

Education and Stress Management Strategies on Levels of Burden in Caregivers of Chronic Mental Illness Individuals



Syamala Buragadda¹, Ganeswara Rao Melam^{1*}, Adel A Alhusaini¹, Dharmendra Kumar¹ and Sindhuja Subramanien²

¹Rehabilitation Health Sciences Department College of Applied medical sciences, King Saud University, Saudi Arabia

²Kovai Medical center and Hospital, College of Occupational therapy, India

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***Corresponding author:** Ganeswara Rao Melam, Rehabilitation Health Sciences Department, College of Applied medical sciences, King Saud University, Riyadh, Saudi Arabia

Abstract

Objective: Vagaries of caregivers are quite commonly observed among patients with mental upset. There is a significant increase in the level of burden on the caregivers. This study aimed to identify the burden and coping strategies perceived by caregivers and to evaluate the effects of educational and stress management strategies on caregiver's burden.

Methods: This is a pretest-posttest design. The Zarit Burden Interview Schedule and the Coping Strategies Inventory was administered to 50 caregivers—24 males and 26 females—aged between 20 and 65 years. Of these, 15 caregivers found to have severe burden formed the experimental group, which received the educational and stress management strategies. Interventions were carried out for 1 month comprising 8 sessions with emphasis on stress management and coping skills training.

Statistical analysis: The information collected was analyzed using t-test and ANOVA and significance was set at $p \leq .01$.

Results: The results showed that, of 50 caregivers, 10 (20%) had little or no burden, 13 (26%) had mild to moderate burden, 12 (24%) had moderate to severe burden, and 15 (30%) had severe burden. Use the coping strategies significantly reduced caregiver stress. Educational and stress management strategies enhanced the coping skills of an individual ($p < 0.01$). Subsequently, using these strategies caregiver's stress was reduced significantly ($p < 0.01$).

Conclusion: Caregivers provided with adequate coping skills, specific assistance, and physical and mental health education programs and effective rehabilitation facilities can reduce their level of stress through an empirically supported guidance program.

Keywords: Disability; Coping Skills; Perception; Mental ill Health

Introduction

India, the second most populated rural areas of the world, with a population of 1.02 billion, is a land of contrasts [1,2]. Advances in medical science have resulted in a concomitant increase in the life span of individuals with disabilities [3]. Vagaries of caregivers were observed quite commonly among the patients of mental upset. In India, unlike in the West, the folks have always remained the major source of concern for the mentally ill even in the past, since there have been never adequate number of hospital beds for these patients. The degree of burden on the caregivers has dramatically increased as the ongoing shift of patient attention from institutions to the residential district [4]. There is a shortfall

in trained work force sources in the rehabilitation of chronic mental illness patients. Successful management of mental malady in the community relies significantly on an informal or non-professional network of caregivers [5]. Caregivers face mental ill health as a direct result of their caring role and experience higher rates of mental ill health than the normal population. The care givers are reported to have 50% more health problems, 70% more prescribed medicines, 25% more to hospitals or emergency rooms, 23% more levels of stress hormones, sleep deprivation & poor eating habits than non-caregivers. These requirements can bring significant levels of stress for the caregiver and can move

their overall quality of life, including employment, socializing and relationships [6]. The traditional family setup in India, unlike the western countries helps to withstand the different kind of stresses encountered in caring chronic ill patients.

The concept of the traditional family is being replaced by nuclear families due to rapid urbanization and industrialization and so more vulnerable to stresses [7]. Stress can manifest as psychological morbidity, including depression and anxiousness. Surveys indicate a substantial kinship between the caregivers' point of loading with the negative effects of psychological health [7-10] and physical health [11]. Interventions can ameliorate these effects and thereby improve the character of the life of people with chronic mental illness [10,12-19]. Previous research done to determine the effect of various stress reduction programs for caregivers of patients with brain tumor provided a valuable insight for designing suitable programs for stressed caregivers [14]. Mindfulness- based stress reduction (MBSR) intervention has enhanced psychological well-being among distress individuals and further led to improved quality of life [16]. Several studies were performed related to adherence and retention of an exercise program among women care givers. Physical inactivity, anxiety, depression are the independent risk factors commonly observed among the caregivers. Strategies such as behavioral modification programs, home based health promotion and counselling help caregivers coping with the stressful situations when delivering care to their loved ones [17].

The objective of this study was to examine the effect of educational and stress management strategies in enhancing the coping strategies and to bring down the load of the caregivers.

