

**CAREGIVER MANAGEMENT IN STROKE PATIENTS:  
SYMBOLIC INTERACTION PERSPECTIVES**

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CAREGIVER MANAGEMENT IN STROKE PATIENTS : SYMBOLIC INTERACTION PERSPECTIVES.

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ABSTRACT

The purpose of this study was to investigate the experience and management of the stroke patient's caregivers. This study uses qualitative methods, especially in-depth interviews with thirteen care givers of moderate and high level of disability patients.

This study found that there are more than half the stroke patients in bad conditions and had to return to hospital many times. The bad conditions of the patients were related to being involuntary care givers or being unsupported care givers. It is involuntary because of having none to take care, social duty, paying back or being sympathy. Therefore, they tend to provide the least sufficient form of care. These care givers tend to experience many problems. They, for example, suffer from the negative meaning of the stroke such as the disable and chronic disease, high burden, being stigmatized. They always get the negative responses of the patients when the patients get stress or sick. They suffer from quarrels with their relatives in many issues such as who will pay and why the patient got worse. They worry about financial problems. They are in conflict with their family members such as being unable to take care of their family. They are tired and got sick of long hours of care. Most of these suffers are not solved or released. As a result, the patients are in bad conditions. It is recommended that for the good of the patient, the health care system should try and receive the care givers

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บทคัดย่อ

การวิจัยครั้งนี้มีวัตถุประสงค์เพื่อศึกษาประสบการณ์และการจัดการของผู้ดูแลในการดูแลผู้ป่วยโรคหลอดเลือดสมอง .การศึกษานี้เป็นการใช้วิธีการวิจัยเชิงคุณภาพระดับลึกในกลุ่มตัวอย่างผู้ดูแลที่ศึกษา 13 รายที่ดูแลผู้ป่วยโรคหลอดเลือดสมองมีความพิการระดับปานกลางและรุนแรงขณะอยู่โรงพยาบาลและติดตามต่อที่บ้านในเขตกรุงเทพและปริมณฑล

ผลการวิจัยพบว่า ผู้ดูแลมากกว่าครึ่งของผู้ป่วยโรคหลอดเลือดสมองมีสภาพแย่และกลับมาโรงพยาบาลหลายครั้ง.ภาวะสภาพที่ย่ำแย่ของผู้ป่วยโรคหลอดเลือดสมองสัมพันธ์กับความไม่เต็มใจดูแลของผู้ดูแลหรือขาดการสนับสนุนช่วยเหลือของผู้ดูแล.ความไม่เต็มใจดูแลเกิดจากไม่มีเวลาดูแล, หน้าที่ทางสังคมที่ย่งยาก, การใช้เงินจ่ายทดแทนหรือความสงสาร.เพราะฉะนั้นผู้ดูแลมีแนวโน้มไม่เพียงพอในการให้การดูแลผู้ป่วย.คนดูแลเหล่านี้เกิดปัญหามากมาย.เช่นพวกเขาทุกข์ทรมานจากการให้ความหมายด้านลบในด้านความพิการเกิดขึ้นจากโรคที่เป็นอยู่และความเป็นโรคเรื้อรัง, ภาระยุ่งยากมาก, รวมถึงการตีตราเกี่ยวกับผู้ป่วยโรคหลอดเลือดสมองที่ดูแลอยู่.คนดูแลแสดงออกและตอบสนองในด้านการดูแลผู้ป่วยไม่ดี ส่งผลให้ผู้ป่วยเกิดความเครียดหรือเจ็บป่วยขึ้น.คนดูแลทุกข์ทรมานจากการทะเลาะกันภายในครอบครัวหลายเรื่องเช่น ใครจะจ่ายค่ารักษาและทำไม่ผู้ป่วยมีอาการแย่ลง. พวกเขากังวลมากเกี่ยวกับปัญหาทางการเงิน.ส่งผลให้คนดูแลเกิดความขัดแย้งกันภายในสมาชิกของครอบครัวตลอดจนไม่สามารถดูแลครอบครัวของคนดูแลเองได้. ทำให้คนดูแลเหนื่อยมากและเกิดเจ็บป่วยที่ต้องดูแลเป็นระยะเวลานาน.พบว่าความทุกข์ทรมานของผู้ดูแลส่วนมากไม่ได้รับการแก้ไขหรือลดความทุกข์ทรมานลง.สรุปการศึกษาวิจัยครั้งนี้ผู้ป่วยยังอยู่ในสภาพที่ย่ำแย่.เสนอแนะว่าการให้ผู้ป่วยภาวะที่ดี, ควรมีระบบสุขภาพเข้ามาดูแล, คำจุนช่วยเหลือผู้ดูแลด้วย

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## **CHAPTER I**

### **INRODUCTION**

#### **Background and Significance of the Problem**

At present, sickness of the Thai people has been deviated. With effectively controllable infection and decrease of death rate, it leads to the increase of population and city expansion. Industrialization has also remodeled society, environment and lifestyle. Being stressed from work, people have changed their lifestyles with inadequate leisure, consumption behaviors, and physical exercises. It tends to create non-infected diseases and escalates the public health problems i.e. heart disease, accident, cancer, and high blood pressure ( Tianchaiy Keeranant, 1996)

Chronic illness has drastically been increases and cannot be cured. People have to spent most of their lives with infirmities. Controls and symptom-based treatments are required to deter its progression in order to reduce the acute of the symptoms and potential side effects. Actually, the health service systems cannot respond to all the needs of the chronic patients. Hospitals then become the health service sites and treating only the recipients with acute illness. Therefore, systematic supervisions over the chronic patients, particularly the secondary caregivers and family play growing roles in the health service systems at present and in the future.

It has been found in a report of WHO (WHO,1995: 361-367) the Cerebrovascular accident or CVA or Stroke is still critical problem and often found among admitted mental disorder patients. CVA is an acute chronic illness affecting the patients and their families both in short-term and long-term. This illness critically causes death among top tens worldwide. It affects economics and socials as well as the patients themselves, their families, communities, and countries. Many researches report that in developed countries such as the United States of America, Europe, and Australia, CVA has been third in the cause of death following the cardiovascular illness, and cancer. (Bonitar, Beaglehole R, North JDR, 1984;12:236-43 )

In Thailand, it is found that there are by average 10-12/100,000 patients died of CVA. (details are in Table 1). Also, it is the fourth cause of death in the country since 1991 (Office of Public Health Policy and Plan, 1998). From the statistics of 1992-1997, there were 38, 602 patients. Those ages were 55 years were found most and more in males rather than females who have met with death of cerebral vascular illness. (Principe et al.,1997). It was also found among other risk groups e.g. patients of diabetes, high blood pressure, cholesterosis, cardiopathy, arteriosclerosis, smoking, drinking, sapraemia, birth control dosing, corpulency, short of physical exercises, family records of parents died by CVA, and prior stroke. During 1994-2000, in Ramadhibordi Hospital, it has been found that number of patients have been increasing in every pathological ward (details in Table 2).

Table 1 Dead Rate of Population Caused by CVA in Thailand (1992-1997)

BE/AD	The Deceased	Average / 100,000(patients)
2535 (1992)	6,776	11.8
2536(1993)	6,560	11.3
2537(1994)	6,220	10.6
2538(1995)	6,463	10.9
2539(1996)	6,508	10.9
2540(1997)	6,075	10.1

Source: Statistics of Public Health, Ministry of Public Health, 1998

**Table 2** CVA Patients in Ramadhibordi Hospital during1994-2000

Ward	1994	1995	1996	1997	1998	1999
Female Pathology	26	18	17	24	25	22
Male Pathology	28	28	24	25	39	18
Male and Female Pathology1	17	25	27	26	12	34
Male and Female Pathology2	9	14	9	12	9	16
Total	118	139	119	117	145	162

Source: Statistics unit of Ramadhibordi Hospital during1994-2000

At present, sciences and technologies of medicine and nursing had remarkably improved. It leads to more effective treatments and enables to survive acute and dilemma CVA as well as drastically reduces death rate. However, chronic CVA patients who are disable have been increasing each year.(Bonita & Beaghole, 1995:541-542; Donglase & Peterson ,1995 : 1999-2003). Survivors of CVA turn to be crippled, permanent disable, and paucity in self-caring. Treatments and rehabilitation are required and pursued assistance both during being admitted into the hospital and sequential caring at home.(Doolittle, 1988:169-173; de Meses &Perry,1993:10-14;Pierce, et al., 1995;138-143)

The supervisions of the CVA patients are complicated and consistent process. It needs at least a family member to take a caregiver's role from the hospital respectively to home. It is not only supervising the health care as being advised by the physician but also assisting the daily routine work, interactions and taking care of the psychological affairs. It is a heavy workload for a family caregiver to attend the patient because of being the additional work to the routine ones. Each daily routine job will be consumed by continuous and prolong caring, which will affect the time management of the family caregiver itself whether it were work-life, career, socialization and privacy.(Periad &Ames, 1993:254). Besides, the family caregiver needs to viably manage the finance and internal environment to fit the patient. (Jensen

&Given, 1991: 183). Further, the family caregiver is required to be tolerant with the changing state of emotions and behaviors surrounding. (Sheehan& Nuttal, 1988: 74). It leads the family caregiver from accumulated oppression and stress to be chronic. (Hoyert & Seltzer, 1992: 74; et al., 1989:210). Stresses from the changes and the responsible workloads physically and psychologically deteriorate the health of the family caregiver. It has been compared that the family caregiver is the hidden patient on account of not only the medical personnel but also the nurses use to ignore the significance of the family caregiver who is helping the patient to live happily. (Ruja Phoopai boon, 1993 : 11;Green, 1991: 6; Haug, 1994: 1)

With the above problems, the researcher finds critical to study the management of the family caregiver of CVA patient significantly focusing on the problem that the family is one of the resources to help handling problems in corporation with the government is reducing its role in social services and returning this responsibility to the family more, which can be witnessed from the policy and application levels (Office of Public Health Policy and Plan, 1996). It is obvious in views of sociology that the chronic patient in a family creates the new phenomena of many forms of disabilities. There is limitations happened in a family but it does not mean that the family caregiver and the family members will similarly define. This study has been concentrated to find answers to behaviors of an individual with the phenomenon. The family has changed its previous role and responsibility. From the restricted states, it leads the family members and others to likely share and to support the role. It is to study how roles have been adjusted to leading to the symbolic interaction happened with the family caregiver and family members. They will have the symbolic interactions to sustain the family. Further, how interactions with surrounding individuals and society as well as oneself will affect behaving and role playing also the state of mind of the family caregiver and the family members. It is focused on explaining the authentic phenomenon, defining, role adjustment, and interactions of self and others. The results from this research will help establish more understanding to this matter, which will be advantageous in better structuring the family of the CVA patient allowing the family caregiver happiness and effectively handling all affairs.

## **Research Question**

How does a caregiver manage the CVA patient?

## **Research Sub-questions**

1. How does the family caregiver and the family manage the CVA patient beginning from defining, family interactions, roles of family members when there is a CVA patient in the family as well as the first stage (4 weeks) of rehabilitation?
2. To what extent does the attributes and roles of the family caregiver affect the management?
3. What is the lifestyle management of the family caregiver and the family for better health of the caregiver?

## **Research Objective**

It is to study the management of the family caregiver and the family in attending the CVA patient informed by the physician that of being the CVA patient till returning to attend consistent rehabilitation at home. The study will focus on defining, family interactions, role adjustment of the family member in attending CVA patient in terms of sociological dimension.

## **Specific Objective**

1. To study the management of the family caregiver in attending the CVA patient beginning from defining, family interactions, roles of family members when there is a CVA patient in the family as well as the first stage (4 weeks) of rehabilitation
2. To study the attributes and roles of the family caregiver and the family which affect the management of caregiver
3. To study the lifestyle management of the family caregiver and the family for better health of the family caregiver

## **Scope of Study**

This study is determined to investigate the management of the family caregiver and the family in attending the CVA patient treated by the Ramadhibordi Hospital in the normal pathological wards. The scope is to study the structural theory of duty in terms of family structure and roles in supporting the symbolic interactionism for understanding. It is to investigate facts related to behaviors of the family caregiver and the family in attending the CVA patient comprising conditional issues bridging the social context, behaving as perceiving, defining the family interaction, roles of family members, and the management of relative staying in the Ramadhibordi Hospital admitted in the female, male , female and male 1 and 2 pathological wards. The study is conducted with the CVA patient attended by the family caregiver and needed to continue the first stage (4 weeks). Of he rehabilitation at home during

Further, it is to study the CVA patient admitted in the Ramadhibordi a public hospital at normal pathological wards, where economic state is restricted since most are government service personnel with money problem (the poor) and specific conditions. This study is therefore inexplicable to other families rather this and to the wealthy families (the rich). This study has met limitations of following-up the 4- week period after being released from the hospital including the study of the disable patients of stage 3-5 (likely sever) who are helpless and have to rely on the family caregiver. The explanation of the study cannot cover the follow-up of 4-week period after leaving the hospital and the disability at the stage 1-2.

## **Definition of Terms**

The qualitative research finds no definition of terms for the management system of the family caregiver attending the CVA patient, which is the research objective. They will be gained from interviews, and the caregiver's perspectives. Therefore, to be as guidelines for interview in data collection, the researcher has set the scope of definition of terms related as follows:

**Family Caregiver** or **Information Caregiver** is referred to a relative or an individual who help the patient at home or a family member intimate with the patient such as father, mother, husband, wife, and a child who lives under the same shelter and is responsible to attend the patient. There are 2 characteristics categorized by level of responsible scope in the attending and time spent over the patient.

**1.The Primary Caregiver** has the regularly and continuously direct care of the patient.

**2.The Secondary Caregiver** is the other person under the domain of care-taking and having the duty to manage other affairs including taking occasional care when the family caregiver cannot fulfill the duty or being the person who assist the family caregiver or the relative of the family caregiver of both characteristics, which is depended on the social domain of the patient and the family caregiver.

**CVA (Cerebrovascular accident) Patient** is the infirm affected by pathology and lost the ability of self-regulating. It is divided by its criticality as follows:

The severity of the illness is reflected by the level of disabilities affected by the cerebrovascular accident illness. Rakin's based of disabilities are used in categorizing into 5 levels as follows; (the researcher selects to study level 3-5)

Level 1: There is no disabilities left and able to do different activities as well as routine job.

Level 2: Slight disability – able to take normal walk but unable to do some routine jobs and able to take care of oneself and need s no assistant.

Level 3: Moderate disability – able to walk with cane but needs help in dressing and the working hand is disable.

Level 4: Moderate sever disability – able to walk by the support of other and needs help for daily routine work.

Level 5 : Sever disability – requires bedding or wheelchair and hard to control urinating and needs close nursing and attention.

**Management** is referred to the dynamic process altering to situation or defining the meaning with management goal to fit the most satisfaction comprising self-reaction, method setting, negotiation, and manipulating the end-results.

**Interaction** is referred to interpersonal action or reaction, which bears performance or changes in another party.

***Family Role*** is referred to an individual behavior indicating the ruling of the existing status under the norms and social expectation for the family member to relevantly express both in doing or being done. At the meantime, an individual can at the same time play many roles.

***Caregiver Role*** is referred to model of duty in attending and assisting the CVA patient with physically disable and limitations in self-caring for health for the purpose of sustaining good health in daily living.

## **CHAPTER II**

### **LITERATURE REVIEW**

In this investigation the researcher has explored theories, concepts and related researches to find answers for 4 questions rested in the conceptual framework, i.e. concepts structure of duty, medical, nursing, psychology, and symbolic interactionism. It is to seek facts of family caregiver 's behavior and the family in attending the CVA (cerebrovascular accident) patient, which contain conditional factors bridging the social context and behaving in light of perceptions.

#### **Research Conceptual Framework**

1. Biomedical Model
  - 1.1 Distinction of Biomedical Model
  - 1.2 Development of Biomedical Model
  - 1.3 Knowledge about Cerebrovascular Accident
  - 1.4 Critiques on Biomedical Model
2. Nursing Science
  - 2.1 Distinction of Nursing Science
  - 2.2 Development of Nursing Science
    - Orem, King
    - Home Visits of the Nurse
  - 2.3 Critiques on Nursing Science
  - 2.4 Nursing Data Supports
3. Structural-Function Theory
  - 3.1 Distinction of Structural-function Theory
    - Parson's Concepts

- 3.2 Structural – Function Theory of Family Duty
- 3.3 Changes of Family Found in Modern Thai Society
- 3.4 Critiques on Structural-Function Theory
- 3.5 Data Supports of Structural-Function Theory
- 4. Psychology
  - 4.1 Distinction of Psychological Concepts
  - 4.2 Development of Psychology
    - Freudian’s Theory, Social Science Theory
  - 4.3 Critiques on Psychology
  - 4.4 Data Supports of Psychology

## **Research Conceptual Framework**

### **1. Biomedical Model**

#### **1.1 Distinction of Biomedical Model**

It is scientific focusing on disease, prioritizing its causation and medical treatment that the patient will be healed. Medical view CVA as a clinical symptom group of immediate neurological deficit symptomizing of more than 24 hours caused by various sapaemia or the irregular blood circulation in the cerebrovascular not mentioning the social and cultural factors which involved and induce.

#### **1.2 Development of Biomedical Model**

It has been divided with 3 eras of scientific development and advancement, i.e. ancient era, scientific era and globalized era.

The Ancient Era is the society of about 2500 BC. Health and medical management relies on mythical and supernatural power and superstition. The public health system management is in form of sacrifice, and rites performed at home. The belief that illness is manipulated by gods causes psychological effect and leads to

belief and trust where it cannot be proved by science. It is counted as “irrational ignorance.” (Uiamporn Thongkrajai, 1990:75)

The Scientific Era – developments of thoughts have gradually been more scientific. It is found in old scriptures such as Confucius philosophy. Hippocrates emphasizes human interaction between human being and environment as well as public health management. Where a part is the family and the other part is the local medical management. Thomas Sydenham ( 1624-1689) has grouped each symptom called Syndrome and also prescribes the disease. At the fall of 18<sup>th</sup> Century, there has been an autopsy and sought the relationship between the findings in the corpse and the syndromes. The ancient Greek philosophers comment about the illness as, “ ignorance to the soul” , which at present, means the “mind”. Reaching the 19<sup>th</sup> Century, the concepts of health and illness are directed to germs and microbes. Then, microscopes have been found where studies can be delved to the organic cells. The definition of disease caused by organic changes reflecting the illness is significantly caused by germs.

Management model of health and illness is therefore changed and begun to take interest in treatment with modern medical techniques performed by professionals. Medical service places have been found. Treatment models have been moved to the roles of public health personnel that health and illness are the state of deviation and dependency. It must therefore be directly and legally attended by physician and by the hospital. Medical treatments will be under the expert physician with high capability and skills and with full authority in decision. The service recipients are the patients who will cooperate with physician for treatments to be healed from the existing illness or receiving best rehabilitation. However, the medical advancement is not yet prevailing.

There would be successful with the uncomplicated illness but the complicated ones and unfound causes could not completely be healed such as cardiac diseases, hepatic diseases and etc. The patients are defunct during staying in the hospital.

The Globalized Era – the advancement of medical sciences and technologies, communication, ducation, social and economic developments and

current politics has brought the medical personnel to be more specialized in medical treatments. There are devices to help accurate diagnoses enabling to save lives during crises or from previous acute disease leading to life prolonging. Even, results of treatments with complicated disease cannot be completely healed or returned to normal state such as cardiac disease, diabetes, neurosis, nephritis, medullitis and so on causing chronic patients increased from 30% to 80% (Levin; referred in Somjin Hanujaroenkul, 1993:3) and affecting increasing needs of being treated in the hospital, and increasing fees, which leads some patients particularly the chronic ones with consistent attending have to return home for continue caretaking.

Medication emphasizes systematic diagnoses, records and check-ups. Advancement of laboratory findings increases diagnostic capacity but restricted to syndromes. The symptoms in the state of changes in physical pathology tend to be the diagnostic goal rather than understanding the patient. Records of the patient find no system to identify the understanding of pain in terms of the patients because the physician never hears them or is unaware of the patients' needs.

Later, emphasis has been imposed to understand a part of human being and allocated in psychiatry of clinical medicine. However, actually, it is never happened on account of the psychiatric subject is systematizing groups of mental disorder, which, in general, focuses on divergent behavior rather than to comprehend the normal behavior of each patient. Even more recently, there is attempts for more integration but no major changes have happened in the lessons of medication. At present, physicians claim that holistic awareness on patients has been practiced. Attempts to understand the thoughts and minds of patients play major roles in treatments and heal. Many diseases have inseparable relationship between body and mind, e.g. stomach ulcer, infected thyroid, cancers and so on. Actually, the holistic approaches are not connected the entire body in corporate with physicians are more specialized allowing the only patient has been split for treatments in each area and it requires many specialists in each disease and each organs. Each organ needs solution, which causes unholistic speculation. It decreases interpersonal relation, sensation and life or sometimes values are never perceived.

### **1.3 Knowledge about Cerebrovascular Accident (CVA)**

CVA by pathological state happens with 2 types of vascular

1. Cerebral thrombosis and cerebral embolism, caused from blood cannot flow to cerebral cells because of the thickness and contraction of the vessel caused by blocks leading to some part of the brain inadequate with blood or deceased. The symptom is gradual and growing to be angiosclerotic or paralyzed, being numb at the skin and stupefied of unable to speak. During and after being treated the family caregiver help in physical rehabilitation to lessen the paralytics.

2. Cerebral hemorrhage – it is the break of the small size cerebral vascular but with the oozing bloods, it becomes acute to the nervous system, the limbs become sudden limp, numb face and limbs, heavy head, acute dizziness and convulsing. All takes 1-2 minutes. Such symptom will prolong till the blood has been absorbed out. It may take weeks or months. If there were heavy hemorrhage, the patient would be 90% unconscious and dead. Only 30% of patients meet less hemorrhage, which made them survive after treatments. However, it takes time in rehabilitation where many disabilities are found and special care taking is needed.

Effect of CVA leads to physical disability and psychological, emotional and behavioral changes. The patient finds restriction in self-caring and all need family caregiver to play the role in caring.

It is to the daily task such as feeding, dressing, moving, evacuating, self-cleaning where the patient cannot fulfill by itself. The family caregiver will help in the task, which cannot be completed by the patient and giving him/her moral support to gain more self-confidence.

#### **Prevention of Side-Effect and Accident**

1. Caring and cleaning humid areas such as perineal, between fingers and toes, armpits and pressing areas where skin diseases are easily infected or tearing. Clean, dried well-aerated dressing should be provided for the patient.

2. Preventing the Infected Lung, which is found most being

the cause of death among CVA patients. (Niphon Puangwarin and Adul Viriyavejkul, 1982:241). The caregiver should provide feeding easy to swallow and chewing, allow the patient at head rise or sitting position during feeding to prevent choking, and see that the patient has adequate warmth during cold climates.

3. Preventing Contracted Joint and Shoulder-pain – the irregularity, which is often found. The patient feels comfortable by the position of bending trunk, hands, and legs in associated with contracting of limbs, which will lead to contraction. The family caregiver should allow the patient often exercise the muscles and joints and encourage to have joints exercising joints using the helps of the normal limbs.

4. Preventing perforated bones – being restricted in movements, the patient is not walking or fully weighing to avoid easily breaking, the family caregiver should encourage the patient to stand, walk, and weigh both legs.

5. Preventing infection of urethral system – in the case of the patient who cannot stop urinating, the caregiver should help always cleaning and drying the area of sexual organ. The patient should be allow drinking 2,000 -, 3,000 cc of water and encouraged to fix time for urinating to practice uresis. In the case of unable to urinate, the caregiver should remind the patient by pressing the abdomen or occasionally take uropoiesis.

6. Preventing swollen tips of hands and feet – it is commonly found because of ineffective blood flows. Pillow or soft materials should be used to raise the hand s and feet and encouraging the patient to change the posture and it is not advisable to allow the patient a prolong sitting position.

7. Preventing limb atrophy – the caregiver should encourage and support the patient in movements and frequently contract the ailment limbs.

8. Controlling diabetes and high blood pressure – it is to prevent the return of CVA, which is often found by 10% among the existing CVA patients. (Jiamjit Saengsuwan, 1987:4). The caregiver needs to see the patient take medicine as prescribed, feeding with proper nutrition, bringing the patient to meet the physician when mishaps are noticed such headache, heavy at the occiput, numb at limbs and difficult to move, confusion, and lethargy.

9. Preventing accidents – the patient is at risk to accidents because of imbalance, weak or contracted muscles, and misvisualizing. The caregiver must

provide convenient living quarter viable for the patient to move such as leveling the floor, pacing bars for holding and clear all possible blockages.

It was found with the caregivers of CVA patients that they feel sprain at limbs, shoulders, back, neck and muscles, which are caused by lifting, supporting and rehabilitating the patients. Colds are found because of inadequacy of sleeping. Some get stomach ulcers because of stress and impunctual in taking meals.(Naphaporn Kaewkan, 1990:40).

#### **1.4 Critiques on Biomedical Model**

Medication emphasizes completely heal. Patients are viewed as fraction of organs rather than holistic, which lacks perspectives of mental, social and economic issues. Causes of illness yielded by other social factors have not been recollected. After CVA has been treated, patients would have been encountered with disabilities such as paralysis, disorder in speaking and communication. The role of the patient has been changed to accept dependency. The family has to admit the burden of rehabilitating the body, mind, emotion and social when the patient returns home.

Medication focuses only on hospitalization and cannot clearly explain the cause why CVA cannot completely been healed. It becomes chronic and needs prolong rehabilitation by pushing the burdens to society, family and caregiver. It emphasizes segmented treatments, keeping the appointment of medical check-up, and strictly following the advice and remarking about the roles of family caregiver in handling the CVA patient. On account of advice and fraction treatments, there are therefore limitations in explaining how the caregiver should handle the patient on the basis of passively viewing people and need to only follow the physician's prescriptions. Then in this study, the medication cannot respond queries about the handling of caregiver in terms of CVA patient because the physician mainly concentrates on the patient and ignores other environments particularly relatives who significantly share the handling. There might have been mentioning about behaving as advised by the physician so that the patient might be healthy, taking tablets as prescribed, and strictly keeping the appointment, where it is counted as medical

success. It proves that medication likely views fraction rather than holistic where treatments are incomplete and unable to read the mind because of seeing patients as materials whereas it is not so.

## **2. Nursing Science**

### **2.1 Distinction of Nursing Science**

Nursing houses the professional philosophy on knowledge and belief used as frame in training and behavioral cultivation so that nursing professionals own principles in living or as guides to follow the nursing roles.

There are 3 natures of knowledge in nursing sciences, which are

1. Principles and rules related to life process, happiness and the theory of Orem, which is called the “ Theory of Self-care” as composition to best performing duty of an individual when being sick or when being healthy.

2. Behavioral models of human being interacting with environments during life crisis

3. Processes affecting the positive change of health, which demonstrates the process of supervising behavior acted when an individual defines illness in each period and each behaving. Care taking has been changed when an individual makes self-assessment and learns from definite experiences.

### **2.2 Development of Nursing Science**

#### **- Concepts of Orem, King**

It is the popular theory of nursing in the nursing professionals and its has been implemented in treating patients. Orem emphasizes individual and focused on individual capacity to respond the need of self-care. Nursing goal of Orem-based is helping an individual to respond the need of oneself at the level of sufficiency and with consistency.

Four (4) concepts of nursing are individual, environment, nursing and health

Individual – under Orem-based, an individual is capable on deliberate action, learning about self, planning activities for self-care, interpretation, and defining different social symbols

Health – it is the perfect state free from deficiency and enabling to perform one's duty as well as self-care at the level of sufficiency and with consistency.

Environment – perfect environment motivates individual to set proper goal and adjust behavior to reach the goal, It shares the development of capabilities of self-care and needs of individual care.

Nursing – it is the services of assistance and the attempts of human being to help others emphasizing capabilities and needs of individual care. The identity of nursing is helping an individual to enabling self-care at the level of sufficiency and with consistency.

Orem's Theory of Self-care comprises of three theories as follows:

**1. The Theory of Self-care:** concepts to explain individual self-care and self-dependency is a mature person learns by doing and the result is to respond the needs of self-care necessary to survive the life, health, and happiness. It includes the action for dependent individual who is the family member or other persons. (Orem,1991:69 )

The Self-care: Self is used in the definition of an individual who is caring oneself. It is an action for an individual and by an individual. A person who cares for oneself is called a self-care individual whereas a caregiver is called the care-provider. A dependent individual is a behavior initiated and acted by oneself to survive one's life, health and happiness.

Self-care comprises two (2) phases as follows:

Phase 1: The period of consideration and decision, which leads to action. It is the phase when an individual seeks information for consideration and decision of self-care.

Phase 2: The period when an individual manipulates activities of

self-care prioritizing setting the goal to determine activities to reach the goal and an individual also assesses the performed activities.

**2. The Theory of Self-care deficit** - it is the concept indicating rationale and time needed for nursing – deficit in self-care. It is the imbalance relation between the capacity in self-care and all needs of self-care of an individual. Whenever an individual can partially or not at all manipulate self-care or inadequacy of capacity to respond the entire needs of self-care, it demonstrates the self-care deficit. (Orem, 1991:70-71)

Self-care deficit happens when the entire needs of self-care overwhelm the capacity of self-care.

**3. The Theory of Nursing System** - it is the concept of the nurse to help an individual having self-care deficit to respond the entire needs of self-care. Also, the capacity of an individual self-care has been protected, or manipulated, or developed by the nurse who has manipulated the nursing capacity in assisting. (Orem, 1991:72)

The nursing system uses the nursing science to improve the balance between the capacity of self-care and the entire needs of the recipient's self-care. It happens when the nurse interacts with the patient or the recipient and the action to respond the needs of self-care including the capacity adjustment and the development of the patient or the recipient in self-care, or the capacity adjustment and development of the responsible person responding the needs of self-care of the dependent individual. The nursing system is an acting system of ongoing changes, depending on capacity, and needs of caring for the patient or the recipient.

Implementing Orem-based theory of Nursing System is using the theory of Self-care Deficit, which manipulates the theories of Self-care and Nursing System. On account of theory of Self-care Deficit indicates the needs of help from the nurse on the basis of inadequacy and inconsistency of self-care to respond the entire needs of self-care. Individuals need the nursing system where the nurse manipulate nursing science in responding the entire needs of self-care and capacity development of self-care of an individual adequately to respond the entire needs of sufficient and consistent self-care.

Supported by the interaction between the nurse, the patient and the caregiver by King-based concepts, Imogene M. King, a nursing theorist ( King ,1981 : 141-50 ) conceptualizes that nursing is a process of interaction between the nurse and the service recipient called the “Goal Attainment Theory.” It is viewed as an opened system and definitely interacting with environment. This opened system has been divided into three (3) levels, i.e. Personal System, Interpersonal System, and Social System. They are all interacted. (King, 1986: 231-42; George, 1995: 551). Here, the Interpersonal System is emphasized in terms of interactions between the nurse, the patient and the caregiver pertaining six (6) psychological dimensions, i.e. stress, role, growth and development, time and space. It emphasizes interactions between strangers but co-stay with the common goal, i.e. to sustain the good health by the nurse plays the service role, and the patient/ the caregiver is the recipient. It helps understanding an individual who one is interacting leading to effective interaction and goal achievement. It helps the patient good health, knowledge and understanding, interchanging each perception that enabling the patient/ caregiver to decide selecting solutions to reach the goal.

In this case study, the handling of the family caregiver toward the CVA patient strongly needs the interaction between the nurse and the patient/ caregiver during being admitted in the hospital before allowing the CVA patient to return home. The building of interaction of the nurse regularly attending the patient and observing the different improvements of the patient/caregiver lead to the perfect understanding of the problem including the pursuance of home visit, which is the essence of public health nursing. (Joan & Katherine, 1988: 350). It is the home health services improvised for the elders of chronic illness, the rehabilitated patients, and the helpless persons for the purpose of being treated and having interaction with society and environment. The CVA patient is mostly meet with psychological problems caused by pains and the remaining disabilities. It causes changes of roles where it turns the patient insecure, inferiority, and Down- syndrome. The family caregiver should share assistance and accept the misbehaving of the patient avoiding the remarks and dissatisfactory demeanor and pay attention when the patient expresses the ill feeling and postures. The patient should be consoled and encourages to face the

problems in order to motivate him/her to share the activities. Also, the family caregiver should treat the patient as common person without expression of disgusting or over protecting the patient. The family members must play role in treating the patient where there will be drastic and consistent changes in the family and the family caregiver. With the supports of the health team to the individual and the family, it should sustain good quality and freedom of self-dependency for better attending the patient and proper environmentalization to enable a happy living.

### **-Roles of Home Caregiver / Hospital Caregiver**

Attending a patient is a burden that the responsible caregiver improvises on account of the patient meets the problem of self-care and there are three (3) major causes as follows:

1. The Physical Disability – it is caused by cripples or the deteriorated organs leading the patient unable to do daily task whether it were basic or specific activities of each illness such as injections, the changing of ureterosecretocine and wound cleaning and so on.

2. The Behavioral Bias such as the Alzheimer, Down syndrome, hallucination and so on, which may be found among elders or cerebral symptoms caused by illness.

3. The Emotional Changes of personal feeling and needs of each patient, which is the ongoing depending on each individual traits.

Needs of handling these problems are turned to be the activities which the family caregiver must totally support the patient. However, activities caused by the physical disability are likely preplanned, anticipated, prearranged what and when should be fulfilled. Nevertheless, the behavioral bias and emotional state of the patient are likely unpredictable. The caregiver at home may therefore feel uncertain on account of unable to preplan.

### **-Home Visits of the Nurse**

It is a branch of jobs improvised by the public health services providing for health supports, disease prevention, attending patients at home, and nursing to prevent disabilities as well as arranging the proper environment. (Janya Siengsanoh, and Varee Rakitti, 1985:282). The public health nursing has begun in England in 1859 emphasizing on home visits and nursing. It has been applied and readjusted to fit the relation building among community members, the attention to the epidemiology, and the study of community regulation and culture. ( Ruth B Freeman, 1984: 25 ). In Thailand during 1914, the government clinics have been established in different provinces to improvise home visits and attendance of maternity and childcares (Probha Limprasutr, 1985:14), the services of health supports, and disease prevention. Nursing is liberal job in nursing (Sakhon Thongthawat, 1995:253). Responsibility in caring for community is likely difficult, it requires skills and expertise, ability of decision making, relation building with the administrators, and focusing on humanity-based services. (Farida Ibrahim, 1993:166-183). Home visits in Bangkok improvising people services among 1,141 communities where it organizes public health nursing or community health nursing to attend home visits, in order to appropriately provide advice, health supports, disease prevention, disability improvements, rehabilitation, environmental arrangements. It includes seeking infirm persons and persons at risk of primary illness, teaching and demonstrating necessary nursing, coordination and ambulancing the sick. (Manual Records of Home Visits, Office of Public Health, 1995:1).

The Central Administration and the Center of Public Health Services have been set the goals and work scope for the home visits in Bangkok responding the Public Health Plan. (Job Orientation Manual, 1992:17). Nurses of home visits attend the responsible communities by visiting new families and pursuing the old ones till they are secure and records of each home visit will always be taken. (Manual Records of Home Visits, Office of Public Health, 1995:1). It is found from the analyses of home visits during 1995 that visits can cover 26.5% of the target with the range of average visits of 42-700 families. During 1996, the visits can cover 20.7% of

the target with the range of average visits of 60-588 families. During 1997, the visits can cover 16.3% of the target with the range of average visits of 53-555 families. It is concluded that there are drastic differences in the home visit performance of each nurse. Also, no centers can reach the target of home visits. It should be revised and sought out problems to seek solutions.

Influences over Home Caretaking: the extending caretaking at home is the societal occurrence based on the perception and defining illness. The development models of capacity in taking care of others similar to self-care is the model of ability to act, to anticipate, to adjust, and to manipulate the caring. (Orem, 1991:175). However, the three-(3) capabilities are differed in each person under the factors of foundational capability and dispositions including the different targeted attendance. It also includes the capacity to act and factors affecting the target searches of the action, perception of occurrences, self-valuations, personal habits, intentions, understanding, concerns, acceptance, and prioritization (Orem., referred in Somjin Hanujaroen, 1993 : 35-36 ). The improvements of the development and interaction with environments generate in an individual the “perception” process, interpretation or translation by using experiences as helps. Individuals cannot perceive all but select to perceive something by interest or related to oneself with action or expression mainly responding the perception and accepting the care taking.

In terms of caretaking, the caregiver helps the patient both physically and psychologically in daily task and treatment activities under prescriptions advised by the medical personnel, e.g. preparation of devices, ambulancing, doing affairs, meal preparation, and house-works, which are vital to the patient, including personal activities such as bathing, feeding, cleaning after evacuation and treatment activities at home such as dosing, wound cleaning, and encouragement. It is assumed that the caregiver spends most time and efforts with the patient at home, which affects other activities, e.g. routine task, caring for other family members, privacy, reducing the social role losing socialization with individual and external environment. All these things might cause the caregiver facing problems at works, interaction within the family and stress leading to the health problems itself.

It is found from the study of Bussaba Unphongphoowanat ( 1985:20 )that without home visit, it leads the patient to return for treatments in the hospital, consuming the medical fees, transportation and time.

### **2.3 Critiques on Nursing Science**

It is viewed like medical, i.e. fraction and the treatments are focused on healing of an individual rather than the entire family, nursing for better health, and prioritized the patient by ignoring the entire context which the patient is living.. It is found that the Theory of Nursing Science is still least used as guidelines for nursing the family since most will prioritize individuals even the recipient has been defined covering also the family but no nursing theories have recognize it. The family nursing has been obvious in its own identity and there is no perfect nursing theories used in explaining family and relationship within a family life. However, the nursing has attempted to integrate different concepts to structure the family model. Though it leads to better changes but they are not enduring directly affected by other factors against the patient and the family caregiver at home. Attendance has been focused on the expedition of the caregiver replacing of the patient to care for affairs where the patient is unable to fulfill. It emphasizes perfect caring for the physicality of the patient, good hygiene, free from side-effect, providing advice and truly applicable, and timely pursuing the home visit. Optimizing facilities for the patient but not the context of fact in daily living and environment considerably influence the living of the patient and individuals or the caregiver in facing different problems. It affects then body, mind and emotion of the caregiver who also needs care and attention. Caretaking is similar to a patient where it is prioritizing understanding and reflecting that there is least mentioned about help and solutions. Therefore, when the situation of the caregiver is perfect with least problem, it positively affects the patient directly as well as the good living of the family caregiver.

- Theory of Nursing of Orem is applicable to take care of the family.

In a level of taking care of a family, there are likely limitations in applying the theory of family caretaking on account of the nursing attempts to care an individual rather than the family. It needs to clear the understanding, and analyses of the nursing related to the family to more covering and applicable. It helps nursing more understand the needs of the family unit, which is significantly the service recipient. It leads the nurse thoroughly seeing the necessity in taking care of family in the social context or the nursing situation.

## **2.4 Nursing Data Supports**

Kalkman (1967:219) says that the interaction in terms of nurses and the patient or the family caregiver is the dutiful interaction. The nurse will emphasize knowledge and specialized skills to ease the patient and using time to solve the problem for the patient. It is to control the situation of contact in the form of nursing to lead the interaction by being the indicator and being the person who decides the beginning period of helps and the period of ending the relation.

