



FAMILY BURDEN AMONG CAREGIVERS OF PATIENTS WITH MENTAL ILLNESS

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ABSTRACT

Background: Family members play a major role in providing care giving assistance to patients with mentally illness and while providing care they may experience considerable amount of distress and may have a poor quality of life, if they are unable to cope with the stress associated with the process of care giving.

Aim of the study: This study was carried out with the aim to assess the family burden among care givers of patients with mental illness.

Materials and Methods: The present study was conducted at the 'Cadabams group of psycho-social rehabilitation centers in Gulkamale village near Bangalore'. It was a cross sectional hospital based study and simple random sampling techniques were used. Descriptive research design was adopted. The sample comprised of 50 Caregivers patients with mental illness. The following tools were used for the current study: Socio-demographic data sheet and Burden Assessment schedule (Thara, Padmavati, Kumar & Srinivasn -1998).

Result: The results shows that majority of the caregivers age groups between 31 - 40 years (40%), half of the respondent (50%) were male and half (50%) were female, Nearly half (i.e.) 46% of the respondents were parents of the patients with mental illness, majority of the caregiver (88%) of the respondents were married, more than three-fourth (i.e.) 78% of the respondents were Hindu, more than three-fourth (i.e.) 76.0% of the respondents were living in urban area, Majority were studied up to Undergraduate (60%), majority 66% of caregivers were doing business. And also this study found that 50% of caregivers of patients with mental disorders were experiencing severe burden, 20% were experiencing moderate burden, and 30% were experiencing mild burden.

Conclusion: This study findings indicates that caregivers of patients with mental disorders experiencing enormous burden and they need to be given proper attention and psychosocial intervention to reduce their burden and increase their quality of life.

KEYWORDS : Burden, Caregiver, Patient, Mental illness

INTRODUCTION

Two aspects of care giving relate specifically to mental health—the care involved in looking after a person with a mental illness and the impact of caring on the mental health of the caregiver. The second type may occur in the caring of a person with a range of physical and intellectual disabilities, as well as mental illness. Caring may not always lead to mental health problems for the carer, but caring experiences are often talked about in terms that may relate to mental health (e.g., stress levels), without expressly being defined as such. It is therefore difficult to clearly distinguish from the literature under what circumstances a carer's mental health is or isn't affected. The mental health status and needs of carers may also go unidentified by families and professionals as they focus on others' needs; carers may avoid self-identification of mental health problems due to their lived reality that the ill family member cannot afford for them to be sick or not coping. As such, the mental health needs of carers may remain unidentified and unaddressed, which may have long-term ramifications for both their own wellbeing and the wellbeing of the care recipient. One of the key aspects of caring that can impact on the mental health of carers is the level of burden involved in the caring role. Similarly to other caring roles, two types of burden associated with caring for a person with a mental illness are highlighted in the literature: objective burden and subjective burden. Objective burden relates to the specific tasks associated with caring, for example managing finances or doing housework and subjective burden relates to the feelings and cognitive appraisals associated with caring, such as finding particular behaviours embarrassing, worrying about the future and dealing with excessive demands (Baronet, 1999; Williams & Mfofofo-M'Carthy, 2006). The degree of burden is most often related to the degree of impairment or severity of the disability and symptoms associated with the illness of the care recipient (Magliano et al., 2002; Wittmund, Ulrich Wilms, Mory, & Angermeyer, 2002). Several studies have specifically examined the mental health impacts of caregiving on the carer, many with a focus on a specific disabling condition or types of condition and/or different groups of carers. Overall, there is consistent evidence that informal caregiving is associated with poorer mental health. The evidence base includes a number of recent large-scale Australian surveys. Edwards et al. (2008) interviewed 1,002 people receiving carer payment or carer

allowance. Carers who were looking after family members who had one or more disabilities, including acquired brain injury, physical, intellectual and psychiatric disabilities, were shown to have very high rates of mental health problems, including higher rates of depression than the general population. Family members of the carer also experienced higher rates of depression, with risks greatest in the first year of care. In another Australian study, Cummins et al. (2007) examined the mental health and wellbeing of carers and found that carers had lower collective wellbeing than any other group previously examined in the survey (including sole parents and people who were unemployed). In addition, more than one-third of carers were found to be severely or extremely depressed. There are a number of factors that may explain the poorer mental health of carers compared to those who do not provide care, such as unemployment, physical health issues, lack of positive social support or financial difficulties (Cummins et al., 2007). Magliano et al. (2002) found that more than two-thirds of carers of patients with schizophrenia reported feelings of loss, cried or felt depressed, neglected hobbies or had difficulties taking holidays because of the needs of the person with a mental illness. These outcomes indicate the impact of caring on the current mental health of carers, but they may also constitute risk factors for future, more serious, mental health problems.

