

## Depression and Associated Factors among Caregivers of Patients with Severe Mental Illness

Dr. K. Vijayalakshmi<sup>1\*</sup>

### ABSTRACT

**Background and Aim:** Successful management of major mental illness in the community relies significantly on an informal or non-professional network of caregivers and their wellbeing. The family is major source of support of mentally ill patients. The needs and experiences of such caregivers have been little studied with respect to major mental disorders. Care of these patients leads to considerable amount of stress and frustration resulting in depression among caregivers. The aim of the present study was to identify the depression among caregivers of patients with severe mental illness and factors associated with Depression. **Methods and Materials:** A descriptive correlational design was used for the study. The sample comprised of 200 caregivers of patients (Schizophrenic patients – 59 and patients with affective disorders - 141) from psychiatric in patient and the outpatient clinic of Department of psychiatry, B. P. Koirala Institute of Health Sciences, Nepal. Samples were selected using purposive sampling technique. Caregivers were screened for depression using 5 items - Center for Epidemiological studies-Depression scale (CES- D) through personal interview. **Results:** With regard to Prevalence of Depression among caregivers of Mentally ill patients, 42.5% of caregivers are depressed. In terms of factors associated with depression among caregivers, findings revealed that, Depressive scores were significantly higher in caregivers of female patients, Patients with low socio economic status (Monthly family income < 10000/), patients from rural background and schizophrenia. Caregivers who were illiterates had severe depression than the educated caregivers. **Conclusion:** Mental Health Professional play vital role in screening caregivers for depression, and implementing family intervention in order to reduce depression and cope effectively while taking care of the patients.

**Keywords:** Depression, Associated Factors, Caregivers, Patients with Severe Mental Illness

Mental disorders figure among the leading causes of disease and disability in the World. The burden of mental health problems is increasing globally [ WHO, 2001]. It is gradually becoming recognized that mental disorders are a public health problem throughout the world. One in four people in the world will be affected by mental or neurological disorders at some point in their

<sup>1</sup> Professor, Apollo College of Nursing, Chennai, India

\*Responding Author

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lives. Around 450 million people currently suffer from such conditions, placing mental disorders among the leading causes of ill-health and disability worldwide. In 2001, mental disorders accounted for 13 % of the world's burden of diseases and this figure is projected to increase to 15 % by the year 2020 [Mental Health: A Call for Action, 2001)

According to the World Health Organization (2004), unipolar depression was the third most important cause of disease burden worldwide in 2004. It has also been estimated that by the year 2020, depression will be the second leading cause of disability throughout the world, trailing only ischemic heart disease. (WHO. Global Burden of Disease Report 2004)

Individuals with a severe mental illness have typically been mentally ill for many years and are unable to fulfill daily roles in society normally expected of individuals of their age and intellectual ability; thus, they are most likely receive family care ( WHO, 2001).

The family is major source of support of mentally ill patients. Families not only provide practical help and personal care such as bathing, eating, taking drugs but also give emotional support to their relative with a mental disorder in the face of insufficient knowledge, skill to provide care, limited social support and poor mental health facilities (El-Tantawy, Raya, Zaki, 2010 & Aadil, Ovais , Javed 2010). Care giving is associated with all the features of a chronic stress experience and challenge. These challengeable tasks, chronic stress, daily hassles and negative caregivers perception bring profound objective and/or subjective burden that involves psychosocial, physical, and financial impact on the caregivers of individuals with severe mental illness which is comparable to that of persons with other illnesses such as Alzheimer's disease or cancer, especially after deinstitutionalization movement began more than five decades ago because there was transferring of responsibility and day-to-day care to family members (Saunders, 2010 & Saunders 2003).

At times caregivers feel guilty and helpless which is further confounded by social stigma, ignorance and lack of knowledge. As caregivers struggle to balance work, family and care giving, their own physical and emotional health is often ignored. As a result of this and lack of personal, financial, emotional resources and stigma, many caregivers often experience significant physical and mental distress but physical effects of care giving are generally less intensive than the psychological effects [Chan 2011 & Schulz , Sherwood 2008). Caring for those with a mental illness requires tireless effort, energy, and empathy and greatly impacts the daily lives of caregivers.