McLean, et al., (1991:559-564) study the needs of services required by the family caregiver of the CVA patient. It is the pilot project to study 11 patients using interviews at home. Findings are needs for data services, knowledge of CVA, attending patient, changes happened with patient, and needs of advice and suggestions when problems arise.

Carberry, (1995: 867) studies the needs of data in Alzheimer caregiver among 17 families and it is found that most needed information are 1) data at risk with symptoms expected to happen, 2) data of treatment, and 3) modern information with genuine delivery. It is similar to the study of Nydevik & Eller,(1994: 155-161) investigating perceptions of 28 family caregivers' ability in taking care of CVA patients. It is concluded that 1/3 of the caregivers need data in caring the patients. The caregivers must take care of the patients in daily tasks on account of most of them are unable for self-help and most caregivers are ignorant about the caring.

Poulshock & Deimling, (1984:230-239) study the needs of caregivers attending 614 infirm elders. It is found that what needed most are 1) needs of physical caring for the patients, 2) needs to know principles of treatments, 3) needs to know the changes in patients, 4) needs to help within the house, and 5) needs to help about economy.

Mayeroff, (1971 ) studies taking care of the dependent and assisting to satisfying a person or to yielding self-achievement to be able to happily living in a society. It requires factors of knowledge of the person and assisting method, relationship between the giver and the recipient, and having goal of consistent caretaking. It is consistent to the concepts of nursing related to attending a dependent person in the theory of Orem that attending a dependent person during chronic illness is happened from the relationship between individuals and the family caregiver must be able to manipulate responding the needs necessary in caretaking of the patient.

Yuwarani Sookwinya (1994) studies the result of preparing family caregiver to attend a paresis patient at home to prevent compressed wound. 5 major caregivers have been personally prepared before the patients being released from the hospital, devices to prevent the compressed wound, teaching method and advice, responses of inquiries, demonstration and the family caregivers' demonstration. In the follow-up evaluation, it is found that the family caregivers have properly applied the activities and compressed wounds have not been found.

Wiphawan Cha-oom (1993) studies task of caretaking and happiness in general of the family caregiver of 100 dependent elders. It is found that the heaviest load is watching of the symptom and accident. The second is the arrangements of travel, encouragement, moral support and befriend stay. The scores of time spent in caretaking are higher than difficulties in caretaking. It is also found that caretaking burden has negative relationship with the ability to perform daily task of the elders and happiness. The caretaking burden and period of study conducted by the caregivers can predict the happiness of the caregivers at 21%.

Jariya Wittayasuporn (1996) studies causation prototype of care taking task among 74 fathers and mothers being the responsible persons to take care of the chronic children. It is found that there is relevancy with the study of Wiphawan Cha-

oom (1993) that the most perceived activity of caregivers is the expenditures. The second is the caution of danger and walking respectively. The Mean of time spent in caretaking is higher than the Mean of difficulties in caretaking.

From the reviews related to the caretaking task of the caregivers both in Thailand and in abroad, it is mostly emphasized that the caregivers must be mainly loaded to take care the physical daily task so that the patients will be happy. Following the advice, returning the demonstration and the follow-up for evaluation whether it has been manipulated an achievable as set in the nursing goal. Emphasis on the family related to caretaking burden is the caregiver must take care the problematic patient, complicated needs of caretaking, being under state of dependency, culture and surround environment directly affect the capacity in responding the caretaking. Most researches never or least mention about the hidden patients – the caregivers. It is counted increasing and critical each day in the case of caring the beginning to be patient and later accumulated when caretaking must be prolong.

If it were not attended, it would obviously become societal issues. It should be attended and prioritized rather than focusing on the patient but together. Had the caregiver been positive with psychological, physical and social health, it would directly affect the quality of caretaking and mostly the patient

### **3. Structural – Functional Theory**

#### **3.1 Distinction of Structural-function Theory**

This theory prefers to view society as systematic with definite territory and self-regulating. The system is homeostasis and equilibrium for its ongoing existence.

#### **-Parson's Concepts**

It prioritizes the medication as part of science. It determines the sick role to exist in the societal institution to yield efficiency as strictly set by society. Actually, society has its own societal conflicts. There are deficit of performing duty

and ignorance of cultural changes when society become complicated including the role set in relation to only specific ailments i.e. obvious acute illness, which can rapidly been healed and effective but cannot be manipulated with other chronic diseases. They are not apparent and the healing will not rely on only medication. The patient will not completely be accepted his/ her own illness but also vested on his/her own social role by being at the same time both patient and worker. These chronic diseases not only need medication but also become complicated in terms of social affairs. Societal significance engulfing the patient must be both heeded and understood. Some may hesitate to use medical services. It needs time and unable to be healed in a short period. It turns to be the medical problem and parts are the misunderstanding of the social norms determining societal role of the patient and the misunderstanding of the chronic diseases. The treatment is strongly relying on daily life of the patient, cultural factors, and medical values will considerably play the leading roles.

Therefore, society views CVA is an illness and deviance, which needs medication, accepts sick role, collaboration to follow medical advice having the hospital as center for treatment. CVA is counted as the secondary deviation, which is painful and leading to physical disorder and unable to return to normal state or least to become normal. It causes chronic illness, time consumed in treatment and obviously causing physical disorder after treatments e.g. paralysis. It is the chronic disorder, time consuming and emphasizing mostly physical rehabilitation. It requires the adjustment of the patient, family, and the caregiver who vitally shares the common treatments to rehabilitate the patient and the interaction.

### **3.2 Structural – Function Theory of Family Duty**

The concepts of social sciences – humanities views the family as the only thing existing in human society. Human is social who needs to learn the living. There is adjustment to the social norms. The family is counted to be an institution playing the role and activities related to other societies. Also, human has used first the family institution to build understanding and determined its own status to co-exist

with other societal levels. It responds to the saying, “ Family is unity of interaction personalities. “ (Paranee Thitiwattana, 1998:29-30).

Nature of a Family is divided into 2 Major Types

1. The Nuclear Family contains only the father, the mother and a child (not yet marry). It is the original pivot for other families or domestic groups. It is also called by other name as the “ Elementary Family.”

2. The Extended Family contains family members from many nuclear families staying together. Most members are likely be relatives for at least three (3) generations, i.e. grand father-mother, father-mother, and children. Co-stay means both staying in the same shelter or within the same proximity. The identity is the single household (help producing and consuming) sharing economic responsibility and security of the family members.

The family is counted as vital primary institution. It is the first society where human beings have intimate relation and much longer than the other social institutions. Further, the family is the smallest fundamental unit and strongly influencing the role of transferring the fostering and the cultivation of the family members. However, from the past, when the Thai families have been the extended families and at present there are increasing the nuclear families in both urban and rural areas. From demographic survey and housing during 1990 nationwide, of the Office of National Statistics, it has been found that 67.58% were the nuclear families. Also, families have tendency to become smaller assuming that in 2000, family members will only be 3.7 persons a family. (Srisawang Puawongpaet, referred in Sasipat Yodpetch, editor, Mor.Por.Por. 11.). Family structure has been prioritized and lacked family relation, relationship, the nature of changes in a family responding to societal condition, lifestyle, culture, belief and values and economics which are directly and indirectly affecting.

### **3.3 Changes of Family Found in Modern Thai Society**

1. There is more restricted family size and number of persons than previous ones. It is the adjustment to fit the era of speedy and oppressed social and economic system. Further, an individual plays more statuses and roles such as a

married woman having children and working will not just only being a mother to foster them and cater the husband but also being the assistance to the husband playing the role to earn income for the family. Or in case of the elder staying with kith and being dependent and at the meantime when the income is inadequate in supporting, it requires the elder to be self-dependent in some part. Further, the elder might have been baby sitter to take care siblings or being a housemaid to handle the household work.

2. The decrease of intimacy among family members, which generates the alienation on account of most members spend more time on work outside home, it lessens the interest for home and less family association.

3. Family members work outside more. Having such differently earned or supported the family from outside, there is opportunity to likely freely exploit the acquired earnings. There is high individuality and it lessens the meaningfulness of the dependency between oneself and other family members as well as neighbors.

4. There are more materialized consumption values and facilities being viewed as modernity and lessening the inherited religious values, tradition, and belief seeing them as outdated.

The family is therefore containing different sub-unit systems by positions and duty of the members. It is the social institution having likely stable and prolonged structure, norms, regulations and tradition. It dimensionally creates different perspectives toward family. The rapidly social and economic changes in Thai societies lead to the drastic changes of structure, composition, and relationship among family members. Being smaller size, the family is unable to help each other and responding to each need. It cannot complete its social duties, which capsizes the family institution. Developing Thai societies to industrialized and monetary societies requires each one to earn for the family. Family factors drastically differ. There are nuclear families, extended families, and families with relatives including other family members and might contain non-relative members. For example, an elder female staying with an employee as caregiver, giving concerns and attachment might be counted as a family. Also, in case of the wide spread of HIV with more death and finally, the rest members might be relatives or non-relatives, or the spread of

HIV in a community or in a family where care taking must be improvised among each other.

To assign a family caregiver when a family member falls sick in each society, many factors might influence the discretion whether who would be proper or as purview to be the mainstay in handling the sick at home. The primary factors are age, gender, marital status, routine task or existing occupation or otherwise there will be over workload for a family member. These factors all affect the readiness and capacity, time and facility in care taking, particularly in handling a CVA patient. It is sudden, unanticipated or unexpected event. IT affects the patient and the family as already being mentioned. Needs of the caregiver have not been recognized in such occurrence what he/she wants or feels to respond the personal needs and to balance life and family in the social context but being really under the social control.

They are found in the studies of Stone et al. (1987); Stevens & Baldwin, (1993:334); Brody & Schonover . (1986); Casertta et al. (1987); Colerick & George. (1986); Morycz. (1985); cite in Seltzer, Hoyert,. (1992:74) that most caregivers are female particularly wives and the eldest sister. It is seen that the role of the caregiver has been determined by interpersonality and nature of either male or female. (Qry et al. 1985; cite in Seltzer. & Hoyert,: 1992:74). Being the closest intimate with the patient has been determined to accept the role of the caregiver. It is likely caused by factors of perception and the nature of defining of care taking is corresponding to the studies of Goldstein et al. 1981; and Wood. 1991: ( in Saiphin Kasemkijwattana, 1993:32-33), who interview the rationale of acceptance to be the caregiver of the chronic patient in the family. It is found that it comes from love and affection with the sick. Some cases reason that there is none others and some prioritize morality to compensate the goodness of the patient.

Gender – society, in general, it is found that there are 3:1 by ratio female and male, who are the caregivers playing the role in taking responsible over the patients. A different gender may differently owe belief, attitudes and values. The female caregivers have been fostered to handle the household works and help caring the family members. The role players of caregiver are better adjusting themselves. ON the contrary, the male has been fostered to earn income to support the family and if he

has to play caregiver's roles, it will be more difficult for him.(Wimonrat Phoowarawuddhipanich, referred in Farida Ibrahim, Editor, 1993:23). It is corresponded with the study of Stroke (referred in Janphen Saewhoon, 1936:18) related to the effects of incapacitation among the CVA patient affecting the family. It is found that the male has more negative perspective against the patient than the female caused by more difficulties in accepting the caregiver's role about the caretaking activities, which the male is unable to adopt as part of his life. However, the female who plays the duty of cooking, and house cleaning, she is able to consolidate the caretaking activities and household works as part of her daily life. (Dwyer & Seccomb, referred in Piangjai Tiraprai Wong, 1997:37)

It is however found that both genders are capable to learn. It is found in the study of Rienhard (referred in Piangjai Tiraprai Wong, 1997:36) related to the task of taking care the mental disorder patient that gender has no any relationships with task. Nevertheless, in other studies, it is found that there are differences among male and female in the needs of training on how to take care the CVA patients on account of the status and experiences in taking care of the patient of both genders are the differences.( Anekkul Kreesaeng, referred in Piangjai Tiraprai Wong, 1997:22)

The female yields and milks the children, which is natural in caring role as well as the female social roles is to handle the well being of individuals at home beginning from cooking, providing facilities and healthfulness. From the past till present, most females work as housewives rather than working outside. Therefore, when there is the sick in the family, the female needs to also handle them at home. It turns her behavior to evolve to care taking becoming the social and cultural expectations that the female has duty in care taking.

It is likely found male caregivers among families housing either the elders or the kids. However, there are differences in care taking between the male and the female. The obvious ones are lesser time spending in care taking than the supports, and facilities such as pivoting in communicating with different work units, as well as supervising the money in care taking. (Horowitz. 1985; Brody,. 1983: cited in Davis. 1992:3; Simon,. 1995:185). It might have been the social belief and expectations that the male is the family economic supporter, which drives him to

work outside to earn income for family supports, which permits him less time in care taking.

It is seen from above that relationship factors of individuals in a family and nature of male-female yield the female caregiver stresses caused by more workload than the male.

The family status and role, particularly the marital status, which most single persons have fewer tasks than the married ones, should be more appropriate. However, in case of the married patient, the expected caregiver should be the spouse rather than either the children or the parents. It is corresponded the findings that the supports from the spouse have positive relationship with morale of the patient. Further, if the caregiver were the family member with strong acceptance in the family, opinion and belief as well as different knowledge of care taking would better be obviously transferable in implementation than other members with less acceptance.

Social/Occupational status and role occupied persons or with permanent occupation or working at home, will be more convenient and less problem than commuters. Further, person with complicated social status and role or multi social roles will less allocate time to take care the patient than those with less social roles who can sacrifice time to better play the role as caregiver.

Different existing family tasks and needs or new ones yielded in the privacy of the family caregiver, affect the conflict in decision of proper time allocation in manipulating and the quality in handling the patient. Reasons are either the needs of the patient or the tasks of the caregiver to take responsibility in supporting the patient in terms of number of jobs and their difficulties.

Family relation is divided into 2 parts, i.e.

Relation between the caregiver and the patient – the previous one before illness is one of the variables affecting the attentiveness of the family caregiver. Had the relation previously been positive, it should be facilitating caring climates. The caregiver is willing to care because of affection and commitment. Had it been contradictory, the caregiver would be more stressed on having to do duty and by necessity rather than willingness.

Relation between the caregiver and other family members, particularly, in the case of having conflict on co-handling the patient. The better relationship helps

adjust the mutual understanding. At the meantime, such conflicts may affect relations among members leading to tense climate in the family in the future.

Customs and traditions – the Thai societies house custom and transition to recognize the dedicating and devoting person who helps the weaker, particularly with individuals in the same clan. It is counted as duty to fulfill and generally accepted that female member group has been emphasized to mainly handle household works, which also cover taking care infirm family members by adopting the principle of intimacy order as criteria.

### **3.4 Critiques on Structural-Function Theory**

As mentioned above, the Structural-Function Theory emphasizes societies in general in terms of the peace and order, and dependency and it supports the Biomedical Model, which focuses on treatment, diagnoses and resolutions that societies can sustain regardless surrounding. Social factors are complicated. However, the Structural-Function Theory focuses on static rather than dynamic structure. It is found in this CVA case that family structural-function plays major role in handling the patient. It may change, depending on external structural-function regarding, social, culture, economic, and politics, where the family cannot similarly fulfill duty as in the past. It directly affects members and society in family begins deteriorating. Teaching knowledge for members is driven to school and educational institutions. Present families are more similar to the western families. They are squeezed from external societies to work causing the major duty to be minor. Attachment is decreasing as well as health, infirmities, and decision process in health-cares.

The structural-function theory cannot explain the above. The deep understanding regarding the nature of Thai family should therefore be made. It must be view as dynamic change to understand the complicated models of the Thai societies, relation, roles and status as well as other direct affected social factors. Families therefore strongly share handling and supervising CVA patients. Family roles are changed under family interactions, heredity structure, social refinement, training, and parental roles. Family roles per a family appropriately adjust and

adapt themselves. Each family differently houses models in handling CVA under the social and cultural conditions, classes, personal traits, status, and the patients' roles, observers, and patterns of care taking including different complicated treatments for the patients.

### **3.5 Data Supports of Structural-Function Theory**

Hausen et al (1985: 99-108 ) study families with diabetes members and it is found that families help the patients how to inject the insulin and diet by themselves. They also help members to accept the disease while the families adjust themselves to the diabetes state of the patients.

From the concepts of self-care of WHO, which propose that level of knowledge in family is a factor influencing the self-care behavior. Having marriage status, and spouse, there will be a person who supports, encourages, and comforts which turns the patient stable in emotion. Among the marriage groups, there are more social supports than the single groups or isolated persons.(Chatwalai Jai-arree, 1990:85)

Dawson (1991) studies family structure and health impact and the wellbeing of 17,000 children with less than 18 years of age. It is found that children living in the different structures differently affect their health and wellbeing. Children staying with the mothers or the mothers and foster fathers were mostly found with psychological problems, class repetition, school dismissals, and at risk of injuries from accidents.

Doherty and McCubbin (1985:5-11) propose the conceptual framework of family roles in handling hygienic health for the members that a family houses mechanism in promoting health to prevent diseases and solutions for illness. It illustrates steps of attempts of family members to reduce risk and illness. Illness is addressed and attempting to adjust selves to the happening illness of the family members as well as death that might occur.

Osterweis, et al. ( 1979: 279-286 ) study social sizes and classes on accepting illness. It is found that large size lower class plays roles of illness and less

seeks sources of treatment than the small size lower class. There is no relevancy between role of illness and size among the middle class

From data of family structural-function as societal sub-unit system in the presence of uniqueness of the family, there is relationship and affecting society. When there is change in family structure, it diverts family functions from social reality and is unable to function as before, which affects many dimensions of behavioral patterns, e.g. small size family, relation, life security and models of handling from the family when chronic member has changed. The family has direct involvement in handling and strongly influences the patient's behavior including the changes of roles and functions among family members that the family remains.

#### **4. Psychology**

##### **4.1 Distinction of Psychological Concepts**

It emphasizes the reaction of individuals to impacting stimulants, which can be both physical such as light, color and sound as well as physiological changes, and physical disorders e.g. exhaustion, and tiredness, including social environments, e.g. following the social norms.

The study of psychology evolves human thinking process on understanding health, roles of lifestyle, health personality, and illness within the systems. It concentrates behavioral and mental processes on:

- Thinking – it contains perceiving, learning, interpreting, believing, and problem solving which affect health and illness

- Emotion – it affects and is affected from thinking and behavior, which yields multi facets of relationships with illness and is still significant in seeking the needed treatments.

- Motivation – it explains why do people express, on what bases they select that direction and confirm to do, search and target to reach.

It also includes Social Support, which is a variable of social

psychology significant to social support on retaining health emphasizing roles and function of easing or buffering stresses, which affect health as well as other health threats. It is seen that the social support is beneficial sources of an individual from environments and perfectly helps encounter stresses. In this study, the researcher focuses on caretaker, who is counted as one of the social supports gained from society.

## **4.2 Development of Psychology**

### **- Freudian's Theory and Social Science Theory**

Psychology has been applied in medical sciences since ancient Greek. At the beginning of 20<sup>th</sup> Century, Sigmund Freud, an Austrian psychologist sees the significance of child development. It is counted as foundation of personality development in adult. It is believed that life instinct and death instinct have been inherited in human being since birth. Both instincts yield psychological energy fusing their functions within 3 parts of personality systems. They are Id as part of unconsciousness reacting to the needs of oneself, while Ego functions the sudden thinking and planning of Id by adjusting to the real situation, and Superego plays the part of controlling human ethics.

Freud observes that some of his patients express physical illness without causes of organic disorder. It is explained by psychoanalysis that such symptoms is yielded by uncontrollable emotional conflicts called Conversion Hysteria

Later, the psychosomatic medicine has investigated roles of emotion and physical processes, which began in 1940 on Conversion Hysteria. At first the researchers focused on the interpretation of health problem under psychoanalysis. Later in 1960, new theories and ideas have been formed engulfing the relationship between psychological and social factors, biological function, somatology, and illness.

The Behavioral medicine follows in 1970 influencing the psychology of behaviorism in part of illness, which emphasizes the classical conditioning of behavior and action pattern.

The classical Conditioning is yielded by conditioned arousal to seek truth form reaction through the relation with another arousal, which has been responded

Action Conditioning is yield by behavioral change cause by consequences.

It includes the Social Modeling of Bandura of Stanford University, USA (1977), which is the Observational Learning or Modeling. It gives equal significance to both environment and the learner. It also states that human being always relates to surrounding environments. Learning is the result of interactions between learner and environments and both influence each other. Bandura counts that both individual needs to know and environment are the causes of behavior.

Bandura proposes concepts of Learning Theory that

1. What is learned – learning is generated from relationship of things, which forms the belief and affects controls of behavior. When an incident has happened, an individual anticipates its results of action.

2. Learning Pattern - learning is generated from direct and indirect experiences by observation, reading, listening, narrating, which widens learning.

3. Belief – it is believed that one thing will relate to the other, which is generated from observation and thinking of an individual as well as the narration, which can determine behaviors of an individual.

4. Behavioral control through knowledge and understanding – an individual owns knowledge and understanding, which is transferable and by observing the consequences, it helps decision making.

5. Ethical decision – it is the process of right-wrong decision under the behavioral principles. On account of individual behaviors are different, criteria and weighing are therefore, different.

6. Self-control – it makes possible to control oneself or to avoid behaving under the personal standards gained from direct and indirect experiences. If it were positively resulted, the behavior would be refined.

Concepts can effectively applied in treating person with behavioral problems in eating and emotion. Birk, (1973 ) also uses Biofeedback, which

techniques have been applied so solve medical problems, it is critical in connecting mind and body directly and indirectly. The human physiological process has been conditioned to heal health problems and widely accepted. Later, health psychology has been formed into applied psychology to systematically study health issues or those affecting psychological impact related to health, diseases, and health service systems.

Post concepts of psychology focuses more on internal and external processes or individual change. Being part of sciences, psychology has clear rational methodology. It is the behavioral sciences and internal mental process obviously segmented prioritizing inner part of individual down to supporting systems of family, society and culture.

### **- Stresses and Health of Caretaker at Home**

In the role and duty of caretaker at home, he/she must encounter countless stresses and effect of health, particularly in the case of there is only a caretaker to take the entire responsibility. The stress might be multiple, rationally, whenever the caretaker and the facilitator are the same person, it means the caretaker must also work outside. All these things can help predict that the caretaker will encounter high stresses with sentiment of heavy burden affecting health and happiness of the caretaker. (Kiecott, et al. 1987 & Vilatino, et al. 1989 : cite in Davis. 1992:3). However, stresses of caretaking are yielded from new roles when the caretaker must spend time and tactics to encounter problems. Psychological development helps caretaker properly adjust. When duration of caretaking is prolonged, it helps the caretaker adjust and illustrate potentiality of caretaking or possibly ability in adjustment will curve down, had the start and the last period of caretaking turned the caretaker to encounter stresses. If it were so, it is proven that the peak potentiality of the caretaker yielded and the intermediary period. (Simon, 1995:182-194: Townsend. Et al. 1989: Zarit. Et al.1986: cite in Seltzer, & Hoyert, 1992:75). However, many researches find that the many caretakers at home positively sense in caretaking, i.e. happiness in caretaking others, positive attitudes in caretaking in future, closer relationship with patient, opportunity to return gratitude, viability, being needed and

recognized from surrounding individuals. Being the capable caretaker and solving problems in the role of caretaker, it brings him/her more role satisfaction rather than burdensome caretaking role. (Blieszner & Shifflett. 1990; Horowitz. 1985 ; Montenko. 1989 :cite in Seltzer. & Hoyert,. 1992:75)

It is observed aathat stresses and changing emotional conditions as well as life impact tend to deteriorate physical and psychological health. Being assisted by individuals or organization, particularly, the medical organization regarding information, skill training on necessary tasks, caretaking activities and social supports will help enhancing caretaking confidence. (Hasselkus. 1988; Baldwin. 1990: cite in Davis,. 1992:3). Also, it eases situations those bring stresses.

The physical and psychological health of the family caretaker, and health problems here cover deteriorating capability, which is often found with caretaker of the elder. Psychologically, some caretakers positively feel that being the caretaker gain life experiences or the meaningful life reward.( Dorfman, et al., 1996 :46 ). However, some negatively feel yielding boredom and stresses. It is expressed with melancholy and easily raging. Personal economic status and security of income will influence as factors positively enhancing quality of caretaking, particularly, in the case of yearly prolong chronic illness. The caretaker must have expenditures during the duration required to earning but have it spent in caretaking. Further, it still effectively builds life security even encountering different changing conditions.

Related experiences, and skills responding needs of caretaking, had they been new activities to the family caretaker and needed to learn for the purpose of developing capacity in caretaking, it might bring more stresses than normal. Also, it is difficult in more encountering stresses than the family caretaker has been familiarized or working as routine. Rationally, previous experiences owned are similar and corresponding as well as help transferring learning to the new situations.( Anekkul Kreesaeng, 1983, referred in Jinnarat Sripattaraphinyo, 1997:22)

Assisting to interact with society and environment, the CVA patient is likely to have psychological problems most. It results from pains and the remaining disabilities, which brings role changes. The patient feels insecure, and inferiority. To prevent the Down syndrome, the family caretaker should accept deviance of the

patient and avoid remarks or dissatisfactory outlook, paying attention when the patient emits happiness and strengthening spirit not to give way to occurring problems including motivating the patient joining activities. Also, the family caretaker must treat the patient as normal person, no trace of pity or over protecting him/her.

With CVA conditions, it affects the patient physically and psychologically having restriction in self-care, which the relative has to play the role of caretaking. It is seen that having an infirm member in a family brings drastic changes in the family and family caretaker. These changes are compared to stressors affecting the family caretaker as follows: (Nattachai Tantisook, 1985:343-344). It drives the relative for retreat with Down syndrome and sensing life valueless, no one understands, and isolated. (Ekberg & Foxall 1986 : 162 ). Some relatives awfully stress so as being admitted for medical treatments. It is seen that the family caretaker is at risk of mental sickness. Had all these problems not been solved, it would have turned to be chronic psychological problems.

It includes social support. Meaning, activities or different factors of both being tangible and intangible occurred by social interpersonal, which brings mutual good will and helps each other in different aspects turning the recipient of social support receive affection, care, recognition, valuation and part of societal network with connectedness. Had the social support been adequate, it would have reduced stress and perfectly adjustable leading to good behavior and health and encouraging perfect quality life.

Sources of Social Support can be divided into 3 Groups as follows: (Ubon Niwaatchai,1984:285)

1. Spontaneous or Natural Supportive System contains 2 types, i.e. first, persons of kin, grandfathers, grandmothers, father, mother, children and grand children who have spiritual attachment, intimate affection, with sincere help to each other. Second are persons of kith, i.e. peers, neighbors, acquaintants, and colleagues.

2. Organized Support is referred to group of persons associating into unit, club or association, which is not grouped by health professionals, i.e. elder association, religious organization, and traditional physician association organized to voluntarily help others or help for mutual benefits among members. Relationship

received by individuals from an organization is likely the spiritual and emotional support, particularly, when being encountered with problems in daily living.

3. Persons in professional group, who encourage, protect, preserve, and rehabilitate health of people such as physicians and nurses.

The social support is counted the concepts directly relate to environments, which influences health conditions. IT directly relates to different critical incidents in life affecting individual health. It helps individual good health and lessens stresses or saying that it can absorb stresses in life occurrences and indirectly affects health. It is critical factor to help change emotion, role, and different stressful situations. Receiving social support, and financial helps, works, advice and options to solve problems help lessen emotional reaction such as sympathy, sentimental emission and help accepting the existing situation, directly help solving problems by lessening the existing problems.

The social support is therefore, strongly play leading role in retaining good health and easing or lessening stresses yielded by environments and societies negatively affecting the health. In particular, had social support more been received, it has relationship with the reduction rate of illness. Physical and psychological illness occurrences are also reduced. Another critical roles are helping stressed person, desperate and frustrated to be able to encounter problems and better adjust oneself. It then helps reduce problems of illness and societal problems.

### **4.3 Critiques on Psychology**

It prioritizes mind, emotion and sensation of human being. It also focuses to significantly explain different individual behaviors born from mechanism of mental reaction at individual level. It believes that mind causes perception, sensation, and thoughts called thinking system with reciprocal rationality. However, it still misses the connection between different individual behaviors, e.g. sensation, belief, and thinking system with the social context, which is actually true but unable to separate.

Behavioral adjustment at individual level, solving problems at end

results while problems from external factors directly affecting have not been solved, will restrict behavioral adjustment and problems are still existing.

Therefore, when a family member get CVA and needs extensive rehabilitation at home with traces of disease yielding disability and restriction of self-care, the caretaker plays major roles at this term and has to encounter the caretaking situation and the CVA patient, assistance conditions, and inability of self-care. The caretaker understands problems and is able to control the situation. the positive caretaking requires a person of close relation, e.g. the kin, and spouse who is willing, compassionate , understanding the patient, and wants the patient rapid recovery.

On the contrary, the negative impact, unavoidable caretaking of relative, returns-driven, and preventing adversary reprimands from surrounding people directly affect the treatment and become irrational social reinforcement and fruitless. Rationally, the relative is not ready, unwilling to care and other social factors, will also affect social support. For example, a nucleus family in a society, readiness, capacity, time, changing lifestyle, lack of supports from surrounding people, unable to play multiple roles at the same time and economic problems, all cause stresses in every dimension. It is also found that the prolong caretaking leads to dumping all caretaking workloads to only the caretaker.

#### **4.4 Data Supports of Psychology**

Ryden (1983 ) studies provision of moral support and perception of capacity in controlling different things among 30 elders admitted in the elder home. It is found that perception of capacity in controlling things becomes direct critical factor predictable to morale at %. At the meantime, health condition is the indirect factor also predictable through dependency state in doing different duties.

Bishop,& et.al, (1986 ) study morale of functioning in families, health condition, and workability among 22 disable persons. It is found that most patients are in good moral, which illustrates good mental state. Only 13% are found with low score of low morale, which reflects the crisis of encountering. It is concluded that health in general and family functioning of the patients are likely good yielding good morale even some problems arise such as travel, and socialization and so on.

Goldberg, and Fitzpatrick,(1980 ) study results of participation in activities of movement therapy toward morale among a group of 30 elders in the elder home. It is found that the elders participate the movement therapy and significantly have better morale than the group of not participating.

Regasdale, et al.,(1993:154-161) study caretakers of cerebrovascular accident . A case study using theory of social support of Caplan& Killilea (1976 ). It is found that there are 3 areas of need in social support of caretakers, i.e. 1) mental and emotional support, which is the most essential to remind the relatives of being human and self-realization of being valuable, 2) supports of information, advice of caretaking, which are compared as mentors positively motivating the caretaking and 3) supports of different materials and services. Needs of social support either more or less depend on situation and criticality in illness of the patient.

Horowitz ( 1985 : 207-211 ) finds that experiences of response and results of caretaking yield both positive and negative outcomes. The positive ones promote happiness and life satisfaction of the relative caretaker. The negative outcomes are affected by increasing roles of multi-dimensional responsibility, inadequacy of supports and different stresses. Impacts received have been changed by caretaking situation and different personal experiences.

Reinhard& Horwietz, (1995 ) assess the caretaking burden of 40 caretakers of mental disorder patients. The assessment is divided into material areas and cognitive areas. What has been found most in material caretaking is the mess of caretaking activities. The second is the household keeping activities, and family conflicts. What has been found in cognitive caretaking is worries of the future, which have the top score. The second is fear of loss, and worries of interaction with the patients.

Jirabha Hongtrakul (1988) studies the relationships of some factors between social support force and capacity in self-care among 100 patients of high blood pressure with unknowing causes in Ramadhibordi Hospital. It is found that the social support force is the predictor of the capacity in self-care.

Janpen Saewoon (1993) studies selective factors predicting boredom of relative caretakers of CVA patients. It is found that inadequacy of social supports,

which are either from relatives or peers, causes boredom and stresses. Also, the social supports ease stresses.

From the reviews of psychological works above, it is found that in behavioral psychology, individual defining is the essence followed by mechanism of action perception in encountering and handling problems, individual behavioral changes, inadequacy of social context, however, social factors and culture have been attempted to be included such as social support to explain at the individual level in order to reduce limitations of concepts, which lack static.

## **CHAPTER III**

### **CONCEPTUAL FRAMEWORK**

#### **Theory of Symbolic Interactionism**

Conceptual Framework in a studying the Theory of Symbolic Interactionism

1. Distinction of the ideology of the Theory of Symbolic Interactionism
2. Theory of Symbolic Interactionism )
3. Mead
4. Responses of the 3 inquiries using the conceptual framework in a studying the Theory of Symbolic Interactionism
5. Data supporting the conceptual framework in a studying the Theory of Symbolic Interactionism

#### **1. Distinction of the ideology of the Theory of Symbolic Interactionism**

The theory of Symbolic Interactionism involves Interaction and Symbol covering to each human being, the relation of the human being and society, and human societal condition. The Micro study prioritizes each human being and emphasizes social interaction. Meaning, an individual action either way affects idea or other human action despite any directions of the action. The social interaction must use either symbol for intercommunication.

The Symbolic Interaction significantly views 4 dimensions, i.e.

1) Emphasizing Individual, or Social Structure of Social Institution affecting human behavior. It emphasizes the dynamic social activity interaction of individuals. The study of interaction has changed individuality and social through interaction and the interaction depends on situation. Human interaction affects others.

2) An individual activity is not only the social interaction but also the effects resulted from individualized interaction, idea, attitudes, values, and thinking process.

3) Viewing Present Picture – human being understands the happening action at present and limitations of the current situation

4) Describing about the human being cannot be predicted and more emphasizing on human activities rather than other things. Human being is free to think and to act. Human actions relate to intelligence. Human being chooses to act and to behave, which affects human being.

## **2.Theory of Symbolic Interactionism**

Applying the theory of Symbolic Interactionism is to considerably prioritize the perceptions and to interpreting individual in interacting. It is believed that interpretation and perception have relationship with behavior or individual practices.

It is also explaining the human lifestyle and behavior resulted from the interpretive process. Meaning, the symbolic interactionism is the identically individual interaction, i.e. an individual will build symbols, interpret, and define behaviors which other expresses and respond to the formed definition rather than directly to the thing or behaviors other directly expresses. The symbolic interactionism has been used in explaining behaviors at two levels, i.e. Behavior or interaction level, and Symbolic level)

## **3. Mead**

Based on George H. Mead (1863- 1931) relating to individualism and mind socially and behaviorally characterized illustrates human's identity into 2 dimensions, i.e.1) capacity in perception with creativity, self- awareness, and selectivity to perception. 2) Human being in the context of participate activity with other is the person who needs to tune self-perception to others' to enabling further co-stay.

Mead studies human being in naturalistic, and human is free with uniqueness, rationality, and communication by using symbols among its own groups and other groups. The study of human being is a process rather than static. It emphasizes process human and social pattern, interaction, prioritization, interpretation

of situation, judgement of other behavior and oneself, and internal dynamism of what is done.

Naturalistic emphasize 4 areas, i.e.

- 1) Human truth to environment depends on processed activities.
- 2) Unerring knowledge of human is applicable with situation and advantageous decision making
- 3) Objectives of encountering situation, interpretation and decision to act.
- 4) Understanding human from action (human behavior) and understanding humanness it self.

Six Principal Perceptions under the Conceptual Framework of Mead's Theory

1) *Act* dominates interaction of an individual and environment. It is distinguished into steps, i.e. 1) impulse, 2) perception, 3) manipulation, and 4) consummation.

2) Attitude is the starting point or internal factors of the act leading to expression. Some tendencies need response. Internal experience and external behaving cannot be separated but the sequent process of the same phenomenon. Internal experience or attitude initiating the act, more or less, influences to what will later be the exposed behavior. The expressed act adopts the unnoticed starting point, which exists in the targeted objective of the person.

3) Symbolization - the middleman is the language, which is strongly vital. It enables us to hear what we speak and to respond ourselves like what others would do unto us. Meaning, we can intentionally respond and roughly anticipate what other will act. It is the capacity in reading other perspectives and likewise.

4) Internal Conversation – when it is the reflexiveness, an individual can adopt the social conditions through each social action. It commonly continues without external movements. The internal conversation creates self-talk regarding the future action. It is not only responding oneself but also engulfing expected responses of others.

5) “I” and “Me”

“I “ is the separated self-response or reaction of other reacting against the starting point of our action including our response to the attitude of others.

“Me” is the responses of others perceived by an individual in the starting point of its own action. Others enter our world and influence our action through responses or the internalized attitude of other adopted by us.

Individualism is the happening resulted from action between “I” and “Me”. Meaning, an individual, all the time, begins to act and is conscious of other attitudes toward those actions including modifies actions assisted by attitudes.

Interaction is the dynamic. With our dynamic response, it leads to the new interrelation. People therefore build new tactics and patterns, all the time to sustain interaction. Sometime, change leaves no previous pattern or unable to actually and obviously predict the future occurrence. Interaction is the state of the ongoing creative experience.

6) Generalization Others - it is the absorption of the internalization of social organization. Besides, individuals not only adjust their actions to follow each other perspectives, but also adjust actions to their own perspectives. It needs to understand the norms and different role patterns of everyone and every group, which they interact. Then individuals enter perfect individualist development or “individualist fulfillment”

Human being and individualist owe the root in otherness. The interesting point is what is happening among human being and emphasizes of clear intercommunication. The social experience in terms of individual will have distinction or identity, when only having been interacting. Whatever nature of relationship should be either affection, or hatred, or conflict or manipulation, or conditioning, and dynamism to yield individualism, there will be diversity in our selection of what is actually happened. Significantly, it is the revelation or the existence of individuals in whatever they are interacting.

Mead attempts to explain the step of process how development and dynamism in each step are. Also, the decision process will be carried out within oneself by determining definition and perception or the actual need of oneself.

1. Self interaction - it will react with self after being aware that problem has happened to oneself. It is to define what has happened according to self-perception,

e.g. in case of family caretaker of CVA patient has been aware that he/ she himself/ herself has definitely to handle, then the family role will change and will certainly affect oneself at present and in future.

2. Determining Behavioral Expression – there is determination for option and methods for oneself by attempting to understand the actual need through responding with oneself to determine definition of selective action and expression must be accepted by society or best at doing or behaving.

Determining selecting Method is the imagination of the consequences that the selective behavior expressed brings oneself no destruction. Determining methods requires different areas of conditioning.

1) Personal factors e.g. gender, age, nature of family, race, occupation, status, economy and culture, and so on.

2) Illness work – it addresses illness of both relatives of the patient, family members and the patient to control illness such as treatment, dosing, seeking medical treatment, and interrelations with illness.

3) Everyday life work such as dining, bathing, travelling, and working as well as privacy in general.

4) Biographical life work – it is a life dynamism of a person for the benefit of existing with the illness including family members to live most normal.

3. Negotiation is the bargaining within oneself and others in the society such as among family members. Therefore, when problem arises, particularly, when it impels an individual to pick the said method. However, the alternative may make the actor ill feeling, conflict and some restlessness regarding belief and social norms. The thinking process will, therefore, help the person seeking rationality to overcome the guilty thinking that it is the best comparing to other methods. There will be weighing and negotiation conscientious to the benefits of the method or the alternative to achieve the most satisfied goal. Self-negotiation is to ease the stress or guilty in what has been done.

Negotiating with others in society, family, colleagues, and society, and if it were the stigma or deviance, the person is conscious of being valueless, unable to negotiate with others. In this case, the CVA is the illness from the disease; the relative

can negotiate with the family members and depending on the previous power of the sick and the family caretaker, themselves.