Research questions:

Why mental disorder is a problem? When does it become a burden? Who are the chronic mentally ill persons? Who are the family caregivers? What are the kinds of problems family caregivers face? How does the presence of the mentally ill member affect the lives of the other members in the family? Do they have their support in caring for the ill member? What is the extent of distress they face? How can these burdens be reduced, so that they can live more productive and stress free lives? Where can they look for such services? Who are the people whom they can approach to solve their non-medical problems? How and where can their problems be addressed? Are family caregivers aware of the psycho-social rehabilitation services within their community? How socio-economic backgrounds help in coping with the mentally ill family members.

SCOPE OF THE STUDY:

While numerous studies have examined the long-term difficulties of living with a person with mental disorders, relatively few studies have examined the psychosocial correlates of caregivers' burden. However, in Tamil Nadu there is a dearth of research, which focuses on the impact of burden, distress and emotional health of the caregivers. The purpose of this study is to evaluate the psycho-social aspects of burden. Further, this study is intended to test the efficacy of a Brief Integrated Supportive Psycho-Social Intervention in reducing burden and emotional distress.

AIM & OBJECTIVE OF THE STUDY

The research has been undertaken with the following objectives.

- To study the socio demographic profile
- To study the level of burden experienced by family care givers of patients with mental illness

MATERIALS AND METHODS:

The present study was conducted at the 'Cadabams group of psycho-social rehabilitation centers in Gulkamale village near Bangalore'. It was a cross sectional hospital based study and simple random sampling techniques were used. Descriptive research design was adopted. The sample comprised of 50 Caregivers patients with mental illness. The following tools were used for the current study: Socio-demographic data sheet and Burden Assessment schedule (Thara, Padmavati, Kumar & Srinivasn -1998).

RESULTS:

TABLE-1: Socio demographic variables of caregivers of patients with mental illness

Variables	Frequency	Percentage
Caregiver age classification		
20-30	4	8
31-40	20	40
41-50	19	38
51 and above	7	14
Gender		
Male	25	50
Female	25	50
Relationship		
Parents	23	46
Spouse	18	36
Siblings	7	14
Children	2	4
Marital status		
Married	44	88
Unmarried	6	12
Family type		
Nuclear	27	46
Joint		54
Religion		
Hindu	39	78
Christian	5	10
Muslim	6	12
Domicile		
Rural	12	24
Urban	38	76
Educational Qualification		
High school	10	20
Under Graduate	30	60
Technical	4	8
Post Graduate	6	12
Occupation		
Government	12	24
Private	15	20
Business	23	66
Duration of contact with the patient		
Below 5 years	2	4
5-10 years	5	10

10-15 years	5	10
Above 15 years	38	76
Diagnosis		
Schizophrenia	29	58
Mood disorder	17	34
Other mental disorder	4	8

The result shows that majority (40%) of the of caregiver between the age group of 31-40 years, 38% between 41-50 years, 14% 51 and above years and 8% between 21-30 years. In terms of gender, the study revealed that 50% of the caregivers were female and 50% were male caregivers. In terms of relationship, the study revealed that 46% of the caregivers were parents and 36% were spouse, 14% were siblings and 4% were others. In terms of marital status, 88% of the caregivers were married and 12% were unmarried caregivers. Regarding type of family, 54% were from joint family and 46% were from nuclear family. In terms of religion the study sample shows that 78% of the caregivers were belonging to Hindu religion, 10% were belonging to Christian and 12% were Muslim. The result suggests that the majority of caregivers 76% were from urban background and 24% of the caregivers from rural background. The result also shows that majority 60.0% were studied up to graduation, high school were 20%, post graduation 12 %. And Technical were 8%. Regarding occupation the result shows that majority 66% of caregivers were doing business, 24% were Govt servants, and 20% were private job. 76% of the respondents were having contact with the patient for the period of more than 15 years, More than half (i.e.) 58% of the respondents were diagnosed as schizophrenia.

