

## A COMPARATIVE STUDY TO ASSESS THE BURDEN AMONG CARE GIVERS OF PATIENTS SUFFERING FROM CHRONIC PHYSICAL ILLNESS AND PSYCHIATRIC ILLNESS ATTENDING OUTPATIENT DEPARTMENTS OF SELECTED HOSPITAL, KOLKATA

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### **Abstract**

Family members play the most important role in giving the care to the patients with psychiatric illness & chronic physical illness at home. During giving care most of the caregivers feel various type of burden. Sometimes they suffer from various psychiatric and neurological symptoms. In India there are limited number of studies in the field of burden whereas it has been reported extensively in studies done abroad. Even among western studies, very few studies have compared the burden status between family caregivers of persons having chronic mental illness and a chronic physical illness. Of late the trend towards caring for chronically ill patients by family members at home is a common phenomenon because of the high costs of institutional care, dissatisfaction with the lack of personalized care in long term settings and the institution's rejection of some clients as unsuitable due to the nature of their illness or the behaviours that result from the illnesses. Quantitative survey approach and comparative descriptive research design was adopted. 94 samples (Arthritis) and 116 samples (schizophrenia) were selected through non probability purposive sampling technique. Demographic data were collected by using valid, reliable structured interview schedule and modified Zarit Burden Scale used for burden assessment. The finding of the study revealed that 52% caregivers of chronic physical illness & 69% caregivers of psychiatric illness told that they feel moderate to severe burden during giving care but only 22% caregivers of psychiatric illness told that they feel severe burden during giving care. Caregivers of psychiatric illness felt more burden than caregivers of chronic physical illness. The result of "t" test is 6.12 which is higher than table value at df 208 at 0.05 level of significance. Significant association present between burden and selected demographic variables such as income, occupation, duration of illness. Assessment of burden of caregivers of psychiatric illness & chronic physical illness is an essential task of mental health professional. Therefore periodic awareness programme in community on coping ability with various situation to improve the quality of life of both patients and caregivers

**Keywords:** Burden, Caregivers, chronic physical illness, psychiatric illness.

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### **INTRODUCTION**

The World Health Organization defines health as "a state of complete physical, mental, social and spiritual well being and not merely the absence of any disease or infirmity". Any deviation from these, individual's health is affected. Caregiver is required when an individual suffering from severe form of physical & mental illness. The responsibility of caregiver to meet the physical and psychological needs of the dependent patient. Every individual has some basic needs that are essential to maintain

quality of life. The caregivers take responsibility to meet the basic needs of the patients. Family members play the most important role in giving the care to the patients with psychiatric illness & chronic physical illness at home. So assessment of burden of caregivers of psychiatric illness & chronic physical illness is an essential task of mental health professional that helps to make plan to give proper mental health services.

## BACKGROUND

The World Health Organization (WHO) states caregiver burden as the “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. A study was conducted by WHO in 2003 concluded that there are about 40 million mentally ill persons in India. The presence of a mentally ill patient in a family cause stressful experience to the care givers especially in physical, emotional, social and financial areas. More the patient behaviour and functional disability put the primary care givers in a great risk as the care giving to a mentally ill patient is a very complex process as most of the mentally illness occur with a change in the behavioral pattern of the patient .These factors may act as a burden to the care givers and can affect even the quality of life of the primary care giver too; as a health professional the mental health nurse has a main responsibility in identifying these levels of burden, coping and quality of life among the care givers specially the primary care givers of the mentally ill patients ignored. In an effort to provide the best possible care for a family member, caregivers often sacrifice their own physical and emotional needs and the emotional and physical experiences involved with providing care can strain even the most capable person.<sup>6</sup> A comparative study of caregiver burden in psychiatric illness and chronic medical illness showed that the caregiver burden scores in the caregivers of psychiatric patients were significantly higher than that of chronic medical illness ( $P<0.0001$ ). The caregiver burden was found to increase with the duration of illness as well as with the age of caregiver. The caregiver burden in the sample population was less as the objective and demand burden did not cross the reference higher value in the given scale, whereas the emotional impact given by the subjective burden was on higher side.<sup>5</sup>

## AIM OF THE STUDY

To compare the burden of care givers of patients with chronic physical illness an psychiatric illness

## OBJECTIVES

1. To identify the burden of caregivers of patients with chronic physical illness .
2. To identify the burden of caregivers of patients with Psychiatric illness .
3. To compare the burden of caregivers of patients between chronic physical illness & psychiatric illness
4. To find out association between burden of caregivers of patients with chronic physical illness & psychiatric illness and socio demographic variables.

