A Study to Assess the Level of Burden among the Caregivers of Mentally Ill Patients in Selected Hospitals of Imphal (Manipur)

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Abstract

The care giving demands of mentally ill patients can bring significant level of burden for caregiver and affect their overall quality of life, including emotional, physical, financial, work, social life and relationship. The aim of the study was to assess the level of burden experienced by caregivers of mentally ill individuals. A descriptive cross-sectional design was adopted for the present study. A purposive sample of 184 primary caregivers were selected from RIMS Hospital, Imphal. This study was conducted using the Zarit Burden Interview Scale (ZBIS). Descriptive and inferential statistics were used to analyse the data. According to ZBIS, mild burden accounted for 41.8 percent, moderate burden for 52.2 percent and severe burden accounted for 6 percent. Highest burden was seen in financial issues. Burden was found to be significantly associated with gender, religion and type of mental illness. The study concluded that caregivers experienced moderate burden as a result of taking care of mentally ill individuals.

Key words: Burden; Caregivers; Mental Illness, Depression

The World Health Organization (WHO) (2004) defines caregiver burden as "the emotional, physical, and financial demands and responsibilities of an individual's illness that are placed on the family members, friends or other individuals involved with the individual outside the health care system". Mental health statistics worldwide show that anxiety affects 284 million people in the world, depression affects 264 million people, bipolar disorder affects 46 million people and schizophrenia affects 20 million people (Dattani et al, 2021).

In India, 56 million suffer from depression and another 38 million Indians suffer from anxiety disorders. In 2017, an estimation of the burden of mental health conditions for the states across India revealed that as many as 197.3 million people required care for mental health conditions. This included around 45.7 million people with depressive disorders and 44.9 million people with anxiety disorders.

In Manipur, as per the findings of the National Mental health Survey 2015-16, the weighted prevalence of mental illness for lifetime and current experiences were 19.9 percent and 13.9 percent respectively. A lifetime prevalence of 2.4 percent was observed for schizophrenia and other psychotic disorder, 9.4 percent for mood disorder (0.4% for bipolar disorders, 9.1% for depressive disorders), 6.3 percent for neurotic and stress disorders (Athokpam, 2020).

The family plays a vital role in the care of a mentally ill patient. A caregiver has been defined as "a family member, who has been staying with the patient for more than a year and has been closely related with the patient's daily living activities, discussions, and care of health. Psychiatric patients are increasing globally and caregivers play a vital role in supporting them. Care giving for mentally ill patients has an impact on various aspects of a caregiver's life, such as physical, emotional, and social life. They also provide personal care and financial support to their mentally ill relatives. These demands can bring significant level of burden for caregiver and can affect their overall quality of life, including work, socialising and relationship.

The burden of care makes family caregivers vulnerable to burden and it is consistent with a study conducted by Walke, et al (2018). This study revealed that severe burden accounted for 40.9 percent and moderate for 59.1 percent, the highest amount of burden was seen in the areas of physical and mental health, spouse related, and in areas of external support.

Literature Review

A study was conducted by Tanna et al (2021) on evaluation of burden felt by caregivers of patients with schizophrenia and bipolar disorder to as-

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sess the burden of care that caregivers feel while giving care to the patients of schizophrenia and bipolar disorder and to compare the difference in burden between these two conditions. The study evaluated the factors affecting the caregiver's burden. This cross-sectional interview-based study was conducted at the psychiatry department of a tertiary care hospital in Gujarat among caregivers of schizophrenia and bipolar disorder. Each caregiver was given the Zarit-Burden Interview scale in vernacular language and asked to rate each statement from 0 to 4. The final score was calculated and interpreted as: 0–21 – little or no burden, 41–60 – moderate to severe burden, and 61–88 – severe burden. Out of 210 caregivers who reported the interview scale completely, 105 belonged to schizophrenia group and 105 to bipolar disorder. Average of burden score was 64.89 ± 15.7 and 59.11 ± 17.8 (maximum score: 88) in schizophrenia and bipolar group, respectively; difference between the group was statistically significant. In both the groups, it was found that with increase in the age of patients, caregiver's burden increased significantly.

It was concluded that caregivers of schizophrenia and bipolar disorder patients feel a burden, in that order. The more vulnerable to burden are females, elderly, low-income groups, and patients in whom longer duration of care is required.

