# Chapter 3

## Methodology

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METHODOLOGY

INTRODUCTION

The methodology adopted for the study is being discussed in chapter III. The aim of the study is to assess the psycho-social problems among terminally ill cancer patients of both sexes who fall under the age group of 20 to 75. With this general objective in mind several specific objectives have been formulated, which would help in encompassing all the possible dimensions of the problems faced by terminally ill cancer patients. Some hypotheses have been formulated with a view to provide the present research study with a direction and beacon light, that would lend it a definite purpose and ensure it success in attaining the professed objective.

Conceptual classification of keywords involved in the study is done in order to help the investigator to gain a theoretical knowledge. Similarly each concept was also operationalised in the way the researcher intended to go forward with the study. The inclusion and exclusion criteria adopted are also mentioned so as to keep the researcher focused on the essential elements of the topic under study. The sources from which data was collected are mentioned in this chapter. The method in which the universe was selected would help in getting a representative sample of the population and the number of samples to be collected from the universe was calculated by
taking an average of the number of cases admitted in a year in the respective centers that were diagnosed as terminally ill by the treating oncologist. The manner in which the pilot study was conducted is explained in details and how the population was stratified on the basis of the income is well explained in this chapter. The research design used in the study is descriptive design which aims at exploring or gaining a new insight into the problematic areas in the life of a cancer patient who are in their terminal stage. 15 case studies were conducted to get an in depth understanding of the psycho-social problems which no rating scale would be able to analyze using their tools. By doing so the researcher was able to use principles of case work such as individualization, acceptance, non-judgmental attitude, purposeful expressions of feelings and maintaining confidentiality. The areas of intervention required in each case have been highlighted analyzing each case. The researcher has been able to provide the psycho-social intervention for the case at the time of the investigation. The data was collected from the samples was by using two standardized rating scales and few interview schedules developed by the researcher. A detailed description of the same is given in this chapter. Appropriate statistical analysis is also applied so as to get maximum results out of the study.

The methodology adopted in this study has been discussed briefly in this chapter. It comprises a profile of the area where the study was conducted, the aims and objectives of
the study, the various conceptual and operational definitions, and information on research design, sampling method, criteria for inclusion/exclusion and the tools of data collection. It explains the pilot study and elaborates on the methodology of data collection and data analysis. The last part is a reflection on the limitation of the study.

**RESEARCH DESIGN**

Descriptive design has been undertaken for the purpose of the study. The purpose of study was to gain new insight into the various aspects of depression and also directed towards bringing about deeper insight and meaning with regard to the ways and means by which, terminally ill cancer patients experience and to cope with their psychological problems. Since the focus of the research was on to assessing the characteristics of the population under study, to discover and test the interrelationship between variables descriptive design was adopted.

The steps involved in such a design are

- A clear formulation of the problem
- Clarifying the objectives
- Specifying the boundaries of the study
- Identifying the sources of data to be tapped
- Selecting appropriate methods and tools of data collection
Choosing the sample design and planning and execution of analytical design

The researcher adopted these steps carefully in order to provide an empirical and logical basis for drawing conclusions and gaining greater knowledge.

A detailed study was done on their socio demographic profile, family burden, the social support extended by family members, coping mechanisms used, and finally to analyze the depression dimensions and its relationship to the other variables under study. 15 case studies were also conducted to get a better view on their psychosocial problems.

**STATEMENT OF THE PROBLEM**

Terminal illness is a state in which an individual lives with a chronic illness which leads to death. (Robert.G.Twycross, 2004) There are different categories of this most dreaded affliction of which the prominent one is cancer.

The greatest problem faced by our society is that the causes of some of the diseases are still unknown. Consequently medical science has failed to find concrete remedies to place a check on the progress of these dreadful diseases. The most pernicious nature of these diseases is that within a very short span of its manifestation the patient is driven to an irrecoverable state which is labelled him as, terminally ill.

