# A PRE-EXPERIMENTAL STUDY TO EVALUATE THE CAREGIVER ROLE STRAIN EXPERIENCED AND COPING STRATEGIES ADOPTED AMONG CAREGIVERS OF PATIENTS WITH CANCER RECEIVING PALLIATIVE CARE BEFORE AND AFTER INFORMATION,EDUCATION AND COMMUNICATION PACKAGE AT GVN HOSPITAL PALLIATIVE CARE UNIT, TRICHY DURING THE YEAR 2011-2012.

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TIRUCHY

**A DISSERTATION SUBMITTED TO THE TAMILNADU Dr.M.G.R.MEDICAL UNIVERSITY, CHENNAI IN PARTIAL FULFILMENT OF THE REQUIREMENT FOR THE DEGREE OF MASTER OF SCIENCE IN NURSING**

**APRIL 2012**

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## CERTIFICATE

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**APRIL 2012.**

# TO WHOMSOEVER IT MAY CONCERN

This is to certify that Ethical committee of Dr.G.Sakunthala College of Nursing has discussed with its members the topic “A pre-experimental study to evaluate the caregiver rolestrain experienced and coping strategies adopted among caregivers of patients with cancer receiving palliative care before and after information,education and communication package at Dr.G.Viswanathan Hospital palliative care unit,Trichy during the year 2011-2012” opted by Mrs.JUDITH MARIAN DOMINICA JOHNSON and its implication on study subjects for her thesis for M.Sc Nursing programme and the committee passed clearance for the same topic for her to persue.

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ETHICAL COMMITTEE

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# ABSTRACT

A pre-experimental study to evaluate the caregiver role strain experienced and coping strategies adopted among caregivers of patients with cancer receiving palliative care before and after Information,Education and Communication package at Dr.G.Viswanathan Hospital palliative care unit,Trichy during the year 2011-2012.

Objectives of the study

1. To assess the caregiver role strain experienced by caregivers of patients with cancer receiving palliative care before and after IEC.
2. To assess the coping strategies adopted by the caregivers of patients with cancer receiving palliative care before and after IEC.
3. To find the relationship between caregiver role strain experienced and coping strategies adopted among caregivers of patients with cancer receiving palliative care.
4. To find the association between the caregiver role strain with selected demographic variables.

After ten days, post test was conducted using the same questionnaire.The same procedure was followed to all groups of caregivers of patients with cancer receiving palliative care.

Conceptual framework :

Penders Health Promotion Model.

Research design :

A pre experimental design, one group pre test and post test.

O1 =pretest assessment of caregiver rolestrain experienced and coping strategies.

X= Intervention.

O2 =post test assessment of

Caregiver role strain experienced and coping strategies adopted.

Population : Caregivers of patients with cancer receiving palliative care admitted at Dr.G.Viswanathan Hospital palliative care unit, Trichy were selected as the population of this study.
Nearly 5 cancer patients receiving palliative care were admitted in the in-patient unit per day.

Sample Size : 30 caregivers of patients with cancer receiving

palliative care.

Sampling : Convenience sampling technique.Each day 3

Caregivers of patients with cancer who met the

inclusion criteria were selected for the study.

Setting : Dr.G.Viswanathan Hospital palliative care unit, Trichy.

Tool : Tool –I a Standardised caregiver role strain index was used to assess the caregiver role strain of patients with cancer receiving palliative care.

Tool-2 A Standardised coping strategies scale was a likert scale,with 4 items with positive coping strategies.

Data Collection : Each day three samples were selected for the interview.A pretest was conducted by using Standardised Questionnaire that consisted of demographic variables,part-II clinicalvariables, part-III caregiver rolestrain index and part-IV coping strategies scale.After the pretest,they were given Information, Education and Communication package for about 30 minutes using digital video disc.

The IEC programme contained information regarding cancer,symptom management, palliative care,grief model,dependency role change and management of social isolation.

After ten days,post test was conducted using the same questionnaire.The same procedure was followed to all groups of Caregivers of patients with cancer receiving Palliative care.

Data analysis : Descriptive statistics Number, Percentage, Mean, Standard deviation and inferential statistics Paired t-test,Chi-Square test were used to test the research hypothesis.

## MAJOR FINDINGS OF THE STUDY

1. Majority of the caregivers of patients with cancer receiving palliative care were having severe strain before IEC.
2. Majority of the caregivers of patients with cancer receiving palliative care had adopted moderately adequate coping strategies before IEC.
3. There was a significant difference between the caregiver role strain experiencedby caregivers of patients with cancer receiving palliative care before and after IEC.
4. There was a significant difference between the coping strategies adopted by caregivers of patients with cancer receiving palliative care before and after IEC.
5. There was a significant relationship between the caregiver role strain experienced and coping strategies adopted by caregivers of patients with cancer receiving palliative care before and after IEC.
6. There was no significant association between caregiver role strain and selected demographic variables such as age and gender.Hence the stated research hypothesis was accepted for selected demographic variables such asmarital status, education,family type, income and occupation.

# CONCLUSION

1. Caregiver role strain experienced can be minimised and coping strategies can be enhanced by a successful Information, Education and Communication package directed to the caregivers of patients with cancer receiving palliative care.
2. The study has given clues that majority of caregivers of cancer patients receiving palliative care had severe role strain and only a few practised moderately adequate coping strategies which guided the investigator to perform a Information,Education and Communication package about cancer and symptom management, palliative care,grief model,dependency role change and management of social isolation .

# CHAPTER –I

# INTRODUCTION

## BACKGROUND OF THE STUDY

Cancer is a major disorder which affects many people ,directly or indirectly.Nearly half of all the newly diagnosed cancer patients will survive longer than 5 years.The course of cancer is shifting from an acute disease with a prompt outcome,usually death,to a chronic disease with long term treatment often implemented in home settings with a continuing need for care.Health policy ,demographic trends and medical –technological developments will lead to an expansive involvement of the informal care system of cancer patients.(American cancer society,2010)

A diagnosis such as cancer influences not only the patient but also the significant others in many aspects.Several studies have shown that patients and their partners reported higher levels of psychological distress as compared to the general population ,and that patients and their partners did not differ significantly in their levels of distress.(Northouse and stetz,2008)

In fact, approximately 80% of home care services are provided by families, introducing a compelling rationale to better understand what they do, how they manage, and what should be done to assist them.Family caregivers frequently step into their new role with little understanding of the complex ways which will alter their lives.

According to the National Cancer Registry Programme of the Indian Council of Medical Research, there are 2-2.5 million cancer patients in the country at any given time, less than half percent have access to palliative care treatment, seven hundred thousand to nine hundred thousand new cancer cases are detected every year, 70 percent of the cancer patients in India require palliative care as a majority of the cases are diagnosed at an advanced stage,resulting in poor survival and high mortality.

In many countries the terms hospice and palliative care are used interchangeably to refer to the support provided to people with active,progressive and far advanced disease with little or no prospect of cure.Deeply rooted within the core of palliative care philosophy is support for the family as well as the patient.The world Health organisation promotes the importance of families receiving input from palliative care services ,identifying the patient and family as the unit of care.However ,the needs of families may not be well served by some professional palliative care providers and family caregivers continue in many instances to provide long term ,24-hour care within the home with little emotional or psychological support.

The impact of caring for a family member in need of palliative cancer care has been well reported in the literature.Many authors assert that caregivers are often prone to negative physical ,social and emotional sequelae.Moreover ,research conducted for more than a decade has demonstrated that caregivers themselves report unmet needs.Commonly these needs encompass a desire for more information and support from health care professionals.As a consequence of the substantive body of literature on the impact of being a caregiver and the unmet needs of caregivers ,there has been an urgent request by many authors for the development of supportive interventions to assist family caregivers.

Preparing family caregivers to care for a dying person should begin in the hospital.Family caregivers may not want to seek or access more information and support pertinent to their role because they believe that health care professionals operate in a system where resources are limited and health professionals time is constrained.Furthermore ,caregivers often perceive their role as more tangenital;hence ,they may not feel that their needs for support and information are important.

Alterations in the patients functional ability bodily functions ,appearance,employment status,sexual functioning,family and social role have a direct impact on the caregiver.(Northouse,2007)

Neale(2001)pointed out that a patients carers often experience physical,emotional,social and economic burdens as a result of the illness and that too often professioinals have accepted these as inevitable.

Sheldon (2006) singles out three areas where carers needs are great and are not always met.First,they need good communication and attention to their emotional strain.Second ,they need well co-ordinated domiciliary support.Third,they need advice on financial problems ,which they may experience as a result of caring for a sick person.An assessment of their needs is therefore vital in order that their support is planned and not left to chance encounters with different health care professionals.

Communication process barriers refer to problems that occur during the course of attempting to provide family –centered care,which prevent or inhibit health care professionals from providing information ,practical advice,and support to families.

Caregivers ability to absorb and retain information may be compromised by memory loss,depression,fear,anxiety and sleep deprivation.Therefore ,clinicians need to attempt to promote an environment that is conducive to information exchange when providing supportive care strategies .Ideally ,there should be privacy and minimal interruptions to allow for optimal communication ;this is not always easy in hospitals and homes.Furthermore ,healthcare professionals need to ensure that caregivers have heard and understood the content of the information and be provided with sufficient time to have questions clarified.

When caregivers are confronted with new practical,emotional,and existential issues many avoid talking about them.Perhaps this conspiracy of silence is not restricted to family caregivers and patients but exists for health care professionals also.Caregivers often perceive their role as more tangenital;hence ,they may not feel that their needs for support and information are important.

People vary in their ability to cope with the demands of the caregiving role.Some partners and caregivers are able to master caregiving tasks and seem to cope well with the challenges involved .Others ,for a variety of reasons ,have more difficulty coping with these demands and report higher levels of depression and strain.(Keefe FJ,2005)

Finally,when partners and caregivers learn coping skills along with the cancer patient,they then have the ability to use these skills to manage their own stress and negative emotions.(Keefe,2005)

One of the most effective educational tools is to give patients and caregivers opportunities to practise using specific pain coping skills and to provide guidance and feedback on how to adopt the skills to their specific needs.Programs for teaching cancer patients and caregivers psychological methods of pain control have been shown to increase caregivers confidence in their abilities to help patients manage pain and other cancer symptoms.(Keefe FJ,Ahles TA,Mckee D,2005)

It is challenging for clinicians to foster coping and allow hope when discussing prognosis and end –of –life issues with terminally ill cancer patients and their caregivers.To the authors knowledge little research evidence is currently available to guide clinical practise.

Although family caregivers are the long term care providers to people with cancer,they receive little preparation,information or support to perform their vital role.(J Clin.Oncol.(2007)(Bishop MM,Beaumont JL,Hannea,et.al(2007)

Cancer patients and their family caregivers react to cancer as one emotional system there is a significant reciprocal relationship between each persons response to the illness,with family caregivers often reporting as much emotional distress,anxiety or depression as patients.The advanced phase of cancer is especially

Difficult for family caregivers ,who sometimes report more depression than the patients themselves.However caregivers seldom use any form of mental healthservices to deal with their own depression or emotional distress and this puts them at risk for long term health problems.(Vanderwerker LC)(J.Clin Oncol(2005)

Although family caregivers are the long term care providers to people with cancer ,they receive little preparation,information or support to perform their vital role.(Bishop MM,Given BA(2007)

Family caregivers often are expected to navigate an increasingly complex and fragmented health care system on their own and to find whatever help that may be available.(Arno PS,Levine C(1999)

Burton and colleagues stated that providing care poses a threat to the overall health of caregivers which can compromise their ability to continue to be caregivers.If caregivers are to continue to provide care,relief from the distress and demands of maintaining the required care must be considered.

Among the greatest challenges for family caregivers is interacting with nurses and other professionals in the hospital settings,and a rough crossing back home ,as the patient is discharged to family.Due to inadequate knowledge and skill family caregivers may be unfamiliar with the type of care they must provide or the amount of care needed.

Evidence shows that community –based education and support for caregivers may help relieve the stressors associated with providing care for a loved one with cancer.

## SIGNIFICANCE AND NEED OF THE STUDY

Family caregivers often experience significant difficulties associated with managing the patients physical care and these difficulties can intensify as the patients condition worsens.This coupled with the distress from watching the physical and sometimes mental deterioration of their loved one,whilst having to cope with the ongoing day-to-day household ,social and financial matters can make caregiving at home extremely challenging.Indeed research findings consistently highlight the physical and emotional demands that caregiving families face and also reveal significant unmet needs for support.(Hull,1999)

Most research about caregivers explores the emotional health of those who care for people with cancer.Little information is available about the knowledge and skills that family caregivers need to provide care or how their knowledge and skills affect care.

Recently investigations on the distress of the caregivers have suggested that family caregivers require both knowledge and skill to provide care and to reduce their own distress.Schumacher and colleagues describe family caregiving skill,is the ability to engage effectively and smoothly incare processes requiring psychomotor cognitive and psychological skills.

The need for the study arose from several factors.The foremost being the researchers experiences with cancer patients and their caregivers.As the condition of the patient deteriorates,the amount of caregiving activity also increases,this affects them physically and emotionally.Hence the researcher felt the need to do a study which would assess the caregiver role strain and coping strategies of patients with cancer.

Understanding caregivers burden and caregiving intensity is important to nursing personal because family participation in the care of cancer patients is essential to obtain outcome for nursing intervention.This gives another reason to do this study where one will know what are the aspects affecting the primary caregivers health and programmes can be implemented by the health personal inorder to reduce their burden and caregiving intensity.

The need for such a study arose to know the domains that affect the caregivers of these patients.The study will also help to identify the positive and negative coping strategies adopted by family members who are primary caregivers of a patient with cancer receiving palliative care and also inorder to get quantified data about the intensity of strain and coping strategies adopted through the illness trajectory of family members of patients with cancer.

The study can also help health care professionals to gain insight into strain of caregivers and the adopted coping strategies in relation to the demographic variables in relation to palliative care settings.This helps in addressing caregiver needs to the optimum extent.

Another reason for doing such a study is that there are studies done with cancer patients and their caregivers in hospital settings but there are very few studies related to caregivers of cancer patients in palliative care settings.

This study also helps in changing the outlook of health care professionals towards the caregivers of patients with cancer receiving palliative care as either hidden patients ,secondary patients or pseudo patients.These interventions could be directed towards communicating and educating the caregiver family member with cancer.So that they learn to live with a loved one receiving palliative care with reduced strain.It also helps in creating a positive approach towards caregiving.It also helps in providing guidance regarding choices of patient care and treatment,end of life decisions and home care of patients with cancer receiving palliative care.

There are 241 palliative care centers in India of which 13 are in Tamilnadu and 2 in Trichy.Kerala is Indias premier with 140 centers.But there is a dearth of service in many parts of the country and development of services are uneven.Around 70-80% of cancer patients are beyond treatment and require palliative care.But the cancer budget is tilted towards treatment.Hence this study can shed light on the importance of strengthening family centered care.

Also caregivers face decreased social interaction with depression and anxiety so the need for caring for caregivers in palliative care settings is imperative.

## STATEMENT OF THE PROBLEM

A pre-experimental study to evaluate the caregiver rolestrain experienced and coping strategies adopted among caregivers of patients with cancer receiving palliative care before and after Information,Education and Communication package at Dr.G.Vishwanathan Hospital palliative care unit,Trichy during the year 2011-2012.

## OBJECTIVES OF THE STUDY

1. To assess the caregiver role strain experienced by caregivers of patients with cancer receiving palliative care before and after IEC.
2. To assess the coping strategies adopted by the caregivers of patients with cancer receiving palliative care before and afterIEC.
3. To find the relationship between caregiver role strain and coping strategies adopted among caregivers of patients with cancer receiving palliative care.
4. To find the association between the caregiver role strain with selected demographic variables.

