# CAREGIVING DEMANDS OF STROKE PATIENTS, PATIENT-CAREGIVER RELATIONSHIPS, AND CAREGIVERS' LIFE SATISFACTION

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This was a descriptive research aimed to: a) assess the caregiving demands of stroke patients, the patient-caregiver relationships, and the caregivers' life satisfaction, b) ascertain the relationship of the caregiving demands of stroke patients and the caregivers' life satisfaction, and c) ascertain the relationship of the patient- caregiver relationships and the caregivers' life satisfaction. This study was conducted on the basis of the Roy Adaptation Model (Roy & Andrews, 1999). One hundred subjects were caregivers who provided the majority of care to stroke patients at home, had a close relationship with them, and had been involved in caregiving for at least 4 weeks. The stroke patients were chronically ill persons who followed up at the out- patient departments and the in-patient departments of Srinakarin Hospital and Khonkaen Hospital from March 1, 2000 to April 30, 2000. First time admission patients were excluded. The caregivers who met the double inclusion criteria were recruited as sample. Data were obtained from interview questionnaires: Personal Data, Caregiving Demand Scale (Oberst, 1991), Intimacy Scale (Walker & Thompson, 1983), and Caregiver's Life Satisfaction Scale established by the investigator using the three psychosocial adaptive modes of the Roy Adaptation Model (Roy&Andrews, 1999). Data were analyzed using descriptive statistics and Pearson's product moment correlation coefficient.

The findings of the study showed that the caregivers perceived the moderate time spent in caregiving, perceived the high level of relationships between caregiver and patient, and had the high level of life satisfaction. The caregivers' life satisfaction did not correlate with the caregiving demands of stroke patients ($r = .15$, $p > .05$), but did appear to be positively correlated with the patient-caregiver relationships ($r = .61$, $p < .01$).

The results from this study provide considerations for nursing practice and further research: caring for the stroke patients who are chronically ill persons needs the continuation of care and the cooperation from caregivers who also need specific care in order to promote their life satisfaction; services should be geared to caregiver as well as patients needs such as, forming a self help group or establishing a counseling clinic for caregivers of chronically ill persons. In addition, nurses should establish a relationship between caregiver and patient such as, using counseling techniques to determine needs and internal feelings of caregivers and patients; then, harmonize their needs and feelings. Further research should conduct intervention studies with the caregivers of stroke patients, study other factors which influence and predict caregivers' life satisfaction, and replicate the study with other groups of caregivers of chronically ill persons.

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ทิตยา ทิพย์สำเหนียก : ความต้องการในการดูแลของผู้ป่วยโรคหลอดเลือดสมอง สัมพันธภาพระหว่างผู้ดูแลกับผู้ป่วยและความพึงพอใจในชีวิตของผู้ดูแล (CAREGIVING DEMANDS OF STROKE PATIENTS, PATIENT-CAREGIVER RELATIONSHIPS, AND CAREGIVERS' LIFE SATISFACTION) คณะกรรมการควบคุมวิทยานิพนธ์: บังอร ผลเนืองมา, M.S., จริยาวัตร คมพยัคฆ์, ส.ด., วรรณี สัตยวิวัฒน์. ค.ม., 105 หน้า. ISBN 974-664-578-1

การศึกษาเชิงบรรยายครั้งนี้มีวัตถุประสงค์เพื่อ 1) ประเมินความต้องการในการดูแลของผู้ป่วยโรคหลอดเลือดสมอง สัมพันธภาพระหว่างผู้ดูแลกับผู้ป่วยและความพึงพอใจในชีวิตของผู้ดูแล 2) ศึกษาความสัมพันธ์ระหว่างความต้องการในการดูแลของผู้ป่วยโรคหลอดเลือดสมองกับความพึงพอใจในชีวิตของผู้ดูแล และ 3) ศึกษาความสัมพันธ์ระหว่างสัมพันธภาพระหว่างผู้ดูแลกับผู้ป่วยกับความพึงพอใจในชีวิตของผู้ดูแล อธิบายโดยใช้กรอบแนวคิดทฤษฎีการปรับตัวของรอย (Roy & Andrews, 1999) ทั้งนี้ผู้ดูแลคือผู้รับผิดชอบหลักในการดูแลผู้ป่วยโรคหลอดเลือดสมองที่บ้าน มีความสัมพันธ์ใกล้ชิดกับผู้ป่วย และมีระยะเวลาในการดูแลผู้ป่วยตั้งแต่ 4 สัปดาห์ขึ้นไป จำนวน 100 ราย ผู้ป่วยคือผู้ป่วยโรคหลอดเลือดสมองที่มารับการรักษาที่แผนกผู้ป่วยนอกและแผนกหอผู้ป่วยในตั้งแต่ครั้งที่สองขึ้นไปของโรงพยาบาลศรีนครินทร์และโรงพยาบาลขอนแก่น ระหว่างวันที่ 1 มีนาคม 2543 ถึงวันที่ 30 เมษายน 2543 เลือกกลุ่มตัวอย่างตามเกณฑ์ที่กำหนด เก็บข้อมูลโดยใช้แบบสัมภาษณ์ข้อมูลส่วนบุคคล แบบวัดความต้องการในการดูแล (Oberst, 1991) แบบวัดความใกล้ชิดสนิทสนม (Walker & Thompson, 1983) และแบบวัดความพึงพอใจในชีวิตของผู้ดูแล (Caregiver's Life Satisfaction Scale) ที่ผู้วิจัยสร้างขึ้นโดยใช้กรอบแนวคิดทฤษฎีการปรับตัวของรอย (Roy & Andrews, 1999) วิเคราะห์ข้อมูลโดยใช้สถิติเชิงบรรยายและสัมประสิทธิ์สหสัมพันธ์ของเพียร์สัน

ผลการศึกษาพบว่าผู้ดูแลรับรู้ความต้องการในการดูแลของผู้ป่วยโรคหลอดเลือดสมองระดับปานกลาง รับรู้สัมพันธภาพระหว่างผู้ดูแลกับผู้ป่วยระดับสูงและมีความพึงพอใจในชีวิตในระดับสูง ความพึงพอใจในชีวิตของผู้ดูแลไม่มีความสัมพันธ์กับความต้องการในการดูแลของผู้ป่วยโรคหลอดเลือดสมอง ($r=.15, p>.05$) แต่มีความสัมพันธ์ในทางบวกกับสัมพันธภาพระหว่าง ผู้ดูแลกับผู้ป่วย ($r=.61, p<.01$)

ผลการศึกษาวิจัยมีข้อเสนอแนะว่าเนื่องจากการดูแลผู้ป่วยโรคหลอดเลือดสมองซึ่งเจ็บป่วยเรื้อรัง ต้องให้การดูแลอย่างต่อเนื่อง จึงต้องการผู้ดูแลซึ่งต้องการการดูแลเช่นเดียวกับผู้ป่วย ทั้งนี้เพื่อส่งเสริมให้ผู้ดูแลเกิดความพึงพอใจในชีวิต พยาบาลควรตระหนักถึงความสำคัญและให้บริการช่วยเหลือผู้ดูแล เช่น การจัดตั้งกลุ่มช่วยเหลือตนเองหรือเปิดคลินิกให้คำปรึกษาสำหรับผู้ดูแลผู้ป่วยโรคเรื้อรัง มีการเสริมสร้างสัมพันธภาพที่ดีระหว่างผู้ดูแลกับผู้ป่วย เช่น การใช้เทคนิคการให้คำปรึกษาเพื่อค้นหาความรู้สึกและความต้องการของผู้ดูแลและผู้ป่วย หลังจากนั้นช่วยประสานความต้องการและความรู้สึกของทั้งสองฝ่ายให้สอดคล้องกัน อันจะนำมาซึ่งสัมพันธภาพที่ดีระหว่างผู้ดูแลกับผู้ป่วย การวิจัยครั้งต่อไปควรมุ่งศึกษาการให้การช่วยเหลือผู้ดูแลผู้ป่วยโรคหลอดเลือดสมองโดยใช้ข้อมูลที่ได้จากการศึกษาเป็นพื้นฐาน ศึกษาปัจจัยอื่นๆที่มีอิทธิพลต่อความพึงพอใจในชีวิตของผู้ดูแล และทดลองศึกษาในลักษณะเช่นเดียวกันนี้กับผู้ดูแลผู้ป่วยโรคเรื้อรังกลุ่มอื่นๆ

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# CHAPTER I

# INTRODUCTION

## Background and Significance of the Study

Strokes are cerebrovascular events (cerebrovascular accident: CVA) that affect the quality of life and well being of an entire family over a long period of time (Bishop & Evans, 1995: 20-31). They are one of the top ten leading causes of death in the world (WHO figures cited in Thorvaldsen, et al., 1995: 361-367). In America, there are two million stroke patients and 150,000 deaths annually. In addition, strokes are the third leading cause of death and the major reason for disability in American adults (Sullivan, 1992 cited in Easton, et al., 1994: 348-351). In Thailand, strokes are the fourth leading cause of death. The prevalence of stroke is rather high, that is 77.4 per 100,000 people (Institute of Public Policy and Plan, Ministry of Public Health, 1999). However, nowadays, the morbidity and mortality rates after stroke are declining as a result of advances in medicine and technology (Dorsey & Vaca, 1998: 62-67). As a consequence, there are an increasing number of stroke survivors.

A stroke can be a serious and debilitating health problem (Thompson, et al., 1989: 239-247). The impact of a stroke on a person represents limitations or abnormalities in the physical, perceptive, cognitive, intellectual, communicative, emotional and behavioral changes. The stroke patients become dependent on help for the most primary activities of

daily living (Nydevik & Eller, 1994: 155-161). During the acute phase of recovery, they may need to be admitted in intensive care. Today, with dramatic discoveries in medical science, longevity has increased to the point that the family often encounters chronic illness and/or disability (Periard, 1989). Furthermore, current techniques of treatment tend to be expensive and time consuming, raising questions concerning their cost-effectiveness. Consequently, many stroke patients may be discharged before they reach full recovery (Turnbull & Wall, 1989: 123-133). When they have not recovered upon reentry to the family unit, a family member assumes the role of caregiver.

Enactment of the caregiving role for disabled stroke patients is considerably difficult because it is an increasingly common family responsibility (Hoyert & Seltzer, 1992: 74; Newman, 1997: 80). In addition, caregiving lasts for a long period of time, and can therefore develop into a pattern that disrupts all aspects of the caregiver's life, including physical, financial and emotional problems; leisure time reduction, familial relationship stress, and occupational problems. Moreover, caregiving affects the caregiver's time management, social life, and life style, which may account for the negative influence of caregiving on the caregiver's mental health (Anderson, et al., 1995; Brody, 1985 cited in Hoyert & Seltzer, 1992; Periard, et al., 1993; Maneewan, C., et al., 1994; Sirapo-ngam, Y., 1996). The mental health of the caregiver has been deemed the most adversely affected (Cantor, 1983, Zarit, et al., 1980 cited in Hoyert & Seltzer, 1992). The mental health problems resulting from caregiving can be: caregiver strain, caregiver stress, caregiver burden, and caregiver burnout (Cantor, 1983; Hoyert & Seltzer, 1992; Newman, 1997; Oberst, et al., 1989; Sheehan & Nuttal, 1988; Williams, 1994;

Gasemgitvatana, S. & Tulyatorn, P., 1995; Maneewan, C., et al., 1994; Sirapo-ngam, Y., 1996; Suwanno, J., 1997). All these effects can ultimately influence the well-being and caregivers' life satisfaction. Furthermore, they can indirectly affect the well being and collective quality of life of stroke patients.

Currently, investigators are devoting significant attention to the study of caregivers (Walker, et al., 1990b: 147). Yet, much of the focus has been on its negative outcomes, particularly its burdens or strains. Although the effect of caregiving responsibilities on family providers is not clearly understood, there is some evidence that caregiving can be satisfying (Oberst, et al., 1989: 210). Some caregivers experience positive outcomes as a result of the caregiving activities, such as gratification and satisfaction from caregiving (Walker, et al., 1990b: 147). Since studies of caregiving satisfaction are fairly new, there is still much to be learned about such positive outcomes. Questions to be answered include: Are some caregivers more likely to experience life satisfaction than others? Is there a connection between the patient-caregiver relationships and the caregivers' life satisfaction? Is there a correlation between the demands of patients and caregivers' life satisfaction? The answers to these questions are critical to family service providers.

The relationships between caregiver and patient play an important role in the interdependent family system. A good relationship entails the understanding, sympathy, and compassion of caregivers. Compassion accounts for the willing motivation of caregivers to care for patients (Sirapo-ngam, 1996). Interpersonal interaction also entails psychological and emotional rewards that enter into the individual's evaluation of the situation (Mutran & Reitzes, 1984 cited in Walker, et al., 1990b: 147). Studies showed

that caregivers who reported positive effects in their relationships with patients had evaluated the experience of caregiving more positively than those who reported negative impacts (Kramer, 1993; Pohl, et al., 1995; Walker, et al., 1990b). The patient-caregiver relationships are considered to be a factor affects the caregivers' life satisfaction.

Caregiving demands represent quantity of time and activities caregivers provide for care. The caregiving role is viewed within the larger context of the caregiver's life situation. The specific caregiving demands are those directly drawn from the patient's chronic condition and needs (Wallhagen, 1992: 113). Because these tasks are imbedded in the caregiver's total life context, it is particularly important to appreciate how the context of caregiving may affect the perceptions of these demands, i.e. how these demands influence the caregiver's life satisfaction.

An important aspect of nursing care for disabled stroke patients is to promote health and help them recover all their functions. Since nurses play a significant role in the assessment of home caregiving situations, nurses need to help caregivers to prepare themselves for their caregiving roles. The chief concept nurses should consider is viewing those caregivers as persons who are required to adapt to environmental stimuli as the stroke patients. Studying the psychosocial adaptation of caregivers, and how environmental stimuli influence the psychosocial adaptation, can help nurses assist caregivers to adapt to their new roles. This can help family service providers target those caregivers with the greatest need for interventions and ultimately lead to quality of care and health of the stroke patients.

## Research Questions

1. What are the caregiving demands of stroke patients perceived by the caregivers?
2. What are the levels of the patient-caregiver relationships perceived by the caregivers of stroke patients?
3. How do the caregivers express their life satisfaction?
4. Is there a correlation between the caregiving demands of stroke patients and the caregivers' life satisfaction?
5. Is there a correlation between the patient-caregiver relationships and the caregivers' life satisfaction?