4. Implementation – the family caretaker is aware in handling the CVA patient what activities will be fulfilled and after having been accepting to take care of the patient what will, each day, be changed and affecting daily living of oneself, family members, roles, and the additional burden of daily life. What methods and process will be used in addressing in this change and adjustment?

Blummer, (1969 referred in Chenitz & Swanson , 1986 : 5 Wanna Srithanyarat, 1997:2, Orrasa Phanpakdee, 1999:8) proposes three (3) Basic Premise of the Symbolic Interactionism.

1. An individual will implement or act or react against things according relevant to cultural interpretation of the thing affecting oneself. The thing may include materials, other person, institution, other ideology of activities, and situation or the entire mentioned.

2. Interpretation of things is resulted from the social interaction between an individual with others.

3. Transferring and adjustment sequential to process of an individual interpreting the encountering thing

Therefore, the emphasis of the symbolic interactionism is where an individual interprets the situation and the interpretation will lead to action and its consequence. (Chenitz & Swanson , 1986 : 4 ). It is the theory giving guideline in raising the research question, interview questions, data collection, and analysis of actual event gain knowledge essentially from the Empirical area of inquiry, which will explain the caretaking of the family caretaker of CVA patient. It helps to understand the behavior and handling process, which is vital to directing and recommendation. It reflects the information happening with an individual in the actual situation or problem, which finds interest in connecting process of the respective action, or interaction related to the management, control and the response to the situation.

This study is to seek the management process of the family caretaker of CVA patient employing the qualitative research using the Symbolic Interactionism. It is to build understanding of an individual and the action of an individual reacting to what is

interpreted, the management related to lifestyle, the understanding of the manipulation context and the direct reflexiveness (perspectives) of the caretaker of CVA patient. It prioritizes the individual life experiences existing in the phenomenon. The one who presents in the situation knows best and factual gives details in every dimension. It yields understanding the individual identified perspective, having perception, interpreting, and behaving to fit the context of what has, at the moment, been investigating. It includes the interaction of an individual with environment, society and culture. The investigation of the interpretation can better clear the interaction in the phenomenon than scientific prediction. ( Wikes,1991; Munhall, 1988; Omery,1983 )

Therefore, the insider of the situation will deeply understand, while the outsider of the phenomenon may provide alternated interpretation because of the different social and cultural contexts. (Suphang Janwanich, 1991; Omery, 1983)

#### **4. Responses of the four (3) inquiries using the conceptual framework in a studying the Symbolic Interactionism**

The symbolic interactionism can happen believing that human internally target when interacting. Each has its own way believing to reach the goal. Behaviors have been picked exploiting the assessment of the consequences. However, sometimes, alternatives selected to reach the real goal rationally not necessarily to be the correct one. It might be the misperception or overlooking something.

From the study of the symbolic interactionism, it obviously witnesses the management of the family caretakers of the CVA patients relating to the process, systematic procedures of interpretation, perception, thinking, self-negotiation what is best appropriate for oneself. It also recognizes surrounding people, roles, self-status, surrounding environment, values, custom and tradition and culture of society entirely based on what has previously been mentioned. It perfects and enables to answer 4 major inquiries and objectives as follows:

1. The management of the family caretaker and the family in handing the CVA patient, counting on the interpretation, the family interaction, roles of the

family member when the family has the CVA patient and the return for the first phase of rehabilitation (4 weeks) at home.

2. Attributes and roles of the family caretaker and family affecting the management

3. Life management of the family caretaker and family so that the caretaker gain better health

4. Family structure affecting and influencing the management of the CVA patient in the family

**1. The management of the family caretaker and the family in handing the CVA patient, counting on the interpretation, the family interaction, roles of the family member when the family has the CVA patient and the return for the first phase of rehabilitation (4 weeks) at home.**

It directly studies the caretaker beginning from realizing having illness to duty accepted in caretaking the CVA Patient at home. The situation helps understand beginning from perception of the caretaker when having sudden illness. Most caretakers shock unknowing what happens with the patient, are helpless, fear, confuse, and are uncertain. Later, they learn how to be caretakers. When the patients are admitted in the hospital, they closely ward and begin to observe, question the nurses and relatives of the neighboring sick-beds as well as the information from the physicians. They witness the state and the changing symptoms, confusing, feeling why such happen, worrying, and fearing death takes the patient, being uncertain of the healing, pitying the patient suffering. The existing symptoms and leaving the disability for healing, which will be rehabilitated at home will be informed by the physicians and the nurses. They emphasizes the caretakers and families to understand that physicians are unable to rehabilitate the patients till they are healed or walkable since it takes time and it takes considerable expenses for the caretakers. Significantly, hospital environment does not facilitate the rehabilitation like home because the patients are at risk of infection if continue staying in the hospital. The climates engulfs the patients and the caretakers with illness, depress, and grief. Before returning home for further rehabilitation, there must be preparation for the caretakers

and families to know about the illness and treatment realizing the problems will be arising with the caretakers where the families can help them at home. Demonstration is used for caretakers to implement in real situation.

Reinforcement and building knowledge of nursing using the symbolic interactionism help the nurses to exploit data what they commonly find daily and having knowledge within the context of the existing nursing. The recorded knowledge enables to bring the knowledge of investigation to profoundly understand person. It is the field study that has academically been recorded rather than relaying the messages of what has been known. This study is highly beneficial and accurate by building trusts with the data providers to disclose the incident. There is systematically consistent management and obvious outcomes since the beginning till the end of the study.

Illness Experience of Janice M. Morse and Joy L Johnson emphasizes Medicalization, illness experience in the hospital, and everyday life related to treatment by significantly contacting medical personnel and hospital environment. It looks deep into the sentiment, interpretation of illness suffering, provide knowledge on identical social issues in fighting, adjustment to the irregularities and tactics in handling everyday life either with illness or effects of illness. There is the experience sharing among the suffering patients, relatives, and the direct caretakers have appropriately been readjusted and not any longer disturbing everyday life.

Mother's involvement in Their Adolescent Daughter's Abortion mentions about the scourging sentiment of the mother waiting for her daughter return after abortion treatment from the hospital. She feels guilty and severely suffers. There are many processes in abortion affecting stresses in her daughter and it is complicated in manipulation. Confidentiality, and reaction to morality, decision to allow the daughter to abort, waiting for the aborting, process of treatment, necessity and acceptance of the youth including safety, fear of danger and the lost when one aborts in the hospital.

Good Days, Bad Days. The Self in Chronic illness and Time of Kathy Charmaz emphasizes Problem in Everyday Life. Experience in living and handling chronic illness excluding the physician interpreting it under self-context as interruption, intrusive, and immersion. The chronic illness has more meaning than

learning to stay with it. It means fighting for existence of the control over illness and time. It is the fight of the control interpreted and disclosure of the chronic patient. The fight indicates the clarity of management experience of daily life. By understanding illness, an individual adjusts and builds the course of life such as if it were the trifle pains and unaffecting with symptoms; it requires attempts to cover. However, if it were greater, absorbing pains should be attempted adopting as part of everyday life.

From the book of *The Experience and Management of Chronic Illness* written by Julius A. Roth, which emphasizes handling the Medical dimension and Social dimension of the patient. Most discuss about social dimensions. Society has been referred in terms of studying the process of illness in the dimension of changes when one is sick. Also, what has happen to oneself when there is change toward illness in terms of family, work, peers, thinking process, and learning regarding the management process and chronic illness in order to reconstruct oneself in using in one' everyday life.

## **2. Attributes and roles of the family caretaker and family affecting the management**

Individual attributes picked to accept role of a caretaker, when a family member is sick. In each society, there might be more factors influencing the consideration. Whether any family member would be appropriate or becoming the mainstay in caretaking at home, the leading factors are age, gender, marital status, and the existing permanent occupation. The family members have over workload and such factors all affect the readiness and capacity, time and convenience in caretaking the patient. Particularly, the CVA patient is the sudden situation and unpredictable with the family caretaker. The consequence affects the patient and the family as mentioned. In all these incidents, there is no contemplation of the caretaker's needs about what is the necessity or sentiment of the caretaker to respond to self-requirement in order to yield the life and family balances within the social context. And, those will be controlled by the existing society in the frame of social culture, i.e. custom and tradition, values, roles and family condition as well as economy and the society.

From the previous study, it has been found that most caretakers at home are women particularly the wives, and the eldest daughters. Individuals assigned to caretaking are determined by interpersonality and nature of either male or female. Most intimacy with the patient makes an individual to accept caretaking roles, which is based on perception and the nature of interpreting caretaking. It is corresponded with the study of Goldstein et al.(1981; Wood. 1991 referred in Saipin Kasemkitwattana), who interview on the rationale accepting caretaking the chronic patient in the family. It is found that it is from affection and attachment with the patient. Some reason that there is none to handle, and some pay significance to morality to return good will of the patient.

#### Two (2) Major Roles in Caretaking

1. Care providers
2. Care managers – whatever positions the caretaker takes, it will be judged by family social condition, particularly, the economy indicates the capacity in the management. (Archbold. 1983: cite in Lubkin,I.M. 1986:152)

The roles of the care manager are to facilitate the caretaking, which are the contributions of time and efforts to learn about beneficial sources and to manage the existing affairs to yield appropriateness in caretaking. Such the care manager owns time for moral support such as shopping, relative visits and others. However, the care manager must encounter the perception of the increasing workloads, particularly in the family having problem of supporting economy. The economic situation within a family facing with the increasing expenses while income is decreasing because of directly deescalating the work of the patient and the caretaker may bring the high stresses.

It is seen that caretaking at home, it requires the caretaker to take two (2) roles consistently without break. Further, the caretaker at home needs to oversee everyday works and privacy in the family to facilitate the caretaking. It contradicts with the caretaking in the hospital where it only encounters illness. There are many medical personnel who are at all time ready to decide in problem solving on caretaking. Besides, the caretaker in the hospital can for a while leave the patient if there is other caretaker to replace. It is therefore, likely the caretaker at home highly and consistently viable to encounter stress affecting the health of the caretaker.

Caretaking an individual with restriction of self-care caused by chronic illness, and prolong rehabilitation is significant to the societal members particularly within the family system. It helps happiness in co-existing. In general, most caretakers are intimate with the patients especially, the family members, relatives and peers.

Accepting to be the caretaker plays roles and responsibilities under societal expectation in the frame of the traditions. Caretaking the CVA patient emphasize the physical rehabilitation and social psychology. It encourages and supports the patient to recover and return to self-care under limitations closest to the previous condition before illness.

Therefore, the caretaker needs to upgrade skills such as walking, communication, and psychological rehabilitation, which may seriously affect the patient.. The patient is unlikely accepting the lost conditions such as image, self-control, family and social roles and sentiment of valuelessness, and dependency. The caretaker needs to understand, to will, and to be compassionate to the patient. On the contrary, ill interaction and negative sentiment increase state of responsibility. Overlooking significance, no time to attend, and negligence will deteriorate the patient and need to often admit to the hospital. Had the patents been neglected, they would be the societal burdens.

### **3. Life management of the family caretaker and family so that the caretaker gain better health**

Life management and actual situation in caretaking at home, the caretaker needs to restlessly and consistently handle two (2) roles. (i.e. the care provider, and working or socializing to retain the existing occupation, including the building of relationship with friends and lovers and family, i.e. spouse and children for the family survival). There is no break and besides the caretaker must take existing burden of everyday life of the CVA patient, the family and his/her privacy to facilitate the caretaking. It contradicts with the caretaking in the hospital where it only encounters illness. There are many medical personnel who are at all time ready to decide in problem solving on caretaking. Besides, the caretaker in the hospital can for a while

leave the patient if there is other caretaker to replace. It is therefore, likely the caretaker at home highly and consistently viable to encounter stress affecting the health of the caretaker. Compensations are sometimes therefore needed, when the caretaker is unable to earn from the family, relatives, friends and other social support cycles or no any assistance and need to encounter the fate alone.

Three (3) principles of management process of the mother relating to Mother's Involvement in Their Adolescent Daughter's Abortion

1) Make understanding with the daughter, which is the process of acceptance of the mother when the daughter is pregnant and needs abortion by seeking solution to allow the daughter feels trust and not sensing isolated, not disappointed with what has happened where solution can be found.

2) Responding to changes happened with the daughter, shape, sexual relation, menstruation, reactions in the daughter as well as acceptance of the daughter herself to acquire adjustments of her attitudes and behavior.

3) Estimating the situation, which is the proper management process for livability and consequences should be contemplated from surrounding people involving with the occurrence.

Supplied Data Should Build Six (6) Major Principles of Acceptance i.e.

1. Accessing Advice containing four (4) things, i.e. solution, participation, sexual relation, decision of pregnancy and abortion.

2. Data Supply – the mother should provide information relating sexual relation, birth control, consequences of pregnancy and abortion.

3. Alertness, observation, menstruation, having boy-friend, peers and lifestyle, when the daughter should be allowed to learn and develop self to be independent having the mother to close care and to guide.

4. Accessing the service – the mother accesses the medical service, sexual relation counseling, birth control, caring the pregnancy, abortion and the consequences.

5. Intervention to prevent the daughter is to share in the decision of pregnancy and the acceptance of abortion of the daughter.

6. Reforms – providing new information and renewing the viewing of the previous reform process relating to abortion and attitudes of the daughter. Profound

seeing and understanding and providing proper course of solution helps her living commonly.

Mentioning about the husband's each day experiences caring for the cancer wife under chemotherapy supervised by the medical doctor and needs guard everything as a guard and best reflect the suffering of his wife. Sometimes, he feels guilty, fears her death, is stressed in witnessing his wife suffers from chemotherapy. Sometimes, he feels desperate and low morale. He adjusts himself by seeking more knowledge on cancer, course of diseases and becomes expert planner on steps of solution

Management process of the husband in tending the wife under chemotherapy leads to the adjustment of the husband and behavioral changes. Adjustment is the process of the husband entering actual situation beginning from threat imposed on the wife, there is planning and procedurally managing so that the wife will recover health which contains 3 steps in Unrelenting Nightmare Husband's Experiences During the Wife' Chemotherapy, i.e.

**1) Misery Step** begins from shock, fear, and loss of self-control when the wife is threatened by cancer. Waiting, watching, and desperation have been pressed under control most like the close caretaker. Curiosity leads to acquire information on cancer life cycle. Adjustment process begins with anxieties that the wife is so depressed. There is uncertainty and curiosity on cancer consequences. The husband is compared to other mirror to reflect the wife's image of severely worries, stresses, and misery with the situation. IT begins from waiting, stressing the waiting process, response, and restressing for certainty in cancer diagnoses, requisitions of information, knowledge and conscientiousness in the situation. Desperation causes the husband anger and much mental sufferings.

**2) Coping Step** – acceptance of diagnoses and discretion to endure brings being threatened and uncontrollable situation, fear of high hope and attempts to accept that the wife needs chemotherapy under the tending of the medical doctor, absorbing side-effect from the chemotherapy, feeling misery as in the dark and disconnect communication feeling like uncontrollable, feeling Helplessness and Powerlessness under passive roles. While witnessing the chemotherapy, he attempts as if it is controllable by hiding the pains inside. Cancer therapy means the death of his wife

and malicious. Misery in seeing the wife changes moods and nausea, enduring with patience, feeling guilty, disconnection with outside like being isolated. However, the situation has been passed, he will feel better from the adjustment process and situational control will follow.

**3) Expertise Step** - the husband can control the situation by seeking knowledge on types of cancer infected the wife including studying the courses of cancer till being expert. He feels confident and eases anxiety, solves the problem and seeks information as much as he can, and learns how to best handle the affairs, plans and procedurally solve the problem. When the chemotherapy is again continuously treated, he becomes expert and acquires specifically on this knowledge and know how to proceed.

#### **4. Data supporting the conceptual framework in a studying the Theory of Symbolic Interactionism**

Literature Review changes from Biological pattern to Social condition (seeing the pattern of social expectation on chronic illness )

Friedson, Kassebaum and Baumann and Gardon closely study the experience of chronic illness bridging medical systems, clear definition, social expectations and individuals of chronic illness and acute illness.

Goffman views more individual level, i.e. speculating levels of individual and society involving the chronic illness and other restricted conditions, speculating from the social peripheral, individual status, devaluing every life and self-concept. Human lifestyle labels and changes ordinary social relation, e.g. shopping, work socialization, stress, necessary physical caretaking, and ongoing chronic illness.

Moos and Tsu identify seven(7) burdens of chronic patient.

1. Pains and disabilities
2. Environment in hospital and specific treatments
3. Relation with medical personnel
4. Sentiments
5. Satisfaction ofSelf image
6. Relation between family and friends

### 7. Readiness for uncertain future

Strauss profoundly understands working and environment, workable everyday life, addressing critical problem, grouping families and organizations. Consequences of addressing MS are more direct. Moos and Tsu illustrate close relationship of individual and society responding the chronic illness and prescribes illness that

1. Models of Long-term illness and Uncertain nature
2. Attempts to ease pains
3. Interaction of many diseases is provable
4. Disturbing things of everyday life
5. Needs of services
6. Expenses

Roth analyzed inside individual emphasizing time in terms of Long-term illness. An individual is meaningful and time in interpreting the experiences of TB. It lays the foundation of chronic illness in society and Social- Psychological

Davis studies the reaction of MS and observes the stresses in the family and relation of friend from illness. The individual self-concept of MS is changed into reaction to social relation and the change of physical capacity. He mentions the health system is inadequate to help person with problem.

Giarrantana-Oehler : Self-awareness changes when time is prolong in Diabetic retinopathy and the pattern of Social-Psychological adjustment. They study the relationship of uncertain illness of Rheumatoid Arthritis exploiting persons and surrounding societies causing illness and fraction and and dysgenopahty.

Weiner studies insider's view and planning, physical symptom of never-ending task and backgrounds of experiencing pain.

Kotarba similarly studies but focuses on interpersonal in the dimension of treatment and backgrounds of experiencing pain like Roth. Interoperation and behaving of chronic conditions, individual background and diversity of medicine and other treatments in social contexts are prioritized.

Schneider and Conrad analyze the social complication and medical influence of Epilepsy to understand disease, encountering social Stigma, medical influence, prevention of acute condition, and addressing uncertain condition of

Epilepsy of the patient and attempts to control over the conditions and environment and it does not follow medication.

The management begins from individual attempts to respond oneself, and does not subdue to medication. It is the in-depth analyses of individual details and the direct interpretation of illness toward the chronic condition relating everyday lifestyle and the illness. The attempt to control symptom and adjustment to oneself is similar to the chronic illness is part of one's life.

Employing the symbolic interactionism in such situation helps us to understand and speculate perspective of interaction among each individual in the family and society. From actual social condition, it illustrates problems and significance of the positive and negative interaction. As in part of society, it digs deep into causes of problems, self-rationale in what has been acted will affect the reshaped image of self and others. Negotiation with self and with others surrounding and selecting the best to express what one is expressing obviously reflects the pattern of the management process of relatives in handling the CVA patient.

From related literature reviews, it is found that most researches are in abroad involving the management process of the relative in consistent caretaking of the patient. It relates the interpretation of the occurring problem, self-response, negotiation with self and with others surrounding in each situation where behaviors have been appropriately changed. Also, it is to select the best thing to handle situation by speculating the everyday life of self that it would find problem and how to solve so as to enable resuming ordinary peaceful living.

It is found from the researches in abroad that sick people mostly focus on direct medical treatments. It is the help within the nucleus family. People are capable to seek information of chronic illness and apply to themselves. Sources of health services and welfare are mostly ready to support. Whereas the Thai societies focus on relative system to considerably play roles on chronic illness. The management focus to seek treatment from other sources prior to medication. It relies on belief, and social norms to drastically play roles in treatment and caretaking including health system is unlikely facilitate the patients. Most need self-dependency.

It is therefore to prioritize in addressing problems of chronic illness, which is increasing, and problem is witnessed in part of individual. However, individual

situation or the family members should see the significance of the management that reflects the authentic situation. It is to propose to see the problem, which sometimes have been overlooked employing the Symbolic Interactionism, which will obviously see the picture of the clear process within the social peripheral.

## **CHAPTER IV**

### **RESEARCH METHODOLOGY**

In this research, it was to understand and to investigate Caregiver Management in Stroke Patients in the perspectives of the family and caregivers, which would reflect misery, caregiver management and family attending patients in hospital and at home based on the Symbolic Interaction Perspectives. A Qualitative Research was employed and in-depth interviews were used for data collection to find sentiments and perceptions, interpretation and definition in relation to actions of caregivers and families including the management of caregiver and family of stroke patients. It would in-depth reflect different methods of management leading to authentic answers to misery of caregivers and it was to thoroughly understand problems more consistently and systematically.

#### **1. Research Fieldwork**

It was a purposive sampling fieldwork, which was a renowned public hospital in Bangkok with advancement and well recognized by common people and countless patients had been admitted. It could diversely and potentially treat stroke patients, which was counted for conducting research.

#### **2. Samples**

A purposive sampling was used under following qualifications.

1. The principal caregivers who volunteered to participate in this project attending the helpless stroke patients medicated in a public hospital and had to continuously attend them at the patient's homes.

2. Stroke patients level (3-5): Moderate disability- severe disability by levels of disability based on Rakin (41,42) containing 5 levels. However, the

researcher needed to focus on only the patients who are selfless and had physical limitations excluded level 1 and 2 who were not disabled and had no affect to their lifestyle and needed no caregivers.

3. The researcher worked in this hospital, which facilitated to access, interacted and familiarized with stroke patients and in turn enabled the researcher to visit their home after discharged from the hospital.

4. 13 purposive samples had been selected from the medicine ward 1 and 2 for male and, from the medicine ward 1 and 2 for female during April 2002-September 2003.

### **3. Accessing Samples**

The researcher had experienced the stroke patients and work in this section for 10 years. Many misery had been observed and they long-term affected caregiving. It drew attractions to investigate and to propose a qualitative research on Caregiver Management in Stroke Patients. 13 samples who volunteered to participate in this project were purposively selected and in-depth interviews were employed to dig deep the lifestyles of caregivers and patients. Areas of investigation were involved with perceptions, the management of caregiver and the stroke patients unto recuperations at home.

Assessing patients was to meet them when being admitted into the hospital at 4 wards, the recuperated wards, having principal caregivers and returning home for further recuperation during April 2002 till September 2003. Case-by-case basis was conducted and each was interestingly diversified, which in turn time had extensively been spent in each case to gain most valid data.

Information had been lost and caused by 3 major cases, i.e.

1. 2 death cases: considerable information had been collected and medicated in the hospital till better and stable but unexpectedly, the symptoms became sharply worsen and passed away in the hospital.

2. 2 cases stopped volunteering to give information and abandoned the project without reasons. At first, the caregiver and the family fully participated but after

sometimes in the hospital, participation and collaboration had completely been inactive.

3. 3 cases had been transferred to be medicated in home provinces when just only 5 days after admission.

Such losses by death cases caused grief and tie to the researcher. They were whip-like in deep despondency and despair. The second and the third cases were unexpected and unprepared and bringing in worries of likely lost some more cases. Even only 13 cases within 12 months, information was likely perfect for investigation with their adequate diversification. All information had been counseled with the advisor on their validity and ended data collection then.

#### **4. Data Collection and Research Instrument**

1. All data had been collected by the researcher herself employing observation, participation and in-depth interviews with patients and caregivers on managing stroke patients.

2. Accessing target group by greeting “Sawaddee Kha” and introducing oneself, “ I am a graduate student...” Allowing them to realize the objective and details of research. Also, personal rights had been informed to decide whether to join or to reject as well as asking permission to record and to take notes during interviews as well as interviewing at home and asking about the route to arrive there with contact number for later interview appointment significantly depending on readiness and convenience of samples.

3. Based on the symbolic interactions, the in-depth interview instrument had been formulated for conceptual framework, literature reviews, documents and related researches covering content and designed objectives. The nature was the interview guideline and in-depth interview approved by the examiner committee: Asst. Prof. Dr. Supot Denduang (thesis Advisor) for its content validity and reliability and Ms. Sujittra Tadtang for linguistic and idiomatic expression.

4. 60-90 minute tape recording has been used during interviews in data collection and there are two locations of interviews, i.e.

4.1. *In hospital* – most information gained were with full willingness and obligedness. Most convenient hours were evening after work and fully free inclusion of caregivers and families were restricted in hospital and likely depended on the researcher.

4.2. *At home* – information were better gained because most caregivers felt more candid than in hospital because at home was where interviewees felt comfortable and home climates helped better informing misery. It showed realistic difficulties and misery of caregivers and felt no restraints like in the hospital.

The researcher was depended much on the conveniences of caregivers and families to reach their homes and they needed to be ready for the visit. It was lucky that most caregivers needed to all time attend stroke patients at home with convenient for conversations and friendliness –oriented.

## **5. Content Validity and Reliability**

The researcher, by herself, conducted all steps of testing content validity to seek authenticity of phenomenal perceptions to check validity during interviews, observations and recording information. Also, the conceptual framework was checked under the consultation of the advisor with regards to concepts and the qualitative research methodology.

Three measures had been taken for testing reliability, i.e.

1. Repetitive or new questioning was used in checking validity of the data. Meaning the same question was used in different time period for cross checking and asked data providers to confirm the accuracy.

2. Checking data from different sources to check its accuracy of individually different sources, i.e. husband and other family members, neighbors and medical personnel to settle common understanding and from the conflict of sources. The relevancy and diversity of data might need to question those surrounding people to gain relevant conclusion. Data collection from samples on the same questions would be repetitively asked samples many times and in different time periods to check their reliability.

3. Checking data was by using different research methodology employing observations, expressions, appearance, facial expression and treating the patients and surrounding persons during interview. Every data form interviews would be checked e.g. the daughter never attended and visited her mother and all the time left the niece to do. Both the daughter and the niece were again asked with the same question and the similar answer was gained. Once the daughter visited the mother but reserved to stay aloof and the mother noticed with trying to beckon but he daughter ignored and left. The mother felt depressed and wept. Asking the sister of the patient, she gave the similar answer, “ Even her own son she never takes interest why she should take interest with her mother?”

## 6. Data Analyses

A qualitative research methodology had been used in this investigation employing in-depth interviews, participatory observation, and historical records as data collection. Analyses were as follows:

1. *Verification of Data* – records were complete on decoding each day to fulfill the research objectives and check whether any aspects should be further gathered during the following interviews. Before data analyzing, they were checked and tested their adequacy to meet requirements as advised by the advisor.

2. *Analyzing Fieldwork Data* - summarized notes during interviews, observation, and decoding form records were tested with the content analysis. Meaning data were systematized, distinguished, grouped and sought their relatedness as follows:

2.1. The open coding – it was to make them relevant to research questions. The researcher needed to many times read and understand all data collected all their details, words by words, and sentences by sentences to seek understanding and sentiment following their descriptions. Then all were analyzed by core categories under the same definition and principles e.g. misery and problems of caregivers.

2.2. The axial coding - relating the coded or the grouped data in the first step with other groups to consider relatedness of the grouped variables, the phenomenal management and consequences.

## **7. Right Protection of All Data Providers**

Personal rights of data providers had been protected since the beginning till the presentation of findings. Information and research objectives were informed as well as methodology and benefits of the investigations, including clear steps in data collection, and informing steps of in-depth interviews. Details of topic in conversation were not more than 50 minutes. If any interviewees were not ready they might immediately reject and decline the conversation. Appointments were mainly depended on readiness and convenience of the interviewees. Recording was by approval and recognized by all. Opportunities were opened had any ambiguities arisen, time taken for review before any responses and any data providers might at all time terminate data supplies without reasons. Also, the researcher needed to be strict to keep confidentiality of all with elimination of all data after research ended.

Data discussions and publicity during the presentation would be carried out without disclosing names and free of effects of medication rights. During conversations, had any questions felt uneasy to respond, they were free not to as well as withholding collaboration at any stages of research also data could be retrieved without informing any reasons under recognizing the research and personal ethics of the researcher.

## **Interview Guideline on Stroke**

- **Patient's Personal Information ( answerability)**

1. What types of stroke being prescribed? When? And age of the patient?
2. What is the status and roles of the patient? How do they affect the patient?
3. How were the work, income, and expenditures affecting this illness?
4. How does the patient encounter and handle this problem?

5. How does the patient define perceptions on illness, values and cultural lifestyles, which affect illness?

- **Caregiver's Personal Information**

1. How is the process of managing the stroke patient?

- 1.1 What are factors of management process? (Distinguish between physiology, emotion and social affecting daily routine job)

- 1.2 What does the family define illness? What action taken if a family member get sick?

- 1.3 How does the family feel encountering unexpected sickness and needed handling?

- 1.4 What are thinking process from perception of illness, anxiety, fear, perplexity, uncertainty and incomprehension of what had happened when being admitted in the hospital (systems of the hospital, physician, nurses, and other staff, and different information, effect of medication, including different supports, prolong treatment time (high expenditures), adjustment difficulties, caregiving burden on recuperation at home?

- 1.5 Acceptance of the stroke patient by family members, recruiting caregivers and all management both in the hospital and at home

- 1.6 To what extent does the stroke affect family relation? Are there any differences? What factors are involved?

- 1.7 Why the family has to think that caregiving, medication is under whose responsibility and why? Are there any relevances and irrelevances affecting the management quality and the caregiver?

- 1.8 To what extents do caregiving experiences related to the stroke patient, roles and status of family member differently affect caregiving management?

- 1.9 To what extents does the stroke patient influence the family and interactions and to what extent do they affect the caregiving management? And what factors are involved?

1.10 How do family actors affect other aspect e.g. family size, income, age, health belief and so on and determine the caregiver's behavior?

1.11 How do different sickness behaviors of family members (Thai, Chinese and others) affect the caregiving and the management?

1.12 How does one seek the medication institution for better recovery of the stroke patients? What are medications, belief and social customs and traditions?

2) What are the caregiver management regarding lifestyle and encountering the incident? How is the state handled? What are unsolved problems severely affecting quality of caregiving? What are alternatives of solutions?

3) How does the Thai context affect the stroke? Are there any differences with other illness in terms of patient, family, and relation? Are there any changes of social state having relationship since the past till present? How?

## **CHAPTER V**

### **ANALYSES AND DISCUSSIONS**

It was found in this investigation that the caregiver was top significance to the disable. He/she suffered on having a disable to take care and to handle a disable would meet problems which led to many misery. Caregivers could not solve those problems by themselves.

Presentation in this Chapter on misery of caregivers tending the disables contained:-

Part 1: State of the Patient

Part 2: Attributes of a Caregiver and Reasons Selecting a Caregiver.

Part 3: The Management Model

Part 4: Consequences of caregiving

Part 5: Definition of disability under the caregiver's perspective and problems of misery yielded by caregiving or being a caregiver.

Part 6: Management of the caregiver

#### **Part 1: State of the Patient**

It was found that most state met misery from the existing illness. Anguish affected physically, psychologically and socially and genuine attention where number of patients were increasing. Viable states were in 7 groups i.e. abandonment, subservience, negligence, conditional state, recuperation, recovery-like and well recovery.

## **1. State of Patient by Symptom or State of Caregiving**

It was found with the state of patient that it reflected misery and anguish of patient in terms of physiology, psychology and social following the symptoms of the stroke and state of caregiving. In terms of psychology, physiology, medication, rotation to visit hospital and environment of patient, it was found that seven states of patients could be grouped, i.e. abandonment, subservience, negligence, individual state, recuperation, recovery-like and recovery.

### **1.1. Abandonment State**

There was no caregiver, no family and the state unit afforded the caregiving. At the meantime, the patient was alone without caregiving from relatives and when facing illness and unconsciousness, the neighbor took to the hospital. After recovery, the patient would be left alone in the hospital for long time. They would be compelled transfer to the house for the aged in Prapadaeng affecting the physical conditions obviously disabled. The condition was still worse but conscious and unable to move. It caused trauma by pressure and needed supported devices. The psychological conditions were misery, low spirit, claimed interest, self-harm and craving death. Socially, the patient was abandoned, no caregiver, lack of attention and had to frequently visit the hospital with following unhealthy environment.

1. Obvious disability was divided into 4 states, i.e. sever condition but conscious, immobile, trauma by pressure and supported devices, i.e.

1.1 Sever condition but conscious, utterable, well-awareness, able to tell needs, left eye blurred, right eye unblurred since the left eye had been operated for new lens and rasoring, hoarse voice, strong irritation, chaotic and resistant and always with turn-away face.

1.2 Immobile patient was disable, fat and short, totally helpless, blurred left eye, weak left side, and worn-out right side, numb and entirely exhausted and immobile, unable to raise left hand, unable to do any thing, fat and short stature, needs someone to support in sitting. The patient could sit by itself by lean forward a bit and use the mobile hand to hold spoon.

1.3 Large trauma by pressure with sharp stench, wound at buttock with 4-7 cm-deep with black spot at center, whitened rim and sharp stench needed cleaning twice a day.

1.4 Equipped with supports such as nutrition tubes at left nose, urinate tubing after having trauma, costiveness, and needed enema or taking out excrement periodically, and lack physical recuperation.

2. Psychological state – it was mental depress to encounter self-disability, downhearted, sorrow, irritation and needed caregiving form other, expressive behavior and emotion to demand interest, self-harm and craving to die as follows: -

2.1 being abandoned, discarded and needed caregiving by demanding attraction e.g. frequent calls and gradually raising voice, knocking bedside alternated with banging one's belly, knocking bedside calling out "pain", " I call the nurse aimlessly but for needed care", " calling often for care, hope not tired."

" banging bedside (pain.. pain) for drinking and they are likely to hear then it needs to tap the belly or calling for changing urinate drapers, during coughing there will be urinating all the time, often changing drapers, soaking with urine, needed changes because of wet, sleeping with urine and need some to change but none. Therefore, it needs to call attraction what I am doing even not wanting to."

" by ding it help relax.. feeling resentful (silent for a while)...it is as if causing difficulties to the nurses...feeling sorry.. why such happens? And being accused of bad behaving, calling for attraction, aggressive,. But sometimes, I am bored and want to lie still and needed some one to care spit saliva to the bedside and sometimes it dirties the nurses."

2.2 Self harming – it craved to hurt oneself, stupefied, unable to do anything only prostrating on bed, behaving and bursting as if hurting oneself such as "can't do as wish, releasing by slapping the belly or limbs," " bad needs bang, worse! needs beating satisfying me," " using right hand twice or thrice beating left hand and make it gradually louder because cannot lift any hands and cannot do anything," " banging belly, " "cannot understand how much it is stupefied in this condition... anxious to all affairs... numb, exhausted and entirely sprain.. it is really misery."

2.3 Crave dying - “it is a short thought... being helpless and sharp misery.” For example, they expressed, “ really want to die than to live.. by hanging if not holding breath to death, “ “ don’t want to do, if being imposed, I would rather die... no one can help just a sick...they do not hear what is spoken so why to stay ( crying of stupefaction) “, “ want to speak to none, all do not care this sick as if need faster death to me.”

3. Socially, there was none to care. Patients were abandoned to be alone because of no relatives and neighbors to visit. For example it was, “ other beds having frequent visits and disheartened me. Why I have no caregivers?” “Staying here for so long but none to visit”, “ one to visit.””

4. Lack of caregiving – patients had no one to attend, dried lips, hoarse voice, soared mouth and throat. “ all wet with urine, “ “ prostrating with urine and excrement needing someone to change but none, “ “ unconscious, with parch skin with many large spot skin spread the whole body, skinny, fungus spread widely in armpits and groin and wound at buttock with 4x7 cm-deep with black spot at center, whitened rim, oozing lymph and sharp stench,” “ the physical state is worsened and sudden death might arrive,”

5. Frequent visit hospital and long stay in the hospital – frequency of stay could be observed as follows:

5.1 40-day period of stay in the hospital arriving at worsened condition. “ Unconscious and down.” “ The nurse from Prapadaeng informed that the condition was worsened and urgently need admission in the public hospital,. “ after 40 days, the patient has returned to Prapadaeng and after just 6 days later the patient passed away.”

5.2 Frequency of stays in hospital should be 5-6 times a year and not less than 14-day admission.

6. Lack of good environment and being admitted to the home of the aged at Prapadaeng. “ It is where nurses do not match the number of the sick, “ “ having water supplies but using underground water to bathe the sick,” “ allocating a nurse and two staff to attend more than ten patients. Each is likely not different from the patient 1.”

It was observed that the abandonment state as above was patients found no caregiver, no relative and the government needed to handle whereas the patient was helpless and had to accepted one's condition, being disable and further treated by social, No rights to choose or to do. Their statuses were the poor. No right can be demanded but directly done. Such consequences strongly affected psychologically, frustrated, de-spirited and de-motivated to future fight, abandoned, self-hurt and crave for death. It was counted deep low spirit directly deteriorated the physical state and inactive and interested in no one. It included surroundings, lack of caregiving, and at any causes, it wounded a large one by pressure in a short period and finally met sudden death.

## **1.2. Subservience State**

A state which was surrendered to misery and bad situation. The patient was an aged lady lay curling in a small bed, skinny and unable to speak. Her left side was unable to move but only right hand. She laid weeping and all time groaning. Upon approaching, her limbs stiffened to each other and her saliva always dropped at the mouth tips with difficulty to move oneself and helpless. It turned obvious disability with severity but still conscious, immobile and having trauma from pressure needed to be equipped with supports. In addition to her broken mental with all time weeping and groaning, it signed deep misery and unable to speak. Socially, there was a caregiver but likely abandoned causing negligence of caregiving and needed to be frequently admitted and long stay in the hospital including worsened environments, i.e.

1. Physically, she was obviously disable and divided into 4 major symptoms, i.e. sever but conscious, immobile, trauma of pressure and needy of equipped supports, i.e.

1.1 Sever but conscious - “ unspeakable, weeping and groaning all the time with dropping of saliva’, ‘much phlegm in the throat, dragging sound’ ‘ unable to swallow, lips cannot completely close to stop saliva drops, and sticky saliva.”

1.2 Immobile patient – “ unable to move by oneself, contracted joints but right arm can better move than other parts, “paralyzed left side but weak

right side”, stiff joints, “ very skinny and stiffened together’, approaching the patient hearing weeping, and groaning, saliva choking, very hard to move by oneself.”

1.3 Having trauma by pressure with size of 5x5-cm wound, wet dilapidated with clear lymph at the bottom caused by scraping and pressure of the same location. Traumas were found along bone knobs of the body, i.e. hips and shoulders with 1 cm-wound wet with lymph covered with cloth unravel with sharp stale-stench.

1.4 Needy of equipped supports such as nutrition tube for 4 meals a day, for urination, urine with bad stench and sludge, phlegm absorber containing green-yellow saliva and lack of physical recuperation.

2. Dispirited – it was being trapped in misery from direct self-encountering with disability, “ realizing of helpless and eyeing with anguish, unspeakable and voiceless, only sobbing with stiffened body.” Limps were stiffened at joints but the right hand was better movable than other parts, having traumas by pressure at bone knobs of the body, difficult to swallow, unable to completely close lips and always salivating with thickly substance. It was a state of helplessness, skinny, curl sleep, mute, crying at all time, upon being approached limps were tensed, always salivating at mouth tips and dragging sound in the throat.

3. Socially, there was only one caregiver. It was as if being abandoned and inadequacy of help from other family members. It was a poor family and all members needed to work with no time to take care.