Methods

A convenience sampling method was used for the selection of subjects – the caregivers of mentally ill patients, from mental health care centers in and around Coimbatore (Kovai medical center and hospital, Vazhikatti mental health center, and Konkanadu mental health center). Fifty subjects based on the following inclusion criteria were recruited; caregivers of patients with affective disorders (bipolar affective disorder), neuroses (obsessive-compulsive disorder) and psychoses (schizophrenia). Caregivers of both genders with minimum of six months of care giving within the age between 20 and 65 years were taken into the study. We included both male and female patients above 18 years, who had been sick for more than a year, and were undergoing active treatment during the survey. The questionnaires used in the survey were; the Zarit Burden Interview Schedule to assess the caregiver burden, the Coping Strategies Inventory for coping strategies and Kuppaswamy Socio- economic status scale for the health professionals.

The Zarit Burden Interview (ZBI) is the most widely utilized burden measures. It is a 22-item questionnaire, which is graded on a 4-point scale [20]. The performance of the score determines the levels of burden in the health care providers. Effects of various studies conducted to assess the psychometric properties of ZBI

demonstrated high internal consistency (Cronbach's alpha 0.92) and good validity due to strong correlations with caregiver life satisfaction and economic crisis, as well as patients' dependency, neuropsychiatric symptoms, and harshness of the circumstance. The grading of the ZBI goes as '0= Never', '1= rarely', '2= Sometimes', '3= Quite frequently', '4= nearly always'. The reading of the scores is '0-21= little or no burden', '21-40= Mild to moderate burden', '41-60= Moderate to severe burden', '61-88= Severe burden'.

The CSI was originally constructed as a 78-item questionnaire [21]. A four-point Likert scale is used to record the participants' responses. Participants are asked to place the general regularity with which they employ each listed coping strategy on the survey and to indicate their responses in the following manner: 1 = "Never", 2 = "Seldom", 3 = "Sometimes", 4 = "Often" and 5 = "Almost Always". The original CSI is reduced to a 16-item version after a validation survey was conducted in Jackson, Mississippi. The CSI-SF was designed to reflect the original scale, with four 4-item subscales: (a) Problem-Focused Engagement, (b) Problem-Focused Disengagement, (c) Emotion-Focused Engagement, and (d) Emotion-Focused Disengagement. Individuals receive scores for each first-tier subscale (Engagement and Disengagement: range 8 - 40), as well as for each of the four second tier subscales (Problem-Focused Engagement, Problem-Focused Disengagement, Emotion-Focused Engagement, and Emotion-Focused Disengagement: range 4 - 20). Each of the four 2nd tier subscales created contained four items each. This 16-item CSI-SF is believed to meet minimum psychometric requirements for measuring coping strategy. All dimensions for each of the four subscales of the CSI-SF were shown to have marginal to acceptable levels of reliability (alpha = 0.58-0.72). Coefficients ranged from 0.58 to 0.72 for second tier subscales, which are problem-focused engagement, problem-focused disengagement, emotion-focused engagement, and emotion-focused disengagement, and 0.59 and 0.70 for the first tier scales, disengagement and engagement respectively. There was evidence that the particulars in each subscale of the CSI-SF were measuring the same underlying construct. They have good reliability in effectively measuring each individual subscale. It is widely applied to measure the socioeconomic position of an individual in urban community based on three variables, namely teaching, business and income [21,22]. The modification of the scale meant to determine the socioeconomic condition of family based on education and occupation of the head of the family and per capita income per month has been widely applied.

Procedure

The survey was conducted at three mental health care centers in Coimbatore. The study was approved by the Kovai Medical center and Hospital ethics committee. Caregivers of both genders, i.e.; 24 (48%) males and 26 (52%) females, of individuals with chronic mental illness, who held a lower limit of 6 months duration of attention giving and who were willing to take part in the survey were chosen for the survey. Fifteen care providers assessed as

having severe burden were included in the experimental group. After a clear explanation about the study purpose and procedure, an informed consent was taken. The cases were divided into 3 groups according to their duration of care giving: 1st group: 6 months- 5 years; 2nd group: 5 years- 10 years; 3rd group: >10 years. The demographic data of the participants (age, gender, duration of care, family type, socioeconomic position, marital status and occupational status) and patients (age, gender, diagnosis and duration of illness) also were recorded.

The Zarit Burden Interview schedule and the Coping strategies Inventory- Short Form were administered in the selected samples to measure their levels of burden and the various coping strategies employed by them. Both of the questionnaires were translated into Tamil by the investigator for the convenience of the participants. Individuals were required to circle the answer, which they feel is the most appropriate, for each question. The Kuppaswamy socioeconomic status scale was administered to sort them according to their socioeconomic status. The interventional group (n=15) received educational and stress management strategies and the treatment sessions were run out on an individual basis by qualified occupational and physical therapists. The therapy plan was administered in 16 sessions of one-hour duration each. The sessions were given twice a week for a period of 2 months.

