Burden of Care Among Caregivers of Mentally Ill Patients, Siliguri.

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ABSTRACT

Caregivers of people with mental illnesses are an essential part of their support system. The responsibility of caregiving can impose a significant burden on them. The degree of this burden experienced by caregivers of people with mental illness is perceived to adversely affect the quality of care that family members can provide to their loved ones. A descriptive cross sectional research design was used. The purpose of the study was to assess the burden of care among 139 caregivers of mentally ill patient in a selected hospital using purposive sampling technique. The Zarit Burden Interview Scale was used to assess the burden of care. Data were analyzed by using descriptive statistical method such as frequency, mean, percentage, standard deviation and chi square test to find out the association between level of burden of care and selected demographic variables. Findings showed that majority (46.04%) of caregivers had moderate burden, 28.78% had mild burden, 20.14% had severe burden and 5.04% had little or no burden of care. There was significant association between level of burden of care with demographic variables like educational qualification, employment, relationship with patient and duration of caregiving at $p \leq 0.05$ level of significance. Caregivers had moderate level of burden of care while caring for their mentally ill patient. Implementing self-help strategies and psychoeducational programs could alleviate this care-related burden. Such measures aim to improve their perceived knowledge on mental health conditions and develop coping skills to deal with their patient's behaviour effectively.

Keywords: Burden of care, caregivers, mentally ill patients.

INTRODUCTION

According to the World Health Organization (WHO), approximately 450 million people globally are affected by mental or behavioral disorders of which anxiety and depression were the most common.[1] It also estimates that about 20% of Indians suffer from some form of mental disorders. Depression affects 56 million and anxiety disorders impact 38 million Indians respectively.[2] The National Mental Health Survey of India (2015-2016) stated that the lifetime prevalence of mood disorders in India was 5.6%, while for schizophrenia and other psychotic disorders, it was 1.41% and depressive disorders was 5.25%.[3] These conditions significantly impact thinking, emotional regulation, and behaviour. [1]

In West Bengal, it is estimated that 6-7% of the population suffers from mental and behavioural disorders. These disorders collectively account for 12% of the global burden of disease, and this burden is expected to increase by 15% by 2020.[4]

Mental illness and distress affects not only the person living with the condition, but it can have a profound impact on family members and communities. As the prevalence of mental health problems grows, the flow-on effect on caregivers is also rising. A caregiver has been defined as a family member who has been living with the patient and has been closely involved in his/her activities of daily living, health care, and social interaction for more than a year.[5] Caregivers are vital partners in the recovery journeys of their loved ones who are living with mental health problems and illnesses. Caregivers provide emotional, social, and material support, which includes navigating and advocating for services.[6] In addition to the emotional, psychological, physical and economic impact, the concept of 'burden of care' involves subtle but distressing notions such as shame, embarrassment, feelings of guilt and self-blame.[7]

NEED OF THE STUDY

Caregivers who care for mentally ill individuals bears substantial burden that affects their physical, emotional and social well-being. The World Health Organization states caregiver burden as "the emotional, physical, 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."[5] The burden of care among caregivers of mentally ill patients is substantial and often underestimated. Their responsibilities include round the clock care, handling unpredictable behaviours, administering medications, and coping with societal stigma. These caregivers frequently experience stress, anxiety and depression, which can compromise their overall well-being. Additionally, financial strain, disruptions to personal lives, and strained relationships are common. Relatives of patients with major psychiatric disorders feel burdened, as these disorders are unpredictable and long lasting.

Previous studies have found that burden is experienced in the form of disruption of family life, family interactions, well-being, health, and financial burden affecting their quality of life.

Cham CQ, Ibrahim N, Siau CS et al (2022) conducted a systematic review and meta-analysis to assess caregiver burden among caregivers of patients with mental illness and determine its prevalence. The study revealed that nearly one third of the caregivers experienced a burden when taking care of individuals with mental illness. The prevalence of caregiver burden was significantly higher for carers in hospital settings and among caregivers of individuals with psychosis.[8]

Thakur V, Nagarajan P and Rajkumar RP (2022) conducted a cross-sectional descriptive research to investigate coping strategies and burden among the caregivers of patients with major mental illness and to assess the relationship between them. Findings revealed that majority of caregivers (52.2%) experienced a moderate level of the burden as rated by the Family Burden Interview Schedule. Disruption of the family routine activities was found to be the domain with the highest burden score among caregivers. Only marginal differences in burden scores were found across diagnostic groups (schizophrenia, 1.75 ± 0.57 bipolar disorder and depression 1.86 ± 0.74). Problem-focused coping was the strategy most frequently used by caregivers.[9]

