

School of Nursing

**Family-Oriented Self-Care: An Ethnographic Study of Stroke
Patients in Thailand**

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I certify that the substance of this thesis has not been submitted previously, in whole or in part, in respect of any other academic award.

I certify that any help received in preparing this thesis, and all sources used, have been acknowledged in this thesis.

(Urai Hatthakit)

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ABSTRACT

The aim of this ethnographic study was to explore and describe the lay care (self-care) phenomenon in Thai culture. Spradley's (1979) ethnographic method was utilised to investigate the meaning of lay care, the lived experiences of 10 individuals who had suffered a stroke and their family caregivers in caring for the sick person at home.

The meanings and perceptions of self-care from the individuals' and their families' perspectives, were explored, including the practices and cultural issues relating to care at home. The data collection was undertaken over a 10 month period in Songkla Province, southern Thailand. The major sources of data were the transcripts of semi-structured informal interviews, focus group discussions, field notes of participant observations and interviews with other individuals who were knowledgeable of health services and cultural issues relating to care and treatment in the community.

Data analysis revealed a number of themes related to family relationships, and home and community care. These themes included the lived experience at both home and healing centres, experiences with change and loss after the stroke and coping with these, perceptions of care-receiving and caregiving, scope of the family's responsibilities in the caregiving role, caregiving burden, factors influencing the quality of care and the recipient's satisfaction with care. Other themes related to support and health services: Western and traditional medicine, social networks and religion. These themes were discussed from three perspectives: the individual, the family and community resources.

The results of the study support the concept of interdependence of family members, and to a lesser extent their wider social network, in health and illness. Consequently the model of care developed from this study focuses on the family, with the family as a whole contributing to the well-being of its members through both the promotion of family members' health and the restoration of the health of the family with a sick member(s). Implications of this model of care were identified for nursing practice, education and research.

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CHAPTER 1: INTRODUCTION TO THE STUDY

1. Introduction

The meaning of 'self-care' in Western culture is clearly focused on individuals' responsibility for their own health (Orem, 1985; Dean, 1989). Orem's Self-Care Theory, which is the most popular theory used in nursing in Western countries, is based on the assumption that people have an innate ability, right, and responsibility to care for themselves; that maturation is accompanied by increasing self-reliance, a desire to be self-directing and encouraging of others to do so; and finally that people are separate entities and distinct from their environment (Orem, 1980; Meleis, 1991). The ultimate goal of nursing care based on these assumptions, is to encourage people to be independent, self-reliant and self-directing in making decisions related to care (Orem, 1991). Nurses provide care only when an individual lacks the ability or is unable to perform self-care activities.

There is no doubt that Orem's Self-Care Theory is successfully used in many nursing practice settings in Western societies. Examples include the use of the theory in caring for chronically ill patients, especially diabetic patients (Fitzgerald, 1980; Frey & Denyes, 1989; Saucier & Clark, 1993); patients requiring acute care such as postoperative head and neck patients (Dropkin, 1981); and terminal stage patients in hospice institutions (Walborn, 1980; Murphy, 1981).

However there have been numerous criticisms of the use of Orem's theory based on the Western concept of self-care, in countries that have different cultural values and beliefs, contexts, and health care systems. In many non-Western societies where people are not individualistically oriented, self-care is clearly not limited to individuals providing their own care. Rather it includes care contributed by others such as the family network and community resources (Chamorro, 1985; Leininger, 1992). Moreover, although Orem includes the socio-cultural aspects of her theory as a basic conditioning factor, the theory is confined mainly to Western professional medical practices based on a biomedical model of health care, and fails to incorporate traditional or folk health care practices (Meleis, 1991; Roberson, 1996).

Despite some limitations of Orem's theory, currently research indicates that this Western concept of self-care is increasingly being applied in non-Western

countries. However there are only a few cross-cultural studies of self-care reported in the literature. Although the results of a study by Morales-Mann and Jiang (1993) demonstrated that Orem's theory had a degree of congruence with Chinese nursing, the authors noted that this examination of compatibility was limited to the North American key concepts of nursing practice (person, environment, health, and nursing), which might not be appropriate to Chinese culture and the development of nursing in China. The authors proposed that the Chinese might need to develop their own nursing theory to direct Chinese nursing education, practice and research.

In contrast to Morales-Mann and Jiang's study (1993), studies by several researchers in other countries, for instance Papua New Guinea and South Africa, have raised some concerns about the incongruity of self-care, defined as it is in terms of the individual, with cultural values. These cultures emphasise other-care values of interdependence, interconnectedness and interrelatedness, and de-emphasise individualism and egocentrism (Leininger, 1992). Likewise, in Japan Minami (cited in *Nursing from a Multicultural Perspective*, 1995) suggested that "Western nursing curricula introduced into Japan has (sic) never had its (sic) validity tested in the field" (p. 2), and these curricula have resulted in uncaring practices amongst Japanese nurses.

In Thailand in the last 10 years, there have been a number of studies covering a wide range of applications of Orem's self-care concept where the focus is on an individual's ability to manage their own care and the nurse's role in facilitating that care (Nuaklong, 1991; Panawatanakul, 1991; Vithayachockitikhun, 1991; Keeratiyutawong, 1994). However, there have been no empirical studies about the phenomenon of self-care, the actual practices of self-care and the involvement in care by family members who are shaped by their cultural values and belief systems, and their lifestyle. The lack of understanding of family structure, family functioning and relationship between family members, may lead to the use of inappropriate strategies to facilitate self-care. For example, who should be the targeted 'self-care agent' in the family unit - the individual or family members, or both - and in what circumstances? If family members play a significant role in the care of a sick member, who specifically in the family is responsible for, or involved in the care?

This study does not intend to test, through the use of quantitative methods, the appropriateness or compatibility of the Western self-care concept in a non-Western

country, specifically Thailand. Rather, it aims at gaining an understanding of the actual self-care practices of Thai people by systematically exploring the reality of care in the Thai cultural context. Then findings of the study will be compared to existing Western literature relating to self-care to gain an awareness of the application of Western self-care theory in other culturally diverse societies. Although commonalities of self-care may be identified across cultures, we cannot simply adopt a theory merely on the basis of these commonalities while neglecting some of the unique features of our own country's culture and society. Leininger (1985) emphasises that the identification of these differences and similarities is crucial for guiding decisions about strategies to facilitate self-care. In addition, understanding of the self-care phenomenon in this cultural context may suggest modifications in other nursing theories in order to make them more appropriate for use in health care delivery in Thailand.

Stroke patients were chosen as the target population for the study, as representatives of chronically ill and disabled people who seem to have been ignored by the Thai health care system, which is more geared to curing acute disease (Jungsatiensap, 1992). In many developing countries such as Thailand where the number of hospital beds is limited and there are not enough to meet the country's needs, chronically ill people whose condition is considered to be stable are discharged to recover at home. Frequently, patients are sent home with a feeding tube, a tracheostomy tube or even bed sores which require skilled care. These patients are left to deal with their health problems by themselves in the community where simple health services such as medical transportation, home health care or respite care for caregivers, are non-existent. The current focus of the health care system is on developing expensive technology to solve or deal with very delicate and complex acute health problems, perhaps because it is more challenging to clinicians and health experts, rather than working with chronic illnesses that need services involving only low levels of technology (Wentz, 1995). With limited or no Western medical rehabilitation services in the community, patients with chronic health problems or disabilities turn to other sources of assistance in the community that are readily available, accessible and often cheaper.

2. Background of the Study

Self-care has appeared as an important element of health care in Thailand over the last 25 years. In a 1970 survey, self treatment, which is a component of self-care, was reported to be a major source of health care (Thailand Ministry of Public Health, 1990). In this context, self treatment is defined as a decision by individuals to treat a perceived symptom themselves rather than to seek professional care. However, health data show that this practice is declining. Between 1979 and 1985, self treatment decreased from approximately 42.3% to 28.6%, while the utilisation of professional health services (health centres, government hospitals, private hospitals and clinics) increased from 47.2% to 70% (Thailand Ministry of Public Health, 1990). The decrease in self treatment is probably partly a result of the earlier campaigns of the Fourth Five-Year Health Development Plan (1977-1981) that encouraged people to use professional health services. This plan was aimed at making basic health services available, accessible and acceptable to the people and tackling the problems associated with health services provided by non-professional health providers, especially in medical care (Thailand Ministry of Public Health, 1990).

In the last decade, it has become evident however that the attempts by the government to encourage people to restrict themselves to Western health services have not solved the health problems. This is because the services available did not meet the demands in either quantity and quality, especially in the rural areas. Today, people still rely on the family and community resources for the major portion of health care. Treatments given by lay people, healers, spiritual consultants and monks have been contributing to health care long before the commencement of health services by Western missionaries in the reign of King Rama the Third, 1828. People, especially those in the rural areas, still primarily use traditional medicine, and their own methods of care and treatment when they are ill. This may be because traditional medicine or alternative treatments are easier to access, less expensive, less frightening and more congruent with their beliefs of causality of the illness and way in which treatments work. However, acceptance of this component of the health services by the government and those oriented to Western medicine is very low as it is seen as inconsistent with scientific knowledge.

Only recently has the government realised that Western medicine relies heavily on foreign technology, imported medicine and medical supplies. This reliance is creating major problems in the current economic crisis. In addition, people, especially in the countryside, have suffered from misuse of these Western medications, for example analgesics and drugs incorporating steroids in single (Yaa-Song) or multiple doses (Yaa-Chud) sold illegally by non-professionals (Thailand Ministry of Public Health, 1994b). Further, it has been estimated that 70-80% of the population experiencing illness have used traditional medicine as an alternative to government health services (Thailand Ministry of Public Health, 1994b). These situations indicate that the Thai health care system cannot rely solely on Western medicine.

The Seventh National Economic and Social Development Plan (1992-1996) stated clearly that the government would continue to develop Western public health services as well as traditional health care services. The emphasis in Western health services is on the allocation of health resources in terms of personnel, medical equipment and supplies, in line with quality and efficiency improvements at the various levels of the system, particularly health centres and community hospitals. Along with the development of Western health services, traditional health care treatments, especially herbal medicine, are included in the plan in order to increase health services in rural areas (Thailand Ministry of Public Health, 1994b).

However, self treatment is only one of a number of components of self-care including health promotion, health maintenance, disease prevention, and disease detection. More importantly, although there is a decline reported in self treatment, there is an increasing number of people with chronic illness in the country (Intarasombat, 1997). Therefore, self-care is likely to become increasingly important, particularly given the lack of funds for health care services and the escalating demands placed on these services by people with diseases such as AIDS. The financial crisis in Thailand and other Asian countries in 1997 is exacerbating the shortage in health funding and the effects on the country's health services are acute.

Additionally, although the current number of newly graduated nurses has achieved the government's target, at the community level there are still enormous demands for nurses as well as doctors, dentists and pharmacists due to the inappropriate distribution of health personnel. The majority of nurses work in

hospitals in Bangkok or urban areas (Thailand Ministry of Public Health, 1994a). Health services at the community level are staffed by technical nurses or junior sanitarians who have a limited ability to provide care and their responsibilities are focused on two main areas: disease prevention and health promotion. This means there is a huge need for health services for chronically ill patients in the community, who require treatment and rehabilitation services. These developments make it important to explore the self-care concept in relation to chronically ill patients in Thailand. People may see their roles as limited in self treatment, but they will need to assume greater responsibility for their own care (Levin, 1981).

International trends also indicate that there has been a significant paradigm shift in the area of care over the past few decades. The focus of care has moved from viewing patients as passive recipients of care from professional care providers, to an active participant in their own care, predominantly by individuals and their family members (Bushy, 1992). Since the mid-1970s the self-care concept has been included in the mainstream American health care system (DeFrieze, Woomert, Guild, Steckler & Konrad, 1989) as it was realised that further improvement in the national health status would be unlikely to come from advances in technological and scientific medicine. The focus was shifted to the individual changing lifestyle patterns that represent the most important risk factors for the leading forms of disease, disability and premature death (Knowles, 1977).

Self-care has become a universal term representing the practices an individual uses on his/her own behalf in health promotion, disease prevention, disease detection and treatment (Bushy, 1992). However, the degree of self and family involvement in care varies culturally, based on social values and beliefs. In the Western nuclear family, self-care is clearly defined as those activities performed and initiated by the individual. In non-Western societies, on the other hand, especially those characterised as being based on the extended family, self-care may include some involvement by their family and social network. One of the purposes of this study is to attempt to identify to what extent, and under what circumstances, self-care is performed by the individual, and/or family members, or the social network in the Thai community.

3. Purpose and Significance of the Study

The main purpose of the study is to explore the self-care phenomenon of stroke patients in the Thai context without applying any existing conceptual framework of self-care which may limit the understanding of the actuality. The experiences of Thai stroke patients and their families were explored and described from their own perspective, as were the individuals' experiences following the stroke and the experiences of the family members in caregiving. The findings from this study were then used to develop a model of self-care in the Thai culture.

Woods (1989) noted that a pluralistic view of health and self-care can provide a broader understanding of how humans care for themselves and with what consequences. It is expected that this study will demonstrate the actuality of self-care, highlight its unique characteristics and its importance in Thai society. Understanding the concept of self-care as defined in broad terms by Thais and the phenomena of self-care practices in the Thai context is crucial if self-care is to be successfully incorporated into the country's health care services and policies. The insights gained are also expected to be useful in teaching people not only with stroke but with other chronic illnesses about self-care strategies and strengthening their families' participation in that care. Finally, a better understanding of self-care in the family context may draw attention to the need for services to support families additional to these that are already provided outside the professional sector. These informal health services in the community should be recognised, understood and valued.

4. Objectives of the Study

The following objectives were developed for the study:

1. To describe the nature and meaning of 'self-care' from the point of view of patients and their families.
2. To describe the actual practices of self-care and the participation of family carers in providing care in home settings.
3. To identify and explore those factors that enhance or inhibit patients' self-care behaviours and their families' participation in providing care.
4. To relate the study findings to the documented Western concept of self-care.
5. To develop a model of self-care within the Thai cultural context.

5. Structure of the Thesis

This thesis is organised into nine chapters. The first chapter identifies the rationale for and background to the study. The use of self-care in Thailand and its development in nursing education and the country's health policy framework since 1970 is reviewed.

Chapter Two presents a review of the literature pertaining to self-care. Different perspectives of the concept of self-care are presented, including self-care theory, and Orem's self-care theory in particular. Factors influencing the practice of self-care and the concept of rehabilitation are identified.

Chapter Three introduces the reader to Songkla Province where this study was conducted. Information about the people, the economy, the religion and the ways of life are described. This chapter also introduces the country's health care and social welfare systems as well as the health services available in Songkla Province.

Chapter Four presents the research design based on the ethnographic method. It describes sampling procedures, data collection, ethical considerations involved in the data collection, data analysis and issues of rigor.

Chapters Five to Seven of the thesis present the descriptive findings of the study. These are described in terms of lived experiences from the perspective of individuals (Chapter Five), and of family caregivers (Chapter Six). The contribution to care by the individual and their family is also investigated, including the motivation behind those practices. The issues arising from the coping strategies of the sick individual and the impact of family caregiving are addressed. Chapter Seven details problems in accessing community resources and discusses how these resources influence self-care practices. In these chapters, many verbatim conversations with the participants have been included to allow them to tell their stories and these are presented in double quotation marks (".....") or indented in plain text. Quotes from journals and books are also presented in the same form. The names of places and people have been changed in order to protect their identity.

Chapter Eight provides a discussion of the findings. In order to help understand the self-care phenomenon in Thai culture, contemporary literature from both Western countries and Thailand is compared and contrasted with these findings. Recommendations on community health services for chronically ill and disabled

persons in rural areas are also included. Finally the common and significant characteristics of self-care, including influencing factors identified by the study are brought together in a model and presented in Chapter Nine. The implications of this model for nursing practice, education and research in Thailand are also discussed in this chapter.

CHAPTER 2: LITERATURE REVIEW

1. Introduction

The major themes to be discussed in this chapter are the factors influencing care of stroke patients and the Western concept of self-care. Orem's self-care theories (the most popular theories used in Western nursing), the use of the theories and criticisms of them are reviewed in order to illustrate the theories' strengths and weaknesses. To enhance the understanding of self-care and care at home, studies relating to self-care, post-discharge care of stroke and other chronically ill patients, including factors influencing the practice of self-care, are also reviewed.

Many aspects of self-care have been studied extensively, especially in Western countries, including perceptions of self-care (Whetstone, 1987; Whetstone & Hansson, 1989); self-care response among various groups of people both in well and ill individuals, for example older adults (Haug, Wykle, & Namazi, 1989), multiple sclerosis (McLaughlin & Zeeberg, 1993), clients with rheumatoid arthritis (Ailinger & Dear, 1997); and teaching self-care educational programmes such as those designed for postoperative and neck patients (Dropkin, 1981). However, prior to reviewing the literature on self-care, several studies of the goals of rehabilitation of stroke victims will be discussed to provide the particular context for self-care in this study.

2. Goals of care

Rehabilitation goals for stroke patients cover three major areas. These are the restoration of a disabled person's physical condition to the highest possible level of independence; reintegration into major functional role activities, particularly gainful employment; and psychosocial adjustment (Safilios-Rothschild, 1970). Realistic individual goals in terms of current levels of disability and the potential for recovery should be set by the patient, family and rehabilitation team (Gresham et al., 1996). Achievement of goals can be measured by a number of indicators, for example normalised health patterns, such as nutrition, continence, and sleep; cognitive and communicative abilities; the ability to perform self-care activities; psychosocial and emotional adjustment to a 'normal' social environment after discharge; and the

quality of life (Ben-Sira, 1981; Gresham et al., 1996). Most of the studies in the literature measure the success of rehabilitation from the care providers' point of view which is usually viewed as 'objective' compared to the 'subjectivity' of the care receivers (Safilios-Rothschild, 1970).

One of the major difficulties in achieving rehabilitation goals is the different perception of these goals between care providers and receivers. It is important to determine just which perspective patients and practitioners are using. To the health care providers, rehabilitation goals focus on the functional component which is measured in terms of task performance, improved mobility and independence in self-care. This focus persists even though there are increased efforts by health care professionals to adopt a more holistic approach to goal setting by incorporating psychological and social aspects with the physical component. Kaufman (1988), in a study of the stroke rehabilitation process, collected qualitative data from both practitioners and patients while the patients were in hospital and after their discharge into the community. He focused his study on the patients' response to the stroke and therapy, medical concerns, reactions to disability and plans for the future. His findings indicated that the practitioner's perspective centred on the demonstrated ability to perform physical, occupational and speech therapy. The goals of the rehabilitation plan were set to help the patients achieve their maximum potential in 'functional independence', that is the ability of the patient to care for themselves as fully as possible with or without assistive devices. Degrees of functional independence were measured by visible signs of self-care and behaviour, generally known as activities of daily living, or ADLs (Kaufman, 1988). The study revealed that the care providers' goals were usually relevant and important to the patient while they were hospitalised or during the first few months following a stroke. As time passed, stroke patients looked toward both medical stabilisation and visible gains in therapy as keys to recovery. They finally came to look on a complete return to pre-stroke life as impossible.

The results of this study were consistent with a qualitative study conducted by Folden (1994), using grounded theory to identify the process stroke survivors used to manage the multiple functional deficits in the first month after the stroke. Interview data were collected from twenty stroke survivors. Each participant was interviewed

twice. The first interview was carried out in the rehabilitation facility within two weeks of the stroke event, and the second was done three to four weeks following discharge from inpatient rehabilitation. The process described by the participants ensured progress. The process included accepting that life would be forever different, maintaining hope, preserving energy and increasing personal control over recovery. The study revealed that the patients' goals were related to improving functional abilities and returning to some of their former activities. Goals were set with the realisation that returning to complete pre-stroke functional abilities was not a possibility. Even though the participants accepted lower levels of functional ability, they were not willing to accept the rehabilitation professionals' prediction of their ultimate functional ability if it was lower than their own goal. However, in a study by Doolittle (1991), recovery from the participants' perspective was seen as a return to the existence they had lived before the stroke. Since goals direct actions and the implementation process, the process of rehabilitation that the patients envisaged differed from that of the health care providers. Hafsteinsdottir and Grypdonck (1997) suggested that despite the patient's goals possibly being different from those of the care providers, care providers should not underestimate their ability, instead they should respect the patient's own goals in relation to functional abilities. Nurses should respect patient's views about their progress and increase the patients' control of their recovery.

3. Definition of the Concept of Self-Care

Self-care is a common term used throughout the world with different definitions from the perspective of various disciplines. Interestingly, all of these self-care definitions have been developed in Western countries and include an explicit or implicit element of independence or autonomy on the part of individuals to initiate, perform and take responsibility for their own health.

Many authors extend the definition of self-care actions to those offered by family members and other care providers when individuals cannot meet their self-care needs due to physical limitations or health related problems. For example, Levin, Katz, and Holst (1979) documented that self-care includes those processes that permit people and families to take the initiative and responsibility for functioning effectively in developing and maintaining their own health. Steiger and

Lipson (1985) and Orem (1985) also extend their definitions of self-care actions to include those performed by others, which Orem categorises as 'dependent care'. However the primary focus of the concept is still on an individual performing their own care (DeFriese, Woomert, Guild, Steckler, & Konrad, 1989).

In the health education and medical social science literature, self-care was first defined as a lay person functioning on his/her own behalf in the promotion of health, disease detection, prevention and treatment (Levin et al., 1979). Dean (1989) used a similar broad concept of self-care when she defined it as "a range of behaviours undertaken by an individual to promote or restore their health" (p. 117). Dean's concept of self-care covers the whole range of self-care activities from those associated with well-being to sickness. She argued that the focus of self-care shifts in response to developments in medical science and attitudes regarding the role of individuals in maintaining their own health. For example, during the era dominated by the germ theory of disease, when health was considered to be maintained and restored by professionals through advanced medical technologies, immunisation, surgery and use of antibiotics, self-care was still regarded as crucial in protecting the 'host'. This provided increased protection from disease, as it was impossible to rely on experts attenuating an unlimited array of potential disease agents. In modern societies with the growth of an ageing population and in numbers of people with chronic illness and disabilities (David, 1990), self-care is focused on restoring and maintaining function and residual health (rehabilitation). Thus in Dean's view, self-care contributes to all aspects of care; self treatment, health protection, health restoration and health promotion.

However, several authors (Sehnert & Eisenberg, 1975; Vickery & Fries, 1976 Roberts, Tinker, & Kemper, 1978) defined self-care education and practices as important adjunct activities to professional health services. In this view, self-care is considered as 'family first-aid' for accident or emergency health problems before referring to the doctor (DeFriese et al., 1989). Haug, Wykle and Namazi (1989) narrowed the concept of self-care to treatment for a perceived symptom depending on whether the symptoms experienced are perceived as mild or serious, with self-care more likely for the milder complaints. Similarly, Hickey (1986) also recognised self-care as complementary to conventional care but not a replacement. Many

professional health care providers regard self-care practices as 'vestigial' health functions to be avoided or deplored in the era of modern medicine; folk practices that contribute to the failure of lay persons to follow prescribed medical regimens (Levin et al., 1979).

As noted by Levin et al. (1979), self-care can be viewed as a decision-making process which involves self-observation, symptom perception and labeling, judgement of severity, and choice and assessment of treatment options. Based on this definition of self-care, people become more active in participating in their own care. A decision is made as to whether care actions should be performed by oneself, the family, alternative medicine providers or professional experts in the community. A decision by an individual to do nothing is also regarded as a self-care action (Dean, 1986).

Ferguson (1979) described self-care as the power to take responsibility for one's own medical education according to individual need, as well as the ability to choose, understand, and evaluate professional health care services. Ferguson added the notion of power or autonomy of an individual to actively participate in health care rather than passively receiving care given by professionals.

Steiger and Lipson (1985) incorporated Orem (a medical approach), Roger (a more holistic and environmental approach) and Leininger's theory (cultural diversity approach) into their self-care concept in order to develop a more holistic approach. Additionally, they included social science theory constructed from adult learning theory, symbolic interactionism, explanatory models of illness and a health belief model. They defined self-care as 'those activities initiated or performed by an individual, family, or community to achieve, maintain or promote maximum health' (p. 12). In their view self-care activities include personal or environmental hygiene, nutrition, preventive practices, and medications and treatment (both folk and scientific) which are intended to heal or cure. In contrast to Hickey (1986), they argued that self-care activities can substitute for, or be used in conjunction with, professional care.

Some investigators (DeFries et al., 1989; Haug et al., 1989) limited self-care to only the actions performed by the individual without formal medical supervision, whereas many researchers such as Shuval (cited in Dean, 1989) and Dean (1986),

included actions performed under the supervision or guidance of professional health providers.

Roles in self-care include health maintenance, disease prevention, self-diagnosis, self-medication, self-treatment and patient participation in the use of professional services (Chang, 1980). Roles of self-care in chronic illness may involve symptom recognition and decisions regarding actions in response to these symptoms, including a decision to do nothing about the symptoms, to treat the symptoms by self-determined actions, or to seek professional advice (McLaughlin & Zeeberg, 1993) and/or folk health services.

In the nursing literature, the most commonly used definition in nursing is provided by Orem. She defined self-care as the action of mature and maturing persons who have developed capabilities to take care of themselves within their environment. Persons who engage in self-care have the requisite action capabilities, that is, the agency or power to act deliberately to regulate factors that affect their own functioning and development (Orem, 1991). These action capabilities include acquired knowledge, decision making and taking action for changes (Orem, 1980).

3.1. An Overview of Orem's Self-Care Theory

Orem proposed three interrelated theories: theory of self-care, self-care deficit theory and a theory of nursing systems (Orem, 1991). Central to all three theories is the concept that people function and maintain life, health, and well-being by caring for themselves (Meleis, 1991). The focus of her concept is on the notion of action being done by an individual on behalf of him or herself (Orem, 1985). Orem draws upon her experience to conceptualise that people need nursing only under certain conditions when they have self-care limitations (Rosenbaum, 1986). Given these limitations the nurse then becomes involved in the provision of self-care. She differentiates the professional and lay roles in self-care (Woods, 1989).

3.1.1. The Three Interrelated Theories

3.1.1.1. Theory of self-care.

This theory defines self-care as a human regulatory function that individuals must, with deliberation, perform for themselves or have performed for them (dependent care) in order to maintain life, to keep physical and psychic functioning and development within norms compatible with conditions essential for life, and for integrity of functioning and development (Orem, 1995). The focus of the theory is on the concept of self-care agency and its relationship to the concept of therapeutic self-care demands. Self-care agency is defined as human capabilities necessary for a person to provide continuing care for oneself and thereby meet their health care needs (self-care requisites) (Orem, 1995). Self-care agency develops in the course of day-to-day living through the spontaneous process of learning. Its development is aided by intellectual curiosity, by instruction and supervision from others and by experiences in performing self-care measures (Orem, 1995). According to Orem, self-care agency is affected by a number of basic conditioning factors: an individual's developmental processes, state of health, educability, life experiences, exposure to cultural influences and use of resources. The adequacy of self-care agency is measured against the person's therapeutic self-care demand; thus when the self-care demand exceeds the self-care agency, there is a greater demand for an individual to engage in self-care.

3.1.1.2. Self-care deficit theory.

This theory describes the situation when a person cannot meet their health care needs ('self-care requisites') due to health-related or health derived limitations (Orem, 1985, p. 34). Self-care requisites arising from health limitations or health-deviated conditions, are called 'therapeutic self-care demands'. Nursing care is required in helping the person to meet these health care needs.

Self-care deficits are identified as complete or partial. A complete self-care deficit means that the individual has no capability to meet a therapeutic self-care demand. Partial self-care deficit means there is limited capability to meet some therapeutic self-care demands (Orem, 1995). The ability of an individual to perform productive actions in knowing and meeting the therapeutic self-care demands of a

socially dependent person is called 'dependent-care agency'. A dependent-care agent refers to a person (parent, family member or friend) who has developed dependent-care agency, and assumed responsibility for meeting the dependent person's therapeutic demands either in whole or in part.

3.1.1.3. Theory of nursing systems.

This theory describes the therapeutic self-care requisites and actions or systems involved in self-care (Meleis, 1991), in particular the nursing systems. Nursing care is required when a patient cannot maintain the amount and quality of self-care necessary to sustain life and health, to recover from disease or injury, or to cope with the effects of disease or injury (Roberson, 1996). Orem defines nursing systems as helping systems designed by nurses who have the requisite abilities to meet the patient's therapeutic self-care demands. The theory attributes to nurses the power of nursing agency, the exercise of which results in maintaining the life, health and well-being of the clients. The nurse's primary focus is on individuals, with actions varying according to the current level of a patient's self-care agency. On this basis nursing actions are categorised into three nursing systems: wholly compensatory, partial compensatory and supportive-educative systems (Orem, 1995).

The wholly compensatory nursing system is required when a patient is totally unable to engage in self-care activities due to physical disabilities such as coma, or pathological processes of a disease or injuries, or for psychological reasons. This group of patients must be protected and cared for. The nurse is expected to compensate for the patient's inability to engage in self-care.

The partial compensatory nursing system is required when a patient has limited ability to engage in self-care. The nurse is expected to compensate for the self-care limitations of the patient and assist the patient as required. The extent of care provided by nurses or self varies with the patient's actual or medically prescribed limitations, the knowledge and skills required, and the patient's psychological readiness to learn and perform self-care activities.

The supportive-educative system is appropriate for a patient who is able to perform all the self-care actions by themselves but lacks the required knowledge, skills or confidence. Assistance from the nurse in this situation includes

combinations of support, guidance, provision of a developmental environment and teaching (Orem, 1995).

3.1.2. Types of Self-Care Requisites

Orem classified self-care requisites into three types: universal, developmental and health-deviation. Universal self-care requisites, which are common to all human beings during all stages of life, are associated with life processes - with the maintenance of the integrity of human structures and functions, and with general well-being. Universal self-care requisites comprise care needs for the maintenance of sufficient intake of air, water and food; elimination processes; a balance between activity and rest, solitude and social interaction; safety and well-being; that is the promotion of 'normalcy' (Orem, 1995).

Developmental self-care requisites are specialised care needs related to human developmental processes at various stages of the life cycle (e.g. infancy, childhood, adulthood), and associated conditions and circumstances (e.g. pregnancy, death of a family member), including events that can adversely affect development (e.g. problems of social adaptation, loss of possessions). Each individual at a certain stage of development becomes personally involved in his/her development and movement to maturity. At other stages of the life cycle such as stages of intrauterine life, infancy and childhood, development requisites can only be met by dependent-care agents - parents or others (Orem, 1995).

Health-deviation self-care requisites are care needs arising from health problems associated with genetic, congenital defects, human structural and functional deviations and their effects, and medical diagnosis and treatment measures. In short, these types of self-care requisites arise from diseases and measures used in their diagnosis and treatment. Understanding these types of self-care requisites requires a foundation of knowledge in medical science and technology. Hence in order to encourage a person with health deviations to become competent in managing health-deviation self-care, they must be helped to apply relevant medical knowledge to their own care.

3.1.3. Critique of Orem's Self-Care Theories

Strengths and limitations of Orem's self-care theories have been identified in the nursing literature. Both will be reviewed and discussed.

3.1.3.1. Strengths.

Orem's theories have demonstrated their strength in both nursing clinical practice and education. Although Orem did not originally explain the application of the theories to the family and community setting, they have been extended and modified to cover caring for the family as a whole unit (Taylor, 1989) and the community (Taylor & McLaughlin, 1991). Taylor (1989) discussed the concept of family within Orem's theories from three perspectives: as a factor that conditions an individual's requirements for care and ability to provide care; as a dependent care unit and as a unit of service. Taylor's purpose was to demonstrate the utility of the theory with groups of clients such as family members within a family unit, who have different patterns of family interactions shaped by their socio-cultural background. These modifications make the theories more applicable to families, emphasising dependent relationships.