4. Conditions of lacking caregiving – ‘the patient found no one for caregiving, “ clothing was shabby and dirty, disorderly and unclean belongings’. “ Even being instructed how to treat the sick, but the behaving is still the same” e.g.. “ Long unchanging posture, weeping and sobbing all the time, upon being approached limps were tensed, always salivating at mouth tips and dragging sound in the throat.’ Joints were stiffened and curl body. There were many traumas and dilapidated at the buttock with bad stale-stench.

5. Frequent visits to the hospital and long stay – duration and frequency could be considered as follows:

5.1 15-day duration of stay in each visit, the last visit was sharply severe: ‘lifeless, open eyes upon calls, groaning, dragging sounds, immobile and weak

limps,” “kith needed to move the sick to the public hospital,” “ a 15 day stay and return home and back to the hospital and within 3 moth, the sick passed away.”

5.2 Frequent stay in the hospital – admission was by respiratory infection, “over salivating, dragging sound in the throat, infection of urethral system,” “attached with urine absorber, stench urine with sludge.” Such practices were endlessly found between home and hospital.

6. Worsen environments – the patient was worst surrounded inappropriate ratio of bedding for the patient, being cornered, living in old flat amid slum at fourth floor. A disable aged lady lies curling on a small bed with ragged mattress with stale-stench. Her clothes were shabby and dirty with no buttons, loosen edge, disorderly and unclean belongings and piling, dirty spotted spread over the floor, sticky floor without mopping and dark dust on the mosquito net and TV.

It was found with the Subservience State as above, i.e. the condition of the patient was with caregiver but abandoned, inadequacy of helps from family members, realizing helplessness and only with anguish eyes, unable to speak and voiceless but sobbing with twisted and tensed body. It created severe downhearted and worsen the body. Traumas by pressure were spreading along the bone knobs of the body on hips and shoulders. The wounds were oozed with lymph and covered with loosen cloth with sharp stale-stench. The patient needed equipped supports such as nutrition tube, urine absorber, stench urine with sludge, phlegm absorber with much substance and lack of physical recuperation as well as bad environment, a flat was located amid slum and discarded and attended. Traumas became larger within short period exposed to infection. It worsened life and finally met sudden death.

### **1.3 Negligence State**

The patient was squab, worsened condition, lifeless and reacted only by wakened, weak, occasionally conscious, thin skin with spot wound, weal limps, difficulty with movements, stayed same posture and unlikely changed, bad symptom, lay alone on bed with small mattress in top floor, difficult for caregiving with equipped such as nutrition tube, urine absorber, no time to be attended, lack physical recuperation, do what one can and died after arriving home for sometime.

1. Physically, it was obvious on disability and divided into 4 symptoms, i.e. worsened condition, immobile, trauma and equipped supports, i.e.

1.1 Worsened condition – lifeless but awakened, occasionally aware, very thin skin, weak limbs, and stay still in the same posture unlikely changed and worsened symptom.

1.2 Immobile – helplessly paralyzed, ‘a squab and helpless, difficult to move and occasionally overturned but crying with pain.’”

1.3 Traumas – big wound at buttock of 5x5 inches size, wet with bas stench, whitened rim with black dots and needed twice attention a day.

1.4 Equipped with supports, i.e. nutrition tubes, urine absorber, stench urine and urine bags were disposed thrice a day.

2. Worsened Mental State – anguish of directly self-encountering disability, misery and painful expression, frown, weeping but unable to speak but “crying and anguish expression when being turned and weeping when conversed with.”

3. Socially, there was only one caregiver as if being abandoned and lack supports form family members.

4. Being Neglected – the patient was discarded, ‘lay alone on bed with small mattress in top floor, big trauma at buttock with bad stench with whitened rim and black spots.’ The patient had short-sleeve shirt open front with button, wore rather new tube skirt, no stale-smelling”. Belongings were shelved and some were disordered. ‘ Wound cleaners were unhealthy, used objects mixed with the clean ones, left and discarded, disposing only once a day in bagging, decayed buttock wound caused by excrement, colony of ants on cloth and some devices, no time to redress and side turn.’ It was difficult to change drapers for excrement”, “ lying face up”, “ body cleaning once a day in the evening.”

5. Frequent visits to the hospital with long stay. Duration and frequency of stay were examined as follows:

5.1 20-day period spent in hospital in each visit, arriving in worsened condition, lifeless, eyes opened when called, immobile limbs’, “ kith had admitted to public hospital and spent 20 day stay. Such practices of home-hospital was circulated for 5 months and died.”

5.2 Frequent stay in hospital was found. Frequent admission was by infection of urinal system. “Urine tube is attached, bad stench with sludge, home and hospital was often and burdens had been shifted to the hospital by wishing no caregiving, admission was preferable rather than care at home, longer stay was better with occasional visit, left the hospital to manage,”

6. Environmentally, the patient was surrounded by bad environment but specific space. It was a two floor old row house of much no different. Bedroom was shared with belonging at one corner. Belongings were disordered. Clean belongings of the patient were shelved. The floor was dirty, sticky with rarely mopped. Belongings were dustful at the corner. The patient lay on a small half-new mattress in bed and unlikely much stench.

The negligence state as above was a helpless patient under subservience with a caregiver but as if neglected and no helps from family member. Environment was worse causing worsened spirit affecting physical conditions. Lacking caregiving and discarded and by lying on bed lonely, the patient got large trauma with bad stench and whitened rim and flesh generally found with black spots. Buttock wound was decayed. The cover cloth was flocked with ant colony. Home and hospital was often circulated with the same symptoms and burdens had been shifted to the hospital by wishing no caregiving, admission was preferable rather than care at home, and after 5 months the patient died.

#### **1.4. Conditional State**

It was a state of big stature difficult to move by condition. Weight was 93.2 kgs uneasy to move, being aware but cannot speak and equipped with devices. For example, they were medicine sprayer, and phlegm absorber, “phlegm is found much in the mouth and throat, periodic panting.” Equipment was borrowable by home visit unit, difficult to move and all time lies in bed with donations. Mattress was slim and hard but convenient to move and recuperation such as sitting and siding, “Later, the buttock became reddish and decayed with wound.”

1. Physically, it was obvious on disability and divided into 4 symptoms, i.e. worsened condition, immobile, trauma and equipped supports, i.e.

1.1 Worsened condition – aware but unspeakable, “ voiceless even attempt, only nodding, and swaying face.” Weak right side and helpless, easy exhausted because of big body and weak diaphragm, weak breathing and needed spraying. The patient needed the phlegm absorber and nutrition tube because of swallowing problems. very thin skin, weak

1.2 The patient’s immobility – it was unable to move, being too stout, little moveability, over weight, difficult to move or slide or to side turn and only lying in bed.

1.3 The patient began infection of bedsore after arriving home. The buttock was reddened and began to decay by bedsore because of over weighting. Moving became difficult and 2 persons were needed for side turning, dress changing or other activities. There were often urinating and excremting and difficult for dress changing. Soft cloth was needed for supports and balming. Even often side turning, still the bedsore was infected.

1.4 The patient needed supportive devices, e.g. nutritional tube, a drug spray, and a phlegm absorber. “Phlegm struck in the moth and throat timely, heavily panting and needed physical therapy for every 15-30 minutes.”

2. Psychologically, there was direct despair to be encountered caused by the personal disability. “The patient was grief, smileless, suffering eyesight following the daughter. Not long, she sobbed, turned the face away, and avoided eye-contact.” “She demanded attention, always longed for caring such as using the strong left side to pullout the urine absorber and dresses, moving the buttock and needed close attention.”

3. Socially, there was a key caregiver and other to support. There was no abandonment but attended by the husband and a hired caregiver at home.

4. Lacking caregiving – being all time attended, often change and turn aside, needed soft cloth for underneath, and balming for prevention, ‘ ‘ during changing, draper is used to protect excrement and it is tough,’ ‘ most of the time lie on the back.” “ Body cleaning and changes are once done every evening.” ‘ The buttock wound begins to decay and reddish by pressure,’ ‘ short sleeve shirt with large size, front button through, dressing big tube skirt like the new drapers and clean, no stale smell,’ Utilities were grouped and shelved near the sick, ‘some belongings are

disordered.’ ‘Misplacing some belongings for convenient uses, a medium size container for wastes and will be once disposed a day in bag.’”

5. Frequent visits to the hospital with long stay. Duration and frequency of stay were examined as follows:

5.1 20-day period spent in hospital in each visit, arriving in worsened condition, very lifeless, eyes opened when called, immobile limbs’, “ kith had admitted to public hospital and spent 20 day stay, occasionally able to make self-care.’

5.2 Frequent stay in hospital was found. 2-3 times a year admission under serious condition, wanted to care at home, except unable to then the patient will be admitted to the hospital.”

6. Environmentally, the quarter for caring was proper. A private room at ground floor was arranged, patient-entered, and the caregiver attended by himself with an assistant. Even time needed for recuperation, but gradually complete. Overall caregiving and preparedness were well settled. A phlegm sober was ready at hand on the stand near the bed when hearing dragging sound or too exhaustion. Unable or unlikely to take out phlegm by coughing. A sprayer was prepared for sudden event. The patient was overweight and encountering weak diaphragm by unable to fully expanded, and more home caregiving than hospital.”

It was observed the conditional state here that the patient was helpless and surrender to the conditional state prostrating on bed. However, there was a caregiver and was not abandoned as well as assisted by other family members. There was downhearted state, unspeakable, difficult to communicate and affected the body directly. The patient was overweight and difficult to move. The physical state was deteriorating with wound at buttock because of pressure and needed soft cloth underneath with balming. Regular caregiving was provided. The patient needed equipped supports, e.g. nutrition tube, sprayer, and phlegm absorber. 15-30 minute physical therapy was daily conducted by an assistant. Occasionally, admitted to the hospital but the patient could attend oneself and only in serious condition because of wishing for personal caregiving and did not wish to shift burden to the hospital except in serious case and hard to care. Environmentally, nursing space was proper having private room for recuperation. Gradual healing needs longer time.

### 1.5. Recuperation State

The symptom was stable and tends for positive recovery and needed long time for rehabilitation. Most times were spent at home with caregiver and patient. Intimate caregiving was needed and there would be gradual recovery. The patient slept in the first floor of the house purposively prepared for the sick. She had diabetes, high sucrose and needed insulin injection periodically. ‘ the daughter injected insulin and periodically, it was a large family housing children and kith where loneliness was none. The husband attended, dialogued, and cared with the assistance from center-staff. In the evening, kith flocked in the room and in weekends, relatives from upcountry never failed to take visits their mother.’

1. Physically, there were 4 obvious disability states, i.e.

1.1 Positive recovery – awareness but difficult to speaking and hearing, ‘ all the time numb, only periodically voicing, weak at right leg and likely helpless and needed help for side-turn.’ Later, the condition was better, ‘ reactions were better and attached with nutrition tube.’

1.2 Restricted movement – it was difficult to act and only lying on bed, unclear speech and needed to hear, which brought irritation to the patient herself ‘( normally, she was impulse and likely irritated.)’ Sometimes, she spoke to herself and hard to communicate with others, exhaustion, periodic voicing, weak right limbs and needed assistance for up-siding.’

1.3 No trauma had been found since relative regularly turned and often moved the patient.

1.4 Equipped supports were used such as the nutrition tube, insulin injection,’ her daughter attended for this injection.’ Also, at least 30 minute therapy was conducted by assistant every day.

2. Psychologically, she was under mental stress because of direct encountering with self-disability. Meaning, they were, ‘ the patient wept for relief, crying for relative occasionally,’ sought attention all the time, ‘ felt inferiority complex and dependency,’ ‘ cannot do anything and felt inferiority and disability.’ ‘Causer of difficulties to children to caregiving and as if treated disability, over

anticipation, over thinking, thought of being burden, easy to get angry by anticipation,' including she was unable to do anything unlike recently.

3. Socially, she was attended by her children amid a large family and a personnel from the center had been employed to support caregiving," returning home, our mom was fresh, bright smile, ate better and heavier."

4. Inadequacy of caregiving – the patient had been cared all the time, time for clothe changing, and regular side turning having air bag to prevent trauma, ' short sleeve shirt button through, clean tube skirt and not stale-smell,' utilities were shelved and neat some were disordered for uses and a medium container with cover to dispose wastes twice a day , and bag mouth was tied before disposal.

5. Frequent visits to the hospital with long stay. Duration and frequency of stay were examined as follows:

5.1 7-day period spent in hospital in each visit, arriving in worsened condition, very lifeless, eyes opened when called, likely immobile limbs', " kith had occasionally admitted to public hospital and spent 7 day stay and returned home and able for self-care. '

5.2 Frequent stay in hospital was occasionally found. 1-2 times a year admission, always cared at home, absorbing the burden rather than shifting to the hospital except with serious condition, then the patient will be admitted to the hospital."

6. Environmentally, the quarter for caring was proper. A private room at ground floor was arranged, patient-entered, and the caregiver attended by himself with an assistant. Even time needed for recuperation, but gradually complete. Overall caregiving and preparedness were well settled and gradual recovery and more home caregiving than hospital."

It was observed the conditional state here that the patient was unlikely helpless, able to react but with difficulties, accepted the situation and prostrating on bed. Recovery had been gradual till stable. There was a caregiver and was not abandoned as well as assisted by other family members with an employed staff from the center.

There was downhearted state, able to speak but difficult to hear and to communicate and physically affected directly and difficult to move. 30 minutes

physical therapy was daily conducted determining full recovery. There was no trauma. She was equipped with supports such as nutrition tube and 30-minute therapy each day. Occasionally admitted to the hospital but the patient could attend oneself and only in serious condition because of wishing for personal caregiving and did not wish to shift burden to the hospital except in serious case and hard to care. Environmentally, nursing space was proper having private room for recuperation. Gradual healing needs longer time.

### **1.6. Recovery-like State**

A positive recovery and able to walk around and able to have normal life but left some trace of illness of disability directly affecting mental by social labeling. The patient had to return to work while the spirit was unprepared under the complete the leave by state regulations. Tough works at emergency ward were waiting where agility was required. Immediate problem solving needed intelligence and stamina particularly direct encounter with patients and their relatives and oneself to handle immediate incident. Direct communication with the patient's relatives had to be made and with other units in the hospital. At the meantime, disability trace was observed, inept, weak walk, and enlarged paces, spent time of thinking and likely stressed, heavily giddy and unable to do anything, feared workmates and misery, feeling uneasy and deep thinking. None helps working as before and felt its heaviness. "There was no stress, thinking that being survived was already lucky since helping others countlessly." "Attempting to work best." "Still walkable amid societies and workmates, more ego-centric when previously it was over dedication to work and left no time for self." At this moment, it was to work as one could and in the evening enjoy shopping for oneself. More would be spent on alms giving."

1. Physically, there were 4 obvious disability states, i.e.

1.1 Positive recovery – the patient was well aware, prolonged thinking and decision, could not follow what was thought, headache, giddy upon sitting and standing, weak limbs, and met difficulties", needed assistance, "overlapped sights at opened eyes, and the body rejected the mind."

1.2 Slightly restricted movement but obvious, difficult in speaking, “ why had I to be like this? Difficult to express!”. Walking was inexpiditious, ‘ jerking and spread walk, it was better after recuperation, walk and self-assistance’. Muscles and balance were unlikely but difficult to hold objects.

1.3 No trauma

1.4 No equipped supports

2. Psychologically, paralysis might not meet sudden death like heart disease, and high blood pressure but bad image of pity or called “ uselessness” and misery to encounter self-disability, frustration, inferiority, sorrow, irritation being cared by others, obviously expressiveness by behavior or by emotion, i.e. self-accusation and self-labeling, as follows:

2.1 Countless self-accusation – self pity, uselessness by self-causes and inability but dementalization such as sometimes felt “ being choked up, like crying for relief” and “ inferiority complex and dependency causing other troubles of caregiving”, “ disease of self-doing, uselessness, and disability.”

2.2 Labeling – the sick had mental bias since labeling oneself disability. “ Anticipation and anxiety that one was burden to others. Easy to anger and rage was rather than anticipation.” ‘ If being shown or recalled, it would be so downhearted and wept.’ “I was so stressed and weeping. Whatever, I did, I anticipated that others were scorning whether could I do; reserved to talk with others; queer eyesight from physicians, superiors, and colleagues.” “ I felt bored of myself, I couldn’t help to be disable; needed fast recovery and return to work rather than in this condition; labeling oneself being disable by social felt that other saw “ inability; troubling other in caregiving as if oneself was disable; people around observed pessimistically; and no self-care and allow disability happened.” “ Finding faults from colleagues and medical personnel turned oneself to re-think and re-decide.” “ It caused anxieties even before sickness, only good deeds had been performed; any mistakes, it was by the illness, which was part but not whole; why they have to find so fault?” The superior should appraise and labeled of “inability while I attempted to improve. Still, they observed that I was still a disable and being more de-valued. To what levels, one could do, still good deed would be unseen but disability only.”

3. Socially, the patient could walk and socialized with others and returned to work with colleagues. There were caregivers and relatives to support and care after home without abandoning. It was felt that one was still valuable to surrounded people excepted workplace rejected supports. “ Were there any units to help and care,? The colleagues? (weeping and wiping tears away)”. “ Superiors helped nothing, even drastically dedicated to heavy works but after sickness, I was accused of self-sickening. I couldn’t understand. Down of unable to do anything. I felt as aimlessly floating, didn’t know what to do?”

“ I was unlucky. Some were not sick like me but they had office job excepted me, but I had to.”

“ I had ever compared myself with the police dressing in Khaki uniform and chased after criminal. He was worse than me and had to report for work by prescription. He was supported to table and assistant to do the job. Their colleagues were so humane. Comparing a white uniform like us, who attended the sick with empathy, ability of self-help, walkable but not stable and no one helped. It was hard to understand. I might over thinking that there should be someone at assistance. Now, thinking that, I might be burden for others rather than helping them. Comparing with the father of a junior. Till he could walk but unclear speech, thinking gone speaking others and faced much difficulties, it made me felt that I might be better than others.”

4. Inadequacy of caregiving – the patient had been always cared and understood since she had passed more critical stages before and mutually looking after each other.” Arriving home, the grandmother would prepare dinner. Eating was better than cooking. Sometimes, dining-out and arrived home to sleep by nine at night as normal.”

5. Frequent visits to the hospital with long stay. No visit hospital was taken since able to gradually recuperate and spend looking after oneself at home for 4 months till able to walk and return to work. It was even hard with image and intelligence used during working.

6. Environmentally, the quarter for caring was proper. A private room at ground floor was arranged, patient-entered, and the caregiver attended with an assistant and self-help. Even time needed for recuperation, but gradually complete.

Overall caregiving and preparedness were well-settled and gradual recovery. The physical condition was ready to proceed and good spiritual support to be healed till able to normally walk even traces of disable illness was still observable which directly affected the mind. Inferiority complex was from social labeling, home caregiving and office life. One could work and socialize with peers, workable, living with surrounding people and not being abandoned felt valuable and useful to those who understood even small in number.

It was observed as above that the recovery-like state was a condition that the patient was well caregiving, not being abandoned, needed no equipped supports and assistance for other family members; met with regular care and gradual recovery by taking time. There was therapy by other and by oneself but needed long time. The patient was able to look after oneself, walking and almost living a normal life. Visiting hospital was by appointment since better condition but it traced the mental scare by being labeled from society surrounding when returned to work. The wisdom and physical condition were deteriorating and had to accept status quo.

### **1.7. Well-recovery State**

The patient was able to walk by herself and return to study till graduated. However, there was trace of disability. She was young having neuroma and hematencephalon., After operations, her right side became weak and occasional headache but with impulses and determination for future in education and aspired to be graduated like other friends within a semester. She took therapy for 3 months after operations with endeavors and dedications. Even with failures not like thinking, she stood up and continued. Currently, she could stand alone, able to walk and graduated as determined with the spiritual supports of her friends. She could live normally traveled as wished. Her parents were pleased with the recovery of their daughter since she was young with bright future.

. Physically, there were 4 obvious disability states, i.e. well-recovery, normal movement, no trauma, and no equipped supports, as follows:

1.1 Well-recovery – well aware, able to stand alone, “ 23 years old” able to eat by oneself but still likely shaking and difficult to control. The body decline to the right, which was weak.

1.2 Normal movement – “stand firm alone”, “ the patient was young with good physiology of youth where repairs was simple and fast even at first, she was hard to walk because of balance.” Later, “ with gradual recuperation, she could return to walk and live a normal life.” “ 3 month therapy with endeavor, perseverance and endurance; many falls by disheartened not being as thought, she returned to overcome all till saving herself g form disabilities. She could walk, graduated as determined with the spiritual supports form classmates. Currently, she spent her normal life and traveled wherever she wanted.”

1.3 No trauma

1.4 No equipped supports

2. Psychologically, at first she had to face disabilities, i.e. “ weeping for relief, silent and turned the face away after wiped away her tears.” And “ she felt inferiority complex, dependency, helpless and disable.” It made the family trouble to attend her as if she was paralyzed, over anticipation of being burdensome. Later, she felt confident by endeavoring to take exercises with motivation and aim to return to study for graduation. Her conditions were improving thinking that she would be fully recovered. Parents and her sister never failed in spiritual supports and assistance. “ My parents believed in miracles and pure love to their daughter affecting her recovery, happy and affection and well-wishes of the family.”

3. Socially, parents attended her with the assistance of her sister. She was not abandoned and her classmates never failed in their spiritual supports.

4. Inadequacy of caregiving – the parents unlikely well attended her because of sewing at home but they spare their time till their daughter could help herself.

5. Visiting hospital only by appointment and collect medicine.

6. Environmentally, recovery room was properly arranged and the mother personally took care of her with other help from the family members, too, even, she had to spend long time for gradual recuperation. “ At home, there were people to converse with all the time, watching television and listen to radio.”

It was observed that the well recovery state was when the patient could normally function without trace of disability. Conditions with being cared and assistance from other family members, gradual prolong medication with regular caregiving both in general and private therapy required 3 months and visiting hospital by appointment with oneself as well as following the prescriptions of the physicians, could recover a disabled to normal state and traveled here ever one wanted.

In conclusion, it was found from the investigation above that the patient's state reflected the drastic misery and it could be divided into 7 types. They were the abandonment state, which was without a caregiver. The subservience state, which accepted the conditions as if like none to attend. The negligence state, which had a caregiver but no time to attend. The individual state and the recuperation state, which was a stable and likely able to help one oneself in bed. The recovery-like state, which could walk as normal but left with traces of disabilities after returning to work and also being labeled by society. Finally, the well recovery state, which was able to walk and live normal life, able to return to socialize with friends without traces of disabilities. Each state reflected misery of each patient.

## **Part 2: Attributes of a Caregiver and Reasons to Become a Caregiver.**

### **Principal Caregiver Was and Intimate Kith**

It was found that most were intimate kith/ relatives e.g. parents, and spouse. Few were found not being relatives such as nephew, a person known, a respected person and officials. When a family member was a stroke patient and unlikely help oneself needed close caregiving, the family agreed to have a person directly take responsibility, well- prepared and proper as well as good relation to take care the sick. For example, if the father or the mother got sick, it was the duty of the children to be grateful. And if the spouse got sick, it was the duty of the couple to take care.

1. Conjugal Care (husband or wife care): a husband and a wife had long been living together with affection and concerns unable to abandon. It was found that even staying with their kith, either one needed to directly care for the other. In a poor family and their kith needed to work outside home, therefore, those who had free time

were most proper, i.e. the spouse, except during weekends, kith might alternatively take care. In a wealthy family, it would hire a staff from the center for additional caregiver since the spouse was also aged and the infirm and had to look after his disable wife, it would have create more difficulties or adding another patient as well as not well-care. Hiring a staff from the center would be better and the spouse might not tiresomely do but supervise.

2. Genealogical Care (offspring's care-either by a son or a daughter): It was found that most daughters were better prepared to take care others particularly the single, without family or married without children, either the eldest or the youngest who would have more free time and willing to do. Most followed social expectations and worked at home. They just readjusted their work from full-time to part-time or stop the job to personal caregiving. Some family, with the eldest son married and separate to build a new home and the parent stayed with him, it then became his duty as in Chinese tradition and sold Kuay Tiew (noodles) to return gratitude to their parents.

3. Matriarchal Care (a mother's care): It was found that a mother directly cared her daughter with genealogical tide. She could do anything with concerns and prioritized her daughter specially during illness, even, sewing at home and household works. With urgent works she had less time for care only during less work, she would more dedicate to her daughter with the assistance of the father and the sister when the mother was unlikely free. In association with the will of the patient was remarkable and works were at home, more attention turned her recuperation faster to normal state with no personal restriction.

4. Kinship Care (Niece cared her aunt): It was found that an only daughter discarded, had no intimacy and relation with the patient as well as married and left home for her family. On the contrary, the patient raised her niece since young with affection and intimacy, the niece was willing to directly care her aunt when her own daughter rejected as well as she was single. It was to return gratitude to the patient even uncertain in better handling or unable to find better solution if there were problems. But if she rejected, she would feel guilty till her death.

5. Philanthropic Care (a grandmother's care): with intimacy, it tied to care during illness because of empathy, relationship, association and even slept in the

same room, knowing the family well, happy and well-settled with each other, or the first thought since the family was in Northeast (Udonthani Province) unlikely to take care and to visit. Besides, all family members had to work, with emergent illness, unprepared and helpless as well as the patient needed time for recuperation, this elder had high endeavor with no relatives but could take good care, mindfulness and understanding. The patient was lucky with this elder to rely on, to give spiritual support, to motivate and attached to religion by joining religious rites and perform good deeds together. All these enhanced the spirit till the patient could help herself and work and not to be burden to others. The patient still lived with the respect elder and more intimate. Sometime, the patient could alone visit her home, burdenless to all and felt relief.

6. Employed Care (hired a staff from the center): The family could afford and less time. It most found with helpless patient in Bangkok and the premises particularly with the case of the back to the bed or after being discharged from the hospital and needed close care. The principal caregiver was unlikely spend time to look after then employing a staff from the center could bridge the gap when personal care was unlikely. Reasons to employ were:

6.1 Stature of the Patient - the caregiver unlikely took full care since the patient was big and unable to move the patient alone as well as time constraint, then it needed someone to bridge the gap during being unable to handle and manage the household as well.

6.2 Time Constraint – the caregiver had less time to care and it was necessary to hire staff from the center under following conditions:

6.2.1 The caregiver was pessimistic in caregiving of the staff from the center in performance and unable to adjust to the considerable big family. The staff needed to all time stay under the supervision of the aged husband of the patient. The husband himself was also inform and unprepared to caregiving except spiritual support and conversations and other simple affairs. He felt happy with able to do something to make his wife happy. He would often visit and in the evening and weekends, children would flock to help to fill spiritual support and helps form them and relatives.

6.2.2 The caregiver was optimistic in caregiving of the hired staff in performance and adjustable to the family members. In this case, a mother and a daughter, the daughter was an official while the mother was weak at right side, spoke short words and lay on bed. The daughter had to work to maintain the right for medical allowance and could not take leave to care the mother. She then employed a staff to take care her mother with concerns. She thought, it was best while being able to work and having a caregiver and personally took care the mother after work. "The staff is quite helpful; not only work but the mother it is likely inseparable. I can call to check. The staff is reliable and took good care of my mother. I feel relief."

7. State Care (government agent to take care): it is for one with no caregiver or might have relatives around but unprepared for caregiving. When the hospital helped better recuperation still the right side was weak and helpless. Even previously, the patient could stay alone and survive daily living among neighbors and relatives, who were dependable and helpful but currently it was not the same, no one visited and could not find. Then the hospital would contact the public welfare unit to handle and transfer the patient to the social welfare home after being discharged from the hospital.

### **Reasons Selecting a Caregiver.**

Proper attributes and reasons selecting a caregiver, it was found that there was agreement among family members a disable needed a intimate caregiver. Primarily, kinship was raised, bond between the patient and family member, economic status, nature of work and free time, which were critical reasons. It was found in the investigation that most caregivers were female, a daughter with single status, living alone, and the eldest ones by kinship of both male and female. Reasons of caregivers were mostly found that living in the same home, affection, concerns by wedlock, kinship, direct kith, well preparedness, and selective by the patient. From the study, they could be classified in son and daughter, spouse, parents, relatives, neighbors (relative network), caregiver form the center and the government caregiver and so on.

1. Gratitude to Parents – it was found with sons and daughter since it was customs and traditional practices. It was found most caregivers were sons and daughters with direct relation. It was corresponded to the Thai and Chinese traditions that when the parents became aged or infirm, it was the duty of their children to return their gratitude. Most worked at home and some only stayed at home and had more to care than others.

Most daughters followed the Thai customs and had direct duty and responsibility but preparedness and time had to be considered. For example, she was well prepared, single, or married but no children, considerable rich, no time constraint, met social expectations, willingness, as well as the one working at home who could readjust the nature of work from full-time job into part-time caregiving.

2. Social Norms – it was the case of the eldest son of Chinese families or the eldest daughter or the youngest one of the Thai families to follow the tradition and doing housework. The Chinese prioritized the son rather than the daughter by inheritance. The son was counted to return gratitude to his mother and as the eldest son, he was willing to take responsibility.

3. Affection and Concerns of Spouse – it was either one by duty to take caregiving even affections and concerns from parents, relatives, kith and peers could not compensate. For example, the husband tended his wife by affection and concern because living long times together and could not abandon each other but by wedlock. “My father is till the principal caregiver, because previously, my father helped my mother everything. Both deeply loved each other.” It was also found that children also joined caregiving even they have to work outside. Then, those who were free and even the retiree, “ once being a volunteer in an air mobile medical unit an now being free. ” Children would alternatively help during weekends.

4. Genealogical Bond – parents inherited practices when a family member was sick particularly it were a daughter. The mother was willing to unconditionally handle even her routine job was increased. She could face at all time in whatever situations. The mother cared her daughter, and the lineal bond, it was indispensable even with private business at home.

5. Bond and Intimacy with the Patient – relatives needed to take responsibility when it happened. Following lineal bond, the relative group with

intimacy and primarily came from affection and concerns not less than the former. When the direct line could not afford, the relative within the same home with bond and intimacy dependency including uncle and aunt who were most intimate. When a niece from India (away from home and family) to Thailand and got immediate sickness and had to be admitted into the hospital, the uncle and the aunt provided caregiving all the time during her stay in Thailand.

6. Returning Gratitude – it could be observed from a niece took care her aunt because she raised her since young. When the direct linear was unable, and unwilling to handle, the niece, then took the responsibility in order to return her gratitude. It was a deeper intimacy than her real mother. So, the niece accepted to take care since her own daughter was uninterested and the niece herself could not abandon her.

7. On Emergency - special case that an uncle had to took care the niece when she got sick in Thailand and he was the closest relative. She was an Indian with SLE and visiting Thailand but got immediate sickness and disable, and needed to be admitted in the hospital with relatives took close care, not only expenses, caregiving, and disseminating information to her parents in India to further transferring responsibility. The mother flew from India to take care her daughter but with communication difficulties and unfamiliar with Thailand, the uncle and the aunt helped in caregiving during her stay in Thailand and coordinated with the patient, visa process, certification from physicians till the patient could return to India.

8. Neighborhood Empathy – a neighbor (a respected elder lady- grandma) took care because of empathy during misery. She was a respected relative living in the same house. By intimacy and concerns during sickness, it bore empathy. Both previously traveled together, enjoy, happy, comfortable, mutual counseling and always helped each other. Grandma was the first in thought since her family was in upcountry with occasional visit and each already had families with grown-ups.

9. On Official Duty – a government unit directly handled the case by state welfare to help a single person with no caregiver, after the patient being discharged from the hospital. The patient stayed too long in the hospital and no one picked her home and the hospital could not further afford. A state unit had been contacted and coordinated for recuperation at the aged home, where the patient could continue her recuperation.

In summary, most caregivers had close bond with the patients and were willing to handle the case.

### **Part 3: The Management Model**

In brief, most caregivers were intimate with the patient and willing to caregiving without any problems. However, in the investigation of management model, it was found that most caregivers sensed unwilling to caregiving. Nine (9) management models were found i.e. coercion, unwillingness, dissension, tolerance, abdication, employment, social reinforcement network, reinforcement teamwork, and tug- team. Their factors were:

1. The Coercion Model: it was the state of the caregivers by duty under the government unit to directly handle the case in a sense under the formalities. The hospital needed to transfer to the Social Welfare Department to coordinate with another government unit. Meaning, the Public Welfare Home of the Aged, which was required to further adopt the patient for caregiving because there was no caregiver, the patient was alone, staying in bed, and full attention. Such case, the patient was unwilling to stay in the aged home but helpless and under direct coerced situation since being alone with no caregiver and helpless voiceless, unheard, no address, staying in the slum of Wat Muong, met with unable to register for 30B-security card. Having the government to totally handle the case, it deeply hurt psychologically, depressed with disability, and hit by misfortune, no refuge, and under social effect, and without personal rights. By being a patient, they are poor, helpless, no rights to think, to choose and to decide for their own selves and with misery, it was drastically a physical and psychological failing situation of an object or being done.

It was found with the coerced model that the caregiver management was obvious with 8 states, i.e. no relatives and relationship, unwilling caregiver, duty-focused, inadequacy of enduring caregiver and needed transferring because out-number of patients causing unprevailed caregiving, financier constraint, back-up constraint, time constraint, and empowerment constraint.

### Caregiver Case 1: states of

1. No relatives and relationship - the state caregivers directly handled in a sense following the official formalities.

2. Unwilling caregiver

3. Duty-focused – no caregiver, living alone, no relative and the hospital needed to transfer to the public welfare for further coordinate with other government unit, i.e. the Aged Home so as the patient would be admitted on the basis of no caregiver, living alone, helpless, stay in bed and needed full-time attention.

4. Inadequacy of enduring caregiver and needed transferring because out-number of patients causing unprevailed and effective caregiving – it was a duty focused, jobs exceeded staff and sometimes patients were neglected and being voiced by other patients who were in the similar condition.

5. Financier constraint – the Aged Home had restricted budget. The beds were old with scratches and erosion with old 1-2 wheels a bed where moving was difficult and noisy. It needed many staff to do. Dressing was almost worn. Public water was supplied but mostly the Home used ground water with dregs-mixed and eroded color when itching was caused from bathing. The hard water bathing felt uncleaness.

6. Back-up constraint- budgets from the government were inadequate and restricted for caregiving observed from utensils, condition of beds, establishments, and inadequate caregivers.

7. Time constraint- the caregivers at the Home of the Aged had not enough time by less staff with overloaded work and restricted time and works surmounted staff.

8. Empowerment constraint- caregivers were authorized in managing their own job but restricted.

It was observed from the above coercion model was the situations of the official caregivers directly handing patients without relatives and relationship, no caregivers, coerced and unwilling ness, inadequacy of staff but surmounting patients, budget inadequacy and back-up, time constraints by paramount works and empowerment constraints with restrictions..

2. The Unwillingness Model: it was a direct responsibility under the Chinese tradition inherited through generations. The caregivers were unwilling to care but no option because of being the eldest son and separate to build his own home and have to solely care the mother in all things. Other kin rarely visited and alienated. His wife and his son rejected to involve in caregiving and besides he sold noodles at home with the occasional assistance from his wife. He was so busy and less time to attend his mother.

It was found with the unwillingness model that there were obvious unwillingness with 8 states, i.e. no relatives and relationship, unwilling caregiver, duty-focused, inadequacy of enduring caregiver and needed transferring because out-number of patients causing unprevailed caregiving, financier constraint, back-up constraint, time constraint, and empowerment constraint

#### Caregiver Case 2: States of

1. Relativeness and relationship - the eldest son directly handled patient because of being direct descendent and by Chinese tradition.
2. Unwilling caregiver- attending with no options under the Chinese tradition
3. Sole caregiver – handling all responsibility, “ I have to shoulder everything, other acknowledge none.”
4. Physical caregiving – he was healthy and able to care but time constraint, “Works busy me, and skip to attend my mother when time permits but still..”
5. Financier constraint – only moderate finical condition unlike before when the mother was still healthy still able put ends meet.
6. Back-up constraint- a lone ranger and even the wife and son rejected to attend.
7. Time constraint- no time to attend and only when time permits, “Works busy me, and skip to attend my mother when time permits but still..”.
8. Empowerment constraint- the caregivers was the house leader and directly made decision.

It was observed from the above unwillingness model that it was a direct responsibility under the Chinese tradition inherited through generations. The caregivers were unwilling to care but no option because of being the eldest son and

have to solely care the mother in all things. He was healthy and selling noodles at home made him very busy and with not time to attend the mother. Being the house leader and full authority in decision making still he found no back-up from the surrounding family members. It was like to lead a solitary existence.

3. The Dissension Model: it was a conflict state among caregivers dissenting in caregiving. The caregiver was obliged to attend since none directly handled caused by direct dissension. Either one was prompt and it turned the family climates much stressed to be a caregiver. Then the family decided to admit the patient in the hospital to end problems. Being likely wealthy and some expenses were reimbursable but prolong stay of hospitalization, the hospital was like a second home and their eldest daughter took full-time caregiving and made the family advantageous. Other occasionally visited with some back-up, i.e. purchasing some utilities and expenses. The patient was sustained and rehabilitativeable at home but unable to finalize the consensus and none rejected the patient's return. The final decision was to for quite times admit the patient in a private hospital where it provided caregivers till the patient lonely passed away.

Dissensions in a family even caregiving could be handled but the caregiver was not empowered even close to the patient and the patient felt lack of family attention and arising consequences of management always conflicting with the patient particularly the relationship. A family conflict needed addressing rather than leaving to the patient. Admitting the patient in a hospital was creating a new context to easier solving problems and ending family quarrels and conflicts. It left the direct caregiving to the hospital and treatment was drug-based by remote caregiving of the family and its financial management for expenses. However, conflicts were not only sustained but also increased. The family was unable to bring the patient home and had to be consecutively isolated, surrendered and followed the demand of the family. When problems arose, the patient would be admitted to the hospital times and again for quite times leading the patient to chronic conditions, low spiritual morale, materialized and moveable as seen fit and isolated from society and finally frustrated and the patient died not long after.

It was found in the dissension model that the dissension was obvious as classified by 8 states. They were the state of having many children but likely negative

relationship and conflict, unwillingness because of no alternatives with exclusive responsibility and a full-time caregiver under the context of admission into the hospital. The caregiver was healthy and full-time attention, rather wealthy, reimbursability, backed-up by other family members, material but not spiritual supports, unrecognized and disregarded the caregiver and the patient. The caregiving was unlikely avail and lacked empowerment on decision, voiceless and just followed the demand of the family.

#### Caregiver Case 9: States of

1. Relativeness but negative relationship – direct family conflicts and negative relationship were the causes. Each dissented in caregiving.

2. Willingness - the caregiver was unwilling to this direct caregiving since none accepted and by best convenience, the eldest daughter handled the case. Others occasionally visited as time permitted.

3. Sole caregiver – direct caregiver staying with the patient in the new context was either the public or the private hospital, which were the second home-like. And the patient never returned home till death.

4. Physical caregiving constraint– the caregiver was healthy and most caregiving was handled by the hospital. The caregiver sometimes participated and familiarized with medical personnel by daily interaction.

5. Financier constraint – the family was wealthy and some expenses were reimbursable. The hospital was a second home since the prolong stay. There were not problems on financial situation but means for convenience to end all conflicts upon taking the patient home.

