Chapter - III

RESEARCH DESIGN AND METHODOLOGY

3.1 INTRODUCTION

The population of India is growing enormously due to the demographic transition occurring in this country now. Consequent to this transition, the age structure of the population would undergo a profound change i.e., the population would become younger initially but ultimately the proportion of older people would increase considerably. There would be a phenomenal increase of elderly population from about 60 million in 1990 to nearly 150 million in 2020 (World Population Prospects –United Nations: 1990).

Kerala is the Southern most state of India where this transition is most marked. The elderly population of the state is growing at about two times faster than the total population of the state. The magnitude of the elderly population has increased from 0.9 million (5.3%) to 2.5 million (8.3%) during 1961-91 and reached to 3.5 million (9.5%) in 2001 due to the increased life expectancy. Dementia is gradually evolving as a major health problem along with this change.

Dementia is not a normal part of ageing but refers to a group of diseases which are associated with progressive and chronic disruption of intellectual functioning. (Gurland et al., 1983; Malamud, 1972).

The Epidemiological study conducted by Shaji et al. shows that 5 to 10% of people over the age of 65 are suffering from this incurable disease. The most affected person in the family due to dementia is the primary Care giver who experiences severe emotional and social stressors. The primary care-giver also can develop many physical as well as
chronic stressors that may develop burnout, which can hamper the quality of life of the patient and the health of the family caregivers.

3.2 STATEMENT OF THE PROBLEMS

Dementia is a syndrome, a cluster of signs and symptoms with myriad of possible causes. It is therefore the acquired global impairment of intelligence, memory, judgement and personality. Dementing disorders are the most common causes of psychopathology in the elderly. About 15 percent of persons above 65 years of age suffer from dementia. This ratio increases dramatically with further ageing. In India, the rough estimate of dementia at present is about 4 per cent of the elderly population over the age of 60. This means that more than four million elderly people in India now have dementia. By 2020, nearly 7.5 million Indians over the age of 60 will be victims of this terrible condition.

It is commonly held that caring for an elderly person who is mentally ill is far more of an emotional drain than caring for a person with physical disabilities (Poulshock & Diemling 1984)

As in many chronic patients, the patients having dementia cannot be considered in isolation from his/her family. Both the patient and the family are the victims of this devastating ailment. As the disease progresses, the demented individual in many ways starts behaving like a difficult child and most often the family member takes the lead role in the patient’s care. The primary care giver is the person, most heavily affected due to the disease. The most common problems faced by primary care givers are the difficulties with activities of daily living (ADLs), difficulties in handling the behavioural problems of patients and emotional outbursts in the form of anger, hostility, anxiety and depression.

This study mainly concentrates (i) on the extent of emotional and social reactions experienced by the care givers in their care-giving process, such as restlessness, hostility, anger, grief, depression, anxiety, social rejection, social isolation and (ii) various problems
faced by the care-givers in the care-giving process. Besides, the study explores (iii) the extent of reduction of social participation and extent of burden of care-givers in the various areas of family functioning.

3.3 SCOPE OF THE STUDY

One of the advantages of this study is that it helps one to understand the magnitude of various problems that the care-givers undergo while caring for the dementia patients in the family setting. The current demographic trend indicates a steady increase in the number of dementia patients in Kerala and very few studies on carer’s issues have been conducted on this subject. Thus, the study analyses the social and emotional reactions of care-givers in a systematic way.

The study aims at providing useful insights to the mental health professionals in planning suitable strategies for the effective implementation of programmes for the care-givers and dementia patients.

Besides, the findings throw light on the need for improving the quality of care-givers as well as patients and develop a culturally suited intervention model for the Care-givers.

This study also brings forth concrete suggestions to organise continuous awareness programmes and counselling facilities to ameliorate the burden of care-givers in different areas of family functioning.

3.4 OBJECTIVES OF THE STUDY

a) General objective:-

The main aim of the study is to understand the social and emotional reactions of caregivers of elderly demented persons in the care giving process.
b) Specific Objectives:-

The present study is carried out with the following specific objectives.

- To find out the socio-economic status of the care givers and patients
- To study the emotional reactions experienced by the Care givers
- To study the social reactions experienced by the Care givers
- To study the nature of various problems faced by the care-givers
- To understand and measure the level of psychological distress of the care-givers.
- To find out the association between selected socio-economic profile of the care givers and the family burden and psychological distress of the Care givers.
- To explore the extent of reduction of social participation of the Care givers
- To measure the extent of burden of care givers in the various areas of family functioning
- To suggest suitable measures for reducing the burden and psychological distress of the care-givers.
3.5 DEFINITION OF CONCEPTS

3.5.1 Emotional Reactions

a) Theoretical

It is a conscious state of experience, characterised by feeling or excitement that is accompanied and frequently preceeded by specific physiological changes and frequently resulting in excitation of the organism to action. Emotions are the physiological forms that result from one's estimate of the harmful or beneficial effect of stimuli.

