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QUALITY OF LIFE OF CAREGIVERS OF GERIATRIC CANCER PATIENTS: A PROSPECTIVE STUDY

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ABSTRACT

Purpose: To assess the quality of life (QOL) of caregivers of geriatric cancer patients by using self-designed questionnaire and to examine examining the QOL based upon their physical health, psychological status, and social relationships. **Methods:** It is prospective study conducted in tertiary care hospital. A questionnaire comprising 22 questions divided into three categories of physical health, psychological status, a social relationship were given to 40 caregivers of geriatric patients with cancer and wasevaluated using scoring from 1 to 5. **Result:** Psychological QOL was highly affected compared to physical health and social relationship among the caregivers of geriatric patient with cancer. Also there is high significant correlation between the domains psychological status and physical health. **Conclusion:** overall the QOL of caregivers are significantly affected in all the three domains (physical health, social relationships, psychological status). Therefore, health care providers can improve the QOL of caretakers by concentrating more on the mental status and by paying more attention on the overall health of the caretakers and involve in interventions involving professional counselors, who can train both the patients and the caregivers in psycho-education and skills training**.**

KEYWORDS: To assess the quality caregivers in psycho-education and skills training**.**

INTRODUCTION

Cancer is one of the chronic disease conditions which need psychological, physical and social support from the caregivers. Therefore caregivers support is inevitable in improving the overall health of the cancer patient. The term quality of life is defined as the evaluation of general well-being of the individual and society's. The effectiveness of the treatment is evaluated using QOL as one of the primary outcome.

Along with the patient, the quality of life of patient's caregivers also drastically affected because of Cancer. Caregivers or caretakers is defined as an individual who is unpaid or paid individual who helps another individual with an impairment/disease with his or her activities of daily living. In case of family caregivers with cancer, who are an extension of the professional cancer workforce, are the individuals who are expected to provide a multiple and varied functions in the betterment of the patient.Caregivers would have to adapt to their loved one's emotional and physical response by changing or adjusting to their new role. Their new role may include various activities in the patients care such as medication acquisition, communication with health care providers, moral support, financial support etc.

Activities such as balancing the patients treatment and symptoms and financial issues, sufferings of other family members are found the most stressful among the caregivers of geriatrics. Caregivers respond to these stress factors in a different way; older spouses may be particularly vulnerable because of their dependent nature. Research shows that most of the caretakers with elderly patients with cancer do not get stressed emotionally compared to other two category of caretakers. Rather the caregivers face depression and feel burdened in care giving due to the patients' behavioural problems, pain, and mood disturbances. Overall, compared to the caretakers of paediatric and adult populations of individuals with cancer, the caretakers of geriatrics patients view this process as burdensome and financially restraining. However, in some studies have shown that supporting an elderly cancer patient makes you feel satisfied with greater sense of self-worth and responsibility.

Caretaking of an elderly cancer patient is practically needs a sacrificial attitude as it involves painful experiences such as emotional, physical and economic stress. Therefore to be a caretaker of an elderly cancer patient is really difficult and challenging take for which they were not prepared earlier. The voluntary work of caregivers involved various factors such as relationship bonding within the family and also the traditional and cultural practices and also the society impact on their day-to-day life. Elderly cancer patients must needs special assistance for medications, transportation for the purpose of cancer treatment and also for activities of daily living.

This study about the assessment of the quality of life of caregivers of cancer patients is very important and vital in understanding the current distressed faced by the caregivers. As there is a mutual relationship between both the patient and the caregiver, interventions can provide to improve the QOL of caregiver and thus improve the patients' prognosis. Interventions can be provided such as:

1. **Psycho-education**
2. **Skills training**
3. **Therapeutic counseling**

Methods

It is a cross sectional prospective study conducted in a Tertiary care hospital, Department of Medical Oncology for a period of 6 months (October 2016 – march 2017). Patients were selected in geriatric population with cancer followed by caregiver's selection based in exclusion and inclusion criteria. A total of 40 caregivers were selected and informed consent was obtained followed by data collection with demographic details and self designed questionnaire. Patients and caregivers fulfilling the selection and inclusion criteria were selected for our study. After getting a written Informed Consent, patients' demographic details such as age, sex, and diagnosis and also the caregivers' demographic details such as age, sex, relationship with the patient, occupation, education status, marital status, number of children if any, annual income, and socio economic status were obtained. A set of questions were asked to the caregivers and based on their responses, the quality of life of caregivers were assessed. Three questionnaires were formulated for each category of caregivers such as caregivers of peadiatric, adult and geriatric patients with different sets of questions on physical health, psychological status and social relationships in each category.