Educational and Stress Management Strategies:

The session comprised an open seminar to educate the caregiver on the patient’s condition- its causes, clinical characteristics, possible personality and behavior alterations, the duration, course and prognosis. Secondly, making them aware of the effects of care giving on the caregiver’s health and well-being, and the possible coping techniques. Tips to handle the Emotion

and problem focused coping strategies were discussed so that they can utilize these coping methods to the situation instead of panicking or giving up.

Once the education session concluded, introduction to stress, its management and an introduction to relaxation techniques and the things to be looked at before embarking on the practice of a relaxation technique were emphasized. Stress management techniques of Jacobson’s Progressive Muscle Relaxation [23,24], mindfulness-based stress reduction (MBSR) [25-27], and other relaxation techniques-breathing exercises (pranayama) [13,14,28,29] were taught to the clients by trained Physical therapists.

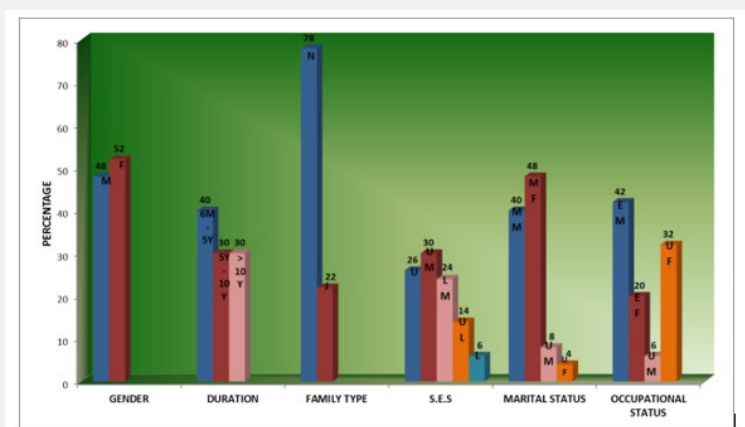
The session further comprised of exercise programs to reduce stress [17,19]. These included stretching exercises and activities such as walking, running or jogging, swimming, physical games/sports. The clients were provided with handouts on various activities for stress management. The suggested activities were reading, writing, poetry writing, horticulture, photography.

Data Analysis

Statistical analysis was performed using the SPSS statistical software version 21.0. The information collected was analyzed using t-test and ANOVA and significance was set at $p \leq .01$. The paired t- test was applied to find the difference between pre and post test scores of both the ZBI and CSI- SF. The independent- t test was calculated to evaluate the levels of load among the male and female caregivers. The duration of care giving, and the levels of caregiver burden were analyzed with ANOVA. The mean differences in the levels of burden among groups were calculated using Post Hoc Scheffe test.

Results

Demographic data of the caregivers



M: males; F: females; Y: years; Family type N: nuclear; J: joint family; S.E.S: socio economic status; U: upper class; U M: upper middle; L M: lower middle; U L: upper lower class; L: lower class; Marital status M M: married male; M F: married female; U M: unmarried male; U F: unmarried female; occupational status E M: employed males; E F: employed females; U M: unemployed males; U F:unemployed females

