American Journal of Nursing Science
2025, Vol. 14, No. 4, pp. 83-90
https://doi.org/10.11648/j.ajns.20251404.13

Research Article

Burden of Caregivers of Patients with Physical Illnesses in SSH, BHU

Srivastava Jyoti[1, *], Khanna Seema[2], Srivastava Mona[3]

[1]College of Nursing, Institute of Medical Sciences, Banaras Hindu University, Varanasi India
[2]Department of Surgery, Institute of Medical Sciences, Banaras Hindu University, Varanasi, India
[3]Department of Psychiatry, Institute of Medical Sciences, Banaras Hindu University, Varanasi, India

Abstract

Background: Chronic physical illness places a heavy burden on both the sufferer and the caregiver. Thus, there is a psychological, physical, and economic burden on family members. Caring for physically ill patients places stress and burden on caregivers. Caregivers adopt different ways to cope with it. This study was conducted to assess the burden among caregivers of physically ill patients. Several studies have specifically focused on the quality of life of caregivers of patients with physical illness. *Objectives:* This study examined the burden of caregivers of patients with physical illness. *Methods:* A cross-sectional descriptive design was employed, and 50 participants from physical illness. The data was collected through Zarit Burden Interview and activities of daily living with Socio-demographic variables of both patient and caregivers. Data was analyzed by SPSS 20 statistical software. *Results:* There was no significant association between caregiver burden and Socio-demographic variables like gender, domicile, educational status, marital status, type of family, occupation, religion, duration of the stay with patient, employment status, family income status except debt due to illness with which association present the findings also showed that caregivers of patients with mental illness experiences more burden than caregiver of patients with physical illness. *Conclusion:* There is a need to provide social support for caregivers. The outcome of this study may help the health care providers in designing stress relief programme and better delivery system of cares for primary caregivers by proper specific framing and psycho-education programs.

Keywords

Physical Illness, Burden, Caregiver, Coping, Patient

1. Introduction

Caregiver burden has become a topic of interest for many researchers due to the deinstitutionalization of individuals with mental illness in the early 1970s. According to the World Health Organization [12], sixteen million deaths due to non-communicable diseases occur before the age of 70. According to the World Health Organization [11], non-communicable diseases or chronic diseases such as cancer, heart disease, respiratory disease and diabetes kill 38 million people worldwide every year. The burden experienced by an individual is typically due to increased demands in daily life, inadequate resources to balance the demand, or a combination of both. The consequences are mental and physical mor-

*Corresponding author: jyotichoithram@rediffmail.com (Srivastava Jyoti)

Received: 26 May 2025; **Accepted:** 6 August 2025; **Published:** 27 August 2025

bidity as well as coping and adaptation. A carer is a person who provides support and takes responsibility for the physical and emotional needs of another person who is unable to care for themselves [8]. A carer is a person who has accepted the responsibility to care for a vulnerable relative. They are paid or unpaid members of a person's social network who help them with activities of daily living. The carer's role has come to be recognized as important both functionally and economically [5]. Burden is the extent to which carers feel that their emotional and physical health, social life and financial situation are affected as a result of caring for their relatives. Caregiver burden refers to psychological pain, physical health issues, financial and social stress, impaired family relationships, feelings of frustration from caregiver tasks, and other negative consequences. Caregiver burden is the stress that is felt by caregivers due to a household care situation. It is the stress or burden borne by a person who cares for a seriously ill, disabled, or elderly family member [13]. Caregiver burden and stress refers to the negative psychological, behavioral, and physical effects caused by the chronic stress and burden of caring for family members. According to Collins [3] 18-47% of caregivers fall into depression. Family caregivers of patients with mental illness play the most important role in caring for patients and preventing them from being readmitted. Because of the need to provide long-term care, they cut down on leisure activities, are irregular at work, or even quit their job to take care of the patient. In India, about 20% of caregivers face a lot of stress, poor health, and disrupted family life. According to the BAS, severe burden was 40.9% and moderate burden was 59.1%. The highest burden was observed in the areas of physical and mental health, spouse-related, and external support. Some studies have noted multiple consequences of caregiver burden, such as mental health problems (e.g., depression, anxiety, stress, and burnout syndrome), deterioration in physical health (e.g., diabetes), and other negative effects (e.g., family dysfunction, social isolation, overuse of health services, and financial problems). Some evidence indicates significantly higher scores of overloads among caregivers of patients with mental illness compared to other conditions, such as another chronic illness. In India, women are twice as likely to become caregivers than men, even though men are more likely to be caregivers. Notably, the care giving burden was higher among working women than among homemakers [7].

