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Perceived Challenges of Home Care Management Among Caregivers of Mentally Ill Patients in A Selected Psychiatric Hospital of Srinagar

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Abstract

The study was conducted with the aim of assessing the perceived challenges (burden or difficulties) experienced by the caregivers while providing care to their mentally ill patients at home settings.

Title of the study: “Perceived challenges of home care management among caregivers of mentally ill patients in a selected psychiatric hospital of Srinagar.”

Objectives of the study: To assess the perceived challenges of home care management among caregivers of mentally ill patients. To determine the association between perceived challenges 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).

Materials and Methods: A quantitative research approach with a descriptive research design was used. The study was conducted in the inpatient and outpatient departments of IMHANS, Srinagar, Kashmir. 80 samples were selected using the non-probability purposive sampling technique. The data collection tool used was the “Zarit Burden Interview” scale. The data was analyzed using descriptive and inferential statistics.

Results:

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 only (3.8%) faced no to mild burden. There was a statistically significant association between perceived challenges and family monthly income ($p = 0.046$).

Conclusions: The findings of the study concluded that caregivers faced moderate to severe burden or challenges in caring mentally ill patients at home. Therefore, the study reinforces the need to organize health camps, teaching programs, and the preparation of informational aids in the form of booklets or pamphlets that sensitize caregivers to incredibly enhance their knowledge regarding home care management of mentally ill patients.

Key Words: *Perceived challenges, caregivers, mentally ill patients, and home care management.*

INTRODUCTION

Health and well-being comprise physical health, psychological and emotional stability, and social engagement. Physical wellness involves self-care and a temperate lifestyle. Emotional well-being is psychological well-being encompassing subjective experience and positive emotionality. Stable mood and emotional equanimity enhance countering negative emotions and burnout. Social engagement revolves around interpersonal and social relations.[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]

The WHO report (2022) highlights that the number of people living with mental disorders rose significantly because of the COVID-19 pandemic. Initial estimates show a 26% and 28% increase, respectively, for anxiety and major depressive disorders in just one year. While effective prevention and treatment options exist, most people with mental disorders do not have access to effective care. Many people also experience stigma, discrimination, and violations of human rights.[3]

A cross-sectional study was conducted in 2022 to assess the caregiver burden and the quality of life among 120 caregivers of patients suffering from psychiatric illness at a tertiary health-care center in India. The Zarit burden inventory was used to measure the burden levels. The results revealed that the majority had mild to moderate level of burden (49.1%), followed by moderate to severe level of burden in about (22.5%) of caregivers.[4]

Descriptive analytic research was conducted in 2021 to assess the psychological distress and burden of care among 378 family caregivers of patients with mental illness in a neuropsychiatric outpatient clinic in Nigeria. The results revealed that approximately (15%) of caregivers experienced no to mild burden, 51.3% mild to moderate burden, and 34.0% high or severe burden. Nearly (49.0%) of participants experienced psychological distress. A severe rate of psychological distress was observed among subjects caring for patients with schizophrenia (60.7%), epilepsy (60.0%), substance use disorder (52.2%), and depression (49.0%). On the burden scale, six factor components were identified as: personal strain, role strain, intolerance, patients' dependence, guilt, and interference in personal life.[5]

In India, more than 90% of the patients with chronic mental illness live with their families.[6] Caregivers often have to sacrifice their own wants, undergo a lot of stress, and are very much ignored. Caregiving draws on one's emotions, and hence caregivers undergo a lot of depression as compared to the general population.[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.

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.[6] 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.[8]

Literature reveals that approximately 60-70 million Indians suffer from severe and chronic mental disorders. WHO stated that schizophrenia, depression, dementia, substance-related disorder, 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. Even the World Health Organization (WHO) estimates that 1 in 4 families will have at least one member suffering from a mental disorder.[9]

A descriptive study was conducted by **Deepa (2023)** to assess the perceived challenges on home care management among 100 caregivers of mentally ill patients in a selected psychiatric hospital of Delhi. The findings of the study revealed that majority of the caregivers were facing moderately perceived challenges with (68%) followed by 26% facing severely perceived challenges, and 8% caregivers were having mild perceived challenges.[10]

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 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 Institutional Ethical Committee (IEC) on 14-09-2022 with refrence no. SIMS 131/IEC-SKIMS/2022-314 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 Neuro Sciences), Srinagar Kashmir from July 13 to August 6, 2023. The variables of the study contains Knowledge & Perceived challenges of home care management.