Emotional reactions are the problems affecting the mind and psychological development of human being. (Oxford Advanced Learners Dictionary, New edition)

Emotional reactions are events that cause mental or emotional disharmony to an individual by destroying the normal balance of his mind.

The dictionary of sociology defines emotional reactions as problems that afflict the emotional and mental processes, consciousness, sensations, ideation and memory.

b) Operational

In this study it is defined as the feeling of ill-being experienced by care givers of elderly demented persons while caring for the dementia patients which is expressed in the form of anxiety, restlessness, guilt, grief, worry, depression, criticism, anger, hostility, rejection, chronic fatigue, loss of interest and fed up with caring.

3.5.2 Social Reactions

a) Theoretical

Dictionary of sociology defines social reactions as the reactions that arise due to living or disposed to live in companionship with others in a community rather than in isolation.
Social reactions are any events that affect the relations of an individual with other persons in the society and that which disrupts the normal social living of that individual. Social reactions are the situations affecting a significant number of people that is believed by them and or by a significant number of others in the society to be a source of difficulty or unhappiness and one that in capable of amelioration.

b) Operational

In the present study it is defined as the difficulties faced by the care givers in their social relationships, which generally lead to social rejection, social isolation, difficulties in social support, social interaction and inter-personal relationship.

3.5.3 Care - giver

a) Theoretical

Zarit & Edwards (1996) define care - giver as a family member (or friend) helping someone on a regular (usually daily) basis with tasks necessary for independent living. In the broadest sense, a carer-giver is a person who provides help and support to another person, usually a relative or friend. More specifically, a Care giver is someone who looks after another person who needs help with daily living and who would not otherwise be able to live independently at home.

b) Operational

In this study the Care givers is the significant member in the family who spends maximum time in the care of dementia patient. This may be either the spouse or daughter in law or daughter or son.
3.5.4 Elderly Demented Persons

a) Theoretical

Elderly persons

Elderly persons are defined as persons who are 60 years and above in their life span.

Dementia

Diagnostic and statistical manual (DSM IV - 1994) defines the term Dementia as a syndrome characterised by impairment from a previous higher level of intellectual functioning. The impairment involves memory and other cognitive domains such as language, orientation, constructional abilities, abstract thinking, problem solving and praxis and must be of sufficient severity to interfere with occupational or social performance or both.

b) Operational

Elderly demented persons

In the present study elderly demented persons are those who are at the age of 60 and above, suffering from a state of chronic, progressive degeneration of the brain leading to inability to think, reason and remember, which is severe enough to impair the social and occupational functioning of the individuals.

National policy on older person 1999 (Government of India) provides all the elderly welfare schemes to the persons who are 60 years and above and thus brings elderly as those who are aged over 60 years.

3.6 HYPOTHESES:

The following null hypotheses have been formulated for the present study.

1. Dementia patients from different age groups, educational groups do not differ with regard to their Total Emotional Reactions, Awareness about the Illness, Social Reactions,
Expressed Emotions, Social Participation, Level of Burden in different areas of Family Functioning and the Extent of problem that they have.

2. Male and Female dementia patients do not differ with regard to their Total Emotional Reactions, Awareness about the Illness, Social Reactions, Expressed Emotions, Social Participation, Level of Burden in different areas of Family Functioning and the Extent of problem that they have.

3. Alzheimer’s disease (AD) and Multi-infarct dementia (MID) patients do not differ with regard to their Total Emotional Reactions, Awareness about the Illness, Social Reactions, Expressed Emotions, Social Participation, Level of Burden in different areas of Family Functioning and the Extent of problem that they have.

4. Care-Givers of Dementia Patients from different Age groups, different Marital status do not differ with regard to their Total Emotional Reactions, Awareness about the Illness, Social Reactions, Expressed Emotions, Social Participation, Level of Burden in different areas of Family Functioning and the Extent of problem that they have.

5. Dementia Patients from different Age groups, Educational level, Occupation level, do not differ with regard to their level of Family Burden and their level of Psychological Distress.

6. Male and Female Dementia Patients do not differ with regard to their level of Family Burden and their level of Psychological Distress.