## Conceptual framework

This study was conducted on the basis of the Roy Adaptation Model, (Roy & Andrews, 1999). Roy considers the human being as an adaptive system. She views a human adaptive system as one that functions with interdependent parts acting in purposeful unity. The adaptive systems consist of inputs, control processes, and outputs.

**1. Inputs**

The Roy model categorizes the inputs into two characteristics: stimuli and adaptation level. Stimuli are classified into three stimuli: focal stimuli, contextual stimuli, and residual stimuli (Roy & Andrews, 1999: 38-39). The focal stimuli are those most immediately in the awareness of the human system while the contextual stimuli are all

other stimuli present in the situation contributing to the effect of the focal stimulus, and the residual stimuli are environmental factors within or without human systems, the effects of which are unclear in the situation. Then, adaptation level is the stimulus that affects the human system's ability to response positively in a situation, and represents the condition of the life processes. The life processes vary at three levels: integrated, compensatory, and compromised level (Roy & Andrews, 1999: 40-41). The integrated adaptation level illustrates the structure and function of the life process working as a whole to meet human needs. Then, the compensatory adaptation level describes the level that the cognator and regulator have been activated by a challenge to the integrated processes. Finally, the compromised adaptation level is the problem that ensues when both integrated and compensatory processes are inadequate.

**2. Control processes**

The Roy model conceptualizes the complex dynamics within the person as the coping processes. These processes are the regulator and the cognator subsystems (Roy & Andrews, 1999: 45).The regulator subsystem is a basic type of the adaptive process responds automatically through neural, chemical, and endocrinal coping channels whereas the cognator subsystem responds through four cognative-emotive paths: perceptual and information processing; learning; judgement; and emotion.

**3. Outputs**

The outputs or behavior that result from the control processes can be observed in four categories or adaptive modes: physiological mode, self-concept mode, role function mode, and interdependence mode.

Firstly, the physiological mode, is associated with the physical and chemical processes involved in the function and activities of living organisms. The underlying function of this mode is physiological integrity. Roy (Roy & Andrews, 1999: 102) defines integrity as the degree of wholeness achieved by adapting to change in needs. When a person's physiological needs are met, physiological integrity is achieved.

Secondly, the self-concept mode, is defined as the composite of beliefs and feelings held about oneself at any given time, and it is formed from internal perceptions and perceptions of others' reaction (Roy & Andrews, 1999: 107). The basic need underlying this mode is psychic and spiritual integrity, or the need to know who one is so that one can be or exist with a sense of unity, meaning, and purposefulness in the universe. Roy views the self-concept mode as having two subareas: physical self and personal self (Roy & Andrews, 1999: 383).The physical self includes the person's appraisal of physical being, physical attributes, functioning, sexuality, health and illness states, and appearance. It includes two components: body sensation and body image. The body sensation applies to the ability to feel and experience oneself as a physical being whereas the body image applies to how one views oneself physically and one's appearance. Then, the personal self, represents three components: self-consistency, self-ideal, and moral-ethical-spiritual self. Self-consistency refers to an organized system of ideas about self while self-ideal pertains to what one would like to be or is capable of doing; moral-ethical-spiritual self includes the belief system and an evaluation of who one is in relation to the universe.

Then, the role function mode, focuses on the roles that individuals occupy in society. Roy (Roy & Andrews, 1999: 109-110) defines a role as a set of expectations about how a person occupying one position behaves toward a person occupying another position. The basic need underlying this mode is social integrity, or the need to know who one is in relation to others so that one can act. The role set is the complex positions that an individual holds which is classified into three roles: primary role, secondary roles, and tertiary roles (Roy & Andrews, 1999: 434-435).The primary role determines most of a person's behavior during a specific period of life. It is determined by age, sex, and development whereas the secondary roles are those that the person assumes to complete the tasks associated with a developmental stage and primary role; the tertiary roles are related to secondary roles and represent ways in which individuals meet their role-associated obligations. For example, associated with the role of wife might be that of primary caregiver. In addition, Roy classifies behavioral components into two components (Roy & Andrews, 1999: 437): instrumental and expressive behavior. Instrumental behavior, or goal-oriented behavior, are those activities persons perform as part of their roles. Expressive behavior, or affective behavior, involves the feelings and attitudes held by the person about role performance.

Ultimately, the interdependence mode, focuses on the close relationship of people and their purpose, structure, and development. Interdependent relationships involve the willingness and ability to give to others and accept from the aspects of all that one has to offer, such as love, respect, value, nurture, knowledge, skills, commitments, material possessions, time, and talents. People who have a comfortable balance in interdependent

relationships feel valued and supported by others, and can express the same for others (Roy & Andrews, 1999: 111-112). The basic need of this mode is relational integrity, or the feelings in security of relationships. This basic need consists of three components: affectional adequacy, developmental adequacy, and resource adequacy (Roy & Andrews, 1999: 112). Affectional adequacy involves the willingness and ability to give to and receive from other aspects of all one has to offer as a person: love, respect, value, nurture, knowledge, skills, commitments, talents, possessions, time, and loyalty. Then, developmental adequacy refers to the process associated with learning and maturation in interrelationships. Finally, resource adequacy is identified as the need for food, clothing, shelter, health, and security (Roy & Andrews, 1999: 480, 484, 489).

In conclusion, individuals are viewed in relation to the four adaptive modes. They provide a particular form or manifestation of cognator-regulator within the human adaptive process. Although these modes are viewed separately, it must be remembered that they are interrelated (Roy & Andrews, 1999: 114). As shown in figure 1, the four modes are depicted as four overlapping circles, central to which is a circle representing the coping processes. It can be noted that each mode in the diagram is intersected by each of the other three modes. Behavior in each mode can have an effect on, or act as a stimulus for, one or all of the other modes. In addition, a given stimulus can affect more than one mode, or a particular behavior can be indicative of adaptation in more than one mode. Such complex relationships among modes further demonstrate the holistic nature of humans as adaptive systems.

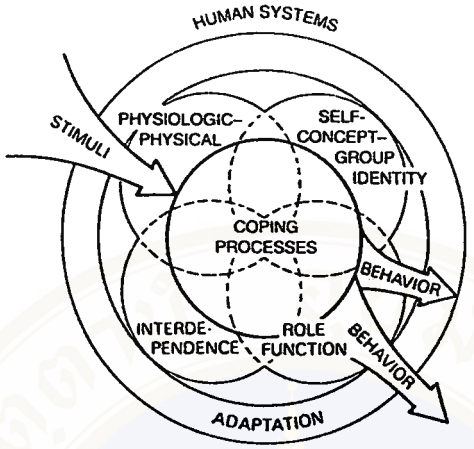


**Figure 1** Diagrammatic representation of human adaptive systems (Roy&Andrews, 1999: 114).

Based on the theoretical framework, the investigator established the conceptual framework for the study, using the caregivers' life satisfaction as the outcome behavior, and the caregiving demands of stroke patients and the patient-caregiver relationships as the environmental stimuli. The relations of these stimuli and the outcome behavior are shown in figure 2.

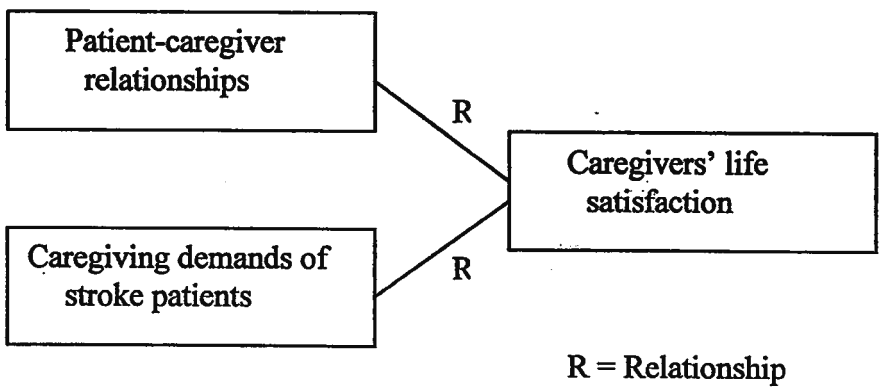


**Figure 2** Conceptual framework of the study

## Purposes of the Study

1. To assess the caregiving demands of stroke patients, the patient-caregiver relationships, and the caregivers' life satisfaction.

2. To ascertain the relationship between the caregiving demands of stroke patients and the caregivers' life satisfaction.

3. To ascertain the relationship between the patient-caregiver relationships and the caregivers' life satisfaction.

## Hypotheses

1. The caregiving demands of stroke patients correlate with the caregivers' life satisfaction.

2. The patient-caregiver relationships correlate with the caregivers' life satisfaction.

## Scope of the Study

This study aimed to search the psychosocial adaptation of the caregivers of stroke patients by studying their life satisfaction, and its relationship with the caregiving demands of stroke patients, and the patient-caregiver relationships. Data were obtained from the caregivers who provided the majority of care to stroke patients, had a close relationship with them, and had been involved in caregiving for at least four weeks. The

stroke patients were chronically ill persons who followed up at out-patient department or admitted into in-patient department of Khonkaen Hospital and Srinakarin Hospital. First time admission patients were excluded. Data collection was from March 1, 2000 to April 30, 2000.

## Definition of Terms

1. Caregiving demands of stroke patients are the perceptions of the caregivers of stroke patients pertains quantity of time and activities they provided for the caregiving role. Such activities are classified into three groups: direct care, interpersonal care, and instrumental care. Direct care includes carrying out of treatments, care of daily living, and assistance with those activities. Interpersonal care involves emotional support, monitoring of health status, managing behavior problems, and contact with health care providers. Instrumental care includes household tasks, financial management, transportation provision, and activity planning. Those caregiving demands can be evaluated by the Caregiving Demand Scale (Oberst, 1991a) applied by Gasemgitvatana,S, 1993.

2. Patient-caregiver relationships are the feelings of closeness and contact between caregiver and patient. These feelings include affectional closeness, understanding, love, sincerity/honesty, satisfaction, help, concern, esteem building, well-wishing, compromise and forgiveness, affective solidarity and the sense of the certainty of the relationship, and the respect and acceptance of the person's ideas and criticisms. Such feelings can be measured by the Intimacy Scale (Walker & Thompson, 1983) applied by the investigator.

3. Caregivers' life satisfaction is the positive outcome of response to the internal feelings of the caregivers. These feelings involve satisfaction with self, satisfaction with roles, and satisfaction with interdependence. They can be assessed by the Caregiver's Life Satisfaction Scale established by the investigator, using the three psychosocial adaptive modes of the Roy Adaptation Model (Roy & Andrews, 1999).

## Expected outcome and benefits

1. To be a guideline for the care providers to assess the factors correlate with the caregivers' life satisfaction.

2. To be a guideline for the care providers to assist the caregivers in providing care considering the caregiving demands and promotion of the patient-caregiver relationships.

## Limitation

One that continues to plague caregiving research is the nonrandom selection of subjects that may introduce response bias and limit the generalizability of study outcomes.

# CHAPTER II

# LITERATURE REVIEW

In this chapter, all the relevant literature in relation to the caregivers' life satisfaction was reviewed within the context of the Roy model. The literature review is presented in four topics as follows.

- Caregiving demands of stroke patients
- Caregiving and its impact on caregivers
- Responses of caregivers to caregiving
- Caregivers' life satisfaction and some relevant factors

## Caregiving Demands of Stroke Patients

A stroke is a cerebrovascular event (cerebrovascular accident: CVA) resulting from the disruption of blood to the brain; the rupture, occlusion, and obstruction of blood circulation (Poungvarin, N., 1991). A stroke might last a few minutes or last for an hour. The prognosis of stroke depends on the location and size of the lesion. Signs and symptoms of stroke commonly appear at the first time attack, the consciousness of the victims gradually worsens until they slip into coma. First time stroke victims may arrive in the hospital with coma or brain damage, such as weakness of the extremities, trouble speaking, vomiting, seizure, high blood pressure, fever, confusion, emotional and

behavioral alteration. These signs generally appear immediately and progress in a few minutes or may last for an hour. The warning signs of stroke are confusion, headache, blur, trouble speaking, and transient ischemic attack (Phuanpatom, N., 1987, Hanucharoenkul, S., 1993 cited in Tirapaiwong, P., 1997). During the acute phase of stroke, critical care mainly focuses on saving the patient's life. Patients receive principal care from the health professionals. As stroke develops to the recovery phase, family are involved in the caregiving role and are introduced to the remained disabilities resulting from the disease or limitations of the patients. Unfortunately, current techniques of treatment tend to be expensive and time consuming, raising questions concerning their cost-effectiveness. As a consequence, treatment for stroke patients may be discontinued before they have reached their full functional recovery (Turnbull & Wall, 1989: 123-133). When they have not recovered upon reentry to the family unit, the role of caregiver is assumed by a family member.

Stroke affects persons in many areas. Some investigators classify the impacts resulting from stroke into three groups: physical or functional impairment, cognitive impairment, and changes of behavior, emotions, and personal feelings or needs (Williams, 1994; Ibrahim, F., 1996; Taboonpong, N., et al., 1994). Physical or functional impairment includes trouble speaking, trouble swallowing, pressure sores, respiratory infections, incontinence, and weakness of extrimities. Cognitive impairment involves depression, forgetfulness, and fear. Changes of behavior, emotions, and personal feelings or needs include confusion, loss of temper, petulance, immature behavior, needing constant

supervision. These problems of stroke patients can mean greater caregiving demands from the caregivers.

As the effects of stroke mentioned, those effects often occur in stroke patients. The stroke patients may become dependent on help from caregivers. Major assistances stroke patients need from caregivers were: a) assistance with the most primary activities of daily living, b) assistance to help them reach their full functional recovery such as physical rehabilitation, c) assistance to prevent of complications or abnormalities such as aspirated pneumonia, urinary tract infection, d) assistance to prevent trauma and injury such as falls, and e) emotional and mental support. All these demands might need responses from caregivers for a long period of time until stroke patients could have reached their full physical and psychological recovery. Therefore, the caregiving demands of stroke patients can have a great impact on caregivers.

## Caregiving and Its Impact on Caregivers

Caregiving is a complex and multidimensional concept (Given, et al., 1990 cited in Swanson, 1997: 68). A review of literature depicted caregiving as a task, a transition, a role, or a process as follows.

**Task** Careging as a task emphasizes the provision of care for individuals in the areas of activities of daily living and instrumental activities of daily living (Bull, 1990: 759). Examples of these activities include personal care and health care, shopping, transportation, financial management, meal preparation, and household help. Another perspective focuses on the amount of care given and the extent of help provided by family

members and/or others (Phillips, 1988 cited in Swanson, 1997: 68). Furthermore, caregiving includes both direct and indirect tasks within the care situation, regardless of setting. Caregiving is defined not only by what tasks are undertaken, but also by the time and efforts involved.

