Summary
CHAPTER - 6

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Chronic physical and mental illness impact both the patients and the entire family system. The family members specially the caregivers are affected emotionally, cognitively and behaviourally and are often faced with changing their day-to-day routines, plans for the future and feelings and meaning about self, others and life.

The terms “caregiving” and “caregiver” have been defined as when family members provide both concrete assistance and mutual support to each other as a part of normal family interactions. Family caregivers provide a complex array of support tasks that extend across physical, psychological, spiritual, and emotional domains. Family caregivers play an important role in the management of chronic illness; enlisting their cooperation and including them as the unit of care from outside are considered critical ingredients to effective chronic illness management.

Individuals and families who face a diagnosis of some chronic illness experience varying levels of stress and emotional turmoil. Just as patients require ongoing evaluation throughout their course of treatment, so do family caregivers. Both male and female caregivers experience significantly more anxiety, depression and burden than normal subjects. Sadness and grief are normal reactions to the crises faced during treatment. Families or caretakers who were able to act openly, express feelings directly and solve problems effectively had lower levels of depression, less burden and low levels of anxiety.

Patient of life threatening disease in the family leads to different type of emotional, financial, and social problem for the caregivers. Chronic illness of any type brings and demands extra attention of family members. Caregivers have to bear the burden and pressure in a long period of time because of the long-term and heavy caring work thus their physical and mental health are seriously affected. Caring for a person with progressive cancer and a person with severe chronic psychiatric illness creates challenges for caregivers. However the needs of caregivers are often not assessed or recognised by health care providers. Research is also lacking in this area,
with little knowledge relating to effective strategies to address the specific needs of caregivers. A little work in India has been done so far to explore the family burden, coping styles, and QOL of the caregivers of psychiatric and cancer patients. Keeping this in mind the present investigation was undertaken with the following problem.

**Problem:**

To assess and compare the burden, coping styles and QOL of caregivers of psychiatric and cancer patients.

On the basis of above problem the current research work was carried out with the following objectives:

**Objectives:**

1. To assess and compare the burden of caregivers of psychiatric and cancer patients.
2. To assess and compare the coping styles of caregivers of psychiatric and cancer patients.
3. To assess and compare the QOL of caregivers of psychiatric and cancer patients.
4. To assess and compare the gender differences amongst caregivers of two diseased groups on burden, coping style and QOL.

**Hypothesis:**

The following hypotheses were formulated:

1. There would be significant difference between the burden of caregivers of patients with psychiatric disorders and cancer (two diseased groups).
2. There would be significant difference between the coping styles of caregivers of the two diseased groups.
3. There would be significant difference between the levels of QOL of caregivers of the two diseased groups.
4. There would be significant sex differences on burden, coping styles and QOL.

To meet these objectives a cross sectional research design was taken and for that a 2x2 factorial design was adopted and a sample of 140 caregivers in the age
range of 25-65 yrs. was taken. The caregiving was varied at two levels i.e. caregivers of psychiatric patients and caregivers of cancer patients, gender includes male and female caregivers. Thus, caregivers were divided into four groups i.e. male caregivers of psychiatric patients, male caregivers of cancer patients, female caregivers of psychiatric patients and female caregivers of cancer patients (35 in each group) were purposively selected belonging to both urban and rural background. The independent variables were caregiving and gender whereas dependent variables were burden, coping styles and QOL. Three scales viz: family burden interview schedule, coping check list and WHOQOL-BREF were used. The obtained data was subjected to a member of statistical analysis pertinent to research objectives and was analysed by descriptive statistics and two-way ANOVA.

The present study focused on assessing and comparing the caregivers of psychiatric and cancer patients on account of burden, coping style and QOL. The two groups i.e. caregivers of psychiatric patients and caregivers of cancer patients differed on all the parameters of burden, coping and QOL. Further to find out the significant difference between means for burden, coping and QOL, the two-way ANOVA was employed. It was evident from the F-values were found to be significant on all the parameters of burden, coping styles and QOL indicating that caregivers of psychiatric patients differ with the caregivers of cancer patients on all these parameters except for problem focused coping style. The present study also focused that gender does not play significant role in caregiving. It also enhanced that interaction between caregiving and gender significantly affects the psychological QOL of caregivers.

However, there are some limitations in the present study since it was cross sectional research design and the study participants were caregivers of psychiatric and cancer patients who accompanied on the day of data collection and follow up or chemotherapy may not always be the main caregivers nor the person who lived in the same house, so study findings cannot be generalized to all the caregivers of psychiatric and cancer patients. Another limitation which can be dealt in future research i.e. a longitudinal research should be conducted to evaluate the factors causative to caregiver burden and QOL. The third limitation is that instead of comparing caregivers of patients with mental illness and caregivers of patient with physical illness though we know that mental health and physical health are fundamentally linked and share many symptoms yet caregivers of patient with
psychiatric illness and caregivers of patients with physical illness should be compared separately.

The present study implicates that caregiving is physically and emotionally demanding so appropriate interventions in the form of development of standardized guidelines that address caregiver assessment, education and resources are needed to promote or enhance the QOL and reduce or lessen the burden of caregivers. As we know that informal care of persons with a serious medical illness provides many benefits to patient but can be costly to caregivers both in monetary terms and in terms of value of time spent in caregiving and learning new caregiving skills so one possible strategy for improving the caregivers’ QOL is to improve the patient’s QOL by improving communication skills, financial planning, distress management skills and spirituality topics that would affect the caregivers’ burden and QOL. Moreover, the results are also valuable to professionals because they indicate negative outcomes so that they can use appropriate interventions for such caregivers to mitigate the harmful effects of caregiving. This would definitely help to determine how best to meet the caregivers’ mental health needs in our society set up.