Inclusion Criteria: Caregivers of mentally ill patients

a) who were taking care of their patients at home for not less than 6 months.

b) Who could read and understand Urdu and English

Exclusion Criteria: Caregivers of mentally ill patients

a) Who were not willing to participate.

b) Who were not available at the time of the study.

Data was collected by the researcher themselves using **Zarit Burden Interview scale.** With a relative precision of 10% and a 95% confidence level, the sample size required was approximately 80.

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 from july 4, 2023 to july 6, 2023 to estimate the feasibility of the study.The findings of the pilot study revealed that 75.00% of the study subjects experienced moderate to severe burden while only 12.50% were having mild to moderate and no to mild burden. The mean perceived challenges score was 42.75 with SD of ± 15.088.

The "**Zarit Burden Interview scale**" was administered to assess the perceived challenges of home care management among caregivers of mentally ill patients.

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

All data collected were coded and organized before entry. Data were entered in statistical package for social sciences (SPSS) version 27.0 and analyzed by using descriptive statistics (frequency, percentage, mean and standard deviation) to describe the extent of perceived challenges.Chi-square **(χ2)** test was used to find out the association between perceived challenges with their selected socio-demographic variables.

RESULTS AND DISCUSSION

Findings related to the socio-demographic variables

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 qualification. About one-third (**37.5%**) of study subjects were unemployed. Almost one-third (**31.3%**) had 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 relationship with the patient as child. Over one-quarter (**28.8%**) of study subjects had 6months -2-years as duration of the caregiver's role. A similar study was conducted by **Jack-Ide and Amegheme (2016)**[11] (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 twelve percent **(12%)** had a tertiary education, almost half **(44%)** were public servants, one-third **(34%)** were self-employed, a small percent **(12%)** were farmers, **10%** were students, and over half **(28%)** were parents. Another similar study was conducted by **Walke, Chandrasekaran, Mayya (2018)**[12] (N=320). 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 (2018)**[9] (n=80). 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 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. The mean score of perceived challenges was **42.76** with a SD of ± **10.67**. A similar study was conducted by **Chothe (2023)** [13] (N=184). 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. Mean ± SD of level of burden was **32.50 ± 14.40**, respectively.

Findings related to the association between 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).

The findings revealed that there was a statistically significant association between 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 (2018)**[9] (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(f)	Percentage (%)
Age of the caregiver	Below 20 Years	3	3.8%
	20-35 Years	44	55.0%
	36-50 Years	28	35.0%
	51-65 Years	4	5.0%
	Above 65 Years	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%
	Less than 10,000/- month	15	18.7%
	10,000-20,000/- month	25	31.3%

Family monthly income (in rupees)	21,000-30,000/- month	20	25.0%
	More than 30,000/- month	20	25.0%
Type of family	Nuclear family	52	65.0%
	Joint family	20	25.0%
	Extended family	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%