## RESEARCH HYPOTHESES

At $p<0.05$ level

- There would be a significant difference in the mean level of the care giver role strain among caregivers of patients with cancer receiving palliative care before and after IEC.
- There would be a significant difference between the mean level of coping strategies adopted among the caregivers of patients with cancer receiving palliative care beforeand after IEC.
- There would be a significant relationship between the caregiver role strain and coping strategies adopted among the caregivers of the patients with cancer receiving palliative care.
- There would be a significant association between the care giver role strains with selected demographic variables among caregivers of patients with cancer receiving palliative care.

## OPERATIONAL DEFINITION

### Evaluate

To assess or form an idea of the amount, quality or value.

This study refers to producing the desired or intended result of IEC for caregivers of patients with cancer receiving palliative care that is measured by a standardized tool oncaregiver role strain index and coping strategies scale.

### Experienced

It is defined as a practical contact with and observation of facts or events.

In this study it is the felt emotion or sensation by caregivers of patients with cancer receiving palliative care.

### Caregiver role strain

Is defined as the negative reaction to the impact of providing care on the caregiver'ssocial, occupational and personal roles and appears to be a precusor to depressive symptoms.

In this study it is the difficulty faced by the individual in carrying out the caregiving tasks, including providing emotional support and supervision and in Performing their role in the care of a client with cancer receiving palliative care as measured by caregiver strain index.

### Coping strategy

These are the strategies in which psychologically healthy people develop relationships.It involves compromise in order to move with.There must be communication, agreement, disagreement, compromise and decisions.

In this study it refers to thoughts and behaviours that are used to manage or cope with stressful situations by caregivers of patients with cancer receiving palliative care as measured by coping strategies scale.

### Patients with cancer

A person who is diagnosed and receiving medical treatment for cancer especially in a hospital.

In this study it refers to all those individuals who are diagnosed with any type of cancer receiving palliative care.

### Palliative care

It has been defined by the World Health Organization (WHO,1990) as the active total care of the patient whose disease is not responsive to curative treatment.In addition it stated that the control of pain and other symptoms of psychological ,social and spiritual is paramount.

In this study it refers to care of a client with cancer receiving end-of – life care either as inpatient or as outpatient.

### IEC

IEC package is combustion of multiple strategies that enable individuals, families, groups, organisations and communities to play active roles in achieving, protecting and sustaining their own health.

In this study IEC package refers to a technique which helps to provide awareness to the caregivers of patients with cancer receiving palliative care which will lead to change in existing coping strategies.

Management by education through powerpoint presentation on cancer and palliative care, handouts on symptom management at home,discussion on Kubler-Ross grieving process, lecture on dependency role change,caregiver meeting in management of social withdrawal.

### ASSUMPTIONS

- All the caregivers of patients with cancer receiving palliative care experience role strain.
- With IEC caregivers of patients with cancer receiving palliative care experience better coping strategies.

## DELIMITATION

- The study was limited to caregivers of patients with cancer receiving palliative care.
- The data collection period was limited to six weeks only.
- The sample size was limited to 30 caregivers of the patients with cancer receiving palliative care.

## PROJECTED OUTCOME

The findings of the study will help to evaluate the caregiver role strain experienced and coping strategies adopted among caregivers of patients with cancer receiving palliative care before and after Information,Education and Communication.

It will motivate the nursing personnel to be more aware of the caregiver role strain experienced and reduce their doubts;and enhance their adopted coping strategies.

The present study is focused to evaluate the caregiver role strain experienced and coping strategies adopted among caregivers of patients with cancer receiving palliative care before and after Information, Education and communication package.

# CHAPTER –II

# REVIEW OF LITERATURE

A review of literature has been very helpful in focussing the widened perspectives of the study.

A review of related literature enables one to get an insight into the various aspects of the problem under study.It uncovers aspects of the problem promising methodological tools,throws light on ways to improve the efficiency of the data collection and suggestions ,how to improve or increase the effectiveness of data analysis and interpretation.

Review of literature is therefore an essential step in the development of the research project.The results of the studies conducted in various aspects of caregiver role strain and adopted coping strategies.

This review of literature helps to develop a richer understanding about caregiver role strain ,coping strategies adopted and interventions that can help develop support strategies for the caregivers of patients with cancer receiving palliative care.It also shows that caregiver participation in family caregiver education helps in understanding disease process and symptom recognition ,reduces social isolation;enhances coping skills;improves communication and problem solving skills and reduces depression and anxiety in caring for a family member with cancer receiving palliative care.

The literature review is arranged in the following sections.

- Caregiver role strain of patients with cancer.
- Coping strategies of caregivers of patients with cancer.
- Information, Education and Communication Package.

## CAREGIVER ROLE STRAIN OF PATIENTS WITH CANCER

George RN, Papastavrou (2011) studied family members of patients with chronic illness experience distress as a result of caregiving roles.This descriptive and correlational study indicates a high level of burden and depression among all caregivers.

Given,B.A(2008)indicated that cancer affects not only quality of life of individuals with the disease but also that of their family members and close friends .A cross –sectional study has accumulating evidence that has supported the concept that cancer affects not only the patients but also their family members.

Spillers, R.L.(2008)concluded that caregiver quality of life may be maximized when caregiver needs in context of cancer care are met.A 3 cohort comparison suggests that interventions designed to help caregivers manage their own emotional distress as well as the survivors distress ,find meaning in the cancer caregiving experience.

Carver ,C.S.(2007)examined how caregivers relate to care recipients can affect how well care is provided and how much burden is experienced .An exploratory study suggests that ineffective caregivers of cancer patients may benefit from educational programs to improve their caregiving skills and to encourage them to utilize resources from other family members or community.

Nijboer et .al and Mittelman MSet.al (2007) stated that tangible social supports considered beneficial to the family caregivers ,we found no studies that showed social support and social assistance improve patient outcomes.

Lewis (2007) stated that a number of studies examining the impact of breast cancer on children in the family showed that increased illness demands resulted in increased levels of depression for both the patient and husband.

Vess, moreland and schwebel (2006) stated that a study found that couples who communicated well were better able to cope with role demands than other couples .They also exhibited less role strain and family conflict.

GivenB,et.al.(2006) insisted that families want information about symptoms ,disease progression ,treatment and possible adverse events.caregivers seek information on skills they need to provide day –to- day care.

Youngmee Kim.et.al.(2006)examined gender differences in caregiving among caregivers of cancer survivors utilizing structural equation modeling which revealed that both caregivers esteem and care recipients psychosocial functioning were significant mediators.

Gaugler,J.E.,et.al(2005) stated that a multivariate regression model also emphasized the diffuse yet potent role care recipient mood problems and caregiver mastery /optimism have on multiple dimensions of subjective stress.

Kim,Y.,Baker,F,Spillers,R.C,Wellisch(2005)examined the effect of caregivers multiple roles such as being employed and taking care of minors on their psychological adjustment.A multivariate general linear modelling analysis revealed that employed caregivers who were also taking care of children had higher strain.

Loscalzo,M.J,(2005)examined how the caregivers perception of providing care to a spouse with cancer differs by gender by a structural equation modelling.Results revealed that both caregiver esteem and care recipients psychosocial functioning were significant mediators.

Grunfeld,coyle,earle.et.al(2004) stated that caregiver burden as the level of psychological ,physical,social and financial suffering perceived by caregivers as an effect of the caregiving role.

Bakas Tet .al (2004) insisted that some caregivers lack the capacity to carry out necessary care, especially when tasks aredifficult and require insights, judgment,and critical thinking abilities that they do not possess.Nurses and social workers need to assess the situation and help caregivers obtain resources.

William E.et.al.(2003)examined with a regression model predictors of depression and life satisfaction among 80 spousal caregivers in hospice and results suggest that female gender were a risk factor for poorer caregiver wellbeing and with more social resources had lower depression and high life satisfaction.

Esther Sales (2001)carried out a study of predictors of strain in families of cancer patients through a prospective study and found degree of family strain is affected primarily by the severity of the illness as well as by suddenness of its onset and the patients own level of distress.

Blank.et.al.(2000)examined family support in advanced cancer suggested that caregivers who lack adequate resources and illprepared experience the most negative health effects.

Emanuel EJ,Fairclough DL,(1999)studied assistance from family members ,friends in the care of the terminally ill.A comparative study has demonstrated that such caregivers experience high levels of burden due to intense physical,psychological and economic strain.

## COPING STRATEGIES OF PATIENTS WITH CANCER

Downe, et.al, (2006) carried out a study on the relationship between meaning of illness, perceived social support resources, coping strategies,and QOL by patients and family members.The cross-sectional study showed that QOL in family members is predicted most by meaning of illness,specifically less adverse impact.

Gorden DB,Paice JA(2005) stated that given common concerns about pain medications it is very important that patients as well as their partners and caregivers are educated about their concerns about pain medications.Clinicians can then address this ,thereby enhancing pain control.

Cambell LC, Abernethy (2005)stated that patients and their partners and caregivers may believe for example that if they admit that emotions such as anger or fear affect their pain ,then the pain will not be taken seriously.

Kotkamp,et.al(2005)examined the consequences of cancer for partners and families.The descriptive study revealed that distress among family members is sometimes very similar to the distress experienced by patients.open communication,a healthy family cohesion seem to positively influence patients coping.

Liu JE,et.al(2005)explored the experiences ofpatients with cancer of supportive communication in the context of chinese culture.The exploratory study revealed that most would only express emotional needs to their close family members and did not expect healthcare professionals support.

Loukisha,et.al.(2004)carried out a study anxiety,caregiver burden,rolestrain and coping in husbands of women with breast cancer.A exploratory study findings indicate anxiety and role strain are significantly related to emotion –focused coping.

Manne,et.al.( 2004)examined benefit finding among wives of men with prostate cancer and found that psychoeducational intervention reported gains in the use of positive reappraisal coping .

Ostroff.et.al (2004) carried out a study on partners of breast cancer survivors and found that participants in a psychoeducational intervention reported gains in the use of positive reappraisal coping and reductions in denial coping.

KeefeFJ,et.al(2003) stated that people vary in their ability to cope with the demands of the caregiving role.Some partners and caregivers are able to master caregiving tasks and seem to cope well with the challenges involved.others have more difficulty coping with these demands and report strain.

Ashing KT,Padillac G(2003)indicated that patients who exhibited greater reliance on spiritual and religious beliefs were more likely to use an active coping style in which they accepted their illness and tried to deal with it in a positive and purposeful manner.

Ting-Ting Kuo,et.al (2002)carried out a study on symptom distresses and coping strategies in patients with non-small cell lung cancer.A descriptive correlational design did not show a statistically significant relationship to the degree of physical and psychological symptom distress.

Sorensons,PinquartM(2002) stated that there is a impressive body of evident showing that family caregivers need much more than just our concern and emotional support ,and the caregivers can show substantial and sustained benefits from psychosocial interventions.

Mittelman M,Roth D (2002) concluded that families who sacrifice so much for the care of their loved ones deserve access to effective interventions and research can help establish effective ways to assist caregivers that go beyond clinical lore in the delivery of psychosocial care.

JexSM,Bliese PD(2001) stated that the various strategies people use to deal will illness and other stressors have been broadly classified into two types of styles:1)active coping or problem –solving 2)passive avoidant coping.

## INFORMATION, EDUCATION&COMMUNICATION PACKAGE

Given and collegues (2006) insisted that a cognitive behavioural intervention to assist caregivers of cancer patients with symptom management .The tailored intervention addressed specific symptoms and severity levels.

Abernethy AP, ScipioCD (2006) indicated that caregivers who participate in educational programs on pain management often report decreases in their psychological distress and improvements in their wellbeing.

Susan C.Mcmillian ,Brent J.Small(2006)carried out a study on the impact of coping skills intervention with family caregivers of hospice patients with cancer .This experimental study findings provided evidence that caregiver skill-training programme improved caregiver well-being.

Pinquart M, Sorensons S (2003) stated that the inclusion of family members in psycho social interventions and delivering to the targeted family may prove beneficial in minimizing the adverse impact of cancer and helping individuals who are touched by cancer maximise positive experiences from family.

Northouse, Walker J(2002) stated that a family based psycho educational program for patients with recurrent breast cancer and their family members were related to higher satisfaction with the programme

Pasacreta.JV (2000) carried out a study on participant characteristics before and after 4 months after attendance at a family caregiver cancer education program through a longitudinal study.Data indicates that perception of burden did not worsen even when caregiving tasks increased in intensity.

Blanchard.et.al (2000) carried out a study to develop an intervention to help spousal caregivers of cancer patients develop problem solving skills when they could no longer provide care.

Jenson C,Mccorkler (1999) stated that a problem –solving skills intervention benefited more distressed spousal caregivers and a home care intervention benefited elderly caregivers of patients with advanced –stage cancer,as demonstrated by longer survival compared with a control group.

Holland JC, PassikS (1999) stated that recent research has found that religious and spiritual beliefs are associated with active coping, not with avoidant or passive coping strategies among patients with malignant melanoma.

## CONCLUSION

There are many studies that show along with cancer patients their caregivers also experience physical,social ,psychological and behavioural problems.So by enhancing caregiver roles in the care of a patient with cancer the health of the caregiver can be enhanced thus improving the care given for the cancer patient in palliative care.

# CONCEPTUAL FRAMEWORK

Conceptual framework for the study was developed from the existing theory and helps in defining the concepts of interest and proposing relationship among them.The model gives direction for the planning, data collection and interpretation of findings.

The present study aims at determining the effectiveness of information, education and communication package on caregiver role strain management of caregivers of patients with cancer receiving palliative care at Dr.G.Viswanathan Hospital palliative care unit at Trichy during the year of 2011-2012.

The conceptual framework of the present study was developed based on Pender N. Health Promotion Model.

The model focuses on the following three areas:

- Individual characteristics and experiences.
- Behaviour specific knowledge and affect.
- Behaviour outcome.

Individual Characteristics /Experiences:

- Prior –related behavior.
- Personal factors.
- Prior related behaviour

In this, caregiver's educational background and basic knowledge about coping strategies will be assessed.

Personal factors

Caregiver's personal factors are assessed in this area such as aggressiveness, sensitiveness and restlessness.

II.Behaviour specific cognitions and affect

1) Perceived benefits of action:

After IEC programme caregivers have gained knowledge regarding caregiver role strain management.

2) Perceived Barriers:

Caregivers lack of knowledge and ignorance acting as a barrier eventhough they are able to adopt.

3) Perceived self efficacy:

Caregivers must realize the importance of management of caregiver role strain.

4) Activity related affect

Some of the caregiver'sactivity affects the practice of coping strategies such as workload, physiological imbalance and psychological imbalance like fear and anxiety.

5) Interpersonal influences

Researchers are to influence caregivers to undergo the IEC programme on caregiver role strain management.

6) Situational influences

Caregivers need to gain knowledge on cancer management based on teaching.

III.Behavioural outcome

1) Immediate change of practice from low control to high control.

Here they may immediately change their coping strategies based on knowledge of cancer and its management.

2) Health promoting behavior

Caregivers gain knowledge thereby caregivers health status will be maintained without affecting their health in future.

3) Commitment to plan of action

The model, Pender N.Health Promotion Model, is best suited for this study which was undertaken to determine the knowledge in the management of Caregiver role strain among caregivers of patients with cancer receiving palliative care, using pre-test and post-test method.

# CHAPTER –III

# RESEARCH METHODOLOGY

This chapter deals with research approach,research design settings, variables, population, population, sample, sample size, sampling technique, development and description of the tool scoring key,validity and reliability ,pilot study,data gathering process and plan for data analysis.

## RESEARCH APPROACH

An evaluative approach was adopted in this study.

