Chapter I

INTRODUCTION

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INTRODUCTION

1.1 Context of the study

Man is the most complex organism in the universe with an indefinable psyche and unpredicted behaviour. The ability to regulate reproduction and control over death to some extent are the characteristic features of human beings. Still the population is rapidly expanding without any control throughout the globe, especially in the developing countries.

Increase in the number of dependable population, especially geriatric is a significant trend in the present demographic cycle. India is the second most densely populated country in the world. According to 2001 census, the number of persons above 60 years is 59.7 million in India. 4.6% of the total population is above 65 years and 6.5% is above 60 years of age. The population prediction studies show that the geriatric population is expected to increase to 78.8 million by 2010 AD, which is 7.7% of the total population. (Government of India, 2003.) In Kerala, the percentage is even higher and is about 10.6% of the total population of Kerala. (Government of India, 2004.)

A similar distribution shall be observed throughout the world. The life expectancy in the developed countries has increased to 70 years and
above in comparison to India, which was 61.5 years in 2001 (Dey, 2002). In England, about 12% of the people are over 65 years as against 4.6% in India (Irudaya, 2004). The age structure of the population in the developed countries has so evolved that the number of old people is continually on the increase. In the U.S. 65+ age group before 10 years was 12.3% of the population. Now those over 65 years are about 13% of the population, which may increase to 21.8% by 2030 (Jorm, 1987). There is currently 580 million people in the world who are aged 60 years or more. The figure is expected to rise to 1000 million by 2020, a 75% increase compared with 50% for the population as a whole (Park, 2007).

The ageing population is both a medical and social problem. It makes a greater demand on the health service of a community. Currently the elderly account for 33% of the physicians’ time, 25% of all medications and 40% of all acute hospital admissions. It is estimated that between the years 2020 & 2030, 75% of all health care providers’ time will be spent with the elderly (Lo Giudice, 1995).

The body of an aged person becomes a nest for many illnesses. Seneca (1945) has mentioned that “Old age is an incurable disease.” They become the only agent of few diseases. Dementia is a disease of that kind.
Dementia is an illness of brain and is manifested with memory deterioration. The brain cells of a person with dementia are damaged and die faster than they do normally. Gradually the person begins to lose the ability to do all activities. Every day tasks become more and more difficult and the person becomes bedridden.

Memory is one of the important abilities of human being. Memory is regarded as a special ability of our mind to conserve or store what has been previously learned or experienced, to recollect or reproduce it after sometime. Memory deteriorates slightly with ageing. The ability to remember immediate and past things and sharing this with others is a major outlet for emotional stability for old age people. If memory deteriorates faster than normal, that condition is termed Dementia.

Dementia is a progressive disease. As the onset of the disease is gradual, it is difficult to identify the exact time it begins. The early stage of the disease may be incorrectly labelled by relatives and friends as a normal part of ageing process. In the early stages the person may show difficulties with language, experience significant memory loss (especially short term), become disoriented in time and lost in familiar places, show difficulty in making decisions, lack of initiative & motivation and signs of depression and aggression (Gelder, 2000).
As the disease progresses to middle stage, problems become more evident. The person with dementia may become very forgetful (especially of recent events and names of people), be unable to cook or clean, need assistance with personal hygiene, experience increased difficulty with speech, show problems like wandering and other behavioural abnormalities and experience hallucinations.

The last stage of the disease is one of total dependence and inactivity. The person may have difficulty in eating, may not recognize relatives, friends or familiar objects, be unable to find the way back home, have bladder and bowel incontinence and become confined to wheelchair or bed till death.

Dementia is a progressive disorder and the burden of caregivers increase as the disease advances. Many researchers classify dementia according to the severity of the disease as questionable dementia, mild dementia, moderate dementia and severe dementia. The decline in cognitive area occurs in memory, orientation, judgment and problem solving, community affairs, home and hobbies and personal care.

