Burden And Coping Behaviour Among the Family Caregivers of the People With Mental Illness

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Abstract

Introduction: Caring for a person with mental disorder is a challenge for the caregivers. Little is known about the ways in which families cope while caring for a relative with mental illness in developing countries. This study has tried investigating the family burden and coping behaviour among the family caregivers of the people with mental illness.

Material And Method: This is a descriptive cross-sectional study conducted at Devdaha Medical College during the period of July 2019-December 2019. The research was approved by the Ethical Committee of the Institutional Review Board of Devdaha Medical College. The protocol approval number is 028/2019. Convenient sampling method was used. Data analysis was done in SPSS (Version 23, SPSS Inc, Chicago, USA). Results were presented as frequencies and percentages where required.

Results: Moderate Burden was experienced by 72% of the caregivers while the rest 28% experienced severe burden. People whose spouses were mentally ill had severe burden. Males coped with higher degree of problem and emotional focused coping strategy than females. Males felt more burden in comparison to the females and burden was found to be significantly higher among the caregivers who were taking care of their mentally ill spouses.

Conclusion: Caregiving is physically and psychologically demanding as it requires an enormous physical and emotional commitment as well as some basic skills. Teaching skills in the form of problem solving and communication are needed to promote the coping abilities and lessen the burden of caregivers.

Keywords: Caregivers; Developing countries; Mental disorder.

INTRODUCTION

The shift towards community care for patients with mental illness has resulted in transferring responsibility for day-to-day care of patients to their family members, which has led to profound psychosocial, physical and financial burdens on patients families.¹ Families use a variety of coping strategies and resources to maintain healthy family functioning. There is a dearth of information on burden among caregivers, and coping strategies used by caregivers for a relative with mental illness in developing countries. It is important to understand caregivers coping strategies for handling burden because it affects not only caregivers day to day functioning and is a constant source of stress, but how this stress is managed also has a bearing on the course of person’s illness and prospects for improvement.² The aim of the study was to explore family burden and coping behaviour among the family members of the people with mental illness.

MATERIAL AND METHOD

This is a descriptive cross-sectional study conducted at Devdaha Medical College and Research Institute during the period of July 2019 to December 2019. The research was approved by the Ethical Committee of the Institutional Review Board of Devdaha Medical College and Research Institute. The protocol approval number is 028/2019. Using convenient sampling method 100 caregivers of psychiatric patients were selected. Caregivers above 18 years or more and staying with the patient currently and
at least for last one year were included in the study.
The tools used for data collection were self designed semi structured proforma, Brief cope scale, Burden Assessment Schedule. Self designed semi structured proforma consist of socio-demographic characteristics of the study population which included age, sex, marital status , educational status, occupation, socioeconomic status, relation with the patient, type of mental illness, total duration of illness and type of care provided.

Brief cope scale: The Brief cope is a self completed questionnaire measuring coping strategies developed by Carver CS. Three composite subscales measuring emotion-focused, problem-focused and dysfunctional coping have proved useful in clinical research and have content validity. The scale can be administered to assess patient’s coping strategies. The brief cope scale is of a 28 item self report measure of problem-focused versus emotion-focused coping skills. Caregivers are asked to respond to each item on a four-point Likert scale, indicating what they generally do and feel when they experience mental illness and related stressful events (1=I have not been doing this at all - 4=I have been doing this a lot). The higher the score on each coping strategy, the greater the use of specific coping strategy. In the present study, based on the definitions of problem-focused coping, items 2,7,10,14,23, and 25 were classified as problem based coping and the rest of the items fell into emotion-based coping.

Burden Assessment Schedule (BAS): Burden Assessment Schedule was developed by Thara. The BAS was developed and standardized by step wise ethnographic exploration method. The inter rater reliability is high. It has high content validity. The values ranged between 0.71-0.82. There are 40 items rated on a three point scale (1-3, 1- mild burden, 2- moderate burden & 3- severe burden). A score up to 41-60 on BAS indicate mild burden, 61-80 indicate moderate burden, 81-100 indicate severe burden and 101-120 indicate very severe burden.

