CHAPTER 5
SUMMARY AND CONCLUSIONS

5.1 Introduction

This study was envisaged on the background of increased prevalence of age related disorders like dementia owing to the increased number of aged persons in population. An extensive survey of literature showed that existing knowledge about management of various problems related to conditions like dementia is limited. 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 was developed and implemented. This information is expected to be of help for professionals and relatives of dementia patients in managing behavioural problems 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 as risk for complications due to administration of drugs and low profile response to drugs in this age group. 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 was 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.

5.2 Statement of the problem

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

5.3 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 care givers of dementia patients.

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

viii. To test the effectiveness of 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.

5.4 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 care givers.

v. There will be no difference in the distress in care givers 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)

5.5 Research design

The design of the present study was experimental. Since there is paucity of experimental studies in the area of efficacy of non pharmacological management strategies for behavioural problems, this design was selected. This study was done on two groups randomly allotted to control group and experimental group. While the experimental group received the specially devised management strategies the control group received only routine care.

5.6 Population of the study

Persons diagnosed with Alzheimer’s dementia (Alzheimer’s disease) constituted the population of the study. The study was conducted in Trissur region in Kerala. Patients who were identified as part of case identification studies conducted by 10/66 dementia research group were selected for the study. Also patients attending special clinics of 10/66 dementia research group were selected. The 10/66 dementia research group is an international network of researchers interested in dementia.
On the auspices of 10/66 dementia research group ‘dementia clinics’ are conducted on weekly/monthly basis and also community/home based services are provided to demented persons.

**5.7 Sample**

Convenience sampling technique was used for selection of subjects for this study. Persons diagnosed with Alzheimer’s dementia was initially selected from either the clinics conducted by 10/66 dementia research group or from the cases identified by this research group in community survey. Each of this case was diagnosed by a senior consultant Psychiatrist based on DSM IV (American Psychiatric Association, 1994) criteria. After the primary selection of Alzheimer’s dementia cases, preliminary assessment was done using Neuropsychiatric Inventory (NPI) to measure behavioural problems.

Once the samples were selected according to the inclusion criteria they were randomly allotted to experimental and control group. This allocation was done by assigning all the odd numbers to experimental group and even numbers to control group. The first sample was selected by drawing lot.

**5.8 Tools for data collection**

The tools for data collection included the following;

1. Neuropsychiatric Inventory (Cummings et al., 1994).
2. Clinical Dementia Rating Scale (Morris, 1993).
3. Socio Demographic data sheet (developed by author).


5.9 Data collection

Data collection process included selecting an Alzheimer’s Disease patient who is willing to participate in the study and is otherwise eligible with presence of minimum score of behavioural problems as specified in the inclusion criteria. All the Alzheimer’s dementia cases reported in 10/66 dementia group either in the clinic or in the community were seen by the investigator. After establishing initial rapport and after obtaining written informed consent the person was screened for behavioural problems using Neuropsychiatric Inventory. If eligible as per inclusion criteria he/she will be allotted to control group and experimental group as the case may be. The initial assessment of the person included collection of socio-demographic details, assessment using Neuropsychiatric Inventory and clinical Dementia Rating scale.

After identifying the behavioural problems, intervention was given for those in experimental group as per guidelines formulated in management programme devised as part of the study.

Post intervention assessments were done after a period of three months and six months of initial assessment, both in experimental and control group. The intervention was reinforced and appropriate modification and alterations were made in experimental group during these visits, which involved active participation of care giver.

5.10 Analysis of data

The data collected were tabulated and analysed using descriptive and inferential statistics. The analysis pertaining to sociodemographic and clinical variables were given in the frequency distribution tables, graphs, and wherever necessary in the form of mean and standard deviations.
The significance of difference in scores of behavioural problem after the intervention was tested by paired students 't' test. Also the difference in distress caused by behavioural problems as a result of intervention in experimental group when compared to control group was tested by paired student’s ‘t’ test. ‘ANOVA’ was used to test the difference in scores of behavioural problems and distress caused by behavioural problems at three different stages of study. The correlation between behavioural problems and distress were tested by determining correlation coefficient.

5.11 Major findings of the study

The major findings of the present study are concluded below.

1. The study showed that 328 patients (84.3%) out of the 389 dementia cases screened during the study had one or more behavioural problems.

2. The behavioural problems present in dementia causes significant distress in care givers of dementia patients.

3. The prevalence of behavioural problems varies among patients and the most common behavioural problem present were irritability, delusions, agitation and apathy.

