

A study to assess the caregiver burden and their satisfaction with palliative care among caregivers of terminally ill cancer patients in a selected Cancer Institute, Kottayam

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Abstract: *The present study was done to assess the caregiver burden and their satisfaction with palliative care among caregivers of terminally ill cancer patients in a selected hospital, Kottayam. The objectives of the study were to assess the burden of caregivers of patients in terminal stages of cancer, to assess the level of satisfaction of caregivers regarding palliative care, to determine the relationship between caregiver burden and caregiver satisfaction with palliative care services and to determine the association between caregiver burden and selected demographic variables. The research design used was descriptive. The samples were caregivers of terminally ill cancer patients those who had received palliative care services in the oncology wards of Caritas Cancer Institute, Kottayam. Subjects were selected by purposive sampling technique. Tools used were Zarit Burden Scale for assessing caregiver burden and FAMCARE 2 Scale for assessing satisfaction of palliative care services by self report technique. The sample size is 100 and quantitative data were analysed using descriptive and inferential statistics. Study results showed that 63 % of caregivers were having little burden, 33% have mild burden and 4 % have moderate burden and nobody had severe burden. Among the samples, 20 % of caregivers were very satisfied, 56 % were satisfied and 24 % were dissatisfied for those who receiving palliative care services in Caritas hospital. There is no significant correlation between caregiver burden and their satisfaction with palliative care services ($t=.2673$, $t \alpha_2 = 1.9$). There is no association between demographic variables such as gender, occupation, income per month, duration of caregiving, morbidity status of caregiver, and type of family with caregiver burden. Age, marital status, educational status, relationship to the patient and number of dependents at home were significantly associated with caregiver burden.*

Key Words: Caregiver; Burden; Satisfaction; Palliative care; Terminally ill; Cancer patients.

1. INTRODUCTION:

Terminal stage of cancer is a progressive, irreversible illness that despite care focused medical treatment will result in the patient death¹. The stress of cancer spreads from patients to family members like a stone dropping in a pond. The responsibilities and experience of caring for someone with cancer can profoundly affect the quality of life of family caregivers. So palliative care is an approach to help the patient's and families to better understand medical condition, benefits and burdens of treatment options and likely outcomes². The objectives of the study were to assess the burden of caregivers of patients in terminal stages of cancer, to assess the level of satisfaction of caregivers regarding palliative care, to determine the relationship between caregiver burden and caregiver satisfaction with palliative care services and to determine the association between caregiver burden and selected demographic variables.

1.1. NEED AND SIGNIFICANCE OF THE STUDY:

Globally cancers account for 5.1 % of total disease burden and 12.5% of all deaths². Cancer is the second most common cause of death in developed world and a similar trend has emerged in the developing countries too³. In 2012, there were an estimated 14.1 million new cases of cancer in the world: 7.4 million in males and 6.7 million in females. An article on cancer statistics shows that there are 14.1 million new cases in 2012. It is predicted that there will be 23.6 million new cancer cases world wide each year by 2030; if recent trends incidence of major cancers and population growth are seen globally in the future⁴. Nearly 14.5 million Americans with a history of cancer were alive on January 2014. Many patients diagnosed with cancer will eventually require support from a family care giver. Infact, family caregivers form the foundation of the health care system in the United States, supporting advances in treatment such as multimodality treatment protocols given in outpatient and home settings⁵. In India, cancer has become one of the ten leading causes of death. It is estimated that there are nearly 2.0-2.5 million cancer cases at any given point of time.

Over 7500,000 new cancer cases are diagnosed every year in India and nearly half of these patients die each year. In view of its large prevalence, the disease puts an enormous burden on the government to cater to the health care need for cancer treatment in the country².

The number of cancer patients in Kerala has registered an alarming increase of over 200 percent in the last three decades. As per the figures released by the 'Hospital Based Cancer Registry' of Regional cancer centre, a premier hospital which handles more than one third of cancer cases in the state 2,49,362 patients visited RCC seeking treatment in the last 30 years. Kerala has roughly 35,000 new cancer cases every year, based on the registry data. There are 913 male and 974 female cancer patients in Kerala. A total of 100,000 cancer patients are prevalence annually in the state⁶. A diagnosis of cancer often leads to physical, mental and social challenges for both patients and their families. Caregivers are involved in many aspects starting from dealing with the diagnosis of cancer, treatment-related adverse events, disease related symptoms, recurrence and end-of-life care. Since active cancer treatment requires only a short-term hospital stay, family members become the key persons in taking care of patients at home. The average time of caregiving for cancer patient's was 8 hours per day. At the same time, the family members still needed to maintain their routine work and responsibilities. If the demands from taking care of the patients could not be handled by the caregivers, this would lead to a burden. The burden of caregiving impacts quality of physical, emotional, spiritual and social health⁷. A study was conducted to examine the psychological and cardiovascular responses in terminal cancer caregivers. Twenty relative caregivers who provided in home or hospice care to terminally ill cancer patients and 20 age- and gender-matched controls were interviewed and assessed for emotional distress. Measures of cardiovascular risk, blood pressure, and heart rate were recorded at rest in 4 separate sessions. Caregivers reported higher levels of depression, state anxiety, and more sleep dysfunctions than controls. They also revealed heightened systolic and diastolic blood pressure in some measurements. Moreover, elevation of heart rate was associated with caregiving length⁸.

