CHAPTER I

INTRODUCTION

Where there is a will, there is a way – if you would like to survive you can…

In recent years there has been an increase in economic and demographic development in developing countries resulting in a shift from disease caused by poverty toward chronic non communicable lifestyle related disease. One among such disease is stroke.

Stroke is also referred as cerebrovascular accident (CVA) or cerebrovascular disease (CVD) and it needs medical emergency requiring immediate treatment. Prompt treatment improves the chances of survival and increases the degree of recovery that may be expected.

According to Masoud Mirzaei, et al. (2012) stroke stands globally as the second most prevalent etiology of death and is rated among the top causes of morbidity in developed and developing countries.

Stroke is a clinical syndrome describing a range of disorders which result in focal cerebral ischemia. The World Health Organization (WHO, 2005) defines stroke as ‘rapidly developing clinical signs of focal (or global) disturbance of cerebral function, with symptoms lasting for 24 hours or longer, or leading to death, with no apparent cause other than of vascular origin’. Data from WHO highlights that the mortality from circulatory disease is more than that of any other disease
group, accounting for 15 million deaths annually, or 30 percent of the annual total in which stroke accounts for 4.5 million (Charles, D.A. Wolfe, 2000).

However when community stroke registers have been specifically set up, as in the WHO MONICA project, the evidence suggests that for the purposes of international comparisons, there is good agreement between mortality rates from official statistics and stroke incidence registers (Thorvaldsen, et al., 1995). In the past, stroke was thought of as mainly affecting industrialized countries. However, recent studies suggest that stroke in the developing countries is also becoming a major health problem, and two thirds of stroke deaths now occur in non-industrialized countries (Wolfe, 2000).

The most vital symptoms of a stroke is sudden weakness or numbness of the face, arm, or leg, most often involving one side of the body, occurring in 90% of the patients with stroke. Other symptoms include misperception, trouble in dialogues or understanding speech, difficulty in seeing the visual fields, difficulty walking, dizziness and loss of balance or coordination, severe headache with no known cause and fainting or unconsciousness.

Stroke is a global health problem and rehabilitation is a major part of patient care where the statistics on cerebro vascular accident quoted by world health organization projects that nearly 15 million people suffers from stroke worldwide each year. Of these, 5 million die and another 5 million are permanently disabled
whereas high blood pressure contributes to more than 12.7 million strokes worldwide. Approximately Europe accounts for 650,000 stroke deaths each year (WHO, 2002). Due to increase in baby boomers overall prevalence of stroke has been inclining and vice versa contributed to the decline in incidence due to the curious efforts of various programmes and agendas formulated to curb high blood pressure and reduce smoking.

In highly developed country like United States, stroke prevalence seems to be high in hotlists like stroke is the third leading cause with a projected mortality rate of more than 140,000 people each year and with residual disabilities. Every year, approximately 795,000 people suffer from stroke where 600,000 of these are first attacks and 185,000 are recurrent. After the age of 55 the risk factor doubles for stroke prevalence. Nearly one fourth of strokes occur in people under the age of 65. Atrial fibrillation (AF) is an independent risk factor for stroke; increasing the risk about five - fold (Dalal, 2007).

World health organization project on stroke describes that Indian terrain has a major risk pose due to stroke where the prevalence was 55.6 per 100,000 at all ages (Dalal, 2007). 0.63 million deaths occur in every year (WHO, 2005). Nearly 1.44 - 1.64 million cases of new acute strokes bloom every year (WHO, 2005). 12% of strokes occur in the population aged less than 40 years (Shah & Mathur, 2006). 28-30 days case fatality ranges from 18 - 41% (Dalal, et al., 2008).
The economic burden caused by stroke has not been explored in India. However, India is estimated to have lost 8.7 billion 1998 international dollars in 2005 due to Coronary heart disease (CHD), stroke and diabetes. This is to increase to 54 billion 1998 international dollars by 2015 and India’s growth of gross domestic product (GDP) is estimated to fall by 1% because of the combined economic impact of CHD, stroke, and diabetes (WHO, 2005).

