Research Report

PSYCHOSOMATIC PROBLEMS IN CAREGIVERS OF PATIENTS WITH MAJOR MENTAL ILLNESSES

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ABSTRACT

Aim: To assess the psychosomatic problems among caregivers of patients with major mental illnesses.
Materials and Methods: In this descriptive study, based on purposive sampling technique, 120 caregivers of patients with major mental illness admitted under Department of Psychiatry in a tertiary care centre were selected. Standardized four-dimensional symptom questionnaires were used to assess psychosomatic problems in caregivers of patients with major mental illnesses.
Results: Caregivers of the patients with major mental illness had moderately high to high level of psychosomatic problems. There was no significant difference in psychosomatic problems of caregivers among major mental illnesses (Schizophrenia, mood disorders, and alcohol dependence syndrome).
Conclusion: Caregivers of patients with major mental illnesses experience psychosomatic problems. There is no significant difference between the specific diagnosis of the patient and psychosomatic problems of caregivers.

Keywords: Psychosomatic problems, caregivers, major mental illnesses.

BACKGROUND AND RATIONALE

World Health Organization (WHO), in 2013, stated that globally, in both developed and developing countries, 1 in 4 (25%) suffer from mental disorders. Four of the six leading causes of Years Lived with Disability are depression, alcohol use disorders, schizophrenia, and bipolar disorder.[1]

Epidemiological studies report prevalence rates for psychiatric disorders varying from 9.5 to 370/1000 population in India. About 20% of the adult population in the community is affected by one or the other psychiatric disorder. More than 70% of mentally challenged patients live with their families, and family is the major care provider.[1] In India, an estimated 30% of the population suffers from some form of psychiatric disorder. Twenty million Indian families have at least one member suffering from schizophrenia. More than 12% of Indian children aged 1-16 years suffer from mental disorders and the incidence of mental retardation is also high. Severe mental disorders that include schizophrenia, bipolar disorders and major depression affect nearly 2% of our population.[2]

The occurrence of mental illness in a loved one is a catastrophic event and often results in enduring consequences for the family. Thus, the impact of the illness is experienced not only by the affected member but by the entire family as well. Families have to shoulder a heavy burden in means of money also. This poses an enormous challenge to the families since it demands considerable time and effort from them in addition to other attributes such as patience, endurance, innovativeness, and

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resourcefulness. It is not surprising, therefore, that those families often feel overwhelmed and helpless in addressing this situation.[3]

As the illness progresses, usually one person in the family comes forward as the caregiver. Much of the caregiving responsibility will fall on him/her.[4] This causes an alteration in physiological functioning of the individual due to psychological factors. "Psychosomatic disorders" indicate changes which occur both in psychic-mind and somatic body. People can convert transference of unexpressed emotions into physical symptoms, and the phenomenon is called somatisation'. As people are largely ignorant of the underlying psychological factors, they usually obtain medical treatment for the physical symptoms and do not opt for a psychiatric evaluation. Chronic stress seems to play a particularly important part and can influence not only the causes of the illness but can also worsen the symptoms and affect the course of the disorder.[5]

Chronic diseases place a considerable burden on family caregivers who take the sole responsibility of caring for chronically ill patients. The profound psychosocial, physical, and financial impact on the family of individuals with severe mental illness is comparable to that of persons with other illnesses such as Alzheimer's disease or cancer.[6]

Living with and caring for an individual with a psychiatric disorder seems inherently stressful. Caregivers experience significantly higher level of psychological distress than the general population. Studies have shown that taking care of a mentally ill person will cause the caregiver to face feelings of insecurity, sorrow, and worry.[7]

Mental health professionals have an important duty to acknowledge the burden of caregivers. They are in a position to render support and refer them to get support through social workers and community agencies. Such measures would ensure caregiver wellbeing. For that, mental health professionals have to assess the psychosomatic problems and provide them adequate care to get out from that scenario. Many studies have been done to assess the burden of caregivers of mentally ill. Caregiver burden is a broad aspect which includes physical, mental, emotional, social, and financial aspects.