## RESEARCH DESIGN

A pre-experimental one group pretest, post test design.

O1 x O2

Key,

O1-pretest

X-information, education, communication package

O2-post test

## SETTING OF THE STUDY

The study was conducted at patient wards of Dr.G.Viswanathan Hospital palliative care unit,Trichy.It is a 50 bedded government approved private oncology hospital as well as referral center for oncology services which is a branch of the Dr.G.Viswanathan Institute of medical sciences and society Trichy.Which has 4 branches comprising 450 beds and serving the community since 1939.The palliative care unit has 15-20 patients who come on an out-patient basis and when they need admission they are admitted in the palliative care unit which has 20 beds with facilities for physical care,psychological and social counseling and spiritualupliftment.Average attendance of patients attending out patient department was 50 to 60 per day.There are specialists (2 Medical oncologists ,1 surgical oncologist and 2 radiation oncologists )and 3 post graduate trainees are available for consultation for patients in the out patient department.

## POPULATION

The target population of this study is caregivers of patients with cancer receiving palliative care at Dr.G.Viswanathan Hospital palliative care unit, Trichy.

## SAMPLE

The caregivers of patients with cancer receiving palliative care at Dr.G.Viswanathan Hospital palliative care unit, Trichy during the study period and those who fulfilled the inclusion criteria were selected for this study.

## SAMPLE SIZE

The total sample size 30 caregivers of patients with cancer receiving palliative care who fulfilled the inclusion criteria were selected for the study.

## SAMPLING TECHNIQUE

Convenience sampling technique was used for the study.

## CRITERIA FOR SAMPLE SELECTION

### INCLUSION CRITERIA

- Caregivers who regularly cared for patients withcancer receiving palliative care.
- Both male and female caregivers were selected for the study.
- Caregivers irrespective of educational status who cared for patients with cancer receiving palliative care.

## EXCLUSION CRITERIA

- The caregivers who were not willing to participate in this study.
- The caregivers who were not available at the time of data collection.
- The caregivers who do not provide care on a regular basis.

## DESCRIPTION OF TOOL

### Caregiver Strain Index

Caregiver strain index was developed by M.TerrySullivan, RN, MSW, MSN, CMC (2004). The tool was prepared with multiple choice questions containing a 13-question tool that measures strain related to care provision .Scoring is 2 points for each "yes" 1 point for each "no" response 0 score. The higher the score, the higher the level of caregiver strain.

### Coping Strategies Scale

Coping strategies scale is an adaptation of the Jalowiec coping scale(JCS) and is a adaptation of the translation by Chiu(1981).The tool was prepared containing s 46 multiple choice questions .Scoring is in likert scale,0-never ,1-sometimes,2-often,3-always.The higher the score the higher the level of coping .

## RESEARCH TOOL AND TECHNIQUE

The tool to be used for this study is questionnaire to assess the caregiver strain of patients withcancer receiving palliative care.

Part1: demographicvariables (age, gender, marital status, education, family, income, occupation)

Part 2: Clinicalvariables (site of cancer, stage of cancer, modality of treatment & duration of cancer)

Part 3: comprised of caregiver strain index has 13 question tools that measures strain related to care provision. There is at least one item for each of the following major domains: employment, financial, physical, social, time.

Part 4: comprised of coping strategies scale consisting of 46 items. The scoring of coping strategies scale is in likertscale.

## SCORING KEY

The Caregiver Strain Index (CSI) has scoring in 2 points for each “yes” 1 point and for each “no”0 point respectively and the respondants were asked to tick their responses in the appropriate columns.

The resulting scores for the level of strain were ranged as follows.

| Level of strain | Range. |
|---|---|
| Mild strain | 0 - 23 % |
| Moderate strain | 24 – 52% |
| Severe strain | 53 – 100% |

In the coping strategies scale the scoring is in likert scale range 0-3 to assess the coping strategies of caregivers.

In the coping strategies,the resulting scores were distributed as

| Level of coping | Range. |
|---|---|
| Inadequate coping | 0 – 33 % |
| Moderately adequate coping | 34 – 67% |
| Adequate coping | 68 – 100% |

## VALIDITY

Internal consistency reliability was high (alpha=0.86)and construct validity was supported by correlations with the physical and emotional health of the caregiver and with subjective views of the caregiving situation.It is a standadised tool developed with a sample of 132 caregivers providing assistance to hospitalised adults and was appropriate for caregivers of any age.

## RELIABILITY OF TOOL

To ensure the reliability of the tools, the tools were administered to four caregivers who are not included in the study.The reliability of internal consistency was established using split half test. The reliability coefficient for this care giver strain index tool is (r=0.94) and for coping strategies scale is (r=0.78) hence the tools are highly reliable.

## PILOT STUDY

The pilot study was conducted to evaluate the feasibility and practicability of the design. A group of 4 caregivers from Shanthalaya hospice was selected for the pilot study. Hence there is no chance of contamination among the pilot and main study samples and the tools were pre-tested.

## PROCEDURE FOR DATA COLLECTION

The period of data collection was from 05/07/2011 to 15/08/2011.Before conducting the study, formal permission was obtained from the head of the institution.Samples were selected with non-probability convenient sampling technique and pre-experimental design was used.The data was collected from Monday to Saturday of the week.The timing of data collection was from 9am to 5pm according to the convenience of the patients.The researcher identified patients receiving palliative care.The investigator introduced herself to the subjects,developed rapport and obtained oral consent from all the participants.Nature and purpose of the study was explained to the selected patients.Pre-assessment was done using caregiver rolestrain index and coping strategies scale.The data was collected from 3 persons in a day. On an average each respondent has taken 30-45 minutes to return their responses.

The IEC programme was administered for 30 minutes soon after the pretest.Then adequate time was given to all study subjects to clarify their doubts for 10-15 minutes.The post test caregiver strain index and coping strategies scale was administered to 30 caregivers 10 days after that the post test was conducted and appropriate responses were obtained from the selected sample.

## PROTECTION OF HUMAN RIGHTS

The researcher had obtained approval from the dissertation committee prior to pilot study. Permission was obtained from the heads of the department of both medical - surgical nursing. Both verbal and written consent was obtained from each sample and explained that there was no risk in participating in the study and the data collected will be kept confidential only numbers were assigned instead of names and anonymity was maintained throughout the study.

This chapter dealt briefly about the methodology the investigator adopted for the study.

## PLAN FOR DATA ANALYSIS

The collected data were analysed by statistical methods. The following statistical tools were used in this study.The descriptive statistical tools frequency; mean, standard deviation and correlation were used for summarizing the information in the collected data.

The inferential statistical tools paired‘t’ test was used to study the effectiveness of the IEC.

Chi-square test was used to study the homogeneity of the means.

Inferential statistics (paired‘t’test, chisquare) was used to compare the level of strain and coping strategies and to associate the demographic variables with the level of strain and coping strategies of caregivers.

# CHAPTER IV

# DATA ANALYSIS AND INTERPRETATION

Rossett (1987) defines analysis as needs assessment getting information to solve problems in the corporation; going out and seeking opinions on optimals, actuals, feelings, causes and solutions.

This chapter deals with statistical analysis .Statistical analysis is a method of rendering quantitative information in a meaningful and an intelligible manner.Statistical procedure enables the research to organize analyse ,evaluate,interpret and communicate numerical information meaningfully.

## ORGANISATION OF DATA

The data obtained were mainly classified into following four sections.

SECTION 1 : Distribution of subjects according to demographic variables.

SECTION2 (a) : Frequency distribution of caregiver rolestrain experienced by caregivers of patients with cancer receiving palliative care before IEC.

SECTION 2(b) : Frequency distribution of caregiver rolestrain experienced by caregivers of patients with cancer receiving palliative care after IEC.

SECTION 2(c) : Percentage distribution of caregiver rolestrain experienced by caregivers of patients with cancer receiving palliative care before and after IEC.

SECTION2 (d) : Comparison between caregiver rolestrain experienced by caregivers of patients receiving palliative care before and after IEC.

SECTION 3(a) : Comparison between coping strategies (problem focused and emotion focused) of caregivers of patients with cancer receiving palliative care before and after IEC.

SECTION 3(b) : Percentage distribution of coping strategies adopted by caregivers of patients with cancer receiving palliative care before and after IEC.

SECTION 3(c) : Comparison between coping strategies adopted by caregivers of patients receiving palliative care before and after IEC.

SECTION 4 : Comparison and correlation between caregiver rolestrain experienced and coping strategies adopted after IEC.

SECTION 5 : Association between caregiver rolestrain experienced with selected demographic variables after IEC.

## SECTION 1

This section deals with the demographic variables of the sample.

Table 1

Frequency and percentage distribution of samples according to their demographic variables. n=30

| S.No | Demographic Variables | f | % |
|---|---|---|---|
| 1 | Age in years | 12 | 40 |
| | 18-35 | 8 | 26.7 |
| | 36-50 | 10 | 33.3 |
| | 50& above | | |
| 2 | Gender | | |
| | Male | 15 | 50 |
| | Female | 15 | 50 |
| 3 | Marital status | | |
| | Married | 26 | 86.7 |
| | Unmarried | 4 | 13.3 |
| 4 | Education | | |
| | Illiterate | 7 | 23.3 |
| | Secondary | 13 | 43.3 |
| | Higher Secondary | 9 | 30 |
| | Graduate | 1 | 3.3 |
| 5 | Type of family | | |
| | Joint | 8 | 26.7 |
| | Nuclear | 22 | 73.3 |
| 6 | Family Income in ₹ | | |
| | < 5000 | 25 | 83.3 |
| | 5000-10000 | 4 | 13.3 |
| | > 10001 | 1 | 3.3 |

| | | | |
|---|---|---|---|
| 7 | Occupation | | |
| | Housewife | 5 | 16.7 |
| | Government employee | 8 | 26.7 |
| | Private employee | 15 | 50 |
| | Laborer | 2 | 6.7 |

Table 1 describes the frequency and percentage distribution of demographic variables.

The following inferences could be made are

Majority of them 40% were at the age group of 18-25years,33.3%of them were 50 and above,least of them 26.7% were at the age group of 36-50 years.Half of them 50% were males and remaining half 50% were females.Marital status shows that majority 86.7% were married and 13.3% were unmarried.

Educational status shows that majority 43.3% of them were at the secondary level,30% of them were educated at the level of higher secondary,23.3% of them were illiterate ,least of them were 3.3% of them were graduates.

Regarding the type of family majority 73.3% were nuclear and 26.7% were joint family. According to income status, majority of the samples income was below Rs.5000 83.3%, 13.3% the income was between Rs.5001-10000 and only 3.3% was above Rs.10001. According to occupation 50% were private employees,26.7% were government employees,16.7% were housewives and 6.7% were laborers.

SECTION 2(a)

This section deals with the frequency distribution of caregiver role strain experienced by caregivers of patients with cancer receiving palliative care before IEC.

Table 2(a)

Frequency distribution of subjects of caregiver rolestrain experienced before IEC. n=30

| S.No | Items | Yes | | No | |
|---|---|---|---|---|---|
| | | f | % | f | % |
| 1 | Disturbed sleep | 25 | (83) | 5 | (17) |
| 2 | Inconvenience | 25 | (83) | 5 | (17) |
| 3 | Physical strain | 25 | (83) | 5 | (17) |
| 4 | Confined role | 25 | (83) | 5 | (17) |
| 5 | Family adjustments | 29 | (97) | 1 | (3) |
| 6 | Changes in personalPlans | 24 | (80) | 6 | (20) |
| 7 | Demands on time | 26 | (87) | 4 | (13) |
| 8 | Emotional adjustments | 28 | (93) | 2 | (7) |
| 9 | Upsetting behaviour | 26 | (87) | 4 | (13) |
| 10 | Changedfrom his/her former self. | 27 | (90) | 3 | (10) |
| 11 | Work adjustments. | 26 | (87) | 4 | (13) |
| 12 | Financial strain | 28 | (93) | 2 | (7) |
| 13 | Overwhelmed completely | 26 | (86) | 4 | (13) |

The above table reveals that the caregiver role strain experienced by caregivers of patients with cancer receiving palliative care before IEC, majority 83% sleep was disturbed, regarding inconvenience, majority 83% felt it was inconvenient,in response to physical strain, majority 83% felt it was a strain,regarding confining, majority 83% felt the caregiving role was confining,in response to family adjustments, majority 97% felt there has been family adjustments.

Regarding personal plans, majority 80% had to make changes in personal plans,in response to if there demands on time,majority 87% felt there was demand on time,in emotional adjustments, majority 93% said there were emotional adjustments,in response to if behavior were upsetting,majority 87% felt behaviour was upsetting,regarding if they felt upset the patient has changed from her former self, majority 90% felt upset,regarding work adjustments, majority 87% felt work adjustments had been made ,in response to financial strain, majority 93% said it was a financial strain.Regarding feeling the number of people who were having a positive feeling, majority 86%.

SECTION 2(b)

This section deals with the frequency distribution of caregiver role strain experienced by caregivers of patients with cancer receiving palliative care after IEC.

Table 2(b)

Frequency distribution of subjects of caregiver rolestrain experienced after IEC. n=30

| S.No | Items | Yes | | No | |
|---|---|---|---|---|---|
| | | f | % | f | % |
| 1 | Disturbed sleep | 26 | (87) | 4 | (13) |
| 2 | Inconvenience | 19 | (63) | 11 | (37) |
| 3 | Physical strain | 18 | (60) | 12 | (40) |
| 4 | Confined role | 3 | (10) | 27 | (90) |
| 5 | Family adjustments | 25 | (83) | 5 | (17) |
| 6 | Changes in personal Plans | 2 | (7) | 28 | (93) |
| 7 | Demands on time | | | 30 | (100) |
| 8 | Emotional adjustments | 23 | (77) | 7 | (23) |
| 9 | Upsetting behaviour | 4 | (13) | 26 | (87) |
| 10 | Changedfrom his/her former self. | 25 | (83) | 5 | (17) |
| 11 | Work adjustments. | 1 | (3) | 25 | (83) |
| 12 | Financial strain | 27 | (90) | 3 | (10) |
| 13 | Overwhelmed completely | 1 | (3) | 29 | (97) |

The above table reveals that the caregiver role strain experienced by caregivers of patients with cancer receiving palliative care after IEC, majority 87% sleep was disturbed,regarding inconvenience, majority 63% felt it was inconvenient,in response to physical strain, majority 60% felt it was a strain,regarding confining, majority 90% felt it was not confining.In response to family adjustments, majority 83% felt there has been family adjustments.

Regarding personal plans, majority 93% had no changes in personal plans,in response to if there demands on time,majority 100% felt there was no demand on time.Regarding emotional adjustments, majority 77% said there were emotional adjustments,in response to if behavior were upsetting,majority 87% felt it was not upsetting.Regarding if they felt upset the patient has changed from her former self, majority 83% felt they did not feel upset,regarding work adjustments, majority 83 % felt that there was no work adjustments.In response to financial strain, majority 90% said it was a financial strain.Regarding feeling the number of people who were having a positive feeling, majority 97% .