Dhami J and Tuladhar S (2021) conducted a descriptive cross-sectional study with a quantitative approach to find out the burden of care among the family members of mentally ill patients. Ninety-seven family members were selected consecutively from the psychiatric outpatient department and wards of the Mental Hospital in Lagankhel, Nepal. The findings revealed that 40.2% of the caregivers had mild burden, 27.8% had moderate burden, 25.8% experienced little or no burden, and 6.2% experienced severe burden. The mean score percentage of burden was highest in the area of relationships (44.46%), followed by loss of control over one's life (40.08%) and emotional wellbeing (39.29%). There was a significant statistical association between burden and caregiver's age

(p=0.017), educational status (p=0.001), marital status (p=0.378), occupation (p=0.307), relationship with the patient (p=0.035) and duration of caregiving (p=0.026). There was a statistical association between burden and patient's gender (p=0.010), age (p=0.40), marital status (p=0.50), duration of illness (p=0.01) and type of illness (p=0.09).[10]

Udoh EE, Omorere DE, Sunday O, Osasu OS, Amoo BA (2021) conducted a study to assess the levels of psychological distress and burden of care experienced by family caregivers who care for their mentally ill relatives in Edo State, Nigeria. This study assessed psychological distress using the General Health Questionnaire (GHQ-12). Burden of care was measured using the 22-item Zarit Burden Interview (ZBI) questionnaire. The findings revealed that 15% experienced no-to-mild burden, 51.3% mild-to-moderate burden and 34.0% 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%). Having a 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 factor components were identified as: personal strain, role strain, intolerance, patients' dependence, guilt and interference in personal life.[11]

Walke SC, Chandrasekaran V, and Mayya SS (2018) conducted a cross-sectional study to assess the burden of caregivers of mentally ill individuals and their coping mechanisms using the Burden Assessment Schedule and Brief Cope Scale. The findings revealed that majority of the caregivers (59.1%) faced moderate burden and 40.9% of the caregivers faced severe burden. The highest amount of burden was seen in the areas of physical and mental health, spouse related, and in areas of external support. The study findings also showed that the most frequently used coping styles were practicing religion, active coping, and planning.[12]

OPERATIONAL DEFINITION

Burden of Care: In this study, the burden of care refers to the load that caregivers subjectively perceive (obstacles involving physical, psychological, social, and financial problems) while caring for the mentally ill patient, which is measured by the Zarit Burden Interview (ZBI).

Caregivers: In this study, caregivers refer to people who have been caring for mentally ill patients for at least six months.

Mentally Ill Patients: In this study, mentally ill patients refer to people diagnosed with schizophrenia, depression, bipolar mood disorders and anxiety disorders for a period of a minimum of six months.

MATERIAL AND METHODS

A descriptive cross-sectional research design was adopted in this study. The sample of this research study was 139 caregivers of mentally ill patients attending Mental Health Centre in Siliguri through systematic random sampling technique. Non-probability convenient sampling technique was used to select the setting. For assessing the burden experienced by the caregivers, Zarit Burden Interview tool was used. This tool consists of 22 items and total score is 88. Based on the obtained score of the participants, level of burden was interpreted as little or no burden (0-20), mild burden (21-40),

moderate burden (41- 60) and severe burden (61-88). Pretesting of the tool was carried out in 10% of calculated sample size. No modification was necessary in the tool after pretesting.

DATA ANALYSIS

Data was organized, tabulated, and interpreted using descriptive and inferential statistics. Frequency, mean, percentage and standard deviation were calculated under descriptive analysis. Chi- square test was used to analyze the association of burden of care with selected socio-demographic variables.

RESULT

Description of sample characteristics

The data presented in table 1 shows that most of the respondents were between the ages 29-38 years (30.94%), 49-58 years (22.31%), 39-48 years (20.86%) and 18-28 years (19.42%). Female respondents were 61.87% and male respondents were 38.13%. Majority of the respondents that is 56.83% were Hindu, 22.31% were Muslim, 12.23% were Christian and 8.63% of respondents belonged to other religion. Maximum respondents (47.48%) were married, 31.66% were divorced and 20.86% were unmarried. Most of the respondents (44.60%) resided in semi urban areas, 30.22% resided in rural areas and 25.18% resided in urban areas. Maximum respondents (78.42%) belonged to nuclear family, 20.14% belonged to joint family and 1.44% belonged to extended family. The majority of the respondents that is 35.97% had up to secondary education, 27.34% had higher secondary education, 17.07% were graduate and above, 13.67% were illiterate and 5.75% had primary education. Most of the respondent (49.64%) were private employees, 22.30% were self-employed, 14.39% were government employees and 13.67% were unemployed. The relationship with patient of majority of the respondents (27.34%) were siblings, 23.02 were spouse, 20.86% had other relation, 17.27% were parents and 11.51% were children. The duration of caregiving of maximum of the respondents (55.39%) were 1 year – 2 years, 20.14% were 6 months – 1 year, 16.55% were 2 years – 3 years and 07.92% were more than 3 years.