OBJECTIVES

1. To assess psychosomatic problems among caregivers of patients with major mental illnesses.
2. To compare the psychosomatic problems of caregivers of patients with schizophrenia, mood disorders, and alcohol dependence syndrome.

OPERATIONAL DEFINITIONS

Psychosomatic problems: In this study, "psychosomatic problems" are the complaints and symptoms reported by the caregivers, like somatization, distress, depression, and anxiety, and are assessed using standardized Four-Dimensional Symptom Questionnaire (4DSQ).

Caregiver: In this study, "caregiver" is a person who resides with the patient and holds major responsibility in the care of the patient for a minimum period of two years and is bonded by a relation — mother/father, husband/wife, brother/sister, son/daughter, son-in-law/daughter-in-law.

Major mental illnesses: In this study, major mental illnesses included are schizophrenia, mood disorders and alcohol dependence syndrome as diagnosed by International Classification of Diseases 10th revision (ICD- 10) criteria[8] and having a duration of two or more years.

METHODOLOGY

This was a descriptive study conducted in the Department of Psychiatry in a tertiary care centre. The study duration was one year from 1st July 2015 to 30th June 2016. The study population comprised of caregivers of patients with a major mental illness who satisfied the inclusion criteria.

Inclusion Criteria

1. Caregivers who are willing to participate in the study.
2. Caregivers who are able to comprehend the instructions in Malayalam.

Exclusion Criteria

1. Caregivers who are already diagnosed to have psychiatric disorders as per ICD-10 criteria and are on treatment.
2. Caregivers who are below 18 years of age.

The study sample constituted 120 caregivers. One caregiver per patient and the non- probability purposive sampling method were used.

STUDY TOOLS

1. Sociodemographic datasheet

An interview schedule was used to assess the demographic data of caregivers such as age, gender, marital status, relationship with the patient, education, domicile, occupation, and total duration of caregiving.

2. Four-Dimensional Symptom Questionnaire

The Four-Dimensional Symptom Questionnaire (4DSQ) developed by Terluin (1996)[9], is a self-reported questionnaire comprising 50 items distributed over four scales. It is developed for general practice to assess the level of distress, somatization, depression, and anxiety among the study participants. One important feature of this tool is that items are worded as questions similar to those that can be asked in everyday primary care practice. The reference period is the last week.

The 'somatisation' scale measures a range of common physical symptoms. The 'distress' scale measures nonspecific symptoms of psychopathology, ranging from worrying and irritability to fatigue and demoralization. The 'depression' scale measures severe anhedonia and depressive thoughts, including suicidal ideation, symptoms that are characteristic of depressive disorders. The 'anxiety' dimension encompasses symptoms such as free-floating anxiety, panic attacks, phobic anxiety, and avoidance behaviour. Reliability of the 4DSQ scales is high, with alpha-coefficients ranging from 0.84 to 0.94 and test-retest coefficients ranging from 0.89 to 0.94.

STUDY PROCEDURE

Caregivers who met the inclusion criteria were selected using non-probability purposive sampling technique. Rapport was established with the caregivers, the purpose of the study was explained to them, and informed consent was obtained. Basic information of caregiver and patient was collected using sociodemographic data sheet. Psychosomatic problems of caregivers were assessed by 4DSQ. Sociodemographic data were analysed by using frequency and percent. Chi-square test was used to compare the psychosomatic problems of caregivers of patients with schizophrenia, mood disorders, and alcohol dependence syndrome. The analysis was done using SPSS version 22.

RESULTS

Sample characteristics:

28.3% of caregivers were aged >58 years. The majority (59.2%) were females, and 78.3% were married (Table 1). Majority of caregivers were either parents (34.2 %) or spouses (35%). Most were

Table 1: *Frequency distribution and percentage of caregivers of patients with major mental illnesses based on age, gender, and marital status (N=120)*

VARIABLES	n	%
Age in years		
18-27	16	13.3
28-37	20	16.7
38-47	21	17.5
48-57	29	24.2
>58	34	28.3
Gender		
Male	49	40.8
Female	71	59.2
Marital status		
Unmarried	17	14.2
Married	94	78.3
Separated	1	0.8
Widow/ Widower	8	6.7

educated up to primary or secondary level. The majority (76.7%) belonged to rural domicile (Table 2).

