CHAPTER VI

SUMMARY, CONCLUSION, RECOMMENDATIONS AND IMPLICATIONS

6.1 SUMMARY

The present study was conducted to ‘evaluate the effectiveness of Comprehensive Stroke Education Program (CSEP) on knowledge and quality of life (ADL, generic and disease specific quality of life) among patients with stroke and knowledge (risk factors, warning signs and symptoms and management of stroke) and burden among caregivers at Sri Ramachandra Medical Centre, Porur, Chennai – 600 116.

The objectives of the study were to

1. Determine the effectiveness of CSEP on knowledge among patients with stroke.

2. Findout the effectiveness of CSEP on quality of life in the following aspects: ADL, generic and stroke specific quality of life among patients with stroke.

3. Evaluate the effectiveness of CSEP on knowledge among caregivers of patients with stroke.
4. Elicit the effectiveness of CSEP on burden among caregivers of patients with stroke

5. Associate the selected background variables with knowledge and quality of life among patients with stroke.

6. Associate the selected background variables with knowledge and burden among caregivers of patients with stroke.

The investigator formulated the hypotheses and they were as follows:

1. There is a significant difference in knowledge of patients with stroke who participate in CSEP than those who do not.

2. There is significant difference in ADL of patients with stroke who participate CSEP in than those who do not.

3. There is a significant difference in generic quality of life among patients with stroke who participate in CSEP than those who do not.

4. There is a significant difference in stroke specific quality of life of patients with stroke who participate in CSEP than those who do not.

5. There is a significant difference in knowledge of caregivers of patient with stroke who participate in CSEP than those who do not.

6. There is a significant difference in level of burden among caregivers of patients with stroke who participate in CSEP than those who do not.
Review of literature on related studies stimulated the investigator to gather related information to support the study, design the methodology and chose the conceptual framework. The related literatures were grouped under the following headings:

1. Stroke and its prevalence
2. Knowledge on stroke
3. Stroke and activities of daily living
4. Stroke and quality of life
5. Stroke and caregivers’ burden
6. Stroke education programme

The conceptual framework chosen for the present study was the individual and family self-management theory by Polly Ryan and Kathleen J. Sawin. The concepts of this model were modified to utilize for the present study.

The research approach was evaluative in nature. A randomized controlled trial was adopted to conduct the study in neurology wards of Sri Ramachandra Medical Centre, Porur, Chennai 600 116. Dyads who fulfilled the inclusion criteria were randomized to study or to control group. 85 dyads in each study and control group were allotted. Comprehensive Stroke Education Programme was implemented to the study group dyads. The CSEP included laptop assisted teaching for 40 minutes each day as inpatient teaching session for three consecutive days for the patients with stroke and their caregivers which included,
Day 1: Lecture on structure and function of the brain and general information on stroke and its management. The content included were stroke definition, cause, risk factors, warning signs, investigations, adherence to medication and collaborative management of stroke.

Day 2: Lecture on managing swallowing problems, bowel and bladder problems, memory problems, speech and vision problems, prevention of complications such as pressure sore, injury to affected limbs, fall prevention, swelling of affected limbs, post stroke depression and tips for caregivers which was tailored to the needs of the individual patients.

Day 3: Lecture on assisting with personal activities of daily living (bathing, toileting, grooming and feeding), Performance of Range of joint movement (ROJM) exercise on the patient that included possible movement of shoulder, wrist, elbow, hip, knee and ankle joint followed by performance by the caregiver on the patient was carried out which improved the confidence of caregiver to work out with joints.

Booklet on “Life after stroke” was provided for the study group participants on the day of discharge and it contained the information on components of Comprehensive Stroke Education Program. Telephone call was made once in every fortnight till the 180th day after their discharge from the hospital for regular follow up and adherence to medication. Reinforcement was carried out as a part of CSEP during posttest I and II by the investigator on CSEP which was tailored to the need of the individual patient.
The instrument used for the present study had two sections: Section I - It consists of three parts. Part A: Demographic variables, Part B: Clinical variables. Part C: Background variables of the caregivers. Section II - Comprehensive Stroke Education Program outcome which consist of five parts. Part A: Stroke knowledge test (SKT), Part B: Barthel Index (BI), Part C: Generic quality of life, Part D: Stroke Specific Quality of Life (SSQOL) and part D: Burden Assessment Scale.