Numerous studies have demonstrated that family caregivers of patients with a severe mental illness suffer from mental distress (especially depression, insomnia, anxiety, somatization, paranoia and obsessive behavior); and often receive inadequate assistance from mental health professionals. Research conducted in British (1992) reported that psychological distress (anxiety, depression, and insomnia) was twice as high as in the general population [Oldridge, Hughes ,

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1992). Successful management of major mental illness in the community relies significantly on an informal or non-professional network of caregivers and their wellbeing.

Study conducted in Latin America and KSA Arab country reported that 40 % of the caregivers compared to 13 %–18 % of general population and 23.33 % of the caregivers group versus 3.33 % of the control group met the criterion for being at risk of depression for the CES-D 10 scale as they got 10 or greater score respectively [El-Tantawy, Raya, Zaki , 2010, Sandy et al 2011).

Because care giving is such an emotionally draining experience, caregivers have high rates of depression when compared to the general population. Psychological distress and depression of caregivers may be linked to various factors such as duration and type of care provided, unemployment, associated behavioral problems, cognitive and functional disabilities of care recipient, perceived stigma, negative care giving appraisal, feeling of isolation, anger, sadness, guilty feeling, shame, insufficient social support, age of patient, negative coping mechanism, real stigma, as well as secondary stressors such as finances and family conflict.

Generally burden of family caregivers leads to negative consequences not only for themselves but also for patients, other family members, and health care systems (Kumar ,Mohanty , 2005). Burden of family caregivers also causes family conflict and financial problem in individual, family, health care system, distorts the entire family functioning and the families under great stress would give up and reject the mentally ill individuals who would become outcasts socially. Caregivers first experience distress and depression, which are followed by physiologic changes and impaired health habits that ultimately lead to ineffective caring of the patients which further results in relapse in patient and chronic distress in care givers.

Recently there have been limited studies on caregivers in India and most of the studies are conducted in Western countries. Successful management of major mental illness in the community relies significantly on an informal or non-professional network of caregivers. The needs and experiences of such caregivers have been little studied with respect to mental illness and there is paucity of the research in the context of India and Nepal. Hence this study was undertaken by the researcher to assess depression and associated factors among caregivers of patients with severe mental illness. Early assessment and interventions by conducting routine assessments of the depression status of caregivers will be helpful in planning strategies to reduce depression and improve their coping thereby preventing or minimizing mental distress in those caregivers.

### **OBJECTIVES**

1. To determine the prevalence of depression among caregivers of patients with severe mental illness.

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2. To identify the factors associated with depression among caregivers of patients with severe mental illness.

### **METHODS AND MATERIALS**

This study was conducted after obtaining ethical clearance from Institutional Review board of the Institution, at Department of psychiatry, B. P. Koirala Institute of Health Sciences, Dharan, Nepal. The Institute, is a tertiary level health care center, located in Eastern Nepal which is neighboring country of India. Psychiatric Department comprises of Psychiatric OPD and 50 bedded Psychiatric ward. Everyday 50-100 patients attend psychiatric OPD.

A descriptive correlational design was used for the study. Purposive sampling technique was used to select the samples. All the available sample who fulfilled the criteria were included in the study. Inclusion criteria included – 1. Primary caregivers (Spouses, parents, siblings and children) who were accompanying the patients with Schizophrenia or affective disorders, in Psychiatric OPD or staying with the patients in Psychiatric ward. 2. Caregivers who are taking care of the patients at least for past 6 months. Exclusion criteria included- 1. Caregivers who are not willing to participate in the study. 2. Caregivers who are also suffering from major mental illness and unable to communicate properly. Total sample size was 200 (Schizophrenia- 59, Affective disorders- 141)

The tools used for the data collection were, 1. Semi structured proforma to collect information on socio demographic characteristics of patients, caregivers and other relevant clinical informations. 2. Center for Epidemiological studies- Depression scale (CES- D). CES- D is a widely used Depression scale, was used to detect depression among caregivers of patients with Schizophrenia or affective disorders. It is a 4 point likert scale which contains 5 items -brief version. Scoring ranges from 0-3. Thus obtainable score of this scale is 0-15. Score of 4 or more indicates possibility of depression. This is a reliable scale with high internal consistency – Cronbach  $\alpha=0.88$  and test-retest reliability - ICC=0.87.