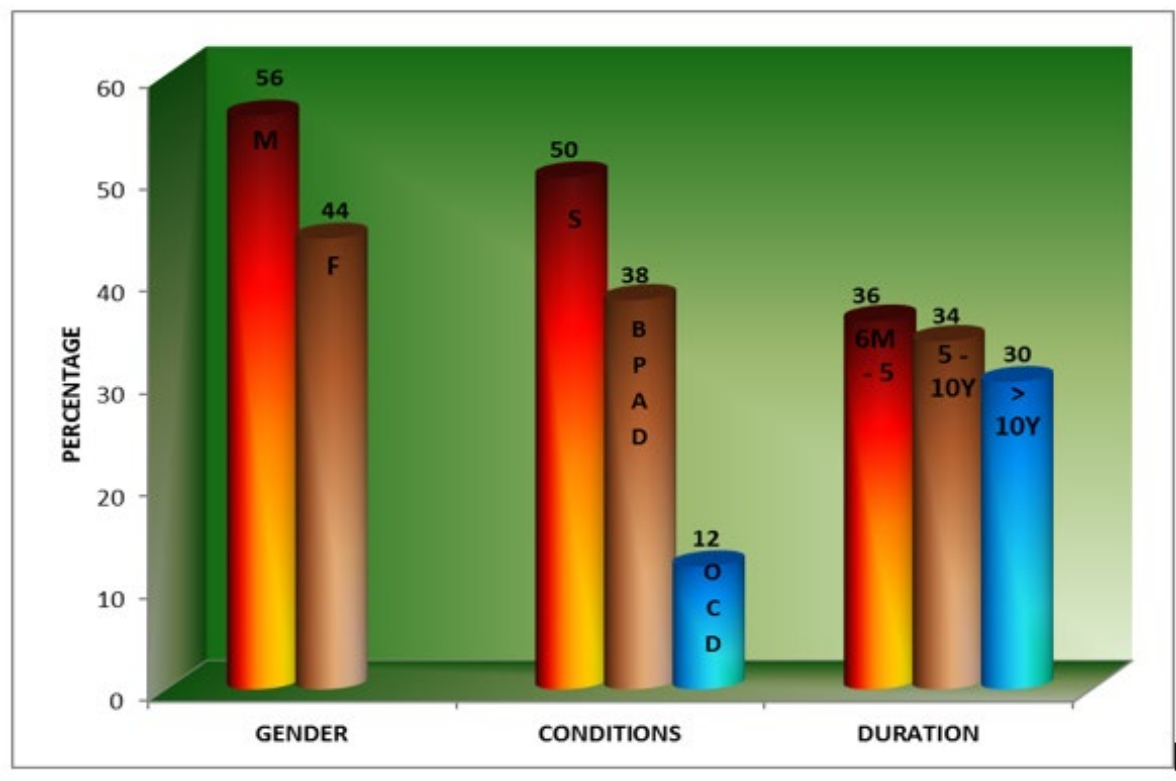
Figure 1: Demographic data of the care givers.

The demographic characteristics of the caregivers are presented in Figure 1. The age of the caregivers ranged between 20 and 65 years. The sample consisted of 24 (48%) male caregivers and 26 (52%) female caregivers. The investigated caregivers were 27 (54%) spouses, 15 (30%) parents, 6 (12%) siblings and 2 (4%) in-laws. The continuance of care giving of the selected samples ranged from 6 months to 18 years. Depending on the duration of care giving, 20 (40%) caregivers belonged to 1st group, 15 (30%) to 2nd group and 15 (30%) to 3rd group. Among the 50 selected cases, 39 (78%) were from nuclear families and 11 (22%) from joint families. According to the Kuppaswamy Socioeconomic status classification, 13 (26%) were from upper class families, 15 (30%) of them were upper middle class families, 12 (24%) lower middle class families, 7 (14%) to upper lower class families and 3 (6%) were from lower class households. Of the 50 caregivers, 31 (62%) were employed, of which 21 (42%) were males and 10 (20%) were females and the 19 (38%) unemployed subjects

included 3 (6%) males and 16 (32%) females. The 50 caregivers included 20 (40%) married males, 24 (48%) married females, 4 (8%) unmarried males and 2 (4%) unmarried females.

Demographic data of the patients:

The age of the patients ranged from 20 to 70 years. The continuance of their illness was between 6 months to 25 years. Of the 50 patients, 25 (50%) were diagnosed as schizophrenia, 19 (38%) have bipolar affective disorder and 6 (12%) were obsessive compulsive disorder patients (Figure 2). Among the 50 caregivers, 10 had little or no burden, 13 had mild to moderate burden, 12 had moderate to severe burden and 15 were having severe burden, according to the ZBI scale. According to the wads of the CSI- SF, the cases received an average grade of 21.42 for the employment sub-scale and 21.08 for the disengagement sub- shell. This displays that the levels of burden and the coping strategies varied in the caregivers of patients with chronic mental illness.



M: males; F: females; S: schizophrenia; BAPD: bipolar affective disorder; OCD: obsessive-compulsive disorder
Figure 2: Demographic data of the patients.

In the interventional group, the ZBI pretest had an average grade of 67.20 which reduced to 49.67 in the post- test and that the difference between the pre and posttest scores is significant at $p \leq 0.01$. The result clearly showed that the educational and stress management strategies can reduce the burden of the caregivers. It was also shown that the engagement subscale of the CSI- SF had a mean pretest score of 15.27, which increased to 25.27 in the posttest, and the difference is significant at $p \leq 0.01$.

