

Original Research Article

Effectiveness of family based educational program on burden of care and stress among family caregivers of young adults with chronic mental disorders: a pilot study report

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ABSTRACT

Background: Living with and caring for a young adult with mental disorders is often challenging and induce enormous amount of burden and stress to Family Care Givers. This area has not received adequate attention in India.

Methods: Caregiver's Stress Scale (KSSC) was used to assess the stress and Burden Assessment Schedule was used to assess the burden of care. The family care givers in the intervention group were provided with family-based intervention on two alternative days and the standard care group received only routine care. A post test was conducted on 30th, 90th and 180 days. Independent t-test was applied to establish the effectiveness of family-based intervention on burden and stress. X² test and Fisher's test was computed to find the association of burden and stress with selected demographic variables.

Results: Family based educational program was found to be effective in reducing the burden of care and stress among the FCGs ($p \leq 0.001$). The study revealed statistically significant association between the age and gender of caregiver to burden and financial support of the caregivers to stress.

Conclusions: The findings of the study suggest family based educational program on home care of young adults with chronic mental disorders was found to be effective in reducing the burden of care and stress among the family caregivers.

Keywords: Family based educational program, Family caregivers, Stress, Burden of care, Chronic mental disorders,

INTRODUCTION

An estimated 970 million individuals worldwide suffered from a mental illness in 2019.¹ Globally 301 million people had anxiety disorders, 280 million had depressive disorders, and 24 million suffered from schizophrenia. Mental disorders accounted for 5.1% of the global burden.² In the treatment of mentally ill people, the family is extremely important.³ Family members of clients with mental disorders constitute an "invisible health system" because they are the main source of care in the community.⁴ They have to shoulder multiple caregiving responsibilities which leads to a lot distress

and FCGs have been described as "the hidden patients".⁵ Mental illness affects FCGs social, psychological, and physical health.⁶ It is critical to assess the level of stress placed on such caregivers and investigate coping methods to design bio-psychosocial treatments.⁷ Prolonged caring of persons with mental disorders (PWMI) demands considerable amount of time, energy, finance, and other resources.⁸

In India, studies have investigated burden and QOL in FCGs of patients with mental disorders, but not investigated change in these variables prior and after interventions.⁸ Caregiving covers a range of

responsibilities. Caregiver burden is usually experienced by those who provide long term care.⁶ FCGs require long-term support and care to ameliorate their stress and burden. There is a need to develop family interventions feasible within Indian settings.⁹ FCGs are at an increased risk of suffering physically, psychologically and socially while providing care for family members with mental health conditions.¹⁰⁻¹³ Studies have shown that caring for family members with mental health problems can lead to social isolation, financial difficulties, occupational restrictions and negative emotions such as anger, aggression, frustration, low self-esteem, constant worry and feelings of helplessness.¹⁴

Psycho-education of the caregiver and skills training such as mood and coping mechanisms can reduce the caregiver burden. Specific management strategies have to be designed in account to improve the caregiver efficiency to manage both patient and care giver.¹⁵ Increase in the deinstitutionalization of patients suffering from chronic mental disorders has led families, by choice or necessity, to assume responsibility for the care of their relatives at home.¹⁶

A systemic review on the multidimensional impact of the serious mental illness (SMI) on the family members revealed the physical, psychological difficulties and socio- economic drift. The study concluded that the serious nature of the impact of mental disorders and calls for interventions.¹⁷ A cross-sectional study suggested community services programs, such as family psycho-education groups, may help to minimize or prevent the effects of burden on family caregivers responsible for patients' home care.¹⁸

METHODS

Study design

A quasi - experimental repeated time series design was used to determine the effect of family based educational program, on burden of care and stress among family caregivers (FCG) of young adults with chronic mental disorders in two selected mental health care facilities from April 2023 to December 2023.

Inclusion criteria

The inclusion criteria were care givers of clients who have looked after the mentally ill patients at any time in the past or staying with the client for the last six months. Care givers of client with chronic mental disorders (mania, depression, Bipolar Affective disorders (BPAD) and schizophrenia) willing to participate in the study. Caregivers of clients with chronic mental disorders in the age group of 20- 40 year. Care givers of the clients who can understand and speak either in English/ Kannada, and residing in and around Bengaluru and availing inpatient or out -patient services.

Exclusion criteria

Family care givers with sensory (hearing and visual) impairments, diagnosed with major mental disorders

Sample technique

The sixty FCGs were selected using purposive sampling technique based on the inclusion criteria were selected from two mental health facility and randomly allocated to intervention and standard care group.

Tools

Tool 1

A demographic proforma consisting of age, gender, marital status, religion, educational status occupation, annual family income, area of residence, relationship with the patient, years of caring, history of financial and social support, history of physical comorbidity and distance from mental health facility. The content validity of the tool was determined by sending it to 11 experts in the field of psychiatry, psychiatric nursing, community health nursing and psychiatric social work.

Family-based educational program

Phase II, thirty family caregivers were randomly assigned to the intervention and standard care group. The pre -test was conducted on the first day of allotment. The burden of caring was assessed using BAS-and the stress among the family caregivers were assessed by KCSS.

The family based educational program on home care of young adults with chronic mental disorder was conducted for two alternative days for 3 hours for the intervention group through lecture cum discussion on disease condition, clinical manifestations, effectiveness of treatment modalities management of side effects of medication and strategies of drug adherence using power point, roleplay on management of activities of daily living, demonstrating yoga and meditation practices, video assisted teaching on management of aggression and suicidal thoughts were provided to the intervention group and standard care group received routine care. The Post test was conducted to assess the burden and stress on Day 30, 90, and 180 days.