The validity and reliability of the questionnaire was tested by a pilot study on 10 caregivers from each category of pediatrics, adult, and geriatric patients. Based on the pilot study, the questionnaire was modified and the spiritual domain was removed for sensitivity of the questions. The questionnaire was validated by subject experts for content and statistics.

The participants were provided with the option of

1. Having the question read to them with assistance and their answers were being documented, or
2. They could read and answer the survey on their own

They can choose their option as they wish to overcome any discomfort in respect to literacy difficulties and also to promote participation rate.

The questionnaire was made available in both English and local language, Tamil in an attempt to increase the participation rate.

The questionnaire has two parts

Part 1: Demographic Data

Patient details such as name, age/sex, OP/HID no, diagnosis and department Caregiver details such as name, relationship with the patient, age/sex, occupation and education status and marital status, no. of children, annual income and socioeconomic status.

Part 2: Questions

This was divided into three domains such physical health, psychological status and social relationships.

Physical health of the caregivers was analyzed based on the following factors

- Energy and fatigue
- Poor Food habits
- Pain and discomfort
- Lack of sleep and rest

Psychological status of the caregivers was analyzed by the following factors

- Negative feelings
- Positive feelings
- Physical safety and security
- Memory and concentration

Social relationships of the caregivers was analyzed by the following factors

- Personal relationships
- Social support
- Lack of Leisure activities/ Development of risk behaviours
- Financial status

Screening of subjects: The study was screened for study participation from both outpatient and inpatient Department of Medical Oncology (G Block 1st floor OP and 5th floor IP), Sri Ramachandra Medical Center. Initial eligibility was determined by assessment of the applicable inclusion and exclusion criteria as listed.No follow up was required in the study.

Statistical Analysis

The collected data were analysed using IBM.SPSS statistics software 23.0 Version. To find the significant difference between the bivariate samples in Independent groups the unpaired sample t-test was used. One way ANOVA with Turkey's Post-Hoc test was used for multivariate analysis. Pearson's Correlation was used to find the relationship between the variables. Chi-Square test was used to find the significance in categorical data. In all the above statistical tools the probability value. 05 is considered as significant level.

RESULT

In our studyMost of the patients and caregivers in geriatric population was found to be female (40.3 %) and (60.5%) respectively. Most of the caregivers were in the age group 18 – 40 (18). The children category was found to be high in the caregiver's relationship with the patient (57.5%) among parents, spouse, siblings and others. The average physicalhealth of the caregivers were evaluated, the domain energy and fatigue were highly affected (3.60), followed by poor food habits, lack of sleep and pain, discomfort. Under psychological status most of the caregivers were affected under domain physical safety and security (4.07) followed by negative and positive feeling. Under social relationship status financial status proved to be heavy burden to the caregivers followed by lack of leisure activities, personalrelationships and social support. Therefore theoverall assessment of QOL showed that caregivers of elderly cancer patients are moderately affected in physical health and social relationship, and very much affected in psychological status. Another finding showed that there is significant correlation between the domains psychological status and social relationships.

	Number	Percentage (%)
Gender		
Male	**16**	**40**
Female	**24**	**60**
Age group		
18-40	**18**	**45**
41-60	**14**	**35**
61 and above	**8**	**20**
Caregiver relationship		
Parents	**0**	**0**
Spouse	**11**	**27.5**
Children	**9**	**22.5**
Siblings	**2**	**5**
Others	**4**	**10**
Number of children		
0	**9**	**22.5**
1	**6**	**15**
2	**16**	**40**
3 and above	**9**	**22.5**
Caregiver occupation		
Housewife	**20**	**50**
Agriculture	**1**	**2.5**
Daily labour	**2**	
Business	**4**	**10**
Professional	**3**	**7.5**
Retired	**5**	**12.5**
Others	**5**	**12.5**

Physical health		
Energy and fatigue	**3.60**	**18**
Poor food habits	**3**	**15**
Pain and discomfort	**2.75**	**13.75**
Lack of sleep	**3.10**	**15.5**
Psychological status		
Negative feelings	**3.80**	**25.3**
Positive feelings	**2**	**13.3**
Physical safety and security	**4.07**	**27.1**
Social relationship		
Personel relationship	**2.73**	**13.6**
Social support	**2.05**	**10.25**
Lack of leisure	**3.15**	**15.75**
Financial status	**3.67**	**18.35**
Overall QOL		
Physical health	**Moderate amount**	
Psychological status	**Very much**	
Social relationships	**Moderate amount**	