Caregivers of patients face heavy burden, poor health, and disruption to family life, with literature suggesting growing concern about their ability to cope. Physical health professionals need to be more aware of and address family burden when caring for a patient with a physical illness. Burden can potentially harm the caregiver's physical health and lead to poor patient outcomes. Therefore, there is a need to investigate factors associated with caregiver burden as well as its prevalence, as this will help plan appropriate interventions. We wanted to assess burden among caregivers of physically ill patients.

2. Methods

This study was conducted at a tertiary hospital in Sir Sunder Lal Hospital, Banaras Hindu University, Varanasi. A cross-sectional descriptive design was adopted. 50 Participants included.

2.1. Eligibility Criteria

1) Caregiver of patient aged between 18 to 65 years diagnosed with Physically illness and receiving treatment in and out patient department.
2) Those caregivers who are willing to give consent and voluntarily participate in the study.
3) Patient who has been physically ill for six months and the caregiver staying with the patient for more than six months.

2.2. The Data Collection Tool was Partitioned in to Three Sections Described Below

1) *Section A*: Socio-demographic data collection sheet to collect information from the caregivers and patients respectively, such as age, sex, level of education and so forth.
2) *Activities of daily living of patients*: Independence in activities of daily living (ADL) was used to assess the functional status and independence of patients. This scale assesses the ability of the individual to perform six functions which include bathing, dressing, toileting, transferring, continence, and feeding. Clients are scored "yes "or "no" for independence in each of the six functions. The score of this ranges from 0-6 dependent, 7-12 partial dependent, and 13-18 independent.
3) *Zarit burden interview*: The Zarit Burden Interview (ZBI) is a widely used scale evaluating the stress experienced by the caregivers of the patients. It can be filled in by the caregiver or an interviewer and it consists of 22 statements identifying the impact of care on the life of the individual. Statements are responded to using a 4-point Likert scale. The range of possible scores on the scale is 0-88, with higher values indicating greater value.

2.3. Statistical Analysis

Categorical and quantitative variables were expressed as frequency (percentage) and mean ± SD, respectively. Chi square test was used to find the relationship between categorical variables. For all statistical interpretations, $P < 0.05$ was considered for statistical significance. Statistical analysis was performed using SPSS, version 20.0. Before the start of the study, ethical clearance and approval were obtained from the ethics and research committee of our institution.

Confidentiality was assured and verbal informed consent was obtained from each willing patient and his or her caregiver.

3. Results

A total of one hundred (100) caregivers participated in the study as shown in Table 1. More than half (56%) of them were male. Majority of the participants were from rural background (65 %), taken education up graduate & post graduate (53%). Most of the caregivers were Hindu (90%), about two-thirds (67%) were unskilled workers and (77%) were married while (53%) belong to nuclear family. Most of the caregivers were mothers (23%). They (84%) stay with the patient were more than 10 years. Helping people (96%) were only family members and half of the caregivers (52%) were not taken debt due to illness of family members. Half of the caregivers (53%) were employed and have income less than expenditure (51%).