Statistical analysis

The statistical analysis was carried out using JAMovi software. Shapiro Wilkies test was used to check the normality of the data. The descriptive statistics was used in this study were mean, standard deviation and percentage. Independent t test is applied to find the effectiveness of the family based educational program on burden and stress among FCGs. The association between the stress and burden with selected baseline variables were tested with chi-square test and Fisher's test.

RESULTS

Demographic characteristics of family caregivers of young adults with chronic mental disorders

Regarding the FCG majority of them in the intervention group were in the age group of 28 to 47 years male, in standard care group were in 38-57 years and male and female were equal in number.

Many were married and Hindus in both the groups. All the caregivers are literate and many were from rural Bangalore, educated and were belongs to middle class and were parents and caring the clients for more than 5-7 years.

Majority (62%) of them were parents and caring the patient more than 3 years. 60% of the caregivers were parents in the intervention group while majority 46 % of them were siblings in standard care group. Nearly 60% of them receives social and financial support from the relatives. Majority of the caregivers had history of physical co -morbidity in both the groups (70 and 83.3 % respectively) and the most common co-morbidities were heart diseases and hypertension.

Effectiveness of family based educational program on burden among the FCG of young adults with chronic mental disorders

There is a remarkable change in the total burden and stress level among the family caregivers in intervention and standard care group from day-1 to day 30, day 90 and day 180. The obtained t value is statistically significant ($p < 0.001$). It indicates the Family based education on home care among the family caregivers was effective to reduce the burden and stress among the FCG.

Association between burden with selected demographic variables in intervention group and standard care group

There was statistically significant association between gender($p=0.49$) of the caregiver in intervention group, and age of caregivers in standard care group (p value=0.044). There is no significant association found between burden with other baseline variables.

Association between stress with selected demographic variables in intervention group and standard care group

A statistically significant association found between history of financial support and stress among the family caregivers in the intervention group.

Table 1: Baseline characteristics of family caregivers of young adults with chronic mental disorders.

| S. no | Variables | Intervention group | | Standard care group | |
|-------|---------------------|--------------------|------|---------------------|------|
| | | Frequency | % | Frequency | % |
| 1 | Age (in years) | | | | |
| | 18-27 | 4 | 13.3 | 4 | 13.3 |
| | 28-37 | 8 | 26.7 | 2 | 6.7 |
| | 38-47 | 8 | 26.7 | 10 | 33.3 |
| | 48-57 | 5 | 16.7 | 10 | 33.3 |
| | 58-67 | 5 | 16.7 | 3 | 10 |
| | >67 | 0 | 0.0 | 1 | 3.3 |
| 2 | Gender | | | | |
| | Male | 18 | 60 | 15 | 50 |
| | Female | 12 | 40 | 15 | 50 |
| 3 | Marital status | | | | |
| | Married | 25 | 83.3 | 20 | 66.7 |
| | Unmarried | 3 | 10.0 | 8 | 26.7 |
| | Widow | 1 | 3.3 | 1 | 3.3 |
| | Separated | 1 | 3.3 | 1 | 3.3 |
| 4 | Religion | | | | |
| | Hindu | 14 | 46.7 | 16 | 53.3 |
| | Christian | 8 | 26.7 | 10 | 33.3 |
| | Muslim | 8 | 26.7 | 4 | 13.3 |
| 5 | Education | | | | |
| | Primary education | 5 | 16.7 | 0 | 0.0 |
| | Middle school | 5 | 16.7 | 2 | 6.7 |
| | Secondary | 9 | 30.0 | 8 | 26.7 |
| | Higher secondary | 8 | 16.7 | 8 | 26.7 |
| | Diploma | 2 | 16.7 | 3 | 10 |
| | Graduate | 1 | 3.3 | 4 | 13.3 |
| 6 | Occupational status | | | | |
| | Unemployed | 0 | 0.0 | 4 | 13.3 |

Continued.

| S. no | Variables | Intervention group | | Standard care group | |
|-------|--------------------------------------|--------------------|------|---------------------|------|
| | Home maker | 7 | 23.3 | 11 | 36.7 |
| | Skilled worker | 12 | 40.0 | 10 | 33.3 |
| | Unskilled worker | 7 | 23.3 | 3 | 10 |
| | Professionals | 4 | 13.3 | 2 | 6.7 |
| 7 | Annual income | | | | |
| | <1.00000 | 6 | 20.0 | 0 | 0 |
| | 1L-2L | 7 | 23.3 | 8 | 26.7 |
| | 2L-3L | 13 | 43.3 | 14 | 46.7 |
| | >3L | 4 | 13.3 | 8 | 26.7 |
| 8 | Area of residence | | | | |
| | Urban Bangalore | 10 | 33.3 | 8 | 26.7 |
| | Rural Bangalore | 18 | 60.0 | 20 | 66.7 |
| | Migrants | 2 | 18.2 | 2 | 6.7 |
| 9 | Relationship with the client | | | | |
| | Parents | 18 | 60 | 5 | 16.7 |
| | Spouse | 8 | 26.7 | 3 | 10 |
| | Sibling | 3 | 10.0 | 14 | 46.7 |
| | Children | 1 | 3.3 | 8 | 26.7 |
| 10 | Number of years cared | | | | |
| | 5-8 years | 14 | 46.7 | 20 | 66.7 |
| | 9-12 years | 1 | 3.3 | 2 | 6.7 |
| | 13-15 years | 9 | 30.0 | 2 | 6.7 |
| | 16-19 years | 2 | 6.7 | 4 | 13.3 |
| | >19 years | 4 | 13.3 | 2 | 6.7 |
| 11 | History of Financial support | | | | |
| | No | 12 | 40 | 14 | 46.7 |
| | Yes | 18 | 60 | 16 | 53.3 |
| 12 | History of social support | | | | |
| | No | 12 | 40 | 12 | 40.0 |
| | Yes | 18 | 60 | 18 | 60 |
| 13 | Source of support | | | | |
| | No support | 12 | 40 | 11 | 36.7 |
| | Relatives | 12 | 40 | 9 | 30 |
| | Religious organization | 6 | 20 | 3 | 10 |
| | NGO | 0 | 0.0 | 7 | 23.3 |
| 14 | History of physical illness | | | | |
| | No | 9 | 30 | 5 | 16.7 |
| | Yes | 21 | 70 | 25 | 83.3 |
| 15 | Types of illness | | | | |
| | No illness | 8 | 30 | 4 | 13.3 |
| | DM | 7 | 23.3 | 5 | 16.7 |
| | HTN | 6 | 20 | 7 | 23.3 |
| | Heart Diseases | 8 | 26.7 | 5 | 16.7 |
| | Kidney Diseases | 1 | 3.3 | 3 | 10 |
| | Others | 0 | 0.0 | 6 | 20 |
| 16 | Distance From mental health facility | | | | |
| | <5 km | 2 | 6.7 | 2 | 6.67 |
| | 6-10 km | 12 | 40 | 8 | 26.7 |
| | 11-15 | 10 | 33.3 | 13 | 43.3 |
| | >16 km | 6 | 20 | 7 | 23.3 |