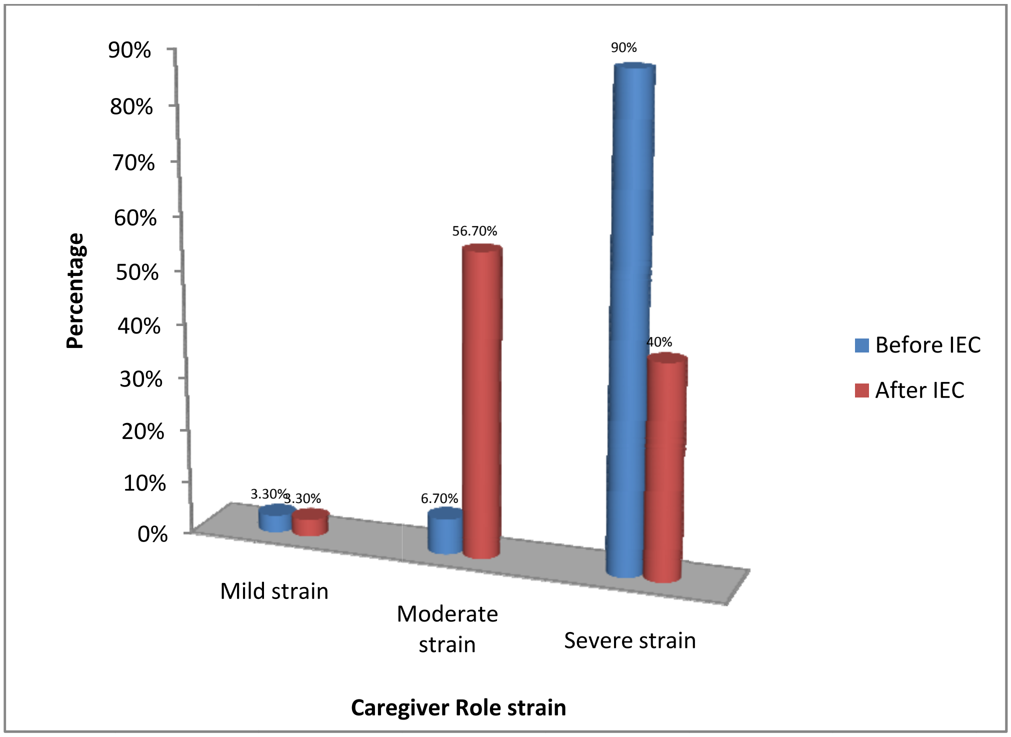

FIGURE 2(c)

Percentage distribution of caregiver rolestrain experienced by caregivers of patients with cancer receiving palliative care before and after IEC.

The inferences made are

In the caregiver role strain experienced, majority of them 90% were having severe strain and 6.7% were having moderate strain and 3.3% were having mild strain before IEC.In the caregiver role strain experienced majority of them 40% were having severe strain and 56.7% were having moderate strain and 3.3% were having mild strain after IEC.

SECTION 2(d)

This section deals with the comparison of mean scores between caregiver role strain experienced before and after IEC .

Figure 2(d)

Comparison between caregiver role strain scores experienced before and after IEC. n=30

| | Mean | S.D | Paired 't' test |
|---|---|---|---|
| Caregiver role strain before IEC | 43.59 | 11.837 | 14.688** |
| Caregiver role strain after IEC | 22.31 | 6.259 | |

**p< 0.01 level

The above table shows that there was a highly significant difference in the mean scores in relation to caregiver role strain experienced by caregivers of patients with cancer receiving palliative care before and after IEC.The mean score before IEC 43.59 is significantly greater than the mean score after IEC 22.31.Hence the stated hypothesis was accepted.The effectiveness of Information, Education and Communication package was more significant at p<0.01level.

SECTION 3(a)

This section deals with the comparison between coping strategies (problem focused and emotion focused)of caregivers ofpatients with cancer receiving palliative care before and after IEC.

Table 3(a) Comparison between coping strategies (problem focused and emotion focused) of caregivers ofpatients with cancer receiving palliative care before and after IEC. n=30

| | Mean | S.D | Paired t test |
|---|---|---|---|
| Existing problem focused coping | 30.6 | 7.01 | 7.905** |
| Adopted problem focused coping | 41.3 | 4.65 | |
| Existing problem focused coping | 42.4 | 8.25 | 3.727** |
| Adopted problem focused coping | 46.8 | 5.66 | |
| Total problem focused coping | 38.5 | 7.52 | 5.736** |
| Total emotion focused copying | 45 | 4.54 | |

**p<0.01 level

The above table shows that there was a significant difference in the mean scores in relation to problem focused coping strategies and emotion focused coping strategies adopted by caregivers of patients with cancer receiving palliative care before and after IEC.The mean score for existing problem focused coping strategies 30.6 and for adopted problem focused coping strategies 41.3.The mean score for existing emotion focused coping strategies 42.4 and for adopted emotion focused coping strategies 46.8. It was significant at p<0.01 level.

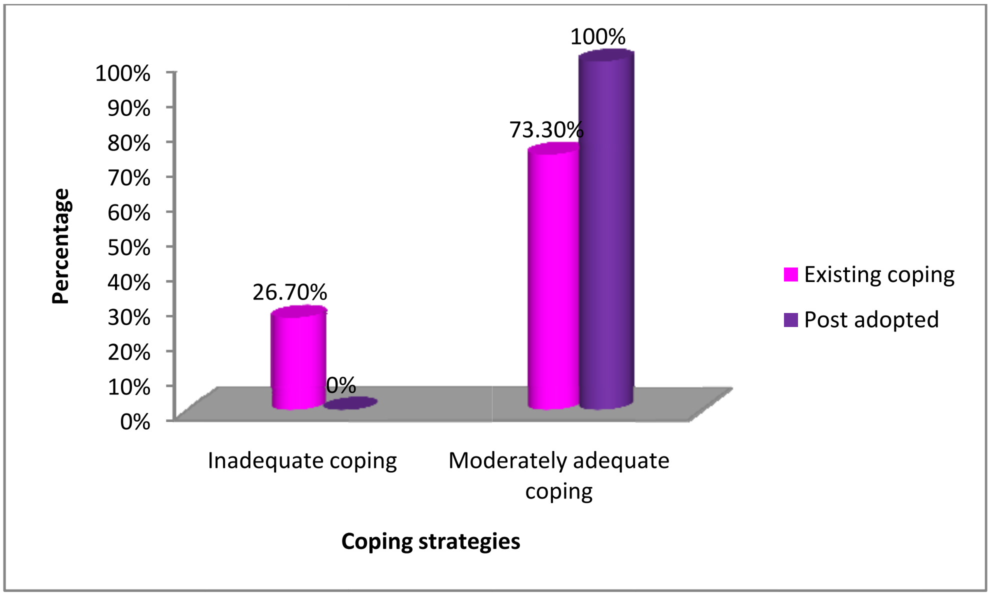

Figure 3(b)

Percentage distribution of adopted coping strategies of caregivers of patients with cancer receiving palliative care before and after IEC.

The inferences made are

In the existing coping strategies score of caregivers of cancer patients receiving palliative care, majority of them 73.3%adopted moderately adequate coping and 26.7% adopted inadequate coping strategies.In the post adopted coping strategies, majority of them 100% adopted moderately adequate coping strategies.

SECTION 3(c)

This section deals with the comparison of mean scores of coping strategies adopted before and after IEC.

Figure 3(c)

Comparison of mean scores of coping strategies adopted before and after IEC. n=30

| | Mean | S.D | Paired ‘t’ test |
|---|---|---|---|
| Existing coping strategies before IEC | 28.95 | 5.646 | 5.763** |
| Adopted coping strategies after IEC | 33.79 | 3.408 | |

**p < 0.01 level

The above table shows that there was a highly significant difference in the mean scores in relation to coping strategies adopted by caregivers of patients with cancer receiving palliative care before and after IEC.The mean score before IEC 28.95 is significantly lesser than the mean score after IEC 33.79.Hence the stated research hypothesis was accepted.The effectiveness of Information, Education and Communication Package was more significant at $p<0.01$ level.

## SECTION 4

Comparison and correlation between caregiver rolestrain experienced and coping strategies adopted after IEC.

Table 4

Correlation between caregiver role strain experienced and copingstrategies adopted. n=30

| | Mean | S.D | Correlation‘r’ |
|---|---|---|---|
| Caregiver role strain after IEC | 22.31 | 6.259 | -.362** |
| Adopted coping strategies after IEC | 33.79 | 3.408 | |

*p < 0.05 level

The above table shows that there was a highly significant correlation between caregiver role strain and coping strategies adopted by caregivers of patients with cancer receiving palliative care. Hence the stated research hypothesis was accepted.

*Correlation is significant at the 0.05level.

SECTION 5

Association between caregiver role strain experienced with selected demographic variables after IEC.

Table 5

Association between caregiver rolestrain experienced scores with selected demographic variables. n=30

| S.No | DemographicVariables | Mild | Moderate | Severe | $x^2$ |
|---|---|---|---|---|---|
| 1 | Age in years | | | | |
| | 18-35 | 0 | 6 | 6 | |
| | 36-50 | 1 | 4 | 3 | 7.85 |
| | 50& above | 0 | 7 | 3 | |
| 2 | Gender | | | | |
| | Male | 1 | 8 | 6 | 1.04 |
| | Female | 0 | 9 | 6 | |
| 3 | Marital status | | | | |
| | Married | 1 | 15 | 10 | 6.38*** |
| | Unmarried | 0 | 2 | 2 | |
| 4 | Education | | | | |
| | Illiterate | 0 | 3 | 4 | |
| | Secondary | 1 | 8 | 4 | 16.8** |
| | Higher Secondary | 0 | 5 | 4 | |
| | Graduate | 0 | 1 | 0 | |
| 5 | Type of family | | | | |
| | Joint | 1 | 5 | 2 | 4.57** |
| | Nuclear | 0 | 12 | 10 | |
| 6 | Family Income in ₹ | | | | |
| | Less than 5000 | 1 | 13 | 11 | |
| | 5000-10000 | 0 | 3 | 1 | 1.66*** |

| | | | | | |
|---|---|---|---|---|---|
| | 10001-above | 0 | 1 | 0 | |
| 7 | Occupation | | | | |
| | Housewife | 0 | 3 | 2 | |
| | Government employee | 1 | 6 | 1 | 6.7** |
| | Private employee | 0 | 7 | 8 | |
| | Laborer | 0 | 1 | 1 | |

**p<0.01,***p< 0.001

The above table portrays the association between caregiver role strain experienced and coping strategies adopted among caregivers of patients with cancer receiving palliative care.

The figure in the table especially the chi-square values indicate that for the demographic variables (marital status, education, family type, income and occupation) attained significant association at p<0.01 for education, type of family and occupation and p<0.001for marital status and income.Other demographic variables (age and gender)were independent on the caregiver role strain index. Hence the stated research hypothesis was accepted for selected demographic variables such as marital status, education, family type, income and occupation.

# CHAPTER - V

# DISCUSSION

The findings from this study support the importance of more structured approaches to family care.It is understandable that in most of the palliative care settings the attention is focused on the immediate needs of the patient,neglecting the caregivers problems and needs.Despite the significant role the family caregivers undertake in the management of people with palliative illness,they are likely to be given less priority by health services and rarely are seen as organizing care and influencing outcomes.Current nursing practise routines do not venture to address the specific needs of caregivers and to plan care in accordance to their problems and needs.The results also raise important issues about how best to provide support and reflect the merits of family centered palliative care during the illness trajectory.

The interventions that the nurse offers to cater to the problems and needs cannot be treated as watertight compartments.One intervention can meet several of the caregiver needs and solve more than one problem as they are interdependent.Moreover individual needs and problems might differ.Nurses continue to play a crucial role in the interaction between informal caregivers and formal healthcare providers.The nurse acts as a liason between the resources and family caregivers and health professionals.(Stoltz et al.,2006).Health professionals come and go but the affected person and his/her caregiver has to continue to deal with the illness.Therefore ,it is understandable that any imbalances on the caregivers physical,emotional,and psychological wellbeing indirectly affects the care rendered and in turn the quality of life of patients.(Loke et al.,2003).

This literature review suggests that caring for a terminally ill person receiving palliative care requires a continuous balance between caregivers needs and problems and the ability to cope.Whether or not the caregiver will succeed in keeping an optimum balance will depend upon a number of factors impinging on their role.

In regard to the distribution of subjects according to selected demographic variables majority of them were in the age group of 18-25years the reason being that many of the subjects of this study were children of aged parents who were with cancer receiving palliative care.

In regard to gender 50% were males and 50% females which clearly shows that in the present day gender has no significant relationship on deciding who the primary caregivers are as both have equal responsibility in the care of their parents.

In regard to marital status, majority 86.7% were married which shows that spinters had less involvement in the care of a patient with cancer receiving palliative care and married primary caregivers could handle the situation of grief in a problem–focused method of dealing with the situation in a better managed way.

In regard to educational status,majority 43.3% were at the secondary school level as the settings for the study was at Dr.G.Viswanathan Hospital Palliative care unit were many people were from the rural background got admitted and their caregivers had not the opportunity to continue their education though they now work in private jobs in the city.

In regard to type of family, majority 73.3% of them were nuclear as in the present day situation people usually prefer to live alone with there wife and children though their aged parents may be residing in the same locality.

In regard to income, majority 83.3% of them had less than 5000 as their income as Dr.G.Viswanathan hospital caters mostly to the low socioeconomic background.

In regard to occupation, majority 50% of them were working in the private sector which clearly shows the reason for low socioeconomic status and the reason for coming to this hospital.

The first objective was to assess caregiver role strain experienced by caregivers of patients with cancer receiving palliative care before and after IEC.In the pre test caregiver role strain experienced by caregivers of patients with cancer receiving palliative care, majority 83% sleep was disturbed.Regarding inconvenience, majority 83% felt it was inconvenient.. In response to physical strain, majority 83% felt it was a strain..Regarding confining, majority 83% felt the caregiving role was confining.In response to family adjustments majority 97% felt there has been family adjustments.

Regarding personal plans, majority 80% had to make changes in personal plans. In response to if there demands on time,majority 87% felt there was demands on time.Regarding emotional adjustments, majority 93% said there were emotional adjustments.In response to if behavior were upsetting,majority 87% felt it was upsetting.Regarding if they felt upset the patient has changed from her former self, majority 90% felt there were changes from former self. In work adjustments, majority 87% felt work adjustments had been made.In response to financial strain, majority 93% said it was a financial strain.Regarding feeling the number of people who were having a positive feeling, majority 86%.

In the caregiver role strain experienced by caregivers of patients with cancer receiving palliative care after IEC, majority 87% sleep was disturbed, regarding inconvenience, majority 63% felt it was inconvenient,in response to physical strain, majority 60% felt it was a strain,regarding confining, majority90% felt it was not confining.In response to family adjustments, majority 83% felt there has been family adjustments.

Regarding personal plans, majority 93% did not make changes in personal plans,in response to if there demands on time,majority 100% said no.Regarding emotional adjustments, majority 77% said there were emotional adjustments,in response to if behavior were upsetting,majority 87% felt not so,regarding if they felt upset the patient has changed from her former self, majority 83% felt so,regarding work adjustments, majority 83 % felt that it was not the case.In response to financial strain, majority 90% said it was a financial strain,Regarding feeling the number of people who were having a positive feeling, majority 97%.

In the caregiver role strain experienced majority of them 90% were having severe strain and 6.7% were having moderate strain and 3.3% were having mild strain before IEC.In the caregiver role strain experienced majority of them 40%were having severe strain and 56.7% were having moderate strain and 3.3% were having mild strain after IEC.

There was a highly significant difference in the mean scores between caregiver role strain experienced by caregivers of patients with cancer receiving palliative care before and after IEC.The mean score before IEC 43.59 is significantly greater than the mean score 22.31 after IEC.Hence the stated hypothesis was accepted.

Similar to the findings of Given, B.A (2008) majority of the caregivers of cancer patients receiving palliative care were experiencing severe strain. The investigator found that reduction in time for self and presence of fatigue,lack of sleep,family adjustments,change in the behaviour of the patient with cancer receiving palliative care and financial burden in most of the caregivers suggest an urgent need for systems of care, which can help provide caregivers with extra time in their own personal care.