7. Alzheimer’s disease (AD) and Multi-infarct (MID) dementia patients do not differ with regard to their level of Family Burden and their level of Psychological Distress.

8. Dementia Patients from Urban and Semi Urban area do not differ with regard to their level of Family Burden and their level of Psychological Distress.

9. Care-Givers of Dementia patients from different Age groups, Educational levels, Religious groups, Occupational groups, and Monthly Income groups do not differ with regard to their level of Family Burden and their level of Psychological Distress.
10. Care Givers such as Male and Female, Unmarried and Married, from Joint and Nuclear families do not differ with regard to their level of Family Burden and their level of Psychological Distress.

11. There is no association between the Level of Family Burden and the Level of Psychological Distress of the Care givers.

3.7 METHODOLOGY OF THE STUDY

3.7.1 Universe and Geographical Area

The universe of the study comprised of all care givers of dementia patients in the geographical area of Cochin Corporation, in the State of Kerala, India.

a) The Inclusion Criteria

* The care givers of diagnosed dementia cases
* The family care givers who regularly look after the patients.
* Male and female Care givers.

b) Exclusion Criteria

* The professional Care givers.
* The care givers of patients who were institutionalised.
* The family care givers with severe neurological and psychiatric problems.

3.7.2. Sample Size

A sample of 250 care givers of dementia patients who fulfilled the inclusion and exclusion criteria was selected for the study.
3.7.3 Methods and Procedure of Sampling

The researcher selected 25 care givers of dementia patients using simple random sampling from the list of 323 Care givers identified by Alzheimer's and related disorders society of India (ARDSI), Cochin who were satisfying the exclusion and inclusion criteria.

3.7.4. Pilot study

The researcher conducted a pilot study at Alzheimer's and Related Disorders society of India (ARDSI) Cochin. The objectives of the study were (1) To find out the feasibility of the study (2) To get the permission and co-operation of the concerned institutional authorities to gather the relevant data (3) To gather information for framing a suitable sampling design (4) To find out which method of data collection would be effective and (5) To fix the universe of the study. The pilot study helped the researcher to modify and design the study appropriate to the research problems and objectives.

3.8 RESEARCH DESIGN

The research design was descriptive in nature focusing on the various emotional and social reactions of care givers of dementia patients.

3.9 SOURCES OF DATA

Both primary and secondary data were used for the study

3.9.1 Primary Data

The respondents viz the primary care givers constituted the source of primary data.
3.9.2 Secondary Data

Research documents, research studies, books related to dementia, study reports, literature pertaining to Care giver's burden and other relevant publications formed secondary data source.

3.10 TOOLS OF DATA COLLECTION

1. Interview Schedule prepared by the researcher to find out the socio-demographic profile and to measure the social and emotional reactions of the Care givers.


3.10.1. Interview Schedule.

The interview schedule was prepared to find out the socio-demographic profile of carer-givers and to measure their social and emotional reactions. The interview schedule consisted of questions framed on the basis of the variables identified, which were related to the objectives of the study. This schedule consists of closed questions, which are divided into six sections. The first section dealing with the socio-demographic profile includes variables like "age, sex, marital status, religion, education, occupation, income, type of family, size of family and domicile" of the Care givers.

The second section consists of emotional reactions faced by the care givers such as "anger, criticism, grief, hostility, rejection, guilt, worry, anxiety, loss of interest, chronic fatigue, fed up with caring and restlessness."
The third section deals with social reactions of caregivers such as “social rejection, social isolation, and difficulties in social support, social interaction and inter-personal relationship.”

The fourth section consists of caregivers extent of problems associated with the care-giving process such as “difficulties with activities of daily living (ADL), and difficulties in handling behavioural problems of the patients.”

The fifth section deals with the extent of “reduction of social participation of caregivers in terms of frequency of visits to relatives, neighbours, community and religious places.”

The sixth section consists of burden of caregivers in different areas of family functioning such as “adequacy of time to carry out household chores, physical needs and meeting the needs of other members in the family.”

3.10.2. Family Burden Interview Schedule by Pai & Kapur

In order to assess the burden placed by the behaviour of psychiatric patients on their respective families, the semi-structured interview schedule developed by Pai and Kapur (1981) was chosen. This instrument consists of seven domains and one extra category to account for any other burden on the family about which they were not asked. The authors have included 24 items in the instrument and also another two mutually exclusive additional questions in the schedule. One of these additional questions deals with any other burden on the family which they were not asked while the other question deals with the intensity of subjective burden as experienced by the family. The schedule has to be filled and the burden rated by skilled raters on a three-point scale such as “severe burden (2), moderate burden (1), and no burden (0)”. Each item clearly demonstrates the intent behind it. Those who have obtained below 19 are considered as having no burden, between 20 and 29 having moderate burden and above 30 have been considered as having
severe burden. The advantage of this instrument is that it was developed in our culture and that it has an additional seventh dimension of subjective burden on the family, and self-evident disadvantages of other instruments of its kind.