Table 2: The Mean, SD of burden and stress among the FCG in intervention group (IG) and standard care group (SG).

| Variables | Group | Day 1 mean±S.D | Day 30 mean±S.D | Day 90 mean±S.D | Day 180 mean±S.D | Independent t test value | P value |
|---------------|-------|----------------|-----------------|-----------------|------------------|--------------------------|---------|
| Burden | IG | 82.67±6.013 | 62.17±8.02 | 60.2±5.756 | 63.579±6.7 | 0.114 | <0.001 |
| | SG | 86.13±10.15 | 82.93±13.199 | 84.2±8.511 | 81.67±11.9 | | |
| Stress | IG | 41±1.15 | 18±2.43 | 23.9±6.68 | 24.4±2.46 | 0.013 | <0.001 |
| | SG | 39.0±3.12 | 37.7±6.43 | 39.3±3.32 | 26.9±3.39 | | |

Table 3: Association between burden and selected demographic variables.

| S. no | Demographic variable | Burden (intervention group) | | | | X ² /f | P | Burden (standard care group) | | | | | | X ² /f | P |
|-------|----------------------|-----------------------------|------|--------|------|-------------------|--------|------------------------------|------|------------|-------------|------|-----|-------------------|--------|
| | | Moderate | | Severe | | | | Moderate | | Sever e | Very severe | | | | |
| | | Freq | % | Freq | % | | | Freq | % | Freq | % | Freq | % | | |
| 1 | Age (in years) | | | | | 0.544 | 0.628 | | | | | | | 14.3 | 0.049* |
| | 18-27 | 1 | 9.1 | 3 | 15.5 | | | 3 | 37.5 | 1 | 5 | 0 | 0 | | |
| | 28-37 | 4 | 13.1 | 4 | 21 | | | 1 | 12.5 | 1 | 5 | 0 | 0 | | |
| | 38-47 | 2 | 18.2 | 6 | 32 | | | 0 | 0 | 10 | 50 | 0 | 0 | | |
| | 48-57 | 3 | 36.3 | 2 | 10.5 | | | 3 | 37.5 | 5 | 25 | 2 | 10 | | |
| | 58-67 | 1 | 9.1 | 4 | 21 | | | 1 | 12.5 | 2 | 10 | 0 | 0 | | |
| | Total | 11 | 100 | 19 | 100 | | | 0 | 100 | 20 | 100 | 0 | 100 | | |
| 2 | Gender | | | | | 4.043 | 0.044* | | | | | | | 0.7 | 0.833 |
| | Male | 4 | 37 | 14 | 74 | | | 5 | 62.5 | 9 | 45 | 1 | 50 | | |
| | Female | 7 | 64 | 5 | 26 | | | 3 | 37.5 | 11 | 55 | 1 | 50 | | |
| | Total | 11 | 100 | 19 | 100 | | | 8 | 100 | 20 | 100 | 2 | 100 | | |
| 3 | Marital status | | | | | 0.295 | 0.283 | | | | | | | 2.27 | 0.927 |
| | Married | 8 | 72.7 | 17 | 89.5 | | | 5 | 62.5 | 13 | 65 | 2 | 100 | | |
| | Unmarried | 2 | 18.2 | 1 | 5.3 | | | 3 | 37.5 | 5 | 25 | 0 | 0 | | |
| | Widow | 0 | 0 | 1 | 5.3 | | | 0 | 0 | 1 | 5 | 0 | 0 | | |
| | Separated | 1 | 1 | 0 | 0 | | | 0 | 0 | 1 | 5 | 0 | 0 | | |
| | Total | 11 | 9.1 | 19 | 19 | | | 8 | 100 | 20 | 100 | 2 | 100 | | |
| 4 | Religion | | | | | 0.702 | 0.704 | | | | | | | 5.19 | 0.337 |
| | Hindu | 6 | 54.5 | 8 | 42.1 | | | 6 | 75 | 9 | 45 | 1 | 50 | | |
| | Christian | 3 | 27.3 | 5 | 26.3 | | | 2 | 25 | 8 | 40 | 0 | 0 | | |
| | Muslim | 2 | 18.2 | 6 | 31.6 | | | 0 | 0 | 3 | 15 | 1 | 50 | | |
| | Total | 11 | 100 | 19 | 100 | | | 8 | 100 | 20 | 100 | 2 | 10 | | |
| 5 | Education | | | | | 6.65 | 0.296 | | | | | | | 14.4 | 0.153 |
| | Primary education | 3 | 27.3 | 2 | 10.5 | | | 1 | 12.5 | 0 | 0 | 1 | 50 | | |
| | Middle school | 0 | 0 | 5 | 26.3 | | | 1 | 12.5 | 7 | 35 | 0 | 0 | | |
| | Secondary | 4 | 36.4 | 5 | 26.3 | | | 3 | 37.5 | 5 | 25 | 0 | 0 | | |
| | Higher secondary | 3 | 27.3 | 4 | 21.1 | | | 1 | 12.5 | 2 | 10 | 0 | 0 | | |
| | Diploma | 1 | 9.1 | 1 | 5.3 | | | 0 | 0 | 4 | 20 | 0 | 0 | | |
| | Graduate | 0 | 0 | 1 | 5.3 | | | 2 | 25 | 2 | 10 | 1 | 50 | | |
| | Post graduate | 0 | 0 | 0 | 0 | | | 0 | 10 | 20 | 10 | 2 | 10 | | |
| | Total | 11 | 100 | 19 | 100 | | | 8 | 10 | 20 | 10 | 2 | 10 | | |