Memory deterioration becomes marked as dementia progresses. A person with mild but consistent forgetfulness, partial recollection of events
and benign forgetfulness is suspicious of dementia. In mild dementia, there is moderate memory loss, marked for recent events, which interferes with the everyday activities and retention of remote memories that make them to talk more about that. In moderate dementia, there is severe and rapid memory loss; only highly learned materials are retained. As the disease progresses to severe dementia, there is severe memory loss and only fragments remain. They will not be able to recognize even their immediate relatives, personal things or familiar objects.

Orientation is not rapidly lost in the initial stages of dementia. It is impossible to detect any orientation disturbances in the questionable stage of dementia. When the person progresses to mild dementia, there is some difficulty with time relationship, but on examination, the orientation for place and person may be remaining intact. A person with mild dementia may have geographic disorientation. As the disease progress to moderate dementia, the affected person becomes disoriented to time and even place. In severe dementia, the person is oriented to person only, which also deteriorates later.

Judgment and problem solving ability is another area of cognitive decline in persons with dementia. A healthy old age person without dementia (i.e. clinical dementia rating, CDR = 0) solves everyday problems
and judge things well in comparison with the past performance. Only doubtful impairment in problem solving, identification of similarities and differences are observed in questionable dementia (CDR = 0.5). In mild dementia (CDR = 1), there is moderate difficulty in handling complex problems; but social judgments remain intact. Judgment is severely impaired in handling problems, similarities and differences, along with social judgment in moderate dementia (CDR = 2). When the disease has progressed to severe dementia (CDR = 3), the affected person is unable to make judgments or solve problems.

Community relationship is highly needed for every man. Normally old men have good social activities. Healthy old people have independent function at the usual level in job, shopping, business and financial affairs. It is very difficult to identify reduction in community affairs in questionable dementia. Doubtful or mild impairment is seen in all social activities. A person with mild dementia is unable to function independently in social activities, but may engage in some. The person with mild dementia may appear normal on casual inspection. When the disease progresses to moderate or severe dementia, the affected is confined to home. There will not be any independent function outside their home. They may find it difficult to identify the way back home, familiar persons or objects. The
ability to count money is lost. Severe reduction in community affairs is the characteristic feature of moderate and severe dementia.

Activities at home are lost at a lesser rate for the demented, when compared to community activities. Some healthy old persons may not perform any activities in home, but may engage in their hobbies. The hobbies may include watching television, chatting, gardening or cooking. A healthy geriatric will maintain the intellectual interest in their hobbies. Majority of old persons with questionable dementia may continue their hobbies. Few persons in mild dementia will show slight impairment in their life at home, hobbies and intellectual interests. Mild but definite impairment of function will occur for the mildly demented. More difficult chores, complicated hobbies and interests are abandoned by them. Simple chores and very restricted interest at home activities and hobbies are sustained. Severely demented persons do not function significantly at home. They will be confined to room spending their time in chair, wheel chair or bed.

Personal care and hygiene depend on many factors such as values, culture, education, resource availability and family practices. Healthy old persons are fully capable of self-care as they had been performing previously. A mildly demented person may require occasional prompting in
all self-care activities. A moderately demented person may require assistance in dressing and meeting other self care needs. The amount of assistance varies according to the functional ability of the demented person. Severely demented persons require much help with personal care. They will be having varying degrees of bowel and bladder incontinence. Incontinence of bowel and bladder along with immobility and impaired personal hygiene cause several problems like bedsores and contractures.

Old age is a period of dependency. The dependency is of a multidimensional nature. There is emotional, economical, psychological and physical dependency. As age advances, the person becomes more dependent on others. The resultant identity crisis or the ego boundary clash is also a common problem for the old age. In a person with dementia, the nature of dependency is determined by the level of dementia. The amount of dependency is directly proportional to the intensity of dementia.

