0	1	0	0				
Gender	Male	4	32	16	1	5.006	3	0.171	NS
	Female	0	13	12	2				
Educational status	Primary School	1	8	5	3	13.966	9	0.123	NS
	Secondary	1	15	10	0				
	Higher secondary	0	10	4	0				
	Graduate and above	2	12	9	0				
Occupation	Government or private Employee	1	9	6	0	7.739	9	0.560	NS
	Self-employed	0	17	6	1				
	Unemployed	3	13	12	2				
	Student	0	6	4	0				

Family monthly income (in rupees)	< 10,000	0	9	3	3	17.125	9	0.046*	S
	10,000–20,000	1	16	8	0				
	21,000–30,000	1	10	9	0				
	> 30,000	2	10	8	0				
Type of family	Nuclear	2	31	17	2	2.627	6	0.854	NS
	Joint	1	11	7	1				
	Extended	1	3	4	0				
Type of residence	Rural	3	34	19	2	0.577	3	0.901	NS
	Urban	1	11	9	1				
Relationship with the patient	Parent	0	12	4	2	17.566	12	0.129	NS
	Spouse	0	5	7	1				
	Sibling	1	14	4	0				
	Child	3	10	8	0				
	Any other	0	4	5	0				
Duration of the caregiver’s role	6 months–2 years	0	12	9	2	14.871	9	0.094	NS
	2–4 years	3	8	11	0				
	4–6 years	1	13	3	1				
	> 6 years	0	12	5	0				

*Significance at 0.05 level, S: Significant, NS: Non-significant

Limitations

The following points were beyond the control of the investigator:

1. The investigator had difficulty in getting samples since caregivers were waiting for their turn to see the doctor in OPD; they felt inconvenienced to answer the tool.
2. The sample size was small due to the limited time frame, so generalisation was not possible.

Conclusion

Based on the findings of the study, the following conclusions were drawn. Findings showed that the majority of the study subjects possessed good knowledge regarding home care management of mentally ill patients but still faced mild to moderate or moderate to severe burdens or challenges in taking care of them. There was a highly significant positive correlation between knowledge and perceived challenge scores. Despite the fact that the majority of the caregivers had good knowledge about the aspects of home care management of these patients including sleep pattern, personal hygiene, communication, physical activities, entertainment, nutrition, fluid intake, safety, drug regimens, and follow-up, they still faced mild to moderate or moderate to severe burden or challenges in taking care of their mentally ill patients. Hence, it can be inferred that the level of knowledge didn’t have any impact in reducing the perceived challenges or burden of caregiving among the caregivers.

Therefore, the study reinforces the need to organise health camps, teaching programs, and the preparation of informational aids in the form of booklets or pamphlets that sensitise caregivers to incredibly enhance their knowledge regarding home care management of mentally ill patients.

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Conflict of Interest: None

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