4. Prevalence of various behavioural problems were similar when the control group and experimental group was compared at the entry level assessment.

5. The specially devised intervention programme was effective in reducing behavioural problems in experimental group in comparison to control group.
6. The behavioural problems in control group at baseline assessment on entry into study worsened gradually during the period of study in contrast to experimental group in which the behavioural problems gradually reduced during the study period which showed the effect of intervention.

7. The reduction in behavioural problems in experimental group was continued throughout the study and the score of behavioural problems significantly reduced from the level at entry to lesser levels after three months and again after 6 months.

8. There was a significant difference in behavioural problem score between control group and experimental group after the intervention in experimental group.

9. The effectiveness of specially devised intervention programme in reducing behavioural problems was statistically tested and established conclusively by comparing the behavioural problems in control group and experimental group before and after intervention.

10. Distress scores related to behavioural problems were common and similar in both control and experimental group at entry into study which is an indication of presence of significant distress related to behavioural problems.

11. The experimental group showed a significant reduction in distress after intervention for behavioural problems in contrast to control group which received no intervention.
12. The control group showed gradual worsening of care giver distress during the period of study from entry level to six months in contrast to experimental group which received special intervention and showed improvement in levels of carer distress.

13. The significant difference in level of care giver distress before and after intervention in experimental group in comparison to control group established the effectiveness of intervention strategies in managing distress related to behavioural problems.

14. The intervention programme was effective in reducing care giver distress and were also effective in maintaining and continuing the reduction in distress. This was demonstrated by reduction of scores of caregiver distress when the distress scores after three months and six months of intervention were compared.

15. A significant correlation between severity of behavioural problems and score of distress experienced by caregiver was established.

16. There were no significant correlation between socio-demographic characteristics like age, gender and educational status with intensity or severity of behavioural problems.

17. There were no significant correlation between socio-demographic characteristics like age, gender and education status with severity of caregiver distress.

18. There was a significant correlation between stage of dementia and intensity of behavioural problems in dementia.

19. Severity of distress related to behavioural problems in caregiver showed a significant correlation with stage of dementia.
20. Among the behavioural problems in dementia, the most severe behavioural problems were delusions, apathy, and irritability.

21. The reduction in behavioural problems after intervention was more significant in group with moderate behavioural problems.

22. The reduction in caregiver distress related to behavioural problems was more significant in group with moderate behavioural problem.

23. Most significant reduction in severity of behavioural problems occurred in irritability and similarly caregiver distress related to irritability showed most significant reduction.

5.12 Limitations of the study

1. The number of subjects on whom the study was completed was only 200. Though 389 persons with dementia were included in the study only 200 of them could complete the study due to various problems. The problems included death of the person, change of residence, change of caregiver etc. Also it was difficult to identify large number of clients due to non reporting and non identification of cases. The requirement of clinical diagnosis by a Senior Consultant Psychiatrist made difficulty in selecting samples. If the number of samples were higher the generalisability of findings would have been better.

2. The initial selection of subjects were done on convenience sampling basis. For allotting samples into control and experimental group random method was used. But for initial selection convenience sampling was used because of difficulty in having an available population to go ahead with random sampling technique, as cases
were not readily available and was difficult to identify. The higher sampling error in convenience sampling could have been covered by opting a fully random sampling method.

3. In allotting study subjects to control and experimental group detailed matching of subjects was not done. Though eligible subjects who met the inclusion criteria was allotted to control and experimental group randomly matching for different variables were not done due to difficulty in getting adequate cases and time gap between identifying each new case.

4. The subjects of the study were living at their own residence and conditions of living and family intervention were widely varying. Such variables could not be controlled which may have affected the findings of the study.

5. The difficulty in identifying samples who met the eligibility criteria for inclusion in study led to the study being extended to many years. Hence the time difference between the first sample selection to last sample section extended over many years. This may lead to variations due to changes in society, knowledge about condition under study and attitudes of family members etc.

6. Each subject under study was followed up for a period of 6 months only. The change in the behavioural problems after this period was not studied. A longer period of follow up for each subject could have been better to arrive at more precise conclusions.

7. The investigator was not blind to the study groups. The investigator collected data with both control group subject and experimental
group with full knowledge about status of each person as to which
group the person belongs. This awareness of the investigator could
have lead to subjective prejudices in scoring though all possible care
have been taken to maintain objectivity.

