FINDINGS AND SUGGESTIONS

Dementia is an "unremitting burden" on the family. Caring a person with chronic mental condition is more stressful than caring a person with a physical disorder or disability. One prominent area of consensus is that caring cognitively impaired relatives constitute chronic stress that leaves many care givers to financial, physical health and psychological consequences. The general objective of the study was to understand the social and emotional reactions of caregivers of elderly demented persons in the care giving process and the specific objectives were 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 and to suggest suitable measures for reducing the burden and psychological distress of the care givers.

A sample of 250 care givers of dementia patients who fulfilled the inclusion and exclusion criteria was selected for the study. The researcher selected 250 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, Kerala, India. The tools of data collection used were interview Schedule prepared by the researcher to find out the socio-demographic profile and to measure the social and emotional reactions of the caregivers, the Family Burden Assessment interview schedule by Pai and Kapur. (1981), General Health Questionnaire (GHQ - 28) by Goldberg & Hillier 1979 for assessment of psychological distress.

The findings of the research study demonstrate two aspects. First it helps to understand the extent of emotional stress the caregivers undergo and secondly, it suggests certain strategies to bring about a change in the perception of care giving. The chapters 4 and 5 doubtlessly point out the followings results

The caregivers who look after Alzheimer’s demented persons experience more of anger. ‘Really fed up’ was the least ranked emotional reaction.

- The awareness level of caregivers towards nature of Alzheimer’s disease (AD) and Multi infarct dementia (MID) are more when compared to the awareness level of improving quality care of Alzheimer’s dementia and multi infarct dementia patients.
- The caregivers get more caregivers support. The community support for the elderly demented persons is very low.
- The most dominant, highly expressed emotion among the caregivers is loneliness.
- The caregivers get more support from social organization. They have very less time to participate to visit their neighbours.
- The caregivers think that many a time their work has been doubled. They have less time to meet the needs of children.
- The caregivers have prioritised the major problem that they have in dressing.
- As age of the caregivers increases, the total emotional reaction decreases.
- The awareness level is high among the caregivers of age 85 years and above.
• The social reaction of caregivers decreases as age increases to the patients.

• The total expressed emotions of the caregivers among all the age groups are almost similar and much difference is not seen.

• The level of burden of the caregivers is high among the caregivers of patients below 65 years.

• The extent of problem for caregivers is found high among the patients of age 66-75 years.

• The Awareness level is found high among caregivers of female patients.

• The social reaction of the caregivers of male patients is high, while comparing with the caregivers of female patients.

• The expressed emotion is high among the caregivers of female patients than the caregivers of male patients.

• The social participation of the caregivers of male patients is high, when compared with the caregivers of female patients.

• The level of burden of caregivers is high among the caregivers of male patients than the caregivers of female patients.

• The caregivers of male patients face much problems.

• The patients who are illiterates are more emotionally reactive.

• The awareness level of patients is found high among the patient who has got secondary education.

• The social reaction of caregivers is found high among the caregivers who had primary education.

• The total expressed emotions of caregivers is found high among illiterates.

• The level of burden of caregivers is very less only among the patients who are illiterates.
• The extent of problem of caregivers based on education of patients decreases as the educational level increases.

• The caregivers of Multi infarct dementia patients are more emotionally reactive, when compared to the caregivers of Alzheimer's dementia patients.

• The caregivers of Alzheimer's dementia have more awareness, when compared to the caregivers of multi infarct dementia patients.

• The caregivers of Multi infarct dementia patients are more socially reactive, when compared to the caregivers of Alzheimer's dementia patients.

• The caregivers of Multi infarct dementia patients express emotion very much, than the caregivers of Alzheimer's dementia patients.

• The extent of problem is high among the caregivers of Multi infarct dementia patients, when compared to the caregivers of Alzheimer's dementia patients.

• The caregivers, who are between 51-60 years, are more emotionally reactive.

• The caregivers, who are between 41-50 years, have more awareness level.

• The social reaction is very high among the caregivers of age 61 and above years.

• The total emotional reaction and social participation is high among the caregivers of below 40 years.

• The unmarried caregivers are more reactive, when compared to the married caregivers.

• The awareness level is high among the unmarried caregivers, when compared to the married caregivers.

• The social reaction is high among the unmarried caregivers, when compared to the married caregivers.