**Transition** Caregiving as a transition extends the perspective of caregiving by incorporating the following important components: provision of care, performance of care activities, care management, delegation and management of activities, and the care transfer from the caregiving individual to an institution (Swanson, 1997: 68).

**Roles** Caregiving is also a role. According to Phillips (1988 cited in Swanson, 1997: 68), caregiving is viewed as a simple extension of the roles customarily enacted by the family members and/or others.

**Process** Bowers (1987 cited in Bull, 1990: 759) identifies five conceptually distinct but empirically overlapping categories of caregiving roles: anticipatory, preventive, supervisory, instrumental, and protective. The categories encompass the multiple tasks and demands involved in caregiving and emphasize caregiving as a process.

These definitions reflect the complexity and multidimensional nature of caregiving. Thus, they encompass the tasks involved in caregiving and the demands within the process of care.

Based on these conceptualizations of caregiving, Swanson, et al (1997: 68-69) recommend the following definition of caregiver role performance: direct care and indirect care. Direct care is the provision by a family care provider of appropriate personal

and health care for a family member or significant other. Indirect care is the arrangement of appropriate care for a family member or significant other by a family care provider.

Caregiver (informal caregiver or informal carer) is the person who has been involved in caregiving at home. The characteristics of caregiver are as follows (Sirapo-ngam, Y., 1996; Suwanno, J., 1997).

1. Person or relative can be a father, mother, wife, husband, son or daughter, sister or brother, and friend or significant other.

2. Patient must be the person whose health status has been changed according to the disease, disability, and deterioration of physical, emotion, and mind resulting in the limitations in activity of daily living or needs for specific treatment. Nevertheless, those needs must be responded continually.

3. Specifically focuses on the caregiving without wages or rewards.

4. The context of caregiving occurs at home or in community setting. It is not in a hospital or health service.

Many studies revealed that most caregivers were middle-aged women, both married and unmarried, both employed and unemployed. The majority of them were family members who had a close relationship with patients, such as a wife, husband, father, mother, son or daughter, or close relative (Bugge, et al., 1999; Gasemgitvatana, S, et al., 1996; Kuaprom, W., 1999; Maneewan, C., et al., 1994; Sirapo-ngam, Y., 1996; Suwanno, J., 1997; Wongjunlongsin, S., 1999).

Major caregiving activities caregivers provide for stroke patients are as follows (Boonkerd, A., 1997; Hirunchunha, S., 1998; Srepatarapinyo, J., 1997).

1. Assistance with activities of daily living, such as eating, bathing, dressing, movement, excretion, etc.

2. Carrying out of medical or nursing treatments; for example, physical rehabilitation, prevention of complications or limitations in activities and movement, prevention of an accident, and monitoring of health status.

3. Giving an emotional support to the stroke patient, such as motivation, hope and willpower.

4. Additional help, such as managing finances, household tasks, communication with health care providers, etc.

As the caregiving activities exhibited, undertaking of the caregiving role for disabled stroke patients is considerably troublesome because it demands extra-familial responsibility (Hoyert & Seltzer, 1992: 74; Newman, 1997: 80). In addition, it means providing care for a long-term period. Therefore, it can develop into a pattern that disrupts all aspects of the caregiver's life, including physical, financial, emotional problems, leisure time reduction, family relationship stress, and occupational problems. Moreover, it affects the caregiver's time management, social life, and life style, which may account for the negative influence of caregiving on the caregiver's mental health (Anderson, et al., 1995; Brody, 1985 cited in Hoyert & Seltzer, 1992; Periard, et al., 1993; Maneewan, C., et al., 1994; Sirapo-ngam, Y., 1996).

## Responses of Caregivers to Caregiving

Based on the Roy Adaptation Model, Roy describes persons as biopsychosocial beings who are required to adapt to environmental stimuli. Environmental stimuli, which influence adaptation, are categorized as focal, contextual, and residual. A stroke patient, or to be more accurate, the caregiving demands of stroke patients, are the focal stimuli most immediately confronting the person who is a caregiver. The caregivers' relationships to the stroke patients represent the contextual stimulus of the caregiving situations. The residual stimuli are unknown factors in the caregiving situation; when they become known, the are usually considered contextual stimuli.

Adaptation takes place in one biologic and three psychosocial modes. The physiological mode, represented by the caregiver's physical health, is associated with the caregiver's physical and physiological responses to stimuli from the environment; this mode is concerned with maintenance of the physical and physiological integrity of the human system. The self-concept mode, exhibited by the caregiver's emotional health, focuses on the person's conceptions of his or her psychological and spiritual dimensions. The role function mode, portrayed by the caregiver's functional status, is concerned with the person's performance of roles on the basis of his or her position in society. The interdependence mode, represented by the quality of relationships with significant other and other support systems of the caregiver, deals with the development and maintenance of satisfying affectional relationships and community support.

The four modes are interrelated. A stimulus may affect more than one mode, or a response may be indicative of adaptation in more than one mode. Adaptive responses of

the caregivers are those that contribute to the caregiver's goals of survival, growth, reproduction, mastery, and person and environment transformation; ineffective responses are those that do not contribute to the caregiver's goals (Roy & Andrews, 1999: 67).

Humans are constantly responding to their changing environment through adaptive responses. Humans' psychosocial modes, three subsystem of interactions with the environment, were the primary target of this study as they deal with the need for psychosocial integrity as earlier indicated. Life satisfaction was submitted to study the psychosocial adaptation of caregivers. The responses of the caregivers of stroke patients can be described in the four adaptive modes.

**Physiological mode responses**

The physical health of the caregiver can be compromised by the stresses of caregiving or an injury to the caregiver caused by a patient relative; fatigue and lack of sleep, or sleeplessness, due to the caregiving demands (Lubkin, 1986; Newman, 1997; Sheehan & Nuttal, 1988; Williams, 1994; Maneewan, C., 1994). Additionally, many caregivers experienced physical health problems, such as back pain, abdominal pain, waist pain, muscle pain, headache, high blood pressure, and gastritis (Gasemgitvatana, S., et al., 1996; Mayou, et al., 1978 cited in Maneewan, C., et al., 1994; Wongjunlongsin, S., 1999).

**Self- concept mode responses**

The caregivers are usually women who are spouses or daughters. All these women typically value concern for others over concern for themselves (Given & Given, 1991). The decision to provide care for a stroke relative may be motivated by a sense of moral

obligation (Fraser, 1999; Newman, 1997). When the caregiving role is chosen freely, it may be less emotionally draining than when it is assigned. Nevertheless, there may be a negative reaction to care for a stroke patient (Given, et al., 1988). Some caregivers have been found to experience worry and uncertainty when the patient was initially discharged home from the hospital (Bull, 1990; Mitchels, 1988 cited in Fraser, 1999: 10). They were concerned about learning new skills to manage prescribed therapies for the recovering family member. In addition, Fraser (1999: 13) discovered that a daughter caregiver of stroke mother was engulfed by grief, feared losing her mother, felt powerless to change the situation, and guilty that she could have prevented her mother's stroke. Moreover, some caregivers experienced depression and strain from the increased expectations of the caregiver role (Given & Given, 1991). Furthermore, there were more negative responses to the caregiving experience, such as stress, frustration, anger and resentment, emotional exhaustion, irritability, low morale, burnout, and burden (Fraser, 1999; Lubkin, 1986; Sheehan & Nuttal, 1988; Gasemgitvatana, S. & Tulyatorn, P., 1995; Maneewan, C., et al., 1994; Suwanno, J., 1997).

On the other hand, caregivers of chronically ill patients reported feelings of self-satisfaction, gratification, and increased self-respect related to the knowledge that they were successfully undertaking a valued responsibility and coping with a personal challenge (Given & Given, 1991). Motenko (1989 cited in Walker, et al., 1990b: 147) reported that wife caregivers of husbands with dementia sometimes report gratification from caregiving, such as experiencing moments of warmth, comfort, and pleasure.

**Role function mode responses**

When the caregiving role is chosen freely, it may have an extended duration, but when the caregiving role is assigned, it may become an undesirable set of role obligations imposed on one person (Given, et al., 1988). Enterlante & Kern (1995: 157-159) found that after their husbands' stroke, wife caregivers increasingly disliked household responsibilities, their responsibilities in the family structure and the degree of marrital unhappiness were increased. In addition, social and community activities can deteriorate, depending on the number of roles that the caregiver has, and their attendant obligations. When caregivers relinguish their social and community roles, they can become isolated. These role obligations can also generate conflict for the caregiver (Newman, 1997: 84). Additionally, personal care activities of the caregiver are affected in that the daily routine is disrupted and there is added role strain, role ambiguity, role change, role overload, role fatigue, and extra demand on time (Bull, 1990; Lubkin, 1986; Ray & Ritchie, 1993, Blank, et al., 1989 cited in Newman, 1997; Sheehan & Nuttal, 1988). Moreover, occupational activities are frequently altered when the person assumes the role of caregiver of chronically ill persons. Work role obligations may have to be compromised to the extent that the primary caregiver, who is usually a wife, mother, or daughter, may have to stop working to care for the ill family member (Newman, 1997: 85). Women who are uncertain about their employment future appear to experience the most stress related to caregiving. Furthermore, many caregivers have a decrease in educational goals (Hileman & Lackey, 1990).

However, there may be a positive effect on caregiving, Wongjunlongsin (1999) found that caregivers of stroke patients feel their pleasure from providing care and making the patient comfortable; they feel happy they could repay the patients' kindness.

**Interdependence mode responses**

When a family member becomes a caregiver of chronically ill relative, his or her relationship with other people can change as a result of the additional caregiving responsibilities. The relationships among family members before the caregiver role were undertaken may influence relationships during the caregiving period (Newman, 1997: 82-83). The positions of the family members (e.g. wife, daughter, or parent), and the quality of the relationships within the family and with the chronically ill family member have an impact on how the decision is made about who will provide care (Given, et al., 1988). In addition, Fraser (1999: 13) found that a daughter of stroke mother experienced many different and conflicting emotions, which were expressed within the context of the relationship: she had strong feelings of connection to her mother, but felt alone in her caregiving efforts, and sometimes she felt abandoned. Furthermore, family relationships are influenced by the availability of other family members to assist in caregiving as well as agency services and social support from a caregiver support group, visiting nurses, respite services, available companions for the chronically ill family member, and sitters. If the caregiver comes to feel abandoned, this can influence her or his relationship with the patient and other family members (Given, et al., 1988). Indeed, caregivers need emotional and instrumental support (Austin, 1991). The quality of the support received may be more important than the frequency or quantity of the support that is actually secured (Given &

Given, 1991). Support systems of the caregiver can provide a buffer against the caregiving demands by increasing the caregiver's belief that he or she is cared about.

On the other hand, Wongjunlongsin (1999) found that caregivers of stroke patients reported positive effects from providing care, such as having more experience and knowledge for self protection and giving advice to others, having close relationship with the patients, feeling more endurance and calm, and having admiration through not neglecting the patients.

As adaptive responses described, these can have a great impact on the caregiver's life satisfaction. Life satisfaction might be represented in positive or negative aspects depending on the internal and external stimuli, including the caregiving demands of stroke patients and the patient-caregiver relationships that enter into the human system. In addition, it depends upon the caregiver's perception to ascribe meaning and value to their life situations; thus, producing adaptation and resulting in life satisfaction.

## Caregivers' Life Satisfaction and Some Relevant Factors

Life satisfaction is an indicator of well-being, which is useful as a measure of care quality because of its linkage to health (Gould, 1988). Life satisfaction is not merely a reflection of a person's current level of goal achievement, but also like a set of orientation to one's environment which is acquired fairly early and remains moderately stable throughout life (Lieberman, 1970 cited in McDowell & Newell, 1987: 222). Life satisfaction varies with individual, time, and situations (Enquist, et al., 1979, Laborde &

Powers, 1980 cited in Ratanasombat, S., 1997: 30). Many investigators have defined the meaning of life satisfaction. Some of them are as follows.

Neugarten, et al (1961: 137-138) mention that the meaning of life satisfaction is similar to the terms "morale" and "psychological well-being". Life satisfaction consists of five components: zest, resolution and fortitude, congruence between desired and achieved goals, self-concept, and mood tone.

Campbell, et al (1976 cited in Daumer & Miller, 1992: 70) state that life satisfaction is the person's perception of the difference between aspiration and achievement.

Ratanamethanon (1989: 13) indicates that life satisfaction is the outcome of responses to the internal feelings of a person. Its meaning is closely related to the quality of life that means a sense of well-being.

Based on the meanings already indicated, we can come to the conclusion that caregivers' life satisfaction is the positive outcome of responses to the internal feelings of caregivers.

In this study, the investigator used the Roy Adaptation Model to establish the Caregiver's Life Satisfaction Scale. The three psychosocial adaptive modes were applied: self-concept mode, role function mode, and interdependence mode.

- Self-concept mode is the satisfaction they could achieve through psychic and spiritual integrity. It consists of satisfaction with physical self, including body sensation and body image, and satisfaction with personal self involving self-consistency, self-ideal, and moral-ethical-spiritual self.

- Role function mode is the caregivers' evaluation of their roles they could meet social expectations. These roles include primary role, secondary role, and tertiary role.

- Interdependence mode is the satisfaction they could reach through relational integrity. It involves satisfying needs for affection, development, and resources.

In conclusion, the Caregiver's Life Satisfaction Scale constructed by the investigator consists of satisfaction with self, satisfaction with roles, and satisfaction with interdependence. Satisfaction with self includes physical self and personal self. Satisfaction with role involves primary role, secondary role, and tertiary role whereas satisfaction with interdependence includes satisfying needs for affection, development, and resources.

**The relation between the caregiving demands of stroke patients and the caregivers' life satisfaction**

The caregiving demands of stroke patients represent the perceptions of the caregivers pertains quantity of time and activities they provide for caregiving role. Caregiving demands are the expectations of caregivers of what they should do for patients (Gasemgitvatana, S., 1993). As indicated in introduction, caregiving activities have been considered difficult as they burden energy, time, and effort, especially, if stroke patients have more emotional and behavior problems, or physical limitations, caregivers will perceive more caregiving demands (Cheewapoonphon, C., 1998: 35-36). Perception of caregiving demands is the focal stimulus enters into the human system and affects the caregivers' behavior.

With respect to roles, caregiving activities disturb other activities related to other roles of caregivers. Caregivers will perceive these responsibilities as a burden (Gasemgitvatana, S., 1993: 11). This burden can range over a variety of psychological or physical impairments that ultimately affect the well-being of caregivers (Montgomery, et al. cited in Hoffmann & Mitchell, 1998).