The pilot study was conducted to assess the feasibility to conduct the main study. The data collected for the main study were analyzed using statistical test. The study findings supported the effectiveness of “the individual and family self-management theory” which was applied to this study. The major findings of the study were given below.

6.2 FINDINGS OF THE STUDY

6.2.1 Background variables

- The background variables of the dyads in the study and control group were found to be homogenous in nature as no statistically significant differences were found between the groups

6.2.2 Knowledge on stroke (patients)

- Comparison of mean scores of knowledge on stroke between the study(13.21, 13.05, 12.75) and control group (7.84, 8.09, 8.13) showed the level of knowledge found to be high among study group which was statistically significant at p<0.001.
Improvement in knowledge on stroke in Study group with pretest mean score of 6.61 and 13.21, 13.05, 12.75 during posttest I, II & III was statistically significant at p<0.001 level.

The repeated measure ANOVA on level of knowledge on stroke revealed a significant difference over a period of time in study group (pretest, Posttest-I, II & III) than control group at p<0.001 (F = 125.51)

6.2.3 ADL

The percentage distribution of level of ADL among study and control group patients revealed that 44.7% of them in the study and 37.6% of them in the control group were in need of minimal help to meet their activities of daily living in pretest. After participating in CSEP, majority (86.5%) of them in the study group were independent to meet their ADL during posttest-III whereas in control group only 42.5% were in the category of independent to meet their ADL in posttest-III.

The independent t test results revealed that the mean scores of ADL in the study group (79.06, 81.29 & 81.76) and in the control group (79.06, 81.35 & 81.63) during posttest-I, II and III was statistically significant at p<0.05 level.
• The comparison of mean score ADL within study group during Pretest, posttest-I, II, & III showed that the Posttest-III (81.76) mean score of ADL was higher than the score of pretest (76.24) and calculated t values were statistically significant at p<0.001.

6.2.4 Generic quality of life

• The comparison of mean score of physical component summary during pretest in the study group was 35.63 and in the control group was 35.68. The mean scores during posttest-I, II & III in the study group were 43.67, 44.53 & 46.53 and in the control group were 42.98, 43.87 & 44.76 respectively. The t-values obtained during posttest-III (2.542) showed a statistically significant differences at p<0.05.

• The mean score of PCS in the study group patients during pretest was 35.63 \( \pm \) 5.983. After implementing CSEP there was a significant increase in the physical component summary score in the posttest-I, II & III at p<0.001 level.

• The mean score of PCS in the control group during pretest was 35.68 in posttest III it was improved to 44.76 which was statistically significant at p<0.001 level.

• Overall PCS score over a period of time from the pretest to posttest-III between the study and control group patients showed an
improvement in the mean scores in both the groups which was statistically significant at p<0.05 (F=38.866).

- The comparison of mean scores of Mental component summary (MCS) in both the groups during posttest-I, II & III in the study group were 38.85, 38.63 & 45.93 and in the control group were 39.61, 36.85 & 34.47 respectively. The t-value obtained during posttest-III (9.931) showed a statistically significant difference at p<0.05.

- The measurement of mental component summary mean score was higher in posttest-I, II & III (38.85, 38.63 &45.93) than in pretest (34.41) and the mean difference were statistically significant at p<0.001 level.

- Statistically significant differences were found over a period of the study (pretest, posttest-I, II & III) with overall MCS score at p<0.001 (F= 59.527) between the study and control group patients.

6.2.5 Stroke specific quality of life

- The independent t test revealed the overall mean scores of SSQOL in the study group (163.53, 179.98 & 181.40) to be higher than that in the control group(163.61, 171.76 & 173.52) during posttest-I, II & III and the calculated t-values during posttest-II and III showed the
presence of statistically significant difference at p<0.01 between groups.

- Comparison of overall mean score of SSQOL within the study group revealed an improvement in posttest-III (181.40) than posttest-I which was statistically significant at p<0.001.

- The comparison of 12 domain mean scores of SSQOL between study and control group during posttest-I, II & III of energy, mobility, mood, social role and work/productivity showed a higher score in the posttest-III (9.07, 25.78, 13.78, 13.61 & 11.05) than in the posttest-I (8.26, 8.72, 23.31, 12.88 &10.76) and these differences were statistically significant at p<0.001 in study group than the control group. Personality, upper extremity functions and vision were statistically significant at p<0.01 and language at p<0.05.