Another strength of Orem's theories is that they provide a clear relationship between a sick individual (as a self-care agent) and a nurse (as a therapeutic-care agent) which enables nurses to handle their roles in a more professional way. The theories help nursing education move away from the 'task orientation' or 'medical orientation' model of care of the past, to more professional care modalities. Nurses provide care according to the patient's care deficit, with active participation from the patient and their family. Moreover, nurses are involved in providing care only when the individual and family are unable to handle the caring tasks. Smith (1987) noted that Orem's work has created opportunities for scholars developing nursing science to examine various aspects of care, and led nursing to be considered as more scientific thereby helping to advance the nursing profession.

3.1.3.2. Limitations.

Orem's theories have also been criticised by many nurse theorists and nurse researchers as having a Western cultural bias (the valuing of individualism), being too oriented to Western medicine, limited in scope, and the locus of control being

with the practitioner. Furthermore the terms used in the theories are not clear and some of them are used interchangeably, which leads to confusion.

Western cultural bias

As Orem's original intention was to address Western needs, she focused on the Western values of self-reliance, freedom and independence (Rosenbaum, 1986). Rosenbaum indicated that the Orem nursing mode would not be appropriate for clients coming from cultures that do not share these values. Similarly, Leininger (1992) pointed out that Orem's self-care theory does not fit with the values, lifeways and practices of people in many countries, such as Papua New Guineans and South Africans as well as some non-Western immigrants in the United States, for instance Mexican-Americans, African-Americans, Asian-Americans (Koreans, Thais, Chinese) and North-Americans who are not fully acculturated to Anglo-American middle and upper class norms.

Western medicine orientation

The focus of Orem's theories on Western medicine is one of their weaknesses when applied to societies where people rely on not only Western medicine but also traditional medicine. Although Orem refers to socio-cultural aspects as a basic conditioning factor, and popular and folk health care practices can be legitimately considered part of self-care, her theories are confined mainly to Western professional medical practices. The theories were originally developed around the ill person and convey the centrality of individual and institutional care. This is perhaps the most appealing feature for the majority of nurses who work in hospitals.

Scope of application

Since the theories were initially developed in clinical practice and focus on clinical therapeutics, the model favours hands-on care of the sick, particularly in hospital settings. The theories, as originally developed by Orem, do not provide a clear framework for the application of self-care to well individuals in the family and community. Meleis (1991) also pointed out that the theories were limited to dealing with individual self-care deficits rather than with all aspects of nursing care for the biopsychological being. They deal essentially with only one nursing domain - clinical therapeutics - and offer only one modality for care - the development of self-care

abilities. In addition, although the theories' concepts reflect a developmental approach, these concepts are not central to the theories nor are stages of self-care development included (Meleis, 1997).

Locus of control - practitioner

The theories focus on actions and deal with knowledge control. They are theories developed using an operational method in which alternative actions are dependent on the nurse's discrimination and decision about the needs and the action (Barnum, 1990). According to Orem, nurses are not only the providers and managers of patients' self-care, they are also the makers of judgements and decisions about the self-care requisites of their patients and designers of nursing care (Orem, 1995, p. 309). In Orem's view, nurses may decide to assume a role of dependent care agent to meet therapeutic self-care demands of others by providing total care; partial care; or they may support, guide, or teach the patient to perform self-care based on the nurses' judgement. This means that the nurse alone determines patients' self-care needs and sets up the self-care plan for them. The nurse-patient relationship is predicated by the one-way transfer of agency (Melnyk, 1983). This is a paradox in Orem's theories. While the theories promote a patient to be self-dependent and self-directed in his/her own care, the theories also give the impression that the patient is dependent, expecting goals to be set for them, goals that involve them in developing the highest potential for self-care.

Conceptual complexity and ambiguity

The concepts in the theories and their relationships are not entirely clear, for example the terms 'self-care agent' and 'dependent-care agent'. According to Orem's theories, the term 'self-care agent' refers to the person who provides self-care activities. The self-care agent can be either self or others, while other care providers are also classified as 'dependent care agent'. These overlapping and undefined boundaries between concepts has resulted in multiple interpretations (Meleis, 1991, p. 394) and raised a number of questions. What is the extent of self-care performed by an agent to make it self-care by self or by others? From whose perspective do you determine the agent? (Anna, Christensen, Hohn, Ord, & Wells, 1978; Smith, 1987). Similarly, terms such as 'self-care requisites', 'demands' and 'needs' are often used interchangeably, which decreases the clarity of the theory (Meleis, 1991, p. 394).

Given the limitations of Orem's Self-Care theories, a broader view needs to be taken. In the following section, both Western and Thai literature will be reviewed to identify factors that may influence the practice of self-care.

4. Factors Influencing the Practice of Self-Care

It has been demonstrated that self-care competence is influenced by an individual's characteristics and capabilities, and socio-environmental factors. The individual's characteristics and capabilities include age, gender, marital status, developmental state, health state (pathological disorders), education, the ability to initiate and perform self-care behaviours, attitudes, motivation, perceptions, expectations and experiences. The socio-environmental factors refer to all the external factors surrounding the individual that can affect the individual's self-care ability. These include socio-cultural orientations, availability of resources, and elements of both family and health care systems (Chang, 1980; Harper, 1984; Orem, 1995).

4.1. Individual's Characteristics and Capabilities

Some of the individual's characteristics affecting self-care ability, such as age, gender, marital status and education, have been reviewed (Whetstone & Hansson, 1989) and intensively investigated by a number of Thai researchers (Hanucharunkul, 1988; Chalearnkusol, 1991; Vithayachockitikhun, 1991; Chaitiamwong, 1992).

Studies on marital status as a factor influencing self-care agency have shown conflicting results. Vithayachockitikhun (1991) examined the relationship of some basic conditioning factors including health status, with self-care agency in elderly persons attending a clinic in Thailand. The results revealed that self-care agency was positively correlated with marital status and health status, that is the elderly who were married demonstrated a higher self-care agency, resulting in better health status, than the elderly who were on their own. The results are consistent with Hanucharunkul's study (1988) in cancer patients receiving radiotherapy. However, other studies by Oprasertsawat (1988) with patients with chronic obstructive pulmonary disease, and Trakulsithichoke (1991) with elderly people, reported no significant relationship between marital status and ability to perform self-care.

Patient education is a vital component in enhancing self-care ability. Although the concepts of patient education and self-care are often used synonymously, they are not the same. Levin (1978) presented a good comparison of these concepts in his article 'Patient education and self-care: How do they differ?'. He pointed out clearly that the distinction between them is that self-care is directed by the individual whereas patient education is directed by the professional. In contrast to self-care, patient education goals are initiated and controlled by the professional. This encourages patients' dependency on the professional for their care needs as well as fostering 'poor compliance' if the education programme is incompatible or unacceptable to the patients. Thus effective patient education should be expanded to include self-care and more active client participation (Steiger & Lipson, 1985). The duration of the education programme is also an important factor in order for the individual to understand and develop self-care skills. Education enables people to understand concepts such as the nature of the disease, health status, the treatment and appropriate care for self. Hence people who have received effective patient education are more likely to look after themselves well, as illustrated in studies by Panawatanakul (1991), Trakulsithichoke (1991) and Chaitiamwong (1992).

Illness often brings about conditions that interfere with the ability of a person to care for themselves, for example fatigue experienced by patients with cancer resulting from the disease, the chemotherapeutic drugs employed, or as a result of psychological distress, can hamper the individual's capability of self-care (Fernsler, 1986). Rhodes, Watson, & Hanson (1988) examined the relationship between the occurrence of symptoms and the performance of daily activities. The results support Fernsler's findings and the author indicates tiredness and weakness as the two major symptoms which interfered most with the patients' lives. Chaitiamwong (1992) investigated the relationships between some basic conditioning factors, including the severity of illness, social support, self-care practice and quality of life in patients with chronic obstructive pulmonary disease. The findings show the same negative correlations between the severity of illness and social support, self-care practice and quality of life. Furthermore, having some health problems that need specialised skills

or modern technological equipment, may lead the patient to become dependent or reliant on care providers, which in turn reduces self-care activities.

4.2. Socio-Environmental Factors

4.2.1. Socio-Cultural Orientation

The effect of socio-cultural factors on health care behaviours has been studied by many investigators. For example, Verbrugge and Ascione (1987) and Maunz and Woods (1988) demonstrated that a patient's response to illness is correlated not only with the nature of symptoms, but with the person's social roles and context. According to Mechanic's (1960) study of illness behaviours, people perceive, evaluate and respond to symptoms in ways that reflect socio-cultural patterns and the stress and strains in their own lives. Bhanumathi's study (1977) demonstrated from the nurses' perspective how cultural differences affect patients' and their families' behaviours. The investigator looked at nurses' conceptions of 'sick role' and 'good patient' behaviours in India and the United States. The findings demonstrated the differing expectations of American and Indian nurses: "The American cultural emphasis is on independence, self-help, interpersonal relationships, and individual sensitivity and Indian cultural beliefs are on interdependence, destiny, fatalism, punishment for past sins and passivity" (Bhanumathi, 1977, p. 23).

These studies suggest that there are differences between cultures in the way patients and families respond to illness. In many Western countries, which are characterised as predominantly nuclear family societies, the focus is of the individual person. Even though the patient is viewed as a whole person who is influenced by biological, psychological, social and spiritual factors, the patient is nevertheless frequently considered distinct from their social group. Whereas in extended family societies, the individual is seen as an integral part of the social groups to which they belong, both family and community. The illness of a member within the family affects the family well-being, so family members work together as a group to restore the health of the sick relative (Kerlake, 1988).

Self-care activities are influenced by the beliefs, habits, and practices that characterise the cultural ways of life of the group to which the individual belongs (Orem, 1991). An individual first learns cultural practices within the family. While

growing up, the individual learns additional activities from other people outside the family such as neighbours, friends and teachers (Orem, 1995). However, Dean (1989) reported that perceived seriousness of symptoms and health status which suggest experienced discomfort rather than health beliefs, were more important for self-care responses to illness.

4.2.2. Socio-Political

Whetstone and Hansson (1989) argued that socio-political differences play a role in people's care practices and health service use. The socio-political system determines the country's health care system with its prevailing ideology, structure and function. These factors can have a profound effect on how people live and meet their health care needs.

Two similar cross-cultural studies comparing the perception of self-care agency between American and East German patients (Whetstone, 1987), and American and Swedish clients (Whetstone & Hansson, 1989) demonstrated how the socio-political structure of a country affects self-care behaviour. At the time of the studies, both East Germany and Sweden had similar health delivery systems based on a socialistic model of health care. In this type of health care system medical care is free of charge, or with minimal consumer expense. In the East German study (Whetstone, 1987), all respondents indicated that it would be very unusual to take responsibility for their self-care. The results show that the mean self-care scores of the East German and Swedish patients were lower than that of the American samples. The authors (Whetstone, 1987; Whetstone & Hansson, 1989) explained these results as being due to decreased incentives for self-care in a socialist state.

The socio-political structure in Thailand only provides a minimal level of welfare services, and requires Thais to take primary responsibility for their own welfare. Even though people have the right to choose health services, a lot depends on how much an individual can afford for those services. If a person can afford to do so, they can access specialised health care; if not they must go to the government health facilities which are very limited in number and services. Under Thai policy there is no formal discrimination between various groups of people, but financial problems and problems of access discourage people from using the government

health services. Consequently one would expect self-care to be more prevalent in Thailand.

4.2.3. Support Systems

4.2.3.1. Family caregivers.

Support from family members facilitates self-care behaviours and helps the patient meet their health care needs. Many research studies have emphasised the role of the nurse in facilitating patient participation in health care (Chang, 1980; Roberts & Krouse, 1988; Utz, 1990; Rourke, 1991; Biley, 1992) with findings indicating that participation leads to positive outcomes such as a greater degree of patient satisfaction with care and also a sense of control (Kim, 1985; Murray, 1986; Dennis, 1990). There has been less focus on the role of the family members, with whom the patients have the most contact, in facilitating a patient's self-care.

Most investigators view the support from patients' families as a form of social support. Some studies have provided relatively strong evidence to support a relationship between social support and self-care. Findings from those studies have shown that patients with high levels of support from family and friends are more likely to successfully manage health related behaviours than those who lack such support (O'Brien, 1980; De Jong & Branch, 1982; Hubbard, Muhlenkamp, & Brown, 1984; Holm, Fink, Christman, Reitz, & Ashley, 1985). Numerous reasons have been offered to explain this positive relationship between social support and health related behaviours. It is possible that people who take better care of themselves are more capable of attracting and maintaining supportive relationships. Alternatively, those people who are enmeshed in a supportive social network may take better care of themselves by engaging in more positive health practices than do people with less supportive networks (Hubbard et al., 1984).

Similar results have been reported from a few studies in Thailand. The relationship between social support, health locus of control and self-care agency in elderly persons was investigated amongst 149 elderly persons attending an elderly service centre in Bangkok (Trakulsithichoke, 1991). Most of the participants (88.6%) were Buddhists and living with their spouses or children in an extended family. The study reported that the existence of social support was scored highly by the elderly

and was positively correlated with self-care agency of the studied populations. There are a number of possible reasons for the perception of a high level of social support by the elderly. Senior or elderly persons are respected in Thai culture and the elderly still live with their children in an extended family structure which strengthens the bond between them and other family members. Commonly the elderly obtain financial and material support from their children, therefore they could perceive this as manifesting love, concern and attention from their family members. The results were congruent with other studies using the same measurement tool of social support developed by Brandt and Weinert (1981). These include the study of social support, self-care agency and health status in elderly person attending the Centre of Elderly Health Promotion in Pitsanuloke province (Chalearnkusol, 1991); and the study of the relationship between some basic conditioning factors, social support and self-care agency in patients with idiopathic hypertension (Hongtrakul, 1989). However, some investigators have noted only a weak influence of general social support on self-care practices of those with chronic illness (Crabtree, 1986; Glasgow & Toobert, 1988; DiIorio, Faherty, & Manteuffel, 1992). These varying results have led researchers to further investigate the type of social support that can effectively facilitate self-care behaviours.

Providing more disease-specific type of support, 'regimen-specific support', has been shown to be more effective in the prediction of actual self-care behaviours than a global measure of social support (Schlenk & Hart, 1984; Glasgow & Toobert, 1988; Ruggiero, Spirito, Bond, Coustan, & McGarvey, 1990). This type of support refers to that received from significant others which may involve reminders or encouragement to perform tasks such as taking medicine, following an appropriate diet or exercising. The effectiveness of regimen-specific support was confirmed by the study of DiIorio, Faherty, and Manteuffel (1994) using social cognitive theory to determine the association between general social support and self management, and between regimen-specific support and self management in 80 persons with epilepsy. Their findings suggest that respondents who have someone to assist them with epilepsy related tasks perform them with greater frequency than those who do not report this form of assistance.

There is some evidence that support from others can ease the trauma of stressful life events and aid in adjustment (Wills, 1985). Positive emotional support from others can help patients avoid feelings of being stigmatised (Hyman, 1971) and may make the transition to new roles easier. However, it is posited that family members can become over protective, resulting in patients becoming more dependent (Thompson, Sobolew-Shubin, Graham & Janigian, 1989; Zuger & Boehm, 1993). Several studies have found that patient satisfaction with family support is associated with poorer progress (Hyman, 1972) and that stroke survivors who live alone show more improvement than those who live with spouses or other family members (Labi, Phillips & Gresham, 1980). This raises the question as to the family's perception of their roles in facilitating self-care behaviour and what are the actual mechanisms through which the family works to encourage their sick relative to engage in self-care.

Apart from facilitating the achievement of self-care competence, family members are also considered to be the main caregivers for patients with multiple disabilities who are not able to meet their own health care needs. Thus assistance or support from others is required. The support from the family in this situation can be viewed as three forms: instrumental, emotional and informational (Friedland & McColl, 1989).

Support for patients in the community has been studied by many researchers. Jackson (1990) studied the use of community support services by elderly patients discharged from general medical and geriatric medical wards in England. The researcher reported that although there are many services available in the community such as district nursing, day centres, day hospitals, homemakers and meals-on-wheels, the majority of the patients are cared for by their families. Another study conducted among the Australian elderly found that although there was a slight increase in patients living with their families on discharge, most older patients remained independent but were in daily contact with family carers who provided for most of their needs (Hawe, Gebiski, & Andrews, 1986). These studies suggest that family members are the most significant care providers in the community. However, care of chronic patients with complicated problems is very stressful. The negative impact of family caregiving has been documented by many investigators (Zarit,

Reever, & Bach-Peterson, 1980; Cantor, 1983; Robinson, 1983; Brody, 1985; Montgomery, Gonyea, & Hooyman, 1985; Thompson & Harran, 1985; George & Gwyther, 1986; Holing, 1986; Zarit, Todd, & Zarit, 1986; Browning & Schwirian, 1994). As a result, some relatives may seek active participation in care whilst others clearly wish to relinquish the caring role to health professionals, desiring only minimal involvement (Sharp, 1990).

Family carers' perceptions of their role in caring for a sick family member was investigated in the USA by Boland and Sims (1996) using grounded theory method. Participants in the study, primary family caregivers, valued the home as a healing place that provided meaning and the reason for participating in caregiving. Although the participants' experiences of the caregiving burden were consistent with many other studies, their commitment to care was absolute and was expressed as personal responsibility. The study showed that there was always one individual, usually a woman, who was the primary caregiver. Participants did not perceive that there were other family members who could or would share in the care and this was the main reason for the burden. However, most of the family caregivers had received some form of home-help support, mainly from home health nurses, but they did not see the nurses in the role of primary caregiver or as caregiving substitutes. Most of the participants felt isolated or lonely as they were tied to the house with no visitors. One of the ways primary caregivers learned to take better care of themselves was by arranging for time away from their ill relative. While there is less support from family members, respite care is normally available in the community for them if they want to avail themselves of this service.

Literature in Western countries has demonstrated that the perceived caregiving burden is higher when the sick family member lives in the same house as the primary caregiver. George and Gwyther (1986) studied the general well-being of family primary caregivers of 510 elderly persons with dementia. The results showed that the primary caregivers who lived in the same house as the elderly experienced more stressful lives and reported lower life satisfaction than those who cared for those living in institutions or separate homes. In addition, many elderly did not feel comfortable living with their children.

Wilner's study (1988) which investigated the usefulness of support groups for the elderly and their caregivers, found that the primary caregivers of relatives with Alzheimer's disease lacked support from their family members. The data were collected by field observations of two self-help support groups: an elderly support group and a support group for the primary caregivers of relatives with Alzheimer's disease. Most participants expressed the view that they did not want to live with their children because they did not want to burden them with their problems and concerns, and to be criticised or ordered around by their children. They wanted their children and grandchildren in their lives but they did not feel free to be themselves in their presence (Wilner, 1988). A similar result was reported by Hochschild (1973) in his book entitled 'The Unexpected Community'. Residents of a housing complex for older, low-income people treasured their children, enjoyed them visiting, and talking with and about them, but they did not want to live with them or to have them visit for long periods of time.

In summary research studies in mainstream Western societies on the effects of family support on health behaviour have revealed that family support is crucial for positive health responses in ill individuals. However, caring for chronic patients has been perceived as a burden by many caregivers. While some may commit to the caring role as a personal responsibility, others may wish to shift the responsibility to health professionals. From the elderly's point of view, a review of the literature has demonstrated a desire not to burden their children. As a result, they prefer to stay on their own rather with their family.

These findings seem to be contradicted by those from two studies in Thailand (Trakulsithichoke, 1991; Chaoum, 1994). A survey of the perceived burden of care and general well-being in family caregivers of dependent elderly was conducted with 100 elderly living in Bangkok, Thailand (Chaoum, 1994). The author reported that more than half of the primary caregivers (55%) were the elderly's children who were mostly daughters. Only 8% of them were cared for by spouses. However most of the elderly in the study (51%) were single (widowed, divorced, separated or never been married) and lived in the same house with the primary caregivers. About 88% of the primary caregivers had other relatives (associated carers) helping with the care. The participants in the study reported a low mean score for dependent care burden. Most

of the primary caregivers did not perceive caregiving as a burden, which was probably because the primary caregivers accepted caring for the dependent elderly as their responsibility. They accepted the caring role and tried to develop caring skills to meet the needs of the elderly. Since all the elderly in the study lived in the same house as their family carers, the author postulated that the love and bond between the elderly and other family members was an important foundation for assuming the caring role. Additionally, Thai culture values the children's responsibility in taking care of their elderly parents, especially when they are sick. Therefore it was a good opportunity for children to repay their elderly parents for bringing them up. Looking after elderly parents is perceived as a great merit in Buddhist beliefs. The results of this study were congruent with Trakulsithichoke's study (1991) which demonstrated a high score by the elderly, most of whom were living with their extended family, on perceived social support.

The interdependent relationship between care receiver and care provider is a crucial factor contributing to the well-being or social support of the care receiver. Stroke patients normally have some degree of disability after their illness. Very often they are unable to meet their health care demands by themselves and are dependent on others for some of their activities. However this patient-carer relationship is not always one way or a completely dependent relationship. In many circumstances, the carers are also reliant in some ways on the disabled. This relationship reflects an exchange relationship rather than one of dependence (Ben-Sira, 1981). On the other hand, dependence occurs when the disabled person's functioning is dependent upon the decision of somebody else. This dependence could be an impediment to his or her readjustment and well-being. Achieving an optimal level of independence or sense of control over events is commonly regarded as crucial in the process of rehabilitation. This was supported by Ben-Sira's study of the readjustment of the disabled to the normal social environment. According to Ben-Sira, readjustment comprises two general goals: the restoration of the disabled person's emotional homeostasis and a satisfactory level of functioning, which is contingent on the dimensions of coping (the state of coping, perceived success and independence) and the disabled person's ability to cope by themselves with the demands placed on them. The achievement of readjustment increases with the increase of the rehabilitee's perceived success in

coping and achieving independence. Dependence is viewed as a lack of a sense of control and as counterindicative to the success of readjustment. Assistance by resources such as vocational training and job assistance in order to enhance the rehabilitee's ability to cope is not viewed as dependence or as failure to cope but rather interdependence. The study showed the crucial role of the family as an inherent component in the process of readjustment. Hence the results highlight the need for rehabilitation activities to include strengthening of the family's coping capacities.

The significance of family support has been documented in both Western and Thai societies. Family support is beneficial in assisting individuals to engage in self-care behaviours and in providing direct care. Care is primarily provided by a female family member. The level of perceived caregiving burden by Western and Thai caregivers is shown to be different. Western caregivers considered it to be heavy when the sick member relies on the family for a considerable amount of care or lives with the family. In contrast, Thais perceive caregiving to be a normal part of the interdependent family relationships. They view it as a way to repay the goodness of their elders and earn merit according to Buddhist beliefs.

4.2.3.2. Self-help groups.

Self-help refers to a process whereby lay people organise in groups to meet mutually identified goals, without professional intervention (Hill & Smith, 1985, p. 14). Individuals with a particular condition or diagnosis, or carers who are responsible for patients may share their experiences and information in order to solve their problems. Although self-help groups are generally originated and run by lay people who are members of the groups, most of the groups obtain support from government agencies or NGOs. Their activities are normally facilitated by professional health personnel from the sponsoring agency in term of providing knowledge or guidance in caring for a particular group of patients. Some institutions provide an instructional package which contains material on personal issues, assertiveness, changes and limitations of the new life situation. Others may be less formalised and health professionals may be invited to provide lectures on some occasions.

There are numerous benefits from joining self-help groups. The primary objective is to create an opportunity for group participants to share their experiences

and information regarding care and access to community resources, to support each other, and to empower their group to negotiate with policy decision makers for the provision of appropriate support for sufferers of their condition. Emotional support from peers provides the most profound benefit to the group participants.

Wilner (1988), in her study of support groups and their caregivers in the USA, found that the participants used the groups to transcend their position of being neglected and rejected by family, friends and professionals. Wilner indicated that the active affirmation of each other's activities served to bolster feelings of self-esteem and accomplishment. Thus it led to an increased ability to care for themselves. Participants felt more self-assured and better able to cope with life. The participants experienced the support from the group as different from that of their own family members and friends. They felt more comfortable in expressing their feelings, to say anything or even cry in the group and be accepted and understood. Participants learned to make use of the group for basic information about the nature and management of their disease and for necessary tension release and mutual support. For the caregiving participants, the group was important in strengthening the morale, emotional well-being and treatment skills of care-providing families. Another important benefit was that the group members increased their ability to interact socially with individuals in a more assertive manner, leading to enhanced life satisfaction, strengthening of coping abilities and ultimately self-care. On a wider scale, the use of the self-help group seems to have prevented the premature placement of a sick relative in an institution (Wilner, 1988).

McLaughlin and Zeeberg's study (1993) also found that support groups were used to cope with loneliness or alienation. In this study in the USA, multiple sclerosis patients described the group as a source of mutual aid, whose members provided support, encouragement and information to each other. They felt understood and accepted by the group members. The respondents indicated that they learned to perform self-care mostly from support groups, books, family, friends and to a lesser extent, health care professionals.

One study of a self-help group in Thailand has been identified. However, although the group was claimed to be fall into the self-help category, the information

provided indicated that it primarily focused on education and was facilitated by a nurse (Aimmak, 1994).

4.2.4. Health Service System

Kleinman's (1980) model depicts the health care system as a cultural system. This model categorised the health care system into three sectors; popular, folk and professional. The model also reflects the Thai health care system. The popular or lay sector is the self-care segment that is embedded in the culture of individuals, families and networks. The folk sector includes traditional and other providers. The professional sector contains services provided by the formal health care system. The availability of these health care services can partly determine what the individual can do to meet their health care needs and what kind of resources they can seek when help is needed.

4.2.4.1. Popular sector.

This is a non-specialised and non-professionalised health care system. Helman (1994) defines this sector as encompassing all therapeutic options that people utilise without payment, and without consulting either folk healers or medical practitioners. It includes care activities initiated by the individual themselves or by family members, friends and neighbours, for example the use of rituals, home remedies or folk medicine, to maintain and restore health. The remedies used by lay persons vary with the culture of an ethnic group and the region where they live. Many self remedies have religious connections. Rituals, believed to add to a remedy's effectiveness, consist of a set of repetitious behaviours, such as dancing, chanting, massaging with ointments or ingesting some forms of herbs in a prescribed manner (Bushy, 1992). Self-help groups are also a part of this sector. There has been a tremendous growth in the use of this sector of care as a result of a number of factors, especially the pressure of budget constraints on official health services.

4.2.4.2. Folk sector.

The folk health care sector is identified as non-professionalised and non-bureaucratic, but it can offer specialised health care services (Kleinman, 1980). This sector encompasses all existing health services in the community that are outside the popular and official health care services. It is more commonly used in non-Western countries where there is less access to the professional sector. Examples of folk health treatments that are common in non-Western societies are herbal, spiritual performances, massage, meditation and acupuncture.

One of the important reasons why the folk sector is commonly used by people is that most of the folk healers share the same cultural values, world view and beliefs, for example the causality and treatment of illnesses, of the communities in which they live (Helman, 1994). Their service is usually based on an holistic approach, dealing with all aspects of a patient's life, including relationships with other people, their environment and natural forces, as well as any physical and emotional symptoms of the illnesses (Helman, 1994). Although some treatments are perceived by the users as ineffective, the folk sector remains popular for several reasons, for example the lack of professional health care, limitations of knowledge about body functions and disease processes, and the perceived effectiveness of a specific treatment by a highly regarded healer (Bushy, 1992).

The attitudes of professional health personnel towards folk healers is likely to be negative, based on a belief that treatments are ineffective and irrelevant to patients. Most doctors have tended to view folk healers as quacks, charlatans or 'medicine men' who pose a danger to their patients' health (Helman, 1994). Increasingly, however, there is a move towards partnerships developing between the professional and folk sectors.

4.2.4.3. Professional sector.

This sector is defined as organised, legally sanctioned healing professions (Kleinman, 1980, p. 53). In most societies, especially Western countries, the professional health sector is based on modern scientific medicine and includes a wide range of health personnel such as doctors, nurses, midwives, physiotherapists and occupational therapists. However, in a number of countries such as China and India,

there is also a professional indigenous medical system operating alongside Western medicine. The latter however is still the dominant health service in these countries.

5. Summary

Self-care encompasses a wide range of activities from wellness to illness, from doing nothing to trying one's best to solve one's own health problems including seeking external assistance when necessary. Self-care can be viewed as family first aid, a complementary role to conventional health services, or even as an activity to be avoided. Although most authors do not limit self-care activities to only those performed by an individual, the primary focus is still on the individual to perform or make decisions about their own care. People's view of self-care and their responses to the self-care role are influenced by two main factors: the individual's characteristics and capabilities, and socio-environmental factors. The contribution of these two main factors to the self-care response is well-documented. Generally, individuals are completely independent and respond fully to their own care needs when they are mature and capable. Their capability is also conditioned by their health status, level of education and experiences relating to care. Apart from the individual's characteristics and capabilities, socio-environmental factors, which include socio-cultural and socio-political factors, social support systems and the health care system, also strongly influence the way people respond to self-care.

Orem's self-care theories which are based on Western culture, are widely used in nursing in both Western and non-Western countries. The claim that Orem's self-care concept is universal or relevant to non-Western countries where people have different cultures, values and beliefs, is controversial. Steiger and Lipson (1985) postulated that the philosophy and practices of self-care are valid for a wide range of socio-economic and cultural groups, if the values of each group are taken into consideration. Other researchers believed that the self-care concept according to Western ideology is incongruent with cultures where people do not value self-care (Leininger, 1992). The latter groups of researchers point out that instead of self-care, 'other care' is more relevant and meaningful to people. Later chapters of this thesis will describe and discuss caring practices of Thai stroke victims in Thai culture, and finally compare the findings with those from Western literature in order to gain an understanding of 'self-care' practices in Thailand.