A recent study indicated that national per-capita income was the strongest predictor of stroke mortality and DALY loss even after adjustment for cardiovascular risk factors (Jeffrey, 2009). Dalal, et al. (2007) stated that worldwide 28.5 million DALYs were lost due to stroke in the year 1997; nearly 6 times higher than that of malaria. This is projected to increase to 61 million DALYs in 2020. Eighty four per cent of these DALYs loss will be in developing countries. Gupta (2008) pointed that in South East Asia alone, where India comprises 81% of the population, 6.36 million DALYs are estimated to have been lost due to stroke.

Recovery after stroke is physically and mentally exhausting since stroke affects each person differently. Patients must be persistent enough to achieve favorable recovery following stroke.

Stroke is a leading cause of functional impairments, with 20% of survivors requiring institutional care after 3 months and 15% - 30% being permanently disabled. (Adams R et al, 2008).

Stroke is a life-changing event that affects not only the person who may be disabled, but also their family and caregivers. There is life after a stroke and there
are things that can be done to reduce the disability and burden imposed on the patient and their caregiver. Complete recovery may not be possible for all the patients but improved quality of life can be achieved often.

1.1 NEED FOR THE STUDY

“The inlet of man’s mind is what he learns,
The outlet is what he accomplishes.
If his mind is not fed by a continued supply of new ideas
Which he puts to work with purpose and
If there is no outlet of in action his mind become stagnant,
Such mind is danger to the individual and is
Useless to the community also”

- Jirminia, W. Jerks

Many people think that they would work until they retire, but sometimes it does not work out that way. There are many different types of illnesses that can affect people at different times and with a little to no warning. CVA is one of these diseases that can strike with little warning and can have a dramatic effect on one’s life.

Stroke is a disease with great consequences for the patients and their family members. The spouses often feel obligated to care for the patients to cope up with the physical and cognitive impairments. This might lead to increased problems as family members struggle to adapt to their new roles and responsibilities. Though it is difficult to predict the degree of success, but it is best to start treatment as soon as possible. Success depends not only on the multidisciplinary team effort but also on support received from family members.
Primary prevention is particularly important because >70% of strokes are first events. Secondary prevention strategies include pharmacotherapy with aspirin, dipyridamole, clopidogrel. More recent evidence suggests that a 24% reduction of death from all vascular causes can be achieved with use of aspirin and dipyridamole, however caution is required with dipyridamole as it is not well tolerated by the patients (Adams R et al, 2008).

Gupta, et al. (2008) pointed that the effective management of co-morbidities such as hypertension and atrial fibrillation is also necessary to reduce the stroke incidence with the use of:

- Anti-hypertensive drugs are estimated to be 35 - 44%.
- Anticoagulants for atrial fibrillation are estimated to be 20 - 45%.
- Statins for high cholesterol is estimated to be 20%.

The most common predictors of death from stroke for those aged more than 65 years of age include previous stroke and atrial fibrillation. Stroke alters day to day life of patients and their family. Caregivers face a burden in taking care of stroke patients due to sudden change in the lifestyle and isolation that often follow a stroke.

Well-organized stroke services are severely lacking in the government sector of India, and most stroke centers are situated in the private and urban settings in India, when 70% of the population lives in rural areas (Murthy, 2005). As such,
modern acute stroke care (with optimal use of intensive care units, neuro-imaging, thrombolytic evaluation, monitoring and intensive rehabilitation) appears beyond the reach of most patients (Dalal, 2007).

Dalal, et al. (2008) widely stated that infectious diseases being endemic and non-communicable disease are at a low priority raising the ethical dilemmas which scare health care resources from control of infectious and nutritional disorders to control stroke and cardiovascular diseases.

An urban, hospital-based study conducted by Srivastava & Prasad (2001) indicated that the median time from the onset of stroke to the arrival at hospital was 7.6 hours and that only 25% of patients were presented to hospital within 3 hours of stroke. In comparison, a similar study undertaken in a rural area identified that the mean arrival time of stroke patients to hospital was 34+/6 hours. Living in a city with a presence of family history of stroke and older age were all positively associated with early arrival. Additionally, another study signifies that the late arrival was associated to lack of transportation with only 12% reaching the hospital by ambulance and 17% by bicycle or rickshaw (Pandian et al, 2007). More specifically related to stroke, national policies should emphasize on:

- Evidence-based training of community physicians and health workers in the prevention, diagnosis, management, and rehabilitation of stroke.
• Evidence-based public education about stroke warning symptoms, risk factors, morbidity, mortality, and importance of time window for acute treatment.