Continued.

| S. no | Demographic | Burden (intervention group) | | | | X2/ | P | Burden (standard care group) | | | | | | X ² /f | P |
|-----------------|------------------------------|-----------------------------|------|------|------|--------|-------|------------------------------|------|------|-----|-----|-----|-------------------|-------|
| 6 | Occupation | | | | | 0.677 | 0.87 | | | | | | | 2.83 | 0.961 |
| | Unemployed | 0 | 0 | 0 | 0 | | | 1 | 12.5 | 3 | 15 | 0 | 0 | | |
| | Home maker | 3 | 27.3 | 4 | 21.1 | | | 3 | 37.5 | 7 | 35 | 1 | 50 | | |
| | Skilled worker | 4 | 36.4 | 8 | 42.1 | | | 0 | 37.5 | 6 | 30 | 1 | 50 | | |
| | Unskilled worker | 2 | 18.2 | 5 | 26.3 | | | 1 | 0 | 3 | 15 | 0 | 0 | | |
| | Professionals | 2 | 18.2 | 2 | 18.2 | | | 8 | 12.5 | 1 | 5 | 0 | 0 | | |
| | Total | 11 | 100 | 19 | 100 | | | 13 | 100 | 20 | 100 | 2 | 100 | | |
| 7 | Income | | | | | 1 | 0.786 | | | | | | | 3.19 | 0.431 |
| <1.00000 | 3 | 27.3 | 3 | 27.3 | 0 | | | 0 | 0 | 0 | 0 | 0 | | | |
| 11-21 | 3 | 27.3 | 4 | 36.4 | 3 | | | 37.5 | 4 | 20 | 1 | 50 | | | |
| 21-31 | 4 | 36.4 | 9 | 47.4 | 4 | | | 50 | 10 | 50 | 0 | 0 | | | |
| >31 | 1 | 9.1 | 3 | 27.3 | 1 | | | 12.5 | 6 | 30 | 1 | 50 | | | |
| Total | 11 | 100 | 19 | 100 | 8 | | | 100 | 20 | 100 | 2 | 10 | | | |
| 8 | Area of residence | | | | | 4.69 | 0.096 | | | | | | | 2.18 | 0.704 |
| Urban bangalore | 2 | 18.2 | 8 | 42.1 | 2 | | | 25 | 6 | 30.7 | 0 | 0 | | | |
| Rural bangalore | 7 | 63.6 | 11 | 57.9 | 6 | | | 75 | 12 | 60 | 2 | 100 | | | |
| Migrants | 2 | 18.2 | 0 | 0 | 0 | | | 0 | 2 | 10 | 0 | 0 | | | |
| Total | 11 | 100 | 19 | 100 | 8 | | | 100 | 20 | 100 | 2 | 100 | | | |
| 9 | Relationship with the client | | | | | 3.44 | 0.367 | | | | | | | 9.44 | 0.158 |
| Parents | 6 | 54.5 | 12 | 63.2 | 0 | | | 0 | 5 | 25 | 0 | 0 | | | |
| Spouse | 2 | 18.2 | 6 | 31.6 | 0 | | | 0 | 2 | 10 | 1 | 50 | | | |
| Sibling | 2 | 18.2 | 1 | 9.1 | 6 | | | 75 | 8 | 40 | 0 | 0 | | | |
| Children | 1 | 9.1 | 0 | 0 | 2 | | | 25 | 5 | 25 | 1 | 50 | | | |
| Total | 11 | 100 | 19 | 100 | 8 | | | 100 | 20 | 100 | 2 | 100 | | | |
| 10 | Number of years cared | | | | | 3.24 | 0.709 | | | | | | | 9.3 | 0.564 |
| 5-8 years | 5 | 45.5 | 9 | 47.4 | 7 | | | 87.5 | 12 | 60 | 1 | 50 | | | |
| 9-12 years | 1 | 9.1 | 0 | 0 | 0 | | | 0 | 1 | 5 | 1 | 50 | | | |
| 13-15 years | 3 | 27.3 | 6 | 31.6 | 0 | | | 0 | 2 | 10 | 0 | 0 | | | |
| 16-19 years | 0 | 0 | 2 | 10.5 | 1 | | | 12.5 | 3 | 15 | 0 | 0 | | | |
| >19 years | 2 | 18.2 | 2 | 10.5 | 0 | | | 0 | 2 | 10 | 0 | 0 | | | |
| Total | 11 | 100 | 19 | 100 | 8 | | | 100 | 20 | 100 | 2 | 100 | | | |
| 11 | History of financial support | | | | | 0.0957 | 0.757 | | | | | | | 1,17 | 0.557 |
| No | 4 | 36.4 | 8 | 42.1 | 5 | | | 62 | 8 | 40 | 1 | 50 | | | |
| Yes | 7 | 63.6 | 11 | 57.9 | 3 | | | 38 | 12 | 60 | 1 | 50 | | | |
| Total | 11 | 100 | 19 | 100 | 8 | | | 100 | 20 | 100 | 2 | 100 | | | |
| 12 | History of social support | | | | | 0.0957 | 0.757 | | | | | | | 0.104 | 0.949 |
| No | 4 | 36.4 | 8 | 42.1 | 3 | | | 38 | 8 | 40 | 1 | 50 | | | |
| Yes | 7 | 63.6 | 11 | 57.9 | 5 | | | 62 | 12 | 60 | 1 | 50 | | | |
| Total | 11 | 100 | 19 | 100 | 8 | | | 100 | 20 | 100 | 2 | 100 | | | |