Involvement of family caregivers is essential for optimal treatment of cancer patients in ensuring treatment compliance, continuity of care and social support, particularly at the end of life. The diagnosis of cancer presents a major crisis not only to the patient but also the patient primary caregivers. Caregivers often assumes this role under sudden and extreme circumstances, with minimal preparation and uneven guidance and support from the health care system. Caring for a family member with cancer poses significant challenges, with considerable psychological and physical consequences for the caregiver. Family caregiving has gained attention in the past decade with growing realization that support for family caregivers benefits, the caregiver, the patient and the health care team⁹. So palliative care is a health care specialty that is why both a philosophy and an organized, highly structured system for delivering care to persons with life threatening or debilitating illness from diagnosis till death and then into bereavement care for the family. Palliative care improves health care quality in three domains: the relief of physical and emotional suffering; improvement and strengthening of the process of patient-physician communication and decision making; and assurance of co-ordinated continuity of care across multiple health care settings-hospital, home, hospice and long term care. The goal of palliative care is, therefore, to improve the quality of life both patients and families by responding to pain and other distressing physical symptoms, as well as to provide nursing care and psychosocial and spiritual support. This is why it is best administered by an interdisciplinary, multi-dimensional team, comprising doctors, nurses, counsellors, social workers and volunteers¹⁰. The investigator during her clinical experience, felt that most of the caregiver of cancer patients were severely burdened with their care giving role. Hence the investigator was interested to assess the caregiver burden and their satisfaction with palliative care services among caregivers of terminally ill cancer patients.

2. LITERATURE REVIEW:

The review of literature is organized under following headings;

- Studies related to caregiver burden of terminally ill cancer patients
- Studies related to caregiver satisfaction in palliative care
- **Studies related to caregiver burden:**

A nation wide population based cohort study was conducted to describe socio-economic characteristics, situational factors, pre-loss grief symptoms, caregiver burden and health status in a general population of caregivers of terminally ill cancer patients. Caregivers were systematically recruited through patients registered with drug reimbursement for terminal illness in 2012. Data on socio-demographic characteristics are mainly obtained from Danish registries, where as data on situational factors, distress and health was measured in questionnaire. Results of the study indicated that caregivers of terminally ill patient's relatives in the general populations have high levels of

pre-loss grief, depressive symptoms and caregiver burden in one third of all caregivers. These findings call for increased focus on care givers need of support.¹¹

A survey was conducted to assess the caregivers stress providing care to the cancer patients at Cipla Palliative Center, Pune. A closed ended questionnaire is used to assess the caregivers stress and it is administered in 137 participants. The study results showed that overall stress level among caregivers is 5.18 ± 0.26 on scale of 0-10 of the total. Nearly 62% of caregivers were ready to ask for professional help from nurses, medical social workers, counsellors to cope up with their stress. Thus interventions are needed to help caregivers to strengthen their confidence in giving care and come out with better quality of life¹².

A path analysis study was conducted, to examine the association of theory driven variables with caregiver's burden. The study was conducted in 96 caregivers of cancer patients in the palliative phase staying at home recruited from a hospital trust in NORWAY. Caregiver Reaction Assessment scales and models are the tools used for the study. Partial least square approach to structure evaluation modelling was used for the path analysis. Test result showed that caregivers depression was the main factor associated with caregiver burden.¹³

A study was conducted to evaluate the following questions: To what extent do bereaved informal caregivers of palliative care [pc] patients experience meaning in their lives? What differences emerge in carers compared to the general German population? How does meaning in life relate to well-being in former caregivers? Eighty four bereaved palliative care caregivers completed the schedule for meaning in life evaluation (MiL), the Brief Symptom inventory, the WHOQOL –BREF, a single item numerical rating scale of quality of life, and satisfaction with life scale. The experience of MiL of bereaved caregivers was compared to a representative population sample [n=977]. The study results showed that overall MiL fulfilment of bereaved caregivers was significantly lower than in the general population as was the overall importance ascribed to their meaning framework. Palliative care caregivers are far more likely to list friends, leisure, nature/animals, and altruism. Higher MiL was correlated with better life satisfaction and quality of life¹⁴

A descriptive study was conducted a study to assess the feasibility of a structured training program on symptom management along with an acute symptom management kit for primary caregivers of cancer patients receiving home care. Thirty primary caregivers of cancer patients attending the palliative care clinic in Vellore, South India were provided training on the administration of drugs for acute symptoms. A structured questionnaire with a 4-point scale was used to assess primary caregiver views and satisfaction. The study result shows that of primary caregivers, 96.7% used a kit. At home, 73% of primary caregivers administered subcutaneous injections. Hospital visits for acute symptoms reduced by 80%; 90% were satisfied with training received; 73% stated it was not a burden to treat the patient at home¹⁵.

A study was conducted to assess the caregiver's role in palliative care planning and decision making, anxiety and depression in caregivers of terminally ill cancer patients and their impact on the caregiver's evaluation of the patient's physical and psychological symptom burden were analyzed. Thirty three patients and their caregivers were recruited through the University Medical Centre palliative care inpatient ward < 24 hour after admission. Memorial Symptom Assessment Scale [MSAS] was used as symptom assessment. Anxiety and Depression were measured in caregivers using the PHQ-9 (Patient Health Questionnaire-9) and the GAD-7 (Generalized Anxiety Disorder Scale - 7). About 55% are male caregivers and 36% are female caregivers shows moderate or severe anxiety ; 36% of male caregivers compared to 14% of female caregivers had moderate or severe depression. Caregivers anxiety was associated with a discrepancy in the patient's symptom, evaluation for shortness of breath [$p < 0.05$]; nausea [$p < 0.05$]; and frequency, intensity and distress due to anxiety [$p < 0.01$]. Depression was associated with a discrepancy in the patient's evaluation of distress due to constipation, as well as intensity and distress due to anxiety. Both the caregiver's anxiety and depression were not significantly associated with an underestimation of symptoms. There was a trend towards a higher risk of overestimation in caregivers with higher levels of anxiety [$r = 0.32$][$p = 0.07$] and depression [$r = 0.33$][$p = 0.06$].¹⁶

A systematic review was conducted to assess the burden of care giving, related factors and the consequences of family caregivers of advanced stage of cancer patients or patients in end-of-life care or palliative care. A search of scientific papers published in EBSCO (Elton B Stephens Co.), web of knowledge and BIREME (Latin American and Caribbean Centre on Health Sciences Information), database was conducted since records on this databases through March 2014. Total 582 articles found only 27 were selected. The results showed that majority of the articles found that the family caregivers were overburdened. Some studies found that the care giving burden was associated with characteristics of the patients and their illness ; while in other studies, it was associated with poor health of the caregiver, greater psycho pathological symptoms and with the development of complications in the grieving process. However hope, social support, the ability of the caregiver to attribute meaning to the experience of caring and feeling comfortable with the tasks of caring were associated with lower levels of burden.¹⁷