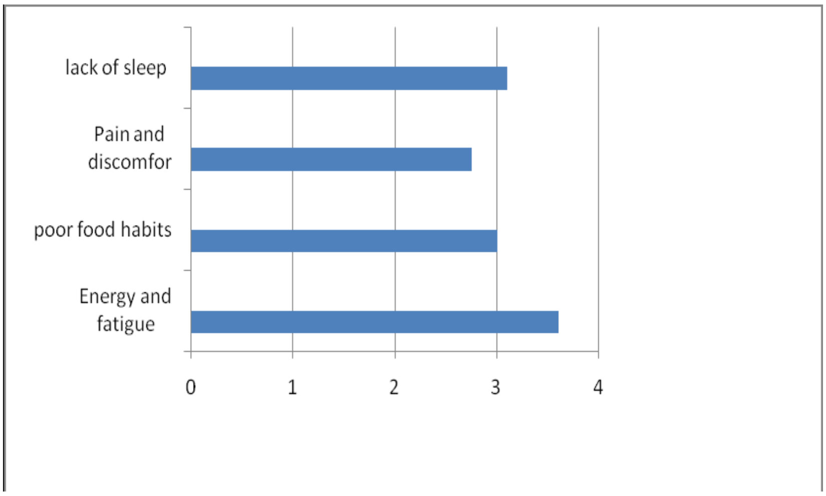
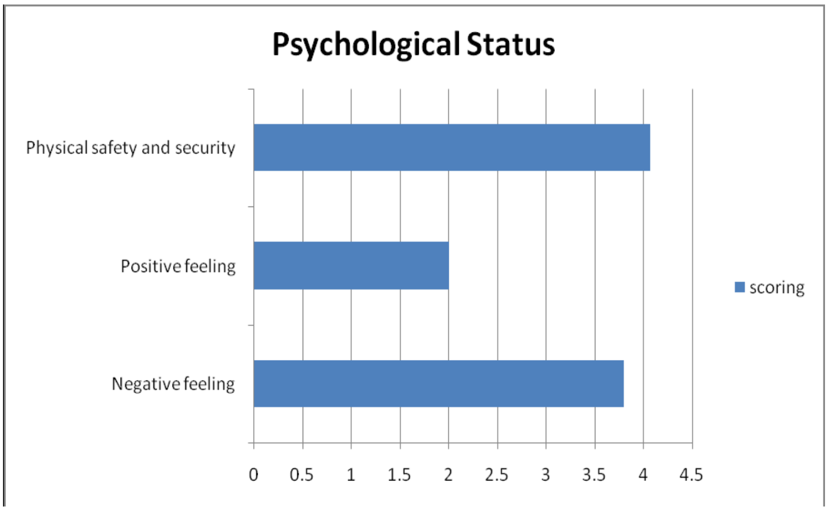
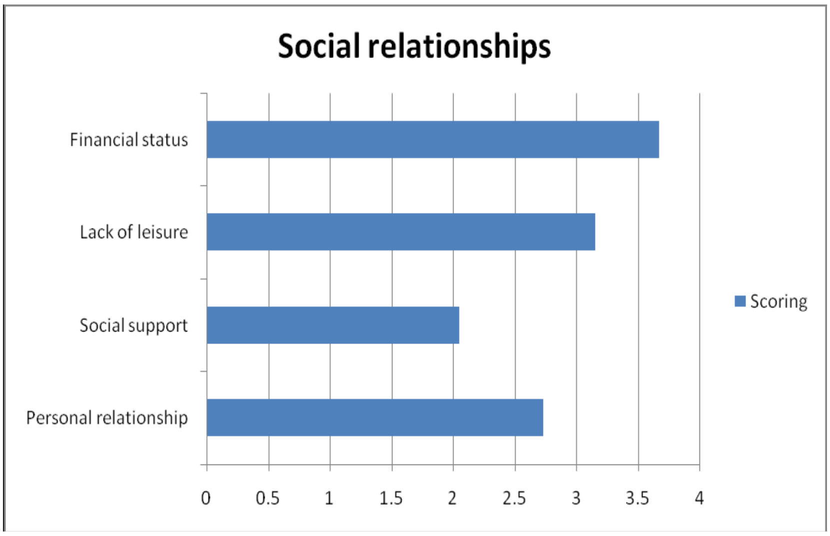
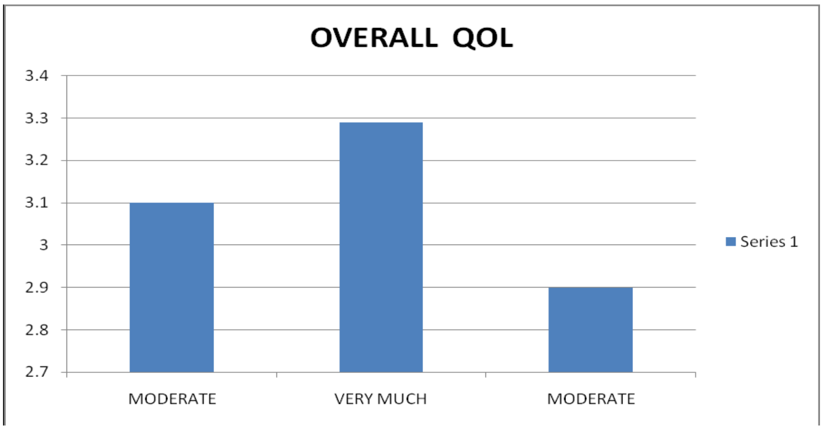