Scoring

The scoring pattern is by three point scale. The items in this schedule are very direct and manifest enquiries. They can be administered and rated easily by the rater. Answers to each item could be rated as ‘0’ for no burden, ‘1’ for moderate burden and ‘2’ for severe burden.

In addition to rating each item on the three point scale, similar rating can be made for each categorical domain of family burden as well as for the family as a whole.

This scale has been used in the Indian settings and the reliability and validity has been established by many researchers like Raja ram (1991), Udayakumar (1992), John Johnson (1994) and Roy (1995) and others.

3.10.3 General Health Questionnaire (GHQ-28) by Goldberg and Hillier (1979)

This is a scaled version of the original GHQ (Goldberg, 1972). It is a self-administered screening questionnaire, which can be used to -(1) establish frequency of psychiatric illness in a population. (2) Identify individuals with mental problems and reduced well being (quality of life) (3) measure changes in such situations over time. There is no theoretical assumption made about the nature of the diagnostic hierarchy within the class of psychiatric illness.

The scaled version of the GHQ consists of 28 items. There are four scales consisting of 7 items each. These scales include (a) somatic symptom (b) anxiety and insomnia (c) social dysfunction and (d) severe depression. The four sub scales are by no
means independent of one another, although correlation between the scales is lower than those between the subscales and the total score. The responses are recorded on a four-point scale and are scored as 0,0,1,1. Thus the total score ranged between ‘no’ distress (0) to high distress (28). Those who have obtained below 5 are treated as free from psychological distress, between 6 and 15 as having moderate distress and 16 and above are treated as having higher distress. The revised version of GHQ - 28 items is as well proposed as a scale to assess the extent of psychological distress among the subjects. The reliability and validity of GHQ of all versions have been established by several authors (Glodberg, 1972 and Jones, 1978). This instrument was also administered to Indian population (Shiv Gautam, 1985; Shamsundar, 1986).

This psychological distress scale has been extensively used by many investigators in Western and Indian setting (Zimmermann - Tansella, 1991). The authors suggest a cut off score of 4/5, which has a sensitivity of 88 %.

3.11 PRE-TEST

A pre-test was done on 10 care givers to find out whether the questions in the interview schedule were appropriate, accurate and meaningful to the situations. Pre testing helped to modify some of the questions in the interview schedule and deletion of certain items in the data sheet. Appropriate modifications were made to enhance the instrumentality of data collection tools.

3.12 DATA COLLECTION

The researcher visited each family of care givers of dementia persons and personally interviewed the Care givers. Each interview lasted for an average 1 to 1½ hours. It took 10 months to complete data collection. Thus a total 250 care givers from the Cochin corporation area were interviewed during this period and data were collected.
3.13 DATA ANALYSIS AND INTERPRETATION

The collected data were edited, coded and then entered into the master chart manually prepared by the researcher. Each item of data was strictly checked for accuracy before being entered into the master chart. After the coding and tabulation of data, it was analysed and interpretations were made according to the sequence of the objectives of the study.

3.14 STATISTICAL TECHNIQUES

To find out whether or not the care givers of AD (Alzheimer’s Disease) and MID (Multi infarct dementia) differ with regard to their selected socio-economic characteristic like age, sex, income, education etc, the non parametric test namely Chi-Square was used.

To find out whether or not the Family Burden, psychological distress are different from 2 types of care givers the t-test was employed.

When there are more than 2 groups and to find out the significant difference between the mean of the groups, one way analysis of variance techniques was used.

To find out the association between 2 or more quantitative variables, Karl Pearson’s correlation technique was used.

3.14.1 Chi-Square test

Chi-Square test is a powerful test amongst the several tests of significance developed by statisticians. It is symbolically written as $x^2$ and this test is applicable in a good number of problems to test (i) the goodness of fit, (ii) the significance of association between population variance (Kothari, 1990). To test the hypothesis whether two attributes are associated or not, we use the Chi-square test for independence. $c^2$ is defined
as $\sum (O-E)^2 / E$ where $O$ refers to the observed frequencies and $E$ for the expected frequencies (the ratio of the product of the row total and column total to the grand total). Generally if the $x^2$ value is greater than its table value at the corresponding degree of freedom, the hypotheses tested is considered as significant.