Studies in relation to caregiving demands and indicated the relationship between caregiving demands and caregivers' life satisfaction are as follows.

George & Gwyther (1986) studied the relationship between caregiver burden and well-being of 510 caregivers of elderly patients with Alzheimer's disease using the Life Satisfaction Index. Findings showed that care burden was negatively correlated with life satisfaction.

Oberst, et al (1989) conducted a study of evaluation of caregiving demands of 47 family caregivers of cancer patients. Study showed that caregivers reported spending the most time in provision of transportation, giving emotional support, and in extra household tasks. The least effort was associated with personal care tasks, assisting with mobility, and carrying out of medical or nursing care. Caregiver load was correlated positively with the length of time on treatment and with patient dependency.

Decker, et al (1989) studied the determinants of well-being in 67 primary caregivers of spinal cord injury persons using the Life Satisfaction Index. Results showed that those caregivers spending more time each day assisting the disabled person and feeling burdened by these responsibilities experienced less life satisfaction. This finding

was consistent with the study of George & Gwyther (1986) that care burden was negatively correlated with life satisfaction.

Hoyert & Seltzer (1992) conducted a study of the factors related to well-being of 605 family caregivers of chronically ill patients. Findings indicated that the relation between caregiving duration and caregiving outcome depends upon the generational relationship between caregiver and patient. The length of caregiving was not related to the well-being of wives, but did appear to be related to caregiving outcomes for mothers and daughters providing care.

Wallhagen (1992) studied the association of caregiving demands and well-being of 60 caregivers of elderly patients using the Life Satisfaction Index. Results showed that caregivers performed a greater number of instrumental activities of daily living than activities of daily living; personal demands were perceived as more difficult than task demands and were associated to a greater extent with caregiver 's life satisfaction ($\beta$ = - .55, $p < .0001$).

Gasemgitvatana (1993) conducted a study using of caregiver role stress in 104 wives of chronically ill patients. Giving emotional support, monitoring of health status, and managing behavior problems were reported as the most time consuming. This study was agreed with the study of Oberst, et al (1989) that giving emotional support was reported as the most time consuming.

Chaoum (1993) studied care burden and general well-being of 111 family caregivers of dependent elderly. Findings reported that the majority of caregivers had moderate distress and the same quality of positive-being. Monitoring/preventing the

dependent elderly from accident was reported as the most difficult and time consuming. This finding concurred with the study of Gasemgitvatana (1993) that caregivers reported spending the most time in monitoring of health status. In addition, care burden was negatively correlated with general well-being ($r = -.40$, $p < .001$). Care burden and duration of education were significant predictors accounting for 21% of variance in general well-being. Moreover, care burden was the best predictor.

O'Brien, et al (1995) conducted a study of the correlates of the caregiving process in multiple sclerosis of 34 husbands and 27 wives of disabled individuals. Findings reported that objective burden and subjective burden were significant predictors accounting for 49% of variance in caregivers' life satisfaction. This finding was agreed with the study of George & Gwyther (1986), and the study of Decker, et al (1989) that care burden was negatively correlated with life satisfaction.

Eamyingpanich (1996) studied caregiving burden and family well-being of 100 mothers of mentally retarded children. Studies exhibited that mothers reported a high mean score on caregiving burden ($\overline{X} = 182.87, SD = 32.33$), and a low mean score on caregiving burden ($\overline{X} = 36.78, SD = 10.03$). Managing behavior problems, monitoring of health status, and additional aids were reported as the most difficult and time consuming. This finding concurred with the study of Gasemgitvatana (1993) that managing behavior problems and monitoring of health status were reported as the most time consuming. Family well-being was not correlated with caregiving burden ($r = -.10$, $p > .05$), but did appear to be negatively correlated with duration of caregiving ($r = -.30$, $p < .01$). Duration

of caregiving and income of family were significant predictors and accounted for 16% of variance in family well-being. Furthermore, duration of caregiving was the best predictor.

Phokudsai (1997) conducted a study of the level of caregiving burden and family well-being in 100 spouses of patients waited for kidney transplantation. Results showed that caregivers had a middle mean score on caregiving burden and family well-being. Caregiving burden was negatively correlated with family well-being ($r = -.45$, $p < .001$). This finding was congruent with the study of Chaoum (1993) that care burden was negatively correlated with family well-being.

Tirapaiwong (1997) explored caregiving burden of family caregivers of stroke patients. Provision of transportation was the most difficult and time consuming, followed by managing behavior problems. This result was congruent with the study of Oberst, et al (1989) that provision of transportation was reported as the most time consuming, and was consistent with the study of Gasemgitvatana (1993) and the study of Eamyingpanich (1996) that caregivers reported spending the most time in managing behavior problems.

Based on the results of 11 studies described, there were 5 studies mentioned about caregiving activities. Two of them revealed that caregivers spending the most time giving emotional support (Oberst, et al., 1989; Gasemgitvatana, S., 1993). In addition, three of them showed that managing behavior problems was reported as the most time consuming. (Gasemgitvatana, S., 1993; Eamyingpanich, R., 1996; Tirapaiwong, P., 1997). Moreover, three of them exhibited that monitoring of health status was reported as the most time consuming (Gasemgitvatana, S., 1993; Chaoum, W., 1993; Eamyingpanich, R., 1996). Furthermore, two of them revealed that caregivers spending the most time in provision of

transportation (Oberst, et al., 1989; Tirapaiwong, P., 1997). However, there was only one study reported that caregivers spending the most time in extra household tasks (Oberst, et al., 1989). There was a study showed that personal care tasks, assisting with mobility, and carrying out of medical or nursing care were reported as the least time consuming (Oberst, et al., 1989).

In relation to the association between caregiving demands and caregivers' life satisfaction, there were 3 studies revealed that care burden was negatively correlated with life satisfaction (George & Gwyther, 1986; Decker, et al., 1989; O'Brien, et al., 1995). In addition, there were 2 studies reported that care burden was negatively correlated with family well-being (Chaoum, W., 1993; Phokudsai, P., 1997). However, there was a study exhibited that care burden was not correlated with family well-being (Eamyingpanich, R., 1996). There was only one study reported that caregiving demands were associated with caregivers' life satisfaction (Wallhagen, 1992)

**The association between the patient-caregiver relationships and the caregivers' life satisfaction**

The relationships between caregiver and patient play an important role in an interdependent family system. Universally, family structure is consistent with the roles of family members; that is, if anyone in a family becomes sick, other members will decide who will responsible for caregiving, while other members stand in relation to both the structures and the processes of providing care (Keith, 1995 cited in Tirapaiwong, P., 1997: 27). Familial relationship exists in the family structure, reflecting the quality of interaction of family members. As mentioned in introduction, a good relationship entails

the understanding, empathy, and compassion of caregivers. Compassion accounts for the motivation of caregivers to willingly care for patients (Sirapo-ngam, Y., 1996). With respect to motivation of providing care, caregiving is motivated not solely by compassion but also by goodwill and a sense of duty (Nydegger, 1983 cited in Walker, et al., 1990a: 54). Furthermore, intimacy in the caregiving was strongly related to motives for providing care (Walker, et al., 1990a: 54). Interpersonal interaction also entails psychological and emotional rewards that enter into the individual's evaluation of the current situation (Mutran & Reitzes, 1984 cited in Walker, et al., 1990b: 147). Relationship quality has important implications for both caregivers and patients. Satisfaction with family relationships contributes to caregivers' psychological well-being (Lopata, 1973 cited in Walker, et al., 1990a: 51; Blieszner & Shifflett, 1990: 57). In addition, relationship quality and change in the relationship were associated with gratification (Motenko, 1989 cited in Kramer, 1993: 373). The patient-caregiver relationships are the contextual stimulus that enters into the human system and influences caregivers' behavior.

Studies in relation to patient-caregiver relationships and showed that caregivers who reported positive effects on their relationships with patients had been evaluating the experience of caregiving more positively than those reporting negatively are as follows.

Walker, et al (1990b) conducted a study of the perception of relationship change and the caregiver satisfaction of 133 daughters of elderly mothers. Findings showed that most mothers and daughters reported no change or positive effects of caregiving on their relationships; daughters who reported positive or no change found caregiving to be more enjoyable, interesting, worthwhile, rewarding, "brings out the best in me", and easy than

daughters reporting negative change ($F = 8.21$, $p < .001$; $F = 6.20$, $p < .01$; $F = 5.53$, $p < .01$; $F = 15.68$, $p < .001$; $F = 7.28$, $p < .001$ and $F = 5.79$, $p < .01$).

Kramer (1993) conducted a study of the spouse relationships of 72 wives caring for husbands with Alzheimer's disease. Studies indicated that poor quality of the prior relationship was associated with quality of life of caregivers and caregiving satisfaction ($r = -.37$, $p < .01$ and $r = -.34$, $p < .01$).

Pohl, et al (1995) studied the patient-caregiver relationships of 98 daughters of elderly mothers. The relationships were measured in both positive and negative aspects. Results showed that attachment between daughter and mother could directly predict caregiving. Attachment and conflict could predict positive beliefs on caregiving ($\beta = .25$, $p < .01$ and $\beta = -.49$, $p < .0001$), but only conflict could predict negative beliefs about caregiving ($\beta = .67$, $p < .0001$).

Tirapaiwong (1997) assessed the patient-caregiver relationships of family caregivers of stroke patients. Findings reported that caregivers had the high mean score on the patient-caregiver relationships. With respect to each item, "sure of the relationship" and "important to me" were reported as the most feeling.

## Summary

A stroke is a cerebrovascular event resulting from the disruption of blood to the brain. Its impact on stroke victims include physical or functional impairments, cognitive impairments, change of behaviors, emotions, and personal feelings or needs. The

consequences of these limitations and abnormalities are the caregiving demands of stroke patients to caregivers. Major activities caregivers provide for stroke patients are: assistance with activities of daily living, carrying out of medical or nursing treatments, emotional support, and additional help, such as managing finances, household tasks, contact with health professionals, etc. These caregiving activities demand for a long-term responses. Therefore, they affect many aspects of life patterns of caregivers, including physical, emotional, and mental health. This study focuses on the psychosocial adaptation of caregivers. The caregivers' life satisfaction and its relation to the caregiving demands of stroke patients and the patient-caregiver relationships were explored. The existing literature of the caregivers' life satisfaction and these two related factors was reviewed within the context of the Roy Adaptation Model.

# CHAPTER III

# METHODOLOGY

## Research Design

This study is a descriptive research focusing on the psychosocial adaptation of caregivers. The caregivers' life satisfaction was studied exploring its relation to the caregiving demands of stroke patients and the patient-caregiver relationships.

## Population and Sampling

The populations in this study were the caregivers of stroke patients who followed up at the out-patient departments of Khonkaen Hospital and Srinakarin Hospital, or admitted into Male Medical Ward and Female Medical Ward of Khonkaen Hospital and Srinakarin Hospital, and Rehibilitation Ward of Srinakarin Hospital. First time admission patients were excluded. Double inclusion criteria for selection of subjects was used in this study. Firstly, the criteria of stroke patients, they met the inclusion criteria of the chronically ill patients as follows (Lambert &Lambert, 1987 cited in Gasemgitvatana, S., 1993: 44).

1. The disability still remains.
2. Need of specific rehabilitation.

3. Long-term need of care, observation, and follow up.

Then, the criteria of caregivers, they met the inclusion criteria of the caregivers of stroke patients as follows.

1. Providing the majority of care to the stroke patients at home
2. Having a close relationship with the stroke patients such as father, mother, wife, husband, son or daughter, sister or brother, and friend or significant other
3. Having been involved in caregiving for at least four weeks

The caregivers who met the double inclusion criteria mentioned were recruited as sample. One hundred subjects were sampled using the formula for sample size of Kerlinger and Padhazer (1973 cited in Vorapongsathorn, T, 1989: 60) as follows.

$$n/k \geq 30$$

Where, n = sample size

k = number of independent variables

## Setting

Settings studied here were Srinakarin Hospital and Khonkaen Hospital. These two hospitals are the central hospitals in the North-east part of Thailand, caring for all patients' needs, such as medicine, surgery, pediatrics, obstetrics and gynecology, etc. In addition, treating and caring the patients from an acute to a recovery phase, and in community setting. Hospital departments studied here were both out-patient departments and in-patient departments. In-patient departments comprise Male Medical Ward and

Female Medical Ward of Khonkaen Hospital and Srinakarin Hospital, and Rehibilitation Ward of Srinakarin Hospital. The service time schedules of the neurology clinic and the medical clinic of those two hospitals are as follows.

**Srinakarin Hospital**

| Clinic | Day | Time |
|---|---|---|
| Medical clinic | Monday & | 9-12 a.m. |
| | Thursday | 9-12 a.m. |
| Neurology clinic | Wednesday | 9-12 a.m. |
| | | and 1- 4 p.m. |

**Khonkaen Hospital**

| Clinic | Day | Time |
|---|---|---|
| Neurology clinic | Wednesday | 1- 4 p.m. |
| Medical clinic | Thursday | 9-12 a.m. |

## Instrumentation

### Instruments

The instruments used in this study are divided into four sections as follows.

1. **Personal data interview** This section includes two parts as follows.

**Part 1** Data of the caregiver

This part involves information about sex, age, marital status, relation to the patient, type of family, number of dependent persons, educational level, average income of family, economic status, occupational status, general health status, disease, illness

during caregiving, duration of care, time spent in caregiving, caregiving assistant, and additional assistant.

**Part 2** Data of the stroke patient

This part comprises information about sex, age, months since diagnosis of stroke, treatment expenses, and method of payment.

**2. Caregiving Demand Scale** This scale is a part of the Caregiving Burden Scale developed by Oberst (1991a) which consists of time spent and the of difficulty associated with tasks. The computation of the Caregiving Burden Scale is made by dividing the square root of the sum score of the multiplication score of time spent and the difficulty associated with tasks. The score ranges from 15 to 75. Gasemgitvatana (1993) modified the scale for measuring the caregiving demands of chronically ill persons perceived by the caregivers; which evaluated only the time spent. The Caregiving Demand Scale is a 15-item self-report questionnaire measuring the quantity of time family members spend in the caregiving activities. Such activities are classified into three groups: direct care, interpersonal care, and instrumental care. Direct care includes carrying out of treatments, care of activities of daily living, and assistance with activities. It comprises items 1, 2, 3, 12, and 13. Interpersonal care involves giving emotional support, monitoring of health status, managing behavior problems, and contact with health care providers. It includes items 4, 5, 11, 14, and 15. Instrumental care includes household tasks, financial management, provision of transportation, and activity planning. It involves items 6-10. A 5-point Likert-type scale ranging from 1 (not at all) to 5 (extremely) was established to assess caregiving demands over the month. The score ranges from 15 to 75.