• The total expressed emotion is high among the unmarried caregivers.

• The married caregivers are more participative, when compared to the social participation of unmarried caregivers.
• The married caregivers experience high level of burden.
• The unmarried caregivers face more problems.
• The financial burden is found to be high when the caregivers' age is less. As age increases the financial burden decreases and the financial burden varies as age of the patient varies.
• The disruption of family leisure of the caregivers decreases, as age increases.
• The effect of mental health of caregivers of patients belonging to age group below 65 years, it is found to be very high.
• Somatic symptoms of the caregivers of elderly demented persons, it is seen that as the age of the patient increases, the somatic symptoms for the caregivers decreases.
• As age of the patients increases the social dysfunction of the caregivers of elderly dementia patients decreases.
• Financial burden of caregivers is found high among caregivers of male patients.
• Disruption of family interaction of caregivers is found high among the caregivers of male patients.
• Anxiety and Insomnia is found high among the caregivers of male patients.
• Financial burden of caregivers based on the education of patients, it is found high among caregivers of patients who had primary education.
• The disruption of family interaction decreases as the level of education increases.
• The disruption of family activities are high among the caregivers, of coolie patients.
• Family burden is high among the caregivers of coolie patients.
• The caregivers of persons who render services are less vulnerable pertaining to most of the selected variables, based on occupation.
• The somatic symptoms of caregivers are very high among the caregivers of coolie patients.
• Severe depression among caregivers, based on the occupation of patients, it is found high among the caregivers of person who do coolie work.

• The caregivers of coolie patients are more vulnerable to any of the variables pertaining to social and economic reactions.

• The caregivers of Multi infarct dementia patients are more vulnerable to the selected variable and they are highly reactive towards socio-economic factors.

• The caregivers of Multi infarct dementia patients are highly psychologically disturbed and are more reactive to socio-economic conditions, when compared to the caregivers of Alzheimer's dementia patients.

• The caregivers of patients from urban domicile are more reactive to socio-economic conditions, than the caregivers of patients from semi urban domicile.

• Financial Burden is very high among the caregivers of 51-60 years.

• Total psychological distress among the caregivers based on their age, it is found high among the caregivers of 51-60 years age group.

• Total psychological distress, is almost similar between male and female caregivers.

• The extent of problem decreases as the education increases.

The total psychological distress decreases, as the educational level increases. The total objective burden decreases, as the educational level of caregivers increases.

• Total objective burden and distress, is high among unmarried caregivers.

• The effect on physical health and distress is seen to be high among the caregivers who are housewives.

• The effect on mental health is observed that as the monthly income increases, the effect on mental health decreases.

• The social dysfunction is high among those who get low wages.

• The total objective burden is high for the caregivers who are living in tiled houses.
• The caregivers who are living in tiled house are more socially - economically reactive than those in house with a terrace.

• The disruption of family Interaction is high among those who are in nuclear family.

• The total objective burden is found to be more among the caregivers with the family a size below 4 members.

• It has been found out that the total family members of elderly demented patient, is positively, significantly associated with the total psychological distress experienced by the patients (r=0.88; p < 0.05 sig)

• The above correlation matrix clearly indicates that there exist a positive and significant association between all the sub dimensions of family burden and the sub dimensions of psychological distress (GHQ). It is also observed that when the family burden increases the psychological distress increases, and this association is statistically significant at 0.05 level. (since, the 't' values of r values are significant). Similar trends were found for the patients from Alzheimer's disease and multi infarct dementia.

• It is found that age of the patients, age of the caregivers are positively, significantly associated with the level of family burden and the level of psychological distress. Where as the education of the patients, education of the caregivers and monthly income of the caregivers are negatively associated with the level family burden and the level of psychological distress. The above-mentioned association is statistically significant.

It can also be observed that as the age of the patients and caregivers increases the level of burden and distress also increases. Whereas the education of the patients as well as caregivers and monthly income of the caregivers increases, the level of burden and distress decreases.
5.9 SUGGESTIONS

The present study suggests series of attempts for the researcher to attribute the maladies faced by the care givers of the elderly people with dementia. The study has focused upon certain major issues which should attract the attention of people from all walks of life ranging from social work professionals to planners, policy makers, mental health professionals, community leaders, psycho-geriatricians and citizens at large. This study has made a few observations, which will be of immense help to mental health professionals especially, psychiatric social workers. The suggestions have been broadly classified into academic suggestions and practical suggestions.

