INTRODUCTION

1.1 Context of the study

Over the past few decades throughout the world there is an apparent increase in the number of aged people in the population. Due to shifts in population trends in many developed countries the percentage of old people has exceeded the percentage of under five children. Report of United Nations (1992) states that the number of old people is proportionally increasing which is a global trend. It is stated that there is a demographic transition towards ageing. Population studies show that in many European countries close to a quarter of population is aged above 65 years and of that three percent is above the age of 85 years. United Nation’s population studies (1992) project that there will be 19 countries in 2050 with atleast 10 percent people with the age above 80 years and will clearly out number children aged under 15 years of age. The rise in old population has lead to an enhanced interest in ‘ageing’ and peculiar problems related to aged people. Ageing as such has become a topic of interest due to the large number of people in this segment of population.

Steiglitz (1962) defines ageing as the element of time in living. Ageing begins with conception and terminates only with death. In fact ageing is more rapid in prenatal and younger years of life than in older years as it is usually perceived. But the term ‘ageing’ is used practically to denote old age almost always.
According to Becker (1959) ageing is those changes occurring in an individual as a result of passage of time. The changes include physical, structural, physiological, social and economic. He adds that ageing is both anabolic and catabolic. The first two decades of life are predominantly anabolic, whereas in middle years there is an essential balance between growth and decay. In later years of life degenerative changes predominate. Though long life is a much cherished desire of human being nobody wants to become old that is, to become an old aged.

Birren & Renner (1977) stated that ageing refers to regular changes that occur in mature, genetically representative organisms living under representative environmental conditions as they advance in chronological age. On the whole ageing seems to mean deteriorative biological and psychological changes that occur in genetically mature people. These changes are irreversible, weaken organisms’ ability for survival and eventually cause death of the organism. Generally age above 60/65 years is considered as old age or senior citizen.

As stated above globally population trends show that percentage of people above the age of 60 has markedly raised in the past few decades. This “population ageing” is due to many factors which have lead to increased life expectancy of man. Primary population ageing is a once and for all shift to an older age structure which is a consequence of long term downward trends in fertility. The shift termed demographic transition has occurred in developed countries in early 20th century. But now it has spread to other parts of the world including China & India.

The current global average life expectancy that is the average number of years a man/woman is expected to live in this world is about
64 years for both men and women. Life expectancy is much higher in developed countries with Japan occupying the top position which has 77.7 years for males and 84.7 years for females (2001). Present life expectancy in India according to 2001 census is 62 years for male and 64 years for females.

The above stated increase in life expectancy has resulted due to a host of factors which include improved modern health care, availability of better medical and social services, effective control and treatment of many diseases which were otherwise fatal etc. But most important factor is low fertility rates and low birth rate which in turn contributes to large proportion of old in the total population. Population studies show that as a result of this increased life expectancy and low fertility rate leading to lesser children, around the world aged population occupy a substantial proportion in the total population. It is projected that by 2050 Europeans aged 60 or more will reach a position that of every one in three in population will be above 60 years and will outnumber children under the age of 15 years by ratio of 2.6 to 1. The elderly made up 14 percentage of population in Great Britain in 1990 which has markedly increased over the past one decade to constitute 20 percentage of the total population. These trends are mirrored in other western countries such as United States of America and are more marked in countries like Japan. In case of Japan a country with lowest birth rate in world, the percentage of old people is naturally very high.

In developing countries also a similar shift is happening but at a shorter pace. In India also the trends in population ageing are in tune with that of other countries. It was estimated that there were over 50
million Indians over the age of 60 years in 1991 and in 2001 it was estimated to be well above 75 millions, as per reports from Govt. of India welfare programmes. This shall be compared against the fact that there were only 25 million people above the age of 60 years in 1961.