**Interpretation of scores**

The obtained scores of the Caregiving Demand Scale are categorized into 3 different levels; perceived less time spent, perceived moderate time spent, and perceived a lot of time spent as the following criteria.

| Description of data | range of scores | interpretation |
|---|---|---|
| Total scores | 15.00-35.00 | perceived less time spent |
| | 35.01-55.00 | perceived moderate time spent |
| | 55.01-75.00 | perceived a lot of time spent |
| Each subscale | 5.00-11.66 | perceived less time spent |
| | 11.67-18.32 | perceived moderate time spent |
| | 18.33-25.00 | perceived a lot of time spent |
| Itemized Caregiving | 1.00-2.33 | perceived less time spent |
| Demand Scale | 2.34-3.66 | perceived moderate time spent |
| | 3.67-5.00 | perceived a lot of time spent |

Oberst (1991b) made the construct validity with a sample of 240 caregivers of cancer patients with factors loading at .49 or greater, and accounted for 57% of variance. The alpha internal consistency coefficient of the total items was .88 whereas the alpha coefficients of the direct care, interpersonal care, and instrumental care were .78, .71, and .83.

In Thailand, Gasemgitvatana (1993) translated the scale into Thai version, and modified the scale for measuring the caregiving demands of chronically ill persons perceived by the caregivers; which evaluated only the time spent. The content validity

was verified by four experts of chronic nursing care. Then, internal consistency was examined with a sample of 104 wives caring for chronically ill husbands. The alpha value of the total items was .77 while the alpha values of the direct care, interpersonal care, and instrumental care were .69, .72, and .71.

The content validity of the scale was examined by three experts of chronic nursing care. They approved with the language used, the population group this scale applied for, and made no any changes. Thus, internal consistency was verified with a sample of 20 caregivers accompanied stroke patients to the out-patient department and the Rehabilitation Ward of Srinakarin Hospital. The coefficient alpha was utilized to examine the internal consistency as its following formula (Luecha, Y., et al., 1991: 127).

$$\alpha = n/n\text{-}1[1 - \sum Si^2/St^2]$$

Where, $\alpha$ = coefficient of consistency of the questionnaires

$n$ = total items of the questionnaire

$\sum Si^2$ = summative variation of the scores on each item

$St^2$ = total variation of the scores on total items

The alpha coefficient of the scale was .73. Then, the investigator adjusted some items in order to make more clarification of their meanings. As the scale was examined with 100 subjects, the alpha coefficient was .82.

**2. Intimacy Scale** This scale was developed by Walker and Thompson (1983) for evaluation of the intergenerational relationship of the family members. It is a 20-item self-report questionnaire. The scale includes affectional closeness, understanding, love, sincerity/honesty, satisfaction, help, concern and self-esteem, well-wishing, compromise

and forgiveness, affective solidarity and sense of the certainty of the relationship, and respectful acceptance of the person's ideas and criticisms. A 5-point Likert-type scale ranging from 1 (not at all) to 5 (extremely) was used to assess patient-caregiver relationships over the month. The score ranges from 20 to 100.

In addition, two further open-end items were included in the scale. First item was performed to give the caregivers an opportunity to express other feelings not including in the list, such as impressed, apologetic, and guilty. One another item was included to evaluate the relationship change between the caregiver and the patient.

**Interpretation of scores**

The obtained scores of the Intimacy Scale are further divided into 3 different levels; perceived low level of relationships, perceived moderate level of relationships, and perceived high level of relationships the following criteria.

| Description of data | range of scores | interpretation |
|---|---|---|
| Total scores | 20.00-46.66 | perceived low level of relationships |
| | 46.67-73.32 | perceived moderate level of relationships |
| | 73.33-100.00 | perceived high level of relationships |
| Itemized Intimacy Scale | 1.00-2.33 | perceived low level of relationships |
| | 2.34-3.66 | perceived moderate level of relationships |
| | 3.67-5.00 | perceived high level of relationships |

Walker and Thompson (1983) developed the Intimacy Scale from the Intergenerational Relationship Scale (Walker, 1979), which consists of five components: intimacy or affection, attachment, disclosure, tension, and worry. The scale was piloted on

a sample of 132 pairs of student women and middle-aged mothers, and 107 pairs of middle-aged daughters and elderly mothers. Construct validity was verified with factors loading at least .50. The alpha coefficient was .91. Additionally, Walker, et al. (1990b) examined the concurrent validity by studying the correlates between the Intimacy Scale and the Relationship Quality Scale and the Intimate Relation Scale. Studies revealed that the Intimacy Scale was related to the Relationship Quality Scale and the Intimate Relation Scale ($r = .45$, $p < .01$ and $r = .52$, $p < .05$). In addition, the Relationship Quality Scale also correlated with the Intimate Relation Scale ($r = .58$, $p < .01$).

The investigator translated the scale into Thai version, and modified the scale for measuring the feelings of closeness and contact between caregiver and patient. The content validity of the scale was verified by one expert of psychology, two experts of behavioral science, one expert of chronic nursing care, and one expert of family nursing. Some items were adjusted for smoothness of the language used, and some items were added. As this scale was piloted on a sample of 20 caregivers of stroke patients, the alpha value was .83. Then, some items were readjusted for appropriateness of the language, and the two open-end items were changed in order to be consistent with the caregiving situations. As this scale was verified with 100 subjects, the alpha value was .93.

**3. Caregiver's Life Satisfaction Scale** The scale was constructed by the investigator using the three psychosocial adaptive modes of the Roy Adaptation Model. It is a 24-item self-report questionnaire measuring the positive outcome of responses to the internal feelings of caregivers. These feelings involve satisfaction with self, satisfaction with role, and satisfaction with interdependence. The satisfaction with self includes

physical self and personal self. It involves items 2, 3, 4, 6, 8, 12, 13, and 20. The satisfaction with roles involves primary role, secondary role, and tertiary role. This comprises items 1, 5, 7, 9, 10, 11, 16, and 21. The satisfaction with interdependence includes satisfying needs for affection, development, and resources. It comprises items 14, 15, 17, 18, 19, 22, 23, and 24. A 5-point Likert-type scale ranging from 1 (not at all) to 5 (extremely) for the items with positive meaning and ranging from 1(extremely) to 5(not at all) for the items with negative meaning. The scale was performed to measure caregivers' life satisfaction over the month. The score ranges from 24 to 120.

**Interpretation of scores**

The obtained scores of the Caregiver' s Life Satisfaction Scale are classified into 3 different levels; low level of life satisfaction, moderate level of life satisfaction, and high level of life satisfaction as the following criteria.

| **Description of data** | **range of scores** | **interpretation** |
|---|---|---|
| Total scores | 24.00-56.00 | low level of life satisfaction |
| | 56.01-88.00 | moderate level of life satisfaction |
| | 88.01-120.00 | high level of life satisfaction |
| Each subscale | 8.00-18.66 | low level of life satisfaction |
| | 18.67-29.32 | moderate level of life satisfaction |
| | 29.33-40.00 | high level of life satisfaction |
| Itemized Caregiver's | 1.00-2.33 | low level of life satisfaction |
| Life Satisfaction Scale | 2.34-3.66 | moderate level of life satisfaction |
| | 3.67-5.00 | high level of life satisfaction |

The content validity of the scale was made by three experts of psychology and two experts of chronic nursing care. They agreed with the population group this scale applied for; some items were trimmed for appropriateness of the language used; some items were modified in order to be consistent with the psychosocial modes of the Roy Adaptation Model; and some items were added. As the scale was piloted on a sample of 20 caregivers of stroke patients, the alpha value was .88. Then, some items were adjusted in order to make more clarification of their meanings, and some items were deleted as they were not congruent with the caregiving situations. When the scale was examined with 100 subjects, the alpha value was .89.

## Data Collection

Following Faculty of Graduate Studies and institutional approval, data were collected. Firstly, by submitting the recommendation letter from Dean of Faculty of Graduate Studies to Dean of Faculty of Medicine, Srinakarin Hospital, and Director of Khonkaen Hospital, requesting their co-operation in data collection from March 1, 2000 to April 30, 2000, 8 a.m.– 4 p.m., Monday to Thursday. The description of data collection is as follows.

| Place | Day | Time |
|---|---|---|
| Medical clinic, Srinakarin hospital | Monday | 8-12 a.m. |
| Rehabilitation Ward, Male Medical Ward, and Female Medical Ward, Srinakarin hospital | Tuesday | 8-12 a.m. |

| Place | Day | Time |
|---|---|---|
| Neurology clinic, Srinakarin hospatal | Wednesday | 8-12 a.m. |
| | and | 1- 4 p.m.* |
| Male Medical Ward, Female Medical Ward, Khonkaen Hospital | Thursday | 8-12 a.m. |

* Data were gathered by the investigator at 1- 4 p.m. in Neurology clinic of Srinakarin Hospital for the first month, and in Neurology clinic of Khonkaen Hospital for the second month.

After permission, the investigator contacted the dean and the director of the two hospitals by using the formal letters from the Faculty of Graduate Studies to explain the objectives and procedures of the study and asked for their cooperation. Then information was gathered throughout in the following way.

1. Eligible subjects were selected. Firstly, the patients with a medical diagnosis of stroke or CVA (cerebrovascular accident) were sought from the medical record, and then their caregivers were screened according to the double inclusion criteria previously indicated. The caregivers who met the double inclusion criteria were recruited as sample.

2. In case of the caregivers who did not accompany stroke patients, they would receive a letter of introduction from the investigator, with the information about the objectives of study, the necessity for the study, and the importance of the subject's participation. The consent form was enclosed in the letter, and was sent with the stroke patients to their caregivers with a self-addressed stamped envelope enclosed for the return of the signed consent form and the completed questionnaire.

3. The investigator approached the participants individually and invited voluntary participation. Thus they were informed about the objectives of the study, the necessity for the study, the importance of their participation, and the consent forms.

4. The participants were asked to voluntarily answer the questionnaires per se or be interviewed, except for the personal data, which were totally interview-based. For the participants who chose to answer the questionnaires, they could independently answer and ask questions whereas those who preferred to be interviewed would be interviewed as per the questionnaires. The amount of time spent in information gathering was 15-20 minutes. Each section of the questionnaire was done in a particular order. For the 50 first-half of questionnaire, the order of sections was: the Personal Data, the Caregiving Demand Scale, the Intimacy Scale, and the Caregiver's Life Satisfaction Scale; while for the 50 second-half was Personal Data, the Intimacy Scale, the Caregiving Demand Scale, and the Caregiver's Life Satisfaction Scale.

5. As the participants had finished answering the questionnaires, the completion of the questionnaires were checked. If there were still some items unanswered, the investigator additionally interviewed and filled them up.

4. The investigator expressed her gratitude to the participants and stroke patients; ultimately giving them an opportunity to ask questions and discuss caregiving situations, as well as giving them suggestions.

## Protection of Human Subjects

The human rights of the subjects were respected in this study. Eligible subjects were approached to voluntary participate in the study. The participants were informed about the consent form. Protections of human subjects involved in the consent form are as follows.

1. Assuring the subjects that all information would be kept in confidentiality. Numerical codes were used instead of names.

2. In case of the caregivers who did not desire to participate in this study, they would be informed about routine care the stroke patients would receive, assuring them that it would not affect the medical or nursing treatments the stroke patients would receive from health professionals. Additionally, the prospective subjects who did not prefer to sign the consent form, but completed the questionnaires and returned them to the investigator; this meant that they were willing to participate in the study.

3. The subjects could terminate their cooperation before the analysis of data. In addition, all data were reported as a group data.

## Data Analysis

Data from 100 subjects were analyzed using program SPSS 7.5 for Windows (Statistical Package for Social Science) as follows.

1. Descriptive statistics were utilized for the personal data of the subjects and the stroke patients such as frequency, percent, mean, standard deviation, range and skewness.

2. Computation of mean, standard deviation, and range of the scores of the Caregiving Demand Scale, the Intimacy Scale, and the Caregiver's Life Satisfaction Scale.

3. Pearson's product moment correlation coefficient was analyzed to examine the correlates between the caregiving demands of stroke patients and the caregivers' life satisfaction, and between the patient-caregiver relationships and the caregivers' life satisfaction.

# CHAPTER IV

# RESULTS

## Results

In this chapter, the sample of the study, including the caregivers and the stroke patients, is described. The results of the study in relation to the research questions are presented.

## Description of the Sample

The sample of the study consisted of caregivers who provided the majority of care to stroke patients, had a close relationship with them, and had been involved in caregiving for at least four weeks. The subjects were obtained from Srinakarin Hospital and Khonkaen Hospital, Khonkaen, Thailand. Data collection was from March 1, 2000 to April 30, 2000. One hundred and seven caregivers were approached; one of them did not complete the questionnaire sent by letter; six did not return the questionnaires; among these six caregivers, five were sent by letter and one was hurried to go home. Therefore, 100 subjects were included in this study; seventy six caregivers were interviewed by the investigator, and the remainder completed the questionnaires per se. Eighty seven caregivers were approached at the out-patient departments, and the remainder were

approached in the in-patient departments. Only ten caregivers signed the consent form, while the remainder did not prefer to sign. There were 12 caregivers who did not accompany stroke patients; letters were sent with stroke patients to those caregivers, and 6 letters were returned. Each of caregiver took about 15-20 minutes to complete the questionnaire.