Data was collected after conducting pilot study with 10% of sample size, using the pretested and predetermined tools using the interview method after obtaining the informed written consent from the patients who had insight and their care givers. Caregivers who met the inclusion criteria of study samples were identified in psychiatric OPD and ward by going through the chart and contacting the caregivers. Personal interview with caregivers was conducted in private room by nurses working in department of Psychiatry who were trained to conduct interview with mentally ill patients. Collected data was analyzed through appropriate descriptive (Frequency, % , Mean and SD) and inferential statistics (Chi square test and t - test) based on the objectives of the study using SPSS version 16.

**RESULTS**

Table 1 shows the socio demographic characteristics of patients with schizophrenia and affective disorders. Patients were homogenous in nature among these two groups with regard to variables such as gender, income, and habitat. However, patients with schizophrenia and affective disorders were significantly different in variables such as age group, educational status and type of family. Table 2 shows the socio demographic characteristics of caregivers of patients with schizophrenia and affective disorders. Patients’ caregivers were homogenous in nature among these two groups with regard to variables such as gender, age and perceived social support. However, patients with schizophrenia and affective disorders were significantly different in variables such as educational status, and relationship with spouse.

With regard to Prevalence of Depression among caregivers of Mentally ill patients, fig 1 indicates that 42.5% of caregivers themselves are depressed.

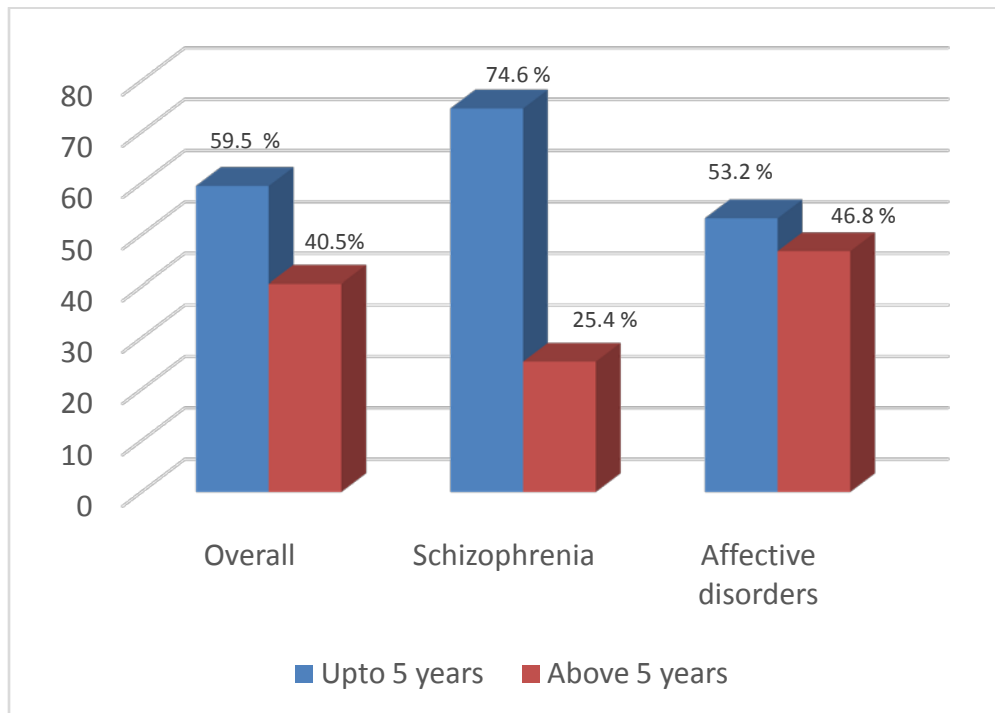
In terms of factors associated with depression among caregivers, findings revealed that, Depressive scores were significantly higher in caregivers of female patients, Patients with low socio economic status( Monthly family income < 10000/), patients from rural background and schizophrenia ( Tab 3). Caregivers who were illiterates had severe depression than the educated caregivers.