More than the percentage of old people it is the staggering large number of old people, that is highly significant in many countries like India and China which has huge general population size. India stands second among the countries having largest number of older population. There is galloping increase of old people in India which is expected to rocket up to 324 million by 2051. It is further predicted that India and China together will have 50 percentage of world’s aged population in 2020. Approximately 70 percentage of old aged will be living in developing countries at that time.

The rapid graying in Indian population clearly reflects more significantly in Kerala, a state with all health indices comparable to the developed countries. It is estimated that the percentage of aged in Kerala will increase substantially over next few decades and in 2021 every one in five (20%) will be aged above 60 years in Kerala. The expected life expectancy by that time being 69.6 for males and 73.6 for females. Rajan and Aliyar (2006) in a survey of Kerala population found that Kerala has 12 percent old aged now, which will reach the figure of 30 percent by next thirty years.

As per the survey by Economics Department (2004) the number of elderly population in Kerala presently is 26.16 lakhs. Kerala with a higher life expectancy above national average which is on par with the developed countries is on the face of a mammoth task of catering and
caring for a fast graying population. In Kerala the demographic transition has already happened with elderly outnumbering children. The number of elderly which was 11 percent in 2001 is 14 percent in 2003. In some districts of Kerala like Kottayam elderly occupies 18.3 percent of population as per census reports 2001.

Ageing brings about variety of changes in each person. It can be described under three aspects, biological, psychological and sociological changes.

The biological changes include increase in connective tissue, decreased elastic property of connective tissue, decreased number of normally functioning cells, decrease in oxygen consumption, decrease in amount of blood pumped, decrease in exhaled air, decrease in muscular strength, decrease in hormone secretion etc.

Psychological changes in ageing are marked with psychosocial transition that alters one’s relation to the world around his/her, demanding new response. Overall psychiatric morbidity is around 12 to 15 percent in this age group (Reiger et al, 1988; Kumar, 1989; Borson & Uniltzer, 2000).

Sociologically ageing brings out changes in his/her role in family, society etc. Retirement from work and decreased earning or no earning results in marked changes in a person’s status, position and role in family, ability for decision making etc.

In general, the beginning of ageing in an individual is associated with many changes which include graying of hair, advent of bifocals, wrinkling of skin, impairment in vital physical capacities, failure of
individual to function independently, ceasing to be productive, retirement from work, gradual giving up of roles in society and family etc.

In addition to the above stated normal changes in ageing there are a variety of diseases and disorders which constitute the pathological changes that commonly occur in old age and contribute to the morbidity and mortality in old age.

Studies of mortality and morbidity among population in general show that morbidity and mortality in old age has surpassed the same in other age zones particularly infancy and young ages. This welcome change not only reflects the reduction of death and disability in early years of life but also reflects age structure changes in population. One most important consequence of this shift of most mortality and morbidity to later ages is that in many populations addressing age related diseases now represents the biggest public health challenge. The ageing related changes in each bodily system leads to multiple diseases and disabilities.

In cardiovascular system usual changes include the decrease in force of cardiac contractions, impaired coronary artery blood flow, increased artherosclerosis which may lead to hypertension, ischaemic heart disease, heart failure, cardiac dysrythmia, valvular heart disease, peripheral vascular disease, varicose veins, dehydration and stroke/transient ischaemic attack.

Changes in respiratory system include increased thoracic cage rigidity, decreased elasticity, decreased vital capacity, increased residual volume, decreased cough efficiency, decreased ciliary action etc. The
Introduction

Pathologic conditions commonly seen in the respiratory system include pneumonia, chronic obstructive pulmonary disease, and dyspnoea.

The gastrointestinal tract also shows aging changes like decreased secretion of gastric acid, delayed gastric emptying, decreased gastrointestinal mobility, altered nutrient digestion, altered bowel elimination, and weakening of the lower oesophageal sphincter. All these changes may lead to diseases like diverticulitis, constipation, diarrhoea, hiatus hernia, faecal incontinence, colorectal cancer, rectal prolapse, dysphagia, anorexia, and gall bladder disease.