An old person suffering from moderate to severe dementia is equivalent to a child with a heavy body. As the dementia progresses, the patient becomes completely bedridden. So they become completely dependent on others for everything like bathing, hygienic care, dressing, eating, toileting, walking, moving and turning till their death.
Care giving is very important in all stages of dementia. Even though the amount and nature of care given may vary from the time of diagnosing till death, it is an essential element that cannot be separated. A person, often a nearest relative who is primarily responsible for giving all the care to a demented person becomes a primary caregiver. A person who helps the primary caregiver in all care giving functions or fills the gap when the primary caregiver abstains become an informal care giver. An informal care giver can be a full time or part time, paid or unpaid person. But the primary care giver stays along with the demented and engages in care giving activities.

Traditionally, caring is the responsibility of women in almost all families. (Adams, 2001). So the wife, daughter, daughter-in-law or grand daughter becomes the primary care giver in majority of persons with dementia.

In earlier days, sick individuals were taken care of in the families by one or the other of the family members. Most of the families in olden days were joint families. Group living in the joint family ensured quality caring. The supportive network in the joint family system reduced the stress of primary care givers. Now most of the families are nuclear. All the family members are engaged in their jobs and responsibilities. They have multiple roles to perform. So they have a lot of stress and strain in their daily life. A minor disease in one
of the family members would alter the whole functioning of the family. So care giving is associated with stress or burden.

Burden is a subjective state of tiring or stress and unhealthy or diseased feeling of an individual. It involves physical, mental, social, spiritual, emotional, economic and vocational burn out. Burden of a person starts when the care giving activity load becomes excessive or unbearable for a person. Multiple causes are responsible for burden of a caregiver and are multi dimensional. It is having multiple effects on persons with dementia and related others.

The burden of family members becomes many – fold, if the old person in the family becomes sick, as there is no other person to look after the sick. The burden increases to unimaginable intensity, if the old person needs complete care including control of emotional and behavioural problems for a prolonged period of time.

Moreover, the increased cost of treatment and caring has become a real problem faced by society. Many people in the community are becoming increasingly poor. The number of people who are becoming rich is also decreasing. The cost of treatment is increasing day by day, even though the per capita income is getting reduced in the country. The average
hospital expenditure for usual sickness is that do not require hospitalization may range from Rs. 100 to Rs. 500 per day (Sweeting, 1994). The cost of medicine, investigations etc. are also increasing.

Institutional care is one of the important alternative methods of care for many chronic diseases. As far as dementia care is considered, institutional care is not available and if available, not affordable in India. This is mainly because of the chronic nature of dementia and the increased amount of care needed. It is difficult for any family to give hospital or institutional care for a person with dementia. The cost for nursing home care alone had risen to $ 75 billion in 1990 from $21 billion in 1981. At least 60% of nursing home residents are estimated to have dementia. (Hu, 1986). After an extensive search of literature, the investigator could not find any studies related to cost of treatment and care of patients with dementia in India.

Paid caregiver may be another alternative in caring. Training auxiliary caregivers and making use of their service to care old age persons with dementia is a useful service. Use of these paid care givers is also costly. Payment of Rs. 4000 per month and other expenses for their stay is needed for getting the service of a trained geriatric caregiver. So this alternate method of caring is also not affordable for majority of the families.
The use of service by an existing worker in the community like an anganwadi worker is a significant alternative to this problem. Anganwadi worker is a trained female worker in the anganwadi who is functioning under the ICDS (Integrated Child Development Scheme) project of Government. Anganwadi workers are selected from the same community and one worker serves for 1000 population. They conduct surveys and involve in several community programmes, in addition to the function of anganwadi. The familiarity, experience & willingness of an anganwadi worker is a positive factor in using them in caring of demented persons.

The caregiver’s activity for the client with dementia is the single most important factor that determines the degree of burden. A person with mild dementia is responsible for burden of psychological nature than physical burden. They forget the things they keep and the meals they eat. It is very common that they complain to others that the caregivers are not giving any meals to them or are stealing their articles. This usually leads to emotional breakdown and even physical fights between the caregivers, demented and other family members.

