

“Level of Caregivers Burden among Family Members of Mentally Ill Patients Visiting Psychiatric Outpatient Department”

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ABSTRACT

Background and Objectives: Mental health is a vital possession that needs to be cherished, promoted, and conserved. According to the WHO, around 450 million people worldwide suffer from mental or behavioral disorders. In India, approximately 20% of the population suffers from psychiatric or mental disorders. Caregivers play a crucial role in caring for mentally ill patients, but they often face significant emotional, physical, and financial burdens.

The researcher aims to assess the level of caregiver burden among family members of mentally ill patients visiting the psychiatric outpatient department (OPD) at Dr. D.Y. Patil Medical College Hospital and Medical Research Institute, Kolhapur. The study seeks to understand the impact of care giving on family members and identify ways to support them.

Objectives: The present study is aimed that to assess the level of caregivers burden among family members of mentally ill patients visiting psychiatric OPD at Dr. D. Y. Patil Medical College Hospital and Medical Research Institute, Kolhapur.

The objectives are as follows,

1. To assess the level of caregivers burden among family member of mentally ill patients.
2. To find the association between level of care givers burden with selected demographic variables among family member of mentally ill patients.

Methods: A quantitative descriptive survey approach was used, with a non-experimental descriptive research design. A sample of 60 family members of mentally ill patients was selected using non-probability purposive sampling technique. The Zarit Caregivers Burden Scale was used to collect the data on level of caregivers burden among family member of mentally ill patients.

Result: The majority of respondents (46.66%) experienced a mild to moderate level of burden. 30%, had no or minimal burden, while 20% experienced moderate to severe burden. Only 3.33% of individuals experienced a severe level of burden. Significant associations were found between caregiver burden and age, residence, and education.

Interpretation and conclusion: The study concludes that the Level of Caregiver's Burden among Family Member of Mentally Ill Patients Visiting Psychiatric OPD at Dr. D. Y. Patil Medical College Hospital and Medical Research Institute at Kolhapur, is the majority of respondents (46.66%) experienced a mild to moderate level of burden. There is a need for healthcare professionals to assess and address caregiver burden among family members of mentally ill patients. The findings have implications for nursing practice, education, administration, and research, as well as general education in schools and colleges. Recommendations for future studies and interventions to support caregivers are also provided.

Keywords: Caregivers Burden, Family Members, Mentally Ill Patients, Psychiatric OPD, Hospital.

INTRODUCTION

They may forget what you said, but they will never forget how you made them feel

- Carl W. Buechner

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Health especially, mental health, is one of the most important possessions of an individual and it needs to be cherished, promoted, and conserved to the maximum. Around 450 million people worldwide are suffering from

some mental or behavioral disorder according to the WHO, of which schizophrenia, bipolar disorder, depression, and alcohol use disorders are important causes for years lived with disability. According to the evidence available, in India, about 190–200/1000 populations have a psychiatric or mental disorder, this account for about 20% of the whole population. The major issues faced in India regarding mental health are lack of mental health workforce, financial aid, stigma, and caregiver burden.¹

The family plays a very vital role in the care of a mentally ill patient. A caregiver has been defined as “a family member, who has been staying with the patient for more than a year and has been closely related with the patient's daily living activities, discussions, and care of health.” Caregivers often have to sacrifice their own wants and undertake a lot of stress and are very much ignored. Caregiving drains one's emotions and hence caregivers undergo a lot of depression as compared to the general population. The WHO 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.” It includes taking care of personal hygiene of the patient and emotional support such as listening, counseling, giving company, and informational caring such as how to alter the living environment of the patient.¹

Burden of care can be understood by its impact and effects on caregivers. The early conceptualization of burden of care can be divided into two distinct components, objective and subjective. Objective burden of care deals with effects on finance, health, routine and leisure of the family whereas subjective burden deals with psychological and emotional

impact of mental illness on family members. In addition, burden of care can be precise in some upsetting notions such as shame, embarrassment, feelings of guilt, and self-blame.²

In 2004, mental disorders accounted for 13% of global burden of disease. Families who perceived a higher level of caregiver burden

are those who lived in a family with poorer functioning, worse health status and less satisfaction of social support.²