*Table 1: Socio demographic characteristics of patients ( N= 200)*

Variables	Schizophrenia	Affective disorders	Chi Square test p- value
	(n= 59) f ( %)	(n= 141) f ( %)	
<b>Gender</b>			
Male	35(59.9)	79(56)	0.990
Female	26(44.1)	62(44)	
<b>Age in Years</b>			
≤20	15 (25.4)	32(22.7)	0.009
21-30	30(50.8)	48(34)	
>30	14(23.7)	61(43.3)	
Mean Age	26.74	30.98	
<b>Educational Status</b>			
Illiterate	4 (6.8)	19 (13.5)	0.045
Primary	41(69.5)	83 (58.9)	
Secondary	3 (5.1)	23 (16.3)	
Hr Secondary and above	11(18.6)	16 (11.3)	

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<b>Family income per month in Nepali Rs</b>			
≤ 10000/	43 (72.9)	96 (68.1)	0.502
>10000/	16 ( 27.1)	45 ( 31.9)	
<b>Marital Status</b>			
Single	24 (40.7)	65 (46.1)	0.482
Married	35 (59.3)	76( 53.9)	
<b>Family type</b>			
Joint	32 (54.2)	38 (27)	0.00
Nuclear	27 ( 45.8)	103 ( 73)	
<b>Habitat</b>			
Rural	38(64.4)	79 (56)	0.273
Urban	21 ( 35.6)	62 (44)	

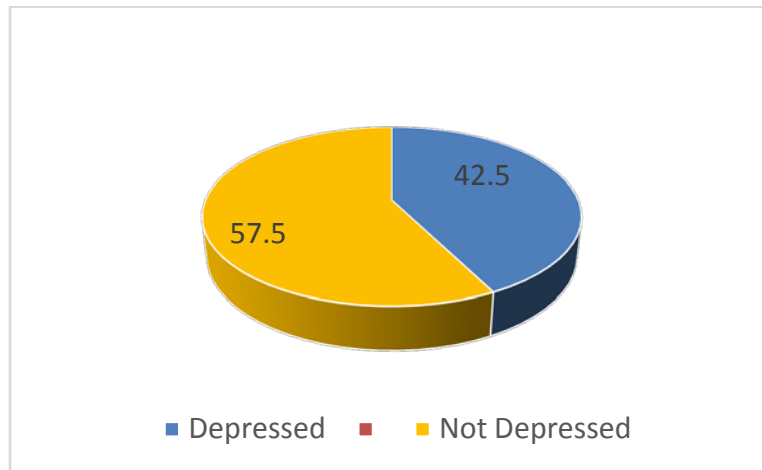


**Fig 1: Percentage distribution of duration of illness of a patients with Schizophrenia and Affective disorders**

**Table 2: Socio demographic Characteristics of Caregivers** (N= 200)

Variables	Schizophrenia (n= 59)	Affective disorders (n= 141)	Chi square test p- value
	f ( %)	f ( %)	
<b>Gender</b>			
Male	33(59.9)	75(53.2)	0.990
Female	26(44.1)	66(46.8)	
<b>Age in Years</b>			
≤30	6 (10.2)	61(43.3)	0.009
31-40	20(33.9)	25(17.7)	
>40	33(55.9)	55(39)	
Mean Age	45.16	36.75	
<b>Educational Status</b>			
Illiterate	15 (25.4)	22 (15.6)	0.045
Primary	11(18.6)	32 (22.7)	
Secondary	21 (35.6)	63 (44)	
Hr Secondary and above	12(20.3)	25 (17.7)	
<b>Relationship with spouse</b>			
Spouse	16(27.1)	54 (38.3)	0.38
Parents	33(55.9)	53 (37.6)	
Siblings	7 (11.9)	19 (13.5)	
Children	3 (5.1)	15 (10.6)	
<b>Perceived social support</b>			
Good	17 (28.8)	46 (42.6)	0.597
Average \ Poor	42 ( 71.2)	95 (67.4)	

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**Fig 2: Prevalence of Depression among caregivers of Mentally ill patients**

**Table 3: Effect of Selected Variables of Patients with Mental illness on Depression among caregivers (N= 200)**

Variables	n	Depression Mean $\pm$ SD	Independent t- value	P value
<b>Gender</b>				
Male	112	3.73 $\pm$ 1.82	4.8	P < 0.001
Female	88	5.17 $\pm$ 2.28		
<b>Marital Status</b>				
Single	89	3.72 $\pm$ 1.76	1.8	P > 0.05
Married	111	4.88 $\pm$ 1.8		
<b>Habitat</b>				
Rural	117	4.96 $\pm$ 2	5.5	P < 0.001
Urban	83	3.53 $\pm$ 1.7		
<b>Previous history of illness</b>				
Present	132	3.55 $\pm$ 1.72	1.18	P > 0.05
Absent	68	5.96 $\pm$ 2.5		
<b>Previous history of illness</b>				
Present	132	3.55 $\pm$ 1.72	1.18	P > 0.05
Absent	68	5.96 $\pm$ 2.5		