Similar to the findings of Given.B.A(2001)majority of caregivers report that their caregiving responsibilities are experienced as a burden and arises as a result of increased caregiver demands that accompany the progressive deterioration of the patient.

Similar to the findings of Aranda.et.al (2001) caregiving had a negative impact on the caregivers own health and triggers for physical burden were duty bound exhaustion,inability to relax,tiredness and other responsibilities apart from caregiving.

Similar to the findings of Carver, C.S. (2007) the investigator found that the findings of the present study in relation to the effectiveness of IEC on caregiver role strain suggests that ineffective caregivers of cancer patients can benefit from educational programs which improve their caregiving skills and encourage them to reduce their strain by utilizing resources from other family members.

The above findings is also supported by Nijboer et.al and Mittelman MSet.al(2007)which shows that social support is beneficial to the family caregivers.

The above findings is also supported by Given et.al(2006)which shows that cognitive behavioural intervention can assist caregivers of cancer patients with symptom management.

The investigator found that the mean of the caregiver role strain experienced before IEC is more than the mean of the caregiver role strain experienced as after the IEC as the caregivers had the knowledge about cancer and symptom management which helped them develop confidence regarding the management of the patient with cancer at home.

The second objective was to assess the coping strategies adopted among the caregivers of patients with cancer receiving palliative care before and after IEC.There was a significant difference in the mean scores in relation to problem focused coping strategies and emotion focused coping strategies adopted by caregivers of patients with cancer receiving palliative care before and after IEC.The mean score for existing problem focused coping strategies 30.6 and for adopted problem focused coping strategies 41.3.The mean score for existing emotion  focused coping strategies 42.4 and for adopted emotion focused coping strategies 46.8.It was significant at $p<0.01$ level.

The investigator found that majority of the subjects showing moderately adequate coping, after IEC is that over time in end-of-life care the caregivers of patients with cancer develop coping strategies inorder to overcome strain.

The investigator found that in regard to the effectiveness of IEC on coping strategies adopted by caregivers of patients receiving palliative care it was found that the mean of existing coping strategies before IEC was less than the adopted coping strategies mean after IEC which shows that the IEC had a significant impact in enhancing the coping strategies of the caregivers of cancer patients receiving palliative care.

This is because after the IEC package the caregivers were able to realise that problem focused coping was more effective than emotion focused coping and the IEC package had helped them in instilling confidence and hope in their minds regarding the future of their family member.It also helped them to change their attitude on the reactions exhibited by the family member with cancer.

Supported by the study by Keefe FJ,Ahles T. Porter L,Sutton l (2003)the findings of the current study shows that people vary in their ability to cope with the demands of the caregiving role and majority of subjects had moderately adequate coping.

The above findings is also supported by Nijboer et.al and Mittelman MSet.al(2007)which shows that social support is beneficial to the family caregivers.

The above findings is also supported by Given et.al(2006)which shows that cognitive behavioural intervention can assist caregivers of cancer patients with symptom management.

The above findings is also supported by Manne.et.al (2004)which shows that participants of wives of men with prostate cancer who participated in psychoeducational intervention reported gains in the use of positive reappraisal coping and reductions in denial coping.

The above findings is also sustainciated by Ostroff.et.al(2004)which also shows that there were gains in positive reappraisal coping when replicated with partners of breast cancer patients.

The above finding is also supported by Weiss(2002)which also shows a benefit finding 1-5 years after their wives have been diagnosed with breast cancer.

The third objective was to find the relationship between caregiver role strain experienced and coping strategies adopted among caregivers of patients receiving palliative care. There was a highly significant difference in the mean scores between coping strategies adopted by caregivers of patients with cancer receiving paliiative care before and after IEC.The mean score before IEC 28.95 is significantly lesser than the mean score 33.79 after IEC.This difference is true difference and not by choice.Hence the stated research hypothesis was accepted.

The findings of this study is also supported by Abernathy AP,Scipio CD(2006)which shows that educational programs on pain management decreases the psychological distress of caregivers and improves their wellbeing.

Supported by Susan C.Mcmillian,Brent J.Small(2006)which also shows that skill –training programme for family caregivers of hospice patients with cancer improves caregiver well-being.

Supported by Keefe FJ,Ahles T.Porter L,Sutton(2003)this study also shows that caregivers who master caregiving tasks seem to cope well than those who exhibit difficulty in the caregiving demands and report strain.

The investigator found that in regard to the relationship between post test caregiver rolestrain after IEC and coping strategies adopted after IEC it was supported by the findings of Abernethy AP, Scipio CD(2006) which also shows that decrease in caregiver role strain can significantly improve the coping of caregivers of patients with cancer receiving palliative care.

The reason for the relationship between post test caregiver role strain experienced and post adopted coping strategies is that when a person has increased strain the coping will be more of emotional focused than problem focused.But in end-of-life care more of problem focused coping is needed.After the after IEC when the caregivers realise the what is the type of care in palliative settings they come to a stage of acceptance and try to gain satisfaction through the care provided by the caregivers to the patients with cancer.So their strain reduces and coping strategies are enhanced.

The fourth objective was to find the association between caregiver role strain with selected demographic variables. (Age, gender, marital status, education, income and occupation)

In caregivers of cancer patients receiving palliative care association between caregiver role strain and demographic variables such as age and occupation showed no significant association as in end of life care irrespective of the demographic variables each and every caregiver experiences strain.

These findings are supported by Ting-Ting Kuo,Chang-Chung(2002)who studied symptom distress and coping strategies in caregivers of patients with Non-small cell lung cancer.Hence the stated research hypothesis was accepted in the other demographic variables such as gender,marital status,education,family type, income.

Supported by Youngmee Kim.et.al (2006)which shows that husband caregivers benefit from programs designed to educate them to effectively assist their wifes psychosocial adjustment to cancer by reducing their stress from providing care.

Also supported by William E.Haley.et.al (2003) which also shows that female gender has risk factor of poorer caregiver well-being and also with more resources caregivers had lower depression and higher life satisfaction.

# CHAPTER –VI

## SUMMARY AND RECOMMENDATIONS

This chapter deals with the summary, conclusion, limitation and implications for nursing practise, nursing education, nursing administration and recommendations for further nursing research.

An evaluative approach was undertaken to evaluate the caregiver role strain experienced and coping strategies adopted among caregivers of patients with cancer receiving palliative care admitted at Dr.G.Viswanathan hospital palliative care unit, Trichy during the year 2011-2012.

The study was conducted from 05/7/2011 to 15/8/2011 in patient unit of Dr.G.Viswanathan Hospital palliative care unit ,Trichy.A sample of 30 caregivers of patients with cancer receiving palliative care were selected by using convenient sampling technique.

Conceptual framework of the study was adopted from Penders health promotion model.After collecting the demographic data, preassessment was conducted using questionnaire.

The instrument consisted of two parts; demographic variables consisted of age, gender, marital status, education, income and occupation.Clinical variables such as(site of cancer,stage of cancer,modality of treatment & duration of cancer).

A standardised questionnaire on caregiver role strain and coping strategies were administered.

After the pretest,the Information,Education and Communication package on caregiver role strain experienced and coping strategies adopted was conducted using audio and video clips in a computed video disc.After 10 days post test was conducted using the same questionnaire.Statistical analyses was done using descriptive statistical methods like numbers,percentage ,mean,standard deviation and inferential statistical methods such as chi-square and paired t test.The posttest data analysis showed that the caregiver role strain experienced decreased and coping strategies increased after the IEC programme.

## MAJOR FINDINGS OF THE STUDY

In regard to caregiver role strain majority of them 90% were having severe strain and 6.7% were having moderate strain and 3.3% were having mild strain before IEC.

In regard to coping strategies majority of them 73.3% adopted moderately adequate coping,and 26.7% adopted inadequate coping strategies before IEC.

The Information, Education and Communication Programme before and after was analysed by paired ‘t’ test. Before IEC the mean score was 43.59 was significantly greater than the after IEC mean score 22.31.This difference is true difference and not by choice after the Information, Education and Communication, which was statistically significant at $p<0.01$ level.This proved that Information,Education and Communication had been effective.

There was a highly significant difference in the mean scores in regard to coping strategies adopted by caregivers of patients with cancer receiving palliative care before and after IEC. Before IEC the mean score 28.95 was significantly lesser than the after IEC mean score 33.79.Hence the stated research hypothesis was accepted.This proved that Information, Education and Communication had been effective.

There was relationship between caregiver role strain and coping strategies adopted by caregivers of patients with cancer receiving palliative care.There was no significant association between caregiver role strain and demographic variables such as age and gender.Hence the stated research hypothesis was accepted for the demographic variables such as, marital status,family type,education, income and occupation.

## IMPLICATION FOR NURSING PRACTICE

The nurses working in the hospital, community and clinical setting should practise the health teaching as an integral part of nursing profession.The standardised tool may be used by the health care providers in the hospital to create awareness among nurses about the importance of teaching regarding caregiver role strain management.

This will help caregivers of cancer patients to prevent role strain and adopt coping strategies.

Nurses should place health in the hands of the people especially for the caregivers of the cancer patients who are receiving palliative care.During investigation it was identified that there is a need for integrated services ,feedback and followup of health team.

The shift from cure to care concept,which implies the need for change that haste is introduced from within the caregivers behaviour rather than the organic system.

## IMPLICATION FOR NURSING EDUCATION

In nursing curriculum, the students need to be strengthened to enable them to identify caregiver role strain related to family members with cancer receiving palliative care.

This study calls for the strengthening of the education in the present system of nursing education regarding caregiver role strain and coping strategies of caregivers of cancer patients receiving palliative care.

This study stresses the significance of educating nurses in conducting caregiver meetings in a effective way in the palliative care settings.

## IMPLICATION TO NURSING ADMINISTRATION

Nursing leaders are challenged to care for patients and their families in the palliative care settings.

The nurse administrators should take active participation in procedures and standing orders related to health of the caregivers of cancer patients.

They should concentrate on placement of nurses depending on interest and ability in education of caregivers of patients receiving palliative care.

Good supervision and motivation for nurses would help nurses to carry out the role of a support person for the caregiver in an effective manner.

## IMPLICATION FOR THE NURSING RESEARCH

As nursing is an evolving profession further research is needed in caregiver role strain in palliative care settings.

The effectiveness of intervention studies for caregivers of cancer patients can be verified by its utility in the practical field.

It helps in providing a base for care of caregivers of cancer patients.

The study findings can be generalised by further replication of the study.

This study helps to develop insight into the development of teaching module and material for promotion of health of caregivers and reducing strain and enhancing coping in care of cancer patients receiving palliative care.

## LIMITATION

1. The caregivers were not randomly assigned.
2. The conveiance sampling restricts the generalisation.
3. This study was done among 30 subjects; hence generalisation is possible only for the selected sample.

## RECOMMENDATIONS

Based on the study findings, the following recommendations were made.

1. An experimental study may be done with larger samples and generalise the findings.
2. A similar study with experimental and control groups can be conducted.

3. An experimental study may be carried out to evaluate other interventions for caregivers of cancer patients receiving palliative care.
4. A study can be conducted by using a qualitative approach on the caregiver reaction assessment of caregivers of cancer patients receiving palliative care.

## CONCLUSION

Not withstanding the limitations ,the finding adds significance to the growing body of research on family caregivers of patients receiving palliative care.Although caregivers carry the burden of care in palliative settings there are very few interventional studies that can clearly indicate which type of intervention will be most appropriate for caregivers in palliative care .There is also limited evidence about whether caregiver interventions in palliative care have the potential of providing long term benefits to caregivers of patients with cancer receiving palliative care.More research is needed to provide complete evidence on which of the interventions will provide long term benefits to caregivers.

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# APPENDIX – A

## A. RESEARCH INSTRUMENT (English)

## TOOL – I (DEMOGRAPHIC VARIABLES)

1. **Age**

   1. 18-35 yrs		2. 36-50 yrs		3. 50-and above

2. **Sex**

   1. Male		2. Female

3. **Marital Status**

   1. Married		2. Unmarried		3. Divorcee

4. **Education**

   1. Illiterate		2. Secondary

   3.Higer Secondary

   3. Graduate

5. **Type of Family**

   1. Joint Family		2. Nuclear Family

6. **Income**

   1. Less than 5000 - 10000	2. 5,001 – 10000

   3. 10001 – above

7. **Occupation**

   1. House wife		2.Goverment Employee		3. Private Employee

   4. Laborer		5. Retired

## TOOL – II CLINICAL VARIABLE OF THE CLIENT

### 1) SITE OF CANCER

1. Head and neck
2. Cervix
3. Others

### 2) STAGE OF CANCER

1. III Stage
2. IV Stage

### 3) MODALITY OF TREATMENT

1. Radiation Therapy
2. Chemotherapy
3. Surgery
4. Symptomatic Management

### 4) DURATION OF ILLNESS

1. Less than 6 MONTHS
2. 6 MONTHS – 1 YEAR
3. Greater than 1 YEAR

## TOOL – III THE CAREGIVER STRAIN INDEX

| S.No | INDEX | Yes | No |
|---|---|---|---|
| 1. | Sleep is disturbed (e.g., because _______ is in and out of bed or wanders around at night) | | |
| 2. | It is inconvenient (e.g., because helping takes so much time or it's a long drive over to help) | | |
| 3. | It is a physical strain (e.g., because of lifting in and out of a chair, effort or concentration is required) | | |
| 4. | It is confining (e.g., helping restricts free time or cannot go visiting) | | |
| 5. | There have been family adjustments (e.g., because helping has disrupted routing, there has been no privacy) | | |
| 6. | There have been changes in personal plans (e.g., had to turn down a job, could not go on vacation) | | |
| 7. | There have been other demands on my time (e.g., from other family members) | | |
| 8. | There have been emotional adjustments (e.g., because of severe arguments) | | |
| 9. | Some behavior is upsetting (e.g., because of incontinence : ____ has trouble remembering things; or _____ accuses people of taking things) | | |
| 10. | It is upsetting to find ____ has changed so much from his/her former self (e.g., he/she is a different person than he/she used to be) | | |
| 11. | There have been work adjustments (e.g., because of having to take time off) | | |
| 12. | It is a financial strain | | |
| 13. | Feeling completely overwhelmed (e.g., because of worry about ____; concerns about how you will manage) | | |
| | **TOTAL SCORE** (Count yes responses. Any positive answer may indicate a need for intervention in that area. A score of 7 or higher indicates a high level of stress.) | | |