Cancer patients are not merely individuals with a diseased body. They have also a throbbing heart, a thinking mind, a
stirring soul and live in a secluded world of their own, with their family, relatives and friends in the penumbra. Although cancer affects individuals, it casts its gloom and despondency on the families of patients and the entire community. Loss of job, family responsibility, financial constraints, social isolation, emotional problems like depression, hopelessness, helplessness, feeling of unwantedness, neglect, etc aggravate the misery of the patient. Strained social relationship and family tensions persist. (Ms. Rosalyn Staveley, 2002). In the absence of concrete evidence as to its causative factors this terrible malady takes a heavy toll of human lives, stunning one and all. Early detection, early treatment and developing positive attitude in these patients can go a long way in alleviating their psycho- somatic agony and social isolation.

**SCOPE OF THE STUDY**

ICD (International classification of disease) defines depression as a common mental disorder that presents with depressed mood, loss of interest or pleasure, feeling of guilt or less worth, disturbed sleep or appetite, low energy and poor concentration.

The effects of depression are severe among the terminally ill and if left untreated, it can cause unnecessary pain and suffering for the patient and his families, and can greatly reduce the quality of life. Depression is also associated with a higher risk for hospitalization and lower rate of survival. The most serious cases can be treated successfully through medication,
psychotherapy, music therapy and by talk therapy or a combination of all. Talk therapy is used to help patients learn coping behaviour or change negative style of thinking.

Depression has an impact on the thinking, feeling, behaviour and physical state of the patient. Each group of symptoms has an impact on the other, driving the individual deep into a negative mental and physical state. Cancer is a condition where the orderly pattern of cell reproduction gets out of control and invades its host body and the only way to respond to this problem is to restore order. Cancer is not an invasion by an alien enemy; it is a sign of internal unrest. The role of a doctor is restoring order. The doctor is aware that spontaneous remission and miracles do not occur. He is aware of the fact that changes in the attitude of people can bring about difference to the outcome of treatment. Psychological response is a key aspect of survival. Similarly hope can help even a sinking person reverse his situation. Hope blows away despair and it can keep the patient going even in the face of the most formidable odds. A person who has hope has still option to explore, that cancer is still treatable and one can do things they enjoyed doing and will not be isolated from those whom they love. Being positive and taking positive action can enhance the capacity for survival in the terminally ill.

Social work measures are not directed towards reducing the symptoms in the patient. Instead, the practice of social work aims at reducing the indulging social problems and the
manifested maladjustment in the patient and poor concentration.

Counselling the dying patients and their loved ones are commonly based on the general model developed by Kubler-Ross. A dying patient passes through several stages—denial, anger, bargaining, depression and acceptance. A study on the emotional disturbance & the multi-factoral psychosocial causes for depression is very much important because it has an adverse effect on the well-being of the patient. This study is of utmost relevance because it is not how you live with the illness but how practically you view a problem or face a real life situation that help one to fight with the disease and survive it. It is the mental strength, belief and hopes in oneself, which give a healing touch to the patient.

This being a pioneer study in the health field the investigator aims at studying the multi-factoral dimension of depression and identifying the areas of intervention. This is done to prepare the patient for a peaceful death, by adding life to his days and not just days to his life.

**AIM OF THE STUDY**

The main aim of this research is to make an assessment of psycho-social problems of terminally ill cancer patients and to identify areas of social work intervention.
OBJECTIVES OF THE STUDY

- To study the socio-demographic profile of the terminally ill cancer patients.
- To assess the family burden of terminally ill cancer patients.
- To study the social support extended by the family members towards the terminally ill cancer patients.
- To study the coping pattern adopted by the terminally ill cancer patients.
- To find out the factors for depression in terminally ill cancer patients.
- To identify specific areas of intervention for the terminally ill cancer patients.

HYPOTHESES

- There exist a significant association between the age and depression experienced by the terminally ill cancer patients.
- There exist a significant relationship between the family burden and depression experienced by the terminally ill cancer patients.
- The social support received by the terminally ill cancer patients are significantly related to the level of depression.
• The relationship between depression and adoption of coping strategies among the terminally ill cancer patients are significant.