41.7 % of caregivers were unemployed. The majority (40%) were caregiving only for 2-6 years (Table 3).

Psychosomatic problems of caregivers of patients with major mental illnesses:

Somatisation level was moderately high in 47.5%, 40%and 30% of caregivers of patients with schizophrenia, mood disorder, and alcohol dependence respectively. Distress level was found to be high in 30% each of caregivers of patients with schizophrenia and mood disorder while 42.5 % of caregivers of patients with alcohol dependence were highly distressed (Table 4).

***Table 2:** Frequency distribution and percentage of caregivers of patients with major mental illnesses based on relationship with the patient, educational level and domicile (N=120)*

VARIABLES	n	%
Relationship with patient		
Parents	41	34.2
Spouse	42	35.0
Son/ daughter	10	8.3
Brother/ sister	21	17.5
Son in law/daughter in law	6	5.0
Educational level		
Primary	42	35.0
Secondary	43	35.8
Pre-university	21	17.5
University	10	8.3
Other	4	3.3
Domicile		
Urban	28	23.3
Rural	92	76.7

***Table 3:** Frequency distribution and percentage of caregivers of patients with major mental illnesses based on occupation and total years of caregiving after the diagnosis (N=120)*

VARIABLES	n	%
Occupation		
Not working	50	41.7
Government Job	10	8.3
Private sector	14	11.7
Self-employed	20	16.7
Daily wages	25	20.8
Contract basis	1	0.8
Total years of caregiving after the diagnosis		
2-6 years	48	40.0
7-11 years	23	19.2
12-16 years	18	15.0
17-21years	12	10.0
>21 years	19	15.8

Level of depression was high in 47.5%, 30% and 40% of caregivers of patients with schizophrenia, mood disorder, and alcohol dependence respectively. Moderately high level of anxiety was found in 22.5%, 12.5% and 27.5% of caregivers of patients with schizophrenia, mood disorder and alcohol dependence respectively (Table 4).

Analysis revealed no significant difference in psychosomatic problems (somatisation, distress, depression, and anxiety) of caregivers of patients with schizophrenia, mood disorders or alcohol dependence syndrome (Table 4).

DISCUSSION

The present study focused on the psychosomatic problems among caregivers of patients with major mental illnesses attending a tertiary care centre.

It was found that 28.3% of the caregivers had age more than 58 years. The majority (59.2%) of the caregivers were females. Caregivers are more likely to be women in many parts of the world. A study conducted in the United Kingdom found that about

Table 4: Comparison of psychosomatic problems among caregivers of patients with schizophrenia, mood disorders and alcohol dependence syndrome(n=120)

Psychosomatic problems of caregivers	Diagnosis of the patient						Chi- square	P value
	Schizophrenia (n= 40)		Mood disorder (n= 40)		Alcohol dependence syndrome (n= 40)			
	f	%	f	%	f	%		
Somatisation level								
Low (0-10)	17	42.5	23	57.5	21	52.5	6.993	0.136
Moderately high (11-20)	19	47.5	16	40.0	12	30.0		
High (21-32)	4	10.0	1	2.5	7	17.5		
Distress level								
Low (0-10)	6	15.0	14	35.0	7	17.5	7.442	0.114
Moderately high (11-20)	22	55.0	14	35.0	16	40		
High (21-32)	12	30.0	12	30.0	17	42.5		
Depression level								
Low (0-2)	15	37.5	19	47.5	15	37.5	2.978	0.562
Moderately high (3-5)	6	15.0	9	22.5	9	22.5		
High (6-12)	19	47.5	12	30	16	40		
Anxiety level								
Low (0-7)	27	67.5	32	80.0	27	67.5	3.488	0.480
Moderately high (8-12)	9	22.5	5	12.5	11	27.5		
High (13-24)	4	10.0	3	7.5	2	5.0		