The burden that is commonly present for the caregiver before the occurrence of dementia to a member in the family may intensify because of dementia. But, this is not true for all caregivers. Some caregivers may not feel
any burden even though their family member is severely demented or fully demented, whereas some others often breakdown because of the burden.

The burden of care giving may be influenced by several socio economic conditions of patients with dementia and by several socio economic conditions of caregivers. The severity of burden may be determined by the factors like age, sex, marital status, education, occupation, income, relationship between caregiver and patient, facilities and members present in home and availability of informal caregiver. The severity of burden also depends on the severity or degree of dementia. The quantity of care and thereby the burden of care giving will increase when the patient progresses from mild to severe form of dementia. The health of caregiver in all its dimensions will be deteriorated by these influencing factors.

The common health problems that are faced by the caregivers include, inability to concentrate when doing any activities, reduced sleep or loss of sleep, feeling that their activity is not at all useful, loosing ability to take decisions, feeling that they are always strained, feeling that they are not able to overcome difficulties, being not able to enjoy daily activities and face personal problems, feeling always sad, loosing self confidence, feeling that they have no value etc. These health problems also vary from caregiver to caregiver depending on multiple factors including degree of burden.
Mental health is an important dimension of health. The relation between body and mind is strong. The physical health problems alter the mental health of a person. On many occasions, the mental health problems manifest as physical health problems. Therefore the caregiver needs help and support of others to maintain their normalcy. The information and knowledge about the disease is a significant factor in reducing the burden of care giving in dementia care. The dissemination of information is possible only through an effective teaching.

A positive change in all three domains of teaching like knowledge, attitude and practice (head, heart & hand) is expected with teaching. Educated persons may have more awareness and better understanding about the things happening around. If the caregiver is able to think why the person with dementia is behaving like that, it may reduce the burden to some extent. The ability for this logical thinking will be more for the more educated person. A mentally healthy person is able to adjust with the changes happening around and is unaltered by others’ criticisms. The amount of burden may be less for a more educated person and for a mentally healthy person.

Awareness about a phenomenon reduces the anxiety related to that, especially when the teaching is structured. Structured teaching is a well-
planned, systematically prepared teaching schedule with objectives, teaching learning activities and A.V. aids. Caregiver’s awareness about dementia is very important to understand the causes and reasons of their behaviour. It will enable him/her to understand why a person with dementia is behaving like that. The caregiver and the family members will be able to expect some of the future behaviours and problems of the demented and can prepare themselves to deal with those, if they are informed. The most important aspect of teaching may be about different aspects of caring. The caregiver should be taught about the general care and the specific problems and the care given to meet these specific problems. The common specific problems include safety in home, care during wandering outside, care during urinary & faecal incontinence, giving food, taking care of personal hygiene, clothing, care for lack of sleep, communication with them and the care if bed ridden.

Reduction in burden to the desired level is not possible with teaching for a few individuals, as human beings are unique. Maintenance of mental health becomes impossible for few individuals as the emotional load crosses its boundaries even after the perusal about the disease. So the reemergence of burden needs further sharing, support caring and concern of significant others. This may act as emotional ventilation for the caregiver.
Sharing sorrows with others naturally reduces the emotional impact. The overburdened caregiver in a nuclear family almost never gets a chance to ventilate. Sometimes, they may not be able to express their concern about the patient even to the nearest relative. Here, counselling is very important. Counselling is the relationship between a counsellor and a counselee, where they involve in a nondirective dialoguing with a purpose of finding a solution to the problems that a counselee has; expression of concerns with family members in a healthy way is the easiest method. The help of a professional counsellor or the conversation with specially trained health workers in the community like an Anganwadi Worker is really helpful to bring the caregiver back to normalcy.