5.9.1 Academic suggestions

Large differences of dementia prevalence have recently been reported between developing and developed countries. These have been used to generate potentially testable hypothesis about the impact of environmental exposures that may have obscured by an exclusive focus on research in developed countries. However, many more studies of dementia prevalence are needed in the various parts of the country especially in rural, urban, tribal areas since more variations in geography, ecology, ethnicity, culture, occupation, lifestyle and socio economic status exist in this country. This will help to understand the various influences of socio-cultural variables.

Social work intervention oriented research in the field of Care givers mental health in our country is scanty. In order to develop suitable models of social work-service, research in the areas of stress, social support, family environment, mental health problem, adjustment problems, interpersonal relationship, psychopathology of dementia and psychosocial stressors could be conducted.

Most people with dementia are cared for in their own homes, which places a heavy burden on the family members who care for them. It has shown that day care centres
significantly reduces the stress on carers. Hence one can possibly make an attempt to conduct study on the impact of day centres, which is an effective substitute for hospital.

The study could have aimed to involve systematic social work intervention wherein an intervention package could have been developed and its efficacy could also have been put under test.

It is suggested to conduct more research studies for care givers with different areas of stressful life events so as to find out if these studies reveal similar trends.

5.9.2 Practical suggestions

The study has brought to the attention that the dementia patients get less support from the community, which further deteriorates their condition. This may be due to lack of awareness about dementia and negative attitudes of general public towards them. Dementia is still considered as a mental illness and various myths, misconceptions and stigmas are attached to it. Hence it is imperative to take effective steps by the professional social workers to educate the general public about dementia and its impact on care givers through awareness classes, seminars, lectures and workshops. The continuous awareness programmes would definitely help for the early diagnosis, better treatment and rehabilitation of dementia victims.

This study has shown that awareness about dementia has helped the care givers of both Alzheimer’s and Multi infarct dementia patients to provide better care to their relatives. Hence it is suggested that more voluntary organisations are to be encouraged to work for dementia patients and sufficient fund should be made available to them.

The study has brought to the attention that the housewives are more psychologically distressed than other care givers. It may be due to their multiple responsibilities of looking after their children, husband and other family members. It has also revealed that they also get very less time to visit their relatives. Home care service is
an alternative in many areas. Home care is sometimes called a sitting service, but good home care is a lot more than just sitting service. The home care worker look after the person with dementia while the carer can have a rest, visit friends, and do the household chores.

The study shows that care givers face various emotional distress in relation to caregiving in the family setting. The social workers need to identify such care givers with psychosocial stressors and organize family intervention programmes and crisis intervention techniques to strengthen family resources and support systems.

The study reveals that social dysfunction is high among low income groups and it is recommended to provide supportive services to care givers from lower income groups, which would help to ameliorate their social dysfunction.

In the study it has been mentioned that care givers undergo immense stress and strain in the caring process. In order to deal effectively with these psycho-social problems the need of professional counsellors become imperative. The services of the professional counsellors may be made available to the care givers at individual and family levels to ameliorate their burden. Besides opportunities should be made available for carer's assessment in order to organise appropriate respite provision to the carers.

The study has revealed that the care givers highly expressed emotion is loneliness, which leads to psychological distress. Day centres can allow carers to continue to work or to have sometime to themselves, while providing appropriate care away from home. Besides, appropriate measures may be taken to provide intensive training course to the care givers either in the day centres or community centres by mental health professionals with the purpose of improving the quality of care of the patients.

The starting of self help groups of care givers could provides immense opportunities to the care givers to get together, empathies with each other, ventilate their feelings, share their problems and obtain remedies from mental health professionals.
Besides it is suggested to start volunteers groups who can visit dementia victims and their carers and provide informal support, which may reduce carer-giver’s severity of burden.

The family members often think that the patient behaves oddly with the intention of causing trouble to the Care givers. This engenders considerable antagonism towards the patient. What the family requires at this stage is the complete information about the nature, course of illness, the potential disability and the psychiatric and behavioural problems the patient may develop in future. The professional social worker can ascertain the patient’s level of functioning capacity in terms of activities of daily living (ADLs) and educate care givers to adopt suitable coping strategies.