# TOOL – IV COPING STRATEGIES SCALE

| **S.No** | **IN RESPONSE TO THIS EVENT, HAVE YOU** | **Never** | **Sometimes** | **Often** | **Always** |
|---|---|---|---|---|---|
| **1.** | Accepted that there was nothing you could do to change your situation? | | | | |
| **2.** | Tried to just take whatever came your way? | | | | |
| **3.** | Talked with friends or relatives about your problem? | | | | |
| **4.** | Tried to do things which you typically enjoy? | | | | |
| **5.** | Sought out information that would help you resolve your problems? | | | | |
| **6.** | Blamed others for creating your problems? | | | | |
| **7.** | Sought the advice of others to resolve your problems? | | | | |
| **8.** | Blamed yourself for your problems? | | | | |
| **9.** | Exercised? | | | | |
| **10.** | Tried to live a better life according to your religious beliefs? | | | | |
| **11.** | Said what you felt no matter what others thought? | | | | |
| **12.** | Gone over your problems in your mind over and over again? | | | | |
| **13.** | Asked others for help? | | | | |
| **14.** | Thought about your problems a lot? | | | | |
| **15.** | Became involved in recreation or pleasure activities? | | | | |
| **16.** | Worried about your problems a lot? | | | | |
| **17.** | Tried to keep your mind off things that are upsetting you? | | | | |
| **18.** | Tried to distract yourself from your troubles? | | | | |
| **19.** | Avoided thinking about your problems? | | | | |
| **20.** | Made plans to overcome your problems? | | | | |

| S.No | IN RESPONSE TO THIS EVENT, HAVE YOU | Never | Sometim | Often | Always |
|---|---|---|---|---|---|
| **21.** | Told jokes about your situation? | | | | |
| **22.** | Thought a lot about who is responsible for your problems (besides Yourself) | | | | |
| **23.** | Told humorous stories etc. to cheer yourself or others up) | | | | |
| **24.** | Told yourself that other people have dealt with problems such as yours? | | | | |
| **25.** | Thought a lot about how you have brought your problems on yourself? | | | | |
| **26.** | Decided to wait and see how things turn out? | | | | |
| **27.** | Decided that your current problems are a result of your own past actions? | | | | |
| **28.** | Gone shopping? | | | | |
| **29.** | Asserted yourself and taken positive action on problems that are getting you down? | | | | |
| **30.** | Sought reassurance and moral support from others? | | | | |
| **31.** | Resigned yourself to your problems? | | | | |
| **32.** | Thought about how your problems have been caused by other people? | | | | |
| **33.** | Been very emotional in how you react, even to little things? | | | | |
| **34.** | Decided that you can grow and learn through your problems? | | | | |
| **35.** | Told yourself that other people have problems like your own? | | | | |
| **36.** | Looked for how you can learn something out of your bad situation? | | | | |

| S.No | IN RESPONSE TO THIS EVENT, HAVE YOU | Never | Sometim | Often | Always |
|---|---|---|---|---|---|
| | | | | | |
| **37.** | Asked for God’s guidance? | | | | |
| **38.** | Kept your feelings bottled up inside? | | | | |
| **39.** | Found yourself crying more than usual? | | | | |
| **40.** | Tried to act as if you were not upset? | | | | |
| **41.** | Prayed for help? | | | | |
| **42.** | Gone out? | | | | |
| **43.** | Held in your feelings? | | | | |
| **44.** | Tried to act as if you weren’t feeling bad? | | | | |
| **45.** | Made humorous comments or jokes? | | | | |
| **46.** | Taken steps to overcome your problems? | | | | |

## TOOL – I (DEMOGRAPHIC VARIABLES)

1. taJ
   1. 18 - 35 tajpw;Fs;   2. 36 – 50   3. 50 tajpw;F Nky;
2. ghypdk;
   1. Mz;   2. ngz;

2. jpUkzj; jFjp
   1. jpUkzkhdth;   2. jpUkzkhfhjth;
   3. tpjit

3. fy;tpj; jFjp
   1) gbg;gwptpy;yhjth;fs;   2) Muk;gf;fy;tp
   3) cah; epiyf;fy;tp   4) gl;lg;gbg;G

4. FLk;g mikg;G
1) $l;Lf; FLk;gk;;   2) jdpf;FLk;gk;

5. tUkhdk;
1) &.5000 f;Fs;   2) 5001 – 10000 f;Fs;
3) 10,000 f;F Nky;

6. njhopy;
1) FLk;gj;jiytp
2) muR Ntiyapy; ,Ug;gth;
3) jdpahh; mikg;gpy; Ntiy nra;gth;
4) $yp Ntiy nra;gth;
5) gzp Xa;T ngw;wth;

## TOOL –II CLINICAL VARIABLES OF THE CLIENT

1. Gw;WNeha; ,Uf;Fk; ,lk;
   1) jiy kw;Wk;    2) fh;g;gigapd; tha;gFjp    3) kw;w ,lq;fs;

2. Gw;WNehapd; epiy
   1) %d;whk; epiy    2) ehd;fhk; epiy

3. fPo;tUtdtw;Ws; ve;j kUj;JtKiwia gpd;gw;WfpwPh;fs;.
   1) fjph;tPr;R    2) fPNkhnjugp    3) mWitrpfpr;ir
   4) mwpFwpfSf;Nfw;w kUj;JtKiw

4. Gw;WNeha; ,Ue;JtUk; fhyk;
   1) 6 khjj;jpw;F Fiwthf
   2) 6 khjk; Kjy; - 1 tUlk;
   3) 1 tUlj;jpw;F Nky;

## TOOL –III THE CAREGIVER STRAIN INDEX

| t.vz; | nghUslf;fk; | Mk; | ,y;iy |
|---|---|---|---|
| **1.** | J}f;fkpd;ik | | |
| **2.** | mnrsfhpak; (cjTtJ kpf ePz;lNeuk; vLf;fpwJ my;yJ cjTtjw;F ePz;l Neuk; Njitg;gLk;) | | |
| **3.** | cliy tUj;JtJ (ehw;fhypia J}f;Fk;NghJ Nehahspf;F ftdKk;, cly;gSTk; ,Uf;fpwJ.) | | |
| **4.** | jLf;fpwJ (cjTtJ Xa;T Neuj;ij Fiwf;fpwJ) | | |
| **5.** | FLk;gj;ij mDrhpj;J NghtJ (Vndd;why;, Nehahspf;F cjTtjhy;, jq;fSf;fhd Neuk;, guhkhpg;Gf; Fiwjy;) | | |
| **6.** | nrhe;j tp\aj;jpy; khw;wk; (Ntiyf;F jhkjkhf nry;tJ, nry;yKbahky; NghtJ) | | |
| **7.** | ek;Kila chpik ghjpf;fg;gLk; (kw;wf; FLk;g cWg;gpdh;fshy;) | | |
| **8.** | kdrQ;ryj;ij Vw;gLj;Jk; (thf;Fthjq;fshy;) | | |
| **9.** | rpy elj;ij ghjpf;fg;gLfpwJ. | | |
| **10.** | jd;dpiyapypUe;J NtW epiyf;F khWgLtJ | | |
| **11.** | Ntiy ghjpf;fg;gLtJ (mjpf Neuk; vLg;gjhy;) | | |
| **12.** | nghUshjhu ghjpg;G. | | |
| **13.** | Nehahspia guhkhpg;gjpy; Fog;gk; (rhpahf guhkhpf;fpd;NwNd vd;W epidg;gJ). | | |

## COOL –IV COPING STRATEGIES SCALE

| t.vz; | ,e;j epfo;T rk;ge;jkhf ePq;fs; nrhy;tJ | ,y;iy | vg;NghjhtJ | mbf;fb | vg;nghOJk; |
|---|---|---|---|---|---|
| **1.** | cq;fshy; ,e;j #o;epiyia khw;w KbAkh? | | | | |
| **2.** | cq;fs; topapy; tUk; midj;J rpukq;fisAk; ifshStPh;fsh? | | | | |
| **3.** | cq;fs; gpur;ridfisg;gw;wp cq;fs; ez;gh;fs; / cwtpdh;fsplk; NgRtPh;fsh? | | | | |
| **4.** | cq;fSf;F kfpo;r;rp jUk; tp\aq;fis nra;a Kaw;rpg;gPh;fsh? | | | | |
| **5.** | cq;fs; rpukq;fis jPh;f;f cjTk; nra;jpfis nrhy;tPh;fsh? | | | | |
| **6.** | cq;fs; gpur;ridfSf;F kw;wth;fis Fw;wk; rhl;LtPh;fsh? | | | | |
| **7.** | cq;fs; gpur;ridfSf;F kw;wth;fspd; MNyhridia Nfl;gPh;fsh? | | | | |
| **8.** | cq;fisNa ePq;fs; Fw;wk; rhl;LtPh;fsh? | | | | |
| **9.** | Kaw;rpg;gPh;fsh? | | | | |
| **10.** | cq;fs; kjek;gpf;ifgb rpwe;j tho;T tho Kaw;rpg;gPh;fsh? | | | | |
| **11.** | kw;wth;fs; rpe;jpg;gij gw;wp epidg;gPh;fsh? | | | | |

| | | | | | |
|---|---|---|---|---|---|
| **12.** | cq;fs; gpur;ridfis jpUk;g jpUk;g cq;fs; kdjpy; epidj;Jg; ghh;g;gPh;fsh? | | | | |
| **13.** | kw;wth;fspd; cjtpia Nfl;gPh;fsh? | | | | |
| **14.** | cq;fs; gpur;ridia gw;wp mjpfkhf epidg;gPh;fsh? | | | | |
| **15.** | nghOJNghf;F jUk; epfo;Tfshy; <LgLtPh;fsh? | | | | |
| **16.** | cq;fs; gpur;ridia gw;wp mjpfkhf ftiyg;gLtPh;fsh? | | | | |
| **17.** | cq;fSf;F tUj;jj;ij cz;lhf;Fk; tp\aq;fis cq;fs; kdjpypUe;J mg;Gwg;gLj;jp itf;f Kay;tPh;fsh? | | | | |
| **18.** | cq;fs; gpur;ridfspypUe;J cq;fs; ftdj;ij jpUg;g Kaw;rp nra;tPh;fsh? | | | | |
| **19.** | cq;fs; rpukj;ij gw;wp epidg;gij jLg;gPh;fsh? | | | | |
| **20.** | cq;fs; gpur;ridfis Nkw;nfhs;tjw;F jpl;lk; jPl;LtPh;fsh? | | | | |
| **t.vz;** | **,e;j epfo;T rk;ge;jkhf ePq;fs; nrhy;Tj** | **,y;iy** | **vg;NghjhtJ** | **mbf;fb** | **vg;nghOJk** |
| **21.** | cq;fs; #o;epiyiag; gw;wp eifr;Ritahf $WtPh;fsh? | | | | |
| **22.** | cq;fs; rpukj;jpw;F fhuzkhdth;fisg; gw;wp mjpfkhf rpe;jpg;gPh;fsh? | | | | |
| **23.** | cq;fisAk;, kw;wth;fisAk; re;Njh\g;gLj;Jtjw;fhf eifr;Rit fijfis $WtPh;fsh? | | | | |
| **24** | cq;fis NghyNt kw;wth;fSk; ,JNghd;w gpur;ridfis | | | | |

| | | | | | |
|---|---|---|---|---|---|
| . | re;jpj;jpUg;ghh;fs; vd;W cq;fSf;Fs;NsNa nrhy;ypf; nfhs;tPh;fsh? | | | | |
| 25. | ,JNghd;w rpukq;fs; vg;gb te;jnjd;W cq;fSf;Fs;NsNa epidj;J nfhs;tPh;fsh? | | | | |
| 26. | nghUj;J vg;gb elf;fpwJ vd;W ghh;f;f KbntLj;Js;sPh;fsh? | | | | |
| 27. | ,J cq;fSila Ke;ija nray;fspd; KbT vd;d epidg;gPh;fsh? | | | | |
| 28. | ePq;fs; filtPjpf;F nry;tPh;fsh? | | | | |
| 29. | vg;NghJk;, ve;j #o;epiyapYk; cq;fSf;F rhjfkhd KbT vLg;gPh;fs;? | | | | |
| 30. | ePq;fs; kWgbAk; cWjpNahL kw;wth;fspd; cjtpia vjph;ghh;g;gPh;fsh? | | | | |
| 31. | ,e;jg; gpur;rid vdf;FhpaJ vd epidg;gJ? | | | | |
| 32. | cq;fs; gpur;rid kw;wth;fshy; vg;gb te;jJ vd;W rpe;jpg;gPh;fsh? | | | | |
| 33. | rpwpa tp\aq;fSf;F $l kdjstpy; ghjpf;fg;gLtPh;fsh? | | | | |
| 34. | cq;fs; gpur;ridapd; %ykhf ePq;fs; ghlk; fw;Wf;nfhs;s KbAk; vd;W epidf;fpwPh;fsh? | | | | |
| 35. | cq;fSf;Fs;NsNa nrhy;yp nfhs;tPh;fsh cq;fis NghyNt gpwUf;Fk; gpur;ridfs; cz;L vd;W? | | | | |
| 36. | cq;fSila ,e;j nfl;l #o;epiyapypUe;J vg;gb ghlk; fw;Wf;nfhs;s KbAk; vd;W vjph;ghh;g;gPh;fsh? | | | | |
| 37. | flTspd; cjtpia vjph;ghh;g;gPh;fsh? | | | | |

| t.vz; | ,e;j epfo;T rk;ge;jkhf ePq;fs; nrhy;tJ | ,y;iy | vg;NghjhtJ | mbf;fb | vg;nghOJk; |
|---|---|---|---|---|---|
| **38.** | gpur;ridfis kw;wtNuhL gfph;e;J nfhs;s tpUk;g khl;Bh;fsh? | | | | |
| **39.** | cq;fspd; gpur;ridfis epidj;J ePq;fs; kpfTk; mOtPh;fsh? | | | | |
| **40.** | cq;fSf;F tUj;jk; ,y;yhjJ Nghy; ebf;f Kaw;rpg;gPh;fsh? | | | | |
| **41.** | cjtpf;fhf Ntz;LtPh;fsh? | | | | |
| **42.** | ntspNa nry;tPh;fsh? | | | | |
| **43.** | kdjstpy; tUj;jk; ,Ue;jhYk; ntspf; nfhzu tpUk;g khl;Bh;fsh? | | | | |
| **44.** | kpf tUj;jkpy;yhjJ Nghy ebf;f Kaw;rpg;gPh;fsh? | | | | |
| **45.** | eifr;Ritahf NgRtPh;fsh? | | | | |
| **46.** | cq;fs; gpur;ridapy; ,Ue;J ntsptu jpl;lk; tFg;gPh;fsh? | | | | |

# APPENDIX B

# SCORING KEY

## PART I

## ITEM SCORE - CAREGIVER STRAIN INDEX

| ITEM NO | YES | NO |
|---|---|---|
| 1 | 1 | 0 |
| 2 | 1 | 0 |
| 3 | 1 | 0 |
| 4 | 1 | 0 |
| 5 | 1 | 0 |
| 6 | 1 | 0 |
| 7 | 1 | 0 |
| 8 | 1 | 0 |
| 9 | 1 | 0 |
| 10 | 1 | 0 |
| 11 | 1 | 0 |
| 12 | 1 | 0 |

| | | |
|---|---|---|
| 13 | 1 | 0 |

## APPENDIX B

## SCORING KEY

## PART - II

## ITEM SCORE-COPING STRATEGIES SCALE

| ITEM NO | NEVER | SOMETIMES | OFTEN | ALWAYS |
|---|---|---|---|---|
| 1 | 0 | 1 | 2 | 3 |
| 2 | 0 | 1 | 2 | 3 |
| 3 | 0 | 1 | 2 | 3 |
| 4 | 0 | 1 | 2 | 3 |
| 5 | 0 | 1 | 2 | 3 |
| 6 | 0 | 1 | 2 | 3 |
| 7 | 0 | 1 | 2 | 3 |
| 8 | 0 | 1 | 2 | 3 |
| 9 | 0 | 1 | 2 | 3 |
| 10 | 0 | 1 | 2 | 3 |
| 11 | 0 | 1 | 2 | 3 |

| | | | | |
|---|---|---|---|---|
| 12 | 0 | 1 | 2 | 3 |
| 13 | 0 | 1 | 2 | 3 |
| 14 | 0 | 1 | 2 | 3 |
| 15 | 0 | 1 | 2 | 3 |
| 16 | 0 | 1 | 2 | 3 |
| 17 | 0 | 1 | 2 | 3 |
| 18 | 0 | 1 | 2 | 3 |
| 19 | 0 | 1 | 2 | 3 |
| 20 | 0 | 1 | 2 | 3 |
| 21 | 0 | 1 | 2 | 3 |
| 22 | 0 | 1 | 2 | 3 |
| 23 | 0 | 1 | 2 | 3 |
| 24 | 0 | 1 | 2 | 3 |
| 25 | 0 | 1 | 2 | 3 |
| 26 | 0 | 1 | 2 | 3 |
| 27 | 0 | 1 | 2 | 3 |
| 28 | 0 | 1 | 2 | 3 |
| 29 | 0 | 1 | 2 | 3 |
| 30 | 0 | 1 | 2 | 3 |
| 31 | 0 | 1 | 2 | 3 |
| 32 | 0 | 1 | 2 | 3 |
| 33 | 0 | 1 | 2 | 3 |

|  |  |  |  |  |
|---|---|---|---|---|
| 34 | 0 | 1 | 2 | 3 |
| 35 | 0 | 1 | 2 | 3 |
| 36 | 0 | 1 | 2 | 3 |
| 37 | 0 | 1 | 2 | 3 |
| 38 | 0 | 1 | 2 | 3 |
| 39 | 0 | 1 | 2 | 3 |
| 40 | 0 | 1 | 2 | 3 |
| 41 | 0 | 1 | 2 | 3 |
| 42 | 0 | 1 | 2 | 3 |
| 43 | 0 | 1 | 2 | 3 |
| 44 | 0 | 1 | 2 | 3 |
| 45 | 0 | 1 | 2 | 3 |
| 46 | 0 | 1 | 2 | 3 |

# APPENDIX - C

# IEC PACKAGE

# TEACHING MODULE (English Version)

| | | |
|---|---|---|
| **TOPIC** | : | Caregiver role strain management. |
| **GROUP** | : | Caregivers of patients with cancer receiving palliative care. |
| **VENUE** | : | Shanthalaya Hospice. |
| **TIME DURATION** | : | 45 minutes. |
| **A.V. AIDS** | : | CD presentation, handout. |
| **METHODS OF TEACHING** | : | Lecture – cum – discussion. |

## GENERAL OBJECTIVES :

The sample (caregivers of patients with cancer receiving palliative care) will be able to gain knowledge regarding cancer and apply this knowledge into their day to day care of patients with cancer and thus reduce their role strain in dealing with clients with cancer receiving palliative care.