CHAPTER 3 : THE STUDY CONTEXT

1. Introduction

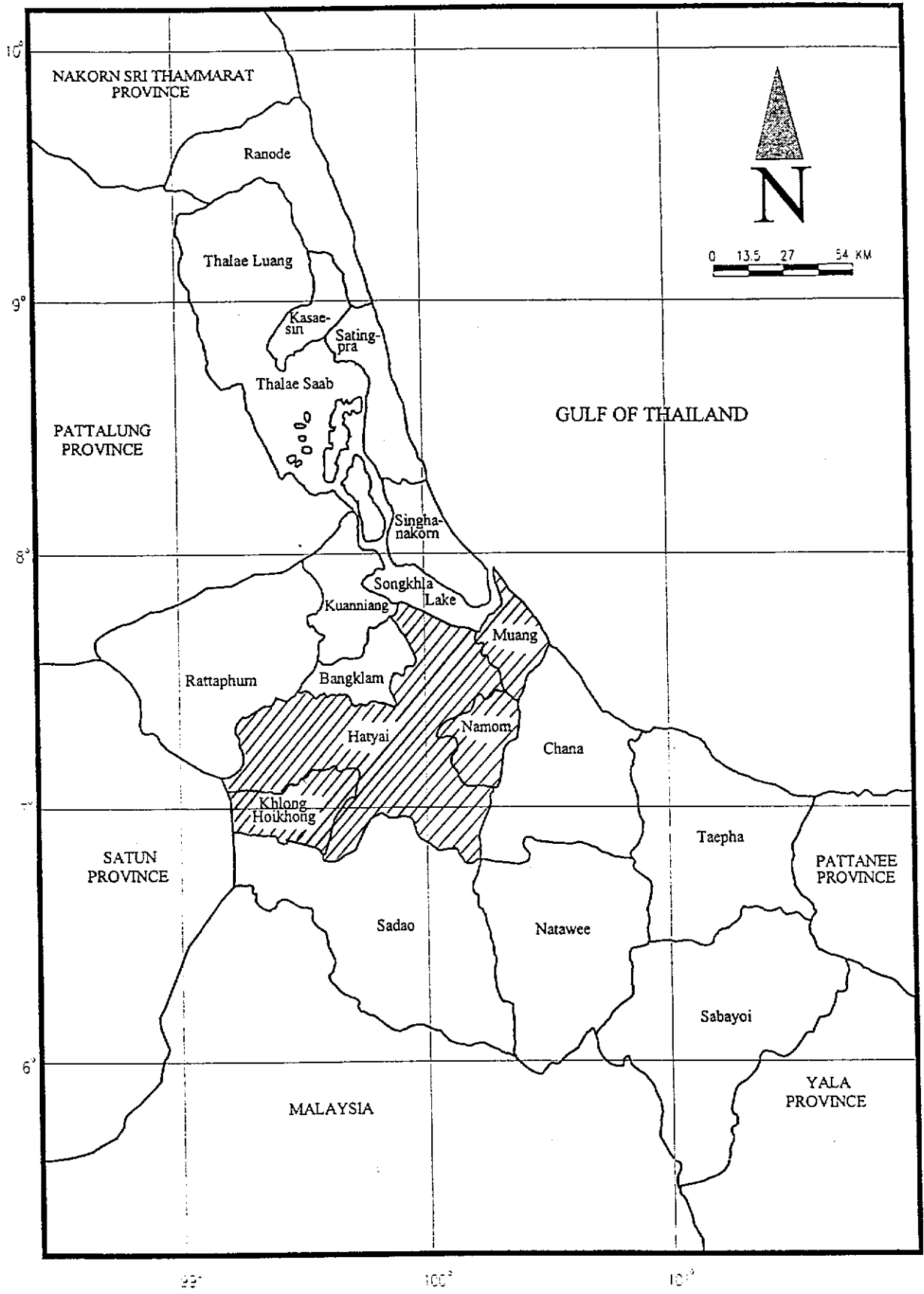
Three main aspects of the study context are described in this chapter: the setting, the people, and the health care service system. Emphasis is placed on rehabilitation services in order to enhance understanding of the situation of individuals with chronic illnesses and disabilities in the community.

2. The Setting

This study was conducted in Songkla Province which is located on the east coast of southern Thailand. The province is approximately 1,000 kilometres south of Bangkok, the capital city of the country, and its southern border is shared with Malaysia. The province covers about 7,394 square kilometres.

Songkla Province has long been a trading and transportation centre for the southern Thailand region. In the decentralisation of urban development and infrastructure services to the regions under the Seventh National Economic and Social Development Plan (1992-1996), the two major towns in the province were assigned complementary roles. Songkla was promoted as the seaport tourism centre and the provincial site for public administration. Hatyai, on another hand, was to be developed as a centre of transport, trade, business, and services linked with Pattanee and several border trade points, such as Sadao (a district of Songkla), Sungai Kolok (a district of Narathiwat), and Betong (a district of Yala).

The national public administrative structure is divided into provinces, districts, tambons (groups of villages) and villages. A village is the smallest unit of administration. Songkla province has 14 districts (Amphoe) (Figure 1): Muang, Kasaesin, Kuanniang, Chana, Taepha, Natawee, Namom, Ranode, Rattaphum, Satingpra, Sadao, Sabayoi, Singhanakorn, Hatyai and two subdistricts: Khlong Hoikhong and Bangklam. Participants in the study lived in both urban and rural areas of the districts Muang, Namom, Hatyai and subdistrict Khlong Hoikhong. Various aspects of people in this province; the economy, ways of life and religions will be discussed.




 Study area

Figure 1: Map of Songkla Province

3. The People

Songkla Province's population was estimated to be 1,144,349 in 1994 (Songkla Provincial Statistical Office, 1995). The population is predominantly rural with the urban population comprising less than 20% of the total population. The bulk of the population lives in Amphoe Muang and Hatyai which have a registered population of 150,212 and 285,776 respectively.

About 78 % of the population are Buddhists, 20 % are Muslims (the vast majority of Thai Muslims live in the four southernmost provinces of the country bordering Malaysia) and only 2 % are other religions (Administrative Centre for the Thai Southern Provinces Bordering Malaysia, 1998). People in Songkla Province use the Southern Thai dialect in their daily interactions while using the Central Thai language for official communication. Bahasa Malaya and Chinese (Teochiu, the southern Chinese dialect) languages may be used in families whose ancestors migrated from Malaysia and China.

3.1. Economic Aspects

In general the economy of southern Thailand, including Songkla Province, is controlled by Thai government officials who are mainly Buddhists and Chinese Thais. The Muslims are generally rubber tappers, fishermen or vendors while the Thais and Chinese Thais, most of whom are Buddhists, occupy the higher socioeconomic strata (Kaplan, 1981).

The significant developments in the social and economic systems in Thailand during the last two decades, since its transformation from an agricultural to a modernised industrial country, have resulted in dramatic changes to Songkla and to the south. Hewison (1993) described the rapid economic and social changes in Thailand as immeasurably diverse, complex and difficult to fully comprehend. The most obvious developments have occurred in the country's infrastructure and the production of consumer goods. The rate of change accelerated during the late 1980's. Many construction and real estate projects commenced after 1985 when the country's economic boom began (Phongpaichit & Baker, 1996). As a result, land prices increased progressively from that time until the recent economic crisis. This led many

farmers to give up rice farming and sell their land to middlemen, real estate or prawn farm businesses which were starting to boom as a result of the development.

Like other parts of the country, the rapid expansion of industry has to some extent shifted the labour force from agricultural activities. Labourers, including women in the rural area who used to work as servants or shop assistants in the towns for low wages, have moved to factories which provide more job security and better pay. Labourers from other regions, especially northeastern Thailand, also migrate to the south to earn their living. However, despite the industrialisation, labour migration in the south is not as significant as in other parts of the country. The main reason is because the land is some of the most fertile in the country. The climatic and geographical conditions in the south are suitable for agriculture, fishing, and related industries such as frozen sea food and canned foods. Fifty six percent of the total labour force in the Southern Region earn their income from activities related to agriculture, mining and fishing (Songkla Provincial Statistical Office, 1995).

In Songkla Province, agriculture, fisheries and related activities form approximately 24.5% of the total provincial products in both unprocessed and processed forms. Consequently these industries provide the major source of employment. Labourers and sales people rank second and third in terms of occupations (National Statistical Office, 1994, cited in Songkla Provincial Statistical Office, 1995). Fishing is the major occupation for those who live near the coastline while rice farming is mainly for the farmers' own consumption. For many people in the province, cross-border trading is a way of earning a living, especially those who live near the Malaysian border and Hatyai, the centre of trading in this region.

Rubber is the most important type of land use in Songkla occupying about 1,539 Rais (approximately 616 acres) or about 14% of the total national land in rubber plantations holdings (Songkla Provincial Statistical Office, 1995). Rising world demand, including that associated with the world AIDS crisis (e.g. the huge demand for rubber in the manufacture of condoms), has added to the economic prosperity of the region. The marked increase in rubber prices has encouraged people to return to rural areas. Rubber plantations have become the new economic hope for many people. About 89,870 households or 44% of the total provincial agriculturists are directly involved with rubber plantations (Songkla Provincial Statistical Office,

1995). Many rubber plantation owners, particularly those who live in or on the outskirts of the town employ others to do this work while they concentrate on trading, usually selling food or groceries at home, which is easier and adds to their income.

3.2. Ways of Life

3.2.1. Rural

Rural lifestyle is characterised by significant family member interaction and interdependence. The close relationships among family members and people in rural areas are influenced by their agricultural work patterns which require the participation of the whole family, and the limited recreation facilities in these areas. Thus rural people usually pass their time by socialising with their family and others in the community.

3.2.1.1. Family network.

The traditional lifestyle is still embodied in the everyday life of people in the rural area. These people normally spend their lives in one place generation after generation. Their homes and land were passed down to them by their parents and will, in turn, be transferred to their children. Therefore the whole family usually lives in the same area. Traditionally parents are more likely to live with the youngest daughter's family (LePoer, 1989). Thus the household normally includes the ageing parents, their daughter and her husband, and their grandchildren. Other sons and daughters move out when they are married to live in their own houses, usually on an endowed piece of land near the parents' house. As a result of this cultural practice, a cluster of household families of sisters and brothers who are members of the whole extended family network develop. The degree of closeness of these related households and the extent of their cooperation in a wide range of domestic activities vary. Generally, in an emergency situation such as a sudden illness of a family member, the family network is called upon to assist. However, if the illness becomes chronic requiring long-term care, responsibility falls to immediate family members

who live in the same house. Other family members will come to help when necessary or when the primary carer is not available.

3.2.1.2. Work patterns.

As indicated earlier, working in rubber plantations is the dominant occupation for rural people in this region. Rubber tapping is considered to be hard work. The workers start after midnight tapping the rubber trees, collecting the milk, and processing the rubber sheets or alternatively selling the unprocessed rubber milk. They normally finish their work before noon. The whole extended family participates. Adults do the physical work with the grandparents providing support by caring for the grandchildren. The elderly may also grow vegetables and raise animals to supplement the family income. Women work hard both on the farm, working side by side with the men, and in the home. After work the men relax while women take care of the housework, children and the elderly who are too old to be independent or are sick.

3.2.1.3. Recreation.

Recreational activities in rural areas are very limited. Watching TV is the most common activity of families. Concerts or special shows are seldom arranged. At night men gather at one another's house for socialising and drinking. Social interactions mainly occur between siblings, relatives and neighbours who live in the same area. People in rural areas also enjoy entertainment such as bull, rooster and fish fighting. Bull fighting has long been a very popular sport among southern Thais. Bull fights involving neighbouring provinces are arranged regularly with the main objective of these activities being gambling.

3.2.2. Urban

A less traditional way of life is seen in the urban area. The high price of land and houses, and problems related to the social environment make it impossible to maintain the characteristic rural culture in urban areas. It is unusual for the whole extended family to live together in one place; however elderly parents still live with one of their children's family. Like the elderly in rural areas, they actively take care

of children and domestic chores while the adult members are at work. Materialistic attitudes add to the expense of living in the cities and towns. Working people tend to work harder in order to earn more money so as to cover the cost and desire for consumer goods which has swept through the society. Economic pressures take away their time with the family which leads to social and family related problems. Parents do not have time to bring up their own children. Old or sick parents are left behind at home without an extended family network for support as they have in the rural areas.

In summary the majority of the population in Songkla Province live in rural areas, and work in agriculture, mining, fishing and related activities. Many of those living in urban areas also maintain a rural type life style that reflects interdependent relationships among family members. The dominant religion is Buddhism. Buddhist teachings, particularly as these relate to health and illness, will be outlined in the next section.

3.3. People and Religion

The daily lives of Thais are strongly influenced by religion. Every single activity from birth to death, involving individuals, family or the wider community has some degree of religious involvement. Ceremonies held in the home such as ordinations, weddings, funerals and house-blessings require the attendance of a monk. Like other religions, rituals and ceremonies have been incorporated into the practice of Buddhism. Buddhism regards these practices as an ornamentation or decoration to beautify the religion in order to attract the public (Dhammananda, 1987, p. 226). They are not prohibited in Buddhism as long as they are reasonable and do not violate the religious principles.

Most popular festivals or ceremonies are based on religion. These activities allow all age groups of people in the community to participate. The following are two examples of popular religious festivals:

Chak-Pra festival. A religious celebration held in October at the end of the three-month Buddhist Rain Retreat. Customarily, revered Buddha images are placed on carriages and ceremonially paraded around towns.

Tum-Bun-Dean-Sib (or Tuk-Baad-Thevo in central Thai). This is an important traditional merit making occasion to worship dead ancestors and relatives.

It is held on the night of the full moon in the tenth lunar month (September). Family members from everywhere gather together in their parents' home towns where their ancestors used to live, to perform this activity. They believe that if they treat their ancestors well it will bring them good luck.

For the religious activities celebrated in the home, guests or participants contribute money, a cooked dish or ingredients, and labour for the preparation of community feasting. Their contributions ensure reciprocity from the host of the function in the future. This give-and-take relationship is considered as gift exchange in Thai society. The relationship is terminated when one refuses to respond or be involved in the function in one of the ways mentioned above. Hence, at least one of the family members needs to go to present their contribution at the function if they can not join the celebrations.

For public festivals or ceremonies, all the villagers gather at a temple or designated public place, bringing food to offer to the monks and to share or exchange with participants. These festivals or ceremonies, often involving a procession with dancing and joyful shouting accompanied by simple musical instruments such as bells and drums, are a frequent occurrence especially in the countryside. These religion based activities are important because they provide the people opportunity to 'do merit' according to their religious beliefs, to relax and socialise, and strengthen interpersonal relations.

3.3.1. Buddhism: Beliefs and Values

The following summary of Buddhist teachings is drawn primarily from the writings of Dhammananda (1974, 1987, 1996) supplemented by several other authors. As in any religion, the actual lives of followers will reflect these teachings to varying degrees.

Buddhism is an approach to human development that encompasses the material, social and spiritual. Underlying the approach is a set of values and beliefs. On these beliefs and values are based judgements about what is good and what is bad. Two things that are valued are merit deeds and being generous. These two phenomena have been incorporated into people's daily lives and expressed through social interactions.

One of the most important social interactions is 'giving and sharing' and is a fundamental behaviour that Buddhists are encouraged to practise. An essential requirement of ritual related functions, either household based (birthday, ordinations, weddings, funerals, etc.), monastery based (Tood-papaa, Tood-khatin, etc.) or community based (New Year Day, Songkran Festival, etc.) is giving and offering. Giving food to attending monks and sharing or exchanging food among participants is the most common activity. Giving is important because it is a fundamental quality contributing to the cultivation of unselfishness (Khantipalo, 1989, p. 75). Giving can break down the sense of ownership which binds one to material things. Once one feels less attachment to possessions, the mind will be free or liberated, thus easier to train to let go when things do not come up to one's expectations or when one fails to obtain the things they think they should have. Moreover, a free and calm mind is required to practise Buddhism more intensively. Giving should be done from the heart without any expectation of return.

However in practice, people still prefer to direct their giving to Buddhist monks and nuns because they believe that 'doing merit' with these 'pure' individuals results in the accrual of merit to the givers, or in other words increases the likelihood of a good life and a happy rebirth. Thus material support provided to monks and temples becomes the chief mode of gaining merit. These activities include feeding the monks, paying and participating in religious ceremonies, and supporting the construction and maintenance of the temple.

The act of giving continues to be an important means of healing or relief of suffering. Performing good deeds by releasing animals or birds, giving food to the monks, donating to the poor can change misfortune to fortune, cure the sick and so on. One explanation is that giving promotes a peaceful mind in the giver, thereby promoting healing.

3.3.1.1. Religion-coping with suffering.

Religion and healing often are highly interrelated. Religion shapes attitudes and responses to illness and suffering. Exploration of some important concepts of Buddhism and how this cultural element is incorporated by the individual and their

families into their self concept and value systems helps the understanding of health related behaviours in Buddhist societies.

The ultimate goal of practising Buddhism is to be free from human suffering arising from the cycle of birth and rebirth. This suffering is inherent in birth, ageing, pain and death. Adding to this unavoidable suffering are disappointment and hopelessness arising out of desire, anger and delusion. This suffering can only end by gaining wisdom through meditation. By practising meditation people can purify and calm their minds. With a peaceful and purified mind people can see and understand the real nature of existence (the truth) and the universal laws.

Buddhists are taught to realise the Four Noble Truths, which is an intellectual approach to reality. The Four Noble Truths consist of the Noble Truth of Dukka (suffering), the cause of Dukka, the end of Dukka, and the path leading to the end of Dukka (Dhammananda, 1987, p. 89). When one perceives and accepts things as they really are and interacts with the truth appropriately, one will be able to attain real peace and happiness. This peace and happiness cannot be found in material possessions and worldly achievement as they are all impermanent and not of the self ('non-selfhood') and thus they are not worth aspiring to, not worth craving for. The only way to avoid suffering is to accept this truth. Once one does not own anything, there is nothing to lose and therefore no suffering. These religious beliefs can therefore influence the way people perceive and respond to suffering.

Noble Eightfold Path, or the 'middle way', is a way of life aimed at achieving the final goal, that is to end the inadequacy or suffering of life. It consists of eight factors. These factors are right thoughts, speech, actions, livelihood, effort, understanding, mindfulness and concentration. This path can help a person develop moral strength through the avoidance of negative actions and the cultivation of positive qualities. In addition, it contains many techniques which a person can apply to purify and cultivate one's thoughts, and gradually bring about positive behavioural changes.

To be truly free from material attachments is not easy in practice. One needs not only powerful strategies but also time and effort to purify and cultivate the mind in order to reach that state. Although intellectually people may accept 'non-self' and impermanence as a truth, they do not believe that these concepts can be put into

practice in everyday life. Most Buddhists therefore do not aim to reach this state in this life, instead they merely use these concepts to overcome their problems and suffering when their desires cannot be met. Many teachings are used as coping strategies which can bring about peace of mind for a certain period of time rather than as a longer term means of escape from suffering.

The following are some examples of Buddhism's teachings which can be incorporated into people's daily life in order to cope with suffering:

- Law of Karma (or the law of cause and effect). This law operates strictly in accordance with the doer's actions. The concept would seem to be simple and understandable, however there are common misconceptions. These misconceptions include the belief that everything is a result of activities in a previous life, and everything occurs without reason and cause (Dhammananda, 1987, p. 89). Hence people are confident that bad things or misfortunes will only occur if they do bad Karma. However, despite doing deeds that are all regarded as good in this life, people inevitably became sick and unhappy at some stage of their lives. In this case they may accept the illness or unhappiness as being the result of bad Karma from a previous life (Payutto, 1993) which must be paid for in either this or the next life. Viewing this positively, people think that once the previous Karma has been paid off, they will experience only a good life in the near future or the next life as a result of good Karma from this life. This is one of the most common strategies that people use to cope with their suffering and to gain strength to face problems. Payutto (1993) claimed that this is a misinterpretation of Buddhism as people cling to the concept of previous Karma and ignore the real cause or reason, leading to misdirected problem solving.
- Tolerance. This is an important quality that people should develop in their way of life. At an individual level, tolerance creates peace and happiness in one's mind, while at the wider societal level tolerance is important to achieve peace and harmony among people. Buddhists are taught to regard, respect and tolerate others' practices such as religion, cultural traditions and customs, although they may not necessarily wish to emulate them (Dhammananda, 1974). The concept of tolerance as used by Thais is to appreciate other people's

practices or to at least refrain from criticism if they cannot appreciate these practices. As a coping strategy in daily life, people try to tolerate the physical and social environment, unwanted things, practices and behaviours, including illness and pain, that are beyond their control. In developing this quality, they must try to realise the Four Noble Truths, to reduce the focus on self and to be broad-minded, or in other words to sympathetically understand others from their point of view (Dhammananda, 1974, p. 4).

- **Patience.** Patience means being able to stay calm and not get annoyed by things or situations. It is a fundamental quality that people require to achieve their goals in their daily lives. Without patience, one may lose control and generate arguments or problems with others, or one may rush around leaving no time to think carefully about all the factors relating to a problem, thereby not being able to deal with the problem appropriately. Many things can sort themselves out given enough time. Most Buddhists are aware of the importance of this quality and use it as a strategy to solve problems and create harmony in society.

- **Contentment.** Contentment is a feeling of happiness and satisfaction with whatever one has or receives. It is important for people to be contented because the more people crave for material things, the more they suffer. In gaining a happy and peaceful mind, one must learn when one has enough, not to be a slave to their own desires. When one can maintain contentment, jealousy and anger do not arise and the individual therefore can live peacefully. This teaching is not idealistic. Not only Buddhist monks and nuns but also many Buddhist householders live contentedly without being disturbed by greed and desire (Dhammananda, 1996). However, most Buddhists only employ contentment to overcome dissatisfaction when they are unsuccessful in achieving their goals in the materialistic world. Other forms of misinterpretation and misuse of this concept can also be observed. For example some people with physical disabilities refuse aids to assist them with the activities of daily living, because they believe they must accept their disability and be satisfied with their own resources. Applying the concept inappropriately in such a case may create more problems and worries for the

family as the individual cannot be independent without these aids and thus can be a burden to their family.

- **Self-reliance.** Buddhism focuses mainly on the self rather than on other people or factors. Self is a creature of one's own life and destination, either good or bad, satisfied or dissatisfied. An individual cannot blame others or evil spirits when they are struggling with their own problems or misfortunes such as an unsuccessful business or illness. Hence people must take all the responsibility for solving their problems by the appropriate means. For instance one must go to a doctor to obtain appropriate treatment when one is sick. No one can be cured by simply praying, worshipping, performing rites or by making offerings to the Buddha. Buddhists are encouraged to face life as it is and not run away from it. In the end salvation can be achieved by the individual's own efforts. One may argue that self-reliance works only for 'normal' people. What of those who have disabilities or handicaps, how does self-reliance apply? Basically, Buddhists are not encouraged to cling to others or any external force or god. Instead they have to apply themselves, to the best of their ability and slowly develop the powers of self-reliance. Therefore those who are handicapped must make an effort, however small, to begin the process. With the right effort, the individual slowly trains him or herself to improve their own powers of self-reliance. The goal will be reached, but not overnight. Patience is an important component of this process (Dhammananda, 1987, p. 192).

- **Avoiding ignorance.** In Buddhism, ignorance means not seeing things as they really are, or failing to understand the real nature of life. Because of ignorance, people fail to realise the truth or the real knowledge pertaining to impermanence, that is they suffer from false knowledge. Being ignorant of the true nature of things, people may behave inappropriately in varying degrees and suffer accordingly. Rather than seeking to understand their difficulty, in some situations where there are perhaps too many difficulties to bear in their lives, individuals choose to deal with these difficulties by ignoring or forgetting them. Although in Buddhist teachings this is not an appropriate

means of dealing with the problem, it temporarily relieves the individuals of their crisis.

3.3.2. Attitudes to Other Belief Systems

Non-religious activities such as astrology; fortune-telling; wearing of talismans, charms or amulets; incantations; seeking of auspicious dates, and other supernatural activities are often practised by Buddhists and even some monks (Buddhadasa, n.d., pp. 61-63). Buddhists are discouraged from clinging or being slaves to any of these activities (Buddhadasa, n.d., pp. 61-63). According to Buddhism, no one can expect to obtain salvation and happiness simply by praying to a god, or by performing ceremonies, rites, rituals and other related activities. An important aim of practising Buddhism is to cultivate wisdom and gain a correct understanding about self, life and all human phenomena. People then can solve problems correctly based on the real truth and condition, not imagination or illusions created by their own minds due to a lack of knowledge. False understanding leads to false practice. In this view, self, not other invisible forces, is considered to be the most important and reliable power. Good Buddhists can overcome their difficulties if they know how to make use of their intelligence and potential ability.

Yet many people give more attention and effort to these non-religious practices than to the core teaching of the religion. When they are sick, especially when the cause of the illness cannot be clearly identified by modern medical technology, they tend to believe that their problems are caused by some external force. Thus they seek a cure by undertaking various activities influenced by their own belief system and in order to ensure that evil spirits do not cause harm, people also pay respect to these spirits by performing required rituals. Even today many people still believe that external powers can cure illnesses, change misfortunes to fortunes, bring good luck in their work and smooth their daily lives. Hence one may go to the temple to seek for good fortune, an auspicious day to undertake a certain activity or to be cured of illnesses by the application of holy water.

Practices relating to beliefs in supernatural powers such as spirits (Phi) and ghosts have some relevance to Thai people's well-being. This belief has been influenced by both Hinduism and Buddhism as well as the people's own belief

system stemming from their ancestors (Ramithanonth, 1990). Although Thais who are well educated in modern scientific knowledge may feel ashamed to express their belief in spirits and ghosts, this belief still has a strong influence in their lives. They still follow their ancestors' traditional ways of practising when they are struggling in their lives. According to the traditional Thai belief system, Phi exists everywhere: in the sun, the moon, stars, trees, hills, water, animals, human beings, earth and so on. All things exist in this world because of the protection of these spirits. These guardian spirits are normally beneficial but they may bring illness or misfortune to people who do not respect them or violate the rules of good behaviour (Ramithanonth, 1990, p. 261).

3.3.3. Support Services

Buddhist monks provide a wide range of services. In addition to spiritual activities, temples are used to teach and train people, and provide temporary shelter for those who have difficulties at some stage of their lives, or travellers who go from one village to another and do not have a place to stay overnight. Many monks are very active in helping to solve social problems and fill gaps in social welfare services, for example the care and treatment of drug addicts (Virasai, 1981). It is not surprising that the Buddhist temple has many meanings for Thai people. It is not only a place for people to meet their psychological and spiritual needs but also serves as a school, an inn or dormitory, a social and medical healing centre. Many monks in the local village temples provide traditional treatments, which are often considered as a primary health service for Thai people or an important alternative for patients in remote areas who are discharged from hospital or who have difficulty in getting to a hospital.

In order to help understand the health related behaviour of the people in this context, health care services available in the community are outlined in the next section.

4. The Health Care Service System

The official national health system consists of Western style (licensed) health services provided by the government sector, non-government organisations (NGOs)

and the private sector. The private sector focuses predominantly on the urban area of each district. Outside the licensed health system, unlicensed health services, both traditional and Western, are widely used in both urban and rural areas. Rehabilitation services for chronic patients and people with disabilities are mainly integrated into the national health system. Efforts have been made to improve these rehabilitation services but have not been very successful.

4.1. Government Health Services

The majority of the government health services, especially in the rural areas, are the responsibility of the Ministry of Public Health. The Ministry is organised into six major sections: The Office of the Permanent Secretary of Public Health; the Departments of Health, Communicable Disease Control, Medical Services, Medical Sciences; and the Food and Drug Administration (FDA) (Thailand Ministry of Public Health, 1990, p. 25). All departments give technical support to the provincial health offices in their respective fields.

The rural public health care services (outside the Bangkok metropolitan area) at the provincial level are managed by a Provincial Health Office. There is a hierarchy of health services in the rural areas:

1. Regional and General (Provincial) Hospitals

Every province has a provincial hospital which has between 150 to 500 beds. Some regions may also have a regional hospital (500 to 1,000 beds) which provides health services as well as training for a variety of medical and paramedical workers. In 1994, there were 17 regional hospitals and 72 general or provincial hospitals throughout the country (Thailand Ministry of Public Health, 1994a). General hospitals provide mainly curative services, but also a certain amount of health promotion, preventive and rehabilitative services. They are predominantly utilised by people in the immediate area of the provincial capital, whereas the bigger regional hospitals serve the larger region and act as a tertiary referral centre.

2. Community (District) Hospital

In the district level community hospitals range from 10 to 120 beds with 2 to 10 medical doctors. Each community hospital provides curative, preventive, health promotion and rehabilitation health services and has official responsibility for the

over-all supervision and technical support of health centre activities and public health programmes in the district in which the hospital is located. The most recent data indicate there are 670 community hospitals in the country (Thailand Ministry of Public Health, 1994a).

3. Health Centre

Each tambon has a health centre staffed by an auxiliary midwife and a junior sanitarian (a technical nurse). Their primary roles are preventive and promotive health services such as prenatal, delivery and postnatal care; immunisation; nutrition; family planning; and water supply and sanitation activities (Thailand Ministry of Public Health, 1990). They provide limited treatment for emergencies or minor illnesses. Referral to a district or provincial hospital is made when the required treatment is beyond their capabilities. The centre's staff also provide support to primary health care (PHC) programmes with the help of Village Health Volunteers (VHVs) in the community.

4. Community Health Service Station

Community Health Service Stations are the smallest health facilities and are located in villages. They are selectively provided to villages that are perceived to be a national security risk in border areas, in remote areas with scattered population and/or in areas inhabited by ethnic minority groups, for example hill-tribe villages.

4.1.1. Government Health Services-Songkla Province

In 1995, Songkla Province had 30 hospitals, 182 health centres, 153 clinics, 2 midwifery clinics, and 43 traditional medicine shops. Of the 30 hospitals, 22 are public and 8 are private (Songkla Provincial Health Office, 1995). The size of the hospitals range from 10 to 700 beds. The public hospital system consists of a university hospital (600 beds), a regional hospital (700 beds), a provincial hospital (500 beds), a neurological hospital (240 beds) and 18 district or community hospitals. Most of the hospitals are in Hatyai and Muang districts (seven and four respectively) (Songkla Provincial Statistical Office, 1995). Like many other provinces in the country, there are no separate rehabilitation services or specialised rehabilitation institutions or organisations in the province to support chronically ill patients. Rehabilitation services are part of the acute hospital and only provided to patients in

the hospital or to people living near the hospital who attend on an outpatient basis. It is therefore difficult for people who live some distance from the hospital to access these services.

All three hospitals from which the study's sample were obtained were large public hospitals. They all provided public and private patient accommodation. Two of the hospitals allow a family carer to reside with a patient in the public wards. The exception was the teaching hospital which because of its educational funding has good staff-patient ratios, so staff can provide patient care themselves. From the consumers' point of view, however this can be a negative aspect of the hospital as many family carers wish to nurse their sick relatives in hospital. On the other hand, all three hospitals required a family carer, preferably female, to reside with a patient in a private room. Two of the hospitals were also referral centres for other hospitals in the region. They provide services mainly for emergency or serious problems which need specialised physicians and/or staff. Therefore, it is very rare for a chronic patient to be able to stay in these hospitals for rehabilitative services.

The ratio of health personnel to population in Songkla province is low. In 1994, Songkla had 439 licensed Western-trained doctors with a ratio of 1:2,565 people, 123 dentists (ratio of 1:9,154), 124 pharmacists (ratio of 1: 9,080), 1,320 professional nurses (ratio of 1: 853), 1,003 technical nurses and nurse assistants, 479 professional midwives, 245 health personnel in health service centres, and 8,094 VHVs (Songkla Provincial Health Office, 1995). These figures indicate that Songkla still faces a shortage of nurses and health personnel to meet the population's health care needs. As already mentioned, most of the professional nurses work in hospitals. However in the last five years the government has set new policy targets for nursing education in Thailand to double the number of students with the planned objective of placing more nurses in the community.

4.2. Non-Government Organisations (NGOs)

The NGOs have long contributed to the development of health services in Thailand along with the government sector. The social, economic and political pressures on society have led to the establishment of numerous NGOs in Thailand as associations, foundations or clubs. Some examples of well known NGOs are the Thai

Red Cross Institution, Family Planning Association of Thailand (1960) and the Children's Philanthropic Foundation (1979). At present there are about 204 organisations actively involved in rural development projects, 20 dealing with the disabled, children and women's issues and 51 devoted to AIDS. The recent growth of this sector is demonstrated by the increase in NGOs from 113 organisations in 1984 to 374 in 1991 (Wasri, Samutvanich, Laotummatud, & Bunmee, 1996). Aware of the importance of NGOs in supporting public health development projects, the government allocated 49.2 million Baht (about \$A 2 million) for the first time in 1994 to promote their role in the National Health Development Plan (Thailand Ministry of Public Health, 1994c).