- Comparison of 12 domains mean score of SSQOL within the study group patients during posttest-I & III of energy, language, mobility, self-care showed a significance statistically at p<0.001, family role, social role and thinking at p<0.01 and mood and work at p<0.05 level.

- Statistically significant differences were found over a period of time on the measurement of overall domain score of SSQOL from the posttest-I to posttest-III between the study and control group patients at p<0.001(F = 59.527).
6.2.6 Knowledge on stroke (caregiver)

- Level of knowledge on stroke among study and control group caregivers showed that 77 (90.6%) of them in the study and 74 (87%) of them in the control group caregivers were in the category of inadequate knowledge during pretest. During posttest-III there was increase in the number of subjects in moderately adequate 69 (87.3%) category in the study group whereas in control group 65 (83.3%) were in the category of inadequate knowledge.

- The comparison of knowledge on stroke between the study (11.46, 11.68 & 11.52) and control group caregivers (7.42, 7.58 & 7.48) during posttest-I, II & III revealed that the mean score were higher in the study group than the control group caregivers during posttests which was statistically significant at p<0.01 level.

- The mean score of knowledge on stroke within the study group caregivers during the pretest was 6.35 and there was a significant increase in mean score of knowledge on stroke during posttest-I, II & III (11.46, 11.68 & 11.52) which was statistically significant at p<0.001 level.

- A statistically significant differences were found over a period of the study (pretest, posttests-I, II & III) with knowledge on stroke at p<0.001(F = 20.581) between the study and control group caregiver.
6.2.7 Burden (caregiver)

- The level of burden experienced by the caregivers during posttest-I 45(53%) in the study and 57(67.1%) of them in the control group were in the category of mild to moderate burden whereas in posttest-III, 50 (63.2%) of them in the study group were in the category of mild to moderate burden and 30(38.5%) of them in the control group were in the category of moderate to severe burden. No one was found in the category of severe burden in the study group whereas in control group 5(5.7%), 7(8.4%) and 6(7.7%) had experienced severe burden in taking care of patient with stroke during posttest-I, II & III.

- The comparison of burden between the study and control group caregivers revealed that mean burden scores were 29.94 and 35.21 during posttest-I, 31.12 and 36.86 during posttest-II, 32.69 and 36.96 during posttest-III in the study and control group respectively. The mean scores were higher in the control group caregiver than the study group caregiver during the posttests and were statistically significant at p<0.01 level during posttest I & II and p<0.05 level during posttest-III.

- Comparison of burden within the study group caregiver using paired t test showed that the post intervention mean burden score during posttest-I, II & III were 29.94 of 31.12, & 32.60 respectively, all these three scores indicated that the study group caregivers were in
the category of mild to moderate burden. The mean difference during posttest I & III were statistically significant at p<0.01 level.

- The comparison of burden within the control group caregiver using paired t test also showed increase in the burden score during posttest-I, II & III was 35.21, 38.92 & 40.37 respectively, all these three scores indicated that the control group caregivers were in the category of upper level of mild to moderate burden and the mean differences were statistically significant at p<0.001 level.

- The comparison of burden between the groups over a period of time from posttest-I to posttest-III showed an increase in burden in the control group than the study group caregivers which was statistically significant at p<0.001(F=17.263).

6.2.8 Association between the selected background variables with knowledge and generic quality of life among patients with stroke

- The association between pretest level of knowledge on stroke with demographic variables of the study group patients were not having statistically significant association with age, gender, educational status, occupation, marital status, residence, total family income, type of family and knowledge with clinical variables.
There was no association between pretest level of knowledge with the clinical variables among the study group patients with stroke risk factors, stroke subtype and neurological dysfunctions.

There was an association between the pretest ADL with family monthly income which was statistically significant at p<0.05 and there was no association with other demographic variables among the study group patients.

There was an association between the neurological dysfunction with pretest ADL which was statistically significant at p<0.001. There was no association between the pretest ADL with the stroke risk factors and stroke subtype.

There was no association between the pretest generic quality of life with the demographic variable of the patient such as age, gender, educational status, occupation, marital status, residence, total family income and type of family among the study group patients.

There was no association between the pretest generic quality of life with the stroke risk factors, type of stroke and neurological dysfunction among the study group patients.
6.2.9 Association between the selected background variables with knowledge and burden among caregivers of patients with stroke

- There was no association between the pretest level of knowledge on stroke with the background variables such as age, gender, educational status, occupation, marital status, kinship with the patient and prior experience as caregiver among the study group caregivers of patients with stroke.