Genitourinary system changes include decreased bladder capacity, decreased concentrating and diluting abilities, decreased creatinine clearance, increased prostate size, which leads to renal insufficiency, urinary incompetence, urinary tract infections, enlarged prostate or prostate cancer, sexual dysfunctions, etc.

Decreased basal metabolic rate, altered pancreatic function, decrease in testosterone, oestrogen and progesterone levels are usual endocrine/metabolic changes in old age. Usual clinical conditions in this system include diabetes mellitus, hyperthyroidism or hypothyroidism, thyroid cancer, hypercalcaemia or hypocalcaemia, hyperlipidaemia, hyperuraemia, hyponatremia, and gout.

Musculoskeletal changes include decreased bone density, decreased muscle size and strength, degenerated joint cartilage, pathological manifestations include Paget's disease, osteoporosis, osteomalacia, rheumatoid arthritis, osteoarthritis, polymyalgia, rheumatoid spondylitis, fractures, foot pathology, gait disturbance, and falls.
In Autonomic nervous system changes include decreased reaction time, decreased temperature regulation, decreased sensitivity of baroreceptors which may result in frequent falls, accidental injuries, orthostatic hypotension, impaired body temperature regulation etc.

Haemotologic and immune system changes due to ageing include decreased erythropoetin production, decreased intrinsic factor, decreased function of T cell, B cell and monocytes.

Sensory changes include decreased accommodation, decreased visual acuity, decreased hearing of high pitched frequencies etc. Pathological manifestations include visual and hearing impairment and diminished smell or taste.

Skin changes include decreased elasticity, decreased secretion of natural oil and perspiration, thinning of skin, decreased heat regulation, decreased epidermal renewal, decreased inflammatory response etc. Dermatological disorders include pressure sores, basal cell and squamous carcinoma, herpes zoster, seborrheic and actinic keratosis, stasis dermatitis, pruritus, hypothermia and hyperthermia.

In reproductive system changes include vaginal muscle thinning, atrophy, decreased breast tissue, sexual dysfunction and decreased sexual desire. Pathological conditions include cervical cancer, breast cancer, prostate cancer, impotence etc.

Neurologic and behavioural changes include decreased speed of neural conduction, decreased number of brain cells, decreased neurotransmitters, decreased rapid eye movement sleep, decreased cerebral circulation etc. Pathologically parkinsonism, essential tremor,
Alzheimer’s dementia and other dementias, depression, anxiety, psychosis or paranoid states, sleep disturbance, subdural haematoma and trigeminal neuralgia. These disorders are often quoted as Neuropsychiatric disorders.

The main groups of diseases that affect the aged can be concluded in the following groups:

1. Cardiovascular diseases including angina and myocardial infarction, arrhythmias, congestive cardiac failure, varicosity and other diseases of great arteries.

2. Cerebrovascular problems including aneurysm, hemorrhage, thrombus etc. which leads to stroke.

3. Gastrointestinal disorders including ulcers, hepatic failure, pancreatic disorders etc.

4. Genitourinary diseases including infections, neoplasms, sexual problems, diseases of prostate, kidney etc.

5. Metabolic / endocrinal disorders including maturity onset diabetes, thyroid dysfunctions etc.

6. Musculoskeletal problems including strained ligaments, painful joints, varying types of arthritis, various fractures and osteoporotic changes.

7. Neuropsychiatric disorders including dementia, depression and other psychiatric disorders.
Neuropsychiatric disorders among old aged include various types of dementia. It has been found that dementia is one of the commonest problem causing high levels of morbidity in this age group.