Table 1. *Sociodemographic variables of caregivers of patients with Physical illness. N= 100.*

S.No	Socio-demographic Variables	Frequency (N)	Percentage (%)
	Gender		
1.	Male	56	56.0
	Female	44	44.0
	Domicile		
2.	Rural	65	65.0
	Urban	35	35.0
	Educational Status		
3.	Up to intermediate	47	47.0
	Graduate and postgraduate	53	53.0
	Marital Status		
4.	Married	77	77.0
	Unmarried	23	23.0
	Type of Family		
5.	Nuclear Family	53	53.0
	Joint Family	47	47.0
	Occupation		
6.	Skilled Worker	33	33.0
	Unskilled Worker	67	67.0
	Religion		
7.	Hindu	90	90.0
	Muslim	10	10.0
	Relationship With Patient		
	Mother	23	23.0
	Father	15	15.0
	Brother	11	11.0
8.	Sister	02	02.0
	Husband	13	13.0
	Wife	14	14.0
	Daughter	04	04.0
	Son	12	12.0

S.No	Socio-demographic Variables	Frequency (N)	Percentage (%)
	Others	06	06.0
	Duration of stay with the patient		
9.	More than 10 years	82	82.0
	Less than 10 years	18	18.0
	Helping People		
	Family members	96	96.0
10.	Neighbours	1	1.0
	Religious people	1	1.0
	Others	2	2.0
	Debt due to illness		
11.	Taken	48	48.0
	Not taken	52	52.0
	Employment Status		
12.	Employed	53	53.0
	Unemployed	47	47.0
	Family income status		
13.	Income less than expenditure	51	51.0
	Income equal to or more than expenditure	49	49.0

Table 2: The mean age of the patients was 41.25 years. More than half of the patients (58%) were females, the educational status were up to intermediate and graduation level while almost two thirds (69%) were employed. More than half of the patients (56%) were living with partner. 30% suffered from neurological disorder, 28% Gastroenterological disorder, 12% of Cardiac disorders, and 22% Oncological disorder followed by 8% suffered from burn disorder.

Table 2. *Sociodemographic variables of patient. N=100.*

S.No	Variables	Frequency (N)	Percentage (%)
	Age		
	Up to 30 years	48	48.0
1.	31-40 years	14	14.0
	41-50 years	18	18.0
	More than 50 years	20	20.0
	Gender		
2.	Male	58	58.0
	Female	42	42.0
3.	Educational Status		
	Low	45	45.0

S.No	Variables	Frequency (N)	Percentage (%)
	Average	26	26.0
	High	29	29.0
	Marital Status		
4.	With partner	56	56.0
	Without partner	44	44.0
	Occupation		
5.	Employed	69	69.0
	unemployed	31	31.0
	Diagnosis Physical		
	Cardiac disorder	12	12.0
	Neurological disorder	30	30.0
6.	Oncology disorder	22	22.0
	Gastroenterology disorder	28	28.0
	Burn	08	08.0

Table 3. *Activities of Daily Living (ADL) of patient.*

S.No.	Activities of Daily Living	Frequency (N)	Percentage (%)
1.	Dependent	23	23.0
2.	Partial Dependent	23	23.0
3.	Independent	54	54.0

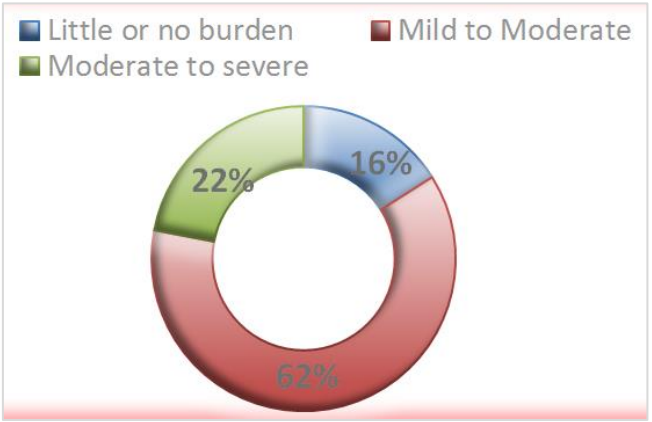

Figure 1. *Pie graph showing level of caregiver burden in physical illness.*

62% caregivers had Mild to Moderate level of burden; 22% Moderate to severe & 16% Little or no burden respectively.

Table 4. Association between caregiver burden and Socio-demographic variables.