4.3. Private Health Services

These services are provided by private businesses investing in health service facilities, a trend which is increasing. According to the Utilisation of Health Services Survey in 1985, 21.8% of people used private facilities when they became ill (Thailand Ministry of Public Health, 1990). Private health services are becoming more popular not only in urban but also in rural areas. Many full time government doctors run their own private clinics after hours. Private health services mainly serve people who are not covered by government welfare as they can receive a quick and more friendly service for a cost that is only marginally higher. The inconvenience of public health services - long queues of patients and brief contact with the doctor - has led to a rapid increase in private service utilisation.

4.4. Unlicensed Health Services

Outside the government sponsored or licensed health services, there are large numbers of unlicensed health practitioners, both traditional and western. The unlicensed practitioners are more numerous and popular in the rural area.

4.4.1. Traditional Health Services

Traditional services enjoy considerable popularity, particularly among rural people in Thailand. There is a wide variety of unlicensed practitioners, for instance: healers (Mhor-Baan), masseurs (Mhor-Beeb, Mhor-Nuad, Mhor-Jubsen), herbalists

(Mhor-Ya), spiritual consultants (Kru-Mhor), fortune tellers (Mhor-Duu or knower), ritual experts, and monks. Various forms of treatments are provided by these practitioners such as herbs, massage, compression, spiritual words and performances. The fee is not always low. It varies from no charge to higher than that charged by the hospital. However many practitioners still following tradition, only ask for a small amount of money plus items used to pay respect to the original teacher (Wai-Kru). Additional payment is left to the patient's discretion. Traditional treatment is characterised as understandable, negotiable and easily accessible, hence it is still the first choice of people in remote areas when they are ill.

Traditional practitioners are usually trained within the family network. The knowledge has been passed on from generation to generation. They have their own medical textbooks describing causes, symptoms, diagnosis and treatments. Others are self taught from their own experiences and textbooks. Most of the traditional practitioners are unlicensed.

Many attempts have been made to control these unlicensed practitioners. One strategy is to provide them with a period of systematic training followed by licensing examinations in order to register them as traditional practitioners. However these courses do not attract practitioners as they find the process of being registered too long and difficult. More importantly, the training does not appear to make any difference in respect to the services they are providing or in increasing clients' trust.

4.4.2. Unlicensed Western Practitioners

Even though there are less unlicensed western style practitioners than traditional practitioners, some of them are very popular and have a good reputation. Their treatments are described as a combination of western and traditional styles. They predominantly provide injections, intravenous fluid and tablets while their explanations of the cause of illnesses and treatments are based on traditional philosophy including the concept of body lines and prohibited foods. This approach gains the trust of people as the practitioner's explanation is congruent with the people's belief system and the services are not expensive. Most of these practitioners obtained their skills and knowledge while they served the army, others by working in

local hospitals or health centres, or from other unlicensed practitioners. A few are full time practitioners, but most of them do it to supplement their income.

4.5. Rehabilitation Services

National health statistics in the last decade show that the number of people with disabilities has been increasing. In 1986, about 0.74% of the Thai population had disabilities (Thai National Statistical Office, 1986). This percentage more than doubled to 1.85%, that is about 1.1 million people, by 1991 (Thai National Statistical Office, 1991). The majority of disabilities were movement dysfunction, with the adult and aged being the most prevalent groups. Only approximately 10% had received rehabilitation services (Thai National Statistical Office, 1986; Thai National Statistical Office, 1991). Later studies have confirmed the trend of increasing numbers. In 1992, the national health survey conducted by the Thai National Public Health Foundation revealed that 6.3% of the Thai population had physical disabilities (Thai National Public Health Foundation, 1992). The most recent study of medical rehabilitation services during 1995-1996 estimated that the percentage of the population with disabilities was 8.1% (Wiboolpolprasert, Pradubmuk, Riewpaiboon, Rujakom, & Pengpaiboon, 1996). This percentage is projected to increase with the ageing population and growing labour force in industry. An epidemiological review showed that physical and movement disability was the major category of disability in Thailand (Wiboolpolprasert et al., 1996). Stroke was one of the most important causes of this type of disability combined with communication and cognitive disabilities. These results demonstrate that the need for rehabilitation services in Thailand has been increasing significantly whereas the actual rehabilitation services in the country remain very limited. Only 3% of the total health budget in the 1996 fiscal year was allocated for this area of care and about 80% of the services provided aimed to prevent complications rather than to increase functional ability (Wiboolpolprasert et al., 1996).

As a result of this minimal level of funding, rehabilitation services in Thailand are not well developed. There is no clear structure for rehabilitation services in the community hospitals with rehabilitation being subsumed in the health promotion service. Only two regional hospitals, out of 17 throughout the country,

have separate rehabilitation units within the hospital (Sribruchayanun, Saisupatpol, & Chantha, 1995). Some efforts have been made to incorporate the service into acute hospitals, however only a small proportion of hospital beds have been allocated for rehabilitation services. In 1995, Sirindhorn National Medical Rehabilitation Centre conducted a study on hospital rehabilitation services by collecting data from 100 hospitals around the country. The results show that only seven hospitals allocated a certain number of beds to rehabilitate people with movement problems.

The existing rehabilitation services are focused on providing the disabled with shelter and care rather than encouraging them to resume their physical and social functions. This is because Thai people view the disabled as disadvantaged persons in the society who need help, care and protection from society. They feel pity for them and provide them with assistance rather than encouraging them to resume their normal roles in the society. Research on the medical rehabilitation system for the disabled in Thailand conducted by Wiboolpolprasert et al. (1996) reported that the disabled and their families still viewed the disability as resulting from previous Karma and the disabled as persons to be pitied and protected. They seemed to accept the condition and expected only some help and free treatment rather than protection of their rights to be treated equally in society.

Most rehabilitation facilities for the disabled in Thailand are run by the government and NGOs. There are six main institutions contributing to the services run by the government: the Ministries of Labour and Social Welfare, Health, Tertiary Education, the Interior, Defense, and Bangkok Metropolitan. Presently most of the services are provided in the large cities while 80% of disabled people live in the country. A study on the status of the previous and current health development plans and direction of health development under the Eighth National Economic and Social Development Plan (1997-2001) clearly acknowledged the lack of services for specific groups such as the elderly and the disabled (Wiboolpolprasert et al., 1996). The lack of opportunity to obtain appropriate rehabilitation services results in the disabled being disadvantaged in society and unable to rely on themselves.

Hospital based rehabilitation is no longer encouraged for a large number of disabled. International trends are to move rehabilitation services for people with disabilities from institutions to the community. A community-based rehabilitation

programme therefore was implemented by the Ministry of Health in 1983. Community-based rehabilitation (CBR) is a strategy within community development for the rehabilitation, equalisation of opportunities and social integration of all people with disabilities. It is implemented through the combined efforts of families and communities, and the appropriate health, education, vocational and social services. This strategy has been widely encouraged in the last few years, not only by the government sector but also by NGOs.

NGOs also play important roles in rehabilitation services in Thailand. A survey conducted by the Sirindhorn National Medical Rehabilitation Centre [1994, cited in (Wiboolpolprasert et al., 1996)] revealed that there were 68 NGOs providing services to people with disabilities. Financial support for the services are received from outside and inside the country from both private and government sectors. Examples of organisations working for the disabled are Save The Children Fund UK, Foundation for Children with Disabilities, Kunakorn Foundation, Sai Jai Thai Foundation, Foundation of Sang Sawang Institution, Thamanikachon for blind people, and the Foundation of Mackane Institution for Rehabilitation. Assistance is provided in different forms such as direct care, financial support or protection of the disabled's rights. The organisations normally focus on a specific group. For example the Sai Jai Thai Foundation mainly serves the army while the Mackane Institution provides help to disadvantaged and low income people.

The existing arrangement of services is also problematic. Lack of coordination can result in inefficient provision of services. Similar kinds of rehabilitation programmes may target the same group of people. Although legislation requires that rehabilitation services be made more accessible to the disabled, the services are still limited to urban areas. Very few disabled or health personnel are knowledgeable about the legislation. Only 2-10% of the total estimated number of disabled are registered to obtain the rehabilitation services outlined by the Act (Wiboolpolprasert et al., 1996). Most disabled are still taken care of by the family in the traditional manner. Attempts have been made to solve the problem by recruiting both government and NGOs to work together under the National Rehabilitation Committee for People with Disabilities and expanding services to the rural area. The continuing challenge is to translate this aspiration into reality.

4.6. Social Welfare in Health

The health welfare system in Thailand can be divided into four types (Thailand Ministry of Public Health, 1990, p. 19):

1. Medical benefits for government officials: permanent employees, and state enterprise employees. These benefits also cover all the expenses of government health services for personnel's parents, spouses, and no more than three children under twenty years of age. Only half of the actual expenses but no more than 3,000 Baht (approximately A\$ 120) can be reimbursed when receiving private services as an in-patient.

2. Medical benefits for the general population. This type of benefit aims to provide free government health services to disadvantaged groups of people throughout the country. These groups include low-income people (monthly income less than 2,000 Baht per family or 1,500 Baht per single person), aged people (60 years or over), primary school pupils.

3. Compulsory health insurance. There are three types of compulsory health insurance. Firstly, protection for work-related accidents or illnesses which is the responsibility of labour compensation funds, secondly, protection of employees for non-work-related illnesses which is applied to work places with twenty employees or more, and lastly, protection of car accident victims which covers up to 50,000 Baht (approximately A\$ 2,000) per injury.

4. Voluntary health insurance. These are optional health insurance schemes provided by both private companies and the government. Private health insurance is mostly held by middle and upper class people who are not covered by any health benefits or wish to ensure access to good private services. The percentage of people holding this type of insurance is very low (1.6%). In contrast the government's voluntary health insurance scheme is aimed at protecting lower income people who are not eligible for other types of insurance. Participating families pay 500 Baht and the government subsidises this with another 500 Baht per year. Card holders are entitled to government health services in the province where their cards are purchased.

Even with encouragement from the government for people to enrol in these voluntary health insurance schemes, only just over a half of the Thai population

(58.4% or 33 million people) are covered by the existing health insurance schemes in term of access to medical services.

5. Summary

The majority of the population in Songkla Province live in a rural area. Despite the effect of rapid economic growth in the last two decades that has shifted the labour force from the agricultural to the industrial sector, the main occupations remain linked to agriculture, especially rubber plantations. People's way of life is still tied to traditional values and beliefs, that is there is much interaction and mutual support among members in their extended family. Outside the family unit, people's socialising is closely linked with religion, the dominant one being Buddhism. Religious activities provide people with opportunities to 'do merit' and interact with their social network.

The official health care system is entirely Western in style. However this system is not popular with the chronically ill and disabled due to inadequate services and the lack of a rehabilitative component of care. These groups still predominantly use traditional medicine as it is more understandable, negotiable and easily accessible.

CHAPTER 4 : METHODOLOGY

1. Introduction

The ethnographic method was chosen for this study because it facilitates exploration of people's socio-cultural knowledge (Spradley, 1979). By using this method the researcher can explore stroke patients' understanding of their lived experiences in their own settings in the community. Ethnography allows the researcher to go beyond what they have observed to inquire about the meaning of those behaviours to the people involved. By these means an understanding of the self-care phenomenon which is a culturally influenced behaviour can be facilitated. A thorough exploration of this behaviour requires an understanding of what patients' lives are like after the illness, how their life experiences have changed, how they describe the meaning of their experiences, what they do to solve or cope with their new life situation, and what their customs and beliefs are in relation to health and illness care.

2. Sample

Contributors to this study consisted of stroke patients, their family carers, neighbours and other key informants. The other key informants included health personnel in the hospital, community health professionals, healers, and persons with knowledge of traditional health services, customs and culture of the studied community.

Ten individuals recovering from a recent stroke were invited to be a part of the study together with their family members. The primary source of the core participants were patients (eight) from three major public hospitals in Songkla Province, Thailand, augmented by two stroke victims from the community.

The following criteria were used for selecting patients to participate in this study:

1. Diagnosis of stroke of recent occurrence
2. Stabilised medical condition
3. Ability to speak Thai

4. Absence of mental or physical impairment which can affect memory or the ability to verbally communicate their experiences and feelings regarding self-care

5. Agreement to be involved in the study

Potential participants were identified by asking nurses or other staff in the hospital to provide access to the records of patients recently admitted with a stroke and whose condition had stabilised. Patients who met the selection criteria and their family carers were then approached to participate in the study before the patients were discharged from hospital. At this time I explained the purpose of the study, the data collection process that would be undertaken, the benefits and risks that might arise from the study, and provided an opportunity to ask questions.

Contact with two of the participants was made outside the hospital setting. One of them was a recent stroke patient who had just been discharged from hospital. I was informed about this new case by one of my existing informants and his family. Participants and their families often told me about other stroke patients in their community and offered to take me to see them so I could include them in my study. Unfortunately most of them were 'old' strokes and did not meet the criteria to be a part of my study. The other study participant had been discharged from hospital for some time and I happened to meet him at the healing centre when I went with one of my other informants to the centre.

This study consisted of 10 stroke participants, six males and four females. The average age was 60.3 years (ranging from 44 to 72). All participants were Buddhists. Five were working before the illness, three were housewives and the other two were retired. Eight of them lived with their families before and after their stroke. The ninth participant who lived on his own before the stroke, now lived in a small house within the family complex and was in daily contact with his family. The remaining participant was placed in a healing centre under the care of a hired carer and was visited by his family. Half of the participants were residing in rural areas while the other half lived in urban areas but still lived a rural type life style. They were admitted to hospital with a diagnosis of hemiparalysis due to left sided stroke (seven cases), and right sided stroke (three cases). The length of hospitalisation ranged from four to 47 days.

Other key informants living in the same community, who were knowledgeable and willing to share detailed information relating to self-care behaviour, were also invited to participate in the study. The information sought included aspects of health care services and culture relating to self-care. These informants were identified by theoretical sampling. This technique is designed to select informants who have specific characteristics or knowledge that can enhance the researcher's understanding of the phenomenon and context (Field & Morse, 1985).

3. Data Collection

Data were collected and analysed using Spradley's (1979) Developmental Research Sequence research method as a guideline. This method incorporates a systematic study of the way of life of an individual, a community or group of people, understood through the study of meaning within the language (Parfitt, 1996). Spradley's research process consists of twelve major steps arranged in sequential order to guide the researcher from the commencement of fieldwork to data analysis and writing the ethnography. The sequenced nature of the method assists the researcher to approach the research in a systematic manner and allows them to study a cultural scene in a way that is efficient and workable.

The Developmental Research Sequence Method (D.R.S.) consists of the following twelve steps (Spradley, 1979, pp. 218-222):

- locating an informant
- interviewing an informant
- making an ethnographic record
- asking description questions
- analysing ethnographic interview
- making a domain analysis
- asking structural questions
- making a taxonomic analysis
- asking contrast questions
- making a componential analysis
- discovering cultural themes
- writing an ethnography

The fieldwork conducted to collect data extended over a period of ten months. A number of data collection strategies were used. These strategies included:

- assessment of activities of daily living
- participant observation of self-care at home

- semi-structured, informal interviews with patients, family carers and key informants. At appropriate stages of the data collection process a card-sorting technique was incorporated into these interviews.
- focus group discussion with primary carers of other patients outside the group under study in order to compare the cultural knowledge obtained from the study informants, and
- collection of demographic and medical information

The first contact with all but two of the patients and family carers was during their hospital stay. Making initial contact with participants in hospital had both advantages and disadvantages. The patients' files in the hospital provided useful personal and medical information. Moreover, it seemed easier to gain the trust of patients and their families by using the link with health personnel and hospitals. On the other hand this first contact in the hospital could also have been a disadvantage as the participants may have viewed the nurse researcher as a service provider rather than a researcher and consequently might have expected professional health services from the nurse.

Just prior to or immediately after discharge from the hospital, the first assessment of the patient's ability to perform activities of daily living (ADLs) was conducted using the standard tool for ADL ability measurement (see Appendix 1) developed by Mahony and Barthel (1965). At this stage, I began to build up a relationship with the patients and their families. Additionally, medical data related to the illness were collected from the patient's file. Arrangements for the first visit to the patient's home were also made before their discharge.

In the case of the two participants who were not initially contacted in hospital, I went back to the hospital where they were first admitted after the stroke to obtain personal and medical data from their files. The ability to perform ADLs at the time they were discharged was also assessed by using information from the patient's file and asking the two patients and their families to recall the patient's condition at that time.

After a patient was discharged to the community, I visited the patient's home regularly. Participants entered the study at different stages of the fieldwork depending on the time they suffered the stroke. The period of contact with the

participants ranged from five to 10 months. More frequent visits were made during the early post discharge stage in order to closely observe of the management of care at home. Two more ADL assessments were done at two to three months post discharge and at the end of the study in order to compare the patient's condition at different phases of the fieldwork.

I participated in the informants' daily lives in order to observe their environment, activities and interactions among family members and neighbours in their own home and community settings. Casual discussions and formal interviews were conducted in natural settings. Then interesting issues related to the topic under study were identified for more detailed discussion. Thus, data collection by both participant observation and interview were conducted concurrently in the field. However, these data collection processes will be discussed separately in this chapter.

3.1 Participant Observation

The social setting for the study was family and community based. I functioned as an active participant observer over a period of months in order to observe and interview the patients and their family members at home and within the local community on numerous occasions. The aim of participant observation is to get close to the people participating in the study and to fit into a day-to-day role in their culture in order to understand the knowledge of others by interviews and observations (Werner & Schoepfle, 1987b, p. 23). Participant observation in patients' homes provided me with a clear picture of the family processes, in particularly the patient's self-care behaviour, pattern of family interaction and ongoing negotiations of family relationships and roles in participating in care provision.

During my first visits, my observations were broad and general. In the initial stages I observed the physical and social setting, the family members' reactions to the patient's condition, kinship relationship, general activities of daily life and interactions with neighbours. Then I focused my observation on the core participants: the stroke patients and their carers. I followed and accompanied the patients everywhere if possible, for example on visits to a health practitioner or to social functions. I behaved as a member of the group being studied. I talked and listened to the participants, recording the discussion if appropriate, and making a brief record of

what I had observed about the settings, the activities, and the interaction between people.

When participants know they are being observed, they may act in the way they want the researcher to perceive them, rather than behaving normally. I employed several strategies to facilitate informants becoming familiar with my presence in their home. I visited the patients and their families regularly at home over a period of a few months, before commencing formal data collection. Visits were also made randomly at various times (spot observation technique) in order to prevent the scene being set before my arrival (Field & Morse, 1985). I also decided to adopt the 'participant as observer' role (Field & Morse, 1985, p. 76), or as I would prefer to call it the 'active participant' role, for data gathering. In an attempt to be close to or a part of an informant's family, I had to use all my personal skills to incorporate myself into the informants' daily lives by participating in their household activities and social functions.

As Thai society is a society of kinship, Thais always recognise each other as brother, sister, son, daughter, father, mother and so on depending on age and type of relationship between them. An outsider can be included as a family member when he/she participates and shares the household and social activities with the family for a period of time which sometimes may be as short as a few months. The quality of the relationship is determined by the personal skills and characteristics of both parties, and the consistent involvement of the outsider.

In the initial stage of the fieldwork, I found that it was difficult for me as a researcher to participate in the patients' family lives or to be present in their homes among their family members. The strategy that I used to become a part of the scene was a gradual integration of myself little by little into the patient's family without annoying them. I helped the families with cooking, washing, preparing food to eat, providing care (if necessary), taking the patient to the hospital for an appointment to see the doctor, etc. Apart from sharing household and social lives with informants, I also asked to stay overnight with a selected family in order to observe and understand the whole life picture of the patient within the family context. I found it very difficult to give the informant good reasons for asking to stay in her home. The family might not understand if I simply told them that I wanted to observe caring activities over a

whole day including night time. I decided to shift the reason for asking to social purposes. I told the patient and her family members that I would like to bring a friend along with me so she could experience country life. Before I and my friend actually stayed with the family, I took my friend to visit the patient and her family at home a few times in order for them to become familiar with her. The response from the patient and her family was positive as a good relationship between us had already been established and they allowed myself and my friend to spend several nights with them. In doing so I had to bring my own bedding including mosquito net in order not to disturb the family too much and we also contributed food to the household for our meals. Our roles as members of their family had been discussed with my friend prior to our arrival and we actively participated in the family's household life.

Staying overnight in this informant's family provided me with significant information regarding the family's provision of care to the patient. In previous interviews, the patient and her husband had identified their daughter as a primary carer who helped her mother with all activities of daily living. However my observations during both day and night time was that the husband took care of all the personal activities, care and help as requested. The daughter only did the cooking, preparing meals for the patient to eat and bathing the patient when the daughter was available to do so. In this example, participant observation raised issues of family caring responsibilities to discuss with the patient and family to confirm the accuracy of the data. It is not uncommon for informants in Thai society to answer questions in the way they think society expects they should. In Thai society caring for sick parents is seen to be a daughter's responsibility. In this case the family, in response to this norm, may have identified this role as their daughter's in order to provide a culturally acceptable response to my questions.

3.2 Field Notes

During these periods of observation in the individual's environment, field notes were taken to note communication and actions, nonverbal behaviour, interactions between patients and their families and aspects of the physical setting that increased understanding of the activities of interest.

All general information about time and duration of each visit, place and events (family and social) at the time of the visit, together with a description of any changes in the physical environment since the last visit, were routinely recorded on a home visit form (Appendix 2) for each informant. I found that the home visit record was very useful as a point of reference for relevant interview transcripts.

Each informant's information was kept in a separate file with relevant materials from the site that related to findings and interpretations, for example, books, photographs, herbal medicines, together with the home visit record of each informant. These materials helped to preserve over time some sense of the context in which observations were made and thus assisted in recalling of events at a later time (Owens, 1982).

3.3. Interviews

Semi-structured formal and informal open ended interviews were used throughout the period of fieldwork with patients and their family carers. Interviews of this type were also conducted with key informants, for example, healers, health personnel in the community and informants' neighbours. When contacted they were informed of the purposes of the study and asked if they would agree to be interviewed about health care services and the cultural aspect of health care behaviours.

An initial interview guide was developed from a literature search to cover issues to be explored for each group of informants: patients, family carers and key informants. The guide consisted of a number of open ended questions (Appendix 3). It provided ideas but no particular ordering of questions to elicit responses about the topic and also allow the informant freedom to discuss relevant information in depth. The appropriateness of the content, length of and setting for an interview was tested with a pilot case before commencing data gathering in the field.

I entered the research scene with the aim of gathering general information on issues or obtaining an overview of the situation, thus general questioning and informal open ended interviews were used during the early stage of the fieldwork. More formal interviews using the interview guide were conducted with patients and their families when the relationship with the researcher was established. As the

process of data gathering was going on, comments or answers provided by informants led to further questions, which were then incorporated into the continuing inquiry. The interviews were audiotaped if possible, and then transcribed verbatim in Thai and then translated into English for further analysis or were noted exactly as possible if the interviews had not been audiotaped. The nonverbal aspect of the observed interactions and the physical surroundings of the interviews were included in the field notes as they can reflect on the issues under study.

The interviews were conducted in the informant's local dialect where appropriate. Although the same written language is used across Thailand and the Central Thai language is the official language for every part of the country, a number of dialects are used in different parts of the country for everyday purposes. In southern Thailand, people use both Central and Southern Thai language for daily communication. Most of the people in urban areas use Central Thai whereas those who live in rural areas normally use local dialect. The researcher used both languages depending on which one was used by the informant.

The length of the interviews varied from one to three hours. This was because the interview took place in a patient's home environment which was more natural. Usually not only the patient participated in the conversation, but also family members and neighbours. This general participation encouraged people to feel more relaxed and thus feel more free to talk. However, it took me quite a long time to be able to collect systematic information because of numerous interruptions to the interviews by other family members and neighbours and I had to be very conscious of controlling the topic of discussion, otherwise the discussion could easily get off track. The length of the interview depended on a number of factors: how interested the participants were in the topic of conversation, the physical and emotional condition of the patient, the personality and mood of the patient and other participants, the general atmosphere and interruptions. Thus I had to use my own judgment as to when I should stop the interview. In respect to gaining initial permission to audiotape interviews, I found a combination of several strategies worked well. At the first interview we would discuss general topics such as family matters, occupation or politics in Thailand which are the most popular topics of the southern Thai natives' daily conversation. Also asking to tape record the

conversation of a group of two or three people in their home settings made it easier to introduce the tape recorder. I then would keep tape recording regularly until the informants got used to the procedure and no longer felt uncomfortable.

Literature from Western culture suggests that interviews with informants should be conducted in private and in a setting free from interruptions in order to encourage an informant to discuss in depth the issues being studied. My first pilot interview was undertaken in accordance with this advice. I took the interviewee to a small air-conditioned lecture room in the School of Nursing that I had already booked for the interview. I thought it was a perfect room for the interview as it was not far from the Physiotherapy Department where the patient, the interviewee's husband, was receiving treatment and more importantly, it provided privacy where we could discuss issues freely.

I found that the interviewee was very uncomfortable with this Western approach. Despite providing a full explanation of the purpose, structure and ethical considerations relating to the interview, and requesting permission to tape record the interview, she did not allow me to audiotape the discussion. She also kept indicating that she would rather be in a less secluded setting. I surmised this refusal was probably because I had not yet gained her trust. This negative response from my first interviewee made me hesitant to ask later participants for permission to audiotape their interviews. I found out later that lack of trust was not the reason, as I was given permission to audiotape the interviews with other informants, even at the first meeting, without any difficulties when I asked to do it in a less private environment. The privacy needs of Thais are culturally different from Western people, thus a more relaxed and less private interview atmosphere appeared to be more appropriate in this setting. The participants would speak about their personal lives to a certain extent in the presence of their neighbours and the researcher who was a stranger. Additionally, they felt more comfortable talking about themselves in more public places than being interviewed in a private setting. I therefore did later interviews in the hospital ward or informants' homes whenever the situation allowed me to do so.

In these situations, family members and neighbours often became involved in the discussion. In many cases, the interview would be interrupted as the newcomer raised a new issue to discuss in the group, resulting in the planned interview not

being finished. In this case, I had to accept the situation and I would not try to bring the group back to the previous discussion unless the topic interested the group and they raised the issue again themselves. I found joining in the group's conversation was also very useful in that it allowed me to learn more about new issues and their reaction to these issues. These data contributed to a more holistic picture of their lives. In these circumstances, some parts of the interview might be audiotaped whereas the others were briefly recorded in writing.

For issues that needed to be discussed with the patient or carer(s) alone, I had to find appropriate opportunities in the natural setting. When these type of issues arose in open discussion, rather than pursue them, I would note this and raise the issue at a later home visit when it was more appropriate to do so. I found with very personal issues such as sexual problems that patients did need privacy to talk about them and they would only discuss them once trust in the researcher had been established. They didn't feel comfortable talking about these issues in the presence of a third person, even their close family members or spouses, so I had to find an appropriate time to discuss the issue with them alone at home.

As has been mentioned earlier, the informants' perceptions of the researcher's ideas and beliefs in the informants' culture can affect their responses to the researcher's questions. Because my background in term of education, occupation and social status was different from those of the informants, they might have only felt comfortable discussing what they thought the researcher believed in and tried to avoid talking about what they thought the researcher did not believe in, for example, issues relating to magical power or religion. When I asked about these sorts of beliefs, informants were reluctant to talk about them. They usually responded to my question by saying that "I engaged in that sort of treatment (a traditional treatment) because I wanted to know what they were doing. I just wanted to learn about it. I know it's not scientific" or "You may think I am stupid or I am being duped by the healer". Some informants asked me to turn off the tape recorder before talking about these beliefs. In dealing with this problem, I had to show them signs of acceptance, respect and interest in their culture rather than making them feel stupid.

Three main types of ethnographic questions - descriptive, structural and contrast (Spradley, 1979) - were used throughout the period of fieldwork. Descriptive

questions were used in the initial interviews in order to obtain informants' experiences in their own words. For example, in order to obtain information on the effect the stroke had had on their lives, I asked: "Can you tell me how your life has changed since your illness?". Or I might ask them to describe their daily life experiences before and after the illness with these questions: "How did you normally spend your day before you were sick?" and "Since your illness what do you normally do from the time you get up in the morning until you go to bed at night?". These questions would help to identify what were seen as changes of their daily activities resulting from their illness.

Structural and contrast questions were then used to obtain more specific information. The purpose of using structural questions was to confirm included terms (folk terms) and cover terms (categories) which had been identified from the initial interviews based on descriptive questions. Structural questions were also used to seek more terms to add to the existing categories. For example, when I was exploring the included terms within the cover term 'Mhor' a category referring to practitioners, I asked "What are all the different kinds of people whom you consider to be a Mhor?" I provided the respondents some time to give me examples of Mhor. Then I would raise some included terms that I was not sure about to ask them to verify whether, in the respondent's opinion, the terms should be included in this domain.

The contrast questions were used to identify the differences and similarities between terms within a domain. As an example, in exploring the domain 'Mhor' in more depth, I asked a patient to sort the lists of 'Mhor' into groups, based on her/his own criteria. This process helped me to understand the relationship between individual included terms or groups of terms within a category. To assist informants answer these structural and contrast questions, I used the card sort technique described by Spradley (1979, pp. 130-131, 168-169).

3.3.1. Card Sort

Card sort is a useful technique as it provides participants with a visual sense of the relationship among the folk terms being investigated (Spradley, 1979). In using the card sorting technique, I wrote all the folk terms obtained from interviews and that had subsequently been categorised into a domain, on to individual cards.

These cards were then displayed for the participants who could move them around or just view them as they talked.

Folk terms included in the domain of 'caregiver' provide an example of the process. I wrote each type of caregiver whom the informant had mentioned earlier as contributing to providing patient care, on an individual card, for example husband, wife, daughter, son, daughter-in-law, son-in-law, grand children, niece, nephew, neighbour and so on. I then asked the informant to identify if there were more types of caregivers that she/he could think of who were not nominated on the cards. Very often the informant could add more folk terms to the list. If some new terms came up, I would write them on cards and add them to the list. I then asked the informant to sort all the cards into subgroups based on similarities and differences according to her/his own criteria.

The informants sometimes found it difficult to sort the cards into different groups. I then needed to provide them with examples of criteria that could be used as a basis for sorting. Providing a cue could quickly lead to the informant identifying the boundary of a folk domain. When I needed more explanation or clarification of a folk term, I would discuss that particular card with the informant. I found the card sorting technique to be very beneficial in focusing the informant's attention on the issue under discussion, especially for those who had short attention spans.

3.4. Demographic and Medical Information

Interviewing for demographic and medical information was conducted by using a data collection form (Appendix 4). Information relating to the illness and some patients' personal information was also collected from patients' files in the hospital.

3.5. Focus Group

A focus group was conducted with primary caregivers of other 'old' stroke patients who had suffered a stroke one or more years previously. The purpose of this strategy was to compare their illness experiences with those of the informants in the study and to seek explanations for some common experiences obtained from informants. As this discussion was arranged in the late stages of my fieldwork when I

had nearly finished my data collection, a number of cultural patterns emerging from the study could be cross-checked and verified with a group who had experience in caring patients with the same illness but for a longer period of time.

The focus group discussion with primary carers was held in a traditional healer's centre treating a number of stroke patients. During treatment, these patients resided at the centre with their families. Six primary caregivers, four females and two males, were invited to participate in the discussion. Before the focus group took place, I visited them a few times in their huts to build up rapport. Based on the advice of a knowledgeable carer in the centre, the focus group was held at a time which did not clash with popular drama programmes on television. As no suitable room was available, the discussion was held in a shed under a tree in grounds of the healing centre. To ensure the discussion would be free from interruptions in a public space like that, the carer in the centre from whom advice had been sought was asked to keep people away from the group. However, this individual herself interrupted the group on several occasions. An assistant was assigned to help with tape recording, and to note contextual information and the participants' interaction in the group.