Caring caregiver is an important concept in dementia care as there is no treatment for dementia. Frequent counselling of caregiver thus becomes a necessary measure of care. Some caregivers are very submissive or introvert. Frequent stimulation may be needed, for them to express their problems. The existing system can be used for giving education and counselling. Proper training of the root level workers like Anganwadi teachers is an effective alternate method of caring. The investigator felt that, if trained, Anganwadi teachers can become good educators and counsellors for dementia care.
The nature of counselling may vary according to the situation and nature of the problem the caregiver faces. The words from the mouth of the counsellor are equivalent to the scalpel blade in the hands of a surgeon. The wrong use of both can make the life of the client miserable. Proper training of the root level worker in all areas of dementia is essential for the proper support and counselling of clients with dementia and their caregivers.

Counselling and teaching become inseparable in some situations. The explanation and clarification of the concepts may lead to sudden emotional outbursts of caregiver, which necessitate counselling. The combination of structured teaching and needed counselling may be effective in reducing the burden of caregivers of persons with dementia. Effect occurs after an intervention. It is a subjective state and can be measured. Effect in this study is the change in burden of primary caregiver in the different periods of time after intervention that is structured teaching and counselling. The effectiveness of this structured teaching and counselling may be influenced by the demographic variables, degree of dementia (mild, moderate or severe), severity of burden and the general health problems of primary caregiver.
1.2 NEED AND SIGNIFICANCE OF THE STUDY

Estimation of the number of cases is needed to initiate any service for any disease. This is especially true when the authorities pay less attention to a disease. Dementia is a case in point, which is present in the community and is highly prevalent among the old age, but has received rather less attention from authorities and researchers.

As per the knowledge of the researcher, no such studies were conducted to find out prevalence of dementia in the suburban communities of Kerala. So a study in the suburban community, like Kadakampally Panchayat of Trivandrum district is highly needed to find out the intensity of the problem and for comparison.

Tremendous increase in the number of old age persons is observed throughout the world. The rate and frequency of disease occurrence is not the same in different parts of the world. More studies are needed to find out the general and specific problems of old age persons.

Burden associated with caring is the most important aspect of dementia care. Well documented burden studies were done in other countries related to dementia. Any attempt to quantify burden of dementia
was not noticed in India. This study is attempting to quantify the burden of dementia care.

The quality of care received by the patient with dementia will be less, if the primary caregiver is burdened. This study is testing the efficacy of an intervention in reducing the burden of caregiver. The quality of care for all documented clients shall be improved, if this intervention is found to be effective.

Mental health of a caregiver is important to increase the physical health. Well documented studies were not available about the general health problems of primary caregivers of patients with dementia. The mental health and general physical health of all caregivers can be improved by the proper use of the result of this study.

Demographic variables of patients and caregivers are assumed to affect caring in many ways. The relation and influence of these variables need to be studied to improve the caring process. The demographic variables will influence the burden of caregiver also. This study is attempting to find the relation between demographic variables and burden.

The present study is highly needed because the quality of life of patients with dementia and caregivers can be improved. These variables are
not studied in its depth in our country as per the knowledge of the researcher.

This study is significant in the present scenario.

Dementia research is becoming more popular because of the increased number of patients affected with dementia. The communication about the result of this study will increase the momentum of dementia research.

The awareness about the disease will be increased among the family members, anganwadi workers and people in the community. This study is hoped to act as a spark for future progress in the field of dementia care.

Cost - effective care can be provided to patients and caregivers if services and resources are coordinated well. A well defined policy guideline regarding the care of patients with dementia will help in effective coordination. Increased awareness about the disease may lead to formulation of a good policy guideline to render cost effective quality care to patients with dementia and their caregivers. The Government authorities shall initiate a national health programme for geriatric care, including dementia care.
Early identification of the disease is possible if the community is aware about the disease or if a trained person is available in the local community. Increased awareness about the disease, secondary to the study and training of anganwadi worker in the studied area, will help in the identification of the disease in the initial stage.

A well informed caring system can be developed based on the theoretical model and results of the study. Quality of care received by the patients with dementia will be improved because of the reduction in the burden of primary caregivers. The use of this module or related module helps in the reduction of burden and increase in general health of caregivers.