Koujalgi et al (2021) studied family burden among caregivers of patients with chronic mental disorders. In this cross-sectional study, purposive sampling technique was adopted. Patients were diagnosed as having mental disorders using International Classification of Disease -10, classification of Mental and Behavioural Disorders, Diagnostic Criteria for Research ICD-10 criteria. Pollack and Perlick scale were used to identify the key family caregivers. Patients with two or more years' duration of illness were included in the study group. The results showed that caregivers of patients with chronic mental disorders experienced considerable high degree of family care burden. The study concluded that a high burden is borne by caregivers of patients suffering from chronic mental disorders.

Udoh et al (2021) conducted a study to assess psychological distress using the General Health Questionnaire (GHQ-12). Burden of care was measured using the 22-item Zarit Burden Interview (ZBI) questionnaire. Multiple linear regression was done to determine factors associated with burden of care and psychological distress, while factor analysis was used to determine the underlying forms of burden of care and psychological distress among participants. Caregivers studied were relatives of patients diagnosed for depression (25.1%), substance use disorder (22.2%), schizophrenia (20.2%) and bipolar affective disorder (11.1%). The results showed that approximately 15 percent experienced no-to-mild burden, 51.3 percent mild-to-moderate burden and 34.0 percent high-or-severe burden. Nearly half (49.0%) of participants experienced psychological distress. 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%). High burden of care was more preponderant among caregivers of relatives with mental retardation and epilepsy (50% each) and schizophrenia (39.3%). Higher educational qualification and being self-employed was a predictor of psychological distress. Gender of caregiver and the diagnosis schizophrenia among relatives of caregivers predisposed to burden of care. Three factors including social and emotional dysfunction, psychological distress and cognitive dysfunction were identified as components of psychological health through factor analysis. On the burden scale, six components were identified as: personal strain, role strain, intolerance, patients' dependence, guilt and interference in personal life. To conclude there is a high prevalence of psychological morbidity and burden of care among family caregivers providing care for persons with mental illness.

A study by Adhikari et al (2020) on burden and coping among caregivers of chronic mentally ill patients adopted hospital-based cross sectional study among 100 caregivers who had attended OPD and IPD of Psychiatric department with mentally ill patients. Purposive sampling technique was used. Caregivers who were staying with the patient for at least 6 months were interviewed face-to-face using the Zarit burden Interview scale and Brief Cope Inventory. The results showed that majority of caregivers (66%) had severe burden, 28 percent had moderate to severe burden and 6 percent of them had mild to moderate burden. Mean score and SD of using Active coping as coping strategies was 6.97±1.167, followed by Acceptance 6.28±1.621 and Religion 6.28±1.471 respectively. Problem-focused coping strategies were adopted more than emotion-focused coping strategies. There was significant association between patient's position in the family and patient's occupation with the burden. Positive correlation was found between caregiver's burden and coping strategies that are statistically significant. It was concluded that majority of the caregivers' experienced severe burden while caring for their mentally ill relatives. Problem-focused strategies were adopted by most respondents. Maximum of the caregivers (66%) had severe burden, less than half (28%) had moderate to severe burden and

least six percent had mild to moderate burden while caring their relatives with chronic mental illness.

In a descriptive qualitative study Loujain Sharif et al (2020) conducted 13 semi-structured interviews with members of the Saudi public, recruited through popular social media platforms. Five main themes were constructed from the data: Type of care, Challenges, Coping and support, Perceptions of public awareness, and Messages to others. The findings brought out the different types of burdens that caregivers experience, and their needs that require a range of responses such as educational training on effective coping strategies, and psychological support in the form of counselling or group therapy.

In the current study, caregivers reported psychological distress and the development of mental disorders, such as depression. Caregivers reported many challenges: dealing with the signs and symptoms of a mental disorder, emotional burden, violence and physical burden, role shifting and disturbed family dynamics, stigma, and public views.

Need for Study

The family caregivers take care of the day-to-day needs of the patients, monitor the mental state, identify the early signs of illness, relapse and deterioration, and help the patient in accessing services. Caregiving requires a high degree of personal sacrifice, and it can be physically exhausting and may lead to burn out and emotional exhaustion. But the burdens faced by the caregivers of mentally ill patients in different areas of caregiving are poorly understood. Hence the researcher conducted a study among caregivers of mentally ill patients to create awareness regarding their burdens and to plan strategies to help them cope with the situation.

Objectives

Primary objectives: To assess the level of burden among caregivers of mentally ill patients in selected hospitals of Imphal.

Secondary objectives: To associate the level of burden among caregivers of mentally ill patients with their selected socio-demographic variables.