3.14.2 ‘t’ test

‘t’ test is an important parametric test, based on the ‘t’-distribution and is considered an appropriate test for judging the significance of a sample mean or for judging the significance of difference between the two means of two samples in case of small sample(s) when population variation is not known. In case two samples are related, we use paired t-test (what is known as difference test) for judging the significance of the mean of difference between the two related samples. It can also be used for judging the significance of the coefficients of sample and partial correlations. The relevant test statistics, $t$, is calculated from the sample data then compared with its probable value based on ‘t’ distribution at a specified level of significance for concerned degrees of freedom for accepting or in case of small sample(s) when population variance is unknown.

3.15 SETTING OF THE STUDY

The setting of the study was Cochin Corporation, which belongs to the State of Kerala the southern most state of India, with a population of 31.84 million and a population density of 819 per sq.km.(Census 2001). It has surpassed all the Indian States in certain important measures of health and social development (Park 1991). Its remarkable achievement in reducing the death rate and in increasing life expectancy and its high literacy rate (90.92%) are worth mentioning. The state is divided into 14 districts and Cochin Corporation where the present study was conducted belonged to Ernakulam district with a population of 1.2 million. There are altogether 66 divisions in the Corporation area.
Alzheimer's and Related Disorders Society of India (ARDSI) is a registered, non-profit, voluntary health organisation dedicated to the care, support and research of dementia in India. ARDSI was the first Afro-Asian national Alzheimer organisation to receive full membership in Alzheimer’s Disease International (ADI), London which is a federation of National Alzheimer’s association and which is officially affiliated to the World Health Organisation (WHO).

The main objective of the organization is to give support, succour, help and information to the families of persons affected by dementia and training programmes for care givers to improve the quality of care of the patients. Its activities include services like day care centre, domiciliary care, geriatric nursing, memory clinic facilities, information and counselling services, training workshops and support group formation for the welfare of the demented persons as well as their Care givers. Alzheimer’s and Related Disorders Society of India (ARDSI) has 13 chapters across the country and the organisation has provided different types of services such as day care and home care to more than 500 dementia patients in the study area since 1995. The epidemiological study conducted by Alzheimer’s and Related Disorders Society of India (ARDSI) gives a projected figure of 4080 dementia patients in the Cochin Corporation area with a prevalence rate of 34 per 1000.

3.16 LIMITATIONS OF STUDY

The present study, like any other studies of its nature has its own limitations. Some of the limitations are as follows.

1. The study could include only the urban population and the rural scene still remains in darkness.
2. The study was focussed on a number of problems present among the care givers. However, the impact of these problems on the care givers' lives and their effects on interpersonal relations with others were not focussed.

3. It is suggested that the data collection may involve all members of the family so that the views obtained pertaining to various issues would be more objective, collective and representative.

4. Most of the time, the interviews with care givers were disrupted due to the disturbances from the patients. Hence, the researcher had to spend more time and pay two or three visits to finish up with interviews.

5. Since some of the questions in the interview schedules and questionnaires were difficult to understand for care givers more explanations and examples had to be given to elicit complete information.

These limitations are to be borne in mind while generalizing the findings of the study to the issues related to burn out among the Care givers.

3.17. CHAPTERISATION

The research report is presented in the following chapters:

Chapter 1

The first chapter deals with the concept of dementia, its causes, the extent of the problem, diagnosis, cognitive and behavioural problems, current status of treatment approaches, problems specific to dementia and psycho-social reactions experienced by care givers of elderly demented persons.
Chapter II:

The second chapter deals with the literature review pertaining to dementia and the family care givers, studies on basic issues of family care givers, emotional and social reactions of care givers and therapeutic approaches to care.

Chapter III:

The third chapter contains the methodology with brief introduction, statement of the problem, significance of the study, objectives of the study, definition of the concepts, hypotheses, universe of the study, sample size, sampling procedure, research design, sources of data, tools of data collection, pre-test, data collection, data analysis, statistical techniques, setting of the study and limitation of study.

Chapter IV:

The fourth chapter introduces the socio-demographic characteristics of the dementia patients and the care givers. It also focuses on the various emotional reactions, social reactions, expressed emotions, elements of social participation, level of burden in areas of family functioning and extent of problems of care givers.
Chapter V:

The fifth chapter focuses on the aspects of family burden experienced by the family members of dementia patients along with the psychological distress experienced.

Chapter VI:

The sixth chapter portrates the summary findings and suggestions of the study.