**DEFINITION OF CONCEPTS**

Concept is a word with a meaning. The major concepts dealt with the study are explained theoretically and operationally. The key words involved in the study are the concepts. The following are the concepts.

**Terminal illness:**

**Conceptual definition:** Terminal illness is a state in which an individual lives with a chronic illness, which eventually causes death. The majority of recipients of hospice care are terminally ill cancer patients. (Robert G.Twycross)

**Operational definition:** Any patient suffering from advanced cancer and are in their end stage of life with no hope of cure but just palliative care.

**Patient:**

**Conceptual definition:** A person who is seriously ill and requires continuous treatment in a hospital or in a similar setting. (Minna Field)

**Operational definition:** A person with cancer in his/her terminal illness stage.
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Social work intervention:

**Conceptual definition:** It is an action or process of interference by an authorized person in another’s affair or it can be otherwise referred as an action taken to improve a medical disorder.

**Operational definition** – Social work intervention is an action given to patients in solving the psychosocial problems they face on living with advanced cancer.

Family Burden:

**Conceptual definition** – Problems faced within the family.

**Operational definition** – The problem include financial problems, family interaction, family activity, psychological and physical problems faced by the family members on having a cancer patient at home and problems connected with activity of daily living.

Economic Status:

**Conceptual definition** – It refers to the economic stability of an individual.

**Operational definition** – The economic status is categorized according to the hospital rating standard scales.

Coping:

**Conceptual definition** – Adjustment made to fulfill a particular task.
**Operational definition** – Terminally ill cancer patients suffer from physical, social, economic & psychological problems. When these patients have also to live with a terminal illness all the above mentioned problems are aggravated and to get relief from the present state of affair patients adopt various coping mechanisms such as, over activity, withdrawal, denial, suppression, which come under negative coping mechanisms and religiosity, optimism, reality, ventilation, listening to music etc. are positive coping strategies used to defend against the open defense of the id and the super ego.

**Depression:**

**Conceptual definition** – ICD -10 (International classification of disease) defines disease as a common mental disorder that presents with depressed mood, loss of interest or pleasure, feeling of guilt or less worth, disturbed sleep or appetite, low energy and poor concentration.

**Operational definition** – Due to terminal illness the patient experience impairment in daily functioning, which upsets their mental balance. The thought process, feelings, the physical symptoms and behaviour exert a direct influence on the activities of the patient. Many physical symptoms manifested are, no energy, tiredness, no pleasure in anything, reduced appetite, sleep disturbance, weight gain/loss and also unexplained physical pain.
Social Support

**Conceptual definition** – Social support is defined as a function performed, for an individual under stress by significant others such as family members, friends or professionals. (Nelles et al 1992) The function is generally classified into instrumental aid such as goods and services, expressive aids such as caring and listening and informational aid such as education or advice concerning the disease or its treatment (Schaefer et al 1981).

**Operational definition** – Social support of various type comprise emotional support from family members, financial support for treatment, information received regarding the patients illness, providing encouragement and positive feedbacks.

**DEPENDENT AND INDEPENDENT VARIABLES**

The various dependent variables are emotional problems, family burden, economic burden, social support, coping strategies and depression. The independent variables are education, age, gender, sex, income, duration of illness, type of cancer, marital status and family history, depression.

**UNIVERSE**

The universe of study is terminally ill cancer patients who fall under the age group of 20-75 years. Samples were collected from Amala Cancer Institute and Research Center, Amala Nagar, Thrissur, and Government Medical College Hospital, Mullankunathukavu, Thrissur.
**POPULATION**

Each terminally ill cancer patient who falls under the age group of 20–75 years and who fulfilled the inclusion criteria was considered as the unit under study.

**SAMPLING TECHNIQUES AND SAMPLE:**

The study is confined to adult terminally ill cancer patients who fall under the age group of 20-75 years. For the purpose of uniformity equal number of samples from the high income, middle income and low income group according to the representation of these patients in the hospital were selected. This was calculated by taking an average. Equal representative samples were selected from both the hospitals. Purposive sampling was adopted for the purpose of selecting the unit.