The results of the study will be presented in a particular order as follows:

1. Profile of the caregivers
2. Health status of the caregivers
3. Profile of the stroke patients
4. The score of the caregiving demands of stroke patients
5. The score of the patient-caregiver relationships
6. The score of the caregivers' life satisfaction
7. The correlates between the caregivers' life satisfaction and the variables related to the caregivers' life satisfaction

## Profile of the Caregivers

**Table 1** Profile of the caregivers (n=100)

| data | number / percentage |
|---|---|
| sex | |
| male | 27 |
| female | 73 |
| age(year) | |
| ≤30 | 27 |
| 31-40 | 24 |
| 41-50 | 25 |
| 51-60 | 15 |
| ≥61 | 9 |
| (range=17-75, $\bar{X}$=40.96, SD=13.94) | |
| marrital status | |
| single | 30 |
| married | 69 |
| widowed / divorced / separated | 1 |
| relationship with the patient | |
| spouse | 36 |
| parent | 2 |
| adult children | 51 |
| brother / sister | 3 |
| relative | 6 |
| close friend | 1 |
| house-keeper | 1 |
| type of family | |
| nuclear | 59 |
| extended | 41 |
| dependent person in family(person) | |
| 1 | 91 |
| 2 | 7 |
| 3 | 1 |
| 4 | 1 |
| educational level | |
| primary school | 39 |
| high school | 26 |
| certificate / diploma | 9 |
| bachelor | 26 |

**Table 1** Profile of the caregivers (continue)

| data | number / percentage |
|---|---|
| income of family (baht/month) | |
| < 5,000 | 35 |
| 5,000-10,000 | 25 |
| > 10,000 | 40 |
| (range=500-60,000, $\bar{X}$=13593.89, SD=13093.59) | |
| economic status | |
| stable, can afford everything | 11 |
| have a certain amount of money saved | 17 |
| have a little money saved | 35 |
| unstable, in debt | 32 |
| occupational status | |
| retired | 3 |
| never worked / unemployed | 42 |
| working | 55 |
| duration of care (month) | |
| 1-6 | 40 |
| 7-12 | 20 |
| > 12 | 40 |
| (range=1-240, $\bar{X}$=21.46, SD=32.29) | |
| time spent in caregiving (hour/day) | |
| 1-5 | 21 |
| 6-10 | 43 |
| > 10 | 36 |
| (range=1-24, $\bar{X}$=12.23, SD=8.08) | |
| caregiving assistant | |
| no | 21 |
| yes | 79 |
| indicate assistant (more than one) | |
| parent | 18 |
| spouse | 6 |
| adult children | 23 |
| brother / sister | 19 |
| relative | 21 |
| house-keeper | 1 |

As shown in Table 1, 100 caregivers were included in this study. Seventy three percent of them were female; their ages ranged from 17-75 years with an average age of 40.96 years (SD=13.94). Sixty nine percent of them were married; 51% were adult children. Surprisingly, 2% were a close friend and a house-keeper. Fifty nine percent lived in a nuclear family with 91% had only one dependent person in their families.

In regard to education, 39% of caregivers graduated from primary school. With respect to economic status, 40% of them had an average income of family more than 10,000 bahts/month; 35% reported they had a little money saved. In regard to occupation, 55% of them were in the work force while 42% were not in the work force. Regarding time, 40% of them had duration of care more than 12 months and another 40% had between 1-6 months; 43% of them spent time in caregiving between 6-10 hours/day and 36% spent more than 10 hours/day. Regarding assistance, 79% of them had caregiving assistants; 23% were adult children and 21% were relatives.

**Table 2** Health status of the caregivers (n=100)

| data | number / percentage |
|---|---|
| general health status | |
| strong | 68 |
| rather strong | 24 |
| rather weak | 7 |
| weak | 1 |
| disease | |
| no | 79 |
| yes | 21 |
| indicate type of disease(more than one) | |
| gastric ulcer | 5 |
| hypertension | 4 |
| headache / migraine | 3 |
| heart disease | 3 |
| diabetes | 3 |
| arthritis | 2 |
| allergy | 2 |
| fatigue | 1 |
| hemorrhoid | 1 |
| kidney disease | 1 |
| hypotension | 1 |
| tonsillitis | 1 |
| illness during caregiving | |
| no | 83 |
| yes | 17 |
| indicate illness(more than one) | |
| sleeplessness | 8 |
| decreased eating | 4 |
| back pain | 2 |
| fatigue | 1 |
| joint pain | 1 |
| muscle pain | 1 |
| gastritis | 1 |
| stress | 1 |
| headache | 1 |

As shown in Table 2, regarding health status, 68% of caregivers perceived themselves to be strong, 79% reported no disease; and 83% reported no illness during caregiving. The diseases reported were gastric ulcer (5%), and hypertension (4%). With regard to the illness during caregiving, 83% of them reported no illness; the illnesses reported were sleeplessness (8%), and decreased eating (4%). Contrary to a previous study, only 1% of them reported fatigue, this might be because they did not perceive their existing fatigue.

## Profile of the Stroke Patients

**Table 3** Profile of the stroke patients (n=100)

| data | number / percentage |
|---|---|
| sex | |
| male | 66 |
| female | 34 |
| age(year) | |
| ≤30 | 1 |
| 31-40 | 3 |
| 41-50 | 16 |
| 51-60 | 35 |
| ≥61 | 45 |
| (range=19-80, $\bar{X}$ =59.41, SD=11.42) | |
| months since diagnosis of stroke | |
| 1-6 | 37 |
| 7-12 | 20 |
| > 12 | 43 |
| (range=1-240, $\bar{X}$=23.45, SD=33.84) | |
| treatment expenses (baht / month) | |
| < 2,000 | 62 |
| 2,000-5,000 | 25 |
| > 5000 | 13 |
| (range=0-20,000, $\bar{X}$=2941.37, SD=3333.31) | |
| method of payment | |
| by oneself | 46 |
| security from employment | 44 |
| social welfare | 3 |
| health insurance card | 7 |
| indicate insurance card | |
| disabled card | 2 |
| elderly card | 2 |
| royal card | 1 |
| veteran card | 1 |
| AIA card | 1 |

As shown in Table 3, 66% of stroke patients were male; their ages ranged from 19 to 80 years with an average age of 59.41 years (SD=11.42). Forty three percent of them had a diagnosis of stroke more than 12 months and 37% had between 1-6 months. With respect to treatment expense, 62% of them paid for treatment expense less than 2,000 bahts/month, 46% paid by themselves.

## The Score of the Caregiving Demands of Stroke Patients

**Table 4** Range, mean, standard deviation, and skewness of the score of caregivers on the Caregiving Demand Scale (n =100)

| caregiving demand scale | possible range | actual range | mean | SD | skewness |
|---|---|---|---|---|---|
| direct care | 5-25 | 6-21 | 14.20 | 3.36 | |
| interpersonal care | 5-25 | 8-22 | 15.44 | 3.21 | |
| instrumental care | 5-25 | 8-25 | 15.56 | 3.61 | |
| **Total scale** | **15-75** | **27-62** | **45.20** | **8.42** | **- .27** |

As shown in Table 4, caregivers had an average of 45.2 scores on time spent in caregiving (SD=8.42, skewness = - .27); which means that caregivers perceived the moderate time spent in caregiving. With respect to subscales, it revealed that they perceived the moderate time spent in caregiving by three subscales: direct care, interpersonal care, and instrumental care.

**Table 5** Mean and standard deviation of the score of the caregiving demands of stroke patients on each subscale (n=100)

| description of caregiving demand | mean | SD |
|---|---|---|
| **direct care** | | |
| - personal care | 3.04 | 1.02 |
| - assistance with mobility | 2.90 | 1.15 |
| - assistance with writing and reading | 2.82 | 1.11 |
| - activity provision | 2.74 | .91 |
| - carrying out of medical / nursing care | 2.70 | 1.04 |
| **interpersonal care** | | |
| - emotional support | 3.75 | .89 |
| - contact with health care providers | 3.50 | 1.01 |
| - monitoring health status | 3.45 | 1.03 |
| - managing behavior problems | 2.92 | 1.05 |
| - additional aids | 1.82 | 1.09 |
| **instrumental care** | | |
| - transportation provision | 3.66 | 1.02 |
| - additional household tasks | 3.26 | 1.04 |
| - extra household tasks | 3.17 | 1.16 |
| - managing finances | 3.12 | 1.02 |
| - other tasks | 2.35 | 1.10 |
| **overall caregiving demand** | **3.01** | **1.89** |

As described in Table 5, caregivers had an overall mean of 3.01 scores on time spent in caregiving (SD=1.89); which means that they perceived the moderate time spent in caregiving. With respect to direct care, they reported spending the most time in personal care ($\bar{X}$ = 3.04, SD = 1.02), and assistance with mobility ($\bar{X}$ = 2.90, SD = 1.15). Regarding interpersonal care, they reported spending the most time giving emotional support ($\bar{X}$=3.75, SD= .89), contact with health care providers ($\bar{X}$=3.50, SD=1.01), and monitoring health status ($\bar{X}$ = 3.45, SD = 1.03). In regard to instrumental care, they reported spending the most time in transportation provision ($\bar{X}$=3.66, SD=1.02), and

additional household tasks ($\bar{X}$ = 3.26, SD = 1.04). With respect to each item, they reported spending the most time giving emotional support, transportation provision, and contact with health care providers. The activities they reported spending the least time were additional aids ($\bar{X}$=1.82, SD=1.09), and other tasks ($\bar{X}$=2.35, SD=1.10).

## The Score of the Patient-caregiver Relationships

**Table 6** Range, mean, standard deviation, and skewness of the scores of caregivers on the Intimacy scale (n=100)

| Intimacy scale | possible range | actual range | mean | SD | skewness |
|---|---|---|---|---|---|
| Total scores | 20-100 | 56-100 | 83.17 | 9.63 | - .64 |

As can be seen in Table 7, caregivers had an average of 83.17 scores on perception of relationships (SD = 9.63, skewness = - .64); which means they perceived the high level of relationships between caregiver and patient.

**Table 7** Mean and standard deviation of the score of the patient-caregiver relationships on each item(n=100)

| statement | mean | SD |
|---|---|---|
| - important to caregiver | 4.52 | .54 |
| - concern for each other | 4.41 | .62 |
| - unselfishness in our relationship | 4.38 | .60 |
| - sure of the relationship | 4.37 | .61 |
| - love each other | 4.36 | .63 |
| - enjoy the relationship | 4.30 | .70 |
| - honest with each other | 4.27 | .65 |
| - wish each other happy | 4.25 | .64 |
| - makes each other feel better | 4.24 | .77 |
| - feel like we are unit | 4.22 | .69 |
| - like each other | 4.13 | .75 |
| - forgive each other | 4.10 | .66 |
| - want to spend time together | 4.06 | .79 |
| - understand each other | 4.05 | .76 |
| - shows love | 4.04 | .74 |
| - respect each other | 4.03 | .76 |
| - care about the way caregiver feel | 3.96 | .84 |
| - compromise for each other's opinion | 3.94 | .90 |
| - accept each other | 3.90 | .76 |
| - thinks of caregiver's best interest | 3.64 | .99 |
| **overall patient-caregiver relationship** | **4.16** | **.92** |

As described in Table 7, caregivers had an overall mean of 4.16 scores on perception of relationships (SD= .92); this can be interpreted that caregivers perceived the high level of the relationships between caregiver and patient. With respect to each item, they reported the most feeling on "important to caregiver" ($\bar{X}$=4.52, SD= .54), concern for each other ($\bar{X}$=4.41, SD= .62), unselfishness in our relationship ($\bar{X}$=4.38, SD= .60), sure of the relationship ($\bar{X}$=4.37, SD= .61), and love each other ($\bar{X}$=4.36, SD= .63). The items

reported the least feeling were "thinks of caregiver's best interest" ($\overline{X}$=3.64,SD= .99), accept each other ($\overline{X}$=3.90, SD= .76), compromise for each other's opinion ($\overline{X}$=3.94, SD= .90), and care about the way caregiver feel ($\overline{X}$=3.96, SD= .84).

## The Score of the Caregivers' Life Satisfaction

**Table 8** Range, mean, standard deviation, and skewness of the score of caregivers on the Caregiver's Life Satisfaction Scale(n=100)

| caregivers' life satisfaction | possible range | actual range | mean | SD | skewness |
|---|---|---|---|---|---|
| satisfaction with self | 8-40 | 21-40 | 31.57 | 4.11 | |
| satisfaction with roles | 8-40 | 20-40 | 32.16 | 4.93 | |
| satisfaction with interdependence | 8-40 | 22-40 | 32.03 | 3.89 | |
| **Total scale** | **24-120** | **70-120** | **95.90** | **11.63** | **- .64** |

As described in Table 8, caregivers had an average of 95.90 scores on life satisfaction (SD=11.63, skewness = - .64); which means they had the high level of life satisfaction. In regard to subscales, they represented the high level of life satisfaction by these three subscales: satisfaction with self, satisfaction with roles, and satisfaction with interdependence.

**Table 9** Mean and standard deviation of the score of the caregivers' life satisfaction on each subscale (n=100)

| statement | mean | SD |
|---|---|---|
| **satisfaction with self** | | |
| - think I do my best | 4.25 | .66 |
| - doing meaning and valuable thing | 4.20 | .84 |
| - felt my everyday life is more worthier | 4.04 | .75 |
| - think I am healthy | 4.02 | .74 |
| - happy to care the patient | 3.97 | .81 |
| - caregiver's health is worsened | 3.97 | .97 |
| - feel guilty I could not care at my best | 3.58 | 1.12 |
| - caregiver's life should be happier than now | 3.54 | 1.05 |
| **satisfaction with roles** | | |
| - cannot stand it | 4.23 | .90 |
| - bored with those caregiving tasks | 4.10 | .87 |
| - discouraged everytime I think of the patient | 4.09 | 1.02 |
| - pleased to be in contact with others | 4.06 | .81 |
| - feel lonely to be abandoned with the patient | 4.05 | .99 |
| - furthering caregiving role, it does not bother caregiver | 3.94 | 1.01 |
| - worry I will decreasing do my best interest | 3.87 | .98 |
| - not sure to further this role | 3.82 | 1.13 |
| **satisfaction with interdependence** | | |
| - feel important to the patient | 4.29 | .69 |
| - proud of doing caregiving activities alone | 4.19 | .68 |
| - makes caregiver improve her self | 4.11 | .65 |
| - receive the other member's empathy | 4.10 | .79 |
| - glad to give suggestion to other caregivers | 4.07 | .76 |
| - satisfied with the family members' help | 3.96 | .82 |
| - anger and resentment nobody can help | 3.78 | 1.06 |
| - feel trouble asking for other's assistance | 3.53 | 1.15 |
| **overall life satisfaction** | **4.00** | **1.01** |

As shown in Table 9, with respect to satisfaction with self, caregivers reported the best response to "think I do my best"($\bar{X}$=4.25, SD= .66), and doing meaning and valuable thing ($\bar{X}$=4.20, SD=.84). In regard to satisfaction with roles, they reported the best response to "cannot stand it"($\bar{X}$=4.23, SD= .90), bore with those caregiving tasks ($\bar{X}$=4.10, SD= .87), and discouraged every time I think of the patient ($\bar{X}$=4.09, SD=1.02). With respect to satisfaction with interdependence, they report the best response to "feel important to the patient" ($\bar{X}$=4.29, SD= .69), proud of doing caregiving activities alone ($\bar{X}$=4.19, SD= .68), and makes caregiver improve her self($\bar{X}$=4.11, SD= .65).