Data were analyzed using SPSS (Version 21, Chicago, Illinois, USA). Descriptive analysis was performed and mean, median and SD calculated. Data were explained in percentage. Pearson’s correlation was used to determine the correlation between total duration of illness and burden in caregiver’s with spouse mentally ill and without spouse mentally ill.

RESULT
There were 33(33%) caregivers within the age group 31-40, 84(84%) of the caregivers were married. Fifty four (54%) of the caregivers were from middle class family and 36(36%) caregivers were spouses while 64(64%) were other family members (Table 1).

| Table 1: Socio-demographic characteristics of care giver of the mentally ill family members. (N=100) |
|---------------------------------|-----------------|------------------|
| Socio-demographic variables     | Frequency | Percentage |
| Male                           | 50          | 50             |
| Female                         | 50          | 50             |
| Age group                      |            |                |
| <=20                           | 1           | 1              |
| 21-40                          | 61          | 61             |
| 41-60                          | 30          | 30             |
| 61+                            | 8           | 8              |
| Marital status                 |            |                |
| Married                        | 84          | 84             |
| Single                         | 13          | 13             |
| Separated+widow               | 3           | 3              |
| Educational status             |            |                |
| Illiterate                     | 8           | 8              |
| Literate                       | 16          | 16             |
| Primary                        | 15          | 15             |
| Secondary                     | 17          | 17             |
| Intermediate                   | 26          | 26             |
| Masters                        | 18          | 18             |
| Socioeconomic status           |            |                |
| Upper                          | 4           | 4              |
| Upper middle                   | 38          | 38             |
| Middle                         | 54          | 54             |
| Lower                          | 4           | 4              |
| Caregiver relation with patient|            |                |
| Parent                         | 34          | 34             |
| Spouse                         | 36          | 36             |
| Children                       | 13          | 13             |
| Sibling                        | 11          | 11             |
| Other                          | 6           | 6              |

| Table 2. Severity of Burden experienced by caregivers of mentally ill patients. (N=100) |
|---------------------------------|-----------------|------------------|
| Severity of Burden             | %               |
| Mild                           | 0               |
| Moderate                       | 72              |
| Severe                         | 28              |
It was found that 72(72%) experienced moderate burden and 28(28%) experienced severe burden (Table 2). The mean of problem-focused coping (PFC) strategy is obtained to be 17.83 with standard deviation 0.49 indicates that the care givers adopt more of PFC strategy than emotional focused strategy (taking mean 2.5 as cut-off point) (Table 3).

Table 3: Descriptive statistics of Problem Focused Coping (PFC), Emotion Focused Coping (EFC), and sex difference on burden, relationship of caregiver with mentally ill patient. (N=100)

| Types of coping | Mean ±SD | Male (Mean±SD) | Female (Mean±SD) |
|-----------------|----------|----------------|------------------|
| PFC             | 17.83±0.49 | 3.06±0.46     | 2.87±0.51        |
| EFC             | 49.2±0.32  | 2.27±0.35     | 2.19±0.28        |
| Caregiver’s relation with mentally ill |          |                |                  |
| Caregiver with spouse ill | 82.44±7.53 | 85.42±5.88     | 79.11±7.92       |
| Caregiver without spouse ill | 73.35±6.65 | 74.20±6.83     | 72.46±6.41       |

The mean score of burden of the caregivers with spouse mentally ill was 82.44 ±7.53 SD which indicates that the severe family burden whereas the mean score of the care givers with other family member ill was 73.35 ± 6.65 SD which indicates moderate burden. There is gender differences in feeling of family burden among caregivers with spouse mentally ill and caregivers with other family member ill (Table 3). From the mean results in both the cases, males feel more burden in comparison to the females. To examine the difference statistically significant, independent sample t-test is computed and was found to be statistically significant (p=0.01) among the caregivers with spouse mentally ill (Table 4).

The total duration of illness is negatively associated with level of burden among caregivers when the spouses were mentally ill but has no association when the spouses were not mentally ill. However, in both the situations, the associations were not significant (Table 5).