6. Back-up constraint- material supports e.g. cash, facilities, utilities and full nourishment

7. Time constraint- full attention in the hospital and sometime nurses were requested to attend for timely personal affairs.

8. Empowerment constraint- attendant was voiceless with no power of decision making and had to only follow the demand of the family.

Another case was found that conflicts happened between the daughter and the niece of the patient. The daughter had negative relationship with the patient. When her mother was disable and needed a full-time caregiver in the daughter's home. But

the daughter was not avail and likely disregarded the niece had to often call to pick her mother rehabilitated in her home. During in the hospital, the daughter took brief visit and rare visits and never touched the mother. She was irresponsible and shifted the direct caregiving to the niece. The niece was willing to fearing opportunity loss and the aunt would pass away and had to feel regretful later. The niece feared the negligent daughter to care the mother but she demand an assistant, minor expenses for the patient even she met considerable financial problems since she was jobless and studying in vocational disciplines. Sometimes, upon serious problem, she sold out her gold for self and the patient's caregiving. She said, " I need another caregiver since alone will be tough. I need devices, such an adjustable bed, spray, and portable phlegm absorber. Fortunately, it is donation and contributed by the home-visit unit. Now I must best attend my aunt, I don't know how long her life lasts. Her condition is sustained. It is better to have an assistant sharing the burden. At first, it suffers but now after adjusting, it is not difficult as forethought and even having time for study."

#### Caregiver Case 10: States of

1. Relativeness but negative relationship – it occurred among caregivers and directly from family. So, responsibility was directly pushed to the niece.
2. Willingness- a caregiver being a niece needed to provide consistent caregiving at home since likely disregarded the mother and left the rest to the niece.
3. Sole caregiver – there is one with a hired assistant. There was agreement between the daughter and the niece that she could not attend the patient alone because the patient is stout and difficult to move. An assistant was needed but the agreement took time to settle.
4. Physical caregiving – the caregiver was likely large and healthy.
5. Financier constraint – the caregiver met with financial problem and use 30 Baht medical allowance for treatment. She ran short of money by excess of miscellaneous things and then her savings began shortened as well as she was jobless. " Fasten the belt is the measure. Miscellaneous was costly; physician fees, transportation, drug, daily utilities, which consumed money. My saving began running short." " Gold object was once sold out for the expenses of oneself and the patient."
6. Back-up constraint- the caregiver was lucky that there was a home-visit team from the hospital and contributed some donated devices for free with regardless

of time. They were an adjusted bed even likely old one but workable, drug spray and a portable phlegm absorber and noisy at functioning.

7. Time constraint- full-time attending was unlikely since the caregiver studied a vocational program and was unable to take full responsibility alone. Most of the time she stayed at home if being free from classes. Time management was tough. Then were her last year but also attending her sick aunt. Sometimes, she admitted she didn't know what to do, sometimes.

8. Empowerment constraint- the caregiver could decide while the daughter never involved even took visit. However, she paid for the assistant. It was good enough, there is no hope from this daughter.

It was found with the dissension model above that it was obvious among the two cases for the wealthy and the poor. By 8 natures of caregiver management, with many children and relatives, they caused conflict among themselves with dissension, conflict of idea and relationship. The caregiver had no option but responsibility on sole caregiving under the context of the hospital and the private aged home while another case was totally at home. The caregiver was healthy but one was wealthy and reimbursable while another was poor and using 30Baht medical allowance. The first was materialized but spiritual constraint, disregarding both the caregiver and the patient. Caregiving became inefficient and unavail. By empowerment constraint and unable to decide, the caregiver became silent and just followed the demand. At the meantime, the poor caregiver was empowered but faced with finance and back-up as well as problems of studying. It was tough on time management and affected future caregiving.

4. The Tolerance Model: a state that a caregiver was in distress but tolerating the direct caregiving. The caregiver was willing to do but situation did not permit because of misery high blood pressure and aged and had to tolerate caregiving even being sick with infirmity and aged, poverty, living in the context of slum flat. Their children had less time for caregiving because of works and this aged solely took care the patient. This retiree suffered high blood pressure, and infirmity but caregiving both oneself and his disable wife. The caregiving was not in full swing and effective. Sometimes, the patient was likely discarded because of discourage, unreadiness and intolerance in association with infirmity and difficulties to move.

It was found with the tolerance model that it was obvious with the caregiver management among 8 states, i.e. relativeness and negative relationship by all had to work. Even the caregiver was willing but his health and illness, there was no option and needed to take responsibility even weak and health problems. There was only one to fully attending the sick. The 30 Baht medical allowance was used because of being poor. Other member visited and provided some material supports. The caregiving was tough as well as looking after oneself and with the burden to care the disable wife. A caregiving was done by affordability and unlikely. However, the caregiver was empowered in decision-making.

#### Caregiver Case 5: States of

1. Relativeness / relationship – the caregiver had many children and each had their own problems and had to work and unready to attend. Negative relationship was involved. The caregiver was willing to attend but infirm and personal sickness in association with solely responsible caregiving. It was hardship for him.

2. Willingness - the caregiver was willing to but unhealthy by personal sickness, which was hardship for him.

3. Sole caregiver – he was the sole caregiver so the caregiving was by physical-based. “We together build mutual karma and we have compensate it together.”

4. Physical caregiving constraint– it was hardship for the caregiver because of his health and infirmity not only to look after oneself but also his wife. It was over excess and tiresome and the caregiving is not quite. “Fear most tiredness, we are old and aged everyday. We do not know how far we can.”

5. Financier constraint – with poverty and some petty pension for spending, the caregiver used 30Baht medical allowance. When problem arose, he admitted the patient to hospital by hiring the people nearby for help or waiting till his children returned.

6. Back-up constraint- with poverty, he was inadequate of money and his children all had their homes. “Their children were growing and needed nurturing, I dare not disturb them.” “ Actually, they know I work alone. Can’t help, I let it go. I must fulfill the patriarchal duty. Beyond this, I think I cannot.”

7. Time constraint- the caregiver had full-time attending depending on his own health. It was hard for him and hard to nurture his wife. It was over burden and tired. The caregiving was ineffective.

8. Empowerment constraint - he owned decision-making power and admitted the patient to hospital, when problem arose by hiring the people nearby for help or waiting till his children returned.

It was found with the tolerance model above that the management in caregiving needed obvious tolerance following the 8 natures of management. The state of having many children in association with negative relationship and they all had to work. Even the caregiver was willing to attend but tolerance with physical health and infirmity. There were no alternatives but directly sole responsibility of caregiving. The contextual location was in a slum flat. He faced unhealthiness, being husband, full-time free, likely poor, able to reimburse golden card of 30Baht medical allowance from outside jurisdiction. Others occasionally attended and materially supported. It became hardship for him to nurture oneself and the disable wife. The caregiving was as health permitted and likely ineffective. Even he owned decision-making but could not decide for the patient just only admitted her to the hospital by hiring the people nearby for help or waiting till his children returned.

5. The Abdication Model: the state of accepting the condition of the caregiver and had to take patient home for rehabilitation since it was rejected by physician and beyond hospital care. The burden was pushed to the family. It was the acceptance state of the caregiver on criticality and coma. The patient would never recover but nearly at deathbed beyond medication and allowed returning home. The caregiver and family members were not ready for the return and the deathbed situation of the patient. It was beyond their caregiving but he hospital coerced and pushed burden that the patient died at home, whereas, the family thought it should be the duty of the hospital by being prolonged hospitalizing. This case had been 22 days admitted but the stroke was not recovered but worsened. Thinking that it was beyond cure, the physician attempted to explain the situations to the family members to accept the situation and to bring the patient home for the last stage. The daughter and the family abdicated the physician prescription that the patient better be at home with the family. The chief physician asked the relatives to sign acknowledgement of the

unrecovered symptom but becoming critical. Life supports were unmanned and the daughter signed the acknowledgement even otherwise. “We are not ready to take her home but everyday insisted by the physician. We cannot resist even in hot pan, thinking she would be better in the hospital.” However, the daughter quickly arranged her mother back home. “ Anyway, they needed to bring her home, we need to trust the doctor since she has been admitted her here quite long time. She might have been critical staying at home and her situation is not better. Her breathing stops timely, even many want her be admitted. But we do not wish to do so since the doctor may not help. Then we ask our mother to bring her for admission, and she refuses. We stayed with her so long – she might wish her deathbed at home among all her children.” And not long, she slept her everlasting peace at her beloved home and among her children.

It was found with the abdication model that cession was obvious under the 8 natures of management. They were the state of having many children and good relationship. All were willing but abdicated to bring their mother home with a single healthy caregiver. She was likely wealthy and the expenses were reimbursable. Other members visited and likely supported, acknowledged and participated in everything. She had full-time attending and decision power to a certain level and bold enough to handle when problem arose as well as accepted any situations might happen.

#### Caregiver Case 6: States of

1. Relativeness /relationship – a state of many children with positive relationship
2. Willingness – the caregiver was the youngest daughter an willing to handle thinking her time to stay with the mother would be short and she fully willing to spend the last minute with her.
3. Sole caregiver – also, many elder brothers remotely assisted and ready to help when being requested.
4. Physical caregiving constraint– the caregiver was healthy and able to handle the caregiving
5. Financier constraint – money paid no matters and expenses were reimbursable from the workplace of the elder brother as well as the common fund.

6. Back-up constraint- the caregiver was supported by expenses and utilities with many helps from elder brothers at home.

7. Time constraint- the caregiver had full-time attending but it was hard to attend the near deathbed patient. Tolerance was reluctant and unable to accept the critical state of the mother. “ Persuade her the hospital, but they never ask mom what she wishes. Mom wished a good death and the hospital rejects medication. It is useless. They do not understand but thinking mom is suffered. It makes me awkward that there is mom and those are brothers and pop. I meet worst misery since I take care of her all the time, understand her more than others. I care nothing what they say.”

8. Empowerment constraint- the caregiver had decision power for minor affairs the greater ones would be among the family members.

It was found with the abdication model that cession was obvious under the 8 natures of management. They were the state of having many children and good relationship. All were willing but abdicated to bring their mother home with a single healthy caregiver. She was likely wealthy and the expenses were reimbursable. Other members visited and likely supported, acknowledged and participated in everything. She had full-time attending and decision power to a certain level and bold enough to handle when problem arose as well as accepted any situations might happen. The caregiver needed to explain the situation to all members but they claimed she suffered the mother. She did what she could in other views but unlikely had decision power. The patient nodded consent in every participation but courageous enough and ready to accept any situations without being admitted to hospital. She loved to be at peaceful deathbed at home among all her children.

6. The Employment Model: a state of no time to care but needed employing during not staying and unable to personally handle caregiving. Either a temporary or a permanent caregiver was hired as seeing fir. It was found that the caregiver and the single family contained 1–2, members and a responsible person took direct caregiving but works did not permit. Then a professional lady was hired during away and what was unable to handle. Currently, such professionals were availing to match urban societies since more stroke patients were also increasing and needed caregivers to handle daily living. City societies became smaller none would shoulder burdens of the

sick and none could replace, then this profession began increasing. It created job and business of caregiving recruitment. The private sector built caregiving centers and organized training for employment. Most of these professional groups had low education and skills, inadequacy of systematic preparation, interests, duty-oriented, moral and ethical like the family members. The caregiving was not complicated but longevity and consistency to meet existing living style. The family became smaller but no caregiver since all needed to work for living.

Therefore the hired caregivers were potential for the disable. In case of her mother's disability by stroke and weak, the only daughter who was an official, handling a grocery, which recently attended by her mother but she was disable then. A hired caregiver was needed to replace her. In the evening after works, she returned to attend her mother and grocery. The hired caregiver from the center was reliable and helpful since she was trained and situation abdicated her to do. it was choiceless.

It was found with the employment model that cession was obvious under the 8 natures of management. They were the state of relativeness and positive relationship, willingness and direct responsibility, healthy caregiver but no time to attend because of works the a hired caregiver was employed, wealthy status, reimbursability, sole decision power, no any back-up because of being only 2 members. Problems were time management, works and the patient.

#### Caregiver Case 8: States of

1. Relativeness / relationship – a single daughter with positive relationship, willing to caregiving but time constraints. A hired caregiver either temporary or permanent was necessary when she was not present and for some caregiving.
2. Willingness – willing to hire a caregiver
3. Sole caregiver – a hired caregiver was permanently employed.
4. Physical caregiving constraint– the caregiver was healthy but a hire caregiver was needed when being absent.
5. Financier constraint – likely wealthy and reimbursable for medication, also able to hire a caregiver to replace oneself.
6. Back-up constraint- only 2 members only the mother-daughter, and there was none to help, a hired caregiver was therefore necessary.

7. Time constraint- she herself had to work and no time, a hired caregiver was therefore necessary.

8. Empowerment constraint- full power of decision-making on the patient's sickness

It was found with the employment model above that cession was obvious under the 8 natures of management. They were the state of relativeness and positive relationship, willingness and direct responsibility, healthy caregiver but no time to attend because of works the a hired caregiver was employed, wealthy status, reimbursability, sole decision power, no any back-up because of being only 2 members unable to request other dependency. Problems were time management, works and the patient, leading to future caregiving.

Another case, hiring a caregiver for an disable in a family caused by stroke and weak right side caregiven by the husband, who was aged, unhealthy and chronic sickness to attend the disable. The family was wealthy and helped hiring a caregiver since the infirm father had to attend the disable mother. It might increase difficulties and another patient in association with likely unprevailed caregiving. Hiring a caregiver convenientiated the father not to handle the caregiving by himself but supervision. In the evening after work hours and study all would flock for help. Thinking that a caregiver from the center was reliable and helpful because of well trained. Sometimes, it was unlikely reliable and adjustable to the family but it was abdicated.

It was found with the employment model above that cession was obvious under the 8 natures of management. They were having relatives and positive relationship. All were willing to caregiving and responsibility. The caregiver was aged and infirm with personal sickness but affordable to hire caregiver, expenses were reimbursable. Other members were helpful. The caregiver had full-time with full decision power. Problems were discussible among his sons and daughters in the family.

#### Caregiver Case 8: States of

1. Relativeness / relationship – having many sons and daughters in a family with positive relationship

2. Willingness – willing to attend but needed no doing only by supervising the hired caregiver.
3. Sole caregiver – There were many helpful caregivers and a hired one from the center.
4. Physical caregiving constraint– health constraint for the caregiver by aged and personal sickness. Then a hire caregiver from the center was necessary.
5. Financier constraint – wealthy and affordable to hire a caregiver
6. Back-up constraint- many family members ready to help and need no doing only supervising.
7. Time constraint- full-time caregiving but unlikely helpful, spiritual support and conversations with closeness
8. Empowerment constraint – wealthy and decision power on the patient but any problems arose would always be raised among family members.

It was found with the employment model, as above that there were 2 cases between the wealthy and the moderate one under the 8 natures of management. The state of having few children with positive relationship, willing caregiver and direct responsibility, with sole full-time caregiver, caregiving at home, infirm caregiver with personal illness while the other case was healthy but no time to caregiving because of daily working. While the other one was wealthy another one was moderate. Both had service units and expenses were reimbursable. Other members flocked for supports with materials while the other case was self-support and stayed only a mother and a daughter, the hired one was negligent and unlikely effective, the caregiver had decision power but raised for counseling or to the descendents. No time constraint but the offspring assisted and handled. The father full-time attended the mother and supervised the hired caregiver from the center. At the meantime, the moderate wealth case had full decision power, stayed with her mother, no supports for other, faced time constraints and time management, which might affect future caregiving.

7. The Social Reinforcement Network: the caregivers were totally the outsiders, not the relatives or the offspring. They were ready and willing to direct caregiving like family members when the patient's family was not ready and inconvenient. A case was a respect elder lady took the caregiving. It was found that currently, the Thai female had longer life and single affecting general nurses were

numerously single because of shift work, unfixed time and duty-oriented. Thai ladies were more confident and able to stay alone to focus more on knowledge for oneself and better life and work, freedom of lifestyle, and independent. However, it affected after old aging with different illness particularly the chronic ones, which needed continuous medication or immediate disability. These would be followed by countless problems and needed caregiving. All relatives were separated since nurses stayed at wards. It was currently found that caregivers and families were unnecessarily to be family members. It might be the respected intimate, helped each other during misery, often visited each other and respecting each other, attached, and fully willing to help each other like family member. Also each could seek counseling and trust, stayed in the same shelter, dependency to each other where it was more often found in Thai societies rather than others. They were not relatives but respected as intimate relative. For example, a case of a single senior nurse during the working age group with advancement of education and work, she met a stroke and emergent medication, escaped disable crisis, almost helpless, dizzy by prolong thinking, weak to walk and needed full-time caregiver. Disability state was found even physicians admitted non-surviving. She said, "I realize every word of the doctor to each other but even they again find my conditions they admit survival but life disability. What words from physicians who save my life and from the same line of command. Doctors whom all view as saints for the distressed. Those words drastically contrast inside me. At those moments, I feel fakeness but I must win and recover. I feel exhausted to response just only think. I must further fight with countless things; this is only the beginning. Who would accept a disable? What should I do? Difficulties would increase, who could accept? I spend 4 months for gradual recovery enabling self-supporting but dragging leg. My leave has been ended and I must return to work. It begins all again as like other job. It's difficult and think of unable to do since all eye at me. The chief differently observes me, none seems to trust me. Is it my fault to face this ailment? None wants especially me; what can I do if I were? None understands my sentiment, how much I suffer, feel uneasy, and depress. None helps but assigns me the same hard work. When they want to I must do and do it best. But how best I can do, they have already labeled me. Currently, I am a nurse like other people. Do what I can, no stress

and lucky to survive, no other thoughts of job since unthinkable. Sometimes, I feel down with the fate particularly because of the chief and colleagues.”

It was found with the social reinforcement network, as above with 8 natures of management. They were a total outsider caregiver and not relative or a descendent with positive relationship, willingness of the sole caregiver but unlikely healthy by aged however comfortable of movement, moderate status under a service unit where expenses were reimbursable. Other family members likely to visit and support, the caregiver fully attended the patient with full decision power but also counseled with the patient.

#### Caregiver Case 7: States of

1. No Relativeness /relationship – the caregiver was a total outsider not a relative or offspring but attached and with close relationship, helpfulness during sickness and handled caregiving when the patient’s family members were not ready and convenient.

2. Willingness - the caregiver was willing and ready for direct responsibility as if a family member.

3. Sole caregiver – being a respected intimate, whom the patient called “auntie” and supported from other members.

4. Physical caregiving constraint– the caregiver was unhealthy by age but strong enough to caregiving.

5. Financier constraint – the caregiver was moderate status and most expenses paid by the patient except advancing the miscellaneous and necessary. Money did not matter.

6. Back-up constraint- the caregiver was not the family member but occasionally communicated. Sometimes the nieces made the patient feel at ease after their classes, which lessened stresses.

7. Time constraint- no time constraint but the patient was obliged and preferred to do by herself.

8. Empowerment constraint – the caregiver had authority to give advice as senior ad having caregiving records (her own daughter had cancer and better drugging).

It was obviously found with the social reinforcement network, among the moderate status as above with 8 natures of management. They were a total outsider caregiver and not relative or a descendent with positive relationship, willingness of the sole caregiver but unlikely healthy by aged however comfortable of movement, moderate status under a service unit where expenses were reimbursable. Other family members likely to visit and support, the caregiver fully attended the patient with full decision power but also counseled with the patient. There was no problem on time management but children would instruct and organize. The father looked after the mother and supervised the caregiver from the center. On the contrary, the moderate status having the decision powers by counseling and supported from others. They met with time management and worry, which would affect future caregiving. The caregiver as senior had caregiving records (her own daughter had cancer and better drugging).

8. The Reinforcement Teamwork Model: a state of a caregiver and few members divided duties by appropriateness and potentials to support each other. Such state grew because of each limitations and could not provide full caregiving, particularly the youngest daughter-the caregiver had personal ailment and drugging, unemployed and full-time stayed at home, then caregiving the disable mother. The eldest daughter was an official and owned a hostel for additional income having authority to decision every affair. The youngest one was weak and not ready turning the caregiving likely incomplete. She had full-time caregiving and rest if being tired, had privacy to private household works e.g. house-cleaning when her mother took long sleep and if time permitted, she would go and supervise the hostel. Sometimes, her father took charges and stayed with the mother when she had took take longer time for outside errands. In the evening, her elder sister helped caregiving. This was a routine and sometimes, when she was sick, the elder sister would take a leave to pay her caregiving.

It was obviously found with the reinforcement teamwork model, as above with 8 natures of management. They were the caregiver was the offspring or descendents with positive relationship, willing to caregiving and with direct responsibility, many caregivers, the main caregiver was unlikely strong with personal ailment but expeditiousness and full-time caregiving, likely wealthy, other family

members helped caregiving and supports. Also, the caregiver had no decision power but always counseled with her elder sister.

#### Caregiver Case 4: States of

1. Relativeness / relationship – a state of a caregiver with few member for reinforcement for proper and potential caregiving, all were reinforcing each other but with personal limitations, which turned caregiving unlikely.

2. Willingness – the caregiver was the willing youngest daughter and unemployed.

3. Multi- caregiver – the key was the youngest daughter and every household but decision needed to counsel the elder one all affairs passed through the elder daughter.

4. Physical caregiving constraint– the caregiver had personal ailment and drugging, weak with physical unreadiness, incompleteness and the caregiving was unlikely effective.

5. Financier constraint – a likely wealthy, the elder was an official with additional income from hostel. There were no financial constraints.

6. Back-up constraint- the key had reinforcement and rotating replacement

7. Time constraint- having full-time caregiving, taking rest when being tired, physically weak, unlikely effective caregiving, if having more spare time, she would also supervise the hostel, and sometimes, the father replaced and took company of the caregiving.

8. Empowerment constraint- no power of decision but counseled the elder and happily follower her instructions

It was found with the reinforcement teamwork model, as above that their reinforcements were obvious under 8 natures of management. They were They were the caregiver was the offspring or descendents, intimate, attached with positive relationship, willing to caregiving and with direct responsibility, many caregivers, the main caregiver was unlikely strong with personal ailment but expeditiousness and full-time caregiving, likely wealthy, other family members helped caregiving and supports. The elder sister was an official and expenses were reimbursable. Other members reinforced other affairs of the caregiver where she was physically weak. Also, the caregiver had no decision power but always counseled with her elder sister.

There were no time constraints but restricted for caregiving. The elder sister considerably instructed and handled things with no time constraints.

Another case was a four-member family. All had to work and to study, even parents had to work at home: sewing; the father needed to supervise the sewing and another 5 employees. “ I have to help all the time but time constraints during sewing orders. But later I have some free time to pay caregiving my stroke daughter during her rehabilitation and her father sometimes helped. The younger sister occasionally helps but the patient herself is enduring, determines and attempts to oneself in rehabilitation as much as she can though knowing time is needed. She needs endurance, perseverance, and good spirited and wants to be cured to return to be complete her graduation. Her classmates always motivate her and she desires normal life. Even many weeps of depression, but she wins all obstacles and is saved from disability, able to walk and returns to classes even slower than her classmates.” The case 12 said, “I am so glad, I make it. It’s my pride. In sum, I am lucky but not all will be like me.” She smiled in tears of raptures.

It was found with the reinforcement teamwork model, as above that their reinforcements were obvious under 8 natures of management. They were the caregiver was the mother with intimate relationship, willingness and direct responsibility with reinforcement from others. The caregiver was healthy and had no personal sickness but unlikely full-time caregiving, moderate status and using 30Baht medical allowance. Other members were occasionally paid caregiving but reinforced by other means. The caregiver had full power for decision-making but always counseled her spouse

Caregiver Case 12: States of

1. Relativeness / relationship – reinforcement job were assigned by appropriateness and properness to each limitations.
2. Willingness – the caregiver was the mother with willingness and sewing at home.
3. Sole caregiver – the key was the mother caring everything, decisiveable but need spouse’s counseling, who was the house leader and handled all things.
4. Physical caregiving constraint– the caregiver was healthy.

5. Financier constraint – a moderate status using cash flows with inflows if there were orders and lessened if there were no orders.

6. Back-up constraint- occasionally helped by other members, e.g. the father, and the younger sister of the patient.

7. Time constraint- when there were sewing order at first but later, the caregiver had more time leaving the spouse to supervise the sewing.

8. Empowerment constraint – the caregiver had full power in decision-making but sought counseling from he spouse, who handled all affairs at home

It was found with the reinforcement teamwork model, as above that their reinforcements were obvious under 8 natures of management. They were the caregiver was the mother with intimate relationship, willingness and direct responsibility with reinforcement from others. The caregiver was healthy and had no personal sickness but unlikely full-time caregiving, moderate status and using 30Baht medical allowance. Other members were occasionally paid caregiving but reinforced by other means. The caregiver had full power for decision-making but sought consultation from her spouse, who handled all affairs at home.

Another case, it was a foreign family having relatives in Thailand and had to take direct caregiving because the niece visiting Thailand and became disable. A stroke could happen with any races regardless places. In this example, she was a beautiful young Indian girl. She was lifeless lying on bed, likely blank, Thai illiterate only Indians, having an aunt and an uncle staying in Thailand, who had to attend and S.L.E niece visiting Thailand admitted in the hospital because of convulsions. It was found that she was infected by brain tuberculosis and cerebrocardiosis and helplessly paralyzed at right side. From computerized x-ray, it was found that the right cerebrum was weak while other parts were likely movable but still weak. The patient was only 17 years, Indian native and part was English literacy.

At first she was admitted in a private hospital for a month, but with affordability, she was moved to a public hospital still her situation was not stable by high blood pressure in cerebrum and need each day vacate water from spine, high fever, and unable to return for treatment in India with existing condition. Her visa was just only 2 months and permission for extension was by the medical certification. Her mother visited her and she could speak Thai a bit. She was then staying with her

relatives and her visa was almost expired and wished to fly her daughter home but she was in critical condition of lifeless and rarely interacted. She was worried how long had she to stay, reluctant and with too expensive spending. Her relatives had always assisted her decision-making but treatment was unspecificly resumed with stagnancy and insecurity if moving. Prolong lying by disability and S.L.E easily created infection with her high water level in the spine and needed 3 times vacating because through stomach would not work well. The right paralyses were stagnant with contractions of joints even physical therapy was unlikely by the unrecovered condition of the patient. She was more than 1 month admitted in the hospital engulfed with side effects, e.g. respiratory system, defected urination caused by drug resistant which prolonged medication even with young age. Her body was contracted with weak right side and such symptom would resume. Her mother and relatives attempted to fly her back to India and within 2 days, they could bring her home for further medication in India.

It was found with the reinforcement teamwork model that the caregiving and the management of the team were obviously synergized under 8 natures of management. They were the caregivers were direct descendents with positive relationship, 2 caregivers were willing and with direct responsibility. They were healthy but unlikely full-time caregiving with many works to fulfill, moderate status and unable to reimburse. Other members were occasionally paid caregiving but reinforced by other means. The caregiver had full power for decision-making but sought consultation from their brother, who was the patient's father.

#### Caregiver Case 13: States of

1. Relativeness/relationship – the caregiver was the uncle, a direct descendent staying in Thailand and with positive relationship handling caregiving fitting one's capability.
2. Willingness – the caregiver was unavoidable and willing to immediately help.
3. 2 caregivers – both uncle and aunt divisively and properly took responsibility.
4. Physical caregiving constraint– they were healthy.

5. Financier constraint – a moderate wealth by prolong stay in Prayathai hospital, they moved her to public hospital to reduce cost since it was unreimbursable but cash

6. Back-up constraint- finally, supports were scarce since all met spending problems and after consultation, they decided to move her back to India for further caregiving by her parents.

7. Time constraint- they had to supervise their own works and spending was rising with cash constraint.

8. Empowerment constraint- they were authorized for decision-making but needed consultation from their elder brother in India except on emergency and if the condition was stagnant, she should be immediately moved to India.

It was found with the reinforcement teamwork model that the caregiving and the management of the team were obviously synergized under 8 natures of management. They were the caregivers were intimately direct descendents with positive relationship, 2 caregivers were willing and with direct responsibility with any assistants handling the patient in the hospital context; a 1 day stay at home and further flew her back to India. They were healthy but unlikely full-time, unready and left the caregiving to the hospital by possibly visiting in the evening. They were moderate status and unreimbursable but by cash. Then, they moved her from private to public hospital and further to India. Other members were occasionally paid caregiving but reinforced by other means. With inadequacy of supporters by spending cost, the caregiver had full power for decision-making but sought consultation from their brother, who was the patient's father, and if the condition was stagnant, she should be immediately moved to India.

9. The Tug-Team Model: it was a condition of many generations well merged for caregiving. Many involved and were consistent in caregiving as tug-team. It was found that the caregiver and the family were well harmonized with the patient by bloodline and family members were well cooperating. In particular, siblings were well express responsibility as being expected by social customs and traditions by heritage. For example, children took care the mother as well as expeditiousness to handle household affairs. They realized the existence of the patient and willing to care the disable even tired and what gains were happiness in caregiving, which created

more intimacy, affection, happiness and returns of gratitude for parents. Other family members also helped when being occupied and privacy to handle business. When problems arose, there were people to give advice and then being stressed and needed help, there were empathy and mutual valuation, reciprocal assistance, additional fund, necessary utilities for the sick, and empathy from family conversations.

In this case, a daughter took care her stroke mother and disable. She had full-time caregiving, concerns for her mother, living in extending family with siblings and the elder sister's family which was helpful and intimate including the nephew who was affectionate and intimate with the patient with no conflict. Such conditions were less found in Thai urban societies since they only strive for living and likely had no time for each other in case 3.

It was found with the tug-team model that the caregiving and the management of the team were obvious under 8 natures. They were the caregiver was a daughter in a large family with remarkable relationship, willingness and direct responsibility, healthy with full-time caregiving, likely wealthy and reimbursability. Other members supported well in all aspects and the caregiver was authorized in decision-making but sought counseling form family.

#### Caregiver Case 3: States of

1. Relativeness / relationship – the caregiver was a daughter with close relationship.
2. Willingness – it was positive and own business at home. All members were willing to help and rotated in caregiving.
3. Many caregivers – the caregiver was the youngest daughter, giving every care to her mother and all family members were willing to help.
4. Physical caregiving constraint– she was healthy and if she were sick other member would replace.
5. Financier constraint – she was likely wealthy having sweets business at home.
6. Back-up constraint- she had been helped and able to seek consultation since all were expeditious to help.
7. Time constraint- she had full time caregiving and dedication.

8. Empowerment constraint- she had full authority to handle the patient, able to decide but every time needed consultation from family before addressing.

It was found with the tug-team model that the caregiving and the management of the team were obvious under 8 natures. They were the caregiver was a direct descendent in a large family with remarkable intimacy and relationship, willingness and direct responsibility with many caregivers in a home context, healthy with full-time caregiving, likely wealthy and reimbursability. Other members supported well in all aspects covering diverse management and remarkable caregiving. The caregiver was authorized in decision-making but sought counseling form family, having minor time management but well addressed, finally.

In summary, by the investigation above, the caregiver management was divided into 9 models. They were the coercion model was when the government mandated handling. The unwillingness model was when the caregivers directly took responsibility under the Chinese traditions through generations. The dissension model was when caregivers disagreed within family. The tolerance model was when the caregiver was unhealthy but tolerated to caregiving. The abdication model was when the caregiver accepted and took the patient home after physicians surrendered medication. The employment model was when the caregivers were occupied and needed hired caregivers. . The social reinforcement network model was when caregivers were not relatives and were ready and willing as if they were family members and caregivers were not ready and occupied. The reinforcement teamwork model was when the caregiver and few family members were divisively assigning duties to strengthen each other as seeing suitable. And the tug- team model was when the caregivers and their generations united to caregiving the patients.

#### **Part 4: The Management Pattern and Consequences against the Patients**

It was observed that the caregiving with relativeness and relationship caused positive effects. Meaning, when a caregiver found out being coerced or unwilling, the consequences were negative for the patients. On the contrary, when the caregiver felt positive or had worthy model of caregiving, the consequences were positive to the patient as seen with the 10 models. They were the coercion model abandoned the

patient. The unwillingness model neglected the patient. The dissension model yielded aloneness of the patient's condition. The tolerance model caused the patient submissive condition. The abdication model affected the capitulation of the patient. The employment model affected rehabilitation. The social reinforcement network model affected healthy-like of the patient. The reinforcement teamwork model affected recovery of the patient. The tug- team model affected positive condition of the patient. The harmonized teamwork model affect the patient's rehabilitation

#### **4.1 The coercion model abandoned the patient.**

It made the patient abandoned and condition that the government needed to directly supervise, and to consecutively follow the formality. The hospital passed the affairs to the Department of Public Welfare to coordinate other service units. Meaning, the home for the aged intervened for caregiving since no caregiver, helpless, and prolongedly abandoned. In case 1, the patient was unwilling to stay in the home for the aged but helpless, and depressed with the disable stage and stay among impoverished conditions. It strongly affected the patient physically and psychologically with crippling at the left side and immobile needed a caregiver. There were bedsores with strong stench, frustrated, dispirited, and sorrow. 3 moods were obviously expressed, e.g. attracting interest, self-injury, and attempting for death. She was dead not long after admitted in the home of the aged without any visitors or participated in cremation but organized by the home for the aged.

#### **4.2 The unwillingness model neglected the patient.**

It caused to neglect the patient. It was the direct responsibility of the caregiver to follow the Chinese tradition through generations-the eldest son supervised all. The caregiver was unwilling but no options and had to take responsibility his only mother without any assistants and had to sell noodles as main career. He had to handle things alone even his wife helped in selling but never helped caregiving the mother-in-law. Selling noodles needed times causing the patient being neglected, worsened the symptom and dispirited, weakened the leg and helpless.

Inclusion of no time to care and lying still, there was a big bedsore at the bottom with whitening rim and blackened at the center. With only one to take care, not long after returned home she was dead and the son organized a simple Chinese burial ceremony as in Case 2.

#### **4.3 The dissension model yielded aloneness of the patient's condition.**

It created aloneness for the patient with the dissension among caregivers in a family. The caregiver needed to since none agreed to take direct caregiving. Each had its own problems and unready to caregiving. Conflicts happened between the daughter, the patient and the caregiver causing stress when having to directly attend the patient alone. She was not ready and had to leave the job and studies as well, which caused the aloneness of the patient, who was stout, difficult to move, helpless and 2 caregivers were needed. The patient got exhaustive symptom periodically, much phlegm in throat and needed absorber and drug spray. She was bed-back and turned to side lying to prevent the bedsore using mattress and soft cloth to support. It was difficult to move the patient by her stoutness. By over lying she after got a reddish bottom and the wound was infected. Returning home, she could occasionally helped herself but quite difficult. After sometimes, it became easier because of familiarity. Once visiting hospital, the patient was so critical and difficult to attend as in Case 10.

#### **4.4. The tolerance model caused the patient submissive condition.**

It caused the patient submissive because the caregiver was unhealthy but tolerating to direct caregiving. He was willing but health prevented him by his high blood pressure and aging and had to tolerate even sick in himself. None helped and incomplete caregiving and was submissive to the sick condition, misery and critical condition of the patient, who is an aged and thin lady, speechless, contracted body, weeping and moaning, dipping saliva all the time at the mouth corner, immobile, and a bedsore with likely humid. Have a caregiver but it was like abandoned, inadequate

attention and living in a shabby flat. The patient was often admitted into the hospital and after 3 months, she was dead as in Case 5.

#### **4.5 The abdication model affected the capitulation of the patient.**

It capitulated the patient and the caregiver accepted and brought the patient home since physicians surrendered medication. She was taken home for further attention as if the responsibility was pushed to home. It was the condition when the caregiver accepted the unmedication, coma, and unrecovery but criticality and finally death. It made the patient accepted the condition, misery and dead-bed. The husband had gouty kidney and needed to clean 4 times a day through stomach (the daughter handled). It was not understood why the mother had to suffer. She had to call her brother from Taiwan to witness the last hour of the mother. At home the mother was restless and exhausted, periodically stop breathing, urinating and stooling. She was in coma and needed admission but the mother disagreed and closed her eyes. She wished her dead-bed at home among all her children. Not long she was peacefully dead at home among them all as in Case 6.

#### **4.6 The employment model affected rehabilitation.**

It affected rehabilitation since the caregiver was occupied and needed to hire a full-time caregiver. It was found that the family had only 2 persons and the caregiver had direct responsibility, preoccupied with being an official to earn reimbursement medicating the mother. She hired a caregiver from a caregiving center to rehabilitate her mother. The condition was sustained and tended to be better but needed prolong rehabilitation. Her movement was restricted and misery and full attention. After work-hour, the daughter could attend her mother after work. The patient stayed at home all the time and periodically she was admitted to hospital only when critical as in Case 8.

#### **4.7 The social reinforcement network model affected healthy-like of the patient.**

It made patient looked better and all caregivers were outsiders rather than descendents. They were ready and willing to caregiving as if being the family members when the family was not ready and convenient to caregiving. This case a respect elder lady was a caregiver. Currently, a caregiver needed not to be the sibling but an intimate or a respected during sickness. They understood each other and visiting each other till reaching intimacy, willing to help and reliable, and living in the same house. It made the patient faster recovery and almost normal but some signs of disability and psychological impact and being labeled by society when returned for work at the emergency ward. She spend more time for thinking, uneasy to walk and in expedite, all time being finding fault but was sociable and spent time in religious deed as in Case 7.

#### **4.8 The reinforcement teamwork model affected recovery of the patient.**

It reinforced rehabilitation among few caregivers who divided duty to strengthen each other to their appropriateness. All family members reinforced each other but restricted on work. The key was the youngest daughter with personal sickness, taking pills and weak. The father sometimes helped and rehabilitated the sick and the condition was better but needed prolong time for recovery. She was difficult to move and to work and was well attended. After returned home the daughter had time to attend the mother. When being tired the daughter could take rest and gradually working. The elder sister supervised everything and was fully helpful. The mother was admitted to hospital only in case of criticality as in Case 11.

#### **4.9 The tug- team model affected positive condition of the patient**

It bettered the patient condition and few caregivers distributed duties to reinforce each other as seeing suitable. The caregiver had family member assistants

and reinforced which other since some restriction among members and caregiving was unlikely complete. Perseverance, and dedication even not much time, the mother attended the daughter and hoped to see her recovered to normal state. It made the daughter positive and able to walk by herself returned to finish her studies, living the normal life, unseen disable traces. With her perseverance, and endurance with therapy for 3 months among falls and rises, she won her days and able to travel by her own, which brought delight to her parents since she was young and bright future as in Case 12.

#### **4.10 The harmonized teamwork model affect the patient's rehabilitation**

It bettered the patient's rehabilitation, which caregivers and the family generations harmonized in caregiving. There were many assistants forming among family members and they were intimate and harmonized with the patient. They were descendents and synergized especially remarkably playing responsible roles and mutual assistance. It likely bettered the patient but needed prolong rehabilitation, restricted movement, difficulties but good attention at all time. When she returned home she could help herself. The patient was at home with full attention. The caregiver had candy business at home with the elder sister and her family as a large family to help. The patient visited hospital only in critical situation as in Case 3

In summary there were 9 models of management (coercion, unwillingness, dissension, tolerance, abdication, employment, social reinforcement network, reinforcement teamwork, and tug- team). They affected 7 areas on patients (abandonment, submission, negligence, aloneness, rehabilitation, pseudo-healthy and healthy and all were different to the situational problems of the patient and its family). It was found that

From 4.4.1-4.4.5, the model were negative, unwilling and coerced worsening the patient till death. The coercion model abandoned the patient. The unwillingness model neglected the patient. The dissension model yielded aloneness of the patient's condition. The tolerance model caused the patient submissive condition. The abdication model affected the capitulation of the patient. They also depended on

attachment, previous family problems, prioritizing the disable of the caregiver, individuality as family defined, poverty, and existing problems faced. All affected caregivers helpless and restricted in the course of life and had to encounter misery and stresses. It strongly threatened and created inability to further handle caregiving.