Continued.

| S. no | Demographic | Burden (intervention group) | | | | X ² / | P | Burden (standard care group) | | | | | | X ² /f | P |
|-------|--------------------------------------|-----------------------------|------|----|------|------------------|-------|------------------------------|-----|----|-----|---|-----|-------------------|-------|
| 13 | Source of support | | | | | | | | | | | | | | |
| | No support | 4 | 36.4 | 8 | 42.1 | 0.524 | 0.75 | 3 | 38 | 7 | 35 | 1 | 50 | 2.86 | 0.826 |
| | Relatives | 4 | 36.4 | 8 | 42.1 | | | 1 | 13 | 7 | 35 | 1 | 50 | | |
| | Religious organization | 3 | 27.3 | 3 | 15.8 | | | 1 | 13 | 2 | 10 | 0 | 0 | | |
| | NGO | 0 | 0 | 0 | 0 | | | 3 | 38 | 4 | 20 | 0 | 0 | | |
| | Total | 11 | 100 | 19 | 100 | | | 8 | 100 | 20 | 100 | 2 | 100 | | |
| 14 | History of physical illness | | | | | | | | | | | | | | |
| | No | 3 | 27.3 | 6 | 31.6 | 0.574 | 0.785 | 0 | 0 | 5 | 25 | 0 | 0 | 3 | 0.376 |
| | Yes | 8 | 72.7 | 13 | 68.4 | | | 8 | 100 | 15 | 75 | 2 | 100 | | |
| | Total | 11 | 100 | 19 | 100 | | | 8 | 100 | 20 | 100 | 2 | 100 | | |
| 15 | Types of illness | | | | | | | | | | | | | | |
| | No illness | 2 | 27.3 | 6 | 31.6 | 1.36 | 0.78 | 0 | 0 | 4 | 20 | 0 | 0 | 9.27 | 0.558 |
| | DM | 2 | 18.2 | 5 | 26.2 | | | 1 | 13 | 4 | 20 | 0 | 0 | | |
| | HTN | 3 | 27.3 | 3 | 15.8 | | | 3 | 37 | 3 | 15 | 1 | 50 | | |
| | Heart diseases | 3 | 27.3 | 5 | 26.3 | | | 1 | 12 | 3 | 15 | 1 | 50 | | |
| | Kidney diseases | 1 | 9.1 | 0 | 0 | | | 0 | 0 | 3 | 15 | 0 | 0 | | |
| | Others | 0 | 0 | 0 | 0 | | | 3 | 38 | 3 | 15 | 0 | 0 | | |
| | Total | 11 | 100 | 19 | 100 | | | 8 | 100 | 20 | 100 | 2 | 10 | | |
| 16 | Distance from mental health facility | | | | | | | | | | | | | | |
| | <5 km | 0 | 10.5 | 2 | 6.7 | 2.01 | 0.692 | 0 | 0 | 1 | 5 | 1 | 50 | 7.53 | 0.583 |
| | 6-10km | 4 | 36.4 | 8 | 42.1 | | | 2 | 25 | 6 | 30 | 0 | 0 | | |
| | 11-15 | 5 | 45.5 | 5 | 26.3 | | | 4 | 50 | 8 | 40 | 1 | 50 | | |
| | >16 km | 2 | 18.2 | 4 | 21.1 | | | 2 | 25 | 5 | 25 | 0 | 0 | | |
| | Total | 11 | 100 | 19 | 100 | | | 8 | 100 | 20 | 100 | 2 | 100 | | |

*Statistically significant.

Table 4: Association between stress and selected demographic variables.

| S. no | Demographic variable | Stress -intervention group | | | | X ² /f | P | Stress -standardcaremgrou | | | | X ² /f | P |
|-------|----------------------|----------------------------|------|----------------|------|-------------------|-------|---------------------------|------|----------------|------|-------------------|-------|
| | | A lot of stress | | Extreme stress | | | | A lot of stress | | Extreme stress | | | |
| | | Frequency | % | Frequency | % | | | Frequency | % | Frequency | % | | |
| 1 | Age (in years) | | | | | 1.9 | 0.754 | | | | | 3.75 | 0.586 |
| | 18-27 | 1 | 9.1 | 3 | 15.8 | | | 4 | 16.7 | 0 | 0 | | |
| | 28-37 | 2 | 18.2 | 6 | 31.8 | | | 1 | 4.2 | 1 | 16.7 | | |
| | 38-47 | 3 | 27.3 | 5 | 26.3 | | | 8 | 33.3 | 2 | 33.3 | | |
| | 48-57 | 3 | 27.3 | 2 | 10.5 | | | 7 | 29.2 | 3 | 50 | | |
| | 58-67 | 2 | 18.2 | 3 | 15.8 | | | 3 | 12.5 | 0 | 0 | | |
| | >67 | 10 | 100 | 20 | 0 | | | 1 | 4.2 | 0 | 0 | | |
| | Total | 11 | 100 | 19 | 100 | 24 | 100 | 6 | 100 | | | | |