Materials and Methods

A descriptive cross-sectional design was adopted for the present study. An ethical approval was obtained from Institutional Ethics Committee, College of Nursing, Medical Directorate, Imphal. Permission to conduct data collection was obtained from Professor and Head, department of Psychiatry, Regional Institute of Medical Sciences (RIMS), Imphal. The purpose of the study was explained to the caregivers of the patients, and a written informed consent was sought before enrolling them and the subjects were assured about the confidentiality of the information provided. The study sample comprised of 184 primary caregivers in the age group of 20 to 60 years. The samples were selected using a non-probability purposive sampling technique. The experts validated the tool to collect the data.

$$\text{Sample Size (n)} = \frac{(Z_{1-\alpha/2})^2\,(p)\,(q)}{(d)^2}$$

Where

n = desired sample size

Z1-α/2 = critical value and a standard value for the corresponding level of confidence.

[At 95% CI or 5% level of significance (type I error), it is 1.96]

p= Expected prevalence or based on previous research

q= 1 – p

d= Margin of error or precision.

Here, the sample size is calculated using previous study which stated that the prevalence of mentally ill patients in Manipur was 13.9 percent.

$$n = \frac{(1.96)^2\,(0.139)\,(0.861)}{(0.05)^2}$$

Z1-α/2 = 1.96

P= 13.9% = 0.139

q= 1 – p = 1-0.139 = 0.861

d= 5% = 0.05

Therefore, the study will comprise of 184 primary caregivers of mentally ill patients. The data was collected using socio-demographic proforma and modified Zarit Burden Interview scale.

Section I: Socio-demographic characteristics: Age, gender, religion, educational status, marital status, occupational status, monthly family income, type of family, relationship with the patient, duration of illness and type of mental illness.

Section II: Modified Zarit Burden Interview (ZBI) scale: It is a widely used scale. Responses were graded and scored according to a five-point Likert scale: never (0), rarely (1), sometimes (2), frequently (3), and always (4).

According to Modified Zarit Burden Interview (ZBI) Scale, the scores were interpreted from the

Table 1: Distribution of caregivers of mentally ill patients according to their socio-demographic variable (N=184)

Characteristics of caregiver	Category	Respondents	
		Frequency	Percentage (%)
Age (years)	≤30	56	30.4
	31-40	56	30.4
	41-50	50	27.2
	≥51	22	12.0
Gender	Male	72	39.1
	Female	112	60.9
Religion	Christian	21	11.4
	Hindu	139	75.5
	Muslim	20	10.9
	Any others	04	2.2
Educational status	Illiterate	07	3.8
	Primary	27	14.7
	High-school	79	42.9
	Graduate	57	31.0
	Post-graduate	14	7.6
Marital status	Single	46	25.0
	Married	136	73.9
	Widower/Widow	02	1.1
Occupation of caregiver	Students	24	13.0
	Unemployed	62	33.7
	Business	59	32.1
	Govt. employed	18	9.8
	Private employed	21	11.4
Monthly family income (Rs)	Below 5999	88	47.8
	6000-34,499	87	47.3
	34,500-62,999	09	4.9
	Above 63,000	-	-
Type of family	Joint family	88	47.8
	Nuclear family	96	52.2
	Extended family	-	-
Duration of illness of the patients	< 1 month	10	5.4
	1-3 months	13	7.1
	4-6 months	10	5.4
	>6 months	151	82.1

maximum score of 88 to the lowest score of 0.Total score was divided as Mild burden (0-27), Moderate burden (28-58) and severe burden (59-88).

Reliability of Tool: The tool was pre-tested to check the clarity of the items, their feasibility and practicability. The prepared tool was administered to 5 individuals. The investigator found that the language of the tool was simple & practicable and average time to complete the questionnaire on one individual was 15 minutes. After validation, the tool was subjected to test for its reliability using Guttman Split Half Coefficient. Reliability of the tool was found to be 0.880.

Data Analysis: Data analysis was carried out using SPSS, version 22.Descriptive statistics calculated frequency & percentages for categorical data and mean and standard deviation for quantitative data. Inferential statistics viz. Fisher's Exact test was applied to determine the association between levels of burden with selected demographic variables. p-values equal to or less than 0.05 were considered statistically significant.

Results

A maximum of the subjects (30.4%) were in the age group of 20-30 years and between 31-40 years of age; majority of the caregivers (60.9%) were female, and majority of caregivers (75.5%) belonged to Hindu religion and most (42.9%) of them had completed their education up to high school (Table 1). Majority of the patients were suffering from mental illness for more than 6 months (82.1%).