The discussion focused on issues of self-care, the contribution of family caregivers to the provision of care, the ability to cope with their problems at home, plus health services and strategies that they used to solve their health problems. The data obtained from the focus group were then compared with the data from the group being studied.

4. Ethical Considerations

Permission was obtained from the University's Human Research Ethics Committee and the ethics committees of the three hospitals in Thailand, prior to commencement of the study. Assurances were provided to the committees that conducting the study would in no way endanger the well-being or chances of recovery of those patients involved. The purpose of the project and detailed information on the research activities to be conducted in the hospital (initial assessments in order to screen for eligible participants for the project and access to patients' files in order to obtain information relating to their illness) were provided.

In dealing with participants' care needs, I provided as little professional care as possible. When necessary, for example when patients asked for help or suggestions, I would not avoid providing these but delayed my responses where possible to a more appropriate time in the visit. When emergency situations arose, I would recommend that the patient return to the hospital to obtain the necessary care.

After receiving permission to proceed, patients who met the selection criteria and their family carers were approached to participate in the study. Participants were informed of the voluntary nature of their participation and advised that they might withdraw from the study at any stage, without penalty or disadvantage to themselves. Informed consent forms were signed by either the patients or the primary carer with a copy given to each signatory. This form served as a written verification that the participant had been informed about the nature of the study, the means of data collection to be used, what their participation would involve, risks that may occur during the project, and that he or she had agreed to participate and could withdraw from the project anytime without negative consequences (Appendix 5).

Two strategies were employed to maintain anonymity and confidentiality. In the field notes and transcripts pseudonyms were used. Also any information by which informants could be identified was altered during write-up of the research. The informed consent form clearly stated that any publication resulting from this study would not include names or identifying information and that pseudonyms would be used. According to the university regulations, all transcripts will be kept in a secure place by the researcher for a period of five years following the study. At the completion of the research, all audiotapes were erased.

Although my visits inevitably disturbed the privacy of the participants and their families, I tried to minimize the effect by regularly asking the participants, to let me know whenever they felt uncomfortable due to my presence or answering my questions. I would ensure that they felt free to stop the tape recording any time they wanted and I also assured them that I was not judging them on their ideas or thoughts but I respected and was really interested in whatever was meaningful to them. I also clearly stated that it was their right not to discuss any given issue if they found it too uncomfortable to do so.

5. Data Analysis

The analytic process involved a description of the situation under investigation, then lead to explanations of relationships and finally to developing a model to describe self-care of stroke patients in the Thai cultural context. Four components of ethnographic analysis as described by Spradley (1979, pp. 107-203) were used for data analysis: domain analysis, taxonomic analysis, componential analysis and theme analysis.

Domain analysis involved a systematic search for large units of cultural knowledge and provided an overview of the cultural scene. In undertaking domain analysis, semantic relationships and structural questions were used to identify, verify and categorise folk terms (included terms) into domains. In identifying included terms into domains, I explored the interview transcripts and field notes for included terms which shared similar meanings in relation to cover terms (the names for cultural domains). These two components - included terms and a cover term - are linked by means of a semantic relationship. For example 'Mhor' is a cover term for 'practitioner' which includes 'included terms' such as doctor, nurse, physiotherapist, Mhor-Baan (healer), Mhor-Nuad (masseur), Mhor-Ya (herbalist), etc., The semantic relationship in this case is 'Kinds of Mhor'. Thus doctor, nurse, physiotherapist, Mhor-Baan (healer), Mhor-Nuad (masseur), Mhor-Ya (herbalist), etc., are kinds of Mhor or practitioner (Appendix 6, 7). Using structural questions as mentioned earlier, helped to confirm and add more included terms to complete the domain. This analysis involved systematic comparison of information across all interviews and observations within cases in order to determine whether or not there was a fit with the existing domains and to ensure that all examples relevant to the issue under study were labelled and fitted into the identified domains.

The domains which were central of the issue being studied were selected from the first step of analysis for further in-depth analysis or taxonomic analysis. This is the process of developing a taxonomy of folk terms within a domain. The folk terms were organised into subsets through their semantic relationships to the cover term. As a result, new relationships among folk terms within each domain were identified and the internal structure of the domain was revealed (Appendix 8).

The third step focused on the differences among folk terms in a domain which were then organised more systematically by using componential analysis. In this step, components of meanings (attributes) associated with folk terms were examined by searching for differences, sorting and grouping them together. These differences helped to understand and distinguish the attributes of folk terms in a domain. For example, in order to understand more about the informants' perceptions of Western and traditional practitioners which were listed under the same domain 'Kinds of Mhor', I searched for references to these terms (Western and Traditional practitioners) in interviews in order to identify differences. When these two terms were contrasted, I discovered that the informants perceived that the Western Mhor provided services in a hospital or a fixed institution and their services were expensive, difficult to access, more effective in treating some symptoms, etc. On the other hand, traditional Mhors provided services at their own homes, or patients' homes or temples. Their services were less expensive, easier to access and more effective for some symptoms relating to a disturbance of 'body lines' (see Appendix 9).

Dimensions of contrast which had binary values were identified by using 'yes-no' (Spradley, 1979) or 'plus-minus' signs as recommended by Werner and Schoepfle (1987a). For example, receiving systemic training, providing herbs, massages, spiritual rituals are contrast dimensions relating to the domain 'Mhor'. Each dimension has two values: 'yes (+)' receiving systemic training or 'no (-)' does not receive systemic training. Other dimensions included: herb provision, massages, undertaking spiritual rituals 'yes (+) or 'no (-)'. This stage of analysis provided a means of eliciting numerous attributes of folk terms and clarifying relationship among folk terms in a domain by contrasting a term with all other terms within the same domain.

Fourthly, theme analysis was used to search for relationships among domains and how they were linked to the culture as a whole. At this stage, all domains which were considered important from the informants' point of view were integrated together to describe the total phenomenon being studied.

The initial analysis of data was undertaken concurrently with data collection. This concurrent approach helped the researcher identify additional questions to ask and guide the data collection. Data analysis was first done within cases, so the initial

analysis was contextually based, and to ensure that the data was as complete as possible for each case. Then the first three cases were translated into English and the included terms and domains were combined and reviewed. The remaining seven were then translated consecutively. New included terms and domains which were identified by later informants were added to the initial English analysis; thus a final complete analysis in English was gradually built up from the initial three cases.

6. Issues of Rigor

Reliability and validity of the findings were established by several means: extended period of data collection in the field, data checks by obtaining information on the same topic or event on a number of occasions, spot observation techniques, triangulation, identification of possible sources of researcher bias and using another researcher to confirm data categorisation.

I spent a period of time with the people being studied as a participant observer on a regular basis in order to reduce the feeling of my being a 'stranger' to the informants and gain their trust, so they would be willing to share their lives as they really were lived. This exposure also provided opportunities for me to check if there were biases in my interpretation or perception of information or activities (Owens, 1982). Time spent with each informant in the present study ranged from five to 10 months depending on when they entered the study. More frequent home visits were made in the early contact stages and regular but less frequent visits were made until I fully understood the participants' situations.

Accuracy of information was ensured by undertaking multiple interviews with the informants on the same topic, and repeated observations of the same daily life activities in the natural context. This also helped the researcher to clarify unclear or incomplete information. The "spot observation" technique as suggested by Rogoff (cited in Field & Morse, 1985, p. 96) and described earlier was also used to verify data from participants.

Triangulation of both data sources and data gathering methods was implemented during fieldwork. The purpose of triangulation is to check the accuracy of information. As themes began to arise from interviews, observations or documents, they were cross-checked with other sources to verify them.

To avoid researcher bias and to increase the objectivity of the data, the researcher identified personal feelings, values, beliefs and any ethical dilemmas or conflicts in order not to impose them on the data collection and data analysis. These were recorded in a field diary for on-going reference. To further ensure the credibility of the findings, interview transcripts, field notes, and analysed data were re-examined for any evidence of researcher bias.

In the process of data analysis, progress, personal experiences and findings from the analysis were discussed with interested colleagues. I randomly selected a set of transcribed interviews and asked a colleague to search for included terms and sort them into categories (domain analysis). Comparing the results of this analysis to my own allowed me to assess the consistency of sorting and the fit of folk terms in each category. This process also increased awareness of biases which might occur from my personal hypotheses about the data.

7. Limitations of the Study

Three main limitations are identified. Firstly, the study was conducted with stroke victims living a rural lifestyle in Songkla Province. Secondly, all the participants were Thai Buddhists. The study was unsuccessful in including Muslim clients, who are the second largest population in the province after the Buddhists. Therefore the findings of this study may best fit with mainstream Thai people living a rural style. Thirdly, individuals suffering from major consequences of stroke such as cognitive impairment and severe dysphasia were excluded from the study, therefore the impact of those factors is not demonstrated.

8. Summary

Ethnography described by Spradley (1979) was employed for this study. Data collection was based primarily on two major methods: participant observation and interview. Fieldwork is central to the ethnographic study. This is because of the belief that human behaviour can only be understood within the context in which it occurs. A period of ten months was used for data collection in the field with ten stroke participants and their families. Ethnographic fieldwork requires the researcher's active participation in the culture being studied as the researcher is the most important

instrument for data gathering. A number of strategies considered to be culturally appropriate were successfully used to gain access, trust and maintain relationships with the group under study in the field. Similarly a variety of means were employed to ensure the trustworthiness of the study. Data collection and analysis proceeded concurrently, using ethnographic methods as described by Spradley (1979). This method of analysis comprises domain analysis, taxonomic analysis, componential analysis and theme analysis. Ethical considerations were based on respect and protection from harm. The latter involved the researcher using nursing knowledge when necessary.

CHAPTER 5 : THE INDIVIDUAL'S EXPERIENCE

1. Introduction

This chapter discusses the lived experiences of the participants following their stroke. The individuals' views about self-care and care-receiving roles in the family context are explored in order to gain understanding about self-care and family interaction in relation to self-care. Their experiences relating to major difficulties or stresses as a consequence of the stroke are identified. Coping strategies employed by individuals are then described and discussed. The focus is mainly on the period after hospital discharge.

1.1. Functional Assessment

An assessment of the individuals' ability to perform activities of daily living (ADLs) was carried out in order to monitor functional recovery. These assessments helped understand the individuals' responses to their condition which were in part influenced by the amount of physical improvement. The assessment was done at three different stages: immediately prior to discharge, two or three months later (during the initial phase) and at the end of the study (see Table 1). The study employed the Barthel Index Assessment tool (Mahony & Barthel, 1965) (Appendix 1) to examine an individual's ability to perform basic self-care tasks. The total score is 100. One hundred BI (Barthel Index) means a patient is continent; can feed, dress and bath him or herself; get up out of bed and chairs; walk at least a block; and can ascend and descend stairs.

The findings show that when discharged, the participants' level of activities ranged from 35 to 75 (out of a possible total score of 100). Five participants scored between 60-75 whereas the other five had scores ranging from 35 to 55. All participants still relied heavily on family caregivers in performing most daily activities such as preparing food, bathing, dressing, and cleansing after bowel movements.

In the first few months after discharge most participants experienced very little functional improvement. Most improvement occurred in the ability to move in bed, personal toileting and walking ability. Dramatic improvement in the first few

months occurred in three individuals (scores increased by 20 to 35). Two of these individuals were readmitted to the neurological hospital for two months to undertake a rehabilitation programme. The third individual was originally complete dependent and semi-comatose on discharge from the hospital. His initial rate of recovery was very rapid, especially in the first month, until he could partially help himself, and then no further improvement occurred.

Seven of the participants achieved a higher score in the final assessment at the completion of the study, indicating further recovery. The score for two of the participants showed no change from the initial phase of the recovery. One participant demonstrated a complete loss of independence due to a fall resulting in a fractured hip and a consequent loss of confidence in recommencing self-care activities. The average score of functional ability of the participants increased from 54.5 immediately after discharge to 66.5 in the first few months and then to 71 at the end of the study.

When asked about perceived functional improvement, half of the participants indicated they had experienced some degree of improvement whereas the other half believed there had been no improvement or that their health had actually deteriorated. The perceived improvement in health was correlated with the score increment from the second to the third assessment. The perceptions of those who had only a small score increment (+5) ranged from improvement, no improvement, or even deterioration depending on their concerns which were used to justify their judgement.

2. Personal Experience

The individuals' lived experiences of the illness as well as their views about self-care and care-receiving roles are discussed. Their experiences are described in two phases: initial and chronic phase. Generally, the individual's activities after the stroke focused on complying with treatment and seeking effective health services in order to be cured and then be able to resume normal life as soon as possible.

2.1. Initial Phase

The initial phase covers the period from the immediate response to the stroke to around three months post-stroke when the individuals started to change their health seeking behaviours. In this early phase, the individuals were hoping that they

would be able to fully recover to the pre-stroke level of functioning. During this phase both the individuals and their families devoted their energies to the treatments they trusted, in particularly traditional massage and traditional medicines.

Table 1: Changes in participants' ability to perform functional activities following hospital discharge and their perceived improvement.

Participants	1. After discharge (baseline score)	2. Degree of change at 2 to 3 months after discharge (1→2)	3. Degree of change at the end of the study (2→3)	Perceived improvement	Remarks
Winai	35	70(+35)	70(0)	no	was readmitted for rehabilitation was readmitted for rehabilitation was readmitted for rehabilitation
Yupa	40	75(+35)	80(+5)	yes	
Plup	45	50(+5)	60(+10)	yes	
Pirat	55	60(+5)	80(+20)	yes	
Choo	60	65(+5)	40(-25)	no	
Laap	60	65(+5)	70(+5)	yes	
Prateep	45	65(+20)	70(+5)	no	
Suree	65	70(+5)	95(+25)	yes	
Nui	65	70(+5)	65(-5)	no	
Pak	75	75(0)	80(+5)	no	

Decision making on health related issues is determined by the client's recovery goals. Most clients saw their goals as the regaining of full physical functioning even though it might not be perfect. These were examples of participants' goals:

- could walk without assistance within two months
- shoulder would be cured after finishing a herbal compress course
- hand could be functioning at least for personal daily activities
- paralysis of facial muscles should be gone after three treatments
- should be able to carry a bucket of water with the affected hand within five months

2.1.1. Prior to Hospital Admission

Most participants blamed their first symptoms (Benlom) on being too tired, not having had enough rest or on the weather being too hot. They did not take the symptoms seriously. The early symptoms were detailed by the study participants as seizure, dizziness, numbness, weakness or heaviness of hand and leg, enlarged tongue, facial paralysis and difficulty in speaking. These symptoms were treated with home remedies based on their knowledge and belief system. These remedies included massage, herbal medicine (Yalom) and resting. The following examples illustrate the initial reaction to the illness and the family's response to the symptoms.

At first, I thought I had 'Benlom'. As I have never been sick before, except for feeling faint which often happens to me and will be gone after having 'Yalom', together with taking a short rest. But this time was different. The healer told me it was 'Lom-Ummapaat' (a kind of fainting which caused paralysis of muscles) (Choo)

They fed me 'Yalom' and did massage over the weak muscles like they usually do when people get faint, but it didn't work this time. I didn't feel better at all. When my husband came back, he called his mother to massage me. At that time, I didn't think it was serious. I thought that if I took a rest, I would be better. Many neighbours and friends told my husband to take me to see a healer and finally my husband decided to fetch the healer who lived near our house to massage me at home. He spent an hour kneading over the entire area of weak muscles and gave me a pack of herbs (Yamor). That night, my illness got worse. I was suffering from a severe headache and couldn't sleep all night. (Suree)

Pirat's account supports the widespread use of massage to treat the initial symptoms:

I just finished shredding coconut and decided to take a bath before I started to cook. In the bathroom, I felt numb on this area (the entire area of his right hand and leg) and I noticed that my right foot dropped down. I couldn't stand properly. I then called my wife and told her my problem but I still kept on bathing until I finished. I told my wife to help me out because I felt that I might not be able to get out of the bathroom and it was true. I had to hold the wall while I was walking to the bed and lay down. At that time I was afraid that I might faint. I told my wife to fetch my mother who lived about three blocks away from my place, because she can do massage. When she arrived, she gave me 'Yalom' but I didn't feel any better. Then I decided to go to the hospital.

His wife added some more details about the initial care given to her husband:

We gave him a massage by kneading his entire muscles and walking on his back and legs but he didn't seem to be improve. He started to yawn and sweat. We then gave him 'Yalom' but he got worse.

Seeking external help occurred when the symptoms persisted or became worse. This could be hours or a few days from the onset of the illness. The initial source of assistance was most frequently folk health services available in the community and then the hospital if the individual's condition had not improved.

At the breakfast that morning, I found out that I still could neither move my mouth nor feed myself. I decided to take some more 'Yalom' which helped me to finish my breakfast. After breakfast, I stayed in bed for about 10 or 20 minutes, and I then decided to go to see Mhor-Beeb in Taa-Sai but I couldn't see any improvement. I then went to see Mhor-Nui in Toong-Loong. He massaged me. Again there was no improvement after the treatment, I finally decided to come here (hospital) to see a doctor on the next day. (Pak)

I didn't think it was this serious and it also occurred during the night which was outside working hours, so I thought I should wait until the next day. The next morning, the healer (whom she saw the previous night) came to see me again but I told him I was too sick to stay at home. I felt that I needed to go to the hospital. (Suree)

All the study participants were eventually taken to the hospital for further treatment. Some of them were referred to the hospital by a traditional healer when they believed the individual's condition was serious, or was accompanied by some medical problems that needed urgent attention.

The mhor came to see my mother at home and suggested we take her to the hospital straight away in order to treat the high blood pressure. (Plup)

This study did not include the individual's experiences with the hospital services. Their attitudes towards Western health services will be discussed later.

2.1.2. Following Hospital Discharge

All the participants entered the hospital with no idea of when they would be discharged. Four of them requested to be discharged as soon as their acute physical problems were solved in order to obtain traditional treatments. The others were discharged as their physical condition stabilised and they were encouraged to recover at home. All of them were initially discharged home in the care of their family members. Only one participant later admitted himself to the local healing centre due to difficulty in obtaining regular treatments because of lack of transport and inability of the family caregiver to cope. Once home, the emphasis remained on obtaining beneficial treatments in the hope of complete recovery rather than merely improving their level of physical functioning and controlling any underlying disease processes.

On arrival home, the person was placed in a position where they could most easily be cared for, most frequently on the ground floor, with the primary caregiver close by, especially at night. This was a permanent arrangement to minimise transferring and lifting. The selected place was usually close to a window or door in order to allow the sunlight in and the individual to maintain at least visual contact with the outside environment. Generally little home modification had been done to facilitate the sick individual's independence. The most common modifications were installing bed rails, bathroom rails or exercise equipment (hanging sling for arm exercise and bicycle); and rearranging furniture in order to prevent falls, accidents, and also to facilitate the individual's mobility at home.

We have rearranged the home furniture in a way that allows her (the sick mother) support when she walks within the house. I think this is more secure than using a walking stick or crutches. (Choo)

It was evident that the sick individuals performed very little self-care or exercises as part of a rehabilitation programme at home. They relied heavily on their family for basic activities and health care needs. It was not surprising that most participants experienced some degree of unhappiness relating to the care they received from their family. They complained about difficulty in getting help and receiving 'inconsistent care' or 'little attention' from family members. These complaints increased over time.

I have been trying to do the things I think I can do myself. You know it is very frustrating when you ask for something and you are always asked to wait. (Suree)

One night, I wanted to go to the toilet and I called my daughter to get me a bed pan and she showed her annoyance and replied that she was very sleepy. She ignored my request. I had to hold my bladder. After a short time passed, she woke up and gave me a bed pan. I tried to understand her and not to get angry with her. (Suree)

I can't do exercises by myself. I need someone to assist me to get on the bicycle and remain with me to support my knee. You know I can't lock my knee. My husband used to help me with the exercises without asking in the first month after my discharge but lately he isn't concerned about my exercises. Now he has changed; he doesn't behave as he used to. I think he's now bored working with me. (Suree)

I'm reluctant to take a bath because I hate cold water and it's very difficult to ask some one to boil a pot of water for me. I have to be patient. I can't complain. (Nui)

Those who did not have a family caregiver to provide daily care, depended heavily on a hired carer. Having a primary carer from non-family sources was normally considered to be the last option by both the sick individual and their family. In the study, two participants were cared for by hired carers. Both individuals were not satisfied with the quality of care. The most serious complaint was a lack of responsibility and attention. This was probably because the carers were not skilled and were not hired on a full-time caring basis, that is they were hired for multiple tasks such as doing gardening as well as giving care.

Difficulty in obtaining treatment was a major concern raised by almost every participant. The difficulty was mainly related to transportation. Inability to obtain a lift and no regular transportation services were found to be the most common problem. Furthermore, during the rainy season it was more difficult for the participants to get to the hospital or healers due to flooding. For those who were normally taken in an uncovered vehicle such as a utz or a modified motorbike, it was even more difficult. Inability to access treatment services and lack of consistent, skilled support at home meant the individuals affected made little if any progress.

2.2. Chronic Phase

In this study, the chronic phase is defined as the period commencing after the first few months post-hospital discharge when the patterns of health-seeking behaviours started to change. These changes varied according to the family situation and how much improvement the participants had achieved during the initial phase of the recovery.

2.2.1. Health-Seeking Behaviour of the Participants Who Experienced Some Progress

Only three participants - Winai, Yupa and Prateep - experienced a marked improvement in the initial phase of recovery (see Table 1). The major improvement was in regaining leg muscle strength and walking ability but there was very little change in hand function. Given these positive outcomes, all three were committed to the treatments they were undertaking in the hope that they would be completely cured. Winai remained with the healer for another two months after the initial positive response to the treatment, until it was clear that no further improvement would occur. The family then started to seek other treatments or remedies. With limited finance and lack of a caregiver, he finally ended up with a healer in a healing centre which suited the family situation and finances. Similarly, Prateep and Yupa also initially decided to maintain contact with the hospital as they could identify potential benefits but in actuality this did not happen due to lack of a clear follow-up plan. Prateep's son expressed his feelings about this:

We haven't been informed about the rehabilitation plan following discharge, so we don't know what is going to happen in the future. The doctor just told my father to come back to see her when he finished the medicines. We probably need to make our own decisions about care.

Yupa started to seek for other treatments when she was told that she had probably achieved the highest level of functioning she could hope for.

I was informed by the doctor on discharge that I couldn't be completely cured. My condition at that moment was probably the best I could reach. I didn't believe her. I'm sure that I could be completely cured. I think I'll go back to see the spiritual healer who used to treat me by using spiritual words and Yamor.

2.2.2. Health-Seeking Behaviour of the Participants Who Experienced Very Little or No Progress

Most participants perceived very little or no improvement in the first few months after discharge. After moving from one practitioner to another without any obvious improvement, these participants started to struggle with what to do next, and where to go for further treatments. They all expressed the view that they had to do something. The main reason of changing treatments was that the expected improvement could not be observed after a certain period of time.

Most participants still clung to the regimens that they trusted while trying other treatments if not contra-indicated by the principal treatment. For example at one stage, Pak was on several remedies at the same time. He also had been to many healers one after another in order to get treatment for his shoulder and arm, including getting x-rays done in order to check the effectiveness of the folk treatments. Some participants started to try some other forms of traditional treatment although they were not sure about their efficacy. Prateep for example mentioned his ambivalent view about a traditional treatment but he finally used it as a major treatment.

I normally don't believe in miracle treatments. When a healer talks about Lom-Ummapaat, an obstruction of the wind gate in the human body, I'm wondering what kind of wind and how it exists in our body. I don't understand the concept and am not sure if it can help my illness.

Chacrit (caregiver) always said that he had no trust in ritual activities but he had taken his wife (Suree) to see many healers for various treatments of this kind.

We have been to everyone who might be useful to her illness. Yesterday, I took my wife and my family to join Suad-Paan-Yak in the temple. I don't trust the activities at all. I just wanted to know what it's like.

In summary, the participants experienced a number of difficulties relating to obtaining care at home, finding transportation to get to treatment, and decision making related to the selection of a particular treatment. Most of the time after hospital discharge was spent seeking beneficial remedies.

2.3. Views About Self-Care Roles

All participants in the study perceived their condition after the stroke, the legacy of which was a residual disability, as 'being sick' or at least some degree of 'being abnormal'. This perception is illustrated by the following quote:

I'm a patient at the moment, I should act and live as a patient. I won't try to do the things that I can't do it myself. I won't take any previous responsibilities with me. I leave all my work there, I can't do it now. I won't think about it. If I think too much, I may get stressed and it can create further problems. When I'm sick, I should behave as a sick person. (Pak)

This statement implies that the sick individual should be exempted from normal activities and responsibilities. The individual's new role is to behave as a good patient in order to get out of the state of sickness as soon as possible, or not to create more problems.

I try not to do a risky task myself. If an accident happens or when things go wrong, they may blame me as I don't know myself and create more problems. They always ask me to be a good patient and that would help them by reducing the risk of creating more problems. (Suree)

This is congruent with the views of her carer regarding this issue:

Do you know when something wrong happens with my mother for example she falls or has an accident, I as a daughter will be blamed, not her. People may think that I don't do my job or leave her unattended which may force her to solve a problem herself. The only thing I want from her is being patient in waiting for me. I will certainly come to assist her. (Suan)

Participants entered the 'self-care' role when perceived as 'being sick' or 'disabled' with different degree of involvement. Most of them considered assistance from their children as a part of the family's obligation. This group of participants were more likely to assume less of the self-care role and had high expectations of care given by family members. Pirat clearly identified his view on this issue:

I do expect my children to help me with the things I can't do by myself or have to spend too much effort to get done. I think it is the

time when they should help me because I have spent my entire life raising and supporting them. Is that too much do you think?

Another participant expressed a similar idea regarding this issue:

Why do I need to learn how to perform self-care tasks while I'm sick like this? I think it is the children's responsibility to take care of the parents when they are sick. I had worked hard and saved every 'Sataang (Cent)' just for their good future. Now is the time for them to 'Tob-Taan-Khun (reciprocate)' the mother. (Yupa)

Those assessed to be more independent had adapted by trying to limit their desires as well as trying to help themselves with their remaining capabilities.

I try to rely on myself as much as possible. I will ask for help only for the things I can't do myself, only when it is beyond my capability. (Pak)

When the actual self-care behaviours of those who perceived themselves to be independent were observed, they in fact still needed some support from family in the form of food preparation, laundering clothes, house cleaning, shopping and other home activities. They could be assessed as being independent as they could perform direct ADLs connected to survival, for example, feed themselves, bathing, toileting and mobilising. Support from their family was considered as 'normal family activities' which were manifested through family members performing their roles according to the situation. The following reflects participants' view of caring as a family responsibility:

Caring is a family matter. If they (family members) are all busy, they have to decide who to assign to be with me. For example if my wife has to be out somewhere, she has to ask my daughter-in-law or whoever to be with me to take care of my meal or help me when needed. (Pak)

This observation indicates that self-care in this cultural context requires some degree of family involvement. Thus self-care is not merely an activity performed by the sick individual. It can be characterised as a shared activity enacted through the individual and family members on the basis of mutual aid, reciprocity and family interdependence. The sick individual is never viewed as separate from the family unit. The sick individual's care needs cannot be met without co-operation from the

unit. The sick individual's care needs cannot be met without co-operation from the family members. The main motivator of care is not only the sick individual but the family as a whole as the wellness of the individual affects the well being of the whole family. There is no explicit or immediate reward for family members' involvement in providing care but in the longer term they will benefit from being part of the well family they are trying to achieve. From this analysis, it is clear that 'self-care' in this context is different from the concept of 'self-care' emphasised in the literature. It is therefore important to include family as a component of self-care in this context.

3. Major Changes and Losses

The participants' experiences of change fall into three major categories: physical, psychoemotional, and social. These changes led to a sense of loss for which participants needed to develop coping strategies.

3.1. Physical Changes

The physical changes occurred as a result of the stroke (immobility due to hemiparalysis, facial palsy, dysarthria, dribbling, ptosis, numbness, headache, body neglect, muscle spasm, and pain), its complications (foot and wrist drop, stiffness of joints, limitation of movement, muscle atrophy, shoulder subluxation, and oedema of the affected hand and foot), and/or accidents after the illness. Of the many physical changes, being unable to move and get around was of most concern for some participants. Another common concern was pain which was associated with shoulder dislocation (inappropriate shoulder exercises, inappropriate or over treatment on the shoulder, and inappropriate sleeping position), muscular spasm and headache.

All participants had been affected to a certain degree by complications. The main reason for these complications was a lack of effective and regular exercises due to physical symptoms (dizziness and pain), loss of motivation, and lack of understanding of how much depended on achieving the right balance between rest and exercise. Suree's comment illustrated these points:

I feel weak and get bored doing exercises... I had totally stopped exercising. I lost my motivation. As I'm weak, I don't have much confidence in walking alone. Nobody offers to help me to walk and I don't want to disturb others either. I think that my condition is just

about the same or worse than in the initial stage because at that time I was hopeful that I would be cured but now I feel hopeless.

Lack of knowledge led several participants to believe electrical equipment such as a vibration machine could substitute for active exercises in the rehabilitation process. General, non-specific advice from health professionals could also lead to misunderstanding and incorrect care. In one case the caregiver appeared to be using this lack of clarity as an excuse for not providing assistance with exercises.

My husband recently doesn't help me much with exercises as he used to do in the first month of my discharge. He sometimes used the doctor's advice (not to do too much exercise) as an excuse but I think he may be bored with assisting me. (Suree)

Falls were also a problem. The most frequent reasons of falls were inability to obtain assistance when needed or the individual overestimating their own ability. Prateep for example experienced frequent falls and accidents while going to the toilet. His daughter normally assisted him during the day and at night. However, Prateep sometimes could not get assistance at night as his daughter was too exhausted and did not respond to his call.

One day I was so tired from taking care of my baby who had been sick for a few days. Actually, that day the doctor wanted to keep my baby in the hospital but I couldn't stay because I had to care for my father as well. That night he went to the toilet 4 to 5 times as the doctor advised him to drink a lot of water. I couldn't hear him sometimes and he fell while he was trying to get to the toilet. (Prateep's daughter)

Most participants realised the importance of avoiding falls and accidents. They described the strategies they used to prevent falls and accidents: being constantly aware not to fall, not taking risks and learning how to fall.

Other symptoms such as sleeping disturbances (either lack of sleep or over sleeping) and inappropriate emotions were observed amongst the stroke participants. These symptoms were partly associated with the emotional disturbances as a consequence of stroke. On the other hand, failure to solve or cope with these problems could also cause emotional distress. Several participants were suffering

insomnia in the first month. Sleeplessness and nightmares were aggravated by the fact that they had difficulties turning and moving around in bed.

Some nights I'm too sore to get some sleep. I have to sit up until I feel tired, I then try to lie down again. Sometimes I can't find a comfortable position in bed and I have to sit up again. I think some nights, I can only get 20-30 minute sleep. When I feel pain, I can't sleep, I have to sit up. (Pak)

Additionally, sleeping too much in the day as there was nothing for them to do, made it difficult to sleep at night. Suree's comments typified many of the participants' experiences:

Well... sometimes I can't get a good sleep at night. I think it is partly because I sleep too much in the day even it is not a deep sleep. I don't do much during the day. I just walk, sit, and lie down. I don't do much exercise, so I can't sleep at night.