From 4.4.6-4.4.10, the effective management, willingness and liberty, the caregivers understood and accepted to handle, willing, easy and not so long they could readjust and adopt as part of life affecting most rehabilitation but needed long period till they were normal. Models were the employment model affected rehabilitation. The social reinforcement network model affected healthy-like of the patient. The reinforcement teamwork model affected recovery of the patient. The tug-team model affected positive condition of the patient. The harmonized teamwork model affected the patient's rehabilitation. It was found in the study that good caregiving was not necessary ever be in a large family. From the case study, it was found with dissension and unreadiness of the family. (Too many cooks spoil the broth and called for problems). There were exceptions for a single family. A good caregiver even restricted and few members but all were willing and ready to caregiving. It all included attachment, previous family problems, prioritizing the caregiver and the family to paralytics, to the disable, and to individuality as family defined, as well as poverty, and existing problems faced. They all affected the caregiver sustained and lived needed to encounter misery, and stresses at first, which less threatened and unable to further bear the caregiving burden.

### **Part 5: Why Such Management (Family Caregiving)**

At this part, it indicated that actually most caregivers had negative attitudes to the disable or negatively defined disability. And, most caregivers suffered with caregiving the disable.

#### **Definition of Disability and the Disable**

1. Disability was not a despised disease and curable. The paralytics was positively defined seeing not a despised disease, curable and recovered to normal,

being understood, explicable the disease of the beloved, chance of survival and cure, willingness of the caregiver and the family, with concerns, intimacy and affection with the patient. They wished the patient recovered enhancing happiness and satisfaction in the life of caregivers' relatives, i.e. values, happiness to return gratitude creating positive relationship with the patient and the family members, being recognized, increasing ability and skills in caregiving, generating pride, being psychologically supported, and an experience priceless to life course. Finally, expecting that the caregiver would be attended if being sick.

“Thinking that my daughter would be cured. There are many like this even worse but they are recovered or most complete as possible but may not as to normal only better will already be satisfied.”

“Caring mom best so that she will recover to be our family ‘s beloved one”

“Our family always attends mom like this. I always teach my children to be gratitude to parents and hoping that they imitate us.”

2. The disability was chronic, and incurable. It was seen despised and the stroke was uncured even medicated. Drug treatment and rehabilitation was to decrease criticality but might contort or be more critical. It was therefore incurable and never recovered but worsened and despaired. The patient needed full-time caregiver with prolong period. It turned some families negative thinking, bored in caregiving and wished the patient faster death, “When will she die!!!” to lift this burden.

“An incurable disease and helpless”

3. The disability created boredom because of burden and increased many aspects of duty. “It unbearable and need some assistant.” There were many inadequate supports drastically diverting life-courses and desocializing, playing many same roles in restricted time or unable to appropriately express roles as being expected by self and by others. It created stress, and accumulated oppression in all aspects, i.e. mental and physical health, exhaustion of caregiving, deterioration, rejecting medication and being occupied and negligence.

“exhausted, no mood, can’t smile, irritating and dispirited..”

“ stay alone with the patient and exhausted, despaired and weeping....”

“boring, never end, like a loop and spiraling, “ “uncertain and disgusting...”

4. Reserved for outsiders on fearing disgust and fearing to tell others

“Fear to tell other having homed a patient..”

5. By definition of disability in views of the caregiver was to clarify and to accept attending the disable according to the caregiver’s perception. Close attention should be consistent at home. From this study, it was found that the caregiver defined disability in 3 heading, i.e. a state of helpless, a state of restricted self-caregiving, and a state of self-caregiving. They were explained as follows:

5.1 A state of helpless – from clarification and acceptance of encountering grief and misery creating much stress and threats.

“tired and difficulties to attend the patient alone. I have been exhausted, disliked to talk and with the noise from neighbor timely, it increases stress. I an exhausted both mind and body but o must do, there is no one else..”

“ I feel much uneasy. It can’ t help. It drive me mad.”

5.2 A state of restricted self-caregiving - it was to understand and the acceptance of encountering with restriction in life-course. It turned the caregiver unable to live a normal life and restrictions of caregiving and might unable to bear the burden any longer.

“ My sister needs to see the doctor and asks the father to replace or me. Then she will meet the doctor at a special clinic in the evening not more than 3 hours and returns to caregiving.”

“Never go outside because of inconvenience..”

“ no patience in caregiving, unlikely interested like before, less fortitude, moody and dislike durance, sarcastic to mom, walking away if dislike, sometimes, but when return, I find mom weeping often..”

“I am fully occupied and contribute less to caregiving. I have a child to fetch everyday. Sometimes, my child has to wait alone at school then I attend my mom till dark..”

5.3 A state of self-caregiving - by clarification and acceptance of able to do, willing, easy, adjustable over time and effective, adopting to be part of one’s life.

“At first, I think I cannot do it alone and it’s hard. But when I actually experience, it’s not so. It’s deception and now I fell fine and familiar with it.”

“My daughter can do it all, I just observe from afar. I am so delighted she can return to study and my wife can produce more of her stitching..”

6. By definition of the caregiver in relation to prioritizing the patient was referred to returning gratitude, unavoidable burden, affection and concerns, disgust, coercion, threat, conflict of mind, and deteriorating body and mind even unexpected. Valuations were varied in leading to action or behaving through obviously defining of the caregiver who attempted to negotiate even it was tough till arriving at a new satisfactory agreement for both parties and either different existing or new needs in private life of the caregiver, which was ongoing and prolonging. It included handling by prioritizing patient, which was classified in to 8 types, i.e.

6.1 As if returning gratitude – the caregiver took attentive caregiving and felt no burdensome, willingness to be a caregiver for a stroke patient, sensed valueness, returned gratitude, yielded power and interest. With positive and consistent incentives and supports, it created awareness and acceptance in the caregiver occurrences. It also created positive motivation in long-term caregiving the stroke patient. Different readiness facilitating caregiving climates would affect attentiveness, willingness and determination. It created positive relationship between the patient and persons involved gaining recognition, increased caregiving capacity and skills. It was the priceless experience in life-course wish the patient happiness without reward.

“I feel delighted and love my mom, willing to do full free time to attend her..”

“ I am not her descendant but she so much attends me. Even my parents forget me. Without her what could I be. I must attend her and cannot abandon her. Good deeds never fail anyone..”

6.2 As if an unavoidable burden - the caregiver never attended and felt as burden. There were distributions of duties to attend the stroke patient because of unavoidability or preventing reprimands from surrounding people. The caregiver was unwilling, inadequate of motivation and supports leading to unawareness and rejection of happening. It was an unavoidable duty and necessity rather than willingness. This affected inattentiveness and sensing burden in long-term caregiving the stroke patient. It lacked promptness to facilitate the caregiving climates leading to

inattentiveness and determination, and negligence. It was additional responsibility and job to attend the patient. Also, having to work and privacy, it led to many roles at the same time. “She is my mom, I must attend her.” “None cares, I have to continue attending...it is our mutual karma..”

“I have to take entire responsibility, he is deaf to it..”

6.3 Affection and Concerns – the caregiver was willing and ready to caregiving without condition focusing on happiness for the patient having one’s attending. It was affection and concerns, determination of best caregiving, sensed no burden, increased more attachment, always concerned and dedicated for the patient even in long-term.

“My father and mother care and love each other for 20 years. They are intimate and never separated”

6.4 Disgust – the caregiver was unwilling, averse, and never socialized, which led to uninteresting and not attending but excusing for other members to attend, never involved or if inevitable just rather remotely financializing and externally supplying means.

“my elder brother conflicts with father and asks other brothers to attend and neither attends or visits..”

“The daughter is undependable but the niece is..”

6.5 Coercion – the caregiver needed to do duty without excuses or avoidance. All had to work and the caregiving was imperative (coerced to attend). No one helped. Even being occupied or unlikely fully attending but caregiving was needed and for long-term.

“I must do, it’s y duty and I’ll only what I can..”

6.6 Threat – the caregiver was always sensing the threat from family members, feeling uneasiness of conflict within the family and caregiving. They were not ready and reject the patient’s return. The caregiver could not decide since other members always held authority and finance of caregiving.

“I feel uneasiness but cannot express, unable to decide since other members hold decision power and money in caregiving. Go ahead! What they want to so..”

6.7 Conflict of Mind – it always reminded. “ Why not them but me to attend, It frustrates me” They never prioritized the patient leading to bargaining for caregiving, lacking awareness and rejecting what was happening. The caregiving was by duty and necessity rather than willingness resulted none to attend, burdensome to attend the stroke patient in the long run.

“sometimes, my husband expressed dissatisfaction and irritation. Having many members but why is it just only me?”

6.8 Deteriorating body and mind - the caregiver felt the patient as burden and responsibility to long-term caregiving. It included over dedication and no or less time for privacy leading to sickness and worsening. “I am usually sick and get cold with no rest and less sleep, which worsen me.” “ the patient never allows me to be far, my rest is out of question.” “ I often keep nodding.” “She sees my company and able to sleep.” “ It awakens me every time the patient timely moves, it’s hard to sleep after waking. I often feel drowsy and hard to sleep at night.”

It was concluded that definitions by the caregiver in prioritizing the patient, it was found that most negatively viewed as if the caregiving was unfavorable, created misery and burdensome to the caregiver in long term caregiving. Few positively viewed it most favorable, created happiness and willingness to return gratitude for long term caregiving.

### **Misery of the Caregiver in Actual Management**

In actual management, it was found with the caregiving problems and the needs of caregivers, children, relatives and intimate persons expecting to return caregiving when being sick and being the responsibility with duty-oriented, necessity and gratitude in caregiving. It was mostly found that most caregivers were worried and exhausted, suffered, no time to attend or to restlessly dedicate. Many activities were needed to continue. Some attended helpless patients with stout stature and needed assistant, which worsen the health and got sick. It barred socialization since the patient needed attentive caregiving. “ Can’t do anything, so much worry about the patient.” Some felt burdensome physically, psychologically, and socially and had to

solely shoulder the burden for a long time. Problems were, still the same, unaddressed. Miseries of the caregivers were as follows:

1. Stresses from Caregiving: a mood and misery yielded with most caregivers, they had to distressfully undergo burdens and difficulties. It depended on each family whether the caregiver needed direct responsibility on increased degrees of the patient's dependency (decreased self-caregiving), regarding physical, psychological and social caregiving. It included the drastically complicated and difficult caregiving for 24 hours and for long period of time. Had the spiral stresses of the caregiver not been addressed like in the past, the burden would have entirely weighed with the caregiver being neglected by the family, and without helps. The caregiver itself therefore felt worsen with ailment from stresses uninterested and unaddressed. Had it been prolonged deteriorating the caregiver's health, it would directly affect caregiving and the patient would have also been worsened. Expression could be seen in 2 types, i.e. the external stress and the internal stress as follows:

- the external stress : it was obviously found with "incorrectly performing, dispiritedness, worries, insomnia, inappetites, unhealthiness and catching cold.

"often head-aching, knee-aching"

"feeling headache and exhausted and no mood to talk with anyone."

- the internal stress – mental stress: it was found that some patients all the time and much created stresses to the caregivers and often expressed aggressive behaviors. They were such as irritation, inexpressibility but all the time groaning, weeping because unable to do as wishes, turned face away, silent and closed the eyes or sometimes using the strong hand pulled the tube skirt, or shirt to call attention, knocking bed-side or belly, often called with pleading sight, and pleading for helps. All these created chronic stresses in the caregivers by feeling "weariness, dispiritedness, and worries." A caregiver said, "Now, I am so worry, unable to attend the sick, get lost and need brothers and sisters, friends or health teamwork to hear, to spiritually support, to converse and to advise me so that it will better my morale."

"I was sometimes so stressed, get lost and sob alone.."

"I retreat to release misery and frustrations during deep stress on always staying with the patient.."

“situations cannot be forecasted, it leeches us and a slow clock-hands without end. Time is always observed which always creates stresses..”

“It is unimaginable, lost but it will be worse if doing nothing. Mom’s situation is worsened..”

2. Over Affection and Concerns till Stressed: It happened when a family member got sick and encountered crisis after sickness by disability and needed a full-time caregiver. After caregiving, there was gradual affection and attachment, doing all things, thinking about the patient and concerns, over caring each other. “ I never stay far till no time to rest.” “For myself. I feel guilty and over-thinking.” “ If I pay bad caregiving, the patient will become worse and I will condemn myself.” The physical and mental conditions were worsened affecting the work and reduced the immune. The body was deteriorated because over dedicated and did not care to oneself. “I give the whole day caregiving-dawn till dark. Still it does not finish.” “I have no time to rest till I also get sick.” “ I can go nowhere. When my father awakes, he calls. He needs me be seen or close to him.” “ My sister replaces me but cannot read him like the caregiver 3 and not skill in caregiving to mom, which yields negative caregiving. And finally, the patient must be admitted to the hospital..” “ I has been since so long because of sleeplessness and attending mom all the time, so stressed, get lost, which worsens my sickness.”

3. Coercion: the caregiver was forced to caregiving by following social duty, which was inexcusable. It became the main duty and unavoidable. In particular, the eldest son of a Chinese family, the wife and son did not help and he had been the only caregiver with less time and being coerced. He had to sell noodles at home and it made him difficult to skip from work to caregiving. “Even if I had little time for caregiving, since I have to sell noodles but I have to attend her because she is my mother and she stays with me. I do it alone and my wife and son do not help me. They have their own burden and do not help. I fear to trouble them but I must do since it is my duty. I do what I can and do my best.”

4. Threat: the caregiver was directly threatened to take the duty when to return the patient from hospital since other members were not ready and did not need the patient to be back home. It made both the patient and the caregiver in a hot pot and at all time encountering threat. “I feel frustrated, inexpressible. How can they

think like this? He is our father and has ever care our family being the commissioned armforce for the nation and nurtures us all..” “The caregiver is the eldest daughter even she separates from the family and has to return for caregiving. She pities him since none attends him and has to take this duty..” It was frustrated when family members got conflicts on caregiving. “I cannot decide since other members have authority to decide and all expenses. What they want to do let them do..”

5. Uncertain of Caregiving: The caregiver had 2 uncertainties in oneself, i.e. between fearing to treat the sick and fearing of unable to do. It feared to do something, felt difficulties in all things, feared to harm the patient and felt better not to do anything.

“I fear if I do wrong and what will happen to my father since I never do it before. It is frightful to absorb the phlegm from the mouth..”

“Problem is the constipation and needs evacuation periodically. I dare not do it but ask the staff to do. I cannot and no courage so I do not do it.”

6. Weakening the Body: it needed to learn and to practice all aspects about the patient. It needed time or all time directly to sacrifice to caregiving. “The aunt is stout, needs assistant to up-side and often lift the body. The niece begins backache and still has no time to see the doctor..”

“Sleepless during night since being called for sitting, siding and sometimes just call the name but tells nothing, calling for 3-4 times and stops, then calls again repetitively and speaking incomprehensibly..”

“ I get backache and do not know it is from lifting the body but I doubt only one can do. I have no time to see the doctor fearing no one for caregiving and it will be hard time. I got headache, backache and knee-ache often.” “Feeling headache and exhausted and wish to speak with no one..”

“Often sit nodding drowsy. When papa sees me sitting there he can sleep. “ I wake every time the sick moves and timely awaken. Then it is hard to sleep after being awakened, feeling drowsy since lacking sound sleep at night.”

7. Weariness to death: the caregiver felt both physically and mentally exhausted in full-time caregiving. It made moody to do anything and completely wearisome during caregiving.

“ I am completely exhausted, since old and aging and know nowhere to reach.” It is our mutual karma that we have to return..”

“It is completely exhausted in caregiving mom but need patience and likely able to do..”

“Exhausted and difficult to attend alone but I dare all and talk to no one. The timely neighboring sound increases stress, physical and mental exhaustion but I must do there is no one.”

“Nodding at night, timely awakening, then it’s difficult to sleep and often drowsy.”

“Wearisome with no mood cannot smile and irritating, it’s dispirited to go anywhere..”

“ Stay silent with the patient is wearisome, frustrating and often weeping..”

8. No Private Time: the caregiver was preoccupied with the sick all the time and no time for oneself. “ Spend little time going somewhere, worry each time as if something tick like a watch in the heart taking long time even short period..”

“wish to meet no one, feel no way to help and without hope. The sick needs close care..”

“I travel nowhere since there is the patient..”

“I go out any since inconvenience..”

“I take a trip but it never lessens stress. It’s useless..”

“ I go nowhere, worrying about mom always..”

“Each day I go nowhere ( telling with tears)” “ Getting cold but no time to see doctor. My brother and sister have to force me and will attend the caregiving for me.”

9. Inattentiveness of one’s family: the caregiver unlikely went home for household works. “ 1-2 times in 3 months I return home. I stay in a condominium, none takes care, with my husband and without a child.” “ A Janitor is called timely, it is too dusty and cannot do because of restricted time..”

“Sometimes, my husband expresses likely dissatisfaction, and irritation. There are many other and why it has to be me.”

10. Not fully working and often absence: the caregiver worried and concerned the sick and needed to pay close caregiving, contacted medication for her mother. She was often absent and not fully works. “We, mom and me stay together. When she is sick the I need to stop working often for my mother’s affairs, contacted the service unit, medication follow-up, necessary devices and return to work but distracting because of worrying and needed to visit her.”

“During this time, it needs often stop working, taking a leave for this and for that when mom is sick. We both stay together and need to hire a staff from the center. I am worry. Sometime I drop at workplace and skip to visit her.”

“I arrive late at work by bring dad to attend mom then send my children to school and arrive at workplace. I leave early in the evening to pick up dad, children and attend mom. Then I arrive home late at night..”

11. Monotonous Life and Boring: long caregiving gave the caregiver dull. “it’s irksome, no end, circle-like and spiraling.” “It ‘s uncertain and excessively boring.”

“Caregiving is repetitive, upon awake, dad is like this and ongoing like this by anticipation..”

“My life is cycled with dad and hospital. Yes, it’s boring but I get familiar and it’s part of my life..”

12. Dissocializing with peers: the caregiver refused and lately dissocialized with friends when her mother got sick. It made her worried even once joined but unhappy, uneasy and better not to go. Staying with the mother made her more comfortable and able to fully attend her.

“Later, I excuse any religious function because of my sick mom.”

“Unlikely wish to meet anyone..”

13. Caregiving till get sick: the caregiver had no time to care for one’s health. The body and mind got worsened, no time for rest till got sick. And unable to caregiving and doing duty. “I attend my mom till I get flu and have to stop caregiving asking my elder sister to resume fearing that my mom would be infected.”

“I all attend and so stressed, no rest and sleepless and mom always calls till I get sick..”

“Latter I always get headache, backache and knee-ache.” “ Feel heavy head and exhausted, insomnia, no appetite, and so tensed to talk with anybody..” (Case 5)

14. Paroxysm: a caregiving was likely burdensome for those with personal sickness. It accelerated previous ailments since the caregiving needed dedication and stayed entirely and lengthily with the patient. Had the caregiver neglected its health and ailments, it would have been accelerated. “Blood pressures are always heightened, a paroxysmal high blood pressure, fainted and sent to hospital.”

“my sister gets Takayasu and cautioned by the doctor about another side. She has to care herself and avoid hard work or over stressed. Any symptom of paroxysm, she needs to see the doctor immediately before appointment. Now, her situation is worse, swollen leg and backache because she attends mom. Now, I would be worse and need to meet the doctor to readjust the drug and take more rest..”

15. Needy of Money: a poor status for the caregiver and expenses were increasing without additional income for supports and only the savings. Sometimes, it was unable to find money and had to sell out golden chain to meet expenses. “Whatever can be economized, so be it, miscellaneous expenses are high – doctor’s fees, transportation, drug, daily uses and what have been saved becomes shortened..”

“Currently, I have no saving, unemployed, my saving has been spent on miscellaneous expenses utility devices are sold out even golden chain otherwise, I cannot survive..”

16. Unsettled Work: the caregiver had heavy job but distracted and tiresome. There was unsettled management, worried about her mother. She needed to send her father to attend the mother, and fetched 2 children to school, which was another burdensome job including employment which stressed her but she could not help.

“a period of exhaustion, many burdensome jobs in workplace and need to take dad to attend mom everyday. Now, all are not well-settled..” ”

“I cannot count my jobs and cannot fully do, my children are young and need fetching at school. Then I resume attending mom and arrive home late over 9 p.m..”

17. Despair in Life: The caregiver found useless in caregiving since medication is meaningless. The situation was not recovered but worsened and hopeless. By condition, it was not proper to bring the sick home and asked the hospital to attend her till her last life but the doctor insisted to further attend her at

home. The caregiver and family felt desperate and likely died shortly. Actually, they preferred admit her in hospital but it was impossible rather to attend her at home. The mother nodded to agree. "Mom may want return home, too." Other members were discussed but at home really it deeply suffered the mother. " Mom is in critical condition, slow and heavily breathing timely, feeling uneasy and struggling and grasping of difficult to breathe and timely cedes breathing. All were shocked with the sight. " I feel miserable and cannot even help." What actually happened was "a most beloved life". The sight electrified emotion, sentiment, and heartbreaking to the caregiver and surrounding persons. "None agrees with me.." all said. "We cannot bear any longer, mom needs admission in hospital." But I thought. "it is useless and mom agrees with me after I ask her." "She wants to stay at home and go nowhere. " " I fully understood her" and finally she peacefully passed away among her family and her beloved home.

18. No Time for Husband and Family: a caregiving needed full-time stay and consecutive causing no time for husband and family. Settlements should be discussed earlier otherwise problems would later follow. For example, a case of an elder sister of 40 years had no child. " We have discussed with that age and find no problems." Her husband concerned and was intimate with her father. "We talk to each other all the time and I need to do my best at this caregiving." Sometimes we quarreled but not so serious. " He may be frustrated and his wife had to attend alone and where are other members. I understand he mocks my relatives. After a while he is better and better speaks and pacifies me. He may realizes I has been tired and worried dad since we often discuss. My husband is easily angry but easy to calm down, there is nothing."

19. No Empowerment: the caregiver had no authority indecision, voiceless and followed other family member.

"Feeling uneasy because conflicts within family during caregiving, unreadiness and no determination to bring the patient home. The caregiver could not decide since other members mandated both decision-making and money to replace caregiving.

"I feel sorry, they are my youngers but they should not express like this. I cannot bear since dad realizes everything what we talk. We should be reserved."

20. Cannot Work like before: the most time had been devoted to the sick. It seemed no chance for routine job, therefore job advancement was dim. Some became jobless or left the job e.g. a company job., “ my niece has to resign from a secretary job having problem with it, studies and needed to her aunt. She think that it is better to leave the work. At first her boss is considerate but not later. The boss becomes bossy, complaining and unfair.” Or some gave up selling minced fish steamed in banana leaf (Hor Mok) and concentrated only caregiving. “ Recently, cannot do Hor Mok, so I better give up and attend caregiving only.”

21. Conflict: situation of opposing between the sick and children before sickness. The children did not want caregiving but allowed other to do it without any interest or attention, leaving burden to the caregiver only.

“the daughter conflicts with the mother. She did not stay since young and often quarrel. She never visits her.”

“the daughter never visits aat the be but asks the doctor and whippy passes. At the moment she wakes and moves her strong hand to hold the daughter with smile and delight on the daughter’s visit. The sick attempts to speak but inexpressible only nodding to call her daughter. But the daughter looks and tells she is busy and needs to be hurry. She does not even touch her mother hand or smile back. How can she do this to her mother? The niece thinks. She is her mother. She bitters her mother and stops her smiles but with gloomily sighting hr daughter. Still the daughter takes no interest, returns home and never turn to look at her mother. No for long, the mother weeps with frustration and turns her face away..”

“Not visiting is better. She bitters her mother’s spirits and returns home. So selfish, no her, the niece and the aunt can survive..”

“Arriving home the daughter never again visits or calls..”

“Even her daughter is indifferent , what about her mother..” (The elder of the sick observed)

22. Life Disaster: the caregiver counted a catastrophe in the life of a youngest brother. It wished no caregiving and not seeing the face of the sick. There was agreement that the elder sister would handle caregiving for him when the father had to return for rehabilitation form prolong stay in the hospital. The youngest and family

members refused to take the father home thinking that he should continue stay in a private hospital near their home to cut short problems. They termed as a strong disaster for their life.

“The elder has prejudice about the father, i.e. dislikes him and often quarrels. The son often goes away form home and when the father is disabled, he doesn’t wish him to stay at home. HE has full authority in decision-making and all must follow.”

The daughter always supports and I am alone cannot do any thing..”

“ Dislike to disclose the sick. Never wish other t now the sick, it is shameful, fearing other to know”

23. Unmanageability of Household Works: the caregiver was in expedite each day since over concerned the sick. Each day, time was consumed with direct caregiving and neglected the routine house works.

“If time permits, I shall sweep but mostly, I have no time. “ (Case 3)

“Most are spent at public hospital and the private ones and likely do thing. IF time permits, I sew cloth-stitch to relax the sick. Often talk with dad, and switch on TV for dad and other to watch. Everyday is like this and spending with dad for 9 months almost a year,. It counts lengthened.”

24. Inadequate Knowledge of Self-care during Caregiving: the caregiver’s health condition was critical affecting the caregiving and vice versa. Particularly, a caregiver with previous health condition would certainly be affected the quality and effectiveness of caregiving. They made caregiving imperfect and ineffective because of the caregiver’s restrictions. A caregiving was enduring and a full-time work but neglecting one’s ailment and health appraisal, it disregarded self-care. In turn, the caregiving then made the caregiver sick and with the previous condition, it would worsen sickness without any help. Heavy burdens fell on the caregiver alone.

“Later, I often get headache, backache and knee-ache, feeling head pains and exhausted, insomnia, inappetite and over stressed not willing to talk with anyone.”

25. Expensive Medication: it was unaffordable while income was lessened affecting the caregiver particularly the poor. These were observations from caregivers

“very expensive and have to move to a public hospital..”

“I admit my mom to a private hospital for 5 days and I have to pay 50,000 Baht while her condition is not better. She has been medicated in a public hospital, then I have to move her there.”

“The niece is lucky since 30Baht medication allowance is reimbursable otherwise would not know where to find expenses. She may have to shamelessly ask from the patient’s daughter.”

26. Restlessness: with inadequate rest, restlessly stressed activities without relax, and insomnia, they helped enhancing physical and mental health of the caregiver to endure caregiving for the purpose of bettering health, welfare and caregiving.

“Everyday, I can’t go nowhere (telling with tears). Even having flu, I have no time to see the doctor, my relatives force me to see the doctor and they would replace attending for me. “ (Case 3)

“Often sit nodding at night and timely awakening and cannot sleep after that with often drowsiness..”

“I am awoken by every movement of the sick and timely with likely sleeplessness during night..”

“likely sleepless during night by calling for sitting, siding or naming and ask for nothing, 3-4 times calling then silent. Again she calls repetitively and with dumb conversation..” (Case of Khun. Noi)

27. Inadequate Information of Disease, Symptom, Medication, Solution or Inquiries: direct assistances on different problems made easier in caregiving or disable condition controls for a patient during staying in the hospital and at home. For example, assistances of caregiving, and information supplies helped clearly acknowledging conditions. It reduced ambiguity or helplessness. A caregiver told, “ I wish a doctor or nurse to visit at least once a month when I can seek advice..” “Mostly, the doctor is likely give information, no time for the caregiver and family and answers when being asked while we dare not ask fearing admonition, not knowing to ask. We wish the doctor converses and informs us.”

“we startle seeing conditions in the hospital. Encumber to act such as vomiting after tube nutrition. After recollected, then I call my elder sister again..”

28. Inadequate Access to Technology and Caregiving Devices: E.g. rehabilitation devices, in this study, it was found that most patients were under rehabilitation period and needed it more. Some were poor and unlikely accessed technology by financial problem but waited for donation or best did what were existing or applicable with cheap price, e.g. using a red rubber bulb to replace the phlegm absorber, using triangular pillow to replace adjustable bed, and using water fill gloves to cushion bottom and feet preventing pressing wounds.

A caregiver with good financial status better purchased materials objects or devices to facilitate life-course and family, e.g. special device for chair, wheelchair, walking stick, and adjustable bed. “ There is a sick-bed in the hospital which has been donated from my dad and since then he was 15 years dead. We use it for mom and it is convenient to adjust the level, bed-head and legs.” “ House-alarm for help is furnished for mom and my elder sister will run to help since she bake cakes selling at home. There is a phlegm absorber, if the phlegm is not evacuated, we need to knock the lung or absorb phlegm and saliva to clear the breathing. Spray is used when mom gets asthmatic in order to expand tube for better breathing. Sometimes, the oxygen tube is used to lessen exhaustion including massage and exercise assisted by the caregiver for better movement and revitalizing muscles, strengthening the limbs and decontracting of joints. The body is better rehabilitated or a neighbor is hired for a home therapeutic massage. It is to relax mom and parts are better exercised. It is convenient better than I have to do myself provided the fees is cheap.”

29. Time Conflict: It was unable to allocate daily job for the patient. With uncertain role of frustration, the caregiver perplexed on action, whether to handle all things or to motivate the sick to do. It suffered the caregiver and created stress and was unable to accurately allocate job in terms of number of jobs, and difficulties of caregiving. It was found from the stroke patient that ability to fulfill routine job decreased but increased the burden to the caregiver, e.g. feeding, toweling, stooling and urinating, and therapy. It included the quality of caregiving, organizing proper activities and sometimes was unable to respond the needs of the patient by time limits in each day even entirely stayed with the patient.

“early rise in the morning to extract food for 4 meals and freeze them, toweling morning and evening, changing the pampers, and physical therapy in free time. Most time is spent with mom and sleep when she sleeps.”

30. No Privacy: The caregiver was so worry and concern to always attend caregiving. “Unable to neglect but continue caregiving.” There were many family members with many helps or replace when being occupied with outside work. Time was dedicated to the sick till forgetting oneself. A caregiver needed to go outside to fulfill one’s needs, life and happiness. However, time was restricted with restlessness, insomnia and 24 hours caregiving, which worsen the health, chronic stress, weariness and sickness including negative mental health.

31. Unlikely Time for Caregiving: some family caregivers were occupied and all needed to work the burden fell to one person only. For example, the case of the aged husband had to attend his wife even though he was weak, with personal sickness and prolong attending. The caregiver was likely left to attend the sick both day and night. “No one helps in caregiving when going outside.” The health was weak with high blood pressure. “I am also stressed, frustrated to take responsibility alone in association with worries on the patient’s condition. How long I can do? I wish my children would and be considerate.” Another case, the caregiver was a noodle seller fully occupied sometimes and had to attend the helplessly sick mother alone. Selling noodles was tough and almost neglected the sick mother. “She stays all the time in bed, just toweling and siding but time constraints. It is hard time and she gets bed sore.”

32. Desocialization: the caregiver needed to dedicate in caregiving, which change its lifestyle. Becoming a home-attached, all socializations needed to be reduced or ceded.

“Sometime, the Buddhist Association calls for dedication of 2-3 day in up country to clean the compound, general work, feeding believers, meditation, reading and etc. Later, I have to excuse telling my mother is sick.”

33. Mismanagement Antemortem: the stroke with immediately medicated will arrive at disability after medication. A stoic state prolonged the patient’s life but needed a devoted and dedicated caregiver to handle all affairs. Sometimes, the patient was unknowingly critical the family sought best medication to extend the patient’s

life, less suffering, close care and devoted time in caregiving, and no negligence. However, it was too late to lose the patient in proper time. The caregiver and the family tried hard to accept but were unable and unprepared. They therefore reacted to the beloved loss and their attachment sharply and swiftly leading to stress, melancholy and panic. "Hearing shivers me. When I see mom, I almost collapse. Why is it so severe? I pity mom, inexpressive, only weeping, and deep alone. I just console her that just be patient but arriving at home I get lost shouting to myself – I can't live without mom.." Some families were well-prepared and the patient realized the condition with willingness and accepted the conditions, it turned death as normal thing, with acceptance and encountering it. They valued the rest period by flocking family members and the beloved one, made thing memorable best for the sick, leaving in peace without worries for those who stayed, they all would cared.

"Sleep in peace and be happy. Don't worry, I can stay, I will not forget you. You are always in my heart. Then she peacefully passes away among her beloved children."

"Mom says she is always ready but still here (then cries). She asks us to bring her corpse to Mahidol since she donates herself there. Her children will not be suffering and before that dad also has donated his body and we have just recently floated his ashes. All members are willing to donate their body."

On the contrary if the caregiver had no time to attend, the chronic patient would not be better and still alive. It became big burden for the working caregiver and leaving to the hospital to handle the case no like before. The caregiver then had more free time and liberty for itself and timely visited to find out and acknowledge the critical condition as being informed by doctor. He felt relief, no more burdens and waited till the patient passed away in the hospital. The caregiver planned well the cremation. "It is nothing, death finishes all and why to force other grief, It's unfair."

34. Mismanagement Postmortem: When the family accepted the patient's death, the loss, grief, and sorrows were deep stress for a family. The caregiver and the family needed time to reflect the incident and accepted the happening. To sustain in handling grieves and changes were needed. It required accepting the happening truth and going on living. But thee are some caregivers and families, which wished the patient dead because of prejudices. " Never dies, only being burden!" " Completely

boring.!” “The doctor says she won’t live long but still alive. How long will she make troubles, it’s too much to bear.!” Finally, when the patient died, “ I feel better and happy, as if releasing burden from me.” The caregiver could live without burden and remarks.

35. Inequality to Access Public Hospital Services: the caregiver often took the patient for emergency medication but beds were unavailable. They oftentimes visited the hospital till being admitted, which in turn made the patient lengthily stayed in the hospital.

“I bring her here many times but bed is unavailable and just distributing drug and asked to return if the conditions were worsened.”

36. Communication Constraint with Medical Personnel: the caregiver and the patient encounter much on communicating with the medical personnel. “I feel irritating when others do not understand what dad communicates. I have to stick for assisting.”

“Sometimes, I do not understand what the doctor says but fear all to ask.”

37. Dissatisfaction with Services: the caregiver dissatisfied with the private hospital services expecting distinct medication and cares worth expensiveness. But it was much disappointed when admitted the patient there. “I am totally dissatisfied with the private hospital services, drastically disappointed in medication. They never tell what the patient is and the condition is not better as well as bed sore during medicated there.”

“I feel bad with medication cost of the private hospital- not only expensive but bad service.”

38. Inadequacy of Medical Personnel: The caregiver dissatisfied when brought her mother medicated in a private hospital but no doctor or nurse to attend. They were just informed that the building was just completed and medical personnel were inadequate. “There are not enough nurses and doctors.” “ I think, had there been inadequate personnel, why should they open a new building.. hopeless.. and we are forced to employ the hospital staff for attending with extra charges. I have to hurriedly move mom to another hospital.”

39. Uncertain with Medication: the caregiver thought, “mom gets infection from tube inserted into the stomach. She gets sharp pain with wound at stomach with infected carbuncular wound. A 30Baht medication allowance gets only antiseptics. But the condition is not better, I have to move her to a public hospital. I think that the private hospital unavailably prescribes the antiseptics. At public hospital, the wound is treated twice a day with stronger antiseptics. Her wound gets better medication and stop stomachache.” ”

40. Unclear Information of Medication: The caregiver was frustrated why the doctor was unable to clearly inform about the medication even attending. “The doctor medicates mom for 5 days and tells nothing while mom is not better with bed sore during staying there.” (Case 3)

“Most doctors unlikely give information, time constraint to treat the caregiver and the family, only when being asked to get answer. We fear to ask and rather wish the doctor to tell us.” (Case 6)

41. Spiritual Misery by Being Labeled: the caregiver feel misery and grief. “I feel grieved since my family members do not understand me and how much outsiders blame us.”

“Dad remarks do we do nothing leaving mom suffering. He cannot bear such sight and blames me. I feel bad.”

“They never see my capacities but a sick and a disable”

## **Part 6: Life Management and Contextual Management of the Caregiver**

It was found in the study of this part that most caregivers were unable to address or handle their own distress or otherwise so little, leading them to suffer as mentioned above. Here, we would discuss addressing grief in different contexts classified into 2 types, i.e.

1. Addressing the Caregiver’s Life and Arisen Problems
2. Managerial Context Prioritizing Family

## **Addressing the Caregiver's Life and Arisen Problems**

It involved families, relatives, spouse, workplaces, housework, perception of self-health, inadequate knowledge of disease and caregiving, accessing technological devices, time management, free time spending, socialization, and arrangement before and after patient's death. All these were affected by the caregiver attending the patient all the time and lengthily.

1. Managing 5 mental distresses, i.e. stress, over affection and concerns, monotony and boredom, despair and life disaster.

1.1 Addressing stresses of the caregiver from the patient and environment around the caregiver; it was found out that most were neglected or least interesting and let go. The caregiver could not handle and it strongly affected body and mind.

1.1.1 Stresses from the Patient: addressing by control anger during the caregiving by walking away for sometimes and returned. If it were too much, the respond would have been by facial expression or sharp rebuke till the patient wept and turned away. "I feel bad to so. Sometimes I cannot control my mood. " Some caregivers encouraged the sick and close stayed. The sick was uncomfortable and entirely painful by being lengthily immobile in bed helplessly and required the caregiver to massage for pain relief. Such suffering was caused by paralytics where the caregiver witnessed and encountered for 24 hours, including the sharp expression of behavior and aggressiveness with irritation when things deserved wishes, or by weeping and turning away, or by banging and pitching the caregiver on disappointing, or harming oneself if being frustrated, or meaningless shouting. All directly reflected miseries of the sick to the caregiver to handle all things about the patient's behaviors and emotions.

"inserting nutritional tube on left nose and urinated tube, parched lips, sore mouth and throat, calling very often and painful asking for siding, moving up but down, thirsty and choking."

"move mouth to speak but inexpressive only shout.. Ooh..!!"

"leg joints are contracting but painful when being extended so loud shout of ..Ooh.."

“Weak and helpless, it’s quite misery by being painful with only slight movement but lying still causes entire pain in the body. Stick phlegm and saliva are evacuated or wiped out by caregiver.”

“Having wound at fore-stomach by nutrition tube, antisepticized thrice a day, both legs were extended and the knee joints start swollen. There are grumbles of knee pain and torment. Both legs are often crossed and apply betadine. “

“The auntie much calls for attention, pinches, beats, knocks at bed-side or belly, spits or undresses.”

“dried smile unlike before, tears flow the cheeks and weak to dry it. We help dry tears, throbbing and weaker. Then she closes her eyes with silent, then again opens her eyes slowly pans her sights to all with sorrow. Her tears slowly flow and stop her sight at me as if to speak but only silent creeps.”