It is found that one person among four families is currently suffering from a psychiatric disorder. The families not only contribute bodily plus moral aid but also carry the adverse effects of dishonor and bias. In a family, if a family member suffers from a psychiatric illness, a lot of alteration and settlements have to be made by the family members to impose their role in their daily functions. Maximum time of the caregiver is consumed in taking care of the psychologically disabled patient, leading to social and economic hardships. Global burden of disease 2000 data show that neuropsychiatric disorders came out to be 30.8% of all YLDs. In fact, depression leads to maximum impairment, coming out to be 12% of all. Out of all psychiatric disorders, 6 were among top 20 sources of disability (YLDs) in the world, namely depression, alcohol abuse, bipolar disorder, schizophrenia, dementias, and headache.³

Hence the researcher wants to assess the level of caregivers' burden among family members of mentally ill patients visiting psychiatric OPD in Dr. D.Y. Patil Medical College Hospital and Medical Research Institute at Kolhapur.

METHODS

A quantitative descriptive survey approach was used, with a non-experimental descriptive research design. A sample of 60 family members of mentally ill patients was selected using non-probability purposive sampling technique. The reliability of the tool was established and the Zarit Caregivers Burden Scale was used to collect the data on level of caregivers' burden among family members of mentally ill patients.

Results.

Part I: Description of Demographic Variables of Caregivers

This part deals with distribution of participants according to their demographic characteristics. Data was analyzed using descriptive statistics and summarized in terms of percentage.

Table 1: Frequency and percentage distribution of sample according to demographic characteristics
n= 60

Variable	Frequency	Percentage
1. Age		
Less than 25 years	12	20%

25to35years	25	41.66%
36to45years	11	18.33%
Above45years	12	20%
2. Gender		
Male	29	48.33%
Female	31	51.66%
3. Religion		
Hindu	47	78.33%
Muslim	06	10%
Christian	02	3.33%
Others	05	8.33%
4. Residentialarea		
Urban	34	56.66%
Semi-urban	20	33.33%
RuralArea	6	10%
5. MaritalStatus		
Married	41	68.33%
Unmarried	18	30%
Divorced/Separated	1	1.67%
6. Typeoffamily		
Joint	30	50%
Nuclear	27	45%
Extended	03	5%
7. Education:		
Noformaleducation	0	0%
Primary	5	8.33%
Secondary	18	30%
Highersecondary	3	5%
Diploma	1	1.6%
Undergraduate	5	8.33%
Graduateandpostgraduate	28	46.66%
8. Occupation:		
Unemployment	5	8.33%
Homemaker	14	23.33%
Farmer	3	5%
Privatejob	27	45%
Govt.Job	4	6.6%
Business	7	11.66%
9. Monthlyincomeoffamily		
<Rs5000	02	3.33%
Rs5001to10000	14	23.33%
Rs10001to 15000		26.66%
>Rs15001	28	46.66%
10. Yearsofcaregiventothepatient		
Lessthan1year	23	38.33%
1yearto5year		38.33%
5yearto10year	10	16.66%
Morethan10 year	04	6.67%

The data presented in Table 1 shows that the majorityofrespondents(41.66%) belonged to theagegroupof25-35years,while20%were less than 25 years, 20% of respondents were above45years.And,18.33%wereinthe36-

45 age group. Regarding gender, 51.66% of respondents were female, and 48.33% were male. In terms of religion, the majority (78.33%)wereHindu,followedby10%who

were Muslim, 8.33% who identified with other religions, and 3.33% who were Christian.

The majority of respondents (56.66%) resided in urban areas, followed by 33.33% in semi-urban areas, and 10% in rural areas. In terms of marital status, most respondents (68.33%) were married, 30% were unmarried, and 1.67% were divorced or separated. Regarding the type of family, 50% of respondents belonged to joint families, while 45% lived in nuclear families, and 5% were part of extended families.