The samples were selected in an unbiased and rigorous way fulfilling the requirement in the inclusive criteria. 100 samples from each population on a 5:3:2 ratio of low, middle and high income group were selected. The advantage of this non-probability sample is that from a small representative sample group of 200 terminally ill cancer patients the behaviour of the larger population can be predicted. It also allows a high degree of representativeness from which results could be generated.

**CRITERIA FOR SELECTION OF PATIENTS**

It is always essential to formulate inclusion and exclusion criteria of the sample under study. This has helped the researcher in having clarity of his boundaries under
investigation. The inclusion and exclusion criteria for the selection of patients are listed below.

**Inclusion criteria**

- Terminally ill cancer patients from all categories.
- Patients who has entered into the last one year of life, and living with cancer.
- Both sexes are included.
- Age group included is from 20 to 75
- The presence of a family member involved in care is a criterion.
- Only hospitalized terminally ill cancer patient.
- Those patients able to communicate.
- Patients, who fall under high income, middle income and low income groups.
- Immediate family member taking care of the patient.

**Exclusion criteria:**

- Patients diagnosed other than cancer.
- Patients below the age of 20 and above 75.
- A patient who was not accompanied by family members.
- A patient who is not able to express his feelings and emotions
- Patients who does not fall under the category of terminally ill.
Those who have a predicted life span of more than one year.

Those other than the immediate family member.

 METHODS AND TOOLS OF DATA COLLECTION

The method used for data collection was observation along with interviewing and active listening. This was to elicit maximum amount of information so as to obtain a holistic picture of the psycho-social problems faced by them in the process of living with it and also to understand the coping strategies adopted by them. Apart from analyzing their problem the researcher aimed at identifying the areas of intervention so as to help the patient to lead a peaceful life. The above mentioned methods were of use in gathering information. Case studies were also conducted with patients belonging to different income strata. Qualitative analysis helped the researcher in getting to know the patient in an in-depth manner as well as in clearing the doubts of the patients and their bystanders in an effective manner. Empathetic attitude of the researcher enabled in gathering valuable information. Case studies really work out effectively with the terminally ill cancer patients. Patients were found relived on giving them a listening ear. Patients in their end stage found it difficult to provide the investigator with information in a single meeting. It could be observed that none of the patients were interested in responding to a set of questions; instead they were willing to have a free flowing interview with them. Due priority was given to the patient while gathering information.
The following six interview schedule were used to study the psycho-social problems of the terminally ill cancer patients.

Socio-demographic interview schedule (developed by the researcher).

Family burden scale (Pai & Kapur 1981)

Social support interview schedule families (developed by the researcher).

Coping Strategy interview schedule (developed by the researcher).

Beck Depression Inventory (BDI) (1996).

SOCIO-DEMOGRAPHIC INTERVIEW SCHEDULE.

The interview schedule was formulated by the researcher herself. This tool was used to obtain information about the socio-demographic variables like age, sex, marital status, education, habit, and income, and diagnosis, duration of illness, family history of cancer and physical discomfort. It was also used to obtain information regarding exposure to risk factors.

FAMILY BURDEN SCALE (PAI & KAPUR 1981)

This is a semi-structured interview schedule to assess the burden placed on families of cancer patients living in the community. Reliability score of the interview schedule was above 90 percent for 20 items and between 87 percent and 89 percent for the other four. Regarding validity the reported coefficient of correlation is 0.72 (d.f=1).
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It assesses six categories of objective burden.

1. Financial burden (6 items)
2. Effect on family routine (5 items)
3. Effect on family leisure (4 items)
4. Effect on family interaction (5 items)
5. Effect of physical health of other family members (2 items)
6. Effect on mental health of other family members (2 items)

The scale also provides for the measurement of subjective burden by asking respondents, how much they have suffered owing to the patients’ illness. Each item of the objective burden is scored on a three point scale, recorded as ‘no burden’ (score zero), ‘moderate burden’ (score one) and ‘severe burden’ (score two). The scores on each category are summated and a total of these scores are indicative of the degree of the objective burden. The subjective burden is also scored similarly on a 3 point scale.