3.2. Psychoemotional Disturbances

Psychoemotional disturbances could be categorised into two major groups according to the original cause of the disturbance: those relating to the illness, and those generated by interaction with other people.

3.2.1. Psychoemotional Disturbances Mainly Relating to the Illness

In most cases, the individual had not been too concerned initially about the stroke as they thought that the illness would be temporary. Hence, their initial goal was to achieve full recovery. Later on they started feeling fearful about the consequences of the disease, and feeling uncertain of the success of the rehabilitation process as they could not reach their original goal. Finally they started to realise that the effects of the stroke would be permanent. However, most of them were still seeking for a successful treatment of their disabilities. They tended to reduce their expectations but never gave up hope. Examples of other stroke victims, including in some cases other participants in the study, who had recovered were used as references for the achievement of their goals. Others finally lost hope after a lot of effort was expended with unsuccessful outcomes. The three main

psychoemotional disturbances that arose from the illness were: fear (Groaw), uncertainty (Mai-Nae-Jai), and hopelessness (Mai-Mee-Wong).

3.2.1.1. Fear (Groaw).

Fear was a predominant feeling for the majority of the participants, for example fear of being dependent, becoming useless or powerless, loneliness, being unwanted, and death. In addition, every participant raised the fear of falling, having an accident, being left alone, and not receiving urgent assistance in time. Initially participants reported becoming fearful and worried when they felt their arm and leg becoming increasingly weak and not improving after taking family remedies. One participant described the feeling of shock and fear about the consequences of the disease based on her prior experience of stroke.

In the early stage, the disease frightened me as I thought that I would not be able to walk again. I cried and cried, I couldn't cope with it. It would have been torture if I had to stay in bed all the time. I couldn't move my left hand and leg, turn my body in bed. At that time I was afraid that I wouldn't be cured. (Suree)

Being dependent was perceived as the most profound impact of the illness. It was also associated with a loss of control over self or powerlessness, and with the feeling of being a burden and useless to society.

Fear of loneliness and being unwanted were raised by participants who did not have a good relationship with their spouses or family members, who were in the younger age bracket and used to have a very active social life before the stroke. Fear of being unwanted was profound in cases where the illness had resulted in a deterioration of the relationship with the spouse or the family as happened to Winai. He cried every time he talked about issues relating to his treatment and family. His distress arose from fear of being left or unwanted by his young wife and family. The more he tried to prevent the anticipated problems occurring, the more he generated conflicts with the family and probably perpetuated the problems. Winai explained his aggressive behaviour as a way of relieving pressure:

I have too much time to myself, which makes me wander in a circle and finally makes me stressed. I have no one with whom I can relieve the pressure, so I shift it to my daughter and my wife. Now my

daughter is too scared to come close to me. My wife is also sick of me. I feel I'm totally lost now. I can't keep in touch with my family.

His wife confirmed his fear:

He is really scared that I may run away with another man one day and leave him behind at the healing centre.

Similarly, Suree was also scared of being left by her husband as he had a second wife. She viewed her situation as at risk as she was disabled and could be a burden for her husband whereas the other wife was normal and could completely replace her. However, for those who lived in an extended family and had good support at home, loneliness was rarely raised as an issue.

With respect to death, most participants mentioned this as a natural thing that everyone had to face one day. Thus they did not show any overt signs of being frightened of dying. However it was different for the family caregivers. They did express fear of their loved one dying especially in the early post-discharge stage when the individual's condition was not stable, and the caregivers were still new to the care experience.

Fear of falling, injuring themselves, being alone, and not receiving urgent assistance in time was common in those who relied on others for most of the daily activities and care, especially in situations where the caregivers had to handle multiple family roles. The realisation of the risk of falling and injury, together with the feeling of not wanting to disturb others led them to choose to stay mainly in bed. As a consequence, most participants did not achieve the anticipated rehabilitation results.

I'm scared to walk alone with only a walking stick because I have been told to be careful, not to fall. If I do, it could lead to a great burden for the family. (Suree)

I'm scared staying alone because I can't manage toileting myself. (Pak and Nui)

I'm afraid that I may not be able to get help when I urgently need it such as when I want to go to the toilet, and I may wet the bed which will create more problems for my carers by having to clean it up. (Nui)

3.2.1.2. Uncertainty (Mai-Nae-Jai).

The feeling of uncertainty was mostly experienced by the participants after the first few months post-discharge which was the period of time by which most healers anticipated positive results from their treatments. They started worrying when their illness has not improved or when they experienced a decline in strength and motor function. The feeling of uncertainty and frustration increased when they were assured prior to receiving the treatment that they would improve but the results did not meet their expectations. These feelings may have been compounded by concerns that their slow rate of progress meant they would not recover.

The feeling of uncertainty was a source of anxiety and confusion. At this stage participants might be anxious and confused about their future, and what treatments they should seek. Most of them chose to try every treatment that was suggested as being effective, and that they could afford. The main activity at this stage was casting around for beneficial treatments.

Well...I'm confused and anxious now. I don't know what I should do about my illness. Just staying at home is hopeless. (Nui)

3.2.1.3. Hopelessness (Mai-Mee-Wong).

The feeling of hopelessness markedly influenced the recovery process. Hopelessness was expressed by almost every one of the participants who could not reach their original goals of being completely cured or at least regaining mobility and other physical functioning. Even though some of them experienced some degree of progress, they were still searching around for beneficial treatments. In many cases, given medical knowledge, achieving the ultimate goal of returning to their pre-stroke condition was often unrealistic. However hope was necessary to ensure progress and prevent them slipping into a life of total dependency. A few participants in the study strongly objected to being informed that they would not achieve full recovery because that cut off their hope and motivation to continue seeking for more effective treatments. They did not want to hear this even though it might be true. Pirat stated strongly that he could not live without hope and he was confident that he knew his condition better than others. As indicated by Brillhart & Johnson (1997), feelings of

hopelessness can inhibit participants' motivation and coping ability thus interfering with their ability to perform rehabilitation-related activities. Hopelessness was found to be more acute after participants had tried many treatments but failed to achieve their goals. Participants at the stage of hopelessness often presented signs of depression, lack of motivation and passivity.

In addition to the above psychological disturbances, participants mentioned negative feelings or discomfort, such as 'being annoyed (Rum-Kaan)', 'being irritated (Ngud-Ngid)', 'being bored (Beur)', which might lead to disruptions in their relationship with spouses and family members. They were aware that if they complained or annoyed others too much, they might be left alone.

..Conversely, now I have to keep quiet, can't complain too much. My husband said that he was tired and stressed too as he had to massage me and take care of me. (Suree)

You know sometimes I can't resist blaming my daughter when she left her son crying and she went off somewhere. Things like that happen in the family, so you can imagine my state when I can't work but only eat and sleep. Not only that but I blame and criticise other people, so how my life is going to be? I sometimes think that if I complain too much, and they all get sick of me and stay away from me, it will be a big problem for me. (Pak)

Male participants who used to be the leader of the family or who still maintained power in the family, most commonly demonstrated overt irritation or annoyance.

3.2.2. Feelings Generated by Interactions with Others

Feelings generated mainly by interaction with other people in their social network were anger (Groe); disappointment (Ped-Wong); being hurt by a very close person (Noy-Jai); concerns that they were annoying (Tum-Hai-Kon-Aern-Rum-Kaan), irritating (Tum-Hai-Kon-Aern-Ngud-Ngid), or disturbing others (Rob-Koan-Kon-Aern); not wishing to disturb or inconvenience others (Grang-Jai) (Table 2). These feelings reflect the expectations and concerns related to interpersonal interaction in the Thai society. When an individual's expectation is not met, feelings of Groe, Ped-Wong, and Noy-Jai may be generated.

On the other hand, concern that one might be annoying, irritating, or disturbing others, or not wishing to disturb or inconvenience them is critically important in facilitating and strengthening good relationships and interdependence among people. Individuals must learn how to develop and incorporate these sensitivities into interpersonal interactions in daily life. When applied appropriately in the right place, time and occasion in this cultural context the individual will be recognised as 'behaving well' or 'having good manners'. However in the situation where an individual is not able to be independent, not wishing to disturb or inconvenience others may lead to the individual becoming more isolated and frustrated. Participants who were more concerned about these feelings, were observed to be very passive, rarely asking for help, and less active in participating in family and outside social activities. Special or extra assistance would be mainly offered by caregivers or family members rather than requested by the participant. All participants in the study mentioned some degree of concern about these feelings which finally caused them to use more strategies based on their own resources to cope with their problems and difficult situations.

3.3. Social Changes

The impact of stroke greatly influences the participant's social functioning. In the study, all participants had almost completely withdrawn from outside social activities and contacts. The main reasons for this withdrawal can be categorised into four factors: individual, caregiver, social, and environmental.

3.3.1. Individual

Participants' isolation from outside social contact was related to negative perceptions of their disabling conditions and their social roles in their new life situation. Changes in their physical looks and abilities as a result of the illness such as muscle weakness, joint stiffness, facial palsy, slurred speech and dribbling, dramatically affected their body image. The perceived changes in their body image made them feel embarrassed and they did not want to be seen as a 'pity person' (Thai Naa-Soong-Saan which has the connotation of 'being protected as a disadvantaged person', or Naa-Tuu-Raat which implies a sense of 'not knowing about self') in

society. Examples of statements demonstrating negative emotion or feeling due to these negative perceptions are shown in Appendix 10.

It would be embarrassing to appear in public in this condition, I'm not supposed to be there. I mean places where there are many people gathered together. It is not the place for a patient. (Pak)

No, I don't think I'm going to join any social activities in this condition. I find it's too pitiful to go like this, you know. I will do it when I can walk by myself. I don't want to take a walking stick with me because it is embarrassing. (Pirat)

I would be ashamed when people see me with slurred speech and dribbling of saliva. (Laap)

If I go to see my girlfriend in her office in this condition with dribbling of saliva she may feel embarrassed. (Prateep)

Most participants viewed themselves as being 'abnormal', or 'sick' or 'disabled' rather a unique person with some physical limitations. Their lives would never be back to normal given the existence of post-stroke disabilities. In their view, 'being sick' exempted them from 'normal activities and responsibilities' including socialising. In fact socialising was the very last priority. As a consequence, stroke patients with permanent disabilities attended a very limited number of outside social functions.

My physical condition doesn't allow me to socialise anymore. If someone walks and accidentally hits me, I may easily fall. (Suree)

When opportunities arose to be taken out, which was not very often, they decided to stay home for a number of reasons. These included:

1. physical difficulties

I don't go to the temple as I used to do because I don't know how I'm going to stay or sit in the temple. (Pirat)

You know now I have very limited physical tolerance. I can't sit long. I think it's appropriate for patients to go the temple but the patient themselves may not be able to participate in all parts of the activity,

for example they may have difficulty in sitting still for a long time to listen to the monk. (Plup)

2. not being in a mood to socialise with others

I don't wish to socialise. (Nui)

I'm now a patient. There is no fun at all for me in attending these functions and people may blame me for appearing there as I have been sick. I'd better not go. (Choo)

If I'm not in a positive frame of mind, I don't like meeting people. (Nui)

Even if I join them, I can't do anything much anyway, only sit and talk to the people who come to speak with you, and the topic of conversation may revolve around my illness which can make me worse. (Choo)

3. being a burden to others (Suree, Nui, Laap, Yupa, Pak, and Prateep)

I don't want to be a burden of others. (Pak)

4. being unable to contribute to the function

I wish they understood my situation. It is not because I don't want to join them but it is too difficult for me to get there and I'm no longer useful. (Choo)

...the important point is why do I have to join them in a situation like this. I'm useless, I can't make anything better or could even impede the progress of the function. I don't want to be like that. (Pak)

Participants expressed similar ideas about recommencing attendance at social functions when they were at least independent in term of functions such as with their mobility.

3.3.2. Caregivers

The caregiver is the most important factor in assisting sick individuals meet their social needs. This is because the person has to rely on family carers for

transportation and company to outings. Since socialisation outside the family was considered less important, participants did not feel comfortable in requesting outings. Several participants had not had any outside social contact since their stroke as nobody had offered them a lift. Difficulty in obtaining transportation was the most common obstacle raised by the participants. Nui provided an example of this problem on the seventieth birthday party of a close friend:

My friend came to invite me to join the party himself which meant it was very special. I thought that if anyone offered to take me to the function in a wheelchair, I would go. I was looking forward to someone taking me there but no one offered to do so, and I didn't ask either.

In being away from the family while they were still functionally dependent, participants also worried about obtaining appropriate assistance. They did not want to risk being embarrassed when things which were beyond their control went wrong.

3.3.3. Social Factors

Participants' self-limiting of social activity was often associated with their own negative perception of social attitudes toward the disabled, and of the reaction from people in the society. Participants often thought that they were expected by the society to behave as a sick person. 'Patients should stay home' was what most participants thought the society wanted them to do.

I think that they may blame us for not understanding the limits of our functioning (Jium-Tua). Disabled people like us should stay at home, shouldn't go to places like that. It's not a place for the disabled. It's not a kind of positive feeling at all. (Pak)

This attitude was not totally negative from the participants' view point. It could be viewed as an 'overprotective reaction' from the society.

I don't think society has a negative attitude towards our disabilities but they just don't want us to be in trouble. I was rarely invited to join friends' functions. They always told me that if it was too difficult, I didn't need to go. (Prateep)

Some participants said that they now were excluded from the outside social network as people might not want to put pressure on them or disturb them. As the societal

expectation is that the disabled do not attend social functions, being invited may make them feel uncomfortable.

However, some participants tried to contribute to social events in order to keep in touch or to maintain reciprocity with their close friends, otherwise they might be completely isolated from their external network. Prateep described his attempt to keep contact with his social network:

Since I became sick, two of my colleagues have married. They didn't invite me to the wedding. I don't think they rejected me but they didn't want to make me worry about a present because they knew that I could not get there. Inviting a sick person can be perceived as expecting them to respond to the invitation. I found out about one of the weddings when I saw our institution bus parking in front of our apartment and sounding the horn to signal people to get in the bus. I asked one of my neighbours what was going on. I then asked her to give 200 Baht as a wedding gift to my friend. My colleagues at work have been good to me. They collected money to support me when I was in the hospital, so I think I should give them something in return when I have the opportunity.

Adaptation occurred in order to maintain external social relationships. Not being able to respond as expected might lead to a breakdown of the relationship. In this situation, participants usually made their contribution by attending the function for a brief period as part of their responsibility, assigning a family member to attend on their behalf or sending a present or money to the host.

They all know I have been sick. If I appear at the function while I'm sick, they may tell me that you don't need to come, or you can let your wife or your daughter come instead. You should stay at home or stay in bed. (Pirat)

If my wife or my daughter can't attend on behalf of our family, I will send some money or a present to them. That is the way I would deal with invitations to social events. (Pak)

Since most social functions involved sharing the work and community feasting, a few participants mentioned their concern that because they could not be of any assistance, they would be perceived as greedy.

I would rather stay at home if I can't be independent. If I join social functions like this, people may look at me in ways that may make me

feel uncomfortable. They may think that we want to have fun or drink even though our condition does not allow us to do so. (Pak)

However, some participants did not agree with those negative attitudes:

I don't think so. I think that the host of the party should be very proud of him if he can attend. They may feel that he really values their friendship if he tries to attend the function even though it is physically difficult. If he doesn't regard the host as a good friend, he may not try to attend. (Nui)

The reactions, both intentional and unintentional, of people in the outside world could generate uncomfortable feelings for the disabled.

I don't want to meet people outside even when I go to the hospital because they look at me and that makes me feel embarrassed. Right, even in the hospital which can't be avoided. I don't feel like going because there are a lot of people in the hospital and they like to look you over from head to toe. It makes me feel uncomfortable. If it's not necessary, I won't go. (Yupa)

People's reaction by 'looking at' was raised by most participants. Participants tended to perceive this attention as being a result of their disabilities, and bad manners. Suree refused to go to the wedding of her close friend because of feeling embarrassed by others' attention:

Everybody in the party might look at me instead of paying attention to the bride. (Suree)

Some supportive reactions from people might be perceived as negative by the participants. Providing too much support and attention to the disabled may make them feel like 'being a burden' or uncomfortable by disturbing others too much. Prateep gave his views about this:

I don't think people in our society or my colleagues do not want me but they are too worried about me. When I first went back to my office after the illness and my colleagues saw me walking slowly with a walking stick, one of them came up and carried me in his arms to my office. I think this was because they wanted to help me. I insisted that I could walk. If they really wanted to help, just let me hold on to their shoulder but in fact that didn't help either because I could not use my weak hand at all but I didn't want to refuse his

offer. You know, their worries and concerns about me make me feel as if I'm 'being a burden' and 'uncomfortable' to go out. (Prateep)

Nui shared similar experiences of people's reactions to the disabled:

When people saw me walking and limping with a walking stick in the office, they stopped working and came up to help me. They are very generous and helpful to me but I feel I could be a burden to them.

Nui also expressed his concern about the public's mistaken belief that the disease could spread to other people. Thus the participants tended to feel that they were not wanted by society. These barriers gradually isolated those who were sick, as Prateep described:

I think I'm in a different world now, I can't keep up with others in terms of career, social status, things like that. As time passes, the gap between myself and outside society will grow bigger and bigger until I find it too difficult to keep in touch with them.

There is no doubt that most Thai people sympathise with these who are disabled and they are ready to help them. However, their attitudes and reactions towards the disabled do not encourage them to resume normal roles. Even worse, they cut off the chance for disabled people to gain access to education, employment, recreation facilities and social life. This is partly because people believe that it is too difficult for disabled people to lead a normal life. This concern impacts negatively on the future of the disabled.

3.3.4. Environmental Factors

The scarcity of public facilities for disabled people was another major obstacle for disabled people wanting to go out. Most public places such as temples, schools, shopping centres, even some hospitals, did not have wheelchair access or facilities for the disabled.

...it's very difficult for those disabled like us to use public toilets as most of them are old style toilets which we can't sit on. (Yupa)

On the other hand, many participants did not know about those facilities which did exist. Winai mentioned his difficulty in getting from the hospital car park to the ward

where his father was admitted. He was therefore unable to see his father, who was seriously ill in hospital, even though he had travelled a long way from his home in another province. He was unaware that a wheelchair would have been available.

Participants always referred to these problems in terms of inconvenience. It was not uncommon for them to accept an invitation to socialise with close family members or friends and then change their mind when they thought of all the inconvenience they might face when going out. One participant said:

Yesterday my son asked me to join them in visiting my sick relative in hospital. At first I thought I would go but when I thought of all the problems relating to transportation and managing my personal needs, I changed my mind. (Laap)

3.3.5. Impact

Participants were asked to identify all the outings they normally enjoyed before their illness and then classify them into three groups: unimportant, less important, and important activities for them to participate in after their stroke. Unimportant activities were characterised as ‘unnecessary’ or in some cases ‘inappropriate’ for the sick to participate in. Unimportant activities included shopping (shopping is also considered a recreational activity by Thais), travelling, visiting friends and relatives, going to the cinema, or joining ordination ceremonies. The main purpose of these activities was to have fun or a good time, which was considered to be unnecessary for a sick person. Travelling and going to the cinema were perceived as inappropriate by most participants.

Less important activities consisted of close relatives’ weddings (must be within a short distance), travelling for a short distance, visiting ill relatives or friends, the birthday party of senior friends or relatives, and religious celebrations. These included Tum-Bun-Deun-Sib (a very important religious day for the Southern Thai people), Kao-Phunsaa (the Buddhist Lent of three months during the rainy season), Tood-Khatin and Tood-Papaa. These activities meant a lot to many of the participants when they were well, in particular the activities relating to religion as they provide the participants with the opportunity to socialise and ‘do merit’ to fulfil

their spiritual needs. Several said that they had never missed a single occasion when they were well.

Tum-Bun-Deun-Sib is one of the most important religious days for people living in Southern Thailand. It's important because people pass on their merit to their ancestors. All family members come to meet each other at their parents' home on that day. It is very meaningful for people in the south of Thailand. (Plup)

Most participants thought these activities were appropriate for them to undertake, but many were reluctant to identify what sort of activities they should do in their new situation.

I think I will join them if I can get a lift. I don't think I should stop going to the temple. This is because the temple is one of our refuges. (Pirat)

If it is a function held by our good friends, I may decide to go. I think my friends will understand and will be very proud that I have tried hard to make it. However, what about other people's opinions? They don't know how close I am to the host of the function. We have to strengthen ourselves not to be concerned with other people's feelings, you know. (Pirat)

However, despite the activities being viewed as appropriate for them to join, in reality no one participated in them after their illness. Most participants merely stayed at home watching television and were cut off from outside social activities, except for two special occasions reported by participants.

Since I have been ill, I have never been out anywhere except to go to the hospital or somewhere else relating to my treatment. I cut off all social activities including religious activities in the temple where my close friend is the abbot. Only once my friends took me in a wheelchair to vote for our representatives. (Laap)

I tried to make it that time because I was appointed to be a leader of the Khatina ceremony, otherwise I would not have gone. (Pak)

Important or 'necessary' activities comprise activities mainly related to their treatment and to their direct family members. Examples include seeing a health

practitioner; attending a funeral service of a direct family member, or a very close or senior relative such as their own parent, parent-in-law or sibling; visiting a sick direct family member, or a close or senior relative; or attending the wedding of a direct family member. The importance of the activities was determined by the significance of the participant's appearance at the function. They would not be blamed by society if they could not attend but they would be admired if they made the effort to go.

Limits on socialising affected the psychological well-being of the participants differently. It partially depended on the nature and personality of a person before their stroke. Those who had led a very active social life prior to their stroke might experience social distress. Changes brought about by the illness suddenly reduced their social lives to a small network of family and kin members. Results show that the participants' socialising was primarily limited to within their own home. While 'being sick' (based on their own perceptions), they expected to be visited at home rather than go out to meet others.

In my present health, I think I need to be visited rather than visit others. (Laap)

'To visit or being visited' is determined by social attitudes constructed by cultural norms.

This expectation was strong in regard to close kin. Family members living a great distance away were expected to make frequent visits to their sick parents or elders during weekends or holidays. Often they might take along some food, everyday items, or money to support their elderly parents. The main purpose of the visit was to provide support, care and companionship, and to ensure the well-being of the person. Supportive activities consisted of active participation in caring and family activities such as assisting the sick person with daily activities, cooking, having family meals, or modifying the house to make life easier for them. The negative social attitude towards socialising outside the family might not affect some older people who feel they can meet their social needs at home. Therefore there was no particular need to engage in social activities outside the family network. Being fulfilled by adequate family socialising within an extended family environment,

means that even those without outside contact can be considered as 'having a good life' by Thais.

I don't feel lonely at all because I always have my family members.
(Plup)

Within Thai culture, the family unit is a powerful social unit, and because of concerns about negative social attitudes, their dignity, the inconvenience associated with physical limitations and the limited environmental facilities for the disabled, as a general rule the sick elderly prefer to stay home rather than go out. However, most participants in the study did not have many family members around at home as they all worked. They were often left with only the primary caregivers. Several participants complained of 'being lonely' and scared of 'being alone'. In this case, socialising within the family was obviously not fulfilling their social needs.

3.4. Losses

The experiences of change mentioned above led to feelings of grief and loss in four major categories: social activities, ability to work and perform role activities, independence, and self-image and self-esteem.

3.4.1. Loss of Social Activities

As already mentioned under 'social changes', the participants were stigmatised by their invalid role, thus they were not supposed to engage in normal social activities. Most of them had withdrawn completely and were discouraged from resuming social functions by their family and society. The following statements reflect the participants' grief at the loss of their social activities:

Previously, I could walk, get around. I usually went to chat with my neighbours but I can't do that now. I feel very isolated and lonely.
(Suree)

I used to enjoy drinking with friends (his wife described his life as being only for work and outings with friends), and suddenly I have to stay in bed. You know it's a very stressful situation. (Pirat)

I miss my social life. When I was well, I went to meet my friends in the coffee shop every morning and we spent some time talking about politics. We enjoyed discussing politics. I also always joined the community activities such as Tood-Khatin and Tood-Papaa. (Laap)

3.4.2. Loss of the Ability to Work and Role Activities (Including the Sexual Role)

Loss of the ability to work and perform role activities was found to be significant for participants who were leaders of the family. Their illness might affect their job and future plans. Pirat was a good example of the impact of stroke on loss of ability to handle the family business.

I found it was an enormous change in my life. I used to work very hard but now I can't. (Pirat)

He expressed that this was the most worrisome problem resulting from the illness as he had run the food selling business when he was well. Pirat's role was to decide on the menu, do the shopping after midnight and the cooking in the morning. His wife's major role was selling the food throughout the day until late evening. He was very proud when he talked about his success with the business. Pirat found that the business was not running well under his wife's management. His wife was not a good cook and the workload was too great. His customers now complained about the quality and taste of the food. Pirat was very disappointed that his wife could not handle the business as well as he expected. He had been trying to teach her, but she learnt very slowly. He said that his plan to extend his business was now not possible, as he did not think that his wife could reach that goal without him.

Another example was the impact of the illness on young stroke survivors. Suree was a housewife as well as an income-earner working from home to support the family. She used to trade every day from home, selling noodles. After her stroke, her life totally changed:

Since I have been sick, I haven't done much. What I have done is mostly for myself only. For example after I wake up in the morning, I try to help myself with toilet things. My role has totally changed. I used to do everything for myself, husband, daughter and son but now I can't help others or even myself. Conversely, I need help from them.

The illness affects all aspects of my life. I used to work very hard in order to earn some money to support our family, but now I have stopped selling groceries and noodles. I feel that I'm really useless.

Individuals' loss of sexual interaction with their partners, especially for young stroke victims, was an important cause of frustration. Interestingly, none of the participants had ever discussed or mentioned sexual issues with the doctor, nurse, or any health personnel as they thought it was embarrassing. Only some participants who trusted me and wanted to discuss the problem, disclosed their sex life since the illness. Some information regarding this topic was obtained from the participant's spouse. This information reflected the participants' ideas, problems and concerns regarding sexual functioning.

Of the ten participants, two were single (a widow and divorcee). The eight participants who were still residing or having regular contact with their spouses, reported having had no sexual intercourse after their stroke. Two of these married participants, Nui (aged 69) and Plup (aged 72), had not been having sexual intercourse with their partners before their stroke. They described their marital relationship as friendships. Of the remaining six participants who were sexually active before their stroke, only one occasionally had sex after the illness. Two of them had not yet had sexual intercourse due to physical difficulties. The rest (three) had terminated sexual interaction entirely, due to their concern about the possible effects.

Refusing to have sex after a stroke was initiated by either the participants or their spouses. There were several reasons given by both parties, the most common of which was the physical difficulty. Another common problem was the fear of harm or unwanted consequences as a result of having sex after a stroke. Due to physical difficulties, Pirat had not had sex with his wife since he became ill. He still had sexual desires, though not often, perhaps because he was getting older. He did not worry about sexual problems and had not been told to avoid having sex with his wife. He did not think having sex would be dangerous, but only that it would not be as comfortable or easy as usual because he had difficulty with his right side of his body.

From the partner's perspective, the harmful effects or unwanted consequences included the worsening of the health of the sick spouse, unwanted pregnancy, and the possibility of catching the disease.

I'm afraid that I may hurt her or make her illness worse. Somebody told me that I could cause her shock or even death, so it is very scary. I don't want to hurt her more. Another reason for not wanting to have sex with my wife now is that I don't want her to get pregnant in this situation. (Suree's husband)

Suree confirmed her husband's reasons and added that another reason her husband gave her for not having sex was that:

Lastly, he himself was stressed and he didn't have sexual feelings.

Although there are many alternatives available now for controlling pregnancy, they seemed to struggle with the problem. The husband, like many other men in Thai society, thought that birth control was the wife's responsibility. In this case, the wife had used contraceptive pills for many years, and it was believed that these partly caused her stroke. The wife was uncertain about these claims and she sometimes thought that it was her husband's excuse for not wanting to get sexually involved with her as he already had another wife. Suree found herself stigmatised by this attitude and not given the opportunity to perform her role as a wife.

I feel a lot better myself. Actually only my left hand and leg are weak. This is what I think but they don't think like this. They might think that half of my body is completely dead, including sexual functioning. They might think that I was disabled, that we now live as friends, or carer and patient. I don't feel that we live as wife and husband. This makes me think a lot. When I compared myself to the minor wife, it made me feel down. I felt useless and stressed.

In this case, loss of ability to perform the wife's role was very painful for her. In response to this issue, her husband said:

I accept that I really perceive her as a patient because she is a patient. If she meant our sex life has changed, I accept that I don't think about it any more since her illness even though I still love her. My love toward her hasn't changed. I don't have sex with her because I worry about her health and I want her to be cured sooner than this. She has never realised that.

Similarly, Winai's wife also refused to have sex with him after his illness because she was scared of worsening his condition and catching the disease via sexual intercourse. This made him very frustrated. His wife told the story:

He wanted to have sex with me one night when I came to visit him in the hut as usual. I didn't allow him to because I have been told that he could go into shock and that there was a chemical in his semen that could spread the disease to his partner. He was so angry with me. He twisted my arms. I was so hurt and angry with him. Frankly, even if I allowed him to have sex with me, I don't think he could due to the physical difficulty. He still needs my help to move around in bed. Since then he has never mentioned it to me again.

Concern over the possibility of delaying recovery as a result of having sex was also raised:

I'm so frustrated that my husband doesn't understand my condition. He has been trying to have sex with me since my stroke but I wouldn't because I have been told to avoid having sex as it can give me a shock and delay the recovery process, but he doesn't believe it. He said that if I didn't allow him to have sex with me, he would go to see other women or prostitutes. What should I do? I have no choice. (Yupa)

Pak was the only person who engaged to sexual intercourse after his illness. He admitted that his sexual performance was not the same, but he coped with this problem by accepting the new situation:

....as I told you I don't want to be difficult. If my wife is not happy to have sex with me after my illness, I will not force her. My sexual performance has changed because half of my body is weak, but I know how much I can do. I will take it as my condition allows me to do so. I will not try to do more than I'm able. I have to accept the fact.

The issue of sexual interaction was a mystery for most participants. Participants had never been counselled about their sexuality, or how to adapt themselves to their new physical situation in relation to their sexual performance. Most of them were not very confident about sexual practices that they previously took for granted. They decided to take the safe alternative and avoid having sex. Communication breakdown was evident in relation to sexual problems. Participants felt that the issue was too embarrassing to discuss, even as a couple.

I don't know how to start to talk about it. It should be initiated by males not females, I think. It's embarrassing. I don't want to talk to the doctor because she may think that though I was close to dying, I'm still worrying about sex. I don't want to be viewed as a person who does not know her own abilities. (Suree)

3.4.3. Loss of Independence

Impairment of movement and hand functioning as a consequence of the stroke left the participants unable to walk and perform personal self-care tasks. The most common sources of stress related to physical function were the inability to perform basic tasks by themselves, in particular toileting activities. Having to rely on others for their basic needs caused the participants frustration.

I think the loss of physical functioning had the most profound impact on me as it affects my body image and my ability to exist. When I first came back from the hospital, I couldn't even undress myself (started to cry). I couldn't be independent. I had to depend on and disturb other people. (Suree)

My incapacity to help myself and my dependence on other people is most frustrating for me. If I can terminate my life, I will do so in order to not create a problem for others. I have been thinking of taking poison, hanging myself, or shooting myself but my conscience stops me. That kind of thought has come and gone many times. I always think of committing suicide when I need help with daily activities: bathing, toileting, urinating, cleaning, and so on. I have to rely completely on them. I can't do anything for myself. What should I live for then? (Nui)

Some participants were extremely frustrated at being unable to take care of toileting activities.