In type of mental illness (Figure 1), the caregiver giving care to the mentally ill patients were highest for patients suffering from depression (32.6%),

The Zarit burden Interview scale (Table 2) shows that highest burden score was seen in the areas of financial issues (42.6%).

According to the results (Figure 2), 41.8 percent of the caregivers had mild burden, 52.2 percent of caregivers had moderate level of burden and only 6 percent of caregivers had severe level of burden.

Among the demographic variables (Table 3), gender, religion and type of mental illness were found to be significant with the burden level of caregivers.

Discussion

This study revealed that 41.8 percent (77 participants) had mild burden, 52.2 percent (96 participants) had a moderate burden and only 6 percent (11 participants) had severe burden which indicate that majority of the participants had a moderate burden level while giving care to patients with mental illness. These present findings are consistent with the study of Varsha Thakur et al (2022) which showed that majority of caregivers (52.2%) experienced a moderate level of the burden and corroborate the fact that caregivers experience family care burden during the

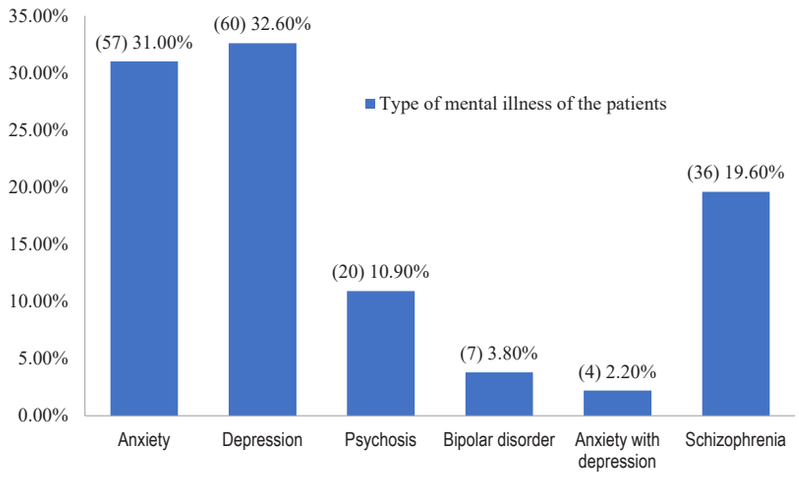

Figure 1: Percentage distribution of type of mental illness of the patients.

Table 2: Mean, median and standard deviation on modified Zarit burden Interview, 22 items rated on a 5-point Likert scale among the caregivers of the mentally ill patients (N=184)

Sl. No	Aspect	Statement	Max. score	Respondents			
				Mean	Mean %	Median	SD
1.	Emotional issues	6	24	8.53	35.5	8.00	4.23
2.	Physical issues	3	12	3.75	31.3	3.00	2.76
3.	Financial issues	2	08	3.41	42.6	4.00	1.77
4.	Role performance	5	20	7.40	37.0	7.00	4.02
5.	Interpersonal relationships and social life	6	24	9.41	39.2	8.50	4.47
Overall Zarit Burden Interview		22	88	32.50	36.9	31.00	14.40

course and treatment of illness.

In this study, the majority of the caregivers (30.4%) were in the age group of 20-30 and 31-40 and were females (60.9%), majority of the caregivers were Hindu (75.5%) and majority of them (52.2%) had experienced moderate burden. It is consistent with a study by Nandakumar (2021) which revealed that majority of respondents (47%) were in the age group of 20-30 years and were females (70%). Majority of the caregivers experienced moderate (50.2%) level of stress. Similar finding was reported by Pratiksha Acharya (2019).

The mental illness included in the present study were depression, schizophrenia, psychosis, bipolar disorder and anxiety. Depression and bipolar disorder belong to Mood Disorder, Psychosis and Schizophrenia belongs to Psychotic Disorder and Anxiety belongs to Neurotic Disorders as per DSM-V classification. In the present study, depression was found to be highest in the type of mental illness of the patient and it was significantly associated with the burden of caregivers. Majority of the caregivers were caring for patients who were suffering from depression (32.6%) followed by patients suffering from anxiety (31%), schizophrenia (19.6%), psychosis (10.9%), bipolar disorder (3.8%) and the least was found in patients suffering from anxiety with depression (2.2%) Balkaran et al (2021) also reported similar finding among caregivers of patients suffering from depression and other chronic mental illness. This can be attributed to the chronic nature of the mental illness and to the fact that caregivers of patients suffering from serious mental illness have greater emotional and physical burden since depression often requires constant supervision due to unpredictable behaviour of the patients.