SOCIAL SUPPORT INTERVIEW SCHEDULE (FAMILIES)

The interview schedule was designed to measure the extent to which an individual perceives that his/her needs for support, information and feedback are fulfilled by and family members.

It is a 25 item interview schedule consisting of declarative statements on which the individual answers always, sometimes, never, ‘don’t know’. For each item, the response indicative of perceived social support was scored as 2, 1,-1 and 0 respectively.
2 indicating good support, 1 indicating moderate support, -1 never and 0 don’t known.

**COPING STRATEGY INTERVIEW SCHEDULE**

This was developed by the researcher. This contains 12 variables for which to know the patients response for a particular variable a number a questions were asked. The coping behaviours adopted by patients aimed at serving one of the three functions. 1) to change a stressful situation 2) to control emotional distress 3) to control the meaning of situation. Therefore these questions are problem focused, emotion focused and appraisal focused coping behaviour.

This interview schedule contains 35 questions and scoring was done for active cognitive always, sometimes, never with scores 2, 1, 0 and reverse marks while answering active behavioural strategy and avoidance strategy.

The respondents were asked whether they have used those particular coping strategy or not in order to deal with the stress of being a terminal cancer patient. The scores for each set of coping strategy is the sum of the scores for the items indicative. Good coping 70-46, moderate 45-23 and poor coping 22 and below.

For correcting the directionality, a reversal scoring was adopted in the present study to reflect single directionality meaning high scores indicating unhealthy coping strategy.
BECK DEPRESSION INVENTORY (BDI, 1996)

The items of the inventory are primarily clinically derived. This inventory is composed of 21 categories of symptoms and attitudes. Each category describes a specific background manifestation of depression and consists of a graded series of 4 to 5 self-evaluative statements. The statements are ranked to reflect the range of severity of the symptoms from neutral to maximal severity. Numerical values from 0-3 are assigned to each statement to indicate the degree of severity. In many categories, 2 alternate statements are presented at a given level and are assigned the same weight; thereby equivalent statements are labeled a and b (for example: 2a, 2b) to indicate that they are at the same level.

The statements were read aloud to those who were unable to read. The respondents were asked to select the statement that fulfilled his/her best at the present time and circle the statement adjacent to each such statement. Scoring was done using the scoring key, where numerical value from 0-3 to each statement was given depending on the response of the summated score. The level of depression is categorized into: No depression, Mild depression, moderate depression, and severe depression.

Internal consistency through split half method showed reliability co-efficient of 0.86 with Spearman’s correlation, comparison between the scores on the inventory and the clinical judgments by diagnosticians indicating high validity. The inventory is found to be useful in discriminating effectively
among groups of patients with varying degree of depression. It is also able to reflect changes in intensity of depression after an interval of time.

In view of these attributes of validity and reliability, this instrument is presented as a useful tool for research study of depression and as a step ahead in the direction of placing psychiatric diagnosis on a quantitative basis.

Interview schedule and case records reference from hospitals and reference from studies conducted in India and abroad were looked into. Interview schedule was used for this purpose. It contained mainly four parts.

- Socio-demographic data
- Personal details.
- Family related details.
- Items pertaining to illness.

**SOURCE OF DATA**

The data was collected from primary and secondary sources.

**Primary sources:**

The patients and their relatives were the primary sources. This method included personal interview, which was recorded in a specific organized manner or complemented by personal observation and active listening by the interviewer.
**Secondary source:**

Quantitative and qualitative data were gathered from psycho-social issues of cancer with special emphasis on Indian background. Oncologist, nurses, cancer registries threw additional light on the various dimensions that could be added in the formulation of the study. Discussion with doctors contributed immensely to the development of a clear vision and phrasing the problem in detail. The next major step involved in surveying was the available literature on the subject understudy, mainly books, oncology journals, psychosomatic journals, British medical journal, articles, reports, doctoral works, other relevant reports, literature from internet websites like pub med, Google, Medline, etc.