## SPECIFIC OBJECTIVES :

**The caregivers is able to:**

- Define cancer.
- Describe the predisposing factors for cancer.
- List down the diagnostic investigation for cancer.
- Explain the treatment modalities in stages.
- Explain the palliative care for cancer.
- Explain the feelings felt by the individual with cancer and the family due to the prolonged illness.
- Explain the dependency role change deviation from the actual role.
- List the possible symptoms of a patient with cancer and the related caregiver management.
- Describe social withdrawal and how caregiver can overcome.

| Sl. No | SPECIFIC OBJECTIVES | TIME | CONTENT | TEACHING ACTIVITY | LEARNING ACTIVITY | EVALUATION |
|---|---|---|---|---|---|---|
| 1. | Define Cancer | 1 mt | Any malignant growth or tumor Caused by abnormal and uncontrolled cell division, it may spread to other parts of the body through the lymphatic system or the blood stream. | Explain with Power point | Listening | Can you define cancer? |
| 2. | Describe the predisposing factors for cancer | 2 mt | Predisposing factors can be multifactorial.<br>A) Life style factors are a long smoking history, alcohol consumption, diet and decreased physical activity.<br>B) Environmental factors are solar ultra violet radiation.<br>C) Genetic factors<br>D) Aging is a significant factor<br>E) Viral causes<br>F) Occupational factors include exposure to asbestos, bezene and radiation.<br>G) Certain drugs. | Explain with power point | Listening | List the predisposing factors for cancer? |
| 3. | List down the diagnostic investigation for cancer | 2 mt | Its based on history and physical examination. The other investigations depend on suspected cancer. It may include cytology srudies, tissue biopsy, chest x-ray, complete blood count, chemistry profile, sigmoiudoscopy, liver function studies, radiology radioisotope scan, CT-scan, PET-scan, tumor markers presence, | Explain with power point | Listening | What are the diagnostic evaluation for cancer? |

| | | | | | | |
|---|---|---|---|---|---|---|
| | | | bone marrow examinations. | | | |
| 4. | Explain the treatment modalities for cancer | 2 mt | The goal for cancer treatment is cure, control or palliation. Factors that dertermine the approach are tumor cell type, location and size and how far the disease has spread.<br>Other important consideration is patient's physiologic status, psychologic status, personal desires.<br>Curative cancer therapy may involve surgery or radiation alone or in combination with chemotherapy. Control is the goal when cancer cannot be completely eradicated but are responsive to anticancer therapy.<br>Palliation is the control of symptoms and maintenance of a satisfactory quality of life rather than cure or control. | Explain with power point | Listening | What are the treatment modalities for cancer? |
| 5. | Define palliative care for cancer | 1 mt | **Palliative care**<br>It is the active total care of patients with advance illness the focus is no longer on curative treatment but on quality of life and integrating physical, psychological, spiritual and social aspects of care. | Explain with power point | Listening | What is Palliative care? |
| | Explain the | | The feelings experienced by the individual and the family include denial, anger, bargaining, | | | What are the |

| | | | | | | |
|---|---|---|---|---|---|---|
| 6. | feeling felt by the individual and family with cancer. | 2 mt | depression or acceptance.<br>We as caregivers should know that these feelings are a part of the grieving process and be able to be calm and listen attentively to the patient and feel optimistic that these feelings will pass and a stage of acceptance will finally come. | Explain with power point | Listening | feeling felt by the individual and the family with cancer? |
| 7. | Explain the dependency role change deviation from the actual role. | 2 mt | As a caregiver for a patient with cancer you may have a change in role as the head of the family. So you may have to take on a changed role from the normal dependency role which may be difficult for you. So you can get social support from friends and extended family members in order to carry out the activities of the changed role. | Explain with power point | Listening | What is dependency role change deviation from the actual role? |
| 8. | Explain the possible symptoms felt by patients with cancer and caregiver role in | 26 mt | **1) Poor appetite**<br>▪ Give small frequent feeds.<br>▪ Offer starchy and high protein foods.<br>▪ Keep drinks and juices within patients reach.<br>▪ Create pleasant settings.<br>▪ Do not blame yourself if patient refuses | | Listening | What are the symptoms felt by patients with cancer and caregiver role in its management. |

| | | | | | | |
|---|---|---|---|---|---|---|
| | their management. | | food.<br>▪ Offer just your company if patient does not eat.<br>**2) Infection**<br>▪ Check the patients temperature.<br>▪ Administer drugs as per doctors order.<br>▪ Offer extra fluids.<br>▪ Help the patient in strictly following drug schedule.<br>**3) Constipation**<br>▪ Offer juice, hot water, lemon juice, coffee or tea.<br>▪ Encourage extra fluids.<br>▪ Help keep a record of bowel movements.<br>▪ Talk with the doctor before using laxatives.<br>**4) Depression**<br>▪ Gently invite the patient to talk about Fears.<br>▪ Do not force the patient to talk before | | | |

| | | | | | | | |
|---|---|---|---|---|---|---|---|
| | | | he is ready.<br>▪ Listen carefully without judging.<br>▪ Decide together what you can do to support each other.<br>▪ Avoid telling the person to cheer up if depressed.<br>▪ Do not try to reason with the person if depressed.<br>▪ Engage the person in activities he enjoys.<br>▪ Reassure the depressed person.<br>▪ Keep in mind to care for yourself.<br>▪ Get support from groups or go for individual counseling.<br>**5) Exercise**<br>▪ Go with the patient for walks.<br>▪ Encourage the patient to do as much as possible.<br>▪ Talk with the doctor about range of Motion exercises.<br>▪ Help the patient set a routine for Activities.<br>**6) Mouth ulcers**<br>• Caregivers must offer a straw to bypass the area. | | | |

| | | | | | | |
|---|---|---|---|---|---|---|
| | | | • Mash foods that make it easier to eat.<br>• Offer pain medications half an Hour before medicine.<br>• Offer a mouth gargle before food.<br>**7) Pain**<br>• Warm baths can be given.<br>• Pleasant distractions that the patient enjoys can be provided.<br>• Offer plenty of fluids and high fibre diet.<br>• Talk to the doctor for round the clock pain Medication.<br>• Provide support by planning activities. | | | |
| 9. | Describe social withdrawal and what can be done for it. | 2 mts | In cancer patient care both the patient and you the caregivers may feel socially withdrawn so decide together what things you can do to support each other. Accept others who render help seek counseling with a psychotherapist as a caregiver we can refer to support groups and seek guidance from them. | Explain with power point and organize family caregiver meeting | Listening | How to handle social with drawal? |

## SUMMARY

So far as we have discussed about cancer, its predisposing factors, diagnostic investigations, treatment modalities and palliative care regarding the feelings felt by the individual and family, the dependency role change deviation from the actual role, possible symptoms and as the caregiver the management and handling of social withdrawal by the patient as a caregiver.

As a caregiver the better you handle the patient with cancer receiving palliative care the lesser will be the role strain and better coping with the caregiver role of the patient with cancer receiving palliative care.

## **jfty; fy;tp njhlh;G njhFg;G**

**jiyg;G : Gw;WNehahspfis NgZNthhpd;**
**kd mOj;jj;ij Fiwj;jy;**
**FO : Gw;WNehahspfis NgZNthh;**
**,lk; : rhe;jhyhah `h];ig];**
**Neuk; : 45 epkplk;**
**fw;gpf;Fk; Kiw : fzpzp %yk; tpthpj;jy;**
**fw;gpf;fg; gad;gLj;Jk;**
**nghUl;fs; : fzpzp %yk; tpsf;ff; fhl;rfs;,**
**ifg;gpujp**
**nghJ topKiwfs; :**

**Gw;WNehahspfis NgZNthh;fs;, Gw;WNehapid gw;wpa mwptpidg; ngw;W, jq;fsJ Nehahspfis ghJfhg;gjpy; mij gad; gLj;Jtjd; %yk; jq;fsJ kd mOj;jj;ij Fiwj;jy;.**

**Fwpg;gpl;l topKiwfs; :**

**Gw;WNehahspfis NgZNthh;fs; njhpe;J nfhs;s Ntz;baJ,**

- Gw;WNehapid tiuaW
- Gw;WNehapf;fhd fhuzpfis njspTg; gLj;Jjy;
- Gw;WNehapidf; fz;lwpAk; Kiwfis thpirg;gLj;Jjy;
- Gw;WNehapd; rpfpr;irfis tpthpj;jy;
- Gw;WNehapf;fhd ghypNal;bt; rpfpr;irapid tpthpj;jy;
- Gw;WNehahspfspd; kdepiyapid tpthpj;jy;
- Gw;WNehahspapd; FLk;g epiyapd; khWjiyAk; khw;wq;fisAk; tpthpj;jy;
- Gw;WNehahspfSf;F Vw;glf; $ba tha;g;Gs;s mwpFwpfSk; mjd; guhkhpg;GfisAk; thpirg;gLj;Jjy;
- Gw;WNehahspfs; r%fj;jpy; ,Ue;J jdpj;jpUg;gJk; mjid NgZNthh;fs; vt;thW rkhspg;gJ vd;gijAk; tpthpj;jy;.

| **t.vz;** | | **Neuk;** | **nghUslf;fk;** | | | |
|---|---|---|---|---|---|---|
| 1. | Gw;WNeha; tiuaW | 1 epkplk | vt;tpj guTk; jd;ikAs;s fl;bfSf;F fhuzkhdit, mrhjuhzkhd kw;Wk; mstw;w nry; cw;gj;jpapdhy; cly;fspd; kw;w cWg;GfSf;F guTfpwJ. vjd; %ykhf vd;why; epzePh; cWg;Gfs;, kw;Wk; ,uj;jj;jpd; %ykhfTk; guTfpwJ. | | | |
| 2. | Gw;WNeha;f;F fhuzkhdtw;iw tpthp | 2 epkplk; | fhuzq;fs; :<br>❖ njhlh;e;J<br>Gifgpbj;jy;, kJ mUe;Jjy;, czT fl;Lg;ghL, clw;gapw;rpapd;ik.<br>❖ #hpa fjph;tPr;R<br>❖ guk;giu %ykhfTk;<br>❖ taJ tuk;ig nghWj;Jk;<br>❖ Ez; fpUkpfs; %ykhfTk;<br>❖ njhopw;rhiy hPjpahfTk; M];ng];lh];, ngd;rpd; kw;Wk; fjph;tPr;R.<br>❖ rpy kUe;Jfs; %ykhfTk; guTfpwJ. | | | |

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| 3. | Gw;WNeha;f;fhd ghpNrhjidfis tpthp | 2 epkplk; | ,e;j ghpNrhjid Nehahspaplk; ,Ue;J ngWk; FLk;gk; kw;Wk; kUj;Jt jfty;fs; kw;Wk; cly; ghpNrhjidia nghWj;J mikfpwJ.<br>kw;w ghpNrhjidfs; :<br>❖ nry; ghpNrhjid<br>❖ gahg;rp(jpR ghpNrhjid)<br>❖ X – fjph;tPr;R<br>❖ ,uj;j ghpNrhjid (nry;fs;)<br>❖ ];Nfhg;gp %ykhfTk;<br>❖ fy;yPuypd; nray;jpwd; %ykhfTk;<br>❖ rpb-];Nfd; %ykhfTk;<br>❖ vYk;G k[;i[ ghpNrhjid %ykhfTk; Gw;WNehia fz;lwpfpNwhk;, bA+kh; khh;f;fiu fz;lwpjy;. |  |  |  |
| 4. | Gw;WNeha;f;fhd rpfpr;irKiwfs; | 2 epkplk; | **Gw;WNeha; rpfpr;irapd; Nehf;fq;fs; :**<br>❖ Gw;WNehia Fzg;gLj;Jjy;<br>❖ Gw;WNehia guthky; fl;Lg;gLj;Jjy;<br>❖ Gw;WNeha;f;fhd mwpFwpfspd; %yk; |  |  |  |

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| | | | Fzg;gLj;Jjy;<br>**Gw;WNehia Fzg;gLj;Jjy; :**<br>❖ mWit rpfpr;ir<br>❖ fjph;tPr;R<br>❖ fjph;tPr;R kw;Wk; kUe;Jfs; %ykhfTk; Fzg;gLj;JfpNwhk;.<br>**Gw;WNehia fl;Lg;gLj;Jjypd; Nehf;fk; :**<br>Gw;WNehia KOtJkhf Fzg;gLj;j KbahJ. Mdhy; kw;w cWg;GfSf;F guthky; kUe;Jfspd; %yk; XusT fl;Lg;gLj;jyhk;.<br>**Gw;WNehapd; mwpFwpfSf;fhd rpfpr;ir Kiwfs; :**<br>Gw;WNeha; mwpFwpapd; %yk; Gw;WNeha;f;F rpfpr;ir mspf;fpNwhk;. ,jpy; mwpFwpia kl;Lk; fl;Lg;gLj;JfpNwhk;. Mdhy; KOikahf Fzg;gLj;j ,ayhJ. | | | |

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| 5. | ghypNal;bt; Nfh; | 1 epkplk; | **ghypNal;bt; Nfh; :**<br>Gw;NehahspfSf;F mwpFwpapd; rpfpr;ir Kiw KOikahd cWJizia mspf;fpwJ. Muk;g fhyf; fl;lj;jpy; ,jdpd; Nehf;fk; Gw;Nehia KOikahf Fzg; gLj;JtJ my;y. Mdhy; mth;fSf;F jukhd tho;f;if Kiw cly;hPjpahfTk;, kd hPjpahfTk;, ,iw ek;gpf;if kw;Wk; r%f hPjpahfTk; tho ,e;j rpfpr;ir mspf;fg;gLfpwJ. |  |  |  |
| 6. | FLk;gj;jpy; xUtUf;F Gw;WNeha; ,Ue;jhy; me;j egh; kw;Wk; | 2 epkplk; | **kdhPjpahd mwpFwp :**<br>❖ Vw;Wf;nfhs;shik<br>❖ Nfhgk;<br>❖ flTsplk; Neh;e;Jf; nfhs;Sjy;<br>❖ kd mOj;jk; |  |  |  |