The elderly population in India is tremendously increasing and at present geriatry is the most neglected field compared with other medical specialities. The professional social workers may take initiatives to conduct various programmes to Dementia patients and care givers including group activities, co-ordinating community resources, establishing partnership with other health and social care organisations.

It is increasingly known that dementia raises psycho-social issues at many levels. The care givers undergo series of social and emotional stresses that may lead to burn out. Hence series of attempts at individual and societal level need to be activated to cope with the growing number of dementia patients and Care givers.

A widely accepted notion within the society and in the family as endlessly supportive is that, care givers may allow governments to continue to accord a low priority to the needs of older people with dementia and other dementing conditions. Assumptions of this kind may be challenged, usefully, by descriptive studies of care arrangements for people with dementia and indeed for older people in general. Even where care is exemplary, it is essential that the impact of providing care on the family, and on the wider community be quantified. Impact should be considered in practical, psychological and in economic terms. It is particularly important that the indirect costs of caring for a person
with dementia is assessed and the broader societal implications of the findings be disseminated effectively. It is probably only thus that strong and effective arguments can be mounted for community support services for people with dementia and their Care givers.

Government may take initiatives to set up memory clinics in the District and Taluk hospitals to screen the elderly people with cognitive impairments and provide appropriate services through partnership with non-governmental organizations (NGOs). The Primary health centres (PHCs) can act as the focal referral points of the potential dementia cases.

Mental health professionals may incorporate the findings of this research study in the state mental health policy so that emotional burn out of the dementia care givers could be checked.

The case studies provide an in depth knowledge about stressful life events and the future research may concentrate on detailed case studies to trace the real impact of emotional distress experienced by the care givers of elderly demented persons. Besides pre and post intervention studies about Care givers various social and emotional problems may be conducted with similar groups to study their impact.

A separate specialisation in geriatric social work may be included in the social work curriculum with special focus on dementia care and management, which is a highly specialised field in western countries.

It is necessary to take steps to include dementia, as a disability of the elderly persons in the national policy for elders so that all benefits entitled for a handicapped person may be made available to the victims of dementia Care givers.
5.10 CONCLUSION

Dementia is a syndrome, a cluster of signs and symptoms with myriads of possible causes. It is therefore all acquired, global impairment of intelligence, memory, judgment and personality. The condition may become much worse in the next couple of decades with the phenomenal increase of dementia patients. The care givers are the real victims of this silent epidemic. Being a Care givers for a demented patient is one of the most stressful situations one can ever imagine. There is no emotional return for the Care givers, to keep the association going as it is progressively a one-way affair. It can be very demanding on one's time, patience and physical resources. It can be a very depressing experience. Comprehensive care and management of Dementia patients and support to the care givers should become the integral part of the geriatric care model. The present study was designed in such a way to address various psycho-social issues of care givers and is hoped that these findings may contribute immensely for the welfare of the care givers of Dementia patients.
Appendix-I

BIBLIOGRAPHY


Alzheimer's Scotland ; What is Dementia, Scotland


Bhatlu P.C : Medical and Health problems in the elderly (1993). National institute of Primary Health Care, New Delhi.


Celline Sunny (1999): An evaluation of Urban Community Dementia Services, Kochi Research Institute, Rajagiri College of Social Sciences, Cochin.


Development of an interview schedule, BJP, Vol.138


Harry C; Nori.G; James. D; Alzheimer’s at Your Finger Tips (1988); Class publishing London.


ICD (International Classification of Disease ) -10 – The ICD-IO Classification of Mental, and Behavioural Disorder, Clinical Description and Diagnostic Guidelines – WHO – organic including Symptoms, Mental disorder, 45-64.


Jones, G.M.M; Miesen., B.M.L. Care giving in Dementia, Research and Application; Routedge, London and New York, 1991 – 92.


Miesen Bere M.L; Dementia in Close up Rouledge. London


Pai & Kapur RL (1981)- The Burden on the Family of the Psychiatric Patient


Shubhakumar; Coping and Impact of Stress on Dementia Care – giver, paper presented at first national seminar on dementia held at Cochin, Kerala, November 1991.


Srinivasa M (1995)- Community Care for the Elderly Dementia news- vol v/95


Vijay C, Alzheimer's Disease and other Dementias, Health for million; 1999.