I feel very uncomfortable being cleaned after bowel movements. It is a pity that my children have to deal with a smelly, dirty task like that. (Prateep)

I can't tolerate being a dependent person who has to be cleaned and dried by others. (Pak)

3.4.4. Loss of Self-Image and Self-Esteem

Physical disabilities and functional impairments severely disrupt a person's self-image and self-esteem. The image of a stroke carried a generalised connotation of a crippling impairment, dependence, uselessness, and powerlessness which further decreased the participants' self-esteem. Its impact on young persons or working men was far more profound as it also affected their careers and social roles.

I'm feeling useless, I can't work, be independent, or even sleep with my husband. (Suree)

Why do I have to survive by disturbing others? I don't want to be useless or delay other people. I don't want to be a troublesome person to anyone: my wife, children, siblings, relatives, or friends. I don't want to be an unwanted one. (Pak)

For older stroke victims, even though the change in physical appearance seemed to be a less important loss than the loss of independence, it was probably the most crucial factor contributing to their social isolation as discussed previously.

At our age, we are not too worried about our image or physical appearance because we don't need to attract other people's attention. We just want to regain our physical functions and capability in order to be able to do our job to support our family. (Pirat)

For the retired participants whose job no longer contributed much to the maintaining of self-esteem, they might expect only to be respected by their children as is the cultural norm of society. In this case, the family might contribute to the restoring of the sick elder's self-esteem by showing respect, giving attention, spending time with them, providing care and support. The family's understanding and avoidance of negative interaction that made the patient feel embarrassed and ashamed were also crucial to restoring the participant's self-esteem. Pirat complained that his wife did not care about his feelings about being sick.

She keeps on speaking about some problems repeatedly without concern for my feelings. For example, she kept complaining about the labourers who did the construction of our houses and who just ran away. This made me so stressed as I couldn't do anything to solve the problem. I sometimes had to tell her to shut up, otherwise she would not stop talking about it... if she could mind her words a bit, that will

be excellent, you know. She doesn't consider my feelings or know how to reassure others. She always says something to make me feel down. You well know that a patient like me needs to be reassured and to avoid stress but... What really upset me about her is that she likes to emphasise my illness and my disability. She likes to make me remember that I have lost my capability. I felt very angry with her regarding this.

Maintaining the role of consultant for the family members provided the sick person with the opportunity to build their sense of successfulness and usefulness.

If you can feel that you are still loved and wanted by your family, you will feel better about yourself, have more confidence and self-esteem.
(Pirat)

4. Coping with the Illness

The participants described a number of strategies they used to cope with various difficult situations related to their stroke. These strategies can be categorised as 'self-focused strategies' and 'externally-focused strategies'.

4.1. Self-Focused Strategies

Self-focused strategies are those employed to relieve the impact of stressful situations by using rational thinking processes to cope mentally with the physical and emotional distress, and by adapting to the new life situation. The focus is on 'self', both mentally and physically, rather than on outside resources. Self-focused strategies include techniques incorporating religious teachings, self-adaptation, self-control, motivation, and a positive outlook.

4.1.1. Techniques Incorporating Religion

Buddhist teachings are widely accepted and used by people to cope with the problems of daily life. All participants in the study described using some Buddhist concepts to deal with their loss and suffering from chronic illness and disability. The most common concepts included the Law of Karma, the Law of Impermanence, choosing not to understand or ignoring, tolerance, acceptance, and contentment.

Pak's experiences after his stroke provide an example of how an individual applies Buddhist teachings to cope with one's difficult life. Pak was diagnosed as

having had a stroke with right hemiplegia at the age of 63. His main occupation prior to his stroke was as a security guard. He retired from his government job when he was 60 but he continued working as a security guard for a private company until he became sick. He was very family-oriented. He liked staying at home after work as he thought that dealing with people could create problems. However, he said that he was willing to help others, neighbours or friends, when they needed it. I saw him as a very religious person. Pak frequently mentioned that the Buddha's teachings guided his daily living and helped him cope with his problems, the most significant of which were loss of independence and a concern of inconveniencing others. These teachings helped him accept his condition, adapt to his new situation, and finally appreciate his existing abilities.

Based on his own knowledge, Pak could not find an explicit cause for his illness, as he believed that he had always been concerned about a healthy lifestyle, both physically and mentally, and been a good provider for the family.

Probably it was a result of previous Karma which needed to be paid off either in this life or next (*Law of Karma*).

I still have a lot of hope that I can be cured, or otherwise die. I can't stay like this for ever (*Law of Impermanence*).

Pak's recovery had been progressing well. He could walk with a walking stick in his second week of hospitalisation. He tried to accept his real self and status in life (*acceptance and letting things go*).

If my illness can't be cured, I can accept it and try to seek the appropriate ways for myself later on. I try not to be stressed. People always get stressed because they can't accept the truth.

...the important thing is that we have to accept the fact of being sick. We can't do much, so we shouldn't try to do what is beyond our capacity. We should behave appropriately according to our existing ability... if I can't perform some of my roles myself, I have to accept it.

He realised that his life had changed, he could not maintain his role as leader of the family, and take control of family matters as he used to do. He tried to relinquish his

previous roles, which was quite hard. When things in the family did not go as he expected, he would try to be tolerant, or otherwise ignore it.

It is not easy for me to adapt myself in that way. I feel frustrated as I told you. I used to work a lot, speak a lot, take over all the decision making in the family, give orders, or even scold them (family members) when they did something I didn't like. Now I have to be more tolerant and keep my real feelings inside in order to smooth the way for the family and ultimately for my own peace of mind (*tolerance*).

With things that I think it is useless to talk about, I close my eyes, and keep my mouth shut (*choosing not to understand, ignore and avoidance*).

During the first year post-stroke, he concentrated his energy on seeking effective treatment, and reducing his needs and desires to fit his remaining physical ability.

One concept that I have used to deal with my daily life is that I try to be satisfied and appreciate what I have, to accept myself as I am (*contentment*).

Other participants reported that other religious techniques such as prayer and meditation were effective in coping with frustration and depression. Praying a potent chant was believed to bring a good and successful life to a person and their family. At the very least, an explicit benefit the person could gain from praying was to bring peace to his/her mind while chanting.

There was a neighbour who introduced her to Japanese chanting in order to get cured, and to bring success in business and a good life, etcetera. It's not the Buddhist way. It's originally from Japan, I guess. My father and I used to pray before but I don't actually know what people expect from doing that. In her case, I think it's good to let her mind rest, otherwise she may keep waiting for my arrival as she has nothing to do. When she prays, she will concentrate on the chanting words and forget about her own problem, forget about me, and finally release her stress. When she is mentally better, this will lead to better health. (Suree's husband)

It was suggested I do 'love and kindness meditation' (Paee-Meettaa-wish her a happiness) in order to purify my mind. (Suree)

Strategies involving religious teaching are very useful when the search for external assistance fails to resolve stressful situations. Understanding the situation enables participants to accept it, especially when the problem becomes chronic or when health deteriorates gradually. Accepting the situation as it really is, indicates that the participant has come to terms with the situation. With this acceptance came contentment. Neighbours observed obvious changes when a person came to terms with and could accept reality:

I can see Winai has calmed down a lot even though his condition seems to get worse. He looks more contented, still sad, but they (husband and wife) don't fight with each other as they used to.

Contented participants were normally less likely to seek assistance. They would be happy with what was being offered by their family members.

4.1.2. Self-Adaptation

The participants initiated a number of ways of adapting to the reality of day to day living. Participants believed that the most effective way to solve a problem was to start with oneself because it was beyond their control to change other people. Systematic problem solving techniques were often employed in their daily lives by confronting, thinking about the solutions, and then trying to do something to solve the problems. For example, most of participants had difficulty with getting dressed in their usual clothing, especially the sarong. Some of them decided to change their clothing style to one which was easier for them to manage such as short pants and a large blouse.

Self-sufficiency was another way of adapting, which must be developed in order to avoid overburdening others in the long term. Many became organised in order to avoid disturbing family carers too much.

Since I can't get around the house myself, I try to keep my stuff handy, for example medicines, drinking water, urinal, and so on, so I don't need to call them very often. (Plup)

I don't want to disturb others too much. I try to do with the things I can manage myself. If it is not something urgent and I can't do it myself, I will wait until I can do it. (Pak)

Participants also learnt from their own experience to deal with and control symptoms. In learning to manage the symptoms, the participants needed to closely observe changes, evaluate them, and learn new skills to deal with the problems.

I have been trying to solve my problems myself and now I think I can cope with them. For example, I have a problem with my hand. I know that the hand position is very important for me, so I try to be careful with it. I put it in the right position, and I have learned that if I put my hand in a lower position, it will make me feel tense ('ket'). I therefore try to support it with a pillow.

4.1.3. Self-Control

Self-control focused on a wide range of physical and emotional expressions such as demanding behaviour, desires and mood.

I have tried to control myself and not be too demanding, not be fussy, not express my bad moods and disturb others. When I was well, I wasn't concerned about it because I could do everything myself. If I really wanted to do something, no one could stop me. I have tried to be careful about expressing my feelings when they do something that I don't like. I have to listen to them more and try not to oppose their ideas if it is not necessary. (Pak)

I will try to limit my desires to what I can afford. I won't hope or expect too much... and therefore I won't suffer from being unable to get the thing I wanted or desired. (Pak)

Maintaining a positive concept of self is a major coping task (Miller, 1992).

I can direct myself to whatever I like. I can be happy, cheerful, and whatever despite my illness. (Pak)

The most important thing about living in this situation is one's own mind. I have trained my mind to be ready for everything. Whatever happens in my life good or bad won't worry me. I will not let it make me suffer. My mind will not swing with those events. If I can control my mind, everything will be under control and easy. (Pak)

4.1.4. Motivation

A number of people attempted to deal with the uncertainty of their illness and long-term suffering by motivating both themselves and their caregivers, and endeavouring to get on with their lives. They were very determined or even obstinate in insisting on keeping going, even despite being rejected by the hospital because their condition would not improve.

I have no choice. I can't be daunted. I have to go ahead. The only thing that I think about is how I can get cured. I'm trying to seek effective treatment. (Pak)

Besides self-motivation, motivation of carers was also considered to be important in helping an individual to successfully cope with their difficulties. Family caregivers also needed to cope with the strain and workload resulting from a person's sickness, so a boost was required for both parties. Some participants tried to show some progress in their recovery so as to increase their carer's motivation, and thus they could move on further together.

They try to foster or encourage me to exercise if they find me not very active. Now, I get up at about 3 to 4 every morning, just to keep my wife company when she gets up to cook. I think I have to show them some progress with my recovery, otherwise they may lose their motivation to help me. (Pirat)

4.1.5. Positive Outlook

Some participants cope with their loss and emotional distress by thinking positively about their current situation, for example the inability to go socialising with friends could save money. A positive outlook towards their own condition could also be gained by comparing themselves with a more seriously ill person.

I sometimes compared my condition with that of other patients whose condition was worse than mine. Thinking in that way makes me feel a bit of relief from myself, my own problems. (Suree)

I don't worry about my illness. Many people have very good health and suddenly die from an accident. What can you expect from life in this world? Anything can happen. If I die from this illness, I think I'm

still better off than those who die from an accident as I still have time to prepare myself to die. (Pak)

4.2. Externally-Focused Strategies

Externally-focused strategies are those used to seek external assistance in solving problems or relieving the distressing effects of stressful situations. These strategies include seeking information, social support, and medication.

Problems associated with obtaining treatment and care requirements appeared to be the main issue for stroke participants post-discharge. Participants would seek information and support from families, friends, relatives, other patients, traditional and western health practitioners, and other health personnel, including the researcher. Seeking assistance or support normally started within the family. Participants always discussed with their spouses or children the things or issues that required family involvement. This discussion gained their approval for the plan of care and family members' co-operation in implementing the care.

It depends on what problem or what issue I'm working on. If it is not a big issue, I may make the decision myself. For things that may require involvement of others, I consult my wife or my children. (Pak)

Participants frequently used others (family members, neighbours, friends, researcher, and practitioners) to remind or communicate patients' health needs to their primary carer. Plup, a 72 year old, sometimes used me to be a go-between or witness negotiations among the family members. Plup lived with her husband, daughter, son-in-law and grandchildren in the country. Her house is an old style Thai house with a raised floor. Every time she went to see a practitioner, her son-in-law had to lift her down the stairs, and drive her to the practitioner. Without his help, it was impossible for Plup to obtain any treatment or make a follow-up appointment. She felt uncomfortable inconveniencing her son-in-law but it seemed to be unavoidable. The son-in-law did a good job for the first few months of her illness, but then hurt his back. She felt uncomfortable (Grang-Jai) asking or reminding him directly. On one visit, after I had taken her blood pressure and found it to be high, she asked me to inform her son-in-law about her problem, which required her to see a doctor in order to obtain appropriate medication.

Information relating to the illness and treatment was obtained mainly from people within their own social network who had experienced the illness or had cared for a stroke survivor. Participants rarely sought information from doctors or health care professionals, or referred to printed material such as pamphlets, or text books.

I have been told about many good practitioners and effective remedies. All were quite convincing with their information. (Nui)

Some participants experienced difficulties in obtaining health services from doctors and health professionals. They learned ways to interact with the doctor in order to obtain attention and services. These techniques involved informing the doctor that they were covered by social welfare, or trying to contact the doctor through his/her own private clinic.

If I go to see him in the hospital in the normal way, they may not pay much attention to me. I just hope that the doctor will sympathise with me and understand my difficulty in not being able to get any treatment or physiotherapy at home unless I'm readmitted to the hospital. (Pak)

The aspect of emotional support appeared to have been ignored by the existing health services. A primary caregiver (the husband) of a participant perceived that they needed counselling services which were not available in either the hospital or community. He saw that his wife's problem was complicated as it involved so many factors. Moreover, he also found himself in a very stressful situation and needed counselling as well.

I think there should be counselling services for people who have mental problems after suffering traumatic experiences from illness or family problems. I'm sure nowadays there are quite a number of people facing problems like we are and they have nowhere to go. I think there should be a service to support this group of people. My wife has an anxious personality. The other day I told her that I might be appointed to work in another province which is further south than Songkla, taking about two and a half hours by car to get there. She started to cry and cry, even though it is still uncertain. I asked a nurse in the hospital about the service but she told me that there was no such service in the hospital. However, she gave me her number and told me to call her if my wife and I needed her as she had been trying to set up a service. I'm thinking of calling her sometime. (Suree's husband)

Counselling services did not exist in most of the health care institutions. Issues related to mental health, including counselling, were assumed to be taken care of by social workers or nurses. As the number of social workers was very small in each institution, they were only able to deal mainly with patients' financial difficulties. Similarly, nurses dealt primarily with patients' physical problems and care relating to modern health technology.

Medications such as tranquillisers were rarely used for the urgent problems which were commonly associated with long term complaints, for example chronic pain and chronic depression. Participants were always aware of the adverse side effects of the medicines. Some participants who had lost contact with the hospital might obtain some over-the-counter medicine to solve their health problems.

I always felt uncomfortable with dizziness and don't know what to do about it except rely on medicine obtained over the counter. I've got no idea how effective it is but the problem is never completely gone.
(Winai)

Most stress was coped with by a combination of both categories of strategies. However, externally-focused strategies were used more frequently in the initial stage of the illness while self-focused strategies were often employed to deal with difficult situations in the later stage of the illness, in particular by those with more functional disabilities. Coping strategies also varied according to the type of stress. Participants normally sought help from both inside and outside the family when their stress stemmed from their illness and treatment. They tended to use self-focused strategies for coping with the difficulties arising from factors associated with their own desires, care needs, and family interaction or relationships. Of all the strategies, religion was one of the most effective. Several participants were able to obtain some level of peace in the turmoil of their lives by using this strategy. Incorporating Buddhist practices, together with a systematic problem-solving technique to help chronic or disabled clients cope with their difficult life situation is probably the most effective approach in Buddhist society. Table 3 summarises both categories of strategies used to deal with various stresses.

Table 2: Examples of self-focused and externally-focused strategies used to deal with various stresses

Source of stress	Coping strategy	Description of coping
<p>1. Difficulty in obtaining help</p> <p>2. Loss of capability</p> <ul style="list-style-type: none"> • ADLs • work • perform role activities <p>3. Suffering with chronic illness and disabilities</p>	<ul style="list-style-type: none"> • self-control • self-sufficiency • problem solving • seeking for information and assistance • Law of impermanence • acceptance 	<p>- "I try to limit my desires to what I can afford..."</p> <p>- "I try to be an organised person keeping all my personal items handy, so I don't need to bother them often"</p> <p>- "I have modified my home environment and some ADL aids to assist with her ADLs"</p> <p>- "I have asked many patients about headaches after stroke, most of them have never experienced this problem before. What is the real cause of my problem then? I don't think it is purely because of stress."</p> <p>- "I like talking to patients who are in the same situation as me, so I don't feel lonely and I can also get some idea about the process of recovery"</p> <p>- "I have been looking for a good treatment for my illness. I would go for every treatment that may be effective for my illness if I could"</p> <p>- Participants believed that things were subject to change. The suffering would not stay forever and nothing would be worse than the present situation. It would either be better or death.</p> <p>- "I don't think much about it 'Yub Nor-Pong Nor' (The phrase that Thai people often use to remind themselves that there is nothing permanent in the world, like the abdomen rising and falling with their breathing).</p> <p>- "if they (practitioners) can't do any more for my illness, I would accept it and try to find appropriate ways for myself in the future"</p> <p>- "I was so scared when I first learnt that I was paralysed but now my feelings are neutral because I realise that it is the nature of life. I have to get ready for everything that may happen to me. I may be cured or I may die. What will happen, will happen"</p> <p>- "I can now accept my new condition and try to adapt myself to the new situation, I therefore don't feel frustrated"</p> <p>- "I sometimes thought that because I couldn't work, I shouldn't take too much time from my family. They should use the time dealing with me to work instead. I have tried to accept it"</p> <p>"...my husband has had a torturous life for a long time. I wish that he would be cured or die peacefully soon, then both of us would have peace of mind"</p> <p>- "Now I'm paying off the bad Karma I may have done either during this life or a previous one"</p>
<p>4. Feeling of hopelessness</p>	<ul style="list-style-type: none"> • wishing for a resolution • Law of Karma 	<p>- "I sometimes thought that because I couldn't work, I shouldn't take too much time from my family. They should use the time dealing with me to work instead. I have tried to accept it"</p> <p>"...my husband has had a torturous life for a long time. I wish that he would be cured or die peacefully soon, then both of us would have peace of mind"</p> <p>- "Now I'm paying off the bad Karma I may have done either during this life or a previous one"</p>

5. Summary

The experiences of the participants with stroke in this study were analysed in terms of how the illness and its consequences affected their lives and how they coped with these difficulties. Their problems were categorised into three major changes: physical, psychological and social. These changes could lead to a sense of loss in four main areas: in social activities, in the ability to work and role activities, in independence, and in self-image and self-esteem.

All participants in the study had very little outside social contact after the stroke. There were three main reasons for a marked reduction in their social activities: they were stigmatised by the sick role and discouraged from engaging in normal social activities; they were discouraged from seeking external contact by their own negative feelings of being a burden to their carers and others in the society; and there were very limited public facilities for persons with disabilities. The loss of ability to work and perform role activities was important for younger participants, especially for those who were the breadwinner of the family. The impact on their work and family functioning contributed to psychological disturbances and a decreased self-esteem. Being unable to be independent was one of the most important concerns expressed by the participants. They felt very frustrated when they had to rely on others for personal care activities, in particularly toileting activities. Self-image and self-esteem were severely disrupted as they usually had some degree of physical disability that affected their physical look and ability. Two major groups of strategies were used to deal with these difficulties: self-focused and externally-focused strategies. While the self-focused strategies relied on their own personal resources, the externally-focused strategies required seeking external assistance. Both strategies were used variably according to the stage of the illness and the type of stress.

CHAPTER 6 : THE FAMILY'S EXPERIENCES WITH CAREGIVING

1. Introduction

This chapter focuses on family caregivers' experiences in providing care for stroke sufferers. Categories of family caregivers are identified. The perceived family caregiving roles as well as the perceived scope of their responsibility in the caregiving role are examined from the family caregivers' point of view. The perception of the caregiving burden by family members is also analysed in order to give a more explicit understanding of the caregivers' experiences within the family context. Lastly, factors influencing the quality of family care and the patient's satisfaction with that care are discussed to provide guidance for the improvement of care.

2. Meaning of Family in Thai Society

Understanding family care in Thai society requires an understanding of how Thai people define family and how they view obligations towards other family members. From the social science perspective, "family" is built around real or putative kinship, and is usually reflected in some way in the physical household unit (Camps & Hernandez, 1997). Thais tend to define family by kinship, by which they mean biological relationship, although putative kinship is also employed.

Family members can be classified as direct family members or relatives. Direct family members in an extended family normally consist of three generations of direct lineal descendants. Other family members are regarded as relatives -aunts, uncles, nieces, nephews, etc. In earlier times, direct family members usually lived together in the same house, or separate houses but in the same compound, or close to each other together with some relatives as an 'extended family'. Now, due to socio-economic changes, families are smaller and less generationally complex, especially in the urban areas. Although many members cannot physically live together as an extended family, responsibility as a member of the family remains relatively strong.

In the study, half (five) of the participating families lived in a three-generation household. In the rest their children were still living in the same compound as part of an extended family. Most participants in the study were elderly, either grandparents or parents of the family. Usually the male participants who were still involved in the management of the family's finances, assumed the role of the head of the family. Family members tended to interact frequently and assist each other. Reciprocal aid included baby-sitting, sharing food, transportation, financial aid, personal advice, and moral support.

Family is considered as the first 'port-of-call' when needing care, followed by community resources and then the government. The elderly, when capable, usually provide unconditional help and support to their children. Parental feelings of well-being or happiness are closely related to the happiness and the smooth running of their family as a whole. On the other hand, the elderly also expect assistance and support from their children. However these expectations are not always met, probably because of an incapacity or unwillingness to provide support. There are several reasons for this unwillingness. The most common reason is disappointment with the role the parents have played in the family which has led to a poor relationship. Others reasons are being too busy with their own family and work commitments. Since there is a scarcity of formal support systems for the elderly in the community, the quality of life of the sick elderly who cannot rely on the family network can be very poor.

3. Categories of Family Caregivers

Most stroke participants in the study were cared for by more than one family carer. The carer who provided most of the care, the primary caregiver, was usually a wife, husband, or daughter who was living in the same house with the participant. Associate family caregivers were usually other direct family members or relatives in the extended family. They lived either in the same house, or in a separate house but normally in the same compound.

3.1. Primary Caregiver

After the ten participants were discharged from hospital, they were cared for completely by family members without support from health care agencies. Fifteen primary caregivers were identified for the ten participants. In the majority of cases (eight out of 15) the primary caregiver in the family was a spouse (five wives and three husbands) when available and capable. The rest of the family primary caregivers were daughters. All of them were new to the caring experience. Since most of the primary caregivers were also working full-time, at least two primary caregivers were needed for 24 hour care at home. In the study, seven of the participants had two primary caregivers. Two of these co-carers were hired; one of them substituted for the family caregiver while she was working, and the other reduced the workload of the family caregiver who could not handle all the caring tasks due to her own health problems. The other three stroke participants had only one primary caregiver.

Primary caregiver ages ranged from 19 to 74 years, with an education range from 4th grade through to diploma (higher education). Three also cared for infants while another three cared for a preschool child. Five worked as a family breadwinner as well as caring for the sick family member. The primary caregiver demographic information is presented in Table 4.

3.1.1. Being the Primary Caregiver

When the husband had suffered the stroke, the wife was expected to assume the role of primary caregiver especially when she did not work outside the home. In contrast, when the wife was sick, the husband would be the primary caregiver only when the daughter, who was supposed to assume the role, was not available. Nui, who was taken care of mainly by his wife, even though his wife also had her own health problems, assumed that the main reason for his children contributing little to his care was because he already had his wife with him.

They (children) all work, they don't have much time for me, or they may think that I already have my wife with me. But when my wife is not available, they do come to see me if I want any help.

In the Thai society, there are a number of factors determining who in the extended family should be the main carer, what kinds of assistance they provide, and the extent of their perceived responsibilities to the sick relative. The four main factors determining who in the family should contribute the most to the caring task are: time available for care, socio-cultural factors (influenced by social norms or expectations), personal commitment, and care recipient's preference.

Table 3: Primary caregiver demographic information

Patient	Caregiver	Family relationship to the patient	Age	Highest Education (Year of schooling)	Occupation
Suree	Chacrit	husband	45	HE* diploma	government official
	Joy	daughter	20	12	resigned from school to care for patient
Nui	Pin + hired	wife	64	7	housewife
Laap	Kun	wife	63	4	housewife
Plup	Pak	husband	74	4	rubber tapping
	Din	daughter	40	4	rubber tapping
Yupa	Kai	daughter	26	4	housewife/ unemployed
	Suwat	husband	56	4	self employed (carpenter)
Pak	Jun	wife	59	4	housewife
Prateep	Jew	daughter	20	10	housewife
Choo	Somsuan	daughter	29	HE* diploma	government official
	Saowaree	daughter	40	4	housewife
Winai	Job + hired	wife	35	4	trader
Pirat	Lun	wife	50	4	trader
	Ning	daughter	19	12	student

*HE: Higher education

3.1.1.1. Time available.

In the extended family, caregiving responsibilities are distributed among family members in order to keep the family functioning as a whole unit. However, the actual caring role usually falls to female family members who have time available.

Actually I have been busy because I do full-time housework and baby-sitting at home but I was considered to be free because I do not work outside. (Jew)

3.1.1.2. Socio-cultural influences.

Thais value self-sacrifice, devotion, and protectiveness. These values encourage family members to fulfil their roles as expected by the society. Chacrit became a primary caregiver for his wife because of his mother's and siblings' influence. He was expected to contribute more to the care of his wife as he in part was seen as causing her illness.

My husband came back to look after me because of his mother's order. He was 'Grang-Jai (not to offend)' his mother. Moreover, his sisters and brothers also forced him to come back to look after me and the family. They said that my husband was the person who made me sick, so he has to take the responsibility. Luckily, his relatives criticised him and put him back on the right track. (Suree)

Neighbours, friends, and the social network outside the family also greatly influence and encourage family members to assume a caregiver role for a sick member by admiring and giving them recognition. This kind of social reinforcement is regularly offered by various organisations in the community to encourage people to fulfil their roles and do good deeds. A prize such as 'The greatest mother of the year' is regularly given at the district level to the mother who demonstrates excellence as a mother as well as a wife according to the social norms. The wife of a stroke patient who was an informant for my pilot study, mentioned with pride the prize she had received. She said that she was given the prize because she had looked after her three children and sick husband well.

I was given the prize by the local district last year. That was two years after my husband became sick. I have committed myself to caring for my husband and looking after my young children without any external support. That was really hard work because at that time my husband was completely dependent.

Neighbours might also contribute in encouraging the family members to assume the caring role by making direct comments.

My neighbours have seen what has happened to me and my family for a number of years. They knew how I suffered and they sometimes commented to him about his caring responsibilities which is very important for my recovery. (Suree)

3.1.1.3. Personal commitment.

Engaging in and maintaining the role of primary caregiver requires a strong personal commitment supported by love, closeness, and a bond between the care recipient and caregiver, including other individual qualities such as morality and responsibility.

Love

To care for the sick spouse or parent certainly implies the recognition of a close bond and affection among them. Callan & Noller (1987) noted that love has been linked with attachment, care, responsibility and respect for each other. In Thai society, love and concern for family members are usually expressed through actions rather than direct verbal expression or physical demonstration of love. Deep feelings can be interpreted from interpersonal interaction, whether love or hate, like or dislike.

Though the word 'love' (Ruk) was rarely expressed verbally in the interviews, it could be sensed and observed by the care and the treatment given by the family members. Feelings of warmth and care toward the individual were demonstrated through the frequency of visits, the amount of support, the ways of caring, and the willingness to help. Pirat enjoyed the benefit of the close bond with his daughters. He did not feel uncomfortable asking for help as he was sure that his daughters were always willing to help him.

After work, they all come to visit every day but I don't know what will happen in the future. I'm lucky that all my kids love me. You know I have a very good relationship with all my daughters... If I ask for assistance, they never ignore my request. I can ask for help any time.

Love and affection towards the sick relative are the most basic reasons for the caregiver strongly committing themselves to taking on the caring role.

Morality and responsibility

A sense of responsibility might develop from feelings of guilt when one thought that he/she in part caused the illness. Chacrit was a caregiver who was informed by the doctor in the hospital that his wife's illness was partly caused by stress. The source of this stress was her husband's involvement with another woman, a second wife, in recent years.

I'm feeling guilty because I partly caused her sickness. I'm trying to do everything humanly possible for her. I try to spend more time with her, to do massage and care for her. You know... now my situation has changed, I have two families to look after. Both sides have put a lot of pressure on me. They never realise how difficult it is to be in my situation. I have to be concerned about the feelings of both sides but I'm in trouble now. I have got health problems, headaches, hypertension and stress. I have been very tired physically and mentally. People all blame me for her illness. I don't have anyone on my side. Right now, it is not possible for me to step backward. It will never be back to the same situation again. I have two children with my other wife, which is why I have to go ahead. It is also my responsibility to take care of my new family.

Conflicting responsibilities also arise from other sources. As Segalen (1997) pointed out, 'personal realisation' can become more important than 'family life' and there is then a dichotomy between family and kinship 'obligation' and 'individual freedom'. Jop's story illustrates this tension. Jop took on the role as primary caregiver for her husband as an obligation and responsibility. Being the main wage-earner of the family as well as the primary caregiver for her husband was undoubtedly a hard job for her. As time passed, she started to realise that it was extremely unlikely that her husband would recover. She began to express her aim to preserve her 'personal life' and 'liberty' by shifting the responsibility to other family members.

He has got many children. They are supposed to contribute something to the care of their sick father.

3.1.1.4. Care recipient's preference.

On the other hand, the care recipient also played an important role in deciding who in the family should be his/her primary carer. The sick person might feel

uncomfortable asking for help from some family members even if they were available. The reason for not wanting a particular family member to care for them might be due to unhappiness with the care provided, or a perceived feeling of unwillingness on the part of the carer to perform the care required.

In summary, responsibility and time available to the carer were the main reasons for them engaging in the primary caregiving role. The maintenance of the role of primary caregiver was influenced in part by socio-cultural factors (social norms, social forces), and personal feelings between caregiver and care recipient. Personal commitment to the caring role might be disrupted by an overload of caring tasks, with not knowing when it was going to be over. Within the family, the degree of shared responsibility to care differs, mainly due to the amount of time, division of labour, and perception of appropriate gender roles.

3.1.2. Role of the Family Caregiver

Obligations and expectations of the caregiving role are strongly associated with gender. Thai men are generally expected to perform tasks having to do with the family business, decision making, and transportation. Women, mostly wives and daughters, are expected to perform caring and domestic tasks. The degree to which the Thai male or female carers in the study adhered to gender role expectations undoubtedly influenced the meaning they gave to caregiving and the burden they felt from it.

Female carers

Generally, the women's commitment to caring tasks significantly exceeded that of the men, whereas men enjoyed greater commitment to paid work. It was evident that the wife and adult female children (usually daughters and granddaughters) provided the most extensive and comprehensive care for a sick family member.

I mostly receive assistance from my daughter more than my son. When I was well, I did everything for everybody in the family and now my daughter has to take my role. That is a huge responsibility because she has to do everything for everybody including looking after me, and being company for me. (Suree)

Male carers

The differences between the female and the male caregiving roles can be summarised as a lower level of support, participation and responsibility; and a lower degree of emotional involvement - sharing, talking and expressiveness.