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<b>Diagnosis</b>				
Schizophrenia	59	5.03± 1.72	2.94	P < 0.01
Affective disorder	141	4.09 ± 2		

*Table 4: Effect of Selected Variables of Caregivers of Mentally ill Patients on Depression (N= 200)*

<b>Variables</b>	<b>n</b>	<b>Depression Mean ± SD</b>	<b>Independent t- value</b>	<b>p- value</b>
<b>Gender</b>				
Male	108	4.33 ± 2	0.82	P > 0.05
Female	92	4.40 ± 2.1		
<b>Relationship with the Patient</b>				
Spouses	70	5.09 ± 2.5	1.23	P > 0.05
Others	130	3.97 ± 1.6		
<b>Educational Status</b>				
Illiterate	37	5.49 ± 2.54	3.33	P < 0.001
Literate	163	4.11 ± 2		
<b>Perceived social support</b>				
Good	63	4.0 ± 1.8	0.96	P > 0.05
Average/ Poor	137	4.53 ± 2.2		

## **DISCUSSION**

Care giving and care receiving can occur at any point in the life-course, and is typically associated with chronic illnesses or disabilities, which result in losses of independence and functioning. Findings of this study indicate that, 42.5% of caregivers themselves are depressed. Depressive rates in this study is lower while comparing to study conducted by the Heru and Ryan (2002) who reported 72% of care givers of mentally ill patients were depressed. In a study conducted in India, it is reported that 53.8 % of mentally ill patients themselves were depressed (Chandigarh News Feb 1, 2005). These findings strongly support that family members of mentally ill patients experience high level of depression. However inconsistent findings in this area may be due to use of different depression screening instruments with different cut off points in different studies. Moreover, since depression is subjective experience, under reporting or over

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reporting is possible based on the context, seriousness of the patients' illness and situational depressive feelings when there is exacerbation of the patients' symptoms.

In terms of factors associated with depression among caregivers, findings revealed that, Depressive scores were significantly higher in caregivers of female patients, Patients with low socio economic status (Monthly family income < 10000/), patients from rural background and schizophrenia ( Tab 3). It is true that in our family system, invariably women take care of the whole family responsibilities and related tasks. When they suffer from illness and unable to fulfil their roles, whole family suffer and caregivers feel frustrated which ultimately results in Depression. Higher depressive scores are also found among illiterate caregivers, Caregivers of patients from rural background, low socio economic status and illiterate caregivers. It may be associated with the fact that illiterates are likely to come from rural background and low socio economic status which might be further confounded with stigma and misconceptions about mental illness which might spill over the family as well resulting in higher level of depression. Overall study findings indicate that mental illness has negative impact on family dynamics, causing stress and depression, even though intensity of distress may vary from person to person based on various psycho social factors including personality of the patient, caregiver and nature of illness.

However it is true that, everyone has negative feelings that come and go over time, but when these feelings become more intense and leave caregivers totally drained of energy, crying frequently or easily angered by their loved one or other people, it may well be a warning sign of depression. Hence there is a need for the identification of psychological factors that protect families from the stress of caring for the mentally ill patients. Mental health professionals need to help care giving families make choices to improve their challenging situations & identify rewards of care giving & to advocate for increased systemic supports to ease caregivers' stress.

**Limitation of the study:** Study was conducted in hospital setting, which reflects the crisis time in the life of a caregiver. Hence there is a possibility of over reporting of depressive symptoms.

## CONCLUSION

Overall findings of the study indicate, nearly half of the caregivers of mentally ill patients themselves suffer from depression which is associated with various psycho social factors, reflecting the magnitude of the problem. This is a major concern because prolonged stress can have serious emotional consequences such as relapse and exacerbation of the symptoms in patients. Emotional impact of any psychiatric disorder on family or primary caregivers can vary from frustration, anxiety, fear, depression and guilt to grief. Depression is one of the emotion, which is experienced by caregivers. Mental health professionals play vital role in assessment, early identification and intervention of not only the patients but also their caregivers. Caring of mentally ill patients is not the curse bestowed upon families, but rather a responsibility of the community, health care professionals and the nation as a whole.

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Unsurprisingly, it is this statement that was echoed by many Ministers of Health during the Round Tables. **“There is no development without health and no health without mental health.”**

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