A multicenter cross-sectional survey was conducted to investigate the determinants of the burden and positivity of family caregivers of Korean terminal cancer patients. In the study, 139 family caregivers participated. Determinants of caregiver's burden and positivity were assessed by the Caregiver Reaction Assessment Scale and by three questions based on a previous study, respectively. Two separate hierarchical multiple regression models were used. Each domain of the caregiver's burden and positivity was explained by different factors, with the total explained variance ranging between 14.4-33.6% and 2.6-18.3%, respectively. Caregivers who were unmarried, less educated, and/or had low incomes were more likely to be negatively affected, while those who shared care giving responsibilities were less prone to negative consequences. Caregivers who were male, religious practitioners, and who perceived a higher burden of schedule disruptions were more likely to have a positive perception of their role, while those who perceived a lack of family support were less likely.¹⁸

A descriptive quantitative study was conducted to examine the relationship between caregiver burden and symptom distress in patients with terminal cancer who are enrolled in hospice. Setting of the study is a large, metropolitan, non-profit based organization in west central Florida. Convenience sample of 30 patient-caregiver dyads enrolled in the hospice. Caregivers completed the Caregiver Reaction scale to measure the level of caregiver burden; patients completed the Adopted Symptom Distress scale. Pearson correlation is used for correlation. The study finding shows that patient sample exhibited low symptom distress and the caregiver sample exhibited moderate caregiver burden. The significant moderate correlation confirms the idea that caregiver sample exhibited moderate caregiver burden.¹⁹

A cross-sectional study conducted to investigate factors associated with caregiver burden among family caregivers of terminally ill Korean cancer patients. Sixty four caregivers of terminally ill cancer patients who were admitted to the hospice palliative care unit of a University hospital in South Korea were included. Caregiver Reaction Assessment scale was used. Study results showed that longer time spent providing care per day, fewer weekly visits from other family members, poor family functioning and low self esteem were considered as modifiable factors associated with caregiver burden.²⁰

A descriptive cross-sectional study conducted to explore the relationship between care giving burden and terminally ill gastrointestinal cancer patient disease characteristics, demographic backgrounds, level of social support, self care efficacy, fear of death and self-perceived symptom distress in both patients and primary caregivers. Data were collected from 178 family caregivers of terminally ill patients with gastrointestinal cancer in the Tainan and Chiayi areas of Southern Taiwan. Study results revealed that care giving burden of caregivers of terminally ill gastrointestinal cancer patients in hospice home care was significantly higher than that of those recruited from outpatient departments. The care giving burden of spousal caregivers was significantly higher than that of lineal blood relatives. The caregiving burden of caregivers with worse self-perceived health status was significantly higher than that of those with better self-perceived health status. The most important explanatory factors of caregiving burden among primary caregivers terminally ill gastrointestinal cancer patients were social support, self-perceived symptom distress in patient, self perceived health status, location of study subject recruitment, fear of death, and relationship with patient ; these factors explained 63.8% of the total variation. Social support was the most important explanatory factor, explaining 37.2% of total variation.²¹

A qualitative study was conducted to assess the psychological distress and quality of life of palliative cancer patients and their caring relatives during home. Quality of life was collected with the palliative module EORTC QLQ-C15 –PAL (European Organization for Research and Treatment of Quality Of Life Questionnaire ‘Core’ 15 Palliative care) [Patient’s] and the short form -8 Health Survey [caregivers]. The psychological distress was assessed using the Hospital Anxiety And Depression Scale, the extent of social support with Oslo 3–items social support scale. Two multiple regression models were employed to examine factors associated with psychological distress. Data from 106 palliative patients [39.6%] female] and their family caregivers [67.9%] were included in the analysis. The study results showed that every fourth patient had clinically relevant anxiety levels and half of the palliative patients had clinically symptomatic depression scores. The main symptoms of the patient’s were: fatigue, loss of appetite, pain and shortness of breath. Patient’s and caregivers anxiety and depression scores were correlated [anxiety $r=0.386$, depression $r=0.416$]. 33% of caregivers suffered from high anxiety and 28% from depression. Spousal caregivers had higher psychological distress than other caregivers. Other relevant factors for higher distress were high financial burden and low social support. There was hardly any family member receiving professional psychological support.²²

A survey conducted to investigate the relationship between unmet supportive care needs and carer burden and happiness in head and neck cancer [HNC]. A postal questionnaire were sent to 285 HNC informal carers between January and June 2014. Multiple regression analysis was conducted to examine the association of carer characteristics, carer situation, unmet supportive care needs, with carer burden and happiness. The study results showed that 197

carers completed the questionnaire, 180 of whom were included in the analysis. The majority were female (76 %), not in paid employment (68 %) and caring for their spouse (67 %). On average, carers reported relatively low levels of burden and high levels of happiness. Carer factors explained 42 % of variance in levels of burden and 24 % of variance in levels of happiness. These findings reveal that different aspects of carer characteristics and unmet needs are associated with caregiver burden and happiness.²³

A study was conducted to assess caregivers burden, needs and satisfaction of terminal cancer patients. A questionnaire and interview technique is used in 659 terminal cancer patients and 659 important caregivers at 11 university hospitals and one national centre in Korea. Study results showed that care burden was not insubstantial in both and the caregiver group felt more burden than the patient group. [$p < 0.001$]. While the patient group needed financial support most [39.01%], the care giver group placed greatest emphasis on discussion about further treatment plans [44.8%]. Stepwise multiple regression analysis showed that in the patient group, the patient health status [OR 2.3;95% CI,1.16-3.56] and burden [OR 2.82;95% CI,1.764.50] influenced satisfaction about overall care, while in the caregiver group, high education level [OR 1.84;95% CI,1.76-4.50], burden [OR 1.94;95% CI,1.24-3.04] were important.²⁴