lack of sleep
Pain and discomfor
poor food habits
Energy and fatigue
0
1
2
3
4

Figure. 1.


Psychological Status
Physical safety and security
Positive feeling
Negative feeling
0
0.5
1
1.5
2
2.5
3
3.5
4
4.5
■ scoring


Social relationships
Financial status
Lack of leisure
Social support
Personal relationship
0
0.5
1
1.5
2
2.5
3
3.5
4
■ Scoring

Overall Quality of Life in Caregivers of Geriatric Cancer Patients.



Correaltion Between Quality of Life Domains in Caregivers of Geriatric Cancer Patient

QOL Domains		**Sig.**
Physical	Psychological	0.001
Psychological	Social	**0.000**
Social	Physical	0.038

DISCUSSION

Caregivers of geriatric cancer patients are mostly affected in psychological status whereas moderately affected in physical health and social relationship. Most of the predominant caregivers were spouse and children. There is a increased burden in taking care of their parents and their wife and children. As the geriatric patients feel dependent on most of things to their children and spouse their work balance is affected. also their physical health is moderately affected (having poor energy and fatigue, food habits, lack of sleep) as a result they fail to take care of their health which leads to deterioration in their physical health. Also their social relationships moderately affected as they were unable to spend time with their family, children and work during caregiving process. As their work is affected there is also poor source of income which made difficult for them to spend on treatment cost. There is a high significance of correlation between psychological and social relationships i.e. when social relationships are affected the psychological status is also affected leading to increased feeling and lack of physical safety and security and vice versa. Overall the psychological status is affected compared to physical and social relationships. Care of older hospice patients with cancer is a complex orchestration of assessment and intervention. understanding how to identify and manage problems that impact QOL will aid in the care of patients and families.

CONCLUSION

The diagnosis of cancer carries with it a significant amount of emotional distress not only in patients with cancer, but also for their caregivers. Optimum care for patients with cancer depends largely upon optimum care of caregivers' ability of care giving.

Results showed that psychological factors were significantly higher in caregivers of geriatric patients with adults, with an increased social burden in the caregivers of adults. There is a need to assist, support and motivate caregiver's in their new and demanding role. The present study suggests that QOL can be improved by decreasing the emotional burden that cancer places on patient's family and also to reduce the social burden on the caregivers of adults.

Therefore, health care providers should pay more attention to maintain the caregivers' health status and improve their QoL by interventions involving professional counselors, who can train both the patients and the caregivers in psycho-education and skills training. Counselors can educate the caregivers about cancer how to communicate with the health care professionals and patient, spend time for themselves, to stay upto date with their medical needs, and to not neglect their personal life. Skills training for caregivers can involve teaching the caregivers about handling of feeding tube, catheters, dressings, monitoring of vital signs and also administering medications to the patient.

This will result in reducing the psychological and social morbidity of caregivers' and brings overall improvement in QoL of cancer patients and their caregivers' as well.

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Self – supported study.

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