The majority of respondents (46.66%) had completed graduate or postgraduate education, followed by 30% who had received secondary education. A smaller percentage (8.33%) had completed primary education, while 8.33% had an undergraduate degree, 5% had a higher secondary education, and 1.6% held a diploma. None of the respondents had no formal education. In terms of occupation, 45% were employed in private jobs, 23.33% were homemakers, and 11.66%

were involved in business, 8.33% were unemployed, 6.6% held government jobs, and 5% were farmers.

The majority of respondents (46.66%) reported a monthly family income of over Rs 15,001, while 26.66% had an income between Rs 10,001 and Rs 15,000, 23.33% earned between Rs 5,001 and Rs 10,000, and only 3.33% had a family income of less than Rs 5,000. Regarding the years of care provided to the patient, 38.33% of respondents had been providing care for less than 1 year, with an equal percentage (38.33%) caring for 1 to 5 years. And, 16.66% had provided care for 5 to 10 years, and 6.67% for more than 10 years.

Part II: Assessment of the Level of Caregiver Burden among Family Members of Mentally Ill Patients.

The level of caregivers burden related to mentally ill patients among family members was assessed using Zarit caregiver burden scale.

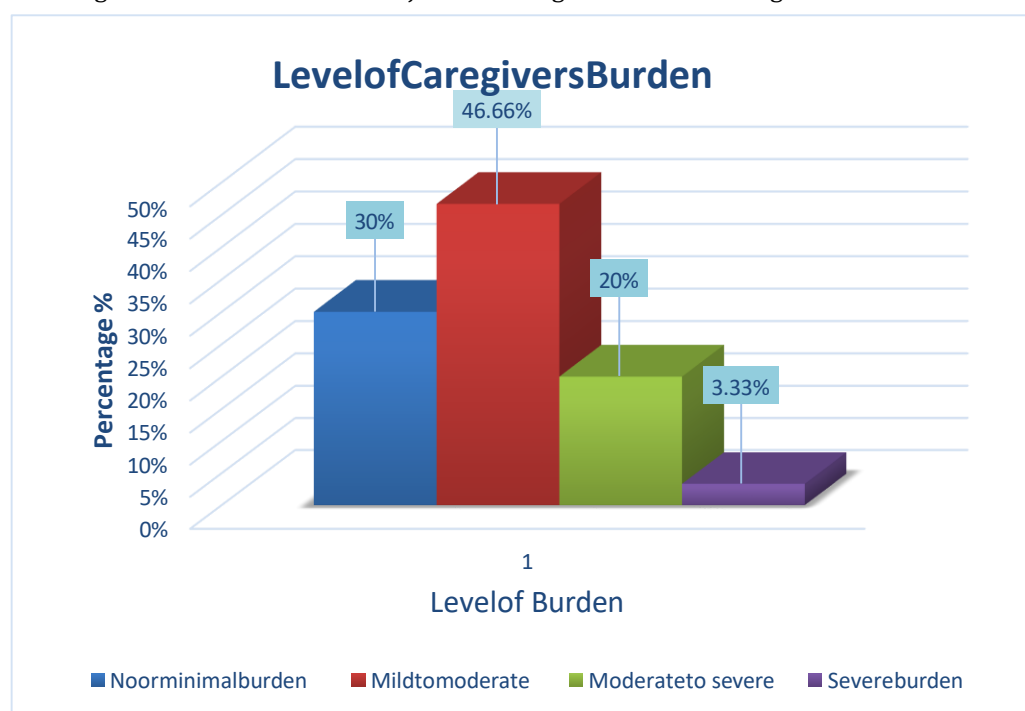
Table 2: Frequency and percentage distribution according to the level of caregivers burden among family members of mentally ill patients. n = 60

Level of Burden	Range of score	Frequency	Percentage
No or minimal burden	0-20	18	30%
Mild to moderate	21-40	28	46.66%
Moderate to severe	41-60	12	20%
Severe burden	61-88	2	3.33%

Data in Table 2 and Figure 12 show that the majority of individuals, 46.66%, experienced a mild to moderate level of burden. 30%, had no or minimal burden, while 20% experienced

moderate to severe burden. Only 3.33% of individuals experienced a severe level of burden.