- **Studies related to caregiver satisfaction in palliative care**

Palliative care as a movement in India gained momentum in early 1990's. The first hospice was started in Shanti Avedna, Mumbai, the way back in 1986. Palliative care can address a broad range of issues, integrating a n individual's specific needs into care. Comprehensive palliative care will take the following issues into account for each patient: physical, emotional and coping, social and practical, spiritual.²⁵

A quantitative exploratory study was conducted to examine relationships between family primary caregiver characteristics and satisfaction with hospice care, quality of life and burden. Settings of the study were five hospice organizations in Eastern Washington and Northern Idaho. Samples of the study was 44 primary caregivers of patients enrolled hospice for more than two weeks. Telephone surveys measured primary caregiver satisfaction with hospice care, QOL (Quality Of Life), and burden. Multivariate regression techniques were used to identify caregiver characteristics that explained the most variation in satisfaction with hospice care, QOL and burden .The study findings showed that caregivers reported satisfaction with hospice care, the caregiver role negatively affects their QOL and they are burdened. 'At risk' caregivers are still working, have been providing care for a long time, and live in a rural locale.²⁶

A cross –sectional survey was conducted to assess the family satisfaction with inpatient palliative care. A 60-item questionnaire was mailed to 1026 bereaved subjects who had lost family members at one of 37 palliative care units in Japan. The study results showed that informal caregivers are generally satisfied with inpatient palliative care services²⁷

A study was conducted to assess caregivers outcome among those caring for symptomatic cancer patients at VA Medical centre. The tools used for the study are three outcome instruments like family inventory of needs, caregiver strain index, FAMCARE scale and 100 caregivers was completed the tool. The study results showed that median number of unmet needs was 2 and median CSI score was 4. Most unmet needs are related to information needs, and the symptom management. The majority of caregivers were satisfied or very satisfied by the patient care received.²⁸

A survey was conducted to assess for patient and caregiver satisfaction with end of life care. Two likert type instruments were used to determine the satisfaction with staff, communication, education, information provided, and symptom management. Samples included in the study are 321 patients and 443 caregivers of patient. Data indicates that majority of patients and their caregivers were very satisfied with hospice services and the care they received.²⁹

An integrated review regarding the experience of palliative care in an acute hospital setting from the perspective of patient and family. The study findings reveal that the patient and family experiences of palliative care in an acute hospital remains limited to discrete aspects of care.³⁰

A survey was conducted to describe and evaluate family caregiver satisfaction with tertiary palliative care and hospice services in the Lightbridge palliative care unit between April 2010 and March 2014. The method used for the study was FAMCARE tool and FAMCARE 2 tool was mailed to the identified closest relative of the patient approximately one month after the patient's death. Since that time, there have been 571 deaths on the unit and 245 forms have been returned. The tools instruct recipients to think about the care that their family member received and to answer the questions as being very satisfied, satisfied, undecided, dissatisfied, very dissatisfied. Each item is rated on a five point likert scale, ranging from 1 to 5. The study results showed that all items of the scale were rated as satisfied or very satisfied by >75 % participants. 78.5% satisfied with practical assistance.³¹

3. MATERIALS AND METHODS:

The research design selected for the study was descriptive research design. The sample consisted of 100 caregivers of patients in terminal stages of cancer admitted in oncology ward of Caritas Cancer Institute who have met the inclusion criteria and it was calculated by using the software 'R' based on the pilot study result.

TOOLS AND TECHNIQUE

In this study, three tools were used. First tool consisted of a personal data sheet to assess the socio-demographic variables of the subject. The subject characteristics may include age, sex, education, marital status, occupation, total family income per month, relationship to the patient, duration of caregiving, number of dependents at home, morbidity status of the caregiver and type of family. Second tool was Modified Zarit Burden Scale used to assess caregiver burden. Modified Farmcare 2 Scale was the third tool to assess the caregiver satisfaction among palliative care. Purposive sampling technique was used for the study.

VALIDITY AND RELIABILITY

Content validity of the tool was established by seven experts in the field of medicine and nursing. Reliability of the tool was tested by using Split Half Technique employing Spearman Brown's Prophecy formula. The Karl Pearson correlation was established by using deviation method. Both the tools have an acceptance level of reliability at 0.9592 and 0.9987.

ETHICAL CONSIDERATION

Ethical clearance was obtained from the ethical committee and get permission from the higher authorities of Caritas Hospital, Thellakom. The data collection for the main study was conducted from 25/04/2016 to 01/06/2016. By reviewing the medical records and consulting with doctors the researcher identified the terminal cancer patients and their caregivers. Informed consent was obtained from the participants. The investigator introduced herself to the subjects and explained the purpose of the study. There were assured that all data would be kept confidential and would be used only for the study purpose. Each caregiver was taken to a private room and administered Modified Zarit Burden Scale to assess the satisfaction of caregivers in Palliative Care. The data was collected by using self report technique. Each tool was administered in 45 minutes. The data collection process was terminated after thanking each of the subjects for their help and co-operation.

4. ANALYSIS AND FINDINGS:

The data was analysed by descriptive and inferential statistics using statistical Packages for Social Sciences Software. The data were organized under the following headings;

Section 1: Distribution of caregiver characteristics based on socio-demographic data

Section 2: Description of caregiver satisfaction

Section 4: Correlation between caregiver burden and their satisfaction with palliative care

Section 5: Association between level of caregiver burden with selected demographic variables.

SECTION I: Distribution of caregiver characteristics based on socio- demographic data.

This section deals with socio demographic data such as age, gender, educational status of the caregiver, family income per month, marital status, occupation, relationship to the patient, morbidity status of the caregiver, duration of care giving, number of dependents at home and type of family.