Table 1 Frequency and percentage distribution of sample characteristics.

n=139

Sample	Characteristics	Frequency	Percentage (%)
Age in years	18-28	27	19.42
	29-38	43	30.94
	39-48	29	20.86
	49-58	31	22.31
	59-68	09	06.47
Sex	Male	53	38.13
	Female	86	61.87
Religion	Hindu	79	56.83
	Muslim	31	22.31
	Christian	17	12.23
	Others	12	08.63
Marital Status	Married	66	47.48
	Unmarried	29	20.86
	Divorced	44	31.66
Habitant	Rural	42	30.22
	Semi Urban	62	44.60

	Urban	35	25.18
Type of Family	Joint	28	20.14
	Nuclear	109	78.42
	Extended	02	01.44
Education	Illiterate	19	13.67
	Primary education	08	05.75
	Secondary education	50	35.97
	Higher Secondary	38	27.34
	Graduation & Above	24	17.07
Employment	Unemployed	19	13.67
	Self-employed	31	22.30
	Private employee	69	49.64
	Govt. Employed	20	14.39
Relationship with Patient	Parent	24	17.27
	Spouse	32	23.02
	Children	16	11.51
	Siblings	38	27.34
	Others	29	20.86
Duration of Caregiving	6 Months - 1 Year	28	20.14
	1 Year - 2 Years	77	55.39
	2 Years – 3 Years	23	16.55
	> 3 Years	11	07.92

Level of burden of care among caregivers of mentally ill patients

Figure 1 shows that 46.04% of caregivers had moderate burden, 28.78% had mild burden, 20.14% had severe burden and 5.04% had little or no burden.

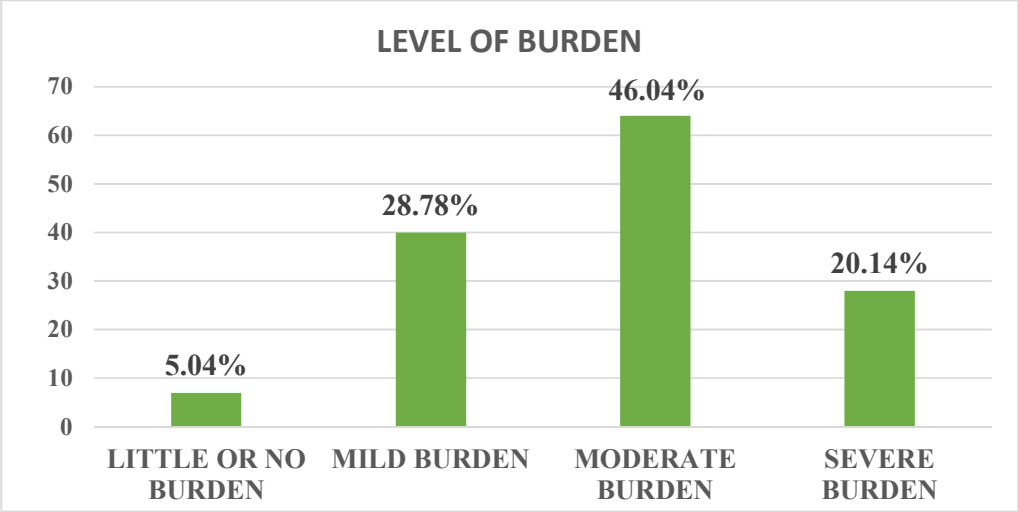

Figure 1: Bar diagram showing percentage distribution of level of burden of care among caregivers of mentally ill patients.

The data presented in table 2 shows that the mean and standard deviation of burden score of the respondents were

Table 2 Mean, median and standard deviation of the burden score

n=139

Variable	Mean	Median	Range	Standard Deviation
Level of Burden of Care	47.52	51	12-80	16.58

Association between level of burden of care among caregivers and demographic variables

Statistically significant association were found between level of burden with demographic variables like educational qualification, employment, relationship with patient and duration of caregiving at $p \leq 0.05$ level of significance.

DISCUSSION

The present study shows that majority of caregivers face moderate level of burden The findings are consistent with the previous studies that found caregivers face significant amount of strain, and difficulties experienced by the caregiver or family of mentally ill people, including a range of psychological, emotional, social, physical and financial problems which increases the burden of caregiving.[13,14,15,16]

CONCLUSION

The study concluded that majority of caregivers face moderate level of burden while caring for their mentally ill patients. These caregivers face emotional, physical, and financial challenges as they support their loved ones. The responsibility can lead to stress, anxiety, and exhaustion, impacting their own well-being. Despite their unwavering dedication, it's crucial to recognize and support these caregivers, providing resources and respite to help alleviate the burden they carry. Nurses can help family caregivers to identify their negative experiences about care-giving and can help them reflect upon their coping strategies to find balance in their situation. There is a need for psycho-social interventions

addressing caregiver burden issues. The study can be replicated with a larger sample so that the findings can be generalized to a larger population. The study can be replicated in other states of India.

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