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|  | FLk;gj;jhhpd; kdepiy gw;wp tpthp |  | ❖ Vw;Wf;nfhs;Sjy;<br>Gw;WNehahspfSf;F cWJizahf ,Ug;gth;fs; ,e;j rkaj;jpy; mth;fspd; czh;r;rp kw;Wk; mikjpapd;ikia Ghpe;J nfhz;L Nehapd; jd;ikia gw;wp tpthpj;J mij Vw;Wf;nfhs;Sk; kd gf;Ftj;ij mth;fSf;F nfhz;L tUjy;. |  |  |  |
| 7. | Gw;WNehahspfs; jd;ikia Njitfis kw;wth;fspd; cjtpAld; vg;gb epth;j;jp nra;fpwhh;fs; vd;gij gw;wp tpthp | 2 epkplk; | Gw;WNehahspfspd; epiyikia czh;e;J FLk;gj;jpy; cs;sth;fs; me;j nghWg;ig jhNk Vw;Wf;nfhz;L jq;fspd; cjtpfspd; %yk; mth;fis nray;gLj;Jfpwhh;fs;. ez;gh;fs; kw;Wk; FLk;g cWg;gpdh;fs; %yk; MWjy; mspf;fyhk;. |  |  |  |
| 8. | Gw;WNeha;f;fhd mwpFwpfs; kw;Wk; mjd; guhkhpg;Gk; | 26 epkplq;fs; | **1) grpapd;ik :**<br>❖ Fiwe;j msT ciz ,ilntsp tpl;L nfhLf;f Ntz;Lk;.<br>❖ mjpf msT fPiu kw;Wk; Gujr;rj;J |  |  |  |

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| | guhkhpg;gthpd; gq;fpid tpthp | | mlq;fpa nghUisf; nfhLf;f Ntz;Lk;.<br>❖ gor;rhW kw;Wk; ePh; Mfhuq;fis Nehahspapd; mUfhikapy; itf;f Ntz;Lk;.<br>❖ kfpo;r;rpahd #o;epiyia cUthf;f Ntz;Lk;.<br>❖ Nehahspf;F gpbj;j czit kl;Lk; cz;zf; nfhLf;f Ntz;Lk;.<br>❖ Nehahsp czT cz;zhkypUf;Fk; NghJ clNd cwtpdh;fs; ,Ue;J czT cl;nfhs;s itf;f Ntz;Lk;.<br>**2) njhw;W Neha; :**<br>❖ Nehahspapd; cly; ntg;gj;jpd; %yk; clypd; khWghl;il mwpayhk;.<br>❖ kUe;Jfis kUj;Jthpd; MNyhridg;gb vLf;f Ntz;Lk;.<br>❖ mjpf msT jz;zPh; Fbf;f nfhLf;f Ntz;Lk;.<br>**3) kyr;rpf;fy; :**<br>❖ gor;rhW, RLj;jz;zPh;, NjePh; Fbf;f nfhLf;f Ntz;Lk;. | | | |

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| | | | ❖ mjpf msT ePh;r;rj;Js;s nghUisf; nfhLj;jy;.<br>❖ kyk; fopj;jiy ml;ltizg; gLj;j Ntz;Lk;.<br>❖ kUj;Jthpd; MNyhridg;gb kyk; fopj;jYf;F kUe;J vLj;Jf; nfhs;sTk;.<br>**4) kdr;Nrhh;T :**<br>❖ Nehahsp Njitaw;w gaj;ij Nghf;f Ntz;Lk;.<br>❖ Nehahspapd; kd mOj;jk; gw;wp Ngr fl;lhag; gLj;jf; $lhJ.<br>❖ Nehahsp NgRk;NghJ ftdkhf Nfl;f Ntz;Lk;.<br>❖ KbTfis $l;lhf fye;J MNyhrpj;J jPh;khdpf;fTk;.<br>❖ kdr;Nrhh;tpy; cs;sthplk; re;Njh\khf ,Uq;fs; vd;W $wf;$lhJ.<br>❖ Nehahspf;F kfpo;r;rp jUk; Ntiyfs; nra;tij jLf;f Ntz;lhk;. | | | |

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| | | | ❖ Nehahspf;F kd mOj;jk; mjpfkhf ,Ue;jhy; jdpegh; my;yJ FO MNyhridfis toq;f Ntz;Lk;.<br>**5) clw;gapw;rp :**<br>❖ Nehahspia jdpahf elf;f itj;jy; $lhJ.<br>❖ Kbe;j msT Ntiyfis Nehahspia nra;ar; nrhy;yTk;.<br>❖ midj;J clw;gapw;rpfisg; gw;wp kUj;Jthplk; MNyhrpj;J nra;a nrhy;y Ntz;Lk;.<br>❖ jpdKk; nra;Ak; Ntiyf;F Nehahspf;F cjtTk;.<br>**6. tha;g;Gz; :**<br>❖ cjtpahsh;fs; Nehahspf;F cwpQ;R Fohiaf; nfhz;L Fbf;ff; nfhLf;fTk;.<br>❖ krpe;j czit mspf;f Ntz;Lk;.<br>❖ typ khj;jiufis ½ kzp Neuj;jpw;F Kd; cl;nfhs;s Ntz;Lk;. | | | |

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| | | | ❖ czT cz;gjw;F Kd; thia nfhg;gspf;f Ntz;Lk;.<br>**7) typ :**<br>❖ ntJntJg;ghd jz;zPhpdhy; Fspf;f itf;f Ntz;Lk;.<br>❖ Nehahspf;F re;Njh\khd #o;epiyia cUthf;f Ntz;Lk;.<br>❖ ehh;r;rj;Js;s czitAk; gor;rhiwAk; nfhLf;f Ntz;Lk;.<br>❖ kUj;Jthpd; MNyhridg; gb typ kUe;ij mspf;f Ntz;Lk;.<br>❖ ve;j nraiyAk; nra;Ak; Kd; jpl;lkpLjy; Ntz;Lk;.<br>❖ czT vLj;Jf; nfhs;tij fl;lhag; gLj;jf;$lhJ.<br>❖ cwtpdUld; czT mUe;JtJ grpapid mjpfhpf;Fk;. | | | |

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| | | | **2) njhw;W Neha; :**<br>❖ cly; ntg;gepiyia ghpNrhjpf;f Ntz;Lk;.<br>❖ mjpfsT jz;zPh; Fbf;ff; nfhLf;f Ntz;Lk;. | | | |
| 9. | rKjhaj;jpd; gpd; thq;Fjy; kw;Wk; mjw;F vd;d nra;ayhk; vd;gij gw;wpAk; tpthp | 2 epkplk; | rKjhaj;jpd; %yk; iftplg;gl;l Gw;WNehahsp kw;Wk; mtuJ FLk;gj;jpdUf;Fk; kdhPjpahf mth;fSf;F cWJiz mspf;fg;gLfpwJ. kNdhjj;Jt epGzh; %ykhf mth;fSf;F kdhPjpahf tpsf;fk; kw;Wk; kd mikjp mspf;fg;gLfpwJ. | | | |

**KbTiu :**

,Jtiu Gw;WNeha; vd;why; vd;d, ,jd; fhuzq;fs;, ghpNrhjidfs; rpfpr;ir Kiwfs; kw;Wk; mwpFwpia nfhz;L Gw;WNehapid guhkhpg;gJ kw;Wk; r%fj;jpd; Nehahspfs; vg;gb jd;id rkhspj;J tho;tJ vd;gij gw;wp ghh;j;Njhk;.

mjdhy; ePq;fs; ,ij Ghpe;J nfhz;L Gw;WNehahspf;F FLk;g cWg;gpduhf MjuTk; guhkhpg;Gk; nfhLg;gjhy; cq;fspd; kdmOj;jk; FiwtNjhL, Nehahspia guhkhpg;gNjhL jq;fspd; NjitfisAk; kdepiwNthL nra;a KbfpwJ.

# Gw;WNeha; Palliative Care mwpFwpfSk; kw;Wk; mjd; guhkhpg;Gk;

1. **grpapd;ik :**
   - Fiwe;j msT czit ,ilntsp tpl;L nfhLf;f Ntz;Lk;.
   - mjpf msT fPiu kw;Wk; Gujr;rj;J mlq;fpa nghUisf; nfhLf;f Ntz;Lk;.
   - gor;rhW kw;Wk; ePh; Mfhuq;fis Nehahspapd; mUfhikapy; itf;f Ntz;Lk;.
   - kfpo;r;rpahd #o;epiyia cUthf;f Ntz;Lk;.
   - Nehahspf;F gpbj;j czit kl;Lk; cz;zf; nfhLf;f Ntz;Lk;.
   - Nehahsp czT cz;zhkypUf;Fk; NghJ clNd cwtpdh;fs; ,Ue;J czT cl;nfhs;s itf;f Ntz;Lk;.

2. **njhw;W Neha; :**
   - Nehahspapd; cly; ntg;gj;jpd; %yk; clypd; khWghl;il mwpayhk;.
   - kUe;Jfis kUj;Jthpd; MNyhridg;gb vLf;f Ntz;Lk;.
   - mjpf msT jz;zPh; Fbf;f nfhLf;f Ntz;Lk;.

3. **kyr;rpf;fy; :**
   - gor;rhW, RLj;jz;zPh;, NjePh; Fbf;f nfhLf;f Ntz;Lk;.
   - mjpf msT ePh;r;rj;Js;s nghUisf; nfhLj;jy;.
   - kyk; fopj;jiy ml;ltizg; gLj;j Ntz;Lk;.
   - kUj;Jthpd; MNyhridg;gb kyk; fopj;jYf;F kUe;J vLj;Jf; nfhs;sTk;.

4. **kdr;Nrhh;T :**
   - Nehahsp Njitaw;w gaj;ij Nghf;f Ntz;Lk;.
   - Nehahspapd; kd mOj;jk; gw;wp Ngr fl;lhag; gLj;jf; $lhJ.

- Nehahsp NgRk;NghJ ftdkhf Nfl;f Ntz;Lk;.
- KbTfis $l;lhf fye;J MNyhrpj;J jPh;khdpf;fTk;.
- kdr;Nrhh;tpy; cs;sthplk; re;Njh~khf ,Uq;fs; vd;W $wf;$lhJ.
- Nehahspf;F kfpo;r;rp jUk; Ntiyfs; nra;tij jLf;f Ntz;lhk;.
- Nehahspf;F kd mOj;jk; mjpfkhf ,Ue;jhy; jdpegh; my;yJ FO MNyhridfis toq;f Ntz;Lk;.

**5. clw;gapw;rp :**

- Nehahspia jdpahf elf;f itj;jy; $lhJ.
- Kbe;j msT Ntiyfis Nehahspia nra;ar;nrhy;yTk;.
- midj;J clw;gapw;rpfisg; gw;wp kUj;Jthplk; MNyhrpj;J nra;a nrhy;y Ntz;Lk;.
- jpdKk; nra;Ak; Ntiyf;F Nehahspf;F cjtTk;.

**6. tha;g;Gz; :**

- cjtpahsh;fs; Nehahspf;F cwpQ;R Fohiaf; nfhz;L Fbf;ff; nfhLf;fTk;.
- krpe;j czit mspf;f Ntz;Lk;.
- typ khj;jiufis ½ kzpNeuj;jpw;F Kd; cl;nfhs;s Ntz;Lk;.
- czT cz;gjw;F Kd; thia nfhg;gspf;f Ntz;Lk;.

**7. typ :**

- ntJntJg;ghd jz;zPhpdhy; Fspf;f itf;f Ntz;Lk;.
- Nehahspf;F re;Njh~khd #o;epiyia cUthf;f Ntz;Lk;
- ehh;r;rj;Js;s czitAk; gor;rhiwAk; nfhLf;f Ntz;Lk;.
- kUj;Jthpd; MNyhridg; gb typ kUe;ij mspf;f Ntz;Lk;.
- ve;j nraiyAk; nra;Ak; Kd; jpl;lkpLjy; Ntz;Lk;.

# APPENDIX - D

# LETTER SEEKING PERMISSION TO CONDUCT THE RESEARCH STUDY

From

Mrs.Judith.M.D.J,
II Year M.Sc. (N),
Dr.G.Sakunthala College of Nursing,
T.V.Kovil,
Trichy – 5.

To

The Principal,
Dr.G.Sakunthala College of Nursing,
T.V.Kovil
Trichy-5.

Respected Madam,

***Sub:*** *Letter seeking permission to conduct the study.*

I am a final year M.Sc., Nursing student of Dr .G.Sakunthala College of Nursing. I would like to conduct a study as a part partial fulfilment for the degree of Master in Nursing. The statement of the problem is 'A pre-experimental study to evaluate the effectiveness of IEC regarding caregiver role strain and coping strategies among caregivers of patients with cancer receiving palliative care at G.V.N.Hospital palliative care unit,Trichy during the year 2011-2012..Kindly grant me permission to conduct the study.

Thanking you in anticipation,

Your's faithfully,

**Judith.M.D.J,**II
Year M.Sc. (N) Student.

# LETTER SEEKING PERMISSION TO CONDUCT THE STUDY

From

Mrs.Judith.M.D.J,
II Year M.Sc. (N),
Dr.G.Sakunthala College of Nursing,
T.V.Kovil,
Trichy – 5.

To

The Principal,
Dr.G.Sakunthala College of Nursing,
T.V.Kovil
Trichy-5.

Through

The Principal,
Dr.G.Sakunthala College of Nursing,
T.V.Kovil
Trichy-5.

Respected sir,

***Sub***:*Letter requesting permission to conduct the pilot study*

I am Judith .M.D.J, M.Sc. Nursing student of Dr.G.Sakunthala College of Nursing, T.V.Kovil, Trichy-5. As part of my course; I am doing a study on the topic mentioned below.‘A pre-experimental study to evaluate the effectiveness of IEC regarding caregiver role strain and coping strategies among caregivers of patients with cancer receiving palliative care at G.V.N.Hospital palliative care unit, Trichy during the year 2011-2012.

I would like to do my pilot study of my research at your hospital,hence I request you to kindly consider my request and grant me permission to do my pilot study.kindly to the needful.I assure you that I will abide by the institutions policies.

Thanking you,

Your’s faithfully,

**Judith.M.D.J,**
II Year M.Sc. (N) Student.

## REQUISITION LETTER TO MEDICAL GUIDE

From

Mrs.Judith.M.D.J,
II Year M.Sc. (N),
Dr.G.Sakunthala College of Nursing,
T.V.Kovil,
Trichy – 5.

To

Dr.V.Govindaraj,M.S.,F.R.C.S.,
Dr.G.Viswanathan Speciality Hospital,
Trichy .

Through

The Principal,
Dr.G.Sakunthala College of Nursing,
T.V.Kovil
Trichy-5.

Respected sir,

***Sub***: *Letter requesting opinion and suggestions from experts for establishing content validity of the tool.*

I am Judith .M.D.J, M.Sc. Nursing student of Dr.G.Sakunthala College of Nursing, T.V.Kovil, Trichy-5. As part of my course; I am doing a study on the topic mentioned below.

A pre-experimental study to evaluate the effectiveness of IEC regarding caregiver role strain and coping strategies among caregivers of patients with cancer receiving palliative care at G.V.N.Hospital, Trichy during the year 2011-2012.

May I request you to go through and validate the content of the tool.Please give your valuable suggestion for modifying the tool.

Thanking you,

Your's faithfully,

**Judith.M.D.J,**
II Year M.Sc. (N) Student.