CHAPTER V – SUMMARY AND CONCLUSION

Summary
The primary aim of the study was to determine the correlates of psychological functioning of the caregivers of different types of cancer patients in palliative care. The objectives of the study were:

To study the relationship between quality of life and select psychological correlates of caregivers of cancer patients in palliative care, to study the demographic variables and its effects on quality of life of caregivers, to examine the differences in the levels of psychological functioning between the caregivers of different types of cancer and to examine the differences in levels of psychological correlates reported by the caregivers of patients in advanced and limited stages of cancer.

The sample consisted of caregivers of cancer patients in palliative care. The caregivers were caring for different cancer types namely lung, oesophageal, gastrointestinal, breast, cervical cancer and lymphoma. The burden of caregiving was assessed using Zarit Burden Inventory (1990), Stress was measured using symptoms of stress Inventory (Carlson.L., 2006), Quality of life for caregivers of cancer by Weitzman.M. (1999), Self efficacy by (Porter.S. 2007) and Becks Anxiety (1990) and Depression inventory (1987).

The obtained data were subjected to appropriate qualitative analysis and the findings were discussed in the light of theoretical, empirical and information collected through interpretative phenomenological analysis.

In summary, the caregivers of different cancer types are affected by burden and stress while caring for the patients in palliative care. The self-efficacy of the caregivers was low regarding the management of the patient symptoms especially in the end of life stage of illness. The role strain and the deteriorating medical condition of the patient have led to anxiety and
depression in caregivers. The psychological distress of caregiving had an effect on their quality of life. The result of the quantitative analysis showed relationship between psychological factors and its negative effect on quality of life of caregivers.

The following conclusions are drawn based on the result of the statistical analysis of the data with the objective of verifying the hypotheses.

**Conclusions**

1. The quality of life of the caregivers of different cancer types are related to psychological correlates of burden, stress, self-efficacy, anxiety, and depression. Relationship is found between burden of caring and quality of life where many demands are placed on caregivers of cancer patients with pain. These complex demands significantly affected the caregiver's quality of life.

2. The long days and long nights of caring combined with fatigue and poor positive adaptation has contributed to physical and psychological stress. The muscle tension during the last phase of illness trajectory is the contributing factor for low quality of life.

3. The caregiving role is a serious and ongoing process. Caregivers often face hardships of various kinds, as caregivers are put on hold and health care costs accumulate. With regard to long term picture the caregivers may continue to feel the impact of the cancer for months or years even after being in the situation during the phases of illness. Lack of social support, family support, and respite care adds to burden of caring during inpatient period of hospitalization. As the patient illness moves to the last phase of illness the disruptiveness in the daily activities of the caregiver is greatly affected contributing to negative adaptation to the situation thus affecting the caregiver's quality of life.
4. A large part of the caregiver role is often associated with symptom and function management of the patient. The patient’s chronic pain during palliative stage of cancer needs to be dealt with. Caregivers feel overwhelmed during the last phase of patient’s life as they lack confidence in managing the patient symptoms, when symptom management can be particularly discouraging. The low self efficacy of caregivers especially in case of lung cancer caregivers was found to be the associated with low quality of life.

5. Normal emotional reactions of caregivers vary dramatically from day to day. Emotions include sadness, anger, depression, and feelings of overwhelmed are common from the day of diagnosis of cancer. During the last phase of illness the patient’s deteriorating medical variable and fluctuating health condition has contributed to anxiety among caregivers.

6. The gender of the caregiver is not associated with the caregiving task among different cancer types. The result of the present study is in contradiction of earlier empirical studies.

7. Age of the caregiver was not found to be associated with quality of life across different cancer types.

8. The type of varied relationship of the caregiver of different cancer types with the patient emerged to be associated with quality of life.

9. The family type whether extended or nuclear family was not associated with the quality of life of caregivers where the extended families are known to provide support or respite care to caregivers.

10. The number of dependents on caregivers was not found to be related the caregiver’s quality of life.
11. The levels of psychological functioning between different cancer caregivers were found to differ among different cancer types. The lung cancer caregivers had substantial amount of burden and high stress level, low self-efficacy and depression compared to other cancer caregivers.

12. Anxiety was greatest among the caregivers of esophageal cancer patients.

13. The stress of caring was substantially greater in caregivers of limited stage of cancer compared to caregivers of advanced stage.

14. The quality of life is low in the caregivers of lung cancer patients compared to other cancer caregivers.

15. No differences in the level of anxiety were found between the caregivers of advanced and limited stage.

16. Depression was found to be high with limited stage cancer caregivers.

**Implications**

1. Providing care for caregivers is challenging and requires planning, implementation and evaluation in fast-paced inpatient treatment setting with often competing priorities.

2. Health care providers need to include in their plan of care specific strategies to assist primary caregivers in coping with psychological distress, burden of care and quality of life issues (Northouse.L.L, 2010). The result of this research may be useful in identifying primary caregivers who are more in need of immediate help.

3. Information seeking is considered to be a general coping to decrease anxiety and increase a sense of control, and therefore information regarding cancer care needs to be provided to caregivers from the time of diagnosis (Reinhard.S.C, 2008).

4. Patient's dependency and symptoms in the end of life phase has a negative impact on the caregiver quality of life. Care characteristics like duration of care, intensity of care
and different types of care may affect the priorities of the caregivers thus leading to disruptiveness. The social or community support can reduce the burden of caregiving.

5. Findings of the study can be utilized by the oncology team to include the caregivers as a part of medical team so that the psychological distress of the caregivers can be avoided or reduced (Haley, 3013).

6. The study provides scope for community service professionals to spread awareness about cancer in semi urban and rural areas of Karnataka.

7. Information about stages or phases of cancer can help the caregivers to be prepared to manage symptoms of cancer during palliation phase. Interventions need to be tailored to the needs of the palliative caregivers and delivered proactively.

Limitations of the study

1. Clinical set up-This study was conducted at a single oncology hospital, using primary caregiver sample that included lung, oesophageal, gastrointestinal, breast, cervical cancer and lymphoma caregivers. Caution must be viewed when generalizing from this sample to other patient caregiver’s population.

2. The phase of data collection-The data was collected at one point in time that is at palliative phase of cancer, giving only a snapshot of caregivers experience at the advanced stage of cancer. Time since diagnosis may have had an impact on the variables that was not captured.

3. Pre-existing variables: In addition pre existing depression, anxiety and quality of life and burden may have an influence on the findings of the study.

4. Small sample size-The study was conducted on a relatively small sample, the primary reason being difficulty in the availability of sample. The inclusion criteria had to be met as one of the criteria was six types of cancer caregivers belonging to low socio economic group.
5. Sample was not an adequate representative of the target population of the whole country.

**Suggestions for future research**

This study adds to the growing body of research examining the variables in the role of quality of life of cancer givers of cancer patients in palliative care. Further research is needed to examine the following:

1. Intervention to target specific variable that affect the caregiver quality of life and burden of caring.
2. The study can include outcomes of caregiving with samples of diverse culture and varied socio-economic status.
3. Different oncology hospitals apart from a single oncology hospital site can be considered.
4. Longitudinal study of quality of life of caregivers from the time of diagnosis to advanced stage can be conducted.
5. Patient and caregiver interaction/relationship has a impact on quality of life of both patient and caregiver and this area can be explored.
6. Interventions to improve competence and confidence of caregiver can help in higher levels of mastery of the care situation which in turn leads to positive responses and self efficacy to provide care.