5.13 Implications of the study

Major findings of the present study primarily suggest that
behavioural problems were commonly present in majority of persons who
were suffering from dementia. Also behavioural problems constituted a
prominent problem that causes distress to caregivers. Further, this
experimental study tested the effectiveness of specially devised
intervention strategies in managing these behavioural problems. It was
conclusively found that the strategies implemented were able to bring out
statistically significant reduction in behavioural problems. Based on the
above facts the implications in the field of mental health in general and
psychiatric nursing in particular are the following:

1. The first finding of this study reported that behavioural problems
   were present in 84 percent of subjects included in this study.
   Hence mental health professionals including nurses shall always
   be alert and sensitive to identify behavioural problems in persons
   with dementia.

2. Since the behavioural problems were found to be commonly
   associated with dementia as reported in this study assessment to
   identify and score the behavioural problems shall be part of
   routine assessment of any person diagnosed with dementia.
In the light of high incidence of behavioural problems reported in this study, in early family/carer education immediately after the initial diagnosis of dementia, chances of developing behavioural problems during the course of dementia shall always be mentioned. This will prepare the family members to expect and identify the behavioural problems and will enable them to seek professional help instead of misinterpreting them as deliberate behaviour and mismanaging it.

Since this study found conclusively that behavioural problems develop in huge majority of persons with dementia, all mental health professionals shall be given adequate orientation and guidance in managing the behavioural problems which shall include training in eliciting the problems, assessment and developing individualized management strategies for each client.

Present study reported that specific non pharmacologic management programme used in the study was effective in managing behavioural problems. Hence culturally and geographically specific management models including day to day management in home setting and institutional setting shall be developed. Also a simple protocol for management of behavioural problems based on the finding of the study and the detailed management programme used in this study shall be used for routine practice in clinical setting.

Since dementia awareness programmes for health professionals, public and caregivers are in the preliminary stages in a country like India, adequate importance shall be given to include
assessment and management of behavioural problems in the content of all such programmes based on the above findings.

7. Behavioural problems being the most commonly misinterpreted behaviour in dementia, carer education shall include detailed session on this topic especially in cases where the patient has behavioural problems.

8. Since behavioural problems was found to be common in majority of clients with dementia, all health professionals especially public health workers including grass root level workers shall be sensitized to identify behavioural problems in dementia as an entity different from psychiatric problems.

9. Considering the steadily enlarging number of aged population owing to increased life expectancy and higher prevalence of age related problems, geriatrics shall be given more weightage in curriculum of health disciplines. Since dementia is the most common age specific problem it shall be covered in detail including topics like management of behavioural problems and findings of studies like this in such curriculum.

10. The present study found that management programme was effective in reducing behavioural problems and distress related to behavioural problems. Hence continuing education sessions for health professionals shall focus more on geriatric problems like dementia and behavioural problems. This will help in bringing out a paradigm shift in attitude of health professionals “that some
major relief can be made in life of demented” rather than present attitude of “nothing can be done”

11. All health professionals shall be made aware of the fact that the behavioural problems are the most disturbing symptoms of dementia causing distress in care givers as reported in this study. This is highly important as about 80 percentage clients were found to develop these problems in this study. The distress of the carer drastically increases when the dementia is associated with behavioural problems as indicated by significant correlation found between distress and behavioural problems in this study. So caring for the carer shall get more importance in dementia care.

12. Since this study found that management programme developed was effective in reducing caregiver distress related to behavioural problems, carer education shall always include tips in managing behavioural problems. Specially prepared handbooks for carers shall include methods to reduce behavioural problems.

13. In view of the findings of the present study that management strategies including carer education, environmental manipulation and behavioural techniques are effective in managing behavioural problems in dementia, continuous research and adaptation of newer techniques shall be popularized in mental health.

In the light of the present study it was felt that it will be desirable to investigate further in the area to broaden our knowledge of behavioural problems in dementia.
5.14 Suggestions for further research

1. A study with larger number of samples in different type of populations can be done.

2. Similar experimental study with double blind technique to avoid researcher obtrusiveness.

3. A study which is extended over full period from diagnosis of dementia till death of patient to investigate the complete course of behavioural problems.

4. An extensive study to compare pharmacological and non pharmacological management strategies for behavioural problems.

5. Study to test effectiveness of management strategies in managing behavioural problems of institutionalized clients.

6. A study to compare the effectiveness of management strategies in institutionalized and home based clients.

7. Study to compare the difference between management strategies implemented by home carers and institutional carers of dementia clients.

8. Extensive study with frequent follow up to investigate the natural course of behavioural problems in dementia.