With respect to each item, caregivers had an overall mean of 4.00 scores on life satisfaction (SD=1.01); which means that they had the high level of life satisfaction. They reported the most feeling on "feel important to the patient", think I do my, and cannot stand it. The items they reported the least feeling were "feel trouble asking for other's assistance" ($\bar{X}$=3.53, SD=1.15), caregiver's life should be happier than now ($\bar{X}$=3.54, SD=1.05), and feel guilty I could not care at my best ($\bar{X}$=3.58,SD=1.12).

## The Correlates between the Caregivers' Life Satisfaction and the Variables Related to the Caregivers' Life Satisfaction

**Table 10** Pearson's product moment correlation coefficients between the caregivers' life satisfaction and the variables related to caregivers' life satisfaction (n =100)

| variables related to caregivers' life satisfaction | coefficient (r) |
|---|---|
| caregiving demands of stroke patients | .147 $^{ns}$ |
| patient-caregiver relationships | .605$^{**}$ |

$^{ns}$ not significant; $^{**}$ p<.01

As shown in Table 10, the coefficient between the caregivers' life satisfaction and the caregiving demands of stroke patients was .147 (p> .05); which means that caregivers' life satisfaction did not correlate with the caregiving demands of stroke patients. However, the coefficient between the caregivers' life satisfaction and the patient-caregiver relationships was .605 (p< .01); it can be interpreted that the caregivers' life satisfaction was positively correlated with the patient-caregiver relationships.

# CHAPTER V

# DISCUSSION

The findings from the study will be discussed in relation to the research questions, the purposes of the study, and the hypotheses; they were presented under five topics as follows:

1. The caregiving demands of stroke patients
2. The patient-caregiver relationships
3. The caregivers' life satisfaction
4. The correlation between the caregiving demands of stroke patients and the caregivers' life satisfaction
5. The correlation between the patient-caregiver relationships and the caregivers' life satisfaction

**The caregiving demands of stroke patients**

The caregivers perceived the moderate time spent in caregiving. With respect to subscales, they perceived the moderate time spent in caregiving by three subscales as shown in Table 4. One possible explanation is the caregivers' burden; caregivers feel minimally burdened by those caregiving tasks; as can be seen in Table 1 that the majority (91%) had only one dependent person in their families, and 42% of them were not in the work force as the majority (28%) had to take care the patients; so they have enough time to provide care for the patients, and rate they used minimum time with those caregiving activities; as can be seen in Table 1 that the majority (43%) reported they spent time in

caregiving between 6-10 hours/day. In addition, most of them (79%) had caregiving assistants; they can share their caregiving responsibilities and can mediate the caregiving demands of stroke patients.

Regarding direct care, caregivers reported the most time spent in personal care and assistance with mobility. One possible explanation is that the majority of stroke patients always have physical limitations; therefore, they become dependent on help for the most primary activities of daily living including mobility. In regard to interpersonal care, they reported the most time spent giving emotional support, contact with health care providers, and monitoring health status. One possible explanation is that subjective demand can press for more time and energy than objective demand. In addition, caregivers always give more concern on the patient's health status; they afraid of the repetition of the patients' stroke, and feel uncertain with the patients' condition. With respect to instrumental care, they reported spending the most time in instrumental care such as transportation provision and additional household tasks. One possible explanation is that for the majority of caregivers, certain instrumental activities of daily living which were not directly related to the patient's health status could have been performed routinely by the caregiver prior to assuming the caregiving role. These instrumental activities were not new responsibilities, but rather a continuation or expansion of tasks they had always performed (Wallhagen, 1992: 119-120).

Regarding each item, caregivers reported spending the most time giving emotional support, transportation provision, and contact with health care providers. This finding concurred with the study of Oberst, et al (1989), and the study of Gasemgitvatana (1993)

that giving emotional support was reported as the most time consuming. In addition, this study also agreed with the study of Oberst, et al (1989), and the study of Tirapaiwong (1997) that transportation provision was reported as the most time consuming. One possible explanation is that stroke patients who were disabled, could not walk, or do the activities of daily living, found that this affected their personal selves; most of them experienced a sense of loss and depression (Hirunchunha, S., 1998: 13). In addition, most of stroke patients often loss of temper, petulance, emotional, and fussy. Furthermore, transfer stroke patients is considerably difficult and waste time, because of their physical limitations including movement and spending time following up at the out-patient department. Therefore, it was not surprising to find that caregivers spent the most time in giving emotional support and providing transportation.

**The patient-caregiver relationships**

The caregivers perceived the high level of relationships between caregiver and patient as shown in Table 6. This finding was consistent with the study of Tirapaiwong (1997) who found that caregivers had the high mean score on the patient-caregiver relationships. One possible explanation is that the majority (51%) were adult children, and the minority (36%) were spouse who lived in the same family and were close and familiar to the stroke patients; as can be seen in Table 1 that 59% of them lived in a nuclear family with the number of family member between 3-5 persons. These caregivers made their decision to provide care for the stroke patients by a sense of moral obligation (Fraser, 1999, Newman, 1997). When the caregiving role is chosen freely, it may be less emotionally draining than when it is assigned (Given, et al., 1988). Additionally, the sense

of moral obligation always accompanies compassion. Compassion accounts for the motivation of caregivers to willingly care for patients (Sirapo-ngam, Y., 1996). Furthermore, caregivers were motivated by goodwill to provide care for their loved patients and expect for the improvement of their patients' health status. Another possible explanation is that caregivers had social support; as described in Table 1 that 79% of them had caregiving assistants; even though the majority (35%) had poor economic status, 35% of them had low income of family, and 42% of them were not in the work force. With respect to stroke patients, the majority (46%) paid for the treatment expense by themselves; 62% of them paid for treatment expense less than 2,000 bahts/month. Based on the relevant data indicated, caregivers who have a comfortable balance in interdependent relationships feel valued and supported by others, and can express the same for the patients (Roy & Andrews, 1999: 111-112). As a consequence, there can be the positive relationships between caregiver and patient.

In regard to each item, caregivers reported the most feeling on "important to caregiver", concern for each other, unselfishness in our relationship, sure of the relationship, and "love each other". These information showed the close relationships between the caregivers and the stroke patients; they give and accept from the others of value, love, and concern. One possible explanation is that the majority (51%) were adult children, and the minority (36%) were spouse who love, respect, care, and value their loved patients. They sure of their relationships; it is congruent with the evidence from the open-end item of the Intimacy Scale that 46% of caregivers reported no relationship change and 37% reported the improvement of their relationships. This finding concurred

with the study of Walker, et al (1990b), and the study of Tirapaiwong (1997) that the majority of caregivers reported the positive relationships between caregiver and patient. While the items showing the least feeling were "thinks of caregiver's best interest", accept each other, compromise for each other's opinion, and cares about the way caregiver feel. One possible explanation is that caregivers typically value concern for others over concern for themselves (Given & Given, 1991). Especially in the female caregivers, who were 73% of them included in this study; they always concern premier needs of the patients and sometimes may forget to respond to their own needs. To support these ideas, here are some expressive statements of the caregiver described in the open-end item of the Intimacy scale:

> "He always loses his temper, but it is just temporary. I think my father has changed a lot, especially in his mind. All of us need to adjust ourselves. The greatest point is the changed feelings: more affection, feeling easier to forgive, and dedication for him. Our familial relationships are better, I feel we deeply need each other." (daughter)

**The caregivers' life satisfaction**

The caregivers expressed the high level of the life satisfaction as shown in Table 8. This information revealed that caregivers delivered a good adaptation. They showed the positive outcome of responses to their internal feelings and the changing environment. One possible explanation is the caregivers' ages; the younger adult caregivers are considered to be adapted to the changing environment easier than the older caregivers according to their strong health status and their readiness to learn new things. Thus, they

can adapt to their caregiving roles very well. As shown in Table 1 that the majority (51%) were adult children, and most of them (27%) aged less than or equal 30 years; the majority (68%) perceived themselves to be strong; most of them (79%) reported no disease, and 83% reported no illness during caregiving.

With respect to subscales, they reported the high level of life satisfaction by three subscales as shown in Table 8. Regarding to satisfaction with self, they reported the best response to "think I do my best" and "doing meaning and valuable thing". These data showed that caregivers expressed their self-ideals and moral-ethical-spiritual selves. They can ascribe and value their caregiving situations; as some caregivers described in the open-end item of the Intimacy scale that "I feel impressed to care my husband", " I feel proud to care my father", and " I feel happy that I could repay the patient's kindness". This finding was congruent with the study of Wongjunlongsin (1999) that caregivers feel their pleasure from providing care and making the patients comfortable; they feel happy they could repay the patients' kindness. In regard to satisfaction with roles, they reported the best response to their tertiary roles, such as "cannot stand it", bore with those caregiving tasks, and discouraged every time I think of the patient. These data revealed that caregivers can meet their role-associated obligations; or they adapted remarkably well to their new roles as caregivers. One possible explanation is that the majority (73%) were female; most of them (69%) were married; they were expected to responsible for the caregiving role; and they feel familiar with caring other family members. In addition, 42% of caregivers were not in the work force, 79% of them had caregiving assistants, and the majority (91%) had only one dependent person in their families. Therefore, they can

adjust this caregiving role to their life style notably well. As some caregivers described in the open-end item of the Intimacy scale that "I went to work in the morning and returned home at noon in order to provide lunch for my husband", and "During the day, my sister take care of my father; while I take this part from the evening to the bedtime". With respect to satisfaction with interdependence, they reported the best response to "feel important to the patient", proud of doing caregiving activities alone, and makes caregiver improve her self. These data revealed that caregivers responded to the need of affectional and developmental adequacy. They increased self-respect and achieved the maturation in interrelationships. Even though they felt trouble asking for other's assistance as described in Table 9, the majority (46%) reported no relationship change, and the minority (37%) reported the improvement of their relationships as caregivers described in the open-end item of the Intimacy Scale.

With respect to each item, caregivers reported the best response to "feel important to the patient", think I do my best, and cannot stand it. These data indicated that caregivers expressed their feelings of self-satisfaction, gratification, and increased self-respect related to the knowledge that they are successfully undertaking a valued responsibility and coping with a personal challenge (Given & Given, 1991). The items reported the least response were "feel trouble asking for other's assistance", caregiver's life should be happier than now, and feel guilty I could not care with my best. One possible explanation is that caregivers, particularly Thai caregivers typically do not feel it is easy to ask for assistance from others; they willingly provide care for their loved relatives without asking for the other's help; although the majority (79%) reported they

had caregiving assistants. Sometimes, they might feel like quitting their caregiving roles; as some caregivers described in the open-end item of the Intimacy scale that "How can I do? I have to care him. We have nobody who can help us". In addition, the feeling of guilt may be imbedded in their consciences that they could have prevented the patients' stroke.

**The correlation between the caregiving demands of stroke patients and the caregivers' life satisfaction**

The caregiving demands of stroke patients did not correlate with the caregivers' life satisfaction ($r = .15$, $p > .05$). This finding was not congruent with hypothesis 1; and the study of Wallhagen (1992) who found that personal demands were perceived as more difficult than task demands and were associated to a greater extent with caregivers' life satisfaction. One possible explanation is the patients' dependency; the elderly patients in the study of Wallhagen's study were become more dependent and pressed on the most personal demands so that caregivers perceived these demands were difficult and affected their life satisfaction. Whereas in this study, stroke patients became minimally dependent; as can be seen in Table 5 that caregivers perceived the moderate time spent in caregiving. In addition, they perceived the moderate time spent in personal care, assistance with mobility, transportation provision, and carrying out of medical or nursing care.

Another explanation is the caregivers' burden; caregivers feel minimally burdened by those caregiving tasks. As shown in Table 1 that the majority (91%) had only one dependent person in their families, and 42% of them were not in the work force as the majority (28%) had to take care of the patients. Thus, they have enough time to provide care for the patients, and rate they used minimum time with those caregiving activities. As

can be seen in Table 1 that the majority (43%) reported they spent time in caregiving between 6-10 hours/day. In addition, most of them (79%) had caregiving assistants; they can share their caregiving responsibilities, and mediate the caregiving demands of stroke patients. In addition, this finding was not agreed with the study of George & Gwyther (1986), the study of Decker, et al (1989), and the study of O'Brien, et al (1995) who found that care burden was negatively correlated with life satisfaction. One possible explanation is the instruments used in the study; this study used the Caregiving Demand Scale which assessed only the time spent in caregiving while those three studies utilized the care burden scale which measured both the time spent and the difficulty associated with tasks. Some activities may need less time to do, but are being maximally difficult. Therefore, measuring the same tasks but using unlike instruments, the results of the study could be much different.

One possible explanation for the finding is that, it is apparent that these caregivers were adapting remarkably well. They can pass through a certain period of caregiving and adjust to the caregiving demands of stroke patients.; as can be seen in Table 1 that 40% of caregivers had duration of care more than 12 months. In addition, many caregivers can ascribe meaning and value to their situation; as some caregivers described in the open-end item of the Intimacy scale that "I feel impressed to care my husband", " I feel proud to care my father", and " I feel happy that I could repay the patient's kindness". These can mediate the demands of caregiving results from feelings of obligation and resentment (Given & Given, 1991). As a result, it brings a sense of balance to caregivers' overall evaluations of their situation.

**The correlation between the patient-caregiver relationships and the caregivers' life satisfaction**

The patient-caregiver relationships were positively correlated with caregivers' life satisfaction ($r = .61$, $p < .01$) as indicated in hypothesis 2. This finding was consistent with the study of Walker, et al (1990), the study of Kramer (1993), and the study of Pohl, et al (1995) that caregivers who reported positive effects on their relationships with the patients had been evaluating the experience of caregiving more positively than those reporting negatively. One possible explanation is that a good relationship entails the understanding, empathy, and compassion to caregivers. Compassion accounts for the motivation of caregivers to willingly care for patients (Sirapo-ngam, Y., 1996). Interpersonal interaction also entails psychological and emotional rewards that enter into the individual's evaluation of the current situation (Mutran & Reitzes, 1984 cited in Walker, et al., 1990b: 147). Another explanation is that the majority stressed a commitment to the caregiving role based on their prior as well as current relationship with the patient. Caregivers who take on the role with commitment and dedication may have more staying power and experience, and less emotional impact than those who fall into the role through family negotiation (Given, et al., 1988). As a result, a feeling of life satisfaction is represented.

Based on the theoretical framework, the Roy Adaptation Model describes persons as biopsychosocial beings who are required to adapt to environmental stimuli. Environmental stimuli influence adaptation are categorized as focal, contextual, and residual. The caregiving demands of stroke patients act as a focal stimulus that most immediately confronting caregivers while the patient-caregiver relationships act as a

contextual stimulus of the caregiving situation. These two stimuli influence caregivers' life satisfaction.