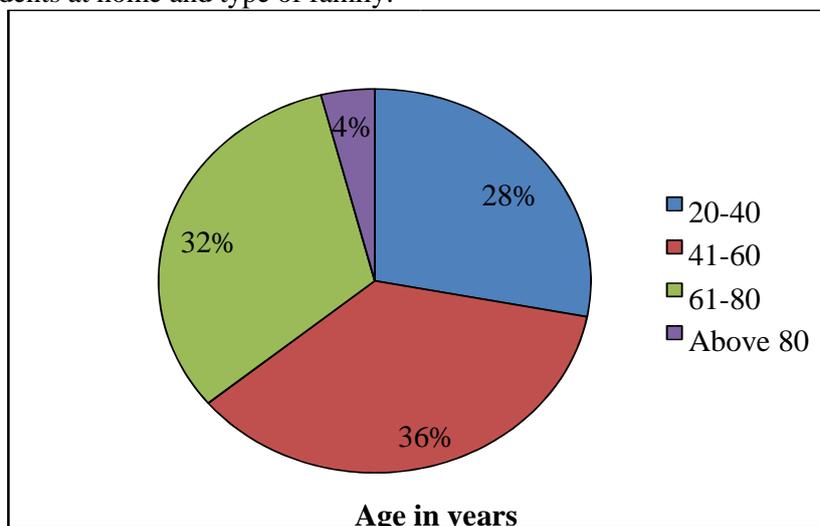


Figure. 1. Pie diagram showing the percentage distribution of caregivers according to age

The above figure 1 shows that, 28% of caregivers were between 20-40 years, 36 % were between 41-60 years, 32% were between 61-80 years and 4 % were between above 80 years of age.

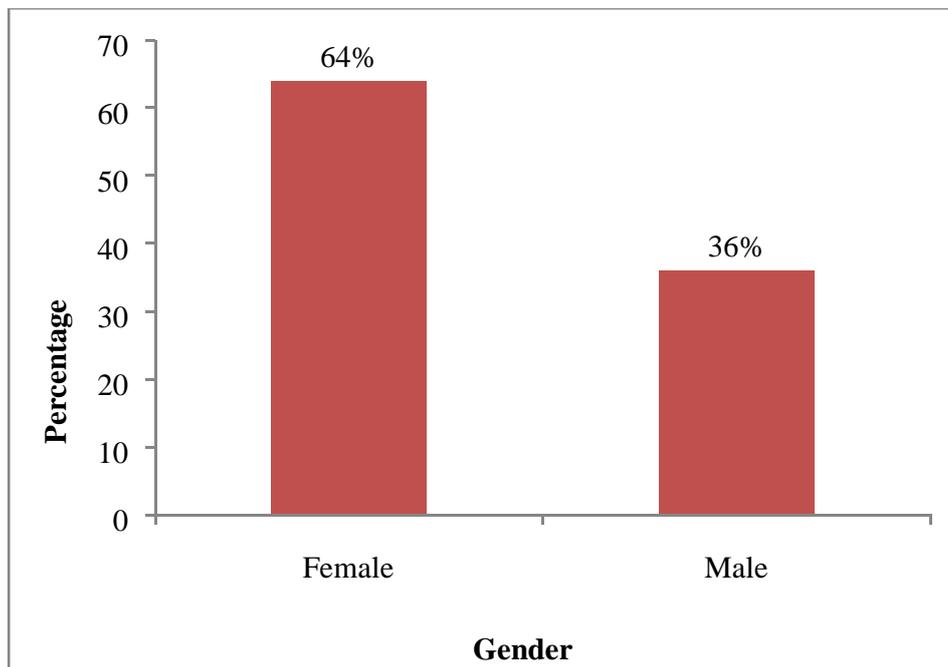


Figure.2. Bar diagram showing percentage distribution of caregivers according to their gender
The data in the bar diagram shows, 64 % of caregivers were females and 36 % of caregivers were males.

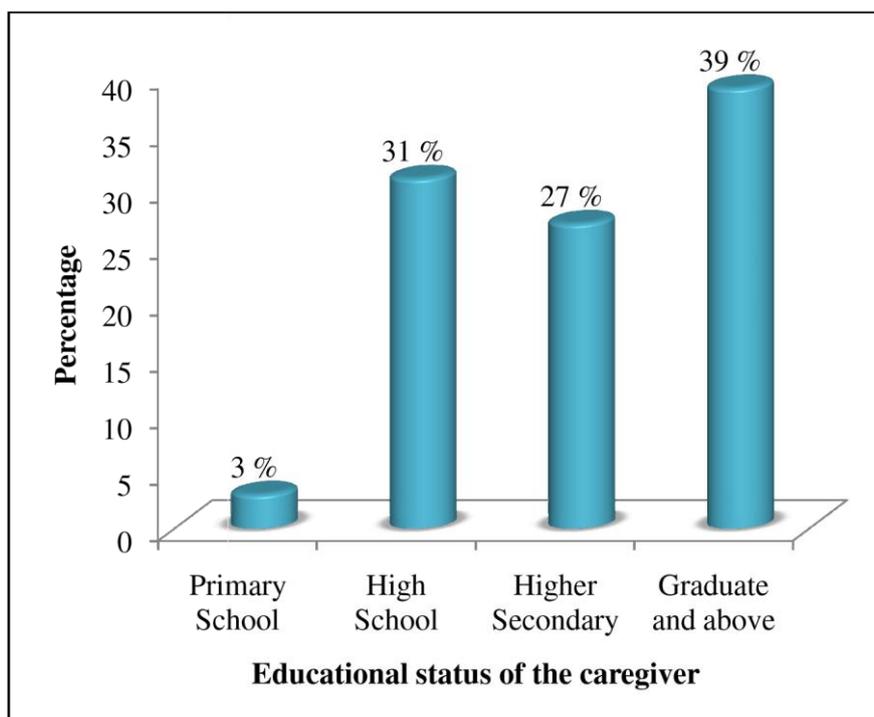


Figure. 3. Cylindrical diagram showing percentage distribution of caregivers according to education

The data in the figure 3 shows that 3% of caregivers had received primary education and 39% were having graduate and above qualifications.