- There was no association found between the posttest - III level of burden with the background variables such as age, gender, educational status, occupation, marital status, kinship with the patient and prior experience as caregiver among the study group caregivers of patients with stroke.

6.3 CONCLUSION

The study conclusions are

1. Structured teaching on stroke education programme enhanced the knowledge on stroke and its management.

2. Stroke education programme is an effective intervention in improving the functional ability of patients with stroke.

4. Caregivers’ burden has significantly reduced with CSEP.

5. This study suggests that the inpatient stroke education programme involving family caregiver will enhance both individual and caregiver wellbeing and promotes quality of life.

The conceptual model adopted was the individual and family self-management theory model, which was more useful in understanding the influence of individual and family involvement in maintaining healthy behavior and prevention and management of complication.

Based on the study findings it is concluded that the combination of interventions like structured teaching, information booklet on “Life after stroke” and telephonic reminder and reinforcement are capable of increasing knowledge on stroke and thereby improving ADL and quality of life of patients with stroke and minimizing the caregiver burden in taking care of the patient with stroke.

6.4 RECOMMENDATIONS

- A comparative study could be conducted between inpatient and outpatient teaching programme.

- Similar study could be conducted as community outreach programme.
- Long term follow up study after comprehensive stroke education programme in patients with stroke could be conducted to assess the obtained benefits.

- The study could be replicated in different setting and larger samples.

- A similar study could be conducted with other teaching aids e.g. video assisted teaching.

- A multicenter study could be carried out with the same interventions.

- Phenomenology study could be conducted to find out the needs of caregivers of stroke survivors.

- A comparative study could be conducted to assess the level of burden among both the genders.

- A correlation study could be conducted to find out the relationship among the study variables.

### 6.5 IMPLICATIONS

#### 6.5.1 Nursing practice

- Public education and control of risk factors at a primary care level is the most appropriate strategy to meet the growing challenge of stroke.

- Booklet may be used to educate and instruct the patient with stroke and their caregiver.
- Continuous practice of rehabilitation program may be advised to maximize physical, psychological and social functioning.

- Nurses have close contact with patient so they must take this opportunity to involve family members to enhance their knowledge on stroke rehabilitation to improve the quality of life of their loved one.

- Nurses can also plan an inpatient stroke rehabilitation program which will pave the way for cost effective and better outcome of both individual and family.

- Providing information on role of caregiver in taking care of patients with stroke will reduce the caregiver’s burden.

- Organizing inpatient stroke rehabilitation program will enhance the functional ability, the quality of life of patient with stroke.

- Nurses must be able to identify and meet the needs of caregiver of patients with stroke which will promote both patient and care giver wellbeing.

- Expanded role of nurse by reinforcement of patient to have control over risk factor of stroke thereby, improving the quality of life after stroke.

### 6.5.2 Nursing education

- In the curriculum there must be inclusion of skill in identifying the family caregiver and how to assess the needs of the family for long term diseases.
Various modes of stroke rehabilitation programs should be added in to the curriculum.

Simple module on stroke risk factor and warning signs of stroke could be display in the public area so that awareness of stroke will be created among public.

Booklet on life after stroke could be used by the nurse educator to educate patient with stroke and their caregiver.

The curriculum should augment the self-management skills to aid patients to adapt such skills to facilitate their quality of life.

6.5.3 Nursing administration

Organizing support and educational program, empowerment, approach and implementing coping strategies will enhance the functional ability and quality of life of patient with stroke.

Take initiatives to organize the stroke units to promote stroke services.

Arrange community outreach program to meet the patients and caregivers at home in order to minimize the burden of the disease.

Policy and protocol must be established to organize CSEP for all the patients who get admitted in the stroke unit.

Collaborate with all the other team members for the effective implementation of stroke education programme.
6.5.4 Nursing research

- Nurse must maintain the registry of morbidity, mortality, institutionalism and disability for the future study purpose.
- A longitudinal research would be more beneficial to assess the long term benefits of stroke rehabilitation.
- Generalization of the study results could be made by further replication in various settings
- Explorative study could be conducted to find the need of the caregivers of patients with stroke.
- Communication of the research findings in an extensive way would create awareness among nursing fraternity.