Dementia is a chronic and progressive neurodegenerative disease characterized clinically by cognitive and functional deficits and behavioural problems. Manifestations of dementia include progressive marked loss of memory, loss of sense of time and place, various disturbances in behaviour, inability to meet basic tasks of daily living etc. Eventually the condition will progress to being uncommunicative, incontinent and many of the affected persons may develop severe behavioural problems, all of which will necessitate 24 hour care. Dementia are of various types which includes Alzheimer’s disease, vascular dementia, AIDS dementia complex, Lewie Body dementia etc. The most common type of dementia is Alzheimer’s dementia (Alzheimer’s disease) and almost half of the total cases of dementia are of this type.

It has been reported that about five percent to eight percent of people over the age of 65 years and 20 percent above the age of 80 years suffer from dementia globally (Evans, Scherr & Cook, 1990; Brayne & Calloway, 1990; Hoffman, Rocca & Brayne, 1991; Hebbert, Scherr & Backett, 1995).

Various community studies in India including those conducted in Kerala have reported about four percent to five percent prevalence rate of dementia. (Varghese, 1994a; Shaji, Promodu & Abraham,1996; Rajkumar & Kumar,1996; Rajkumar, Kumar & Tara, 1997; Chandra, Ganguli & Pandav, 1998; Shaji, Kishore, Lal & Prince, 2000).
Introduction

Dementia as a major public health problem has aroused enhanced interest in researchers due to the high prevalence. Dementia has surpassed even stroke in its incidence at the age of 80 years (Katzman, 1988; Varghese, 1994b; Chapman, 2006).

Dementia involves a number of disorders which is characterized by deterioration of previously acquired abilities that interferes with social and occupational functioning. It presents with multiple cognitive deficits in a person which is sufficient to interfere with daily activities and quality of life. The predominant complaint is loss of memory with progressive loss of sense of time, lack of orientation to place and person. The poor conduct of accustomed activities by a demented patient when compared to past performance level is highly characteristic of the condition. It is also usually accompanied by mild to severe behavioural problems finally leading to chronic impairments and debilitation requiring close supervision and care. In many cases behavioural and psychological symptoms of dementia are reported to be the most disturbing symptom to the care givers (Grigsby, Kaye, & Robbins, 1995; Shaji, 2000).

The behavioural problems associated with Alzheimer’s dementia occurs in about 80 percent to 90 percent of patients (Grossberg, Fine, Sherman, & Tait, 2000; Finkel, 2001). The behavioural problems associated with Alzheimer’s dementia though similar in presentation with many psychiatric disorders, are characteristically different from similar symptoms in other mental health disorders. These disorders are also termed as neuropsychiatric symptoms or behavioural and psychological symptoms of dementia. The commonly seen behavioural
problems in dementia include delusions, hallucinations, paranoia, depression, anxiety, aggression, wandering, sleep disturbances, inappropriate eating behaviour, disinhibition etc.

Several studies have highlighted the importance of developing management strategies for behavioural problems. (Tarriot & Blazira, 1994; Tonchon, Porter & Ritchie, 1998). Many researchers have stated that behavioural and psychological symptoms of dementia are common and are often confusing because they do not meet criteria for typical discrete psychiatric disorders (Tarriot, 1999; Tonchan et al., 1998).

The behavioural problems of dementia patients are secondary sequence of an irreversible condition. Hence it is important to device specialized measures for assessment and management of these problems. Recognising and managing behavioural problems associated with dementia is important because these problems can adversely affect quality of life of patient and caregiver and may lead to dangerous interactions with others or environment and/or may lead to institutionalization (Sunderland, Cumming & Christensen, 1996; Tarriot & Blazira, 1994; Tarriot, 1999).

Also it is of special significance to develop more non-pharmacological measures for management of these symptoms in view of the higher risk for complications due to administration of drugs and low profile response to drugs in this age group. Many of these patients are living in homes or community where care facilities are almost practically absent. Hence it is of high importance to develop specific management strategies especially suited for community and home management.
1.2 Need and significance of the study

Detailed review of related literature showed that in countries like India studies in geriatrics and problems of old age are practically minimal. The scene is even more dismal and neglected as far as identification, assessment and management of particular aspects like that of behavioural problems in dementia are concerned. Very few studies were found reported in India from this area. It was also found that even in other parts of the world interest in aspects like management of behavioural problems in dementia are of recent origin.