Continued.

| S. no | Demographic | Stress -intervention group | | | | X ² | P | Stress -standardcaregroup | | | | X ² | P |
|-------|------------------------------|----------------------------|------|----|------|----------------|-------|---------------------------|------|---|------|----------------|-------|
| 2 | Gender | | | | | | | | | | | | |
| | Male | 5 | 45.5 | 13 | 68.4 | 1.53 | 0.216 | 12 | 50 | 3 | 50 | 0 | 1 |
| | Female | 6 | 54.5 | 6 | 31.6 | | | 12 | 50 | 3 | 50 | | |
| | Total | 11 | 100 | 19 | 100 | | | 24 | 100 | 6 | 100 | | |
| 3 | Marital status | | | | | | | | | | | | |
| | Married | 9 | 81.8 | 16 | 84.2 | 4.69 | 0.82 | 17 | 70.8 | 3 | 50 | 4.69 | 0.196 |
| | Unmarried | 2 | 18.2 | 1 | 5.3 | | | 6 | 25 | 2 | 33.3 | | |
| | Widow | 0 | 0 | 1 | 5.3 | | | 1 | 4.2 | 0 | 0 | | |
| | Separated | 0 | 0 | 1 | 5.3 | | | 0 | 0 | 1 | 16.7 | | |
| | Total | 11 | 100 | 19 | 100 | | | 24 | 100 | 6 | 100 | | |
| 4 | Religion | | | | | | | | | | | | |
| | Hindu | 7 | 63.6 | 7 | 36.8 | 3.09 | 0.214 | 12 | 50 | 4 | 66.7 | 1.25 | 0.535 |
| | Christian | 1 | 9.1 | 7 | 36.8 | | | 8 | 33.3 | 2 | 33.3 | | |
| | Muslim | 3 | 37.3 | 5 | 26.3 | | | 4 | 16.7 | 0 | 0 | | |
| | Total | 11 | 100 | 19 | 100 | | | 24 | 100 | 6 | 100 | | |
| 5 | Education | | | | | | | | | | | | |
| | Primaryeducation | 2 | 18.2 | 3 | 15.8 | 3.69 | 0.384 | 0 | 0 | 0 | 0 | 3.69 | 0.592 |
| | Middle school | 1 | 9.1 | 4 | 21.1 | | | 2 | 8.3 | 0 | 0 | | |
| | Secondary | 2 | 18.2 | 7 | 36.8 | | | 5 | 20.8 | 3 | 50 | | |
| | Highersecondary | 2 | 18.2 | 3 | 15.8 | | | 7 | 29.2 | 1 | 16.7 | | |
| | Diploma | 4 | 36.4 | 1 | 5.3 | | | 2 | 8.3 | 1 | 16.7 | | |
| | Graduate | 0 | 0 | 1 | 5.3 | | | 3 | 12.5 | 1 | 16.7 | | |
| | Post-graduate | 0 | 0 | 0 | 0 | | | 5 | 20.8 | 0 | 0 | | |
| | Total | 11 | 100 | 19 | 100 | | | 24 | 100 | 6 | 100 | | |
| 6 | Occupational status | | | | | | | | | | | | |
| | Unemployed | 0 | 0 | 0 | 0 | 3.24 | 0.79 | 8 | 33.3 | 3 | 50 | 3.24 | 0.818 |
| | Home maker | 2 | 18.2 | 5 | 26.3 | | | 7 | 29.2 | 3 | 50 | | |
| | Skilled worker | 5 | 45.5 | 7 | 36.8 | | | 3 | 12.5 | 0 | 0 | | |
| | Unskilledworker | 2 | 18.2 | 5 | 26.3 | | | 2 | 8.3 | 0 | 0 | | |
| | Professionals | 2 | 18.2 | 2 | 10.5 | | | 0 | 0 | 0 | 0 | | |
| | Total | 11 | 100 | 19 | 100 | | | 24 | 100 | 6 | 100 | | |
| 7 | Annual income | | | | | | | | | | | | |
| | <1.00000 | 3 | 27.3 | 3 | 15.8 | 1.91 | 0.609 | 0 | 0 | 0 | 0 | 2.77 | 0.251 |
| | 11-21 | 3 | 27.3 | 4 | 21.1 | | | 6 | 25 | 2 | 33.3 | | |
| | 21-31 | 3 | 27.3 | 10 | 52.6 | | | 10 | 41.7 | 4 | 66.7 | | |
| | >31 | 2 | 18.2 | 2 | 10.5 | | | 8 | 33.3 | 0 | 0 | | |
| | Total | 11 | 100 | 19 | 100 | | | 24 | 100 | 6 | 100 | | |
| 8 | Area of residence | | | | | | | | | | | | |
| | Urban bangalore | 2 | 18.2 | 8 | 42.1 | 1.82 | 0.403 | 6 | 25 | 2 | 33.3 | 0.625 | 0.732 |
| | Rural bangalore | 8 | 72.7 | 10 | 52.6 | | | 16 | 66.7 | 4 | 66.7 | | |
| | Migrants | 1 | 9.1 | 1 | 5.3 | | | 2 | 8.3 | 0 | 0 | | |
| | Total | 11 | 100 | 19 | 100 | | | 24 | 100 | 6 | 100 | | |
| 9 | Relationship with the client | | | | | | | | | | | | |
| | Parents | 6 | 54.5 | 12 | 63.2 | 0.395 | 0.821 | 4 | 16.7 | 1 | 16.7 | 0.744 | 0.863 |