• Capacity building to provide sufficient resources for above education and delivery of stroke-related services.

Well Wood, et al. (1994) identified that the need for better information, in addition to greater provision of support which had been voiced out by the stroke patients and their caregivers. 40% of the stroke patients and 45% of the caregivers were dissatisfied with the information received about stroke before they discharge. He also stated that the information needs of patient and their caregiver in hospital and after discharge are not being met, despite the efforts of health services and voluntary agencies. This may be due to the stressful situation, or the information was not clear, was too complicated, was too general and did not address the patient or caregiver own issues of concern.

Limited amount of patient knowledge and public awareness of stroke, its symptoms and risk factors exist in India. In future studies need to focus on different Indian communities, giving the vast diversity within India. Lastly, efforts are urgently needed to educate the public about stroke symptoms, diagnosis, and treatment. So as to optimize health care decisions and behaviors in order to help curb the growing stroke problem in India (Pandian, et al., 2005).

Cross sectional survey conducted by Cleusa Ferri, et al. (2011) investigated prevalence of stroke and related burden among older people living in
Latin America, India and China. Self-reported stroke diagnosis, caregiver burden were assessed using a standardized protocol. The proportion of stroke survivors who needs care varied between 20% and 39%. 87.5% of caregivers in rural India had to cut back their own jobs to take care of the stroke patients and 20% of them employed paid caregivers. Increasing age and dementia made largest contribution to caregiver’s strain.

Self-reported survey executed by Nina Fudge, et al. (2010) among 1251 stroke patients to identify the long-term needs after stroke among UK population with 44 closed questions revealed 50% of them reported three unmet needs that are physical & other stroke related problems (mobility - 5%, fall - 21%, pain - 34%, incontinence - 21%, emotional problems - 39%), 54% reported that they needed more information regarding stroke and 52% of them mentioned social problems that changed leisure activities, loss of income due to stroke and increase of expenses.

Larson, J., Franzen-Dahlin, A., Billing, E., Arbin, M., Murray, V. & Wredling, R. (2005) determined the impact of a nurse led support and education program for spouses of stroke patients. The study findings revealed that intervention group had significant decrease in negative wellbeing and increased quality of life over a period of time whereas the control group showed significant decrease in negative and general wellbeing. The results showed that the support and educational program might have positive effect on spouse’s wellbeing.

After stroke the patient may needs help to relearn functional skills and need to adapt to remaining disability. Education program helps the stroke patients and their caregiver to learn to use the affected body parts after stroke and redevelop
balance and coordination. This also helps to gain skills to perform important activities and conserve energy. Outcome depends on each individual’s striving, confidence and motivation level.

The need to manage chronic conditions and to actively engage in a lifestyle that fosters health is increasingly recognized as the responsibility of the individual and their family. Individuals and families are expected to sort through the myriad of contradictory health information of varying quality and engage in behaviors promoting their health. The management of chronic health conditions leads to the improvement of their health outcomes, increased quality of life and realignment of health care expenditures including a decreasing demand for health services; self-management also contributed to the overall health of the society (Polly Ryan & Kathleen Sawin, 2009).

Self-management skills and activities are designed to enhance health behavior change, decrease health care cost and increase quality of life or wellbeing. Comprehensive stroke education programme which is designed for the stroke patient and their caregiver enhances the knowledge on stroke, improve functional ability, management of post stroke complications, adherence to medication, engagement in healthy behavior to prevent further stroke, reduce the health care cost and to promote quality of life. With these ideas the investigator had chosen “The Individual and Family Self-management theory” (Polly Ryan & Kathleen Sawin, 2009) for the present study.