## OPERATIONAL DEFINITIONS

**Burden :** Burden is something that is exacting, oppressive or difficult to bear. Burden is a concept that describes the physical, emotional ,social, and financial problems that can be experienced by family caregivers.

**Caregiver:** Caregiver is defined as an individual who is related with blood or marriage and who is

staying with the patient after the diagnosis of chronic physical illness and psychiatric illness. Caregivers can be anyone from spouse, parents, siblings, grandparents and in laws.

**Chronic physical illness:** Long lasting in its effects or a disease that comes with time. The term chronic is often applied when the course of the disease lasts for more than three month. In this study c: A chronic condition is a human health condition or disease that is persistent or otherwise chronic physical illness are arthritis.

**Psychiatric illness:** Mental and behavioral disorders are understood as clinically significant conditions characterized by alteration in thinking, mood (emotions) or behavior associated with personal distress and/or impaired functioning. In this study psychiatric illness are schizophrenia

### ASSUMPTION

The study assumes that

- 1, Caregivers of patients with chronic physical illness may have burden
2. Caregivers of patients with psychiatric illness may have burden.
3. Caregivers of patients will give reliable information for the study.

### HYPOTHESES

1.  $H_1$  : There is a significant difference between level of burden in caregivers of psychiatric illness and caregivers of chronic physical illness.
2.  $H_2$  : There is a significant association between burden of caregivers and selected demographic variables( age, duration of illness, occupation, income).

### CONCEPTUAL FRAMEWORK

Hill's Expanded ABC-X Conceptual model adopted for this study.

### DELIMITATIONS

1. The study is delimited to adult care givers of chronic physical illness e.g arthritis & psychiatric illness e.g schizophrenia.
2. The study is delimited to only those care givers who accompanying the patients in the OPD of government hospital.

### METHODOLOGY

#### Research Approach:

In this study quantitative survey approach is chosen to assess burden of caregivers.

#### Research Design:

Comparative Descriptive research design adopted.

#### Variables:

1. Research Variables: Burden of caregivers of patients with chronic physical illness. Burden of caregivers of patients with .chronic Psychiatric illness .
2. Demographic Variables: Age, gender, marital status, education, occupation, income, residence, duration of illness, relationship with patient,

### Setting of the study

Final study was conducted OPD of Calcutta Pavlov Hospital and Rheumatology OPD of IPGMER & SSKM Hospital.

### Population:

Caregivers of chronic physical ill and psychiatric ill clients . **Sample**

The caregivers of chronic physical illness attending Rheumatology OPD & caregivers of psychiatric illness attending Psychiatric OPD of selected hospital Kolkata.

### Sample size :

Sample size was 94 caregivers of chronic physical illness and 116 caregivers of psychiatric illness.

### Sampling Technique

Non probability purposive sampling technique was selected.

### CRITERIA FOR SAMPLING

#### Inclusion Criteria :

1. Both male & female caregivers of psychiatric ill & chronic physically ill aged 20yrs & above.
2. Who are willing to participate in the study.
3. The study is restricted to only outpatient departments of selected hospital, Kolkata.

#### Exclusion Criteria :

Caregiver of psychiatric ill& chronic physical ill patients who are below 20 years.

### DATA COLLECTION TOOLS AND TECHNIQUES

#### Section I

A structured interview schedule to obtain the demographic data of the participants. There were total 9 items, as follows: age ,sex, marital status ,residence ,education, monthly family income, occupation, duration of illness and relation with the patient.

#### Section II

Zarit Burden Assessment Interview Schedule is a standard tool developed by Dr. Steven H. Zarit It is a standardized tool. This tool is modified after taking permission of authority. Permission was Modified Zarit Burden Assessment interview schedule is used to collect information about burden of caregivers of patients with chronic physical illness & psychiatric illness. It consists of 22 items (ratings are on 5 point Likert scale) where the responses are scored as 0 – never, 1- rarely,2– sometimes ,3- quite frequently, 4 – always. Score range from 0-88, with higher scores indicating increased burden. The scale levels of burden are categorized as no or little burden (0-20), Mild to moderate burden(21-40), Moderate to severe (41-60) and severe(61-88).