Continued.

| S. no | Demographic | Stress -intervention group | | | | X ² | P | Stress -standardcaregroup | | | | X ² | P |
|-----------|--------------------------------------|----------------------------|------|----|------|----------------|-------|---------------------------|------|---|------|----------------|-------|
| | Spouse | 3 | 27.3 | 5 | 26.3 | | | 2 | 8.3 | 1 | 16.7 | | |
| | Sibling | 2 | 18.2 | 2 | 10.5 | | | 12 | 50 | 2 | 33.3 | | |
| | Children | 0 | 0 | 0 | 0 | | | 6 | 25 | 2 | 33.3 | | |
| | Total | 11 | 100 | 19 | 100 | | | 24 | 100 | 6 | 100 | | |
| 10 | Number of years cared | | | | | | | | | | | | |
| | 5-8 years | 6 | 54.5 | 8 | 42.1 | | | 15 | 62.5 | 5 | 83.3 | | |
| | 9-12 years | 1 | 9.1 | 0 | 0 | | | 2 | 8.3 | 0 | 0 | | |
| | 13-15 years | 3 | 27.3 | 6 | 31.6 | 3.39 | 0.709 | 2 | 8.3 | 0 | 0 | 3.44 | 0.487 |
| | 16-19 years | 0 | 0 | 2 | 10.5 | | | 4 | 16.7 | 0 | 0 | | |
| | >19 years | 1 | 9.1 | 3 | 15.8 | | | 1 | 4.2 | 1 | 16.7 | | |
| | Total | 11 | 100 | 19 | 100 | | | 24 | 100 | 6 | 100 | | |
| 11 | History of financial support | | | | | | | | | | | | |
| | No | 5 | 45.5 | 7 | 36.8 | | | 14 | 58.3 | 0 | 0 | | |
| | Yes | 6 | 54.5 | 12 | 63.2 | 0.215 | 0.643 | 10 | 41.7 | 6 | 100 | 6.56 | 0.01* |
| | Total | 11 | 100 | 19 | 100 | | | 24 | 100 | 6 | 100 | | |
| 12 | History of social support | | | | | | | | | | | | |
| | No | 5 | 45.5 | 7 | 36.8 | | | 10 | 41.7 | 2 | 33.3 | | |
| | Yes | 6 | 54.5 | 12 | 63.2 | 0.215 | 0.643 | 14 | 58.3 | 4 | 66.7 | 0.139 | 0.709 |
| | Total | 11 | 100 | 19 | 100 | | | 24 | 100 | 6 | 100 | | |
| 13 | Source of support | | | | | | | | | | | | |
| | No support | 5 | 45.5 | 7 | 36.8 | | | 8 | 33.3 | 3 | 50 | | |
| | Relatives | 3 | 27.3 | 9 | 47.4 | | | 8 | 33.3 | 1 | 16.7 | | |
| | Religious organization | 3 | 27.3 | 3 | 15.8 | 1.29 | 0.524 | 3 | 12.5 | 0 | 0 | 1.88 | 0.598 |
| | Ngo | 0 | 0 | 0 | 0 | | | 5 | 20.8 | 2 | 33.3 | | |
| | Total | 11 | 100 | 19 | 100 | | | 24 | 100 | 6 | 100 | | |
| 14 | History of physical illness | | | | | | | | | | | | |
| | No | 4 | 36.4 | 5 | 26.3 | | | 4 | 16.7 | 1 | 16.7 | | |
| | Yes | 7 | 63.6 | 14 | 73.7 | 0.335 | 0.563 | 20 | 83.3 | 5 | 83.3 | 0 | 1 |
| | Total | 11 | 100 | 19 | 100 | | | 24 | 100 | 6 | 100 | | |
| 15 | Types of illness | | | | | | | | | | | | |
| | No illness | 4 | 36.4 | 4 | 21.1 | | | 3 | 12.5 | 1 | 16.7 | | |
| | DM | 5 | 45.5 | 2 | 10.5 | | | 4 | 16.7 | 1 | 16.7 | | |
| | HTN | 0 | 0 | 6 | 31.6 | | | 6 | 25 | 1 | 16.7 | | |
| | Heart diseases | 2 | 18.2 | 6 | 31.6 | 8.78 | 0.067 | 3 | 12.5 | 2 | 33.3 | 2.25 | 0.814 |
| | Kidney diseases | 0 | 0 | 1 | 5.3 | | | 3 | 12.5 | 0 | 0 | | |
| | Others | 0 | 0 | 0 | 0 | | | 5 | 20.8 | 1 | 16.7 | | |
| | Total | 11 | 100 | 19 | 100 | | | 24 | 100 | 6 | 100 | | |
| 16 | Distance from mental health facility | | | | | | | | | | | | |
| | <5 km | 0 | 0 | 2 | 10.5 | | | 2 | 8.3 | 0 | 0 | | |
| | 6-10km | 5 | 45.5 | 7 | 36.8 | | | 6 | 25 | 2 | 33.3 | | |
| | 11-15 | 2 | 18.2 | 8 | 42.1 | 4.81 | 0.22 | 10 | 41.7 | 3 | 50 | 0.845 | 0.839 |
| | >16 km | 4 | 36.3 | 2 | 10.5 | | | 6 | 25 | 1 | 16.7 | | |
| | Total | 11 | 100 | 19 | 100 | | | 24 | 100 | 6 | 100 | | |

DISCUSSION

The pilot study was conducted in two mental health facilities to assess the feasibility of a family based educational program among family caregivers of the young adults with chronic mental disorders. Caregiver were selected for each patient to ensure that the interventions are implemented in regular and in long term by the care givers. The study included 30 caregivers in the age group of 18-67 years with young adults diagnosed with chronic mental disorders in the age group 20 to 40 years. Among the caregivers. The age range of 38–57 years old comprises the majority of caregivers (52.7%). The majority of them were Hindus, 83% of them were married, male and female caregivers were equal in number.