Helen Rodgers, et al. (1999) proved that provision of structured, personalized information to the patient with stroke and their caregiver by a specialist nurse will improve knowledge, quality of life and satisfaction with the information that they received.
Nurses specializing in rehabilitation train the stroke patients to relearn how to carry out the basic activities of daily living. They also educate survivors about routine health care, such as how to follow a medication schedule, how to care for the skin, how to move out of a bed and into a wheelchair, and special needs for people with diabetes and hypertension. Rehabilitation nurses also work with stroke patients to reduce risk factors and provide training for caregivers.

With the growing number of studies on this intervention for the stroke population, there is a need to consolidate the evidence to determine the potential use of stroke education programme particularly for stroke patients and their caregiver.

The challenge for the future is to develop new approaches that will enhance stroke outcome. More randomized controlled trials comparing stroke educational programme are thus urgently required.

Nurses have come a long way in a few decades. In the past our attention focused on physical, mental and emotional healing. Now we talk of healing life, healing the environment and healing the planet.

- Lynn Keegan

In light of these findings the investigator felt a strong need to undertake the present study on “Effectiveness of Comprehensive Stroke Education Program (CSEP) on knowledge and quality of life among patients with stroke and knowledge and burden among caregivers at neurology wards”.

1.2 STATEMENT OF THE PROBLEM

A study to evaluate the effectiveness of Comprehensive Stroke Education Programme (CSEP) on knowledge and quality of life among patients with stroke and knowledge and burden among caregivers at neurology wards, Sri Ramachandra Medical Centre, Porur, Chennai – 600 116.

1.3 OBJECTIVES

The objectives of the study are to

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

2. Find out 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.
1.4 HYPOTHESES

**H1:** There is a significant difference in knowledge of patients with stroke who participate in CSEP than those who do not.

**H2:** There is significant difference in ADL of patients with stroke who participate in CSEP than those who do not.

**H3:** There is a significant difference in generic quality of life among patients with stroke who participate in CSEP than those who do not.

**H4:** There is a significant difference in stroke specific quality of life of patients with stroke who participate in CSEP than those who do not.

**H5:** There is a significant difference in knowledge of caregivers of patients with stroke who participate in CSEP than those who do not.

**H6:** There is a significant difference in the level of burden among caregivers of patients with stroke who participate in CSEP than those who do not.

1.5 OPERATIONAL DEFINITIONS

1.5.1 Effectiveness

Find out the outcome of CSEP on knowledge of stroke and Quality of life (generic and disease specific quality of life) among patients with stroke and knowledge of stroke and burden among caregivers of patients with stroke.
1.5.2 Comprehensive Stroke Education Programme

One to one laptop assisted teaching to the dyad (patient + caregiver) by lecture method which is used to teach the patients with stroke and their caregiver. It consisted of 40 minutes of inpatient teaching session each day for three consecutive days which include,

**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 were 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 issued on the day of discharge. Telephonic reminder once in every fortnight for regular follow-up and adherence to medications, reinforcement on CSEP following posttest I & II which were tailored to the needs of the patients.

1.5.3 Knowledge

Response of patients and caregivers on risk factors, signs and symptoms and management of stroke as elicited by the stroke knowledge test (SKT).

1.5.4 Quality of life

Person’s perceived view of overall life satisfaction and their functional ability which are measured by Short Form - 36 V2, Stroke specific quality of life (SSQOL) and Barthel Index respectively.

1.5.5 Stroke

Patient with the diagnosis of ischemic or hemorrhagic stroke based on the CT- Scan findings with modified Rankin grade of 1 - 4 score which indicated mild to moderate disability following stroke.

1.5.6 Caregiver

An individual who provides care to the patient in the hospital and thereafter at home for a period of 180 days or above.
1.5.7 Burden

Caregiver’s hardships in the care of patient with stroke at home in the aspects of feelings regarding care of relative, sense of responsibility, impairments, relationship with family and friends as measured by Burden Assessment Scale (BAS).

1.6 ASSUMPTIONS

- Education enhances overall wellbeing of an individual
- Caring chronically ill patient is stressful
- Rehabilitation enhances quality of life
- Personal effort enhances healthy behavior
- Self-management promotes healthy living