Variables	Little or No burden	Mild to Moderate	Moderate to Severe	Total	χ2	P value
Gender						
Male	14	29	13	56	0.087	0.957 NS
Female	10	23	11	44		
Domicile						
Rural	15	37	13	65	2.170	0.338 NS
Urban	9	15	11	35		
Educational Status						
Up to intermediate	13	26	8	47	2.482	0.289 NS
Graduate and Post graduate	11	26	16	53		
Marital Status						
Married	18	40	19	77	0.118	0.943 NS
Unmarried	6	12	5	23		
Type of Family						
Single Family	14	29	10	53	1.672	0.434 NS
Joint Family	10	23	14	47		
Occupation						
Skilled Worker	7	18	8	33	0.222	0.895 NS
Unskilled Worker	17	34	16	67		
Religion						
Hindu	23	45	22	90	1.674	0.433 NS
Muslim	1	7	2	10		
Duration of stay with the patient						
More than 10 years	20	44	18	82	1.067	0.587 NS
Less than 10 years	4	8	6	18		
Debt due to illness						
Taken	5	24	19	48	16.507	0.000 S
Not taken	19	28	5	52		
Employment Status						
Employed	12	29	12	53	0.334	0.846 NS
Unemployed	12	23	12	47		
Family income status						
Income less than expenditure	8	25	18	51	8.707	0.013 NS
Income equal to or more than expenditure	16	27	6	49		

NS= Not significant, s = Significant

Table 4 showed that there is no association between caregiver burden and Sociodemographic variables like gender, domicile, educational status, marital status, type of family, occupation, religion, duration of stay with the patient, em-

ployment status and family income status did not statistically significantly differentiate caregivers who had burden of care from those who did not. There was significant association between caregiver burden and debts due to illness (Chi2 = 16.507 p = 0.00).

4. Discussion

This study examined the Burden of caregivers of patients with physical illnesses in SSH, BHU. Most caregivers were male, came from rural backgrounds, were educated up to graduate and postgraduate level, belonged to Hindu religion, worked in unskilled sector, and were married. Like the findings of some previous studies that were closely related to Jain et al. (2019).

Majority caregivers had single family, the duration of stay of caregivers with the patient was more than 10 years and Patient & their family members had not taken debt due to illness. Our study also revealed that the status of family income in most caregivers was less than expenditure and family members as a helping people. A comparative data related to these variables in the research under the [1] which showed that the caregiver's and patients income status was insufficient for expenses and also family members as a helping people which represents a burden of financial problems for the caregivers is particularly high.

Most patients were in the age group of up to 30 years, male. According to Chandran et al. [2] the most of the patients were in the age group of up to 30-40 years, female.

Majority of the patient were with partner and having lower education which was very different from the research study conducted under Souza et al [9] which showed majority of the patient without partner and having lower education.

Many patients in our study were employed which was similar the study conducted by Jane et al. [6]. We also noted that 54% of patients were independent in performing ADL such as bathing, dressing, toileting, transferring, continence and feeding in contrast the study of Dhandapani et al. [4] having 40% of the patient were dependent in performing ADL.

Most of the caregivers 62% reported mild to moderate burden, 11 (22%) had little or no burden and 8 (16%) had moderate to severe burden while providing care to patient with illness. Mathur et al. [8] reported in their study that 52.5% caregivers had mild to moderate burden, 37.7% had moderate to severe burden and 9.8% had little or no burden while providing care to patient with illness. The finding of not significant association between caregiver burden and gender, domicile, educational status, marital status, type of family, occupation, religion, duration of stay with patient, employment status, debt due to illness and family income status, in this study supported by Walker, et al, [10] and his colleagues.

Chi-square showed significant relationship only with debt due to illness and caregiver burden, as the highest caregiver burden was found in the category of mild to moderate burden. This is directly or indirectly associated with financial distress. A caregiver who takes debt due to illness suffers from mild to moderate burden as the caregiver faces financial distress during diagnosis and treatment.

5. Conclusion

This study concluded that caregivers of physically ill individuals suffer from mild to moderate levels of burden or stress. The highest burden was observed in neurological disorders. Caregivers need support and understanding. Healthcare workers working with caregivers of patients with chronic illness should systematically assess caregivers' coping styles and encourage the use of adaptive and problem-focused coping methods to improve care and patient-related outcomes. Therefore, there is a need to develop strategies that can help them such as providing them with a support structure and counseling services.