Table 1
Frequency and percentage distribution of caregivers according to their total family income per month (n= 100)

Total family income per month	Frequency (f)	Percentage (%)
< Rs. 15,000	57	57
Rs. 15001-35 , 000	23	23
Rs. 35001 -50,000	11	11
Rs. 50,000 Above	9	9

Data in table 1 shows that, 57% were having Rs.15,000 and only 9% having above 50,000 family income per month.

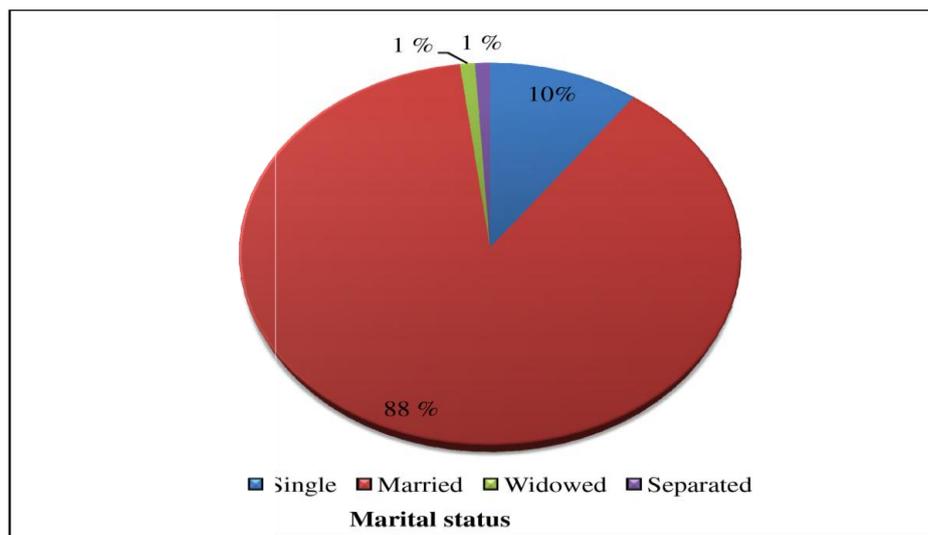


Figure. 4. Pie diagram showing percentage distribution of caregivers according to their marital status

The data in figure 4 shows that, 88% of caregivers were married, 10% were single and 1% were separated and 1% were widowed.

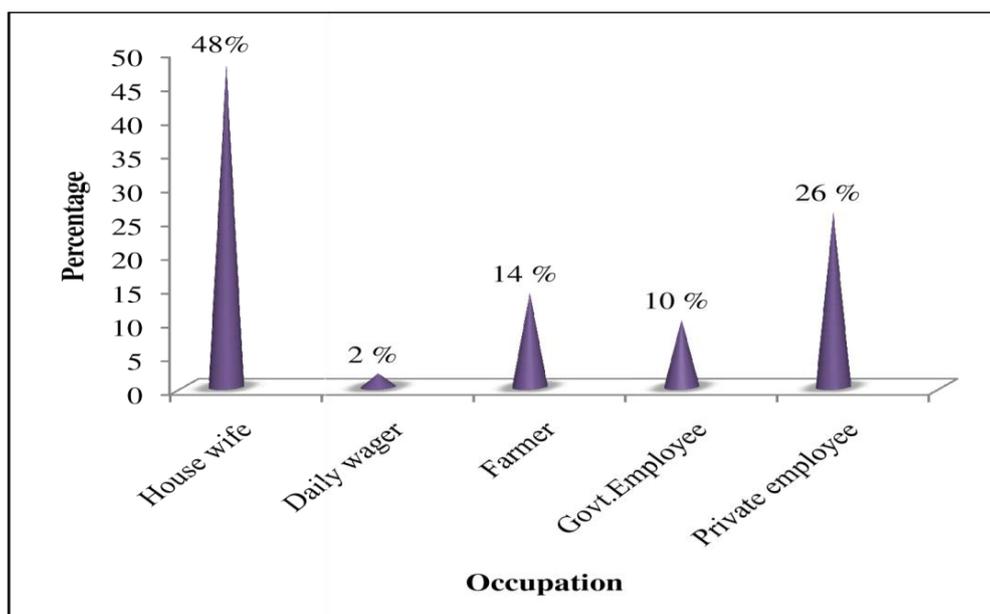


Figure. 5. Cone diagram showing percentage distribution of caregivers according to their occupation

Figure 5 shows that, 48% of care givers were house wife and only 2% of caregivers were daily wager /coolie.

Table 2

Frequency and percentage distribution of caregivers according to the relationship to the patient (n =100)

Relationship to the patient	Frequency (f)	Percentage (%)
Spouse	51	51
Parents	23	23
Children	12	12
Siblings	9	9
Others	5	5

Data in table 2 shows that 51% of caregivers were spouses, 23% of caregivers were parents, 12% of caregivers were children, 9% of caregivers were siblings and only 5% of caregivers were other relatives of the sample.