**Data analysis:** Descriptive and inferential statistics are used to analyze the collected data.

### RESULT

#### Section 1: Description of demographic characteristics of the subjects

**n = 210**

**n<sub>1</sub> + n<sub>2</sub> = 94 + 116**

Sample Characteristics	Percentage(%) of caregivers of	Percentage (%) of caregivers of chronic
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	chronic physical illness	psychiatric illness
<b>Age</b>		
20 – 35 years	34	39
36 – 50 years	49	30
51 years and above	17	31
<b>Sex</b>		
Male	23	28
Female	77	72
<b>Marital status</b>		
Married	82	77
Unmarried	18	18
Others	0	5
<b>Residence</b>		
Urban	31	34
Rural	69	66
<b>Education</b>		
Illiterate	12	23
Primary	39	42
Secondary	30	22
H.S	11	7
Graduate and above	8	6
<b>Family income</b>		
Less than Rs. 938/-	30	47
Rs. 938 – 1875/-	29	28
Rs.1876 – 3126 /-	18	18
Rs.3127 – 6253/-	14	4
More than Rs. 6253/ -	9	3
<b>Occupation</b>		
Unemployed	58	62
Daily worker	13	13
Businessman	12	12
Service Holder	17	13
<b>Duration of illness</b>		
Up to 12 months	15	14
13 – 36 months	21	27
37 months and above	64	59
<b>Relationship with client</b>		
Parents	28	48
Spouses	43	24
Daughter	6	12
Daughter in law	11	7
Sister	12	9

**Section II: Description of burden among caregivers of chronic physical illness & psychiatric illness.**

**Table -2: Frequency percentage distribution of caregiver's burden among chronic physical illness & psychiatric illness**

n = 210

n<sub>1</sub> + n<sub>2</sub> = 94 + 116

Sl. no.	Burden Score	Chronic Physical Illness		Psychiatric Illness	
		Frequency	Percentage (%)	Frequency	Percentage (%)
1	Little or no burden (0-20)	0	0	0	0
2	Mild to moderate burden (21-40)	45	48	10	9
3	Moderate to severe burden (41-60)	49	52	80	69
4	Severe burden (61-88)	0	0	26	22

**Section III: Findings related to compare the burden of caregivers of patients between chronic physical illness & psychiatric illness.**

**Table – 3 : Comparisons of burden of caregivers of patients between chronic physical illness and psychiatric illness.**

n = 210

n<sub>1</sub> + n<sub>2</sub> = 94 + 116

Groups	Mean	MD <sub>D</sub>	SD <sub>D</sub>	SE <sub>MD</sub>	“t” Value
Caregivers of Chronic Physical Illness	39.23	10.04	2.51	1.17	8.58
Caregivers of Psychiatric Illness	49.33				

“t” df (208) = 1.97 \* p<0.05

**Section IV: Findings related to association between burden of caregivers of patients with chronic physical & psychiatric illness and socio demographic variable.**

**Table- 4: Association of burden with some selected socio-demographic variables (Income) among caregivers of chronic physical illness & psychiatric illness.**

n = 210

n<sub>1</sub> + n<sub>2</sub> = 94 + 116

Group	Variable	Burden of caregivers			χ <sup>2</sup>
		Mild to moderate burden	Moderate to severe burden	Severe burden	
Chronic Physical Illness	Less than Rs. 938	8	20		5.95*
	More than Rs.938	37	29		
Psychiatric Illness	Less than Rs. 938	10	23	21	
	More than Rs.938	19	32	11	6.87*

χ<sup>2</sup> = 3.84 at df (1), 5.99 at df(2) P< 0.05

**Table - 5: Association of burden with some selected socio-demographic variables (Occupation) among caregivers of chronic physical illness & psychiatric illness.**

n = 210

n<sub>1</sub> + n<sub>2</sub> = 94 + 116

Group	Variable	Burden of caregivers			χ <sup>2</sup>
	Occupation	Mild to moderate	Moderate to severe	severe	

		moderate	severe	burden	
		burden	burden		
Chronic Physical Illness	Not Working	25	30		0.31
	Working	20	19		
Psychiatric Illness	Not Working	16	30	26	
	Working	13	25	6	

$\chi^2 = 3.84$  at df (1), 5.99 at df (2)  $P < 0.05$

**Table-6: Association of burden with some selected socio-demographic variables (Duration) among caregivers of chronic physical illness & psychiatric illness.**

n = 210

$n_1 + n_2 = 94 + 116$

Group	Variable	Burden of caregivers			$\chi^2$
		Mild to moderate	Moderate to severe	Severe burden	
Duration		burden	burden		
Chronic	Upto 36 months	21	13		4.12*
	Above 36 months	24	36		
Psychiatric Illness	Upto 36 months	15	21	12	1.71
	Above 36 months	14	34	20	

$\chi^2 = 3.84$  at df (1), 5.99 at df (2)  $P < 0.05$

### DISCUSSION IN RELATION TO OTHER STUDY

The study result is consistent with a study conducted by Prasanth A et al conducted a study regarding burden of caregivers of patients with chronic physical & mental illness. The results showed that caregiver burden in families of psychiatric clients is higher than that of other medical illness, & increases with the duration of illness.