1.1.2 Stresses from Environments around the Caregiver: mostly, the caregiver could not eliminate problems and ignore environments. It was found that most caregivers in this study encountered heavy burden and distress of caregiving. It also depended with each family that the caregiver directly took responsibility by degree of increasing dependency (self-care decreased). The caregiver needed to handle all aspects physically, psychologically and socially including complicated attention by 24 hours and lengthily. Had stress spirals of the caregiver not been addressed, burdens of caregiving overweighed to the caregiver only, and without supports, most caregivers would feel down followed by sickness and continuously destroyed health. They affected the caregiving followed by worsening condition of the sick since being neglected, concerned and disregarded and had to be re-admitted to the hospital. It would rotate such conditions without able to address problems and inadequate interest and finally leading to the death of the patient. (Case 2)

“Endurance cedes, unlike before, less patience, irritating, anger, moody, intolerable, sarcastic remark (loud) with the patient.”

1.2 Over Affection and Over Concerns Leading to Stresses: It was found with few caregivers blamed oneself and felt guilty of doing badly. It affected the physical and mental health deteriorating by unbearability since thinking all the time about the patient. It created over attachment, and always self-care. When the mother was worsened, “ I also get flu unable to attend mom and fear mom infected. “

Addressing this Case<sup>3</sup>, nose covers was always used during treating. This case 3, the caregiver was so stressed unable to do any thing since the mother's condition was not better and she was going to be wild. She herself was sick and fear the mother was infected. " I urgently call elder sister for advice, she advise me to meet the doctor and take full rest. The physician advises me to take full rest. Then, I leave my elder sister to attend mom by admit her in the hospital and if I were well, I would return to attend her. I am so worry and concern thinking that my elder sister can replace me better. " (Case 3)

1.3 Managing Monotony and Boredom: when the caregiver felt monotony and boredom in caregiving, it was as if without end, cycling and spiraling. Like in the Case 9, the caregiver changed atmosphere by tripping or went outside for private business to avoid such conditions. " I think of escape hate to resume, but after awhile I return because of concerns and guilty and cannot do any other things. I is not better since I am worrying about dad. I cannot not take long trip because of concerns and return to attend him. I think to find something to do during attending dad or watching TV, and listen to radio with dad to reduce monotony and boredom rather than going outside. " (Case 9)

1.4 Managing Life Despair: It was bad to bring mother home in despair and might die shortly. What was caregiving for. It was hopeless and desperate by medication. Her condition was never better but worsened and died shortly. There was all time despair, hopeless and worries. Case 6 addressed at first attempt to accept misery to bring mother home even thinking that it was safer and best in the hospital but after being informed by doctors on her unrecovery and allowing the family to attend her at home, it much suffer the caregiver. Then, it had to be accepted to bring mother home by doctor's information. " Naturally, I feel miserable and I have to attend her all the time as well as dad gets Takayasu needed four time a day refining. I alone handle the affairs. It is a heavy burden, and I don't know how far I can bear. Dad doesn't understand and cannot accept the suffering state on mom waiting at the dead-bed."

"Dad says, do we do nothing leaving mom in such suffering.? We explained, "the hospital rejects medication and mom want to be back home. We have to handle by ourselves." The father rebuked so much. "I feel so hurt by the

misunderstanding of my family and what outsider blame.” “ We had to force our elder brother working in Taiwan to return otherwise he would not see her dead-bed. It is difficult to inform him and ask him to return. But with the wish of mom, she wish to see all last time at dead-bed.” The elder brother flew back and also found another worse condition of the father and just stayed near but could do nothing. The mother was delight and smiled with tears and the members helped to wipe away tears. Her breath was throbbing and exhausted, silently closed her eyes and opened again looking around and sorrowful, tears began to flow and stopped at the caregiver. She tried to speak but inexpressive. She might concern since the caregiver was the youngest and intimate to her. The caregiver told her not to worry since all would look after her, and kept worries away only though of Good Lord and Good Things. The caregiver said she loved her mother and she smiled back and went deep sleep. Her breath was timely with urinating and stooling often. Her clothes were often changed and so much pitied her, and could not do more than this only with prolong experience staying with her. Her life would be soon extinguished and the caregiver determined to stay with her till the last minute and finally she peacefully died with less suffering.

1.5 Managing Life Disaster: the worse conditions of a male caregiver who disgust to caregiving, refused to meet and to stay with each other. Then he picked up his elder sister to replace him and rejected to take the patient home by admitting the sick in a private hospital near the residence and the elder sister had to further attend. It was to end his further problems and suffering and with good financial status, he could faster make decision. He counted that if taking father home, it meant bringing in disaster into his life but delighted to pay in compensation for good spirit and avoidance encountering with the father.

“The elder brother has prejudice with dad. He dislikes dad and often quarrels. At that time he often go outside and when dad gets disability, he hates to bring him home but admit him in a private hospital near his home. He has power to decide and follow him with the supports of my sister. I alone have no authority, what can I do?”

“Dislike to disclose about the sick, hate other to hear and feel shame..”

2. Managing 5 Unsettled Household Affairs, i.e. threat, inadequate care to one's family, time constraint for husband and family, powerless and conflict.

2.1 Threat: addressing threat from family members, powerless to decide and continuing to take responsible since other family member had authority over the caregiver whether in decision-making, attention, and finance. Even the caregiver felt uneasiness by internal conflict among members when bring the patient to be attended at home since unreadiness and disliked bringing the patient home. Then the caregiver was coerced to handle the case in a private hospital as a second home between the sick and the caregiver. The caregiver needed to resume and the patient felt frustrated with threat but speechless.

2.2 Powerless: the caregiver handle thing as seeing fit but if other member visited she would allow them to handle and skipped for a while to pacify the mood and returned. Sometimes, the caregiver skipped to sew cloth-stitch and watched TV or stayed outside for a while. Sometimes, the caregiver felt frustrated of powerlessness in decision0making on attending the sick where all other members prevailed and just followed. It was so frustrated even when one knew and full-time attending the sick and being the member. However, the caregiving needed to go on thinking that it was suffering but the father might suffer more. (Sometimes, the father kept silence or closed his eyes). “Anyway, I am their elder sister, or father is more important.” “ if they want to speak to me, they are my younger and in the same family. I don’t want dad to feel more misery. He suffers much and has to realize such a thing where it would worsens him. Thinking that it is good that they visit dad.” “ It makes me better attempting to accept and strengthens me since they do not stay with me but dad whom I must think of more..”

2.3 Conflict: there was no harmony between the sick and the children before sickness. Others were asked or hired to replace. There were 2 cases, i.e.

The first example was Case 10. There was conflict and disharmonizing. A daughter separated to have her own family, no attachment and unlikely stayed together. The mother separated from the father and had a new husband by adopting a niece since small and intimate attachment. The niece had everything today because of her aunt. Therefore the management of the daughter since being the only descendent and had direct responsibility. She ignored to attend and rarely visited. And never touch the mother or conversed and never visited only left the hospital to medicate but with a niece. When taking her home, all burdens had been weighed to

the niece, who conflicted and never talked with each other. The aunt had adopted the niece since young therefore the daughter was not interested and took any responsibility counting that it was under the e direct responsibility of the niece even while the daughter was most ready and should handle the case but rejected. So, others blamed her on attending her mother by only left the niece to do, which was inhumane. To prevent accusation, she accepted the dislike niece to replace herself having previous townhouse for them to stay in Bangkhen where her father had also been staying.

Another case was No. 9 among a son and his father. They both disharmonized before the father was sick even hated to see each other. The son had his own business and quite wealthy. The management when the father got disability handled by this son and other family members by not taking the father home but admitting the him into a private hospital near his home to buy his satisfaction and needed further no encountering each other.

2.4 Time Constraint for Husband and Family:       addressing such situation the caregiver directly discussed and settled affairs with her husband. Formerly, the husband was so intimate and often visited with her father. The wife did not meet the husband but only by calls and sometimes visited home. The caregiving needed full-time and consistent that made her had no time for her husband. Sometimes, the husband took long period to visit her father, it seemed to have a problem since he was closed and concerned his father-in-law. It was better to clear the air since both were adult. Sometimes both had minor quarrels. “ He might be resentful why only me attending and where are all other. I understand him that he spites my relatives.” No long he returned to himself and spoke well with his wife. “ He likely knew that I am wearied and worried about dad. We always discuss. He is easy to get angry but fast to stop. There is nothing there.” The wife handled the affairs by discussion because both were almost 40 years and without children which made her less concerns. “ Otherwise, I will be in hot pot whether my son will understand me like his father. I try my best in caregiving since I do not know how long my dad will stay. I am also worry about my husband and home. Often we talk by phone (and more). When my husband is free from work, he will visit dad and me and spend time together, eat together and share happiness together.”

2.5 Inadequate Care to One's Family: it was addressed by phone everyday and if the husband was free, he would visit her father and her and discuss. Both attempted to alone and emphasized that it was indispensable that her father needed caregiving since rarely she went home and cared for the family. She visited her home only 1-2 times in 3 months. She had got a condominium without housekeeper, only husband and wife without children. A janitor was timely hired for cleaning the thick dust. "Sometimes, my husband expressed dissatisfaction and irritation, why there were many family members but only me?" "We eat together but we are adults, it is easier to explain. If when there is disconnection, I will call to ask what wrong?" "He understands and concerns much about my dad."

3. There were 2 statuses, i.e. needy of money and expensiveness were found in caregiving.

3.1 Managing Needy of Money - it was addressed by economizing. It was lucky that the aunt can reimbursed from 30 Bath medication allowance. It helped reduce expenses otherwise the niece might be badly affected and used the savings. Least case, the golden chain saved was sold out. The case of poor caregiver with restricted budget with increasing expenses and without additional income rather than savings. Then, with utmost needy, they had to sell out gold to cover miscellaneous expenses since the standards of living increased, e.g. doctor fees, transportation, drug and daily utilities were gradually used out. Case 10 thought that, it could be found again the caregiver of Case 10 should not suffer, and the aunt's relative (not the daughter) could afford to find money by working for two thousand Baht a month but how long should they survive.

3.2 Managing Expensiveness of Caregiving: if it were so, it financially affected the caregiver directly, particularly those poor and moderate caregivers and with lengthy caregiving. In Case 3, it was addressed by move out to the public hospital where they could reimburse thinking also that her mother would be better recovered not like the private hospital. "it is too expensive, mom then was move to the public hospital." "With 50,000 Baht and mom is not better so I decide to move her to a public hospital where she once been admitted."

In Case 10, It was lucky that the expense was 30, 000 Baht (which was so high to cover) but with the Gold Card for Medical Allowance, so only 30Baht had

been charged. Other personal budget had been used for other expenses. It should not be too expensive like the medication. The caregiver herself could afford but the mother's relative could also help without depending on the daughter.

4. Managing Unsettled Household Works: addressing caregiving by oneself affected routine household works, inexpediteous in daily work by being too concerned with the sick. Each day was consumed with caregiving with the elder sister baked cakes at home and supported as well as always handled the household works. "If time permits I shall clean the house but very rare (Case 3). After mom sleeps, I have free time to make the home in order and mop near mom's bed. So, if she wakes, I can attend her, if she cannot see me she will call but if she sees me she can go on sleep then I will have my free time and discuss household work. Other members are willing to help."

5. Managing Unsettled Workplace Works: It was divided into 3 kinds, i.e. undedicated working, unsettled jobs, and below standards.

5.1 Undedicated Working: the caregiving made the caregiver often absent and stop working with contacting medication for the mother. They were just only two in the family and indispensable. In Case 8, the caregiver was worried and concerned about medication turning her to be absent so often. When the mother was sick, she had to stop work to handle the case even to her service unit and even her mother was not better. All amenities were necessary for the mother and she would return to work after all things were settled. She could not work and had to drop to see her. Prioritizing the mother since at last and only a person and with a sick mother she had to be often absent from work. Had her mother been better, she would visit during break and after work since she can walk there without damaging the works and the boss might understand.

5.2 Unsettled Jobs: For the moment jobs might not be well settled but later since they might not so heavy like this. Jobs at office were so tough but unlikely fully dedicated. It made the caregiver worried but could not do anything, so exhausted, both worrying about the mother and had no spirit for work. In the case of Ms. Janjira, a caregiver, she had tough job but unlikely fully work, was exhausted. She had to fetch her father to attend the mother in the hospital, then picked up her 2 children to school as another burden thinking that the husband would help her about

her 2 children. She had to fetch her father because he was aged and difficult to go alone. “I may not be complicated since I have to visit mom and when she returns home, it will be easier. I hire a staff from the center with the supervision of my dad, it makes me less worry. However, I shall often call at first, if there is nothing serious and they can handle things then problems are addressed.”

5.3 Below Standards: the work done was no like before since most time dedicated to attend the sick. Chances were closed for dedication to routine jobs. There were 2 cases, i.e. addressed by no advancement and jobless.

No advancement: with undedication, it made the caregiver worry and helpless, exhausted with much worries about the mother and lifeless to work. Case 8, was met with difficulties and had to attend parents and family, i.e. fetching the father to attend the mother in the hospital, sending her 2 children to school. She would select her mother and family and the work was second.

Jobless: some became jobless from the current company. In Case 10, she agreed with the daughter but the daughter certainly rejected she bargained that if she handled the affairs there had to be an assistant by hiring a staff from the center since the caregiving was tough and never handled before. The sick was big and likely helpless and needed close care. The caregiver was intimate and attached with the sick and wish to attend her. Then she hastily decided to quit the secretarial job from a private company losing her income for the purpose to attend the sick only.

Or another case stop his selling Hor Mok in Case 3, so that he would be fully attended his mother otherwise he would be completely exhausted and got sick. All members were counseled and agreed. There was no needy of fund for support and the caregiver had his own reserved fund without difficulties.

6. Managing Inadequacy of Perceiving One’s Own Health: there were 7 issues, i.e. deteriorated health, weariness, timeless, no privacy, restlessness, sickness by caregiving, and paroxysm.

6.1. Deterioration – managed that a caregiver having no time for self-care but flu and unable to caregiving, having to spend 24 hours to learn and experience caregiving but no time to care oneself, restlessness by dedication leading to exhaustion, and weakness. In Case 3, the caregiver got flu, coughs and mucus and feared her mother to be infected, she contacted her elder sister to replace her so that

she could meet doctor of medication and took full rest. At the meantime, her mother had to be admitted into the hospital. The caregiver followed up by phone and left her elder sister to attend her mother till she was well and to resume her caregiving.

6.2 Weariness – management by thinking of mutual karma and took caregiving. It was too exhausted physically and mentally, so exhausted to do anything. It was close to death attending the sick and taking long time, the endurance was gradually shortened. Sometimes, it was unbearable, it was suffering physically and mentally. In Case 5, who had high blood pressure and deteriorating each day and had to attend his wife who was helpless with heavy burden. “I was weak body and mind. I shall do what I can but to bear. None attends and we are couple. All our children work and I have to bear till we part.”

6.3 Timeless - pleased in managing all affairs for the mother’s happiness and timeless to think of oneself and such period was the most valuable. The caregiver preoccupied with the sick. In the case of Ms. Wanitcha who attended her mother at her dead-bed, she only focused the sick even little time was left with grief having the mother stayed among family members. She stayed close to her mother. “ I am happy mom dies among her beloved family members.”

6.4. No privacy – unable to neglect caregiving, the caregiver was happy to attend the mother even to dedicate her life. So, she was all time worried and concerned the mother even having other member to help and spend not much time outside home on business, but still did not confident in other members. The caregiver did not care and interest for oneself, restricted, restless, which affected health deterioration, stress, exhaustion, and finally got sick as well as mental deterioration. “ I was so stressed and unable to eat and do not know what to do, so exhausted and sick. I only weep to relieve my stress in toilet fearing other to see.”

6.5 Restlessness – managed to have the sick more rest and skip for others to replace with discussion among family members since caregiving paid no time for oneself, restless, inadequate rest and having activities with the sick causing stress all the time. There was relentless and insomnia. In case of the youngest sister, i.e. some rests while the sick slept but awakening to resume duty. Sometimes, the elder sister helped after her work so that she could rest to enhance her health and spirit to endure future works.

6.6 Sickness by Caregiving - managed by stop awhile and asking the elder sister to attend the mother so that she could see the doctor, took pills and took rest. After she was better she would return to resume her duty. Being serious sick because she had no time to attend herself, restless and deteriorating till sick and could not resume her duty.

6.7 Paroxysm – thinking of having mutual karma and staying for caregiving till parting form each other, since caregiving was burdensome and self-forsaking and if one had personal sickness, it made caregiving imperfect and ineffective by such restriction, particularly previous condition of high blood pressure. Even it increased but still he resumed.

7. Managing Inadequate Knowledge of Disease and Caregiving could be divided by 2 types, i.e. reluctance and inadequate knowledge of disease and caregiving.

7.1 Reluctance: managed by assisting staff and seeking information by reading and questioning staff, the caregiver began self-learning. At first, it was by reluctance fearing inability and misperception by reluctance. By often arousal of the staff by doing but it needed time. “It may take more time to be expedite since I fear dad feel pain or in danger.”

7.2 Inadequate Knowledge of Disease and Caregiving: managed by enduring learning but the sick was staying in hospital and the caregiver could do nothing. “ It makes me dare not do anything thinking it’s the nurse’s duties but observe since never do before. I fear to treat the sick or inability to do. There is reluctance fear to do anything but others do. I am not interested in learning or experiencing. It causes inconfidence. I fear dad will get hurt and I don want to do. “ Reluctance to do was from inadequate knowledge about disease and direct caregiving, as in the Case 9.

8. Inadequate Access to Technological Devices - using rehabilitate devices was found in this study that most patients were at the stage of rehabilitation and needed it.

It was found with most caregiving that finance was ready and skills in managing finance in purchasing materials, things and utilities to facilitate life-course and family, e.g. special devices for wheelchair, wheelchair, cane, adjustable bed,

alarm for help. In Case 3, the caregiver brought out her father's dead-bed for re-uses. It helped and convenient for the sick in movements. Devices were easily found and inexpensive e.g. alarm to increase facility in usage for both the caregiver and the sick.

For the caregiver with needy of finance as in Case 5 that the sick got phlegm and saliva, with restricted budget the visiting team advised to use read rubber bulb to replace the absorber. But with much phlegm and saliva and deep in throat, the sick was admitted into hospital for a short period and depressed with blocked phlegm and saliva in the throat. It was the similarly circular problems.

9. Improper Time Management could be divided into 2 types, i.e. no time for caregiving and unsettled time allocation for caregiving.

9.1 No Time for Caregiving – it was managed to defend oneself of doing alone, doing best, and fulfilling duty and following traditions. The caregiver needed to sell noodles at home and fully occupied as well to attend the sick mother which was heavy burden and felt being isolated, no helps, did not know where to turn to and feared blames from relatives. “I have my work and all members have to work. I alone attend mom and tell oneself that I do my best. I am not the one who worsens mom but she needs medication and best I can do.” (Case 2)

9.2 Unsettled Time Allocation for Caregiving – most time management was inadequacy and the caregiver spent most time in caregiving both oneself and the sick including side-effects in each day. It began from activities e.g. arousing hearing and perception, toweling, teeth cleaning, siding oneself, therapy, joint massage to prevent stick and falling toe-tips, observing skin particularly bedsore among helpless patients, and tube nutrition patients, who needed to learn preparing spin food. “All times are consumed in caregiving and activities, which I cannot finish by prioritizing but I do as best as I can.” (Case 3)

10. Managing Unsettled Social Activities, which were divided into 2 types, i.e. de-socialization and restrictions of socialization.

10.1 De-socialization – “I better spend time caregiving my mom. I have my limitations, unready, concerns about mom and refuse the innovation I decrease my socialization with friends and sometimes isolate myself thinking that I can take a trip whenever I can if I were more ready. I have ever taken a trip but

unhappy worrying about mom. It is better for me not to take trip. If there is something to talk it is better through phones and all my friends know that my mom is sick.”

10.2 Restrictions of Socialization – “ Before this , mom can help herself. She and I would regularly join the Buddhist Association in up country and help religious donation. Since mom is helpless and disable, I can not do it anymore and I have told them that I would stay to attend mom. It changes my life and desocialization. I think that the Association can replace me by other but no one can understand and pay her caregiving and she has only me and we can discuss problems. (Case 3)

11. Inadequate Management before Death: there were differences between the caregiver and family that lose the beloved one before proper time and those lose the beloved one had no time to attend. They were:

The first case, the management needed acceptance the unexpected and unready conditions. There were reactions for the loss of the beloved and the attached one severely and rapidly. It created deep stress, grief, and distress for the caregiver. They needed companion for console and spiritual supports. It took long time to adjust and to accept what had happened.

On the contrary in the second case, the caregiver had no time for caregiving and thought that the sick were burdensome for oneself and family. Management helped reduce worries and needed no caregiving any more but more time for work with free time. Being occupied with works but having a sick mother, therefore she was admitted to the hospital and left her to be attended by the hospital and he needed not attend her like before. He occasionally visited after work and hearing her worsened condition. Upon hearing that she might shortly die, the son had prepared her moderate cremation. (Case 2)

12. Inadequate Management after Death – it was acceptable with the loss but with grief, misery and stress for the family. To sustain for relief and following changes, truth needed to be accepted and lived on. The caregiver and the family needed time for reflection on the incident. Some admitted that they wished the patient die because of prejudice and created difficulties for themselves. “When she will die, what a burden!” “ Boring” “The doctor says that she will not stay long but still alive. How long will she make troubles. It’s unbearable now.” Then finally the

patient died. “Feeling better as if burden has been lifted. We can live without burden and no one blames anyone.”

### **Managerial Context**

It prioritized family as a very significant institution because it could found the growth and development of its members. However, currently, there were economic and social changes and natures of a family were more changed from the extended family into the single family. It minimized families under the Thai social nature and values and still adhered to nurturing parents and elders when they were aged or any members when they were sick and helpless and had to depend on family members. They therefore needed to readjust their roles and each duty most appropriately so much so that it also further stemmed the family e.g. the social support network family, a hired staff family, and a family-less family having the government unit in caregiving.

1. A Single Family - it was very common with 3-5 members and responded to the Thai societies. There were a father, a mother and children with a higher proportion. When a member got sick, burden of caregiving was weighed to the family member and few direct caregivers, who were intimate and restricted alternatives. Some were ready and unready within those families and to directly adopt burden with no excuses. They had to follow duty fearing being blamed from surrounding people. However, some single families had more member and readiness with caregivers, who had time and were willing to caregiving. Such families were divided into 3 types, i.e.

1.1 A Single Family with Awful Caregiving: being preoccupied with selling noodles and paying caregiving the mother alone, no assistant, no time to caregiving, a lifeless mother staying alone in bed and neglected, having infected bedsores, being admonished by surrounding people, over stressed, weak and could not support the patient, thinking that doing what could be done and not one's fault of the patient's bad condition but worsened and often admitted into the hospital.

1.2 A Single Family with Bad Caregiving: a small family stayed in a flat and all had their own jobs. When a member got sick the husband had to directly attend and with aging, physically unfit, high blood pressure, and regular dosing

turning the caregiving was imperfect and incomplete. Also, the patient was in helpless condition, needed full-time caregiving, felt isolated, inadequate caregiving from the family. These formed ineffective caregiving and if returning home, the family would similarly treated. All the same problems were similarly unaddressed and the patient endlessly circulated around home and hospital.

1.3 A Single Family with Likely Good Caregiving: it was by deep bond of a mother to a daughter and willing in caregiving even she had to help her husband in sewing business. Her husband was key supervising business while she attended her daughter even being preoccupied she also sacrificed her time to caregiving.

2. An Extended Family: It was found that some were still found among the Thai societies even less in number. The family therefore directly confined a stroke patient to the prompt caregiver, who had time and was willing with many family members. The caregiving was extensively supported by rotation of members. The caregiver was affectionate and well attended sensing the concerns, able to familiarly discuss anything and being understood with problems arisen in caregiving. It helped reduce problems and stresses arisen from caregiving and helped address problems with good relationship in tuning to each other. At the meantime, there were conflicts among family members in managing the patient, the caregiving and the caregiver. It also included the management of household works, and complications, and problems unaddressed would worsen the relationship among members. There were arguments and even consensus handled by powerful decision-maker, which enabled future stresses within the family climate.

2.1 An Extended Family with Bad Caregiving: with conflicts and problems among family members, the kith were not ready for caregiving and the separated daughter had to handle the caregiving. She was not empowered and there was conflict when the mother was brought home. However, being wealthy, the mother was admitted in to a private hospital nearby rather at home.

2.2 An Extended Family with Good Caregiving: being a large family with baking business at home, members were ready for caregiving also there were other members such as kith at home. They all supported and helped when the caregiver was away and unable to attend. Members were intimate and attached with

the patient also willing to caregiving. Problems could be discussed within the family. The eldest nephew helped in caregiving particularly in conversation, moving the sick. "The patient loves this nephew so much and has confidence and feared no falling". It made the patient fresh and happy. Her rehabilitation was remarkable yielding happiness among the patient, the caregiver and the family members.

3. The Social Support Network Family: having affection and attachment during ailments before, they supported each other and alternatively attended each other. In misery, they had sympathy and affordably helped without compensation. It was a spiritual bond in each other because the actual family of the patient was in a province and unable to attend. Her mother was aged and infirm while her brothers and sisters already had their own separated families with their own burdens.

4. A Hired Staff Family: in a wealthy single family and the caregiver had to work unable to personally attend, it was indispensable to hire any staff from a center because they were trained for. There was a recruitment company to organize fearless to harmful intention and danger. It was better to afford an expensive employment but secured and worth the price because there were only two members in this family. Previously, the mother supervised a grocery before being disabled and had to close since then or any free evening, the daughter would open the grocery for additional income. The miscellaneous expenses for the patient were costly and expenses of caregiving were consistently and lengthily needed.

5. A Family-less Family Having the Government Unit in Caregiving: the patient was moved to the home for the aged in Prapadaeng, she was alone and helpless. In the future, there would have been increasing. It indicated that the existing societies had changed into more single families and some had to be alone and isolated, and inadequate caregiving from anyone since they alone attended themselves. All relatives had passed away, lacked warmth, completely abandoned and were lonely with misery. When aging, visited by illness, covered by health problems as in the Case Sample, she was a lonely aged, encountering a situation with being disabled and helpless. She could previously work but not the moment. "I feel numb and stiff the entire body and so suffering." "It is confusing, despair, none to care and to attend." "I cannot do anything except lying (drowsy). A slight move pains me (loudly cried)." Such condition needed a caregiver and understood the patient.

They were lost and abandoned, and none took interest. “I wish I had a caregiver who understands me.” The patient felt frustrated, despair, grieved, irritated, and needed a caregiver because they had limitations and moved to a home of the aged, which was new and unfamiliar where the patient did not wish to stay. “None sympathizes me. They do what they like and I cannot do anything.” Not long arriving there, she died without relatives and the Home of the Aged arranged a cremation for her.

In summary, the worse conditions of the patient were the misery of the caregiver. Meaning, even most caregivers were intimate relatives for common good but met most patients were in worse conditions. Rationally, most actual caregiving models were the caregivers were unwilling to attend. The caregiver negatively defined a disable and encounter misery in caregiving with different problems as well as unable to address them.

## **CHAPTER VI**

### **CONCLUSIONS, DISCUSSIONS AND RECOMMENDATIONS**

#### **Conclusions**

A qualitative study on Caregiver Management in Stroke' Patients: Symbolic Interaction Perspectives used in-depth interviews with purposive samples among 12 stroke patients levels 3-5 classified by Raskin admitted in the Ward 1 and 2 for Male and Ward 1 and 2 for Female in a public hospital in Bangkok during October 2002 – April 2003. There were 11 female patients and 1 male patient aged between 20-85 years. The average age was 60-75 years. There were 4 single and 8 married. 6 Patients could reimburse the expenses while 3 patients could not reimburse but 2 patients owned Golden Card of 30Baht for Medical Allowance, and 1 patient was admitted in the Home for the Aged. All 12 patients had caregivers by 7 were female, 4 were male and 1 was a government official. Caregivers were 26-67 years with the average ages of 30-45 years and 6 were single, 5 were married and 1 was an official.

Presentations: The caregivers was key in attending the patient. It was found that the caregiver met misery to handle the disable patient because the caregiver encountered many rising problems. This chapter contained 6 parts. Part 1 encompassed the conditions of the disable patients under the caregivers. Most patients were critical. Part 2 was reports who were caregivers and on what basis in accepting to be the caregiver. Part 3 discussed on how and what were the caregiver management models. Part 4 discussed on the consequences of the caregiver management models. Part 5 discussed on disability defined by the caregivers, problems or misery arisen by caregiving or being a caregiver. Part 6 discussed on addressing arisen problems as follows:

**Part 1 The conditions of the disable patients under the caregivers. This part would indicate that most patients were critical.**

The conditions reflected the suffering and misery of patients, which divided into 7 types. They were the abandonment state, which was without caregiver and the patient claimed attention, no one helped, hurt oneself, demanded attention and craved to die. The subservience state, which was submissive to aged physiology, contraction and helplessness. The negligence state, which was paying caregiving alone and had to sell noodles at home with no time to attend the patient. The conditional state and the recuperation state, which was a state during rehabilitation and likely able to help oneself in bed. The recovery-like state, which was able to walk and almost normal but leaving some traces of disability such as unsteady walking, and needed time to think but able to return to working and being labeled by societies. The well-recovery state, which was able to live normal life, and able to return to society and socializing with friends leaving no trace of disability. All these showed different states or conditions by suffering and misery of each patient.

**Part 2 Reports on who were caregivers and on what basis in accepting to be the caregiver. The key was the close relatives.**

Most caregivers were close relative circle such as father, mother, kith and spouse. Few were not close relatives such as niece, respected person and official. The family agreed that it needed person to directly handle the affair but the person had to be most ready and appropriate in caregiving including close relationship with the patient. For example, when the parent fell sick, it was the duty of the kith to return gratitude and appreciativeness. If it were a couple, it were the duty of the spouse to pay caregiving since they lengthily stayed with each other and would never separate but continued living together. Few were outer relatives such as a niece who was single and attended her aunt. Also there was a neighbor (a respected grand mother) who was intimate before with attachment and ever attended each other. She then volunteered to pay caregiving well during misery and illness. A special case was an official, who attended a family-less patient since there was no caregiver. The was from the hospital

coordinated with the Social Welfare Unit to handle, to recruit, and moved the patient to the welfare-home so that the patient would be admitted after being discharged from the hospital.

### **Reason of Being a Caregiver**

It was found with the attributes and reasons accepting to be a caregiver were there were an agreement among family members on having a disable and needed a close caregiving after medication. Priority was weighted on close heritage, attachment between the patient and other family members, economic status, nature of work and free time to attend the sick. It was found with selecting a caregiver that most were female, a single daughter staying in the same home and either male or female elder kith but most were the eldest son. It was found with reasons accepting to be a caregiver were affection, concerns by prolong marriage, and heritage bond. Most were direct nieces or nephews, who were well prepared and better in caregiving including the patients might select caregivers by themselves.

There were 9 reasons accepting to be a caregiver. They were the Gratitude to Parents, Social Norms, Affection and Concerns of Spouse, Genealogical Bond, Bond and Intimacy with the Patient Returning Gratitude, and On Emergency, Neighborhood Empathy , and On Official Duty It was concluded that most caregivers were entirely attached and being relative to the patient. They were willing in caregiving, which unlikely had problems except Case 1 that the patient was alone without a caregiver and it was the official who had no attachment but duty. Case 7 had got an outsider as a caregiver (a respected grand mother) by sympathy during misery, intimacy, and attachment during previous illness. Case 13 had got the uncle and the aunt who by emergency handled the caregiving but were close relatives who facilitated every affair in Thailand. Such 2 later cases were special case and rarely found still there were. It communicated that even with advanced technology when people sought comfortability, modern civilizations, egoistic and negligence, but the sympathy of Thai societies never ran dried, and helpful to the misery as in this investigation. It was the strongpoint needed to pay priority of interest and attention.

### **Part 3 How and what were the caregiver management models.**

It was concluded that most caregivers were intimate and attached with the patient accepting duties with willingness and there should not be any problems. However, from the investigation on the caregiver management models, it was mostly found that most of them felt unwilling but there were 4 positive models from 9 models. They were the coercion models, which the state directly handled. The unwillingness model, which directly handled by the caregiver under the Chinese traditions through generations. The dissension model, which were the conflicts between the caregiver and family members. The tolerance model, which the caregiver was physically critical but tolerated to handle but unlikely. The abdication model, which the caregiver accepted and surrendered to bring the patient home for further caregiving because medication was unlikely and unwillingly to bring the patient back home. The employment model, which the caregiver had no time to attend and to organize activities and had to hire a caregiver to substitute. The social reinforcement network model, which the caregiver was an outsider, not a relative or generation but well-prepared and willing as if a family member to substitute when the family of the patient was not ready and inconvenient to handle the caregiving. The reinforcement teamwork model, which the few family members distributed duties by competencies to support each other, and the tug- team model, which the caregivers and many generations synergized in the caregiving.

### **Part 4 The consequences of the caregiver management models.**

This part was to point out that the caregiver management models had relationship with the consequences of the caregiving. Meaning when a caregiver sensed being coerced or unwilling to handle, the caregiving was unlikely effective, which would negatively affect the health of the patient. On the contrary, had it been otherwise the consequence would have been positive.

It was observed from 10 models of caregiving that the coercion model resulted abandonment. The unwillingness model resulted negligence. The dissension model resulted personal conditions. The tolerance model resulted submissiveness. The

abdication model resulted surrender. The employment model resulted rehabilitation.

The social reinforcement network model resulted recovery-like. The reinforcement teamwork model resulted rehabilitation, and the tug- team model resulted well recovery and rehabilitation.

It could be further concluded that the 9 models (the coercion model, the unwillingness model the dissension model, the tolerance model, the abdication model, the employment model, the social reinforcement network model, the reinforcement teamwork model, and the tug- team model) affected 7 states of the patient (abandonment, subservience, personal condition, recuperation, recovery-like, and recovery and each had differences by problem conditions of each patient and in each family). It was found from 4.1-4.5 that negative models leading death to the patient were the coercion model leading to abandonment, the unwillingness model leading to negligence, the dissension model leading to personal condition, and the tolerance model leading to submissiveness and the abdication model leading to surrender. It was also depended on nature of attachment, previous family problems, prioritizing the caregiver and family toward disease, toward disability, and toward the patient contributed by each family, poverty and each problem then encountering.

From No, 4.6-4.10, the positive models affected rehabilitation of the patient to recover to normal life. They were the employment model leading to rehabilitation, the social reinforcement network model leading to recovery-like, the reinforcement teamwork model leading to rehabilitation, and the tug- team model leading to rehabilitation. The positive models were not necessarily be the extended families they might encounter dissension and unprepared (too many cooks spoil the broth followed by endless problems). There were some exceptions among the single family even with restriction of family members but all were willing and well prepared for the caregiving. It was also depended on nature of attachment, previous family problems, prioritizing the caregiver and family toward disease, toward disability, and toward the patient contributed by each family, poverty and each problem then encountering.

## **Part 5 Disability defined by the caregivers, problems or misery arisen by caregiving or being a caregiver.**

This part was to show that actually most caregivers brood negative attitudes on disability or negatively defined about the disability. Also, most caregivers suffered the caregiving.

1. there were 6 definition of disability and the disable in views of the caregivers, i.e.

1.1 Disability was not a despised disease and curable. The paralytics was positively defined seeing not a despised disease, curable and recovered to normal, being understood, explicable the disease of the beloved, chance of survival and cure, willingness of the caregiver and the family, with concerns, intimacy and affection with the patient. They wished the patient recovered enhancing happiness and satisfaction in the life of caregivers' relatives, i.e. values, happiness to return gratitude creating positive relationship with the patient and the family members, being recognized, increasing ability and skills in caregiving, generating pride, being psychologically supported, and an experience priceless to life course. Finally, expecting that the caregiver would be attended if being sick.

1.2. The disability was chronic, and incurable. It was seen despised and the stroke was uncured even medicated. Drug treatment and rehabilitation was to decrease criticality but might contort or be more critical. It was therefore incurable and never recovered but worsened and despaired. The patient needed full-time caregiver with prolong period. It turned some families negative thinking, bored in caregiving and wished the patient faster death, "When will she die!!!" to lift this burden.

1.3. The disability created boredom because of burden and increased many aspects of duty. "It unbearable and need some assistant." There were many inadequate supports drastically diverting life-courses and desocializing, playing many same roles in restricted time or unable to appropriately express roles as being expected by self and by others. It created stress, and accumulated oppression in all aspects, i.e. mental and physical health, exhaustion of caregiving, deterioration, rejecting medication and being occupied and negligence.

1.4. Reserved for outsiders on fearing disgust and fearing to tell others having a patient at home. It was a disgusted condition, pitiful, genetic disease, paralytic, bad luck for family and separated the sick from home and could not tell anyone fearing disgust. In turn, the caregiver and the family fear to tell anyone, fearing outsider's disgusting, dissocializing, and disinteraction.

1.5. By definition of disability in views of the caregiver was to clarify and to accept attending the disable according to the caregiver's perception. Close attention should be consistent at home. From this study, it was found that the caregiver defined disability in 3 heading. 1) A state of helpless – from clarification and acceptance of encountering grief and misery creating much stress and threats. 2) A state of restricted self-caregiving - it was the encountering with restriction in life-course. It turned the caregiver unable to live a normal life and restrictions of caregiving and might unable to bear the burden any longer. 3) A state of self-caregiving - the caregiver would be adjustable over time and effective, adopting to be part of one's life.

1.6. By definition of the caregiver in relation to prioritizing the patient was referred to returning gratitude, unavoidable burden, affection and concerns, disgust, coercion, threat, conflict of mind, and deteriorating body and mind even unexpected. Valuations were varied in leading to action or behaving through obviously defining of the caregiver who attempted to negotiate even it was tough till arriving at a new satisfactory agreement for both parties and either different existing or new needs in private life of the caregiver, which was ongoing and prolonging. It included handling by prioritizing patient, which was classified in to 8 types. 1) As if returning gratitude – sensed values, and returned gratitude, 2) As if an unavoidable burden - never attended, unwillingness and negligence, 3) Affection and Concerns – focusing on happiness for the patient having one's attending and unconditional, 4) Disgust – unwilling, uninteresting and not attending, 5) Coercion – imperative duty without excuses or avoidance. 6) Threat – sensing the threat from family members conflicting each other, 7) Conflict of Mind – abiding in conflict mindset, doing duty by necessity rather than willingness, and 8) Deteriorating body and mind - as burden and responsibility to long-term caregiving and worsening the physiology.

It was concluded that disability and the disable defined by the caregiver were actually most caregivers had negative attitudes or mostly defined negatively. Most suffered in attending the patients viewing as offensive, chronic, unrecovered, burdensome, disgusting, coerced, threatening, conflicting of mindset, and deteriorating the caregiver. It made the caregiver encounter misery, oppressed by stresses, restricted lifestyle, and unable to live normal life. Few positively viewed of inoffensive, curable, and recovered to normal, returning gratitude, affection and concerns. They were drastically defined and leading to actions or behaving. It was found from summary that the caregiver had no awareness causing inadequate attentiveness and negligence.

## **2. Miseries of the Caregiver was Actually Arisen**

It was actually arisen and found out that problems of caregiving and needs of the caregivers, kith, relatives and intimate persons had been expected for substitution during ailments became directly responsible, dutiful, necessary, and grateful caregiving. It was also found that most caregivers suffered in many aspects not only themselves, the patients but also the surrounding people, i.e. family members, medical personnel and so on.