This study intended to assess behavioural problems in dementia. On the basis of this assessment specific management programme will be developed and implemented. This information is expected to be of help for professionals and relatives of dementia patients in managing behavioural symptoms in dementia. Also an effective management programme will help in reducing care giver distress related to behavioural problems. This attempt is of special significance, as it is intended to develop a non-pharmacological management programme. Higher risk for complications due to administration of drugs, low profile response to drugs in this age group etc. increases the significance of this study. More over most of these patients are living in homes or community, where care facilities are almost practically absent which necessitates attempts for development of specific management programme especially suited for community and home management.

This study is expected to be helpful in identifying prevalence of behavioural problems associated with dementia and is devised to give
specific information regarding presence, nature and severity of various
behavioural and psychological problems associated with dementia.
Further the management programme developed may help as a guideline
to manage the behavioural problems in dementia. Also effective
management of behavioural problem is expected to make the caring
process less strenuous for the caregiver and thereby reducing distress of
the caregiver.

Hence in view of above factors, it can be concluded that the
present study is a worthwhile attempt to assess and analyze the
behavioural problems and also to devise and test suitable management
measures for a comparatively new health problem in the community.

1.3 Statement of the problem

The problem of this study was stated as “Assessment and
Management of Behavioural Problems in persons with Dementia”.

1.4 Operational definitions

1. Dementia - in this study the term dementia is used to denote
Alzheimer’s dementia (Alzheimer’s Disease), diagnosed as per
diagnostic criteria set by DSM IV (Diagnostic and Statistical

2. Behavioural Problems - are those behavioural and psychological
disorders often observed in dementia patients which are not
associated with any other discrete psychiatric disorder. In this
study the term behavioural problems are used to denote any
changes in behaviour associated with dementia such as apathy,
depression, aggression, agitation, psychotic disturbance like hallucination, delusion, sleep disturbance etc.

3. Distress - in this study term distress is used to denote any difficulty, stress or disturbance occurring in the family care giver which the care giver perceives as caused by the abnormal behaviour of the person with dementia.

4. Management programme - in this study management programme means specifically planned and systematically implemented methods/techniques devised for managing the various behavioural problems of person with dementia. This programme includes carer education, techniques of behavioural management and environmental modification which are used as part of the intervention in this study.

1.5 Objectives

i. To identify dementia patients with behavioural problems.

ii. To determine the prevalence of behavioural problems in patients with dementia.

iii. To assess the severity of behavioural problems in dementia patients.

iv. To study socio-demographic characteristics of patients with dementia.

v. To study the association between different severity stages of dementia and severity of behavioural problems.
vi. To determine the amount of distress caused by behavioural problems of the patients in caregivers of dementia patients.

vii. To devise a management programme for non pharmacological management of problems in dementia patients.

viii. To test the effectiveness of devised management programme for behavioural problems in dementia.

ix. To study the effectiveness of management programme in reducing caregiver distress caused by behavioural problems of the dementia patients.

1.6 Hypotheses

i. There will be no significant difference in behavioural problems before and after implementation of the management programme.

ii. There will be no significant difference in behavioural problems between experimental group and control group after intervention with management programme.

iii. There will be no escalation or worsening of behavioural problems in the control group during the study period when the score at entry and final score of assessment is compared.

iv. There will be no positive relationship between severity of behavioural problems in dementia patients and distress in caregivers.

v. There will be no difference in the distress in caregivers before and after intervention to manage behavioural problems.
vi. There will be no significant difference in distress between experimental group and control group before and after intervention.

vii. There will be no significant difference in presence of behavioural problems between patients in different severity stages of dementia.

viii. The behavioural problems of dementia patients will not differ in relation to the selected socio-demographic variables (like age, gender, educational status)