P Ampalam et al<sup>3</sup> conducted a comparative study of caregiver burden in psychiatric illness and chronic medical illness to compare the caregiver burden in psychiatric illness and chronic medical illness and to study the association of caregiver burden with demographic factors like age, gender, duration of caregiving. The caregiver burden scores in the caregivers of psychiatric patients were significantly higher than that chronic medical illness ( $p < 0.0001$ ).<sup>21</sup> The study result also consistent with my study result.

### MAJOR FINDINGS OF THE STUDY

1. Maximum caregivers of chronic physical illness belonged to 36 -49 yrs. (49%) & while maximum number of caregivers of psychiatric illness belongs to 18- 35 yrs. (39%).
2. Majority of the caregivers of chronic physical illness (77%) were female & similarly among the caregivers of psychiatric illness most of the caregivers (72%) were female.
3. Most of the caregivers of chronic physical illness (82%) were married & majority of caregivers of psychiatric illness (77%) were married. Only 5% caregivers of chronic physical illness were widow.
4. Majority of caregivers of chronic physical illness (69%) & caregivers of psychiatric illness (66%) were lived in rural area

5. Maximum respondents had only primary level of education among caregivers of both chronic physical illness (39%) & psychiatric illness (42%). 12% were illiterate among caregivers of chronic physical illness & 23% were illiterate among caregivers of psychiatric illness. Only 8% caregivers of chronic physical illness & 6% caregivers of psychiatric illness were graduate.
6. 47% of family's monthly per capita income were less than Rs. 938 /- among caregivers of chronic physically illness & 30% among caregivers of psychiatric illness. 9% caregivers of chronic physically illness & 4% caregivers of psychiatric illness had monthly per capita income more than Rs. 6254/-
7. Maximum (58%) of caregivers of chronic physical illness were housewife & similarly among the caregivers of psychiatric illness 62% were housewife.
8. Majority (64%) of clients of chronic physical illness suffering from 37 months & above & similarly 59% of clients of psychiatric illness suffering from 37 months & above.
9. Only 28% caregivers of chronic physical illness & 48% psychiatric illness were parents. 43% caregivers of chronic physical illness & similarly only 24% caregivers of chronic psychiatric illness were spouse.

### **Findings related to burden of caregivers of patients with chronic physical illness & Psychiatric illness :**

None of the caregivers (0%) from each group conveyed that they feel little or no burden during giving care. 47% caregivers of chronic physical illness & 25% caregivers psychiatric illness told that they feel mild to moderate burden during giving care. 51% caregivers chronic physical illness & 47% of caregivers psychiatric illness told that they feel moderate to severe burden during giving care & only 28% caregivers of chronic physical illness told that they feel severe burden during giving care

### **Findings related to comparison of burden between caregivers of chronic physical illness & psychiatric illness.**

Caregivers of psychiatric illness felt more burden than caregivers of chronic physical illness.

### **Findings related to association between burden of caregivers of patients with chronic physical illness & psychiatric illness and socio demographic variables.**

1. There was significant association in both of caregivers of chronic physical illness & psychiatric illness between income of family and burden (caregivers of chronic physical illness  $\chi^2 = 5.95$ , caregivers of psychiatric illness  $\chi^2 = 6.87$ )

2. There was no significant association in caregivers of chronic physical illness between occupation & burden. Caregivers of chronic physical illness  $\chi^2 = 0.31$ . But significant association present in caregivers of psychiatric illness between occupation of family and burden (caregivers of psychiatric illness  $\chi^2 = 6.91$ ).

3. There was significant association in caregivers of chronic physical illness between duration of illness & burden (caregivers of psychiatric illness ( $\chi^2 = 4.12$ )). But no significant association present in caregivers of psychiatric illness between duration of illness and burden as the obtained value of chi-square in caregivers of chronic psychiatric illness was 1.71.

### **CONCLUSION**

The present study reveal that caregivers of psychiatric illness feel more burden than caregiver of physical illness. Burden depend on their occupation and income. Some burden may be overcome by



improving their socioeconomic condition. But most of the burden may be overcome by increasing their coping ability and awareness about mental illness..

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