Our study also showed that majority (82.1%) of the caregivers were caring for their mentally ill relative for 6 months and above, which increased burden on caregivers. This is comparable to the findings of Honamore & Ghorpade (2020) who showed majority were caregiving for 1 to 3 years. This implies that the emotional and physical wellbeing of the caregivers is affected

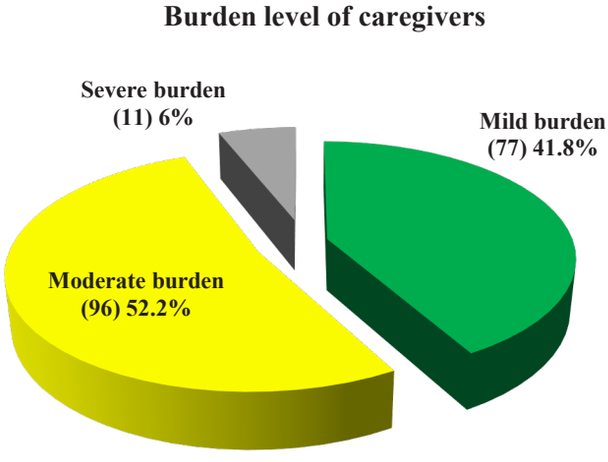

Figure 2: Burden scores level of caregivers while taking care of mentally ill patients

Table 3: Association between burden of caregivers with demographic variables using Fisher's Exact Test (N=184)

Demographic variables	Category	Burden score level (%)			Total (N)	p-value
		Mild burden	Moderate burden	Severe burden		
Age (Years)	≤ 30	26 (46.4)	28 (50.0)	2 (3.6)	56	0.160
	31-40	21 (37.5)	33 (58.9)	2 (3.6)	56	
	41-50	25 (50.0)	21 (42.0)	4 (8.0)	50	
	≥51	5 (22.7)	14 (63.6)	3 (13.6)	22	
Gender	Male	36 (50.0)	35 (48.6)	1 (1.4)	72	**0.040***
	Female	41 (36.6)	61 (54.5)	10 (8.9)	112	
Religion	Hindu	56 (40.3)	76 (54.7)	7 (5.0)	139	**0.034***
	Christian	13 (61.9)	8 (38.1)	0 (0.0)	21	
	Muslim	8 (40.0)	8 (40.0)	4 (20.0)	20	
	Other specify	0 (0.0)	4 (100)	0 (0.0)	4	
Educational status	Illiterate	2 (28.6)	5 (71.4)	0(0.0)	7	0.867
	Primary	11 (40.7)	16 (59.3)	0 (0.0)	27	
	High school	33 (41.8)	39 (49.4)	7 (8.9)	79	
	Graduate	25 (43.9)	29 (50.9)	3 (5.3)	57	
	Postgraduate	6 (42.9)	7 (50.0)	1 (7.1)	14	
Marital status	Single	19 (41.3)	26 (56.5)	1 (2.2)	46	0.711
	Married	57 (41.9)	69 (50.7)	10 (7.4)	136	
	Widow / Widower	1 (50.0)	1 (50.0)	0 (0.0)	2	
Occupational status	Student	11 (45.8)	12 (50.0)	1 (4.2)	24	0.419
	Unemployed	20 (32.3)	36 (58.1)	6 (9.7)	62	
	Business	27 (45.8)	31 (52.5)	1 (1.7)	59	
	Government employee	8 (44.4)	8 (44.4)	2 (11.1)	18	
	Daily wages	11 (52.4)	9 (42.9)	1 (4.8)	21	
Family income	Less than up to 5,999/-	41 (46.6)	43 (48.9)	4 (4.5)	88	0.645
	6,000-34,499/-	32 (36.8)	48 (55.2)	7 (8.0)	87	
	34,500-62,999/-	4 (44.4)	5 (55.6)	0 (0.0)	9	
	63,000/- and above	-	-	-	-	
Type of family	Nuclear family	41 (42.7)	49 (51.0)	6 (6.3)	96	0.971
	Joint family	36 (40.9)	47 (53.4)	5 (5.7)	88	
	Any other specify	-	-	-	-	
Relationship with the patients	Mother	10 (27.8)	23 (63.9))	3 (8.3)	36	0.438
	Father	3 (20.0)	10 (66.7)	21 (3.3)	15	
	Spouse	22 (44.0)	25 (50.0)	3 (6.0)	50	
	Daughter	6 (46.2)	6 (46.2)	1 (7.7)	13	
	Son	7 (46.7)	8 (53.3)	0 (0.0)	15	
	Siblings	19 (55.9)	14 (41.2)	1 (2.9)	34	
	Any others	10 (47.6)	10 (47.6)	1 (4.8)	21	
Duration of illness	< 1 month	5 (50.0)	4 (40.0)	1 (10.0)	10	0.181
	(1-3) months	7 (53.8)	6 (46.2)	0 (0.0)	13	
	(4-6) months	7 (70.0)	3 (30.0)	0 (0.0)	10	
	>6 months	58 (38.4)	83 (55.0)	10 (6.6)	151	
Type of mental illness	Anxiety	33 (57.9)	23 (40.4)	1 (1.8)	57	**0.001***
	Depression	27 (45.0)	31 (51.7)	2 (3.3)	60	
	Psychosis	3 (15.0)	14 (70.0)	3 (15.0)	20	
	Bipolar disorder	1 (14.3)	6 (85.7)	0 (0.0)	7	
	Anxiety with depression	4 (100)	0 (0.0)	0 (0.0)	4	
	Schizophrenia	9 (25.0)	22 (61.1)	5 (13.9)	36	