Figure 1: Distribution of the Subject According To the Level Of Caregivers Burden



Part III: Association between the Levels of Caregivers Burden with Selected Demographic Variables among Family Members.

The data reveals that the obtained Chi-square values indicate a significant association between the Level of Care givers burden with Age, Residence and Education respectively (18.381, 15.401 and 28.688 at 0.05 levels).

But there is no significant association between the Level of Care givers burden and other demographic variables such as Gender, Religion, Marital Status, Type of family, Occupation, Monthly income, Years of care given.

However, the above finding reveals that there was association between the Level of Care givers burden with Age, Residence and Education respectively. So the hypothesis (H_1) was accepted.

H₁: There is a significant association between level of care givers burden with selected demographic variables among family members of mentally ill patients.

DISCUSSION

1. Demographic Characteristics

The data presented in Table 1 shows that the majority of respondents (41.66%) belonged to the age group of 25-35 years, while 20% were less than 25 years, 20% of respondents were above 45 years. And, 18.33% were in the 36-45 age group. Regarding gender, 51.66% of respondents were female, and 48.33% were male. In terms of religion, the majority (78.33%) were Hindu, followed by 10% who were Muslim, 8.33% who identified with other religions, and 3.33% who were Christian.

A study with similar finding was conducted to assess the level of family burden among caregivers of schizophrenic patients. The purposive sampling method was used to select 30 samples. The tool consisted of two sections: Section A – demographic variables and Section B – standardized questionnaire. The study result reveals that the majority of respondents (47%) were in the age group of 20-30 years and were females (70%); One-third of them were Hindu (60%); half of them were married (73.3%), were residing in rural areas (53%); and were employed (37%).²⁴

A study with similar finding was conducted to assess factors associated with the burden of family caregivers of patients with mental disorders in the psychosocial care centers, in three cities in the southwest region of Goiás state, Central Brazil. A 281 number of samples were selected by non-probability sampling

method. The study result reveals that the caregivers were mostly female and parents of the patients were remarried, with low education, and of low income.⁴⁵

2. Assessment of the Level of Caregivers Burden Among Family Members of Mentally Ill Patients.

The majority of individuals, 46.66%, experienced a mild to moderate level of burden. 30%, had no or minimal burden, while 20% experienced moderate to severe burden. Only 3.33% of individuals experienced a severe level of burden.

A study with similar finding was conducted to assess the burden of care among the caregivers of mentally ill patients. The quantitative approach was used. A total of 97 family members were selected consecutively from the psychiatric outpatient department (OPD) and wards of Mental hospital. The study result 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.²⁹

A study with contradictory findings was conducted to assess of caregiver burden in psychiatric illness patients admitted in tertiary care hospital. A sample size of 200 care givers of psychiatric patients were selected by face to face interviewing using socio-demographic and Zarit burden interview questionnaire. The study result reveals that Perception of caregiver burden found in the present study was mild in 24%, moderate in 31% and severe in 45%. Female experienced severe burden in comparison to male.²⁸

3. Association between Caregivers Burden Score with Selected Demographic Variables among Family Members Of Mentally Ill Patients.

The present study finding reveals that there was significant association between the level of care givers burden with Age, Residence and Education respectively (18.381, 15.401 and 28.688 at 0.05 levels). But there is no significant association between the level of care givers burden and other demographic variables such as Gender, Religion, Marital Status, Type of family, Occupation, Monthly income, Years of care given.

A study with similar finding was conducted to assess the burden of care among the caregivers of mentally ill patients. A total of 97 family members were selected consecutively from the psychiatric outpatient department (OPD) and wards of Mental hospital. The study

result revealed that, there was 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 patient ($p=0.035$) and duration of care-giving ($p=0.026$). There was 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 ($p=0.09$).²⁹

A study with contradictory findings was conducted to assess the level of stress among caregivers of individuals with mental disorders attending psychiatric OPD of selected hospitals in the city. A total of 100 caregivers were selected for the study. The result reveals that, there was no significant association between age, gender, type of family, educational status, occupational status, relationship with patient diagnosis of family members, giving care to relatives, visited psychiatric OPD, no. of times admitted to psychiatric ward and significantly associated with monthly family income.⁴⁴

CONCLUSION

Majority of the caregivers participated in the study have moderate level of burden and gave free and frank responses regarding caretaker burden. The study was based on the general system model. It provides a comprehensive frame work for assessment of level of caregivers burden among family members of mentally ill patients. The research approach used is descriptive study and the samples were selected by using non-probability purposive sampling technique. Data was collected by Zarit Caregivers Burden Scale and analyzed, interpreted by applying statistical methods.