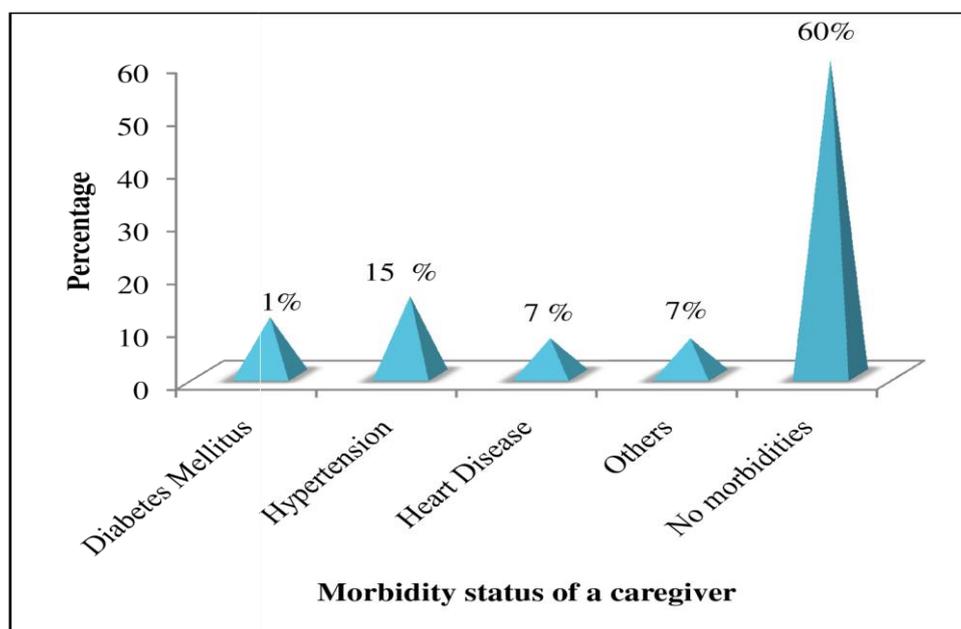


Figure.6 Pyramid diagram showing percentage distribution of morbidity status of a caregiver

The data in figure 6 shows that 11% of caregivers were having diabetes mellitus, 15% of caregivers were having hypertension, 7% were heart disease, 60% have no morbidities and 7% have other diseases.

Table 3

Frequency and percentage of caregivers according to their duration of care giving (n =100)

Duration of care giving	Frequency (f)	Percentage (%)
< 3 months	20	20
3-6 months	34	34
7-12 months	12	12
Above 1 year	34	34

The above table 3 shows that 20% of caregivers were caring their relative for < 3 months, 34% of caregivers were caring their relative for 3-6 months, 12% of the caregivers were caring their relative for 7-12 months and 34% of caregivers were caring their relative for above 1 year.

Table 4
Frequency and percentage distribution of caregivers according to the number of dependents at home
 (n =100)

Number of dependents at home	Frequency	Percentage
	(f)	(%)
1	23	23
2	17	17
Above 2	47	47
No dependents	13	13

Data in the above table 4 shows that, 47 % were having above two dependents at home and 13 % were having no dependents at home.

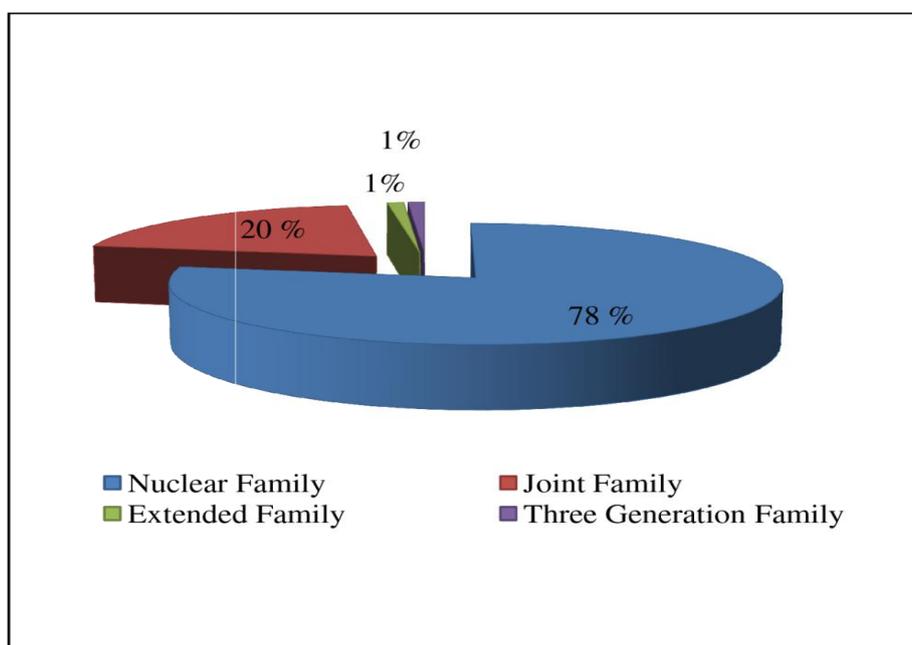


Figure.7. Pie diagram showing percentage distribution of type of family

The above figure 9 shows that 78 % of caregivers belongs to nuclear family, 20 % caregivers were joint family, 1 % belongs to extended family and 1 % belongs to three generation family.

SECTION III: Description of caregiver satisfaction with palliative care

This section deals with description of caregiver satisfaction with palliative care.

Table 5
Frequency and percentage distribution of level of caregiver satisfaction with palliative care.
 (n = 100)

Level of satisfaction	Frequency	Percentage
	(f)	(%)
Very satisfied	20	20
Satisfied	56	56
Dissatisfied	24	24

Data above in the table 5 reveals that 20 % of caregivers were very satisfied, 56 % were satisfied, 24 % were dissatisfied with palliative care services.

Section 4: Correlation between caregiver burden and caregiver satisfaction with palliative care services.

This section describes the correlation between caregiver burden and their satisfaction with palliative care services. Karl Pearson Correlation coefficient and parametric tests were used to determine the relationship between caregiver burden and their satisfaction with palliative care services.

Table 6: Mean, Standard deviation, ‘r’ and ‘t’ value of caregiver burden and caregiver satisfaction with palliative care services.

In order to determine the relationship between caregiver burden and their satisfaction with palliative care services “t” test was used.

Ho: There is no significant relationship between caregiver burden and the level of satisfaction

	Mean	SD	r	t	df	t $\alpha/2$
Caregiver burden	19.85	12.16	-.027	.2673	98	1.9
Caregiver satisfaction	47.4	14.19				

Data in the above table 6 shows that the correlation between caregiver burden and satisfaction which means, ‘r’ value shows that there is slight linear correlation between caregiver burden and satisfaction. The calculated ‘t’ value .2673 is less than the table value (t₉₈=1.9) at 0.05 level of significance. So we accept null hypothesis i.e., there is no significant relationship between caregiver burden and their satisfaction with palliative care services.