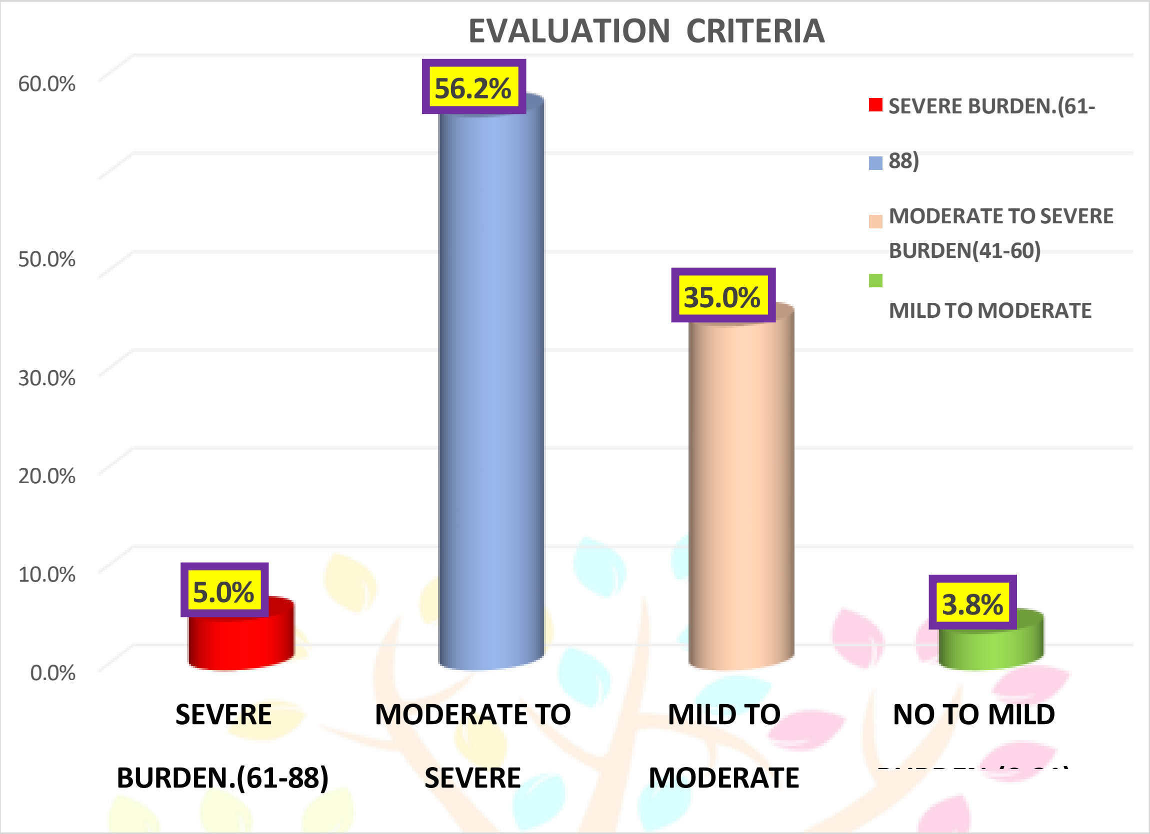

Figure 1. Cylindrical diagram showing the percentage distribution of study subjects according to their perceived challenge scores

Table 2. Mean, standard deviation, and mean percentage of study subjects according to their perceived challenges scores

n=80

Descriptive statistics	**Mean ± sd**	**Mean%**
Perceived challenges score	42.76 ± 10.67	48.59

Maximum=88 Minimum =0

Table 3. Association of perceived challenge scores of study subjects with their selected socio-demographic variables

n=80

Variables	**Categories**	**SEVERE BURDEN** **(f)**	**MODERATE TO SEVERE BURDEN** **(f)**	**MILD TO MODERATE BURDEN** **(f)**	**NO TO MILD BURDEN** **(f)**	**Chi Test (χ2)**	**df**	**P Value**	**Result**
Age of the caregiver	Below 20 Years	0	1	2	0	14.283	12	0.283	NS
	20-35 Years	4	24	16	0				
	36-50 Years	0	16	10	2				
	51-65 Years	0	3	0	1				
	Above 65 Years	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)	Less than 10,000/-month	0	9	3	3	17.125	9	0.046*	S
	10,000-20,000/-month	1	16	8	0				
	21,000-30,000/-month	1	10	9	0				
	More than 30,000/-month	2	10	8	0				
Type of family	Nuclear family	2	31	17	2	2.627	6	0.854	NS
	Joint family	1	11	7	1				
	Extended family	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

LIMITATION:

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 generalization was not possible.

CONCLUSION:

Based on the findings of the study, the following conclusions were drawn:

Findings showed that majority of the study subjects faced mild to moderate or moderate to severe burden or challenges in taking care of their mentally ill patients Therefore, the study reinforces the need to organize health camps, teaching programs, and the preparation of informational aids in the form of booklets or pamphlets that sensitize caregivers to incredibly enhance their knowledge , so that they will not face or experience any type of burden or challenges while managing or/ caring their mentally ill patients at home.

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

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