58% of the caregivers were women and Asian studies found that about 70% of family caregivers were females.[8] The World Federation of Mental Health estimated that, globally, about 80% of the caregivers were women.[9] This study too has similar findings may be because in most families in Kerala males are the breadwinners and females look after the home and care for the patients. In the present study, the majority (78.3%) of the caregivers were married, 35% of caregivers were spouses, and 34.2% were parents. A study conducted in Bangalore to assess burden among caregivers of the mentally ill patients also found that 23.3% of the caregivers belonged to the spouse category.[10]

In the present study, the majority of caregivers of patients with major mental illnesses (35.0%) had secondary school education. We also found that majority (41.7%) of caregivers of patients with major mental illnesses was not working. A study conducted in Canada found that approximately 30% of informal caregivers work outside the home. Over one million working Canadians take care of a person diagnosed with a mental illness. Of these, one-third report that it interferes with their paid job due to chronic health problems, depression, and excess stress when the caregiving increases in intensity.[11] Caregivers could not get enough time to go for a job while caring for a patient with a major mental illness.

A study conducted by National Alliance for Caregiving found that about one in ten caregivers report that caregiving has caused their physical health to get worse.[12] Caregivers also reported chronic conditions (including heart attack/heart

disease, cancer, diabetes, and arthritis) at nearly twice the rate of non-caregivers. Caregivers suffer from increased rates of physical ailments (including acid reflux, headaches, and pain/aching), increased tendency to develop serious illness, and have high levels of obesity and bodily pain.[13] A study conducted in Malaysia found psychological distress in 14% of the caregivers and depressive disorders in 6% of the caregivers.[14] Studies have consistently shown that at least one-third of caring relatives had elevated levels of anxiety or depression connected with the caring role.[15]A research study conducted at Sri Lanka to assess the impact of long-term psychotic disorders on caregivers found that up to 60% of caregivers felt very anxious and depressed.[16]

One of the major findings of the present study was that there was no significant difference in psychosomatic problems of caregivers of patients with schizophrenia, mood disorders or alcohol dependence syndrome. This finding was contradictory to the findings of some past studies that caregivers of schizophrenia had a higher level of distress, depression, and anxiety than caregivers of patients with other major mental illnesses. A cross-sectional study conducted in India to compare family care burden in families of schizophrenia patients and patients having depressive disorders found that caregivers of patients with schizophrenia had significantly increased mean burden score.[17] A study conducted in Hyderabad to assess the extent and pattern of burden felt by the caregivers of patients with schizophrenia in comparison with bipolar disorder found that the caregivers of schizophrenia had significantly higher total burden score.[18] Such a contradictory finding in this study may be because the study included caregivers of only inpatients who were in an active phase of the illness, which might have coloured the responses given by the caregivers.

LIMITATIONS

Generalisability of our findings is limited due to only one setting and limited sample size (120). Considering the time factor and feasibility, our sample included caregivers of only inpatients who were mostly in an active phase of illness, and this might have confounded the results.

CONCLUSIONS

The present study revealed that caregivers of patients with major mental illnesses experience psychosomatic problems. This study also found that there were no significant differences between the psychosomatic problems experienced by the caregivers of the three groups of patients. Findings of the study suggested that caregivers of patients with major mental illnesses experience different psychosomatic problems, which need immediate attention.

RECOMMENDATIONS

On the basis of the present study, following recommendations are made for the future:

- A similar study can be conducted using large sample size with probability sampling technique.
- A study can be done to compare the psychosomatic problems of caregivers of patients with major mental illnesses and caregivers of patients with chronic medical illnesses.
- A comparative study can be conducted to assess the psychosomatic problems of caregivers attending government and private hospitals.
- Day care centres and occupational training centres can be started for mentally ill patients in attachment to primary health centres.

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