The investigator felt the need for more trained geriatric caregivers for taking care of persons with dementia, as the number of the patients is increasing with disproportional reduction in number of caregivers. Result of the study may initiate more training programme, to create an army of dedicated caregivers by non Governmental organizations and agencies, to take care of patients with dementia.

Accurate information about the disease and correct method of caring will reduce the burden and improve the general health of caregiver.
The content and teaching methodology determine the effectiveness of teaching. A well planned lesson plan with objectives and suitably selected relevant content is highly significant in the success of a teaching. The content selected for the preparation of the module for the present study like definition, causes, symptoms, types and care of persons with dementia are significant, as this information naturally reduce the burden of caregivers.

As a community health nursing person, the investigator has to make home visits. The knowledge deficit related to dementia and its care is total for the majority of affected family members. So the investigator has personally felt the need for educating the caregivers regarding the disease. The investigator also felt the importance of counselling in reducing the burden of caregivers.

The need for nursing is universal. The lack of care to an old demented person and overburden of caregivers is a challenge to nursing profession. No documented studies are found reported in India by nursing personnel about caring persons with dementia. So the clinical experience of the investigator, and the information collected while going through the literature has prompted the investigator to take up the present study.
1.3 STATEMENT OF THE PROBLEM

EFFECTIVENESS OF STRUCTURED TEACHING AND COUNSELLING IN REDUCING THE BURDEN OF CARE GIVERS OF PERSONS WITH DEMENTIA.

1.4 OPERATIONAL DEFINITIONS

1. Dementia: is a progressive disorder of brain which manifests itself by loss of memory, progressive loss of sense of time and place and increasing inability to do the most basic tasks of everyday living such as washing, eating and dressing without supervision, eventually progress to being uncommunicative, incontinent, some with severe behavioural problems, requiring full day care and ultimately die of natural causes.

2. Caregiver: is a person usually a close relative who is primarily concerned and responsible for the needed care of a person with dementia.

3. Burden: is the feeling of caregiver about their stress, embarrassment, anger, straining, emotions, suffering, loss of control and uncertainty when they take care of a relative with dementia and the intensity of that can be measured as a score using the burden interview schedule.

4. Structured teaching: is the formal systematic classes given to the primary caregivers by the investigator for changing their knowledge, attitude and
practice about meaning, causes, manifestations, treatment & prognosis of dementia and caring persons with dementia.

5. **Counselling**: is the continuous support and assistance given to the caregiver by education, skill development and the problem solving using specific techniques.

6. **Effectiveness**: is the difference in the score in burden and general health of caregivers before and after each intervention.

### 1.4 OBJECTIVES OF THE STUDY

1. To identify persons with dementia in the selected panchayat area.
2. To study the burden of caregivers of persons with mild, moderate and severe dementia.
3. To study the general health of caregivers of persons with mild, moderate and severe dementia.
4. To prepare a structured teaching module.
5. To study the effect of structured teaching and counselling, together on the burden of caregivers.
6. To study the effect of structured teaching and counselling, together on the general health of caregiver.
To study the influence of selected demographic variables on burden of caregivers.

To study the influence of selected demographic variables on general health of caregivers.

Based on the objectives, the following null hypotheses are formulated.

1.5 HYPOTHESES

1. There will be no significant difference in burden among the primary care givers of persons with mild, moderate and severe dementia in the pre intervention visit, first, second and third post intervention visits.

2. There will be no significant difference in general health among the primary care givers of persons with mild, moderate and severe dementia in the pre intervention visit, first, second and third post intervention visits.

3. There will be no significant difference in the burden of caregivers in the pre intervention visit, first, second and third post intervention visits after structured teaching and counselling in relation to selected demographic variables.

4. There will be no significant difference in the general health of caregivers in the pre intervention visit, first, second and third post
intervention visits after structured teaching and counselling in relation to selected demographic variable.

5. There will be no significant difference between the burden of caregivers in relation to the selected demographic variables.

6. There will be no significant difference between the general health of caregivers in relation to the selected demographic variables.