**Table 4: Independent sample t-test for sex differences of feeling family burden**

|                          | Levene’s Test for Equality of Variance | t-test for Equality of Means |
|--------------------------|----------------------------------------|-----------------------------|
|                          | F    | Sig. | T    | Df  | Sig. | Mean difference |
| RWSMI                    | 1.61 | 0.21 | 2.72 | 34  | 0.01 | 6.30            |
| RWOFMI                   | 0.88 | 0.34 | 1.28 | 94  | 0.20 | 1.73            |

**DISCUSSION:**

The current study showed that 72% caregivers of mentally ill patients had experienced moderate amount of burden. The findings are consistent with the findings of Chakrabarti, who reported that 80% of the caregivers suffered from moderate amount of burden. Similar findings were seen in the study by Howritz, and Oshodi. The high percentage of burden experienced by caregiver could be because of more severe illness like schizophrenia and mood disorders present in our study, as our study site was also a tertiary centre where patient with...
more severe illness tend to report than neurotic disorders. High mean score was seen in caregivers with spouse mentally ill than the caregivers with other family members ill. Males caregivers feel more burden than females caregivers when their spouses are mentally ill (p<0.05). Similar findings were seen in a study conducted in Nigeria which showed males appeared to experience more than average burden than their female counterparts (p< 0.005). This might possibly be due to negative care giving appraisals coming from men who traditionally are not involved in care giving roles. Our result contradicts with the result of study conducted at UCMS Bhairahawa where female felt more burden compared to male. Several studies have shown that female caregivers experience more distress than their male counterparts. Some studies showed that male and female caregivers feel same kind of burden and adopt similar type of coping styles.

In our study it is seen that the total duration of illness is negatively associated with level of burden i.e. longer the duration of illness, feeling of burden gets reduced gradually. This might be because of the long average illness duration may have allowed the families in our study considerable time to adjust to the stresses and strains of caregiving and to learn coping skills. Another reason could be a significant number of patients may show improved functioning over time. In this regard there is evidence that persons who are provided with supports and skills in community living, appear over time to learn to live with the illness and recover from its effects.

There were no statistical significant association between age, marital status, education, socioeconomic status and burden among caregiver of mentally ill patient. The findings are consistent with findings of study conducted in Egypt. The study conducted in China is not in agreement with the current study findings which showed that age of caregiver was positively correlated to burden of caregiver. When caregiver becomes older, they are worried about who will take care of their family member in future. Older caregiver also cannot provide care well to the patient. This study also showed that the education level has negative correlation with caregiver’s burden. It is assumed that higher the level of education, higher the salary. High salary would decrease financial problem related to providing care for ill family member. Level of education of the caregiver also tends to have more knowledge to deal with the stressful event. This study showed problem focused coping strategy was used more than emotion focused coping strategy and male used slightly more problem focused coping and emotional focused coping than female. The present study are in agreement with the study conducted at other parts of the globe which showed there is no difference between male and female caregivers coping startegies. Study conducted in India also showed problem solving as a better coping mechanism and can decrease the burden of illness on caregivers and may even improve the level of functioning of patients. This study contrasted with the findings by Hassan which showed the most coping strategies used by caregivers of schizophrenic patients was self controlling, positive reappraisal, and escape avoidance i.e. emotion focused coping was found more. Similarly, Chandrasekaran reported that an emotion-focused coping strategy was found to be more commonly employed by the relatives, than other strategies. This could be because as the problem focused coping is considered the best type of coping strategy, it points out the ways of solving the problem and minimizes negative emotional consequences. In this approach an individual review the problems several times to enhance understanding, come up with a variety of probable solutions, work harder to manage the situation, analyze the problem bit by bit and seek assistance from others. One of the limitations of our study was small sample size and convenient sampling techniques, the results may not be generalizable to all relatives of people with mental illness.

CONCLUSION:

The presence of a person with mental disorder in a family is often associated with a significant objective and subjective burden on other family members. The large prevalence of more than average burden among almost half of the caregivers emphasizes the importance of investigating the impact of such burden. Caregiving is physically and psychologically
demanding as it requires an enormous physical and emotional commitment as well as some basic skills. So teaching skills in the form of problem solving and communication are needed to promote the coping abilities and lessen the burden of caregivers.

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