**PILOT STUDY:**

The investigator visited the hospitals where the research was intended to do. The purpose was to find out the number of samples required for the research study so that it will be a representative of the universe and also to find out the scope of this particular study.

During the pilot study, it was observed that terminally ill cancer patients admitted to Amala Medical College and Research Institute and Government Medical College hospital, Thrissur, were almost equal in number and nature. The sample was classified into high, middle and low income groups. 50% belongs
to low income group, the remaining 30% from middle income and 20% from high income.

In Thrissur, the hospitals having an oncology department for cancer diagnosis and treatment are Government Medical college hospital and Amala Cancer Institute and research centre. So samples were collected from these two institutions for the purpose of study.

Interview schedule was administered on 6 patients’ one male and female each from high income, middle income and low income groups. Slight modifications were made in the instrument after the pilot study to make it more suitable for the present study.

PROCEDURES:-

Official permission from the District Medical Officer, Thrissur and Head of the department of Oncology, Medical college, Mullankunathukavu, Thrissur and from The Director and Head of the Department of Oncology, Amala Medical College were obtained to collect the data for the study. Subsequently, information about desired study group and purpose of the research study was explained to them. The details of the study and the inclusion criteria for the sample with request to refer the case.

Individual interviews with the terminally ill cancer patients were conducted to get information on the above-mentioned tools. Before the interview, the respondents were informed about the
objectives of the study and the requirements from the patient to participate in the study. They were given freedom to make decision about their participation in the study. Subsequently, the informed consent was obtained from each respondent using the formal informed consent form for the study.

The data was collected during the period from October 2005 to October 2006 using interview schedule. 15 case studies were also conduct through the method of free flowing interviews.

**INITIAL INTERVIEW AND INFORMERS CONSENT**

An initial interview was done with each of the patient, in which they were asked about their reasons for admission, symptoms and their knowledge and understanding of their diagnosis. Patients were then informed about the nature of the research and their consent to participate in the study was obtained, if they agreed to participate in the study, the pre-assessment was done using the tools mentioned. The interview package was started individually.

**STATISTICAL ANALYSIS:**

Statistical methods adopted for analysis are tabulation, graphical representation and numerical analysis. In quantitative data one way and two way tables were used to represent the data by which comparison and elementary analysis was performed. The percentage occurrences of cases with two variables are used for comparison.
The predominant statistical applications used are. Chi-Square test for measuring independence, Pearson's coefficient correlation coefficient to find out positive or negative correlation. Confidence intervals were constructed to assess the maximum variation that can happen in the variable. Equality of two sets of data was assessed in the study using Chi-square test for goodness of fit and to test significance of ratio. Further interrelationship between some variables was examined using Mean. 5 percentage level of significance was adopted for testing the reliability of conclusion. P-value indicated the percentage reliability. In case of $P < .05$ the hypothesis was accepted and otherwise rejected. Statistical package for social scientist was administered for data analysis.

**ETHICAL ISSUES:**

As the first step patients were given information about the present study and their consent for which participation was sought.

- Confidentiality was maintained throughout the study.
- Willingness of the participants was ensured.

**CONCLUSION**

The methodology which was formulated systematically helped the researcher in arriving at the exact meanings of the various units of measurements used for the purpose of study. The sampling device selected for the study was purposive sampling. First the population was divided into strata’s of high,
middle and low income group. Samples were selected from the strata and then the sub samples were joined to form the total sample. Data was collected from two hospitals having specialized oncology departments. The reason for selecting these two hospitals was that during the pilot study it was observed that the terminally ill cases found at both the hospitals were more or less same in number. On an average it was found that in a month 25 terminally ill cases are admitted in both the hospitals. After selection of the units of study, interview schedules were administered on 200 terminally ill patients. Apart from these 15 case studies were also conducted. It helped the researcher to secure a lot of information about the unit of study and has also provided clues and ideas for further research and areas of social work intervention. The collected data was coded and entered for computation. Interpretations of the table along with diagrammatic representation have been depicted in Chapter IV.