Frequently met problems had never been addressed and the caregivers were the middleman among all parties and encountered critical effects. Meaning, the caregiver was the scapegoat of not admitting the patient if the patient was critical, serving relatives and family members, untidy housework, bad mood of the patient irritating disability and could not do anything as wished, and critical quarrel between the sick and the family. Would there anyone ever think of miseries of the caregiver encountering 24 hours attending the sick and have another social activities?. Does anyone know the caregiver was suffering, and completely exhausted? Had any one asked whether the caregiver was tired in this dedication, attempting to satisfy all to meet every expectation.

There were 41 problems encountered by the caregiver. They were worries and weariness, stress, suffering by sleeplessness of caregiving, restlessness, no privacy, stressed by affection and concerns, coerced, threatening, reluctant on

caregiving, physically deteriorating, unending different activities, handling helpless patient with big stature and needed assistant, which deteriorating the caregiver's health, and get sick, no communication with people surrounding since the patient needed close and consistent care, anxiousness on the patient, powerless, sensing likely physical-mental-social burdensome, undedicated and often absent of career, inattentive to one's own family, desocializing, expensive expenses, despair, lacking access of modern technology and devices, lacking information and knowledge of the disease, and lacking management of pre & post mortem. Therefore, if there were inadequacies of supports, the caregiver had to afford alone and lengthily, where the same problems were unaddressed. So, miseries of the caregiver were endlessly ongoing

## **Part 6 Addressing arisen problems of the Caregiver**

### **Addressing the Caregiver's Life and Arisen Problem:**

It involved 12 issues, i.e. 1. Mental defects, 2. Unsettled household affairs, 3. Status, 4. Unsettled housework, 5. Unsettled workplace, 6. Inadequacy of perception of self-health, 7. Inadequate knowledge of disease and caregiving, 8. Accessing technological devices, 9. Time management on caregiving, 10. Desocialization and free time spending, 11. Arrangement before the patient's death and 12. after patient's death. All these were affected by the caregiver attending the patient all the time and lengthily.

1. Managing 5 mental distresses, i.e. 1. Stresses from the patient which were unaddressed and uninterested and let go where they hurt the caregiver's health and could not handled only by walked away and later returned. 2. Over affection and concerns which led to stress. 3. Monotony and boredom, which were like unending cycle. 4 Despair and helplessness of medication and 5. life disaster, which was the worse that the only son rejected caregiving. In summary, the mental defects were complicated for managing. The caregiver attempted to address but only some even with substitution and had to continue encounter. Most were met with negative mental

defects except the over affection and concerns, which drew stress in by dedication to the patient. Therefore, it was better to take medium course.

2. Unsettled Household Affairs- there were 5 issues i.e. 1) Threat and internal conflict: they were unprepared fore caregiving and hated to bring the patient back home. 2) short of attentiveness for one's family, 3) No time for one's husband and family, 4) powerless in decision making and disharmonizing and other members overshadowed in everything and 5) Disharmony with kith before sickness. It was concluded that there was no time to settle the household affairs since caregiving needed close attention.

3. Status -there were 2 statuses, i.e. 3.1 Managing Needy of Money – with restricted budget but expenditures were increasing and without any additional income rather than saving. when money ran short, it was addressed by economizing. It was lucky that the aunt can reimbursed from 30 Bath medication allowance. 2) Managing Expensiveness of Caregiving: it financially affected the caregiver directly, particularly those poor and moderate caregivers and with lengthy caregiving. In Case 3, the patient was immediately moved to a public hospital where expresses were reimbursable and low cost and affordable for the extra charges. It was concluded that handling statuses had been appropriately resumed with economic status in each family and the caregiver. Had it been poor, so then economizing was imperative since money was indispensable in prolonged caregiving and no money worth the words.

4. Unable to Manage Household Works: Inability to handle household works affected expeditiousness of daily work. The caregiver was too concerned with the sick. Each day was consumed with caregiving and negligent to the housework. Only if there were with minor works but most of the time was preoccupied (Case 3). It was managed by the elder sister baked cakes at home and the maid helped janitor works. Then when the patient slept, some putting things in order and mopping around the sick-bed so that when she awoke she would see otherwise she would loudly call. There was little time for housework but other members were willing to help.

5. Management by Unable to Manage Work Place Works: It was divided into 3 kinds, i.e. 1) Undedicated Working: often absent and stop working with contacting medication for the mother, no caregiver, worry about the sick mother she needed close attention, and then returned to work but distracted by anxieties and often visited

the sick mother. 2 ) Unsettled Jobs: Jobs at office were so tough but unlikely fully dedicated, and so exhausted leading to unsettled jobs. both worrying about the mother and had no spirit for work. . 3) Below Standards: most time dedicated to attend the sick. Chances were closed for dedication to routine jobs (Case 8) and became jobless (Case 10). In summary, the caregiver could not settle the workplace jobs, because of many jobs at the same time. It needed time to think. It was not lonely affected office work and salary, but also people around and expensive caregiving.

6. Inadequacy of Perceiving One's Own Health: there were 7 issues, i.e. 1) Deterioration – because of restlessness, by dedication to the patient leading to exhaustion, and weakness till she was well and to resume her caregiving. 2) Weariness – the endurance was gradually shortened till unbearable, it was suffering since no caregiver but we passed happiness and suffers together, family members all had work to do. 3) Timeless - The caregiver preoccupied with the sick, only focused the sick and handling everything for the patient made her happy and there was no time for oneself. 4) No privacy – , the caregiver was happy to attend the mother even to dedicate her life, completely despair even weep to relieve my stress in toilet fearing other to see. 5) Restlessness – caregiving paid no time for oneself, restless, inadequate rest and having activities with the sick causing stress all the time. There was relentless and insomnia. 6) Sickness by Caregiving - restless and serious sick because she had no time to attend herself, restless and deteriorating till sick and could not resume her duty. 7) Paroxysm – caregiving was burdensome and self-forsaking it raised the previous sickness it one was negligent about it. In summary, lacking one's health perception was varied and using immediate addressing. Little families still helped each other but some got lost by exhaustion since the caregiver was critical in health and had to attend the sick wife. It was burdensome. It was remarkable that the spouse asserted to continue caregiving.

7. Inadequate Knowledge of Disease and Caregiving could be divided by 2 types, i.e. 1) Reluctance: managed by assisting staff and seeking information by reading and questioning staff, the caregiver began self-learning, 2) Inadequate Knowledge of Disease and Caregiving: managed by enduring learning but the sick was staying in hospital and the caregiver could do nothing. This could be addressed by increasing knowledge to raise confidence in performing or asking other for help.

8. Inadequate Access to Technological Devices - using rehabilitating devices was found in this study that most patients were at the stage of rehabilitation and needed it. It was found with most caregiving that finance was ready and skills in managing finance in purchasing materials, things and utilities to facilitate life-course and family, e.g. special devices for wheelchair, wheelchair, cane, adjustable bed, alarm for help. In Case 3, the caregiver brought out her father's dead-bed for re-uses. It helped and convenient for the sick in movements. Devices were easily found and inexpensive e.g. alarm to increase facility in usage for both the caregiver and the sick. For the caregiver with needy of finance as in Case 5 that the sick got phlegm and saliva, with restricted budget the visiting team advised to use read rubber bulb to replace the absorber. But with much phlegm and saliva and deep in throat, the sick was admitted into hospital for a short period and depressed with blocked phlegm and saliva in the throat. It was the similarly circular problems.

9. Improper Time Management could be divided into 2 types, i.e. 9.1 No Time for Caregiving – it was managed to defend oneself of doing alone, doing best, and fulfilling duty and following traditions. The caregiver needed to sell noodles at home and fully occupied as well to attend the sick mother which was heavy burden and felt being isolated, no helps, did not know where to turn to and feared blames from relatives. 9.2 Unsettled Time Allocation for Caregiving – most time management was inadequacy and the caregiver spent most time in caregiving both oneself and the sick including side-effects in each day. It began from activities e.g. arousing hearing and perception, toweling, teeth cleaning, siding oneself, therapy, joint massage to prevent stick and falling toe-tips, observing skin particularly bed sore among helpless patients, and tube nutrition patients, who needed to learn preparing spin food.

10. Managing Unsettled Social Activities, which were divided into 2 types, i.e. 1) De-socialization – the caregiver refuse socialization after her mother got sick because of restrictions, unprepared and concerns about her mother. It was better to stay with mother at home and tripping could be done anytime she wanted when she better prompt. Away from her mother caused worries then it was better to decline. 2) Restrictions of Socialization – the caregiver stop all religious participation but informed them of her preoccupation. In summary, lack of socializing and spent full-

time with the mother by suspension of socialization till her mother's recovery or being confident that other could handle.

11. Inadequate Management before Death: the unexpected loss of the beloved one before proper time, there were reactions for the loss of the beloved and the attached one severely and rapidly. It created deep stress, grief, and distress for the caregiver. They needed companion for console and spiritual supports. It took long time to adjust and to accept what had happened. On the contrary in the second case, the caregiver had no time for caregiving and thought that the sick were burdensome for oneself and family. Management helped reduce worries and needed no caregiving any more but more time for work with free time. Being occupied with works but having a sick mother, therefore she was admitted to the hospital and left her to be attended by the hospital and he needed not attend her like before. He occasionally visited after work and hearing her worsened condition. Upon hearing that she might shortly die, the son had prepared her moderate cremation.

12. Inadequate Management after Death – it was grief, misery and stress for the family. The caregiver needed time to reflect the incident to accept it. To sustain for relief and following changes, truth needed to be accepted and lived on. Some caregivers admitted that they wished the patient die because of prejudice and created difficulties for them. Finally when the patient died, it was as if a relief and able to live on free from burden without any admonition. The cremation was moderate and just informed only relatives.

## **Discussions**

1. Previous medical system was an acute medical system and there was no adjustment to chronic disease. A special hospital is therefore required or medical team for home visit covering caregiving the caregivers or special services for the caregiver. Among the modern medicine technology-oriented, it more pinpoints each disease as specific acute ones and classified into anatomical specialist and patients are viewed as material with separating body and soul. By being a material, a bad parts can be repaired still medicine does not adjust itself to chronic disease, which is gradually increasing. Few hospitals are well prepared to this area such as increasing bed to

match the number of patients for prolong stay. Then the hospitals therefore encourage to fastest bringing patients home for further recuperation rather than handled by the hospital with readjusting strategies on continuing process preparing both the caregiver and the patient before leaving. There will be trend of increasing problems among the patient, the caregiver and family and transferring information for further caregiving at home. The specific home-visit team should meet number of chronic patients leaving hospital and will be widespread network for better effective visits so that solution and help should be found. It will enhance quality of caregiving and life for both patients and caregivers in order to reduce chronic patients often circulating between home and hospital.

Many chronic patients leaving hospitals and returning home for continued recuperation have not been prevailed and covered by the public hospital services. Private units owning networks should respond helping the patients and their families. In case of Uncle Prasert, he has spent 15,000 Baht a month for the caregiving, food and residence in a special private hospital while King Mongkut Hospital a public hospital charges a special caregiving for 800 Baht a day. (24,000 Baht a month).

HotLine for the stroke should be installed for those anxious and suspicious caregivers regarding cardiovascular accident either by automatic response telephone for basic and frequent question or conversing with operators well-informed of the stroke. Any unrespondable questions will be collected for further response and returns the call to the caregiver the precise answer and practices.

2. Focusing only the patient and not also the caregiver should be a new approach. Families of patients should be holistically figured out on complicated problem and acceptance of family differences. Therefore holistic views of the system and health should be part of the system. Then if the system were effective, the patient's health will also better. The holistic and panoramic view should help understand problems in deep and address the precise point rather than finding fault or chastising someone.

3. Project Golden Card of 30 Baht for All Disease is to push cost burden of caregiving to the family. Rationally, this project turns the hospitals to screen patients for admission due to restriction of beds and attempts to reduce medication cost and in turn the period of a specific treatment is shortened. But the stroke patients and other

diseases are chronic diseases and need time for medication, dosing turning each treatment difficult and complicated. Each patient needs prolonged time for treatment and high spending and when arriving at better condition the burden will be shifted to home caregiving. Reasons are hospitals house too many infections, it is better recuperated at home and make checking appointment if the condition were not better. There should be encouragement for well-preparedness faster before leaving for home and home-visit team should follow and increase more staff to reduce often visiting hospital unnecessarily and with simple and precise information.

4. Capitalist mediation at present is interest-oriented ignoring values of the patient and the family. The more the state restricts budget, the hospital must make best out of it and seek other fund to support such as medication fees, donations, private and public research fund otherwise the hospital cannot survive by its high expenses paying personnel, devices and other expenditures. Medication is therefore viewing patient as material focusing only recovery and least stay in the hospital to reduce cost of each patient but can increase admission. So, spirituality of the patient and family are unaware even their sentiments. “The doctor discussed with my sister-in-law to hurry home the patient, she will not be better and it is useless and it is better to allocate the bed for other. I cannot understand why the doctor speak such and where is medicine ethics?” The doctor informs the condition of the sick and asks to sign for acknowledgement.

5. Ill-treatment from the state welfare home – on account of the sick has no relatives, direct caregiver, family-less and the state had to handle, so the caregiving is directly weighed on the state in formality. The hospital submit the affairs to the social welfare unit to coordinate the Home for the Aged to admit the patient for caregiving since the sick is helpless, alone and disable needed a close and consistent caregiver. The sick is not willing to stay in the Home for the Aged but cannot help only despair with disability, living in a new environment, failure of physical and psychological system, left-side paralytic, immobile, stench bedsore, critical mental condition, despair, sorrow with obvious expression such as demand attention, hurting oneself, an craving death. Not long after arriving at the Home of the Aged, where caregivers are few flocked with disable like her causing caregiving unprevailed. Those demanding patients found such climates would scare to demand. Then comes boredom and

speechless, bathing with underground water in a wheelchair, get skin infection and finally she shortly passes away.

6. The caregiver has previous affection with the patient and volunteer to caregiving – when the patient has to encounter sustain disable, helpless, needs a caregiver for necessary help so as the patient can live normal life, then a social network caregiver, who is an outsider, not relative or kith. It is the affection and bond, sympathy, help without reward, a spiritual attachment, readiness and willingness as if a family member. A caregiver needs not be a kith but a close and respected person who can attend during sickness, understanding, intimate socializing, willing to help, trust, living in the same house and under encountering sickness, she is always helpful.

7. Redefining disability – it is found from the investigation that it is the negative attitudes or negatively defining. Most caregivers suffer in caregiving the disable. It turns the caregivers, the families and outsiders again understand disability has been changed in thinking and previous belief through redefining, new good values, clarification, which will lead to new acting or behaving

### **Recommendations for Further Study**

1. This investigation on cardiovascular accident is focused on the caregiver management model only; therefore other areas should be conducted for better perfection such as the patient and circumstances.

2. This investigation on cardiovascular accident is focused on in-depth interviews and observations of the patients and key caregivers admitted in the public hospital in Bangkok. Therefore, investigation should be conducted on the patients and key caregivers admitted in other hospitals or in provinces to gain information and issues of interested.

3. Establish the stroke caregiver group for mutual assistance, which might start small having the hospital as spearhead in assistance and advising. Meeting and exchange of problems and experiences should strengthen the group and increase the members for better assisting group peers.

## BIBLIOGRAPHY

- Anselm Strauss.(1990).Basics of Qualitative research. London:New Delhi.
- Blumer Herbert.(1969).Symbolic Interactionism.Englewood Cliffs,N.J.:Prentice-Hall.
- Carolyn E. Schwartz & Rabbi Meir.(1999).Helping others helps one self: response shift effects in peer support. Social Science & Medicine,48,1563-1575.
- Chenitz W. C.&Swanson.J.M .(1986).Form practice to grounded theory: Qualitative research in nursing.Menlo Park,Calitonia: Addison- Wesly.
- Joseph A.Maxwell.(1996).An Interaction Approach.Qualitative research design. London:New Delhi.
- Joseph T .S. Low& Sheila Payne.The impact of stroke on in journal carers:a literature review.Social Science & Medicine,49, 711-725.
- Mona Benz.(2000). Rules of relevance after a stroke . Social Science & Medicine,51,713-723.
- Munhall,P.L. (1989). Philosophical pondings on qualitative research methods in nursing. Nursing & Science Quarterly,2(1), 20-28.
- Orem,D.E.(1995). Nursing Concept of practice. St. Louis :Mosby Year book.
- Parsons,Talcoff.(1951).The social system.New York:Free Press.
- Scheider,Joseph W.and Peter Conrad.(1980).Having Epilepsy. Philadephia:Temple University Press.
- Sharon S.Brehan and Saul M. Kassin.(1996) Social Psychology.Third Edition.Boston:Houghton Mifflin Company.
- กนกนุช ชื่นเลิศสกุล.(2541) . ประสบการณ์ชีวิตของสตรีไทยที่ป่วยเป็นมะเร็งเต้านม. วิทยานิพนธ์พยาบาลศาสตรบัณฑิต .บัณฑิตวิทยาลัย มหาวิทยาลัยมหิดล.
- กรุณาภรณ์ อิศรางกูร ณ อยุธยา . (2538).ความสัมพันธ์ระหว่างภาพลักษณ์ สัมพันธภาพของคู่สมรสกับการปรับตัวของสตรีวัยหมดประจำเดือน.วิทยานิพนธ์ปริญญาวิทยาศาสตรมหา

บัณฑิต(สาธารณสุข) สาขาวิชาเอก อนามัยครอบครัว. บัณฑิตวิทยาลัย มหาวิทยาลัยมหิดล.

จอม สุวรรณ โณ.(2538).ความสามารถของญาติในการดูแลผู้ป่วยโรคหลอดเลือดสมองก่อนจำหน่ายออกจากโรงพยาบาล. วิทยานิพนธ์ปริญญาพยาบาลศาสตรมหาบัณฑิต สาขาวิชาการพยาบาลผู้ใหญ่.บัณฑิตวิทยาลัย มหาวิทยาลัยมหิดล

จิตรา เจริญภัทรเกตุช.(2537).การสนับสนุนทางสังคมของครอบครัวต่อผู้ป่วยเอดส์เต็มขั้น:การศึกษาเฉพาะกรณีครอบครัวเอดส์เต็มขั้น โรงพยาบาลบารายญ์. วิทยานิพนธ์หลักสูตรสังคมสงเคราะห์มหาบัณฑิต .คณะสังคมสงเคราะห์ศาสตร์ มหาวิทยาลัยธรรมศาสตร์.

จันทร์เพ็ญ แซ่หู่่น.(2536). ปัจจัยคัดสรรที่ทำนายความเป็อหน่ายของญาติผู้ดูแลผู้ป่วยโรคหลอดเลือดสมอง. วิทยานิพนธ์ปริญญาพยาบาลศาสตรมหาบัณฑิต บัณฑิตวิทยาลัย มหาวิทยาลัยมหิดล.

ตุ้ย ย้งน้อย. วิทยาการระบาดในงานอนามัยชุมชน. พิมพ์ครั้งที่1.กรุงเทพมหานคร: ม.ป.ท.:2538. เทียนฉาย กิระนันท์. เศรษฐกิจการเงินสาธารณสุข. กรุงเทพมหานคร โรงพิมพ์จุฬาลงกรณ์มหาวิทยาลัย.2539. “

นงลักษณ์ พันชม.(2540).การรับรู้ประสบการณ์การดูแลผู้ป่วยล้างไตทางช่องท้องอย่างต่อเนื่องของผู้ดูแลที่บ้าน. วิทยานิพนธ์ปริญญาพยาบาลศาสตร สาขาวิชาเอกการพยาบาลผู้ใหญ่ บัณฑิตวิทยาลัย มหาวิทยาลัยมหิดล.

นพมาศ ชีระเวทิน.(2542).จิตวิทยาสังคม.(พิมพ์ครั้งที่3).กรุงเทพมหานคร :สำนักพิมพ์มหาวิทยาลัยธรรมศาสตร์.

นัยพรรณ วรรณศิริ. (2540).มนุษย์วิทยาสังคมและวัฒนธรรม.(พิมพ์ครั้งที่1). กรุงเทพมหานคร: สำนักพิมพ์มหาวิทยาลัยเกษตรศาสตร์.

นิลรัตน์ วัชรภิชาด.(2540).บทบาทผู้หญิงในฐานะผู้ให้การดูแลผู้ป่วยเรื้อรังของครอบครัว. วิทยานิพนธ์ปริญญาพัฒนาชนบทศึกษา(พัฒนาชนบท) บัณฑิตวิทยาลัยมหาวิทยาลัยมหิดล.

บุบผา วิริยรัตนกุล.(2539).ประสิทธิภาพผลการประยุกต์ทฤษฎีของการพยาบาลของกิ่งในการเยี่ยมบ้านมารดาตั้งครรภ์วัยรุ่น. วิทยานิพนธ์ปริญญาวิทยาศาสตรมหาบัณฑิต(สาธารณสุข) สาขาวิชาเอกพยาบาลสาธารณสุข. บัณฑิตวิทยาลัย มหาวิทยาลัยมหิดล.

- บุญมา หลีสิน.(2535).บทบาทครอบครัวในการดูแลผู้ป่วยโรคหัวใจในภาวะวิกฤต:ศึกษารณีย  
ครอบครัวโรคหัวใจ โรงพยาบาลราชวิถี.วิทยานิพนธ์ปริญญาสังคมสงเคราะห์ศาสตร์  
มหาบัณฑิต คณะสังคมศาสตร์ มหาวิทยาลัยธรรมศาสตร์.
- ประคอง อินทรสมบัติ. ( 2539 ).การดูแลตนเองในผู้ป่วยโรคเรื้อรัง.ใน สมจิต หนูเจริญกุล(บรรณ  
ธิการ) .การดูแลตนเอง:ศาสตร์และศิลป์ทางการแพทย์พยาบาล( หน้า 133-164 ).กรุงเทพ :  
วิศิษฐ์สิน.
- พาริตา อิบราฮิม.( 2539 ).ผู้ป่วยอัมพาตครึ่งซีกและการดูแล.กรุงเทพ : สามเจริญพาณิชย์.
- เมธาวี อุดมธรรมนุภาพ.(2544).พฤติกรรมมนุษย์กับการพัฒนาตน.กรุงเทพมหานคร :สถาบัน  
ราชภัฏสวนดุสิต.
- มัลลิกา มัติโก. สังคมวิทยาสุขภาพและความเจ็บป่วย. โครงการสังคมศาสตร์การแพทย์และสาธารณสุข  
สุข.ภาควิชาสังคมศาสตร์และมนุษยศาสตร์ มหาวิทยาลัยมหิดล.
- วรรณภา ศรีชัยรัตน์.(2540). ทฤษฎีปฏิสัมพันธ์สัญลักษณ์: การประยุกต์ใช้.วารสารคณะ  
พยาบาลศาสตร์,20(3-4)1-8.
- วิวรรณ มุ่งเขตกลาง.(2540). ค่าใช้จ่ายของผู้ป่วยโรคหลอดเลือดสมอง. วิทยานิพนธ์ปริญญาวิทยา  
การระบาดมหัศจรรย์ (วิทยาการระบาด). บัณฑิตวิทยาลัย มหาวิทยาลัยมหิดล.
- สมฤดี สิทธิมงคล.(2541).ความเครียด การเผชิญปัญหา และคุณภาพชีวิตของผู้ดูแลผู้สูงอายุที่  
เจ็บป่วยต้องพึ่งพิง.วิทยานิพนธ์ปริญญาพยาบาลศาสตร์มหาบัณฑิต สาขาวิชาการ  
พยาบาลผู้ใหญ่.บัณฑิตวิทยาลัย มหาวิทยาลัยมหิดล.
- สมาคมพยาบาลแห่งประเทศไทย.(2544).พยาบาลครอบครัว:กรอบแนวคิดสู่การปฏิบัติ  
.กรุงเทพมหานคร :สมาคมพยาบาลแห่งประเทศไทย.
- สายพิน ลิจิตเลิศล้ำ.(2542). .ความเครียดและการเผชิญความเครียดของผู้ดูแลผู้ป่วยโรคพิษสุรา  
เรื้อรัง.วิทยานิพนธ์ปริญญาพยาบาลศาสตร์มหาบัณฑิต สาขา สุขภาพจิตและการ  
พยาบาลจิตเวชศาสตร์.บัณฑิตวิทยาลัย มหาวิทยาลัยมหิดล.
- สายพิน เกษมกิจวัฒนา.(2536). แบบจำลองเชิงสาเหตุของความเครียดในบทบาทของภรรยาผู้ป่วย  
เรื้อรังในฐานะผู้ดูแล. วิทยานิพนธ์ปริญญาพยาบาลศาสตร์ดุสิตบัณฑิต.บัณฑิตวิทยาลัย  
มหาวิทยาลัยมหิดล

- สีดา สุจริตกุล.(2541).ความรู้ด้านสุขภาพและพฤติกรรมการดูแลตนเองของหญิงรับจ้างดูแลสุขภาพในกรุงเทพมหานคร.วิทยานิพนธ์ปริญญาพยาบาลศาสตรมหาบัณฑิต สาขาวิชาการพยาบาลผู้ใหญ่.บัณฑิตวิทยาลัย มหาวิทยาลัยมหิดล.
- สุดศิริ หิรัญชุนหะ.(2541).การพัฒนารูปแบบการดูแลสุขภาพที่บ้านของผู้ดูแลผู้ป่วยโรคหลอดเลือดสมอง. วิทยานิพนธ์ปริญญาพยาบาลศาสตรมหาบัณฑิต สาขาวิชาการพยาบาลผู้ใหญ่.บัณฑิตวิทยาลัย มหาวิทยาลัยมหิดล.
- สุถางค์ จันทวานิช. ( 2539 ).วิธีการวิจัยเชิงคุณภาพ. ( ครั้งที่ 6 ).กรุงเทพมหานคร:สำนักพิมพ์จุฬาลงกรณ์.
- สุริรัตน์ ช่วงสวัสดิ์.(2542).ความต้องการของญาติในฐานะผู้ดูแลผู้ป่วยโรคหลอดเลือดสมอง. วิทยานิพนธ์ปริญญาพยาบาลศาสตรมหาบัณฑิต สาขาวิชาการพยาบาลผู้ใหญ่.บัณฑิตวิทยาลัย มหาวิทยาลัยมหิดล.
- สุเทพ สุนทรเกษม.( 2540 ).ทฤษฎีสังคมศาสตร์ร่วมสมัย:พื้นฐานแนวความคิดทฤษฎีทางสังคมและวัฒนธรรม.เชียงใหม่:บริษัทสำนักพิมพ์ โกลบอลวิชั่น จำกัด.
- สัญญา สัญญาวิวัฒน์.(2536).ทฤษฎีสังคมวิทยา:เนื้อหาและแนวทางการนำไปใช้เบื้องต้น.(พิมพ์ครั้งที่6).กรุงเทพฯ:จุฬาลงกรณ์.
- สำนักงานปลัดกระทรวงสาธารณสุข สำนักนโยบายและแผนสาธารณสุข สถิติสาธารณสุข พ.ศ.2539.ม.ป.ท; ม.ป.ป.
- อรฉัตร โทยยานนท์.( 2534 ).Storke Rehabilitation.ใน นิพนธ์ พวงวรินทร์(บรรณาธิการ),โรคหลอดเลือดสมอง. (หน้า591-649 ).กรุงเทพฯ: เรือนแก้วการพิมพ์.
- อรษา พันธุ์ศักดิ์. (2542).กระบวนการดูแลตนเองของผู้ป่วยความดันโลหิตสูงชนิดไม่ทราบสาเหตุ. ผู้ดูแลผู้ป่วยโรคหลอดเลือดสมอง. วิทยานิพนธ์ปริญญาพยาบาลศาสตรดุษฎีบัณฑิต.บัณฑิตวิทยาลัย มหาวิทยาลัยมหิดล

## **APPENDIX**

## APPENDIX

### **A Case Study of the 13 Caregivers and the 13 Patients:**

Case 1: A staff in the Home for the Aged paid full-time caregiving. The requisitions were from the Social Welfare in the hospital (no card of 30 Baht Medical Allowance because no one saw to the affairs). The patient was poor living alone in slum, no relatives and any caregivers, stayed too long in the hospital and the hospital had coordinated with the government unit for further action. The Home for the Aged from Prapadaeng took the patient for the caregiving after leaving the hospital. The patient got diabetes, high blood pressure, heart disease, over 22-year asthma and stroke. However, she was still conscious and could tell her needs but difficult to speak with weak right side and needed assistance for routine activities. She met with swallow difficulties and choked when taking meal. So, nutritional tubes were needed. Her shin was glossy, dried and spotted throughout the body, and there was a 4x7-cm bedsore. The patient was not willing to be admitted in the Home for the Aged since she was not familiar; knowing she herself had no affection and no concerns, no caregiver, despair and frustration with self. She refused to eat and lifeless. Not long, she died and her cremation was hosted by the Home for the Aged.

Case 2: The caregiver was the eldest Chinese son aged 47 years and being a single family staying with his wife and a son. He took responsibility and directly followed the Chinese tradition under gratitude to the mother without any helps from other members. He sold noodles at home and all spending were in cash. He was moderate in economy but later he met monetary problems since he was the only caregiver. Therefore, he unlikely paid attention to caregiving as if negligence but only selling noodles. He only did his duty as best as he could by caregiving his 79-year-old mother, who had brain stenosis, nasopharynx, and infection in blood circulation for over 10 years, over stupor, weak limbs, thin skin, lying still in bed, supported by nutritional tube and urinating devices, having 10x10 cm. bedsore with stench with oozing lymph on the cloth, and twice treated a day. She was often in critical condition and had to be circularly admitted in hospital till she was dead.

Case 3: The caregiver was the youngest daughter aged 42 years and she was so intimate with her mother and stayed together for over 10 years, particularly, for recent 5-6 years when her mother was sick since she paid caregiving to her. At first, she cook Hor Mok (steamed pasted fish) for selling at home when her mother was sick by stroke she had to stop selling Hor Mok and attended her mother only. She was willing in caregiving, with affection and concerns and other family members who had baking business at home. They all love each other and willing to help each other as well as the eldest nephew always freed himself to help supporting for daily activities particularly during visiting the doctor and some outing for special events. The daughter attended her 85 years old mother who had diabetes and brain stenosis for over 4 years. She was conscious with ability to speak short words but unclear ones and weak at the right side, needed supports, staying in bed with 2 cm bedsore. The expenses were reimbursable from the service unit. The family was likely wealthy living in an extended family. The patient was smiling and strong, happy among of family's concerns and their visits with conversations. She was under recuperation and her recovery was better and the bedsore was cured.

Case 4: The caregiver was the youngest daughter aged 30 years and attended her 74 years old mother. The mother suffered diabetes, heart disease, and cerebral infraction for over 30 years, having been conscious and able to tell the needs, stiff tongue, difficult to speak, ever been fallen and under operations of the right hip and if moving it was timely painful. Previously, she used walker but more disable at the moment and unable to walk but mostly lying. Her legs began contracted and painful when being extended. She met problems of inserting nutritional tube so it was operated and insert through the stomach. There was no bedsore, her expenses were reimbursable (she was the retired nurse) and her eldest daughter was an official. She was rather wealthy with additional income from rented hostel. It was a single family but the youngest daughter suffered Takayasu with high-specialized treatment and under dose. There was strong affection and concerns within the family and other members particularly the eldest daughter after her office hours she was willing to help and sometimes the patient's 83-year-old husband. Harmony prevailed in the family and the elder sister handled everything while the younger sister followed without any conflict.

Case 5: The caregiver was an elder (a retired husband) aged 67 years with limitations of suffering high blood pressure and elderliness caregiving his 63-year-old wife suffering diabetes and high blood pressure for over 3 years and cerebral infraction. However, she was able to walk by walker. At the moment the cerebral infraction was more critical in association with infection in the urine system, phlegm in respiratory passage, conscious but skinny, contracted lips, the left side was weaker, helpless, lying in bed, timely groaning, speechless, choking when eating then nutritional tube was needed. There was bedsore and along the bone knots, being poor and using 30 Baht Medical Allowance. Here was a single family, with willingness and responsibility and there was no other members to help because all worked. The self-caregiving was difficult and had to attend the patient leading to ineffective caregiving. The condition of the patient was worsened with often admitted to the hospital and finally she passed away.

Case 6: The caregiver was the youngest daughter attending her 71 –year-old mother who suffered diabetes, high blood pressure for over 10 years, heart disease for over 2 years and cerebral infraction under critical condition but conscious. Her left leg was so weak with infection of urine and respiratory systems, more phlegm, helplessness, weariness, mostly lying in bed, nutritional tubing, no bedsore, and her son could reimburse all expenses. The family status was moderately wealthy and a single family. Her stay in the hospital worsened her condition and after the doctor had discussed the condition for the patient to acknowledge, she was discharged home. All members welcome her home except the father who could not accept the condition. The youngest daughter was so worry of the father who rejected to understand that the mother wished to die at home among all her beloved. Some other members were helpful but the caregiver was despair with the dead-bed mother since she was gradually lifeless, grasping for breath to still, gushing urine and excrement. It was unbearable to witness her condition. She spoke softly and only shaking her head and not long she passed away among all beloved family members and her home as she wished.

Case 7: The caregiver was an elder lady (strong) aged 62 years an intimate and respected attending a niece aged 36 years, who was suffering the high blood pressure (being a nurse of emergency ward). She was stressed and intensely working

on promotion to Classification 8, which made her unconscious and 2 spot of Cerebral hemorrhage and needed emergent operation. After operations she was admitted in the hospital for 40 days, her muscles and equilibrium was negative, unable to walk, difficult to pick up things and colleagues were drastically changing. “It is my prolong ailment and unable to work. So, I must recover for myself and eradicate all disparagement. I come to know this grandmother since I have assisted her child suffering cancer but now she has been already dead. The 4-floor house was located in Din-Daeng and we stay together for 4-5 years and sleep in the same room. This home housed all kith and intimate, helpful and I seek her advice when being frustrated till I am revival to further my personality rehabilitation and better coped with problems. 4 months are tough for me to recover to walking even likely swaying a and not ready to return to work but I must to since it cover the official leave. Arriving at workplace, I have to suffer by being labeled from myself and surrounding people seeing me as a disable, always being found fault, stressed and worry. Later, I can compose employing Dhamma to survive limitations and now I am still working.”

Case 8: The caregiver was an only 35-year-old daughter also she was an official and all expenses were reimbursable when she had less time for caregiving. There were only 2 in this family so she hired a caregiver to attend her mother. The mother was 68 years suffering the cerebral infraction, conscious and reacting with soft tune, weak right limbs, not choking when eating, needed help and the full-time caregiving. Formerly, she owned a grocery but at the moment she had to stop but moderately wealthy. “I think that I have to work since I must continue curing my mother and many expenses are waiting. Now, income is consistent and I need to plan about my mother and myself. Now she is better even slow recovery but I am delighted. I want her to stay with me as long as possible”

Case 9: The caregiver was the eldest daughter aged 36 years, married but no child. She had agreed with her husband that because of none handled the caregiving and she had to take the burden caring her father even realizing without any power of decision but to follow demand. He thought only to do for her 72-year-old father, who suffered ANLL and cerebral hemorrhage but no operations. He was conscious and able to tell what were needed, skinny and contracted legs, right side was likely

moveable, blocked and unclear voice and difficult to listen, nutritional tube by nose because of swallow problem, much phlegm in mouth and throat in yellow mixed opaque white. He had regular urinating into the plastic bag, and no bedsore. All expenses were reimbursable. This was an extended family with many members and there was conflict between the father and son. When the father was disable, the son held power to caregiving and with wealthy status, he paid all. He rejected to bring his father home for caregiving but forwarded him admitted in a private hospital, which suffered much the patient and the caregiver. The hospital was like the second home with prolong stay and never return home. The patient finally died and the cremation was honorary hosted by family duty.

Case 10: The caregiver was a 27-year-old niece, who was intimate with the patient sharing good and bad time together. She was certain not to leave her since her own daughter rejected. The patient was 72 years suffering diabetes and high blood pressure for over 10 years with a stout body, unable to move the right leg. She could only shaking her head but speechless and sometimes her questions were unable to understand. She always moved her buttock, her left hand was strong enough to undress. It needed to support her with soft cloth, which later, her buttock became reddened from her weight. She often urinated and excremented even with side-turned and supported by soft cloth with Vaseline balming. The daughter preferred to discourage her and selfish even the niece could attend but it could not replace the heritage-bond between the mother –daughter. "I pity her she often sobbed and hired a caregiver from a center under negotiation of a caregiving under the condition of 30 Baht Medical Allowance. The niece was not wealthy but the daughter was not helpful but also negligent leaving her to the caregiver only. She stayed in a two-storey house new Kasetsart Market residing also Mr. Pin, the patient's previous husband but lengthily divorced who helped side turning and caregiving in the morning during I went to school. The patient always stayed in bed and needed a full-time caregiving and extensive recuperation."

Case 11: The caregiver was the 76-year-old husband staying together for over 30 years with affection and concerns and never neglecting. He was the direct caregiver and hired a caregiver from a center under his supervision. The patient was 70 years suffering cerebral infraction, insulin injection by her daughter. A the

moment, the condition was worse but still conscious and difficult to hear, the communication was mostly by face shaking, weak right leg, likely helpless, the patient was likely irritating, burst with short and unclear words, depressed and avoided eye contact with sobbing. The husband suffered the high blood pressure and dosing with aging but helpful. They were wealthy and being an extended family for 5-6 years. There were many kith residing, still young but intimate by raising them since infancy. The patient was recovered, ate good meal and less irritating, good caregiving from the hired caregiver under the husband supervision. The daughter was helpful after work. All wished their mother to stay with them and never wished as before.

Case 12: The caregiver was the 42 year-old mother attending her 23 year-old daughter suffering SLE, cerebral tumor and hemorrhage, having operations, fully conscious, weak at right leg and stayed only in bed with full attendance. She had to stay 2 moth in the hospital and had to drop her studies (the last semester for higher vocational degree). She has strong endurance, courageous and attempting for herself. Her expenses were reimbursable by 30 Baht Medical Allowance. They resided in a 2-storey commercial building with a single family of 4 members. The home-business was sewing and spending by cash flow without debts. She loved her daughter and high spirited, hoping on her recovery. Many had been like this still they all cured and some were worse but also cured. She also weighed that her recovery would not totally up to normal. All were not discouraged attending her for more than 4 months with falls and ups, felt depressed, and many times stopped but still rose up to fight and to effort for herself and the family. "I get spirited, loved my father and mother more, do all things best to meet their wishes till I can return to routine studies and working."

Case 13: The caregiver was an 42-year-old uncle staying in Thailand attending his 17 –year-old niece suffering SLE visiting Thialnd from India. She got acute brain stenosis, weak right leg, only Indian literacy, staying all the time in bed, using nutritional tube, often urinating, too expensive and unreimbursable medication for over a month. The uncle could no longer afford only counseled with her father periodically, that if her condition were better, she should be moved home for further treatment. At the moment the uncle handled all things, e.g. medication fees, other expenses, and visa extension fees, which were gradually burdensome and asking for helps from other family members who were willing t o help. The mother flew to

directly attend her daughter but likely helpless and stayed aloof but gave moral support. By 2 months her condition was positive and returned to stay with her uncle for a day. All members were helpful and coordinated with her father to fly her back home to India safely.

## **BIOGRAPHY**

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