Implications of the Study

The findings of the study have implications for the nursing profession. The implications have been written under the following headings, nursing practice, nursing administration, nursing education, nursing research and general education in schools and college.

Nursing Practice

1. Assessment of Caregiver Burden: Nurses can assess caregiver burden in family members of mentally ill patients and provide support and referrals to resources as needed.

2. Individualized Care Plans: Nurses can develop individualized care plans that take into account the unique needs and circumstances of family members.
3. Support and Education: Nurses can provide support and education to family members on managing caregiver burden, stress management, and coping strategies.

Nursing Education

1. Nursing curriculum is responsible for preparing future nurses with emphasis on curative, preventive and promotive health practices.
2. Nursing educators can develop curricula that include content on caregiver burden, family-centered care, and support services for family members.
3. Nursing educators can educate students on the importance of assessing caregiver burden and providing support to family members.
4. Nursing educators can collaborate with educators from other disciplines, such as social work and psychology, to provide inter professional education on supporting family members.

Nursing Administration

1. Development of Support Services: Nursing administrators can develop support services, such as counseling, respite care, and education, to help family members manage their caregiving responsibilities and reduce their burden.
2. Staff Education and Training: Nursing administrators can provide education and training to nursing staff on the importance of assessing caregiver burden and providing support to family members.
3. Policy Development: Nursing administrators can develop policies that support family-centered care, including paid family leave, respite care, and education and training programs.
2. Resource Allocation: Nursing administrators can allocate resources, such as funding and personnel, to support the development of support services for family members.

Nursing Research

1. Longitudinal Studies: Nursing researchers can conduct longitudinal studies to examine the long-term effects of caregiving on family members of mentally ill patients.
2. Intervention Studies: Nursing researchers can design intervention studies to test the

effectiveness of support services and other interventions in reducing caregiver burden.

3. Exploratory Studies: Nursing researchers can conduct exploratory studies to examine the experiences and needs of family members from diverse backgrounds.
4. Instrument Development: Nursing researchers can develop instruments to measure caregiver burden and evaluate the effectiveness of support services.

General Education in Schools

1. Mental Health Education: Schools can incorporate mental health education into their curricula, including information on mental illness, treatment options, and support resources.
2. Stress Management and Coping Strategies: Schools can teach stress management and coping strategies to students, which can help them manage caregiver burden if they have a family member with a mental illness.
3. Breaking Stigmas: Schools can work to break stigmas surrounding mental illness and encourage students to seek help if they or a family member is struggling.
2. Support for Students with Family Members with Mental Illness: Schools can provide support and accommodations for students who have a family member with a mental illness, such as counseling or academic support.

General Education in College

1. Mental Health Courses: Colleges can offer courses on mental health, including the impact of mental illness on families and caregivers.
2. Caregiver Support and Resources: Colleges can provide support and resources for students who are caregivers for family members with mental illness, such as counseling or support groups.
3. Stress Management and Self-Care: Colleges can emphasize the importance of stress management and self-care for students, particularly those who are caregivers.

Limitations

1. No broad generalization could be made due to the small sample size and limited area of setting.

Recommendations

1. A similar study needs to be conducted in other healthcare settings to allow for broader generalization of caregiver burden.

2. A similar study can be conducted on a larger sample to ensure the results are representative and applicable across various populations.
3. A training program for caregivers about managing the burden of care for mentally ill patients should be periodically implemented to enhance their coping mechanisms and mental well-being.
4. A comparative study could be conducted to assess the differences in burden levels between caregivers of patients with different types of mental illnesses (e.g., schizophrenia, bipolar disorder) or between professional and non-professional caregivers.

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