*p-value < 0.05, significant by applying Fisher's Exact Test

significantly with the duration of illness due to severity of mental illness which in the present study is highest in depression, anxiety, schizophrenia & psychosis requiring longer duration of care.

The Zarit Burden Scale showed that highest amount of burden was seen in financial issues (42.6%) followed by interpersonal and social relationship (39.2%), role performance (37.0%) and emotional issues (35.5%). Least amount of burden was seen in the area of physical issues (31.3%). The present study showed that caregivers experienced highest burden in financial issues. This was consistent with the finding of Grover et al (2020) and Rachana Sharma et al (2018) which also showed highest burden in financial area which was also found in this study as majority of the caregivers (47.8%) were low income earners. This can be attributed to the fact that they had to bear additional financial burden in the treatment cost of their mentally ill relative with respect to their income.

Nursing Implications

Nursing practice: Nurses taking care of the mentally ill patients should assess the burden faced by the primary caregivers and provide psychological support. Health education and demonstrations can be conducted by the nurses periodically to enhance knowledge of the caregivers in order to promote their own psychological well-being and coping strategies.

Nursing education: Nurse Educator can help students understand various burdens faced by the caregivers and their vital role. Students can be taught to provide psycho education to primary caregivers of mentally ill patients and plan health talks that can be beneficial for the primary caregivers.

Nursing administration: Nursing administrators can organise programmes to create awareness regarding the burden experienced by the primary caregivers and encourage the staff nurses to provide psycho education. Nurse managers can set up policies regarding interventional strategies to support the role of caregivers.

Nursing research: The findings of this study can be utilised by nursing researchers for future reference to gain knowledge regarding the vital role of caregivers and their burden which in turn can help them to contribute to the noble nursing profession. Future studies on the burden of primary caregiver can be attempted based on descriptive, quasi-experimental, experimental studies with wider base of nursing knowledge and evidence and the interventions can contribute in reducing the level of caregiver burden.

Recommendations

- Family caregivers of the mentally ill patients should be provided with psycho-educational programs to improve their knowledge and attitude towards mental illness and enable them to cope with the behaviour of their mentally ill relatives. This will provide necessary support to caregivers to deal effectively with the demands and challenges encountered in caregiving.
- A similar study can be conducted in a community setting on burden management strategies among caregivers of mentally ill individuals.
- A psycho-education module can be prepared in various aspects of caregiving to minimise the burden of caregivers.

Limitations: The researcher enrolled only those caregivers of the mentally ill patients who were available in the hospital setting at the time of data collection and willing to participate in the study since it is a hospital-based study. Also, caregivers of patients with substance abuse were not enrolled in the study.

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Conclusion

Majority of the participants had a moderate burden levelwhile giving care to patients with mental illness. Majority of the caregivers experienced highest burden in financial issues. In the present study, gender, religion and type of mental illness were found to be statistically significant with the burden level of caregivers. Burden was significantly higher among female caregivers, caregivers belonging to Hindu religion and caregivers of patients suffering from depression.

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