SECTION V: Association between caregiver burden with selected demographic variables

Chi square test was used to find out the association between caregiver burden with selected demographic variables such as age, marital status, education and occupation, gender, family income per month, relationship to the patient, duration of caregiving, number of dependents at home, morbidity status of the caregiver and type of family.

Ho: There is no significant association between caregiver burden and selected demographic variables.

Table 7

Chi square value showing association between caregiver burden and age (n=100)

	Level of burden		df	χ^2
Age in years	0-21	Above 21		
20-40	23	5		
41-60	22	14	2	7.067*
Above 61	18	18		

* Significant at 0.05 level

The table 7 shows that the calculated value of Chi square at 2 degree of freedom is 7.067, which is greater than the table value (5.991). So it is significant at 0.05 level of significance. Hence null hypothesis is rejected. Therefore it is a significant association between caregiver burden and age.

Table 8

Chi square value showing association between level of caregiver burden and marital status (n =100)

	Level of burden		df	χ^2
Marital status	0- 21	Above 21		
Single	10	0		
Married	52	36	2	6.595*
Others	1	1		

* Significant at 0.05 level

Table 8 shows that, the calculated value of Chi square at 2 degree of freedom of marital status is 6.595, which is greater than table value 5.991. So it is significant at 0.05 level of significance. Hence null hypothesis is rejected. Therefore it is a significant association between caregiver burden and marital status.

Table 9
 Chi square value showing association between caregiver burden and educational status
 (n = 100)

	Level of burden		df	χ^2
Education	0-21	Above 21		
Primary	1	4		
High school	14	15	2	9.342*
Above high school	48	18		

*
 Significant at 0.05 level

The data table 9 shows, that calculated value of Chi square at 2 degree of freedom of educational status is 9.342, which is greater than table value 5.991. So it is significant at 0.05 level of significance. Hence null hypothesis is rejected. Therefore it is a significant association between caregiver burden and educational status.

Table 10
 Chi square value showing association between caregiver burden and relationship to the patient
 (n = 100)

	Level of burden		df	χ^2
Relationship to the patient	0-21	Above 21		
Spouse	27	24		
Parents	19	4		
Children	6	6	3	8.334*
Others	11	3		

*
 Significant at 0.05 level

The data table 10 shows, that calculated value of Chi square at 3 degree of freedom of relationship to the patient is 8.334, which is greater than table value of 7.815. So it is significant at 0.05 level of significance. Hence the null hypothesis is rejected. Therefore there is significant association between caregiver burden and relationship to the patient.

Table 11
 Chi square value showing association between caregiver burden and number of dependents at home
 (n = 100)

	Level of burden		df	χ^2
Number of dependents at home	0-21	Above 21		
1	10	14		
2	10	6	3	9.654*
Above 2	31	16		
No dependents	12	1		

*
 Significant at 0.05 level

The data table 11 shows that calculated value of Chi square at 3 degree of freedom of number of dependents at home is 9.654, which is greater than table value of 7.815. So it is significant at 0.05 level of significance. Hence the null hypothesis is rejected. Therefore, there is a significant association between caregiver burden and number of dependents at home.

5. RESULTS:

SAMPLE CHARACTERISTICS

The present study results showed that 36% of the caregivers belong to the age group of 41-60 years. Majority of caregivers were female [64%]. Most of the subjects were graduates [39%] and above qualifications. Majority of the caregivers were married [88%]. The data on the occupational status of the caregiver revealed that 48% of caregivers are house wives. More than half of the caregivers ,57% of caregivers having monthly income Rs.<15,000. Most of caregivers were spouses. Among the samples 20% of caregivers were caring their relative for <3 months .47% of caregivers having two persons were dependent at home. Regarding morbidity status of the caregiver 60% of caregivers were having no morbidities. 78% of the caregivers coming from nuclear family.

LEVEL OF CAREGIVER BURDEN

Among 100 caregivers of terminally ill cancer patients ,63% of patients having little burden,33% were having mild burden and only 4% were having moderate burden while caring their relatives.

LEVEL OF CAREGIVER SATISFACTION

Out of 100 caregivers, 20% of caregivers were very satisfied ,56% were satisfied ,24% were dissatisfied with palliative care services.

CORRELATION BETWEEN CAREGIVER BURDEN AND THEIR SATISFACTION WITH PALLIATIVE CARE SERVICES

There is no correlation between caregiver burden and caregiver satisfaction with palliative care.

$[r = -.027][t = .2673][t_{0.05/2} < 1.9] p < .05$

ASSOCIATION BETWEEN CAREGIVER BURDEN AND THEIR SATISFACTION WITH SELECTED DEMOGRAPHIC VARIABLES

The present study shows that, there is significant association between caregiver burden with selected demographic variables such as age ,marital status ,educational status ,relationship to the patients ,number of dependents at home and no significant association were found between other selected demographic variables

6. RECOMMENDATIONS :

The study paved the way for the following recommendations:

- A similar study may be undertaken ,using the same tool on a larger sample and for a longer period, for better generalization
- A similar study may conduct to caregivers of various terminally ill patients (other than cancer) those who receiving palliative care.
- A study to assess the gender difference burden of caregivers in terminally ill patients may be conducted.
- Qualitative studies may be conducted on caregiver burden among caregivers of terminally ill cancer patients.
- Experimental study can be conducted to find out the effect of interventions like focused group discussion, palliative care training programmes etc on reducing the caregiver burden.

7. CONCLUSION:

Caregivers have little burden while caring their relative and also most of the subjects are highly satisfied with palliative care. Oncology nurses are uniquely positioned to play a vital role in recognizing caregiver strain and intervening to break the cycle of unremitting physical and psychosocial burden of caregivers. It is also useful for organizing the depression screening and treatment programs for caregivers in palliative care settings thereby decreasing the burden .A very less number of studies conducted in this area.

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