It also indicated that the disengagement subscale of the CSI- SF had a mean pretest score of 25.60, which reduced to 15.53 in the post-test. The difference between the pre and posttest scores was significant at 0.01 levels. Therefore, the evaluation of the loads of the CSI- SF scores show that the educational and stress management strategies helped in improving the coping strategies of the care givers (Table 1). It was also observed that there was no statistical difference in the levels of burden between male

and female caregivers ($p < 0.01$) (Table 2). Table 3 expresses the magnetic declination in the levels of burden, according to the duration of care giving. The caregivers who belonged to 1st group (6 months to 5 years) exhibited the highest levels of burden, when compared to the other two groups. The mean difference between the groups was significant. It indicated that the level of burden decreases with an increase in the duration of care giving as they get accustomed to their changed roles, procedures and their restrictions due to care giving (Table 1-3).

Table 1: Pre and post test scores of the intervention group.

Scores	Sample (n)	Pre- test M(SD)	Post- test M(SD)	t- value	p
ZBI score	15	67.20 (5.1)	49.67 (6.6)	23.417	0.01*
CSI scores					
Engagement subscale	15	15.27 (2.6)	25.27 (3.6)	14.07	0.01*
Dis engagement subscale	15	25.60 (1.9)	15.53 (2.7)	12.37	0.01*

Paired t-test. (*) statistically significant difference ($P < 0.01$); SD: standard deviation; M: mean; ZBI- Zarit Burden Interview; CSI: Coping Strategies Inventory

Table 2: Comparison of the Levels of Burden between male and female caregivers.

Category	Sample(n)	M	SD	't' value	p
Males	24	40.21	22.579	0.365	**
Females	26	42.46	21.112		

Paired t-test. (**) statistically no significant difference ($P > 0.01$); SD: standard deviation; M: mean

Table 3: Duration of care giving and levels of care giver burden.

S No.	Duration	Sample	M(SD)	F	p
1	6months- 5 years	20	58(14.6)	38.583	.01
2	5 years- 10 years	15	43.2(14.5)		
3	More than 10 years	15	17.3(10.8)		

ANOVA (*) statistically significant difference ($P < 0.01$); SD: standard deviation; M: mean

Discussion

The care providers of patients with psychiatric illness who were undergoing treatment in an in- patient basis or out- patient basis in three mental health care centers were chosen for the survey. The age of the caregivers ranged between 20 and 65 years. The sample included both male and female caregivers. The duration of care giving was from 6 months to 18 years. Almost half of the respondents ranged from 6 months to 5 years duration of care giving. More than half of the participants belonged to middle class group and 60% of them were employed and married. The

age of the patients ranged from 20 to 70 years and the majority (50%) was suffering from schizophrenia. There was no significant difference observed among male and female care providers. Hence, it was clear that the gender differences do not cause much impact on the levels of load. Although previous studies by Baila Miller and Lynda Cafasso "Gender differences in care giving: Fact or Artifact?" showed that females carry a higher point of burden [30,31]. The outcome of our work indicates a decrease in the levels of caregiver burden with an increase in the duration of care giving, which was supported by the previous study [32]. Among the 50 caregivers, 15 participants had severe level of burden and were included in the intervention group. They received educational and stress management strategies to aid in reducing the burden and to improve coping skills. The results of our survey showed that there was substantial improvement in coping strategies and the level of burden. Similarly another study "A Study of Socio Cultural Perspectives of Care Givers in Burden Coping Behavior in Bipolar Disorder and Schizophrenia Cases" by Ganguly et al. also proved that intervention sessions have a positive effect on the caregivers coping skills [4]. Similarly, another pilot study showed that caregivers with high levels of load were willing to participate and learn about stress reduction programs [33]. It was clear that chronic mental illness can be best handled by enhanced coping strategies, home based health promotion counselling. However, it requires emotional and physical support and commitment from the other family members and the society.

The findings of our study are of interest to rehabilitation professionals involved with mentally ill patients. One of the limitations was the lack of a control group and small sample size. Secondly, the authors did not analyze the relationship between socioeconomic status and the level of burden. However, the other factors such as the duration of care giving, effect of gender and effect of intervention on the level of burden were studied. There are many reasons why health professionals need to focus on caregivers. Patients themselves are more prone to have unmet needs if their health care provider holds a high level of burden/ stress. Furthermore, as caregivers psychological needs increase, the patients' activities may decrease. Caregivers provided with adequate coping skills, specific assistance, physical and mental health education programs and effective rehabilitation facilities can reduce their level of stress by empirically supported guidance program. Furthermore, longitudinal studies involving large sample size are important to identify evidence based interventions on specific illness.

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Conflicts of interest

There are no competing interests for any of the authors.

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