Abbreviations

WHO	World Health Organization
ZBI	Zarit Burden Interview
BAS	Burden Assessment Schedule
ADL	Activities of Daily Living

Acknowledgments

Authors thank all the respondents who participated in this study and my colleagues for their support in conducting this study.

I would like to express my sincere thanks to all the caregivers who trustfully participated in the study during data collection.

Declaration of Patient Consent

The authors certify that they have obtained all appropriate patient consent forms. In the forms, the patients' guardians have given their consent for their images and other clinical information to be reported in the journal. The patients understand that their names and initials will not be published.

Limitations

The study population is limited and collected from one Government super-specialty hospital in BHU Varanasi.

Ethical Policy and Institutional Review Board Statement

The study has been approved by our Institute Ethical clearance Board: Ref No: Dean/2023/EC/6097.

Conflicts of Interest

The authors declare no conflicts of interest.

References

[1] Adib-Hajbaghery M, Ahmadi B. Caregiver burden and its associated factors in caregivers of children and adolescents with chronic conditions. International journal of community based nursing and midwifery. 2019 Oct; 7(4): 258.

[2] Chandran V, Madi D, Chowta N, Ramapuram J, Bhaskaran U, Achappa B, Jose H. Caregiver burden among adults caring for people living with HIV/AIDS (PLWHA) in Southern India. Journal of Clinical and Diagnostic Research: JCDR. 2016 May; 10(5): OC41.

[3] Collins RN, Kishita N. Prevalence of depression and burden among informal care-givers of people with dementia: a meta-analysis. Ageing & Society. 2020 Nov; 40(11): 2355-92.

[4] Dhandapani M, Gupta S, Dhandapani S, Kaur P, Samra K, Sharma K, Dolma K, Mohanty M, Singla N, Gupta SK. Study of factors determining caregiver burden among primary caregivers of patients with intracranial tumors. Surgical neurology international. 2015; 6.

[5] Evandrou M, Glaser K. Family, work and quality of life: changing economic and social roles through the lifecourse. Ageing & Society. 2004 Sep; 24(5): 771-91.

[6] Jane OA, Olatunji A, Bamiso MA, Kola OJ, Ayodele OJ, Ideraoluwa BO. Burden of care and psychological distress in primary caregivers of patients with type-2 diabetes mellitus in a tertiary hospital in Nigeria. Ethiopian journal of health sciences. 2019; 29(6).

[7] Kaur N, Puria A, Kumar A, Chaudhury S, Goyal E, Singh VP. Caregiver burden among working women and homemakers taking care of psychiatric patients. Industrial Psychiatry Journal. 2021 Oct 1; 30 (Suppl 1): S166-71.

[8] Mathur S, Chandran S, Kishor M, Prakrithi SN, Rao TS. A comparative study of caregiver burden and self-efficacy in chronic psychiatric illness and chronic medical illness: A pilot study. Archives of Mental Health. 2018 Jul 1; 19(2): 115-22.

[9] Souza AL, Guimarães RA, de Araújo Vilela D, De Assis RM, de Almeida Cavalcante Oliveira LM, Souza MR, Nogueira DJ, Barbosa MA. Factors associated with the burden of family caregivers of patients with mental disorders: a cross-sectional study. BMC psychiatry. 2017 Dec; 17: 1-0.

[10] Walker CL, Rudan I, Liu L, Nair H, Theodoratou E, Bhutta ZA, O'Brien KL, Campbell H, Black RE. Global burden of childhood pneumonia and diarrhoea. The Lancet. 2013 Apr 20; 381 (9875): 1405-16.

[11] World Health Organization. Noncommunicable diseases country profiles 2018.

[12] World Health Organization. The world health report 2003: shaping the future. World Health Organization. 2003.

[13] Yue L, Jia C, Hu B, Zhang Z, Bai M, Wang S, Yao N. Caregiving stress among family caregivers of older adults living with disabilities in China. Geriatric Nursing. 2022 Sep 1; 47: 226-31.