Table-2: Family burden among caregivers of patients with mental illness

Burden experienced by family caregivers of patients with Mental disorders	No of respondents	Percentage
Severe	25	50.0
Moderate	10	20.0
Mild	15	30.0

The table (2) shows that the caregivers of patients with mental illness 50% were experiencing severe burden, 20% were experiencing moderate burden, and 30% were experiencing mild burden.

DISCUSSION

The results shows that majority of the caregivers age groups between 31 - 40 years (40%), half of the respondent (50%) were male and half (50%) were female, Nearly half (i.e.) 46% of the respondents were parents of the patients with mental illness, majority of the caregiver (88%) of the respondents were married, regarding type of family, More than half (i.e.) 54% were from joint family, more than three-fourth (i.e.) 78% of the respondents were Hindu, more than three-fourth (i.e.) 76.0% of the respondents were living in urban area, Majority were studied up to Undergraduate (60%), majority 66% of caregivers were doing business. 76% of the respondents were having contact with the patient for the period of more than 15 years, More than half (i.e.) 58% of the respondents were diagnosed as schizophrenia. This study results match with previous study done by Rosdinom (2001) and the author found that most of the caregivers were in the middle age group (mean age of 49.23 years), about two-thirds (66.2%) were female, more than half (55.4%) were Malays, majority were married (81.5%), mostly were patients' own daughters (40%), still employed (55.4%), and enjoyed shared caregiving with other family members (58.5%). Most of them had educational level up to secondary school level (43.1%) and reported no financial difficulties (81.5%). And also this study found that 50% of caregivers of patients with mental disorders were experiencing severe burden, 20% were experiencing moderate burden, and 30% were experiencing mild burden and this results matches with the previous study done by jensiya et al in 2016 says caregivers of patients with schizophrenia were having high burden in almost all the domains such as financial burden (9.39±1.24), Disruption of routine family activities (8.69±1.09), Disruption of family leisure (6.48±.99), Disruption of family interaction (6.35±1.82), Effect on

physical health of others (3.46±.73), Effect on mental health of others (3.57±.49), and Family burden Total (37.87±2.19).

LIMITATION OF THE STUDY:

The sample size of the current study was 50 care givers of patients with psychiatric illness and the small sample size may reduce the generalization of the study findings. Only family burden have been examined, the researcher could have assessed the some of the variables such as family interaction pattern, quality of life, social support and coping strategies.

SUGGESTIONS:

A large measure of the stress experienced by caregivers may be associated with the lack of essential supports such as crisis information and support services, continuity of care, psychosocial rehabilitation programs for skill development and participation in work or education, caregiver counseling, and respite services. [Mental health] staff can help to raise caregiver awareness by providing educational support on issues such as mental health policy and legislation, and caregiver rights, and the role of treatment and rehabilitation programs for recovery. Advances in behavioural science have proven that mental and behavioural disorders are treatable like any other physical illness (WHO 2001), so early identification and early intervention is necessary at all levels. The Mental Health Gap Action Programme (MHGAP) initiated by the WHO urges the governments to scale up their efforts to provide mental health care at the community level (WHO, 2002). Mental Health Professionals should lobby for services and improving existing services. Rehabilitation is based on the bio-psycho-social model, should be designed to instill independence, humaneness, dignity, honour, hope, the work ethic, autonomy, self respect, self discipline, self regulation, and interpersonal skills. The long-term mentally ill should be made the highest priority in public mental health and a comprehensive system of care that recognizes their heterogeneity needs to be established.

CONCLUSION:

This study aims to analyze the burden experienced by family care givers of patients with mental illness from cadabams group of psycho-social rehabilitation centers in Gulkamale village near Bangalore. This study has attempted to identify the support needs of a diverse group of caregivers whose relatives were at various stages of recovery from mental illness. Despite the limitations of the study, the findings are significant because they highlighted the fact that the needs of caregivers may vary depending on several factors. The study also suggested that mental health staff need better training and support to assess the diversity in those needs and to provide appropriate holistic interventions. Caring for people with a progressive mental illness may negatively influence the life of family caregivers in many ways. All agree that the reduction of the negative consequences of caring for those who provide it constitutes a main goal in its management.

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