Adaptation takes place in one biologic and three psychosocial modes. Even though the present study primary focuses on caregivers' psychosocial modes, but the surrounding evidence showed that the biologic mode were interrelated with the other three psychosocial modes. The caregivers adapted to biologic mode very well; as can be seen in Table 1 that the majority (68%) perceived themselves to be strong, reported no illness (83%), and reported no disease (79%). These data were congruent with the positive outcome of adaptation, or caregivers' life satisfaction.

The results of this study revealed that the caregivers' life satisfaction did not correlate with the caregiving demands of stroke patients but did appeared to be positively correlated with the patient-caregiver relationships. These data showed that those two environmental stimuli act as inputs to the caregiver's human system, and pass through two subsystems of control processes, namely the regulator and cognator subsystems. The inputs to these subsystems have a role in forming perceptual and information processing, learning, judgement, and emotion. The caregivers perceived information through the process of these four channels; they considered information, ascribed meaning and value to their life situations. The caregiving demands were mediated through this process from negative feelings and the patient-caregiver relationships motivated positive evaluations of the situation. As a consequence, the sense of balance to caregivers' overall evaluations of their situation, represents in caregivers' life satisfaction.

# CHAPTER VI

# CONCLUSION

## Summary of the Study

This study aims to a) assess the caregiving demands of stroke patients, the patient-caregiver relationships, and the caregivers' life satisfaction, and b) ascertain the relationship between the caregiving demands of stroke and the caregivers' life satisfaction, and c) ascertain the relationship between the patient-caregiver relationships and the caregivers' life satisfaction. Data were obtained from 100 caregivers who provided the majority of care to the stroke patients, had a close relationships with them, and had been involved in caregiving for at least four weeks. The stroke patients were chronically ill persons who followed up at the out-patient departments or admitted into the in-patient departments of Khonkaen Hospital and Srinakarin Hospital. First time admission patients were excluded. Data collection was from March 1, 2000 to April 30, 2000.

Findings revealed that caregivers were predominantly female (73%); their ages ranged from 17 to 75 years with an average age of 40.96 years (SD=13.94; most of them (69%) were married; the majority (51%) were the patient' s adult children, and the majority (55%) were in the work force. Most of them (68%) perceived themselves to be strong; the diseases reported were gastric ulcer (5%), and hypertension (4%); and the

illnesses reported were sleeplessness (8%), and decreased eating (4%). Forty percent of them had duration of care more than 12 months, and another 40% had between 1-6 months. The majority (43%) spent time in caregiving between 6-10 hours/day, and the minority (36%) spent more than 10 hours/day.

Stroke patients were predominantly male (66%); their ages ranged from 19 to 80 years with an average age of 59.41 (SD=11.42). The majority (43%) had a diagnosis of stroke more than 12 month. Most of them (62%) paid for treatment expenses less than 2,000 bahts/month; the majority (46%) paid for treatment expenses by themselves.

Data were obtained from interview questionnaires: the Personal Data, the Caregiving Demand Scale, the Intimacy Scale, and the Caregiver's Life Satisfaction Scale.

Data from 100 caregivers were analyzed using the SPSS 7.5 for Windows program; descriptive statistics and Pearson's product moment correlation coefficient were utilized. Studies showed that the caregivers perceived the moderate time spent in caregiving, perceived the high level of relationships between caregiver and patient, and had the high level of life satisfaction. The caregivers' life satisfaction did not correlate with the caregiving demands of stroke patients ($r = .15$, $p > .05$), but did appear to be positively correlated with the patient-caregiver relationships ($r = .61$, $p < .01$).

## Implications and Recommendations

### Implication and application of research findings

The findings from this study provide considerations for nursing practice as follows.

1. Caring for the stroke patients who are chronically ill persons needs the continuation of care, and the cooperation from caregivers who also need specific care in order to promote their life satisfaction. Nurses should give importance to the caregivers, key persons who can provide an effective care for the patients. Services should be geared to caregiver as well as patient needs such as, forming a self help group, or establishing a counseling clinic for caregivers of chronically ill persons.

2. As the patient-caregiver relationships have an impact on the caregivers' life satisfaction, nurses should establish a relationship between caregiver and patient. Nursing strategy such as counseling techniques may need to assist nurses to determine needs and internal feelings of the caregivers and the patients. Then, harmonize their needs and feelings, this can be represented in the positive relationships between caregiver and patient.

3. Using the Roy Adaptation Model in nursing practice with caregivers of chronically ill persons may help nurses identify specific responses of caregivers to a complex caregiving situation. Nurses working with caregivers of chronically ill persons can evaluate the biologic and psychosocial responses of caregivers and determine whether their biologic and psychosocial health is compromised and needs intervention.

**Implication for further studies**

The finding from the study provide specific information of the caregiving demands of stroke patients, the patient-caregiver relationships, and the caregivers' life satisfaction; which is useful for further research to conduct specific nursing interventions for the caregivers of stroke patients. The recommendations of the study based on the findings and limitation of this study are as follows.

1. Conduct intervention studies with the caregivers of stroke patients using the findings from this study as baseline information.

2. Study other factors which influence and predict the caregivers' life satisfaction such as duration of care, time spent in caregiving, patient dependency, etc.

3. Replicate the study with other groups of caregivers of chronically ill persons such as caregivers of paralytic patients, caregivers of patients with Parkinson 's disease, caregivers of patients with Alzheimer 's disease etc.

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# APPENDIX A

# LIST OF EXPERTS

# APPENDIX A

## List of Experts

The experts who had validated the Caregiving Demand Scale, the Intimacy Scale, and the Caregiver 's Life Satisfaction Scale are as follows.

**Caregiving Demand Scale**

1. Farida Ibrahim, M.S.
   Associate Professor
   Department of Medical Nursing, Faculty of Nursing, Mahidol University
2. Yupapin Sirapo-ngam, D.S.N.
   Assistant Professor
   Department of Nursing, Faculty of Medicine Ramathibodi Hospital
3. Chongjit Saneha,D.N.S.
   Lecturer
   Department of Medical Nursing, Faculty of Nursing, Mahidol University

**Intimacy Scale**

1. Chalempol Tansakul,Dr.P.H.

   Assistant Professor

   Department of Health Education and Behavioral Science,

   Faculty of Public Health, Mahidol University

2. Roongrote Poomriew,Ph.D.

   Associate Professor

   Department of Health Education and Behavioral Science,

   Faculty of Public Health, Mahidol University

3. Atirat Wattanapailin,Ed.D.

   Lecturer

   Department of Psychaitric Mental Health Nursing,

   Faculty of Nursing, Mahidol University

4. Chongjit Saneha,D.N.S.

   Lecturer

   Department of Medical Nursing, Faculty of Nursing, Mahidol University

5. Yupin Chandaragga,M.Ed.

   Assistant Professor

   Department of Obstetric and Gynaecologic Nursing,

   Faculty of Nursing, Mahidol University

**Caregiver 's Life Satisfaction Scale**

1. Pensri Rabieb,M.S.

   Associate Professor

   Department of Surgical Nursing, Faculty of Nursing, Mahidol University

2. Farida Ibrahim,M.S.

   Associate Professor

   Department of Medical Nursing, Faculty of Nursing, Mahidol University

3. Chomchuen Somprasert,Ph.D.

   Assistant Professor

   Department of Psychaitric Mental Health Nursing,

   Faculty of Nursing, Mahidol University

4. Chuchuen Cheewapoonphon,D.N.S.

   Assistant Professor

   Department of Medical Nursing, Faculty of Nursing, Mahidol University

5. Tipawan Photitaen,M.N.S.

   Department of Fundamental Nursing,

   Faculty of Nursing, Khonkaen University

# APPENDIX B

# CONSENT FORM

# APPENDIX B

## Consent Form

### Explanation for the Participant

Dear Caregiver:

I'm Miss Thitaya Thipsamniag. I'm studying a Master's degree at the Faculty of Nursing, Mahidol University. I'm conducting a research focusing on the caregivers' life satisfaction and its relation to the caregiving demands of stroke patients and the patient-caregiver relationships. The necessity for the study is that the present caregiving situation has a large impact on the well-being of caregivers. Your information will be of great value to the nurses to plan to help stroke patients and their caregivers.

If you decide to participate in this study, I would like you to co-operate in data collection for about 15-20 minutes You can voluntarily choose to answer the questionnaire by yourself or be interviewed. If you prefer to answer it per se, you can ask me questions whenever you want. You can be assured that your information will be kept in confidentiality. Your information will be reported as a group data and I will use numerical code instead of your name.

Please keep in mind that you volunteer to participate in this study. I assure you that, if you do not prefer to participate, it will not affect any medical or nursing treatment a stroke patient would normally receive from health professionals. One more important

thing, if you decide to terminate your collaboration later, please be assured that you can do it before the analysis of data.

If you have some questions relating to this study, please let me know, or you can ask me later at my office: Department of Fundamental Nursing, Faculty of Nursing, Khonkaen University. Telephone number (043) 237606 or my apartment 's telephone number (043) 347389.

Thank you for your kind cooperation.

Sincerely yours,

Thitaya Thipsamniag

# Consent Form for the Study

I have read and heard the explanations from Miss Thitaya Thipsamniag about the objectives, necessity, and importance of the study, including what I should do to participate in this study. I can terminate my co-operation before the analysis of data.

I have read and heard the explanations described above. I fully understand them and wish to participate in the study.

Signature.....

(.....)

Date/Month/Year...../...../.....

# APPENDIX C

# INSTRUMENTS

number.....

# APPENDIX C

## Instruments

## Personal Data

**Part 1** Data of the Family Caregiver

1. sex ( ) male ( ) female
2. age.....years
3. marital status

   ( ) single ( ) married ( ) widowed/divorced/separated
4. relationship with the patient. I am the .....of the patient
5. type of family

   ( ) nuclear family, family members.....persons,

   number of dependent person.....persons, indicate.....

   ( ) extended family, family members.....persons,

   number of dependent person.....persons, indicate.....
6. educational level.....
7. average income of family.....baht/month

8. economic status

( ) stable, can afford everything

( ) have a certain amount of money saved

( ) have a little money saved

( ) unstable, in debt

9. occupational status

( ) working, indicate occupation.....

( ) retired

( ) never worked or unemployed, indicate reason.....

10. general health status

( ) strong

( ) rather strong

( ) rather weak

( ) weak

11. disease ( ) no ( ) yes, indicate.....

12. illness during caregiving ( ) no ( ) yes, indicate.....

13. duration of care.....months

14. time spent in caregiving.....hours/day

15. caregiving assistant ( ) no ( ) yes, indicate.....

16. additional assistant, such as financial or emotional support

( ) no ( ) yes, indicate.....

**Part 2** Data of the Stroke Patient

1. sex ( ) male ( ) female
2. age.....years
3. months since diagnosis of stroke.....months
4. treatment expenses.....baht/month
5. method of payment
   ( ) by oneself
   ( ) security for employment
   ( ) social welfare
   ( ) health insurance card / social insurance card
   other card indicate.....

# Caregiving Demand Scale

**Note** These following statements refer to the tasks you perform for the patient. Each task may need varying amounts of time. Please carefully read each statement, then circle the number that accurately describes the amount of time you spend in carrying out each activity over the month.

| statement | The amount of time spent | | | | |
|---|---|---|---|---|---|
| | not at all | little | moderately | very much | extremely |
| 1. carrying out of medical or nursing care, such as suction, wound dressing, tube feeding, rehabilitation. etc. | 1 | 2 | 3 | 4 | 5 |
| 2. personal care, such as eating, bathing, dressing, etc. | 1 | 2 | 3 | 4 | 5 |
| 3. assistance with mobility | 1 | 2 | 3 | 4 | 5 |
| 14.additional aids, such as religious ceremony, black magic, and asking for help from the foundation or welfare. | 1 | 2 | 3 | 4 | 5 |
| 15.contact with health care providers | 1 | 2 | 3 | 4 | 5 |

# The Intimacy Scale

**Part 1** These following statements refer to those situations or feelings encountered between you and the patient since you have undertaken the caregiving role. Please carefully read each statement, then consider have you encountered those situations over the month or felt like that? And to what extent? Circle the number that precisely marks your feelings.

| statement | Level of feeling | | | | |
|---|---|---|---|---|---|
| | not at all | little | moderately | very much | extremely |
| 1. We want to spend time together. | 1 | 2 | 3 | 4 | 5 |
| 2. She shows that she loves me. | 1 | 2 | 3 | 4 | 5 |
| 3. We are honest with each other. | 1 | 2 | 3 | 4 | 5 |
| 4. We can accept each other's criticism of our faults | 1 | 2 | 3 | 4 | 5 |
| 19. We forgive each other's unintentional faults. | 1 | 2 | 3 | 4 | 5 |
| 20. I am sure of this relationship. | 1 | 2 | 3 | 4 | 5 |

**Part 2** Please answer the following questions on your feeling accurately.

1. Since you have undertaken the caregiving role, are there any situations that make you feel impressed, apologetic, or guilty? And how?

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2. Undertaking of the caregiving role, how did the relationship change between you and the patient?

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# Caregiver's Life Satisfaction Scale

**Note** These following statements refer to those situations or feelings that you may have encountered since you have undertaken the caregiving role. Please carefully read each statement, then consider have you encountered those situations over the month or felt like that? And to what extent? Circle the number that precisely matches your feelings.

| statement | Level of feeling | | | | |
|---|---|---|---|---|---|
| | not at all | little | moderately | Very much | extremely |
| 1. Even though I have to further my caregiving role, it does not bother me. | 1 | 2 | 3 | 4 | 5 |
| 2. I think I am healthy. | 1 | 2 | 3 | 4 | 5 |
| 3. I feel guilty that I could not care for the patient at my best. | 5 | 4 | 3 | 2 | 1 |
| 4. Caregiving makes feel my everyday life is worthier. | 1 | 2 | 3 | 4 | 5 |
| 24. Caregiving makes me feel that I have improved myself. | 1 | 2 | 3 | 4 | 5 |

# BIOGRAPHY

| | |
|---|---|
| **NAME** | Miss Thitaya Thipsamniag |
| **DATE OF BIRTH** | 9 April 1968 |
| **PLACE OF BIRTH** | Buriram, Thailand |
| **INSTITUTIONS ATTENDED** | Khonkaen University, 1986-1990<br>Bachelor of Nursing Science<br>Mahidol University, 1998-2000<br>Master of Nursing Science (Adult Nursing) |
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