All of them were educated. Everyone was working and fell into the 2L–3L income range. Siblings made up the majority of the caregivers (40 %), followed by parents and children. Most of them lived in rural Bangalore. 60% of the recipients received social and financial support, with NGO accounting for 40% of the support. Heart disease, diabetes mellitus, and hypertension were the most prevalent illnesses among the caregivers, who were mostly physically unwell. There were just two caretakers living <5 kilo meters away from a mental health hospital. The findings of the study were supported by a study undertaken by Illengovan et al, who reported that the majority of the caregivers were siblings (42.3%) and resided in rural area (56.7%) and the major diagnosis of their relative was schizophrenia ((31.7%).²¹ A hospital based cross sectional study on caregiver burden in chronically mentally ill patients in Northern Kerala by Roby et.al found that majority of the patient is from rural background (58%) belongs to middle class family (71.3) and were unemployed.²¹ Our findings were also supported by a study by Rohit et al, who reported 80% of the patients were from rural area and were non adherent to medication.²³

The results of current study demonstrated significant difference in all the domains of burden in both experimental and control group across time and in between the group. The high mean score of burden was found in Domain-2 (Physical and mental health) with mean in experimental group 15.2 ± 0.847 and 14.87 ± 1.59 in control, Domain 3 (External support) with mean 12.07 ± 1.484 and 12.23 ± 1.55 . with p value <0.005. A study conducted by Rohit et al. reported 11.73 ± 3.36 in physical and mental health domain 8.07 ± 2.07 mean score in external support.²³ A study from Kerala too found the highest amount of burden in areas of physical and mental health.²⁵ A study conducted by Gandhi and Thennarusu tertiary neuro psychiatric hospital in Bangalore found similar study findings.²⁷ The present study found statistically significant association between gender of the caregivers (0.044) and age of the caregiver (0.049) with burden of care. The findings are similar to the study conducted in Tamil Nadu which revealed association

between gender and burden ($p=0.34$).²⁴ A community based study in southern Kerala reported association with gender of caregiver and not associated with any other socio demographic variable.²⁵ In contrast with the current study findings a study from Nepal found statistical association of burden with marital status ($p=0.378$), relationship with patient ($p=0.035$) and duration of caregiving ($p=0.026$). Which reported significant association of burden with marital status ($p=0.05$), relationship with patient ($p=0.001$) and duration of caregiving ($p=0.001$).²⁶

The findings of our study show that the perception of the burden by the family-caregivers in the last decade is all most same with the burden of caregivers in the current decade. Family based educational programme on homecare is an effective measure to reduce the burden and stress among the caregivers of clients with chronic mental disorders. The services in our country are mainly focusing on the patients alone without an emphasis on a long-term holistic approach that benefits both patient and family caregivers. The family based educational program on homecare provided by the investigators made a remarkable change in the total burden score from day 1 to day 30, day 1 to day 90 and day 180. All nine domains of the burden in between the group and within the group across the time period of day 1, day 30, day 90 and day 180 among experimental and control group.

There is a significant low score in BAS mean score across the time span (p value <0.005). The findings of study are similar to a study conducted in India to assess the effectiveness of a brief group psychoeducational program on burden of caregivers of schizophrenia, mania and depression.²⁸ The mean scores of burden in the control group was 49.04, 55.76, and 52.88 at baseline, after 1 month 3 months and 6 months intervention, respectively. The mean scores in the experimental group were 52.48, 25.44, and 29.44, respectively ($p=0.001$, $F=71.99$). The interaction between group members and the level of burden for the three stages measured was also significant ($p=0.001$, $F=61.23$). An Indonesian study revealed that before the intervention of nursing psychoeducation, the average family burden was 49.02 and 46.28 in the treatment and control groups. This decreased to 38.24 and 37.56 in the first and fourth weeks of posttreatment. Meanwhile, the control group was 44.86 in the first week and 45.62 in the fourth. The psychoeducation had an effect on decreasing the family burden with a p value <0.001.²⁹ In our study, interventions were effective to reduce the stress across the time span and in between the group evidenced by significant reduction in stress mean score from day 1, day 30, day 90 and day 180. The maximum reduction of score is experienced by the caregivers on day-30. The mean score of experimental-group was 41 ± 1.15 , 18 ± 2.43 , 23.9 ± 6.68 , 24.4 ± 2.46 , with highly significant p value <0.001. An Australian study finding was supportive to the current study. Through a stress less 5 weeks psycho education module on line the intervention group experienced reductions in stress

($b=-2.07$, $p=0.04$) and depressive symptoms ($b=-1.36$, $p=0.05$) from baseline to postintervention.³⁰

CONCLUSION

Caregivers burden and stress are significant issues not usually addressed in a busy, under resourced clinical areas. Our study found significant levels of burden and stress among the family caregivers of young adults with chronic mental disorders and significant association between age and gender of the caregiver with burden of care. The family based educational program on homecare found to be an effective measure to reduce the burden in all the domain and stress among caregivers. This pilot study enabled the researcher to understand the various issue faced by the caregivers of young adults with mental disorders. A family support group should be created by each health care facility exclusively for family caregivers so that they can voice out their concern and gain support from each other.

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