The male carer, usually the husband, the son, or son-in-law living with the sick person, often dominates decisions of service selection and the rehabilitation programme for the patient at home. Other assistance usually included activities which involved transportation such as taking the participant to the hospital, buying herbs, and shopping.

When my mother-in-law was in the hospital, my main job was a driver taking family carers to take their turn to care for her in the hospital. (Plup)

They mainly help me with transportation because there is not good public transportation here. (Prateep)

Participants were happy with the males' degree of involvement. Most of them did not expect to obtain assistance with daily activities or domestic chores from a male family carer.

My son doesn't help me much, I think that is just the nature of a boy. He loves to be out with friends rather than being at home, so he is usually unavailable when I need his help. I used to ask him to share some domestic chores with my daughter but he ignored the request. I think I just can't expect anything from him as he is a boy. Anyway, I think he is a responsible person. I do assign him to take care of buying food for the family and to give a ride to his sister to and from school. Other than that he is free, he can get out with his friends as usual. We don't expect anything more from him. (Suree)

I can't get any assistance with daily activities from my sons at all. They probably don't want to get involved with women's tasks. (Yupa)

3.2. Associate Caregiver

The distribution of responsibilities among kinship networks is a very important feature of care in Thai society. Associate caregivers contribute to the care

of the sick relative in several ways, either directly or indirectly. Direct care is normally given in an emergency situation, or when the primary caregiver cannot handle the caring tasks, or when the associate caregivers are available. Their indirect contributions can be in the form of activities such as sharing the primary caregiver's overall workload.

3.2.1. Role of the Associate Caregiver

Admission to hospital is the period requiring the whole family to become involved in caring for the participant. This was because most of the government hospitals require a family carer to stay with the patient in a private ward as well as in most of the public wards. In the study family members normally took turns to take care of their sick relative. The primary caregiver usually took the day shift, whereas the associate caregivers often contributed time after work to care for the patient, so that the main carer could rest.

Associate caregivers who lived in the same house or nearby might contribute many hours each day to take a turn in providing care while the primary caregivers tried to maintain a normal family life with their spouses and children. Young family members (children and grandchildren) were also involved in caregiving activities, especially after school. Some of them contributed many hours each day during school holidays to care of the sick elder. Adult children living outside the village or far away, made frequent trips to visit and provide respite care and support to their sick relative. The older relatives, often sisters or sisters-in-law, were somewhat frail themselves. Despite their own declining health, they were willing to contribute to the care of the sick person and family if needed. Thus associate caregivers were the main source of respite care for the primary caregiver.

My sisters, and my sister-in-law live not far from my place. They kept me company and stayed overnight with me in the hospital. When I came back home, they usually came to visit and massaged me. (Plup)

My sisters-in-law can't see me very often as they are always busy with their family business. However they try to come to visit me because they know that I'm sometimes alone in the evening when my daughter has gone to school and my son hasn't yet come back from school. (Suree)

Associate caregivers might provide indirect care for the sick relative by helping with family matters, so that the primary caregiver could have more time to deal with the caring tasks. For example in the case of Prateep's family, the eldest son did the shopping for the family, allocated the caring tasks to his siblings and provided some financial support to the family. The amount of care each family member contributed to the sick member was not clearly specified in advance. It was basically left to their own judgement and willingness.

4. Family's Perception Regarding the Caregiving Role

Like the participants, as identified in the previous chapter, the family perceived the disabled family member as a sick person who should assume the sick role. In their view, the sick person should be exempt from social roles and normal activities. This included regular work commitments, role activities and social responsibilities. They were not expected to care for themselves but they would be expected to comply with the treatment regimens and co-operate with the health practitioner. As a result of assigning this sick role, the family's responsibilities could be characterised as direct care and financial support for the health service expenses, not just visiting or having a meal together. The caregiving role was assumed by family members as soon as the participant became sick.

Thai society values caregiving for sick elders in the family in many ways. Firstly, caregiving is a way to pay back the parents' goodness (Tob-Taan-Khun). In Thai society, parents are important people who give life to and raise their children with love and care. They are always ready to give help and support to their children whenever they are in need, no matter how old they are. Hence, the parents' goodness is considered the highest rank of moral debt which is never able to be repaid. To reciprocate the parents' goodness, children should be obedient, showing gratitude and respect to their parents. They are also expected to take care of their parents when they are old or sick. Generally, children will try to contribute to their care in some way. In the study, if children who lived a considerable distance from their parents worked for the government, they would try to transfer to the branch which was closest to their parents' home, so that they could make frequent visits to care for them.

My daughter has been trying to find a vacant position to move back here, so that she can take care of her parents who are getting old and are not so healthy. (Nui)

Secondly, caring for sick parents is a great source of merit earning. The good Karma performed by caring for parents in this life will ensure a better life in the future. On the other hand, the spouses who cared for their sick husband or wife might tend to think that it was a way to repay the debt of the previous negative Karma they had done to their partners.

Thirdly, caring for a sick elder can be perceived as a source of pride for both the younger caregivers and the elders, as Thais view the actions of the younger generations as a result of the efforts of the older generations. Children are good or bad partly as a result of the way the elders have taught and raised them.

Consequently, the role of caregiving for a sick family elder was perceived positively as it provided an opportunity for the family to reciprocate their parents' goodness, to do great merit, to raise their self-esteem and to feel proud as a result of providing care. These perceptions help to strengthen the family role of caregiving for the family elders. However, as will be discussed later, there were also negative effects of caregiving for the caregivers and the family.

5. Scope of the Family's Responsibility in the Caregiving Role

Caregiving tasks were mainly focused on assisting with ADLs (activities of daily living), role activities, psychological needs, the prevention of accidents and complications, and health treatment decision making.

5.1. Assistance with ADLs

Participants classified the activities of daily living into three groups: personal, general, and skilled activities.

5.1.1. Personal

This category included very private or personal activities such as managing the bladder and bowels (using the commode, bed pan or urinal), dressing, undressing, and bathing. Participants felt most uncomfortable receiving assistance with these activities, especially with cleaning after bowel movements. Some participants

preferred only direct family members, usually female carers, to assist with these activities.

I prefer my daughter to do it for me. It could be my husband but apart from him I think it should be female assistants. I feel shy even with my son. (Suree)

However, some participants explained that they were not in a situation where they could select the carer.

I have no choice, I may ask whoever comes close to me or is willing to help. I can't feel embarrassed now. There is no embarrassment any more. I'm concerned only about my hygiene and care needs. How I can get cleaned, that is all. (Nui)

5.1.2. General

This category comprised a wide range of general daily activities, for example: cleaning the teeth and face, shaving the beard, preparing food, preparing medicines, exercising, massaging for comfort, moving around the house (especially getting to and from the toilet), boiling water for bathing and hot compresses, keeping warm at night, transportation, accompanying the patient to the hospital. Direct family members, relatives and friends could all assist in this area.

5.1.3. Skilled activities

Some participants viewed massage and training to walk as skilled activities which needed a carer who knew exactly how to assist in case adverse effects or an accident resulted. In some cases a family member had gained these skills.

I think massage needs to be given by a skilful person such as a healer. But my husband can do it for me because he has learnt how to do it from the Thai traditional medical textbook. I do need proper guidance while I'm training to walk. I won't walk with a person who doesn't know how a patient learns to walk as I may not be able to get help when I need it. I may fall. (Suree)

For Suree, her husband was also expected to act as a healer. He massaged her and also directed her while she was doing exercises and walking. Her husband was

always with her when she was training to walk and he would prompt her to walk or correct her posture.

5.2. Assistance with Role Activities

Thais value the family as a whole unit above an individual. The term 'family comes before individual' is emphasised. An individual's well-being and sense of identity are closely tied to the family. Since the elderly in Thailand are normally still active in the family, illness of an older member impacts on the family in some way. The wish of the older person to keep the family functioning, may shift the focus to family achievement rather than the recovery and well-being of the individual. Taking over the participant's former role in order to maintain family functioning was considered a way of caregiving. Some families felt that assistance with role activities was the most important way of supporting the participant's psychological needs. There were two kinds of role activities identified in the study: the housework and family caring role, and the working or business role.

5.2.1. The Housework and Family Caring Role

This role normally belonged to the housewife of the family. When the wife was sick and could not perform this role, the functioning of the whole family is affected. Some family members had to resign from their jobs to take care of her roles which included domestic chores such as house cleaning, washing, doing the dishes, cooking, shopping, ironing, taking care of children and sick family members.

5.2.2. Business

The working or business roles that needed to be taken care of while an individual was sick, usually concerned a family business, such as trading or farming, that was the major source of the family income. Related activities identified in the study included obtaining and providing food for sale, taking care of a rubber plantation, raising chickens, helping with rubber collection and processing, and house construction.

5.3. Assistance with Psychosocial Needs

Most family caregivers perceived their responsibility as dealing exclusively with the physical, while a few of them considered the sick individuals' psychological and social needs. Those who were aware of the sick person's psychosocial needs might contribute their support by avoiding putting stress on her/him, and reassuring the sick person that he/she continued to be cared for, loved, esteemed and valued by the family.

What I worry about is the mental problem. I know she is frustrated by her physical disability and still can't cope with it because she can't get around on her own. She has to stay in bed all day. It's really boring. I realise that she wants to get out even if it's not convenient. I have done everything that is probably useful to her. I think this disease needs help and support in many ways. One important thing is mental support, that is trying to not put stress on her by not saying things to annoy her and being with her more often. (Chacrit)

However, most of the family carers shared the same attitudes as the sick member towards limiting his/her outside socialising while being sick and hoped that the sick member would be able to adapt to his/her social limitations.

I sometimes like to encourage her (the sick mother) to meet other people, so that she can talk and release the pressure on her but I don't want her to join any parties or ceremonies which require someone to accompany her all the time. (Suan)

I think she (the sick wife) will finally get used to her condition...I think that she will be all right eventually. (Chacrit)

5.4. Assistance to Prevent Accidents and Complications

It is known that stroke survivors are five times more likely to have a second stroke six to 12 months after being discharged from hospital and that they may lose ground in maintaining the self-care skills they learned following their stroke (Johnson, Pearson, & McDivitt, 1997). Most participants and their family members were warned by health professionals to avoid accidents, especially falls. The most common measures the family employed to prevent accidents and stroke complications were awareness of abnormal symptoms and keeping the environment

safe. Daily activities and exercise equipment were organised with the primary concern being safety, for example the height of the walking rails being at about the level of the axilla in order to provide secure support.

5.4.1. Awareness of Abnormal Symptoms

Abnormal symptoms that might cause accidents while training to walk or doing exercises included dizziness, pain, muscle fatigue or tiredness. Caregivers always asked the sick person about these symptoms and made sure that he/she was accompanied by someone while walking.

I always put some chairs within walking distance, so she can take a short rest whenever she feels tired. (Chacrit)

5.4.2 Maintaining a Safe Environment

Although some caregivers mentioned their concerns about keeping the environment safe for the sick person by keeping the floor clean and dry, in reality the kitchen and bathroom floors were often wet and slippery. I often saw many pieces of cloth spread all over the floor.

Overprotection by the family could result in limitation of the patient's activities rather than putting her/him at risk of having accidents. For example, in many cases the study participants were not encouraged to perform self-care activities or do exercises even though their physical condition was good enough to do so. Chacrit always encouraged his daughter to do things for her mother when her mother's condition had improved.

I try to encourage my daughter to do things for her mother because it is too risky to let her do it herself. If an accident happens, her condition may become worse which could cause her to be confined to bed. That would be a great burden for the family.

5.5. Assistance with Health Treatment Decision Making

The family was always involved in the process of health treatment decision making. Several participants preferred to delegate the decision making to family members. This was because the participants could not obtain treatment by themselves

and they were not comfortable asking for help directly from family members. Several participants achieved this shift in decision making about the treatment plan to the primary caregiver by encouraging direct interaction between carer and practitioner. From the individual's perspective, shifting the decision making role to the carer is an important way of communicating needs to the carer and provides further encouragement to the carer to actively participate in the delivery of care. Since decision making was closely linked with authority for the management of the participant's finances, the family carer could then make appropriate decisions about the rehabilitation plan from the beginning.

6. Caregiving Burden

The word 'burden' has negative connotations and denotes physical and psychological 'heaviness'(Lim et al., 1996: 259). The caregiving burden included a wide range of negative responses and effects that the caregivers identified as the result of caring for their sick relatives.

6.1. Factors Contributing to the Caregiving Burden

The caregiving burden emanated from many interrelated factors: lack of knowledge about the illness and care, the degree of the care recipient's dependence, the care recipient's expectations, the multiple role responsibilities, the long term care needs, a low level of support from the family network and financial difficulties.

6.1.1. Lack of Knowledge About the Illness and Care

Lack of knowledge of the disability and how to care for the sick family member at home was found to be an important cause of stress, especially during the days immediately following hospital discharge. Based on the assumption that the patient's home was the best place for recovery and rehabilitation, most participants were encouraged to return home as soon as possible, without realising the caring problems they might encounter. There was little recognition that caregivers were usually novices in providing complex physical care and were not prepared for the consequences of long term care of a sick family member. Most of the participants' hospital stay averaged about seven days. Only three (out of ten) stayed for a longer period of time (24, 30 and 47 days). With a short hospital stay, there was limited time

for both the individual and the family to learn new daily care routines in the hospital, thereby placing additional demands on caregivers to cope with complicated care needs. In the study, only a few of the patients and family carers had prior experience in caring for serious illnesses. All carers complained about not having enough information or knowledge to care for their sick relative at home. Inevitably, caring skills based on their own experiences were often used by the carers.

Jop's experience of caring for her husband in the initial stage of his illness, reflects a very stressful situation when she was confronted with her husband's unstable condition on the day of discharge, seven days after admission, and did not know how to deal with the situation. Jop described her husband as being in a stage of confusion. He was being fed via a feeding tube which was taken out just before he was sent home. He was given medication to take home and an appointment was made for a follow-up visit in a month's time. Jop was shocked when she was told to take her husband home, without physical and psychological preparation to care for a husband who still needed complicated care. She had not been informed of or taught the caring skills needed to care for her husband at home. Her husband had not been seen by a physiotherapist during his hospital stay. Jop was very disappointed with the service from the hospital. She described the events of the first week after his discharge:

He was drowsy, didn't speak, didn't eat. I didn't know how to deal with his problems. I heard the secretion sound in his throat but I didn't know how to help. I thought that was probably the last day for him. It was a very stressful and scary feeling...a feeling of confronting death. I just stayed, watched and did what I could do to comfort him for the whole night. I provided him with hot and herbal compresses on his hands in order to keep him warm and massaged him to stimulate his feelings of sensation for the whole night. Luckily he survived but he was unconscious for three nights. His consciousness gradually returned. Since he had had nothing to eat or drink since he came home, I then tried to feed him but he aspirated every time I did. I was so frightened and I gave up. I could only drip saline into his mouth drop by drop. It was a very stressful situation because I had no one to discuss it with. I had no knowledge to deal with the problems. I used only common sense to solve them. For example, I noticed that his tummy was very tense... do you know he did not have a bowel movement while he was in the hospital for seven days. I thought this could create pressure inside his body which might affect his consciousness. I talked to his eldest son and he bought him a packet of

soap enema. I used both the packet and manual evacuation to remove faecal matter. That was a big relief for him. Bath time was awful. Since I had no one to help, I pulled him along the floor to and from the bathroom. You can imagine how difficult it was. The first week of his discharge was really a nightmare for him and me. He fell off the bed many times that night as I didn't want to leave him outside the bedroom, being bitten by mosquitoes.

For the participants who were hospitalised for a longer period of time, although their family caregivers had more time to learn how to care for the patients while they were in the hospital, some of them still did not have the confidence to handle the care alone at home. Chacrit said:

At first everybody (children) was very worried about the problems that might arise from the illness of their mother. They were afraid that they couldn't take care of their mother, they couldn't do this and that.

Lack of understanding of the individual's condition and his/her responses added more burden to the caregivers. Caregivers of two participants mentioned their sick mothers' inappropriate emotions such as laughing without good reason. The carer of one participant thought that the inappropriate laughter was probably due to the side effect of medicines whereas the carer of the other participant interpreted it as the sick individual's way of gaining attention from family members. In the latter case, the family members tended to ignore the individual's inappropriate reactions, which was thought to be the way to modify the behaviour.

My mother sometimes suddenly laughs a lot even when she is on her own. When being asked she could not give you a reason. She often laughs until she is tired, unable to lift her feet, and ends up being incontinent. That makes every one very angry with her behaviour. I sometimes left her alone until she calmed down and then I would go to see her. Carers of other stroke patients thought that she wanted to gain attention from family members. When I talked to my brothers and sisters, they told me to limit my time with her but my father always blamed me for not looking after my mother well enough. (Yupa's daughter)

6.1.2. Degree of Care Recipient's Dependence

The degree of the care recipient's dependence was determined by functional impairment and disabilities. These disabilities had a significant impact on the nature

of the caregiving burden as they determined the amount of care the caregiver had to provide. In the case of a paralysed family member, caregiving was described as an intense, continuous responsibility with no respite or knowledge of how long this responsibility would continue.

Since my mother was sick, my hands were never dry. There was always another caring task after finishing one. (Din)

Other studies have shown cognitive impairment to be a very influential factor in the burden of caregiving (Browning & Schwirian, 1994; Bull & Jervis, 1997). Although this study excluded individuals with this disability, a few of the participants had shown a gradual deterioration in cognitive function and memory since hospital discharge which appeared to increase the burden.

6.1.3. The Care Recipients' Expectations

The participants' high expectations of the caregiver and demanding behaviour contributed to the caregiving burden. These expectations were not confined to the caregiving role but also related to other family roles such as income generation or running the household. Lun (Pirat's wife) always complained that her husband had never been happy with her management of the family business. He was still in command, directing his wife to do as he wanted. As Pirat explained the situation:

I work with my mouth now. I teach her how to cook from here. I tell her to put this in and put that in the food while she is cooking, but sometimes she is not very happy with my involvement. She told me to shut up. She wanted to do it her own way. She says 'You don't row the boat, you shouldn't slow the speed by putting your foot in the water'.

The situation had not improved five months after discharge:

You know he has been mad. He is very aggressive, irritable, gets angry easily. He yelled at everyone this morning. He has never been satisfied with what I have done for him. Everything seems to be wrong. There are so many problems to worry about these days, especially the house construction problems. Many labourers have been hired to build the houses but they leave before they finish the job. I'm very stressed about it as I'm the only person who takes responsibility for all the family jobs, including buying materials for construction,

looking for labourers, following up the progress of the construction, taking care of the trading, and housework, including him.

Pirat responded to the same issue in a similar way which confirmed his high level of expectation of the family caregiver.

My wife was very angry because I blamed and criticised her. I was really angry with her today. I scolded her and said something rude to her. I felt very frustrated with some silly things she has done. I have high expectations of her. She has improved so slowly. You know our customers have made a lot of complaints about the quality of the food in the shop. They said that the taste of the food was different from the past and not consistent. This is because she has never done the cooking before and she doesn't have skills in cooking. She has no head for cooking. You know, selling food nowadays you have to be more careful because things are more expensive. If you don't know how to manage the budget, don't know what should be spent, it means that you lose a lot of money. Like shopping in the market, one should know how to manage the menu using the cheap foods that are available. We should be mindful to spend less but maintain the quality. When I was well, I organised the menu. I would see what was available in the market and then the menu would automatically come to mind, but my wife doesn't have skill for that and it is very hard to teach her all these things. My plan in extending the business will never be successful without me.

Jop and Jew provided similar perspectives of patient expectations and demanding behaviour:

I can accept his physical dependence but I can't tolerate his demanding behaviour. He wants to be visited more often, he wants to control my personal life and does not trust me. I find it very annoying.
(Jop)

You know, taking care of my father is a very difficult job. He has been difficult, aggressive, irritable since he was ill. I seem to do every thing wrong. He has never been happy with what I have done so far.
(Jew)

6.1.4. Multiple Role Responsibilities

Most primary caregivers in the study had several other roles such as spouse, parent and worker. Female carers were more likely to suffer from role strain as they

attempted to combine caring, family and work roles. Caring for an dependent elder in addition to the stroke victim, was a heavy task which often affected other roles of the carer. When the carer failed to cope with this role strain, it led to negative changes in family relationships and eventually affected his/her own well-being. Jun was one of the carers who occupied many roles and carried a lot of family responsibilities as she was the only person staying at home.

I was exhausted and bored from too great a workload, taking care of my sick husband (the stroke victim), a baby (grandchild), my dependent father and looking after all the household chores...My daughter and her husband are working full-time, I'm the only person who is able to take care of her baby when they are out at work, as well as looking after my father who is 81. Caring for three adults (including her husband) is very hard work...I'll do it as long as I can.

Multiple role strain was often experienced by a young spouse or daughter who was still working as well as caring for the sick relative, parenting their own children, and taking care of the housework. Conflicts might arise from the multiple roles with caregivers having to make decisions about the time they could allocate to each role. Lun became the main income-earner for the family after her husband was sick. Her job as a food shop owner occupied most of her time. Despite this very hard and time consuming occupation, she was trying to handle the care of her husband and contribute to the care of her own elderly dependent father.

Before he (her husband) was sick, I used to cook and bring food to my father every morning and evening but now I do not have the time, so I take care of only the morning meal and my sister has to cook dinner for him. Even though arrangements have been made for other family members to take on some of the caring activities, we still often bring him (father) dinner as we sell food from home.

In Jop's case, after her husband became sick, she became the only carer for her husband, in addition to being a mother of a preschool child and the primary wage-earner for the family. Without any family support it was very difficult for her to handle all these roles. The situation forced her to move her sick husband to a healing centre where he had company and received some support from other residents in the centre. The best she could do in this situation was to pay her husband regular visits after work, during which she provided him with care and support.

6.1.5. Long Term Care Needs

Family members found the greatest burden was the physical and mental tiredness caused by continuous day and night care for a long period of time.

My husband wants me around all the time, I can't leave him alone. His need for me to be around is related to his fear of emergencies that may arise when he is alone. (Jun)

The period of care needed by participants in the study tended to be longer than it should be because of lack of an effective discharge plan, loss of hospital contact after discharge and lack of community health services. Most participants' health condition fluctuated due to a lack of knowledge of the illness and appropriate care, and lack of realistic goals for rehabilitation. In addition, many of them had had accidents and suffered complications of the illness which could have been controlled and prevented.

6.1.6. Financial Difficulties

Financial difficulty, due to loss of income and increased expenses related to treatment costs, was one of the most important sources of burden for the low income family, or for those who were not covered by social welfare benefit.

Family financial strain can be the most important source of emotional burden. My mother is lucky because she is covered by the government social welfare, so we don't need to worry about the hospital fees. (Choo)

The degree of burden became greater when the main wage-earner (usually the husband) of the family became sick.

Since I was the main income-earner of the family, when I'm sick, I can't work, so there is no regular income for the family whereas there are regular expenses for private treatment fees and for the youngest daughter's study. My present aim is to find beneficial treatment and be cured as fast as possible in order to get back to work. (Pak)

For the family in which both husband and wife worked, finances were considered to be less of a problem compared with the family with only one wage-earner. However, in many circumstances, the healthy spouse had to assume the

caring role as well as the income-earning role which placed more burden on the family caregiver. Jop and Chacrit described their anxiety about the family finances:

I have to handle all the family expenses for example gas, electricity, children's education, hospital fees and so on. I don't want to think about how my family will survive if I'm sick. (Jop)

Well .. it has affected our family a lot since she was the person who took care of the household work as well as the business to earn more income to support our family. (Chacrit)

In adapting to the situation, family caregivers might try to cope with this crisis by committing themselves to carrying out their duty and responsibilities, accommodating and growing accustomed to the situation, and balancing between rejection and acceptance of the caring role.

I think now they have become used to it. They gradually accepted my wife's condition and took on part of the workload in our family. I think my daughter is more mature since her mother was sick. Previously, she never did anything herself, even her own clothes, her mother did the washing for her. She never did the washing, cleaning or cooking. Now she has to do everything herself. (Chacrit)

6.1.7. Minimal Level of Contribution From the Family Network

Most of the primary caregivers did not feel they had enough support from family members even though they were available and supposed to contribute to the care as a member of the family. Jew described her situation:

I was so stressed one day when my baby was sick and I had to take her to the hospital. The doctor wanted her to stay in the hospital because she had a high temperature and was so sick but I couldn't stay because I couldn't leave my father at home even though I still had a sister and brother at home. I therefore took some medicines home. I nearly went mad due to not enough sleep because my daughter couldn't sleep and my father often needed help with urinating. At that time, my father went to the toilet very often, about 3 to 4 times a night as a result of drinking a huge amount of water on the doctor's advice. I did call my sister sometimes when I ran out of energy. She did help but she also complained a lot. I normally ask her to take care of my baby and do her own washing, so I can have

more time to care for my father. Basically, others contribute support only when I can't handle it all.

The reasons for other family members contributing very little to care were either unwillingness to get involved, or the sick person wanting only the primary caregiver and refusing assistance from the others, especially with personal activities. In the case of Pak, his youngest daughter was at home during school holidays but could not help with caring tasks such as toileting, bathing and dressing. If not his wife, he preferred his sons to help him with these activities, but they were usually not available because they all worked and had their own families to take care of. The whole workload therefore fell to the wife.

6.2. Impacts of the Caregiving Burden

The negative impact of family caregiving on the caregiver's physical and psychological health included health deterioration, role strain, social isolation, emotional distress and disruption of individual and family life.

6.2.1. Impact on Physical Health

The impact on the caregiver's physical health as a result of caregiving was described as tiredness and health deterioration. These effects were associated with the degree of care recipient dependence, a 24-hour commitment to giving care for an extended period of time, multiple role responsibilities and a minimal contribution to care from other family members. Additionally, older spouses caring for their partners with serious impairment and disabilities were more likely to be susceptible to ill-health themselves. Their health problems might be in part attributable to natural health deterioration due to old age, accelerated by the physical strain of caregiving. Some of them expressed anxiety about the caregiving situation and uncertainty of continuing in the caring role.

I don't know how much longer I can care for him because my health is not good either. I think I have to accept this caring role until one of us dies. If I die before him I don't know how he is going to survive.
(Pin)

6.2.2. Impact on Social Life

Having restricted time for self and social activities due to caregiving responsibilities contributed to the feeling of social isolation in the majority of caregivers. The feeling of isolation also included the feeling of being cut off by family members and social network. Kai expressed her loneliness:

Everyone in the family is trying to stay away from my mother. They know I can't see her lying wet in bed or being smelly, that sort of thing, so they just keep their eyes shut. When I discussed the problems with them they convinced me to let her try to do things for herself, which was meant to be good for her health. They make me feel like I have been working hard because I want to. They have never given me any useful advice or suggestions because they are afraid that they may need to become more involved with her care. (Kai)

Jun was occupied by multiple role responsibilities which drained her energy resources and time, and therefore limited her social life.

I have been very tired and I got bored because I can't go out. I have to be with her all the time. (Jun)

6.2.3. Impact on Psychological Health

The emotional distress and mental exhaustion from caregiving was complex and resulted from many interrelated factors: lack of knowledge about the illness and care, long term care needs, lack of family support, the caregiver's perceptions of the care recipient's expectations, and financial difficulties. These factors increased the caregiver's feeling of depression and in some extreme cases led to the idea of committing suicide when caregivers felt they could no longer cope with multiple stresses. Lun's feelings are clearly illustrated in the following:

He is very demanding. I've nearly hung myself many times. I sometimes want to commit suicide as he always blames me. I seem to do everything wrong. I was really frustrated especially in the first few weeks of his discharge.

I don't mind caring for him but he always upsets me and blames me. I have never done anything right or met his expectations. You know it is a very stressful situation. Now I'm confused, I don't know what I should do next. I really don't know what to do. I told him to kill

himself by hitting his head against the wall in order to escape from this stressful situation.

Jew's and Kai's stories, in particular, highlighted the problems of extreme emotional distress due to lack of family support, being unable to handle the workload, and a decrease in contact with their own family. The emotional impact was far worse when the caregiver was involved with the household and child-care tasks, especially caring for a baby.

It is a really stressful situation for me. Everything in the house falls on me- taking care my father, my baby, my sister's baby, and all the housework. (Jew)

High expectations of the caregiver and the patient's demanding behaviour had a significant impact on the caregiving burden. The patient's expectations of the female family members could put more stress on these women. In a similar vein, a younger generation family carer who cared for an aggressive older person in a society which discourages the outward expression of burden, might shift the anger to other weaker family members, for example, a baby or a child.

...but I'm the main person who is with my father all the time, day and night, 24 hours a day, 7 days a week. I feel very exhausted and sometimes I think I may need to see a doctor myself too. I found I got irritated easily and I sometimes lost my temper with my baby. I used to hit her terribly. I don't know how many times I hit her which was very unfair on her and that made me feel guilty afterwards. I thought about running away or suicide many times. (Jew)

Some family carers expressed a desire for emotional support and counselling services from health professionals. However these were unlikely to be provided by the acute care services as most social workers in the hospital dealt only with financial problems.

6.2.4. Impact on Family Functioning

The main causes of disruption of family functioning resulting from the illness of a family member were lack of a family carer and financial strain. Disruption of family functioning was evidenced in many ways, for example resignation from work of a family member to take on the previous roles of the sick person or to provide

care, while young family members might need to leave school to take on these tasks. Pirat's daughter was requested by the family to take leave from her job when her father was sick to help the family business which he ran, until he was better or the family could cope with the situation. Similarly, Yupa's son-in-law was forced to resign from work, leaving his wife to earn the family income, to take care of their baby, previously cared for by the patient. Work overload due to the multiple role responsibilities of the primary caregiver, would further affect other family members' functioning. In some cases, other family members were requested to leave school in order to share the primary caregiver's workload.

I feel sorry for my daughter because she just finished year 12 last year. She actually wanted to go to college this year but unfortunately her mother has been sick, so she has to stop her schooling for a while to take care of her mother. (Chacrit)

A greater degree of family disruption could be observed when the sick person was the breadwinner of the family because of the loss of the major family income.

If he is ill long, it will be a big problem for us. (Pirat's wife)

The captain of a ship (Thais usually compare the leader of a family with the captain of a ship) is ill, having a great impact on the family...I think that if I'm not be cured soon, my family will be in trouble. I don't want to imagine further than that. I try to stop my thoughts there, otherwise it will affect my illness. (Pirat)

Caregivers and family members might also experience a loss of normal family life after the illness of the family member, especially the wife who looked after the well-being of the family.

Since her illness, we have closed our kitchen and bought cooked food. We just eat to survive. We don't enjoy the meals as we used to do. (Chacrit)

Because of the tremendous energy and time spent on the caring tasks, it was not surprising that caregivers often felt that they had no time for themselves or for their immediate family. This could further affect the relationship with their immediate family members, and other roles of the caregivers in the family.

Since my mother has been sick, I don't have time for myself, my husband and my little son. We are not able to take my son to a playground or for a walk as we used to do. (Kai)

In the study, despite the hard work of caring tasks which were added to their normal responsibilities, a few primary caregivers did not show any signs of burden. This was because they accepted that caring was a part of their roles and they were ready to sacrifice themselves for their loved one.

7. Factors Influencing the Quality of Family Care and the Recipient's

Satisfaction with Care

The recipients' level of satisfaction with their care varies according to personal standards, concerns and expectations which can reflect the cultural system of the society. What a person views as 'good quality of care' or as 'satisfactory' may not accord with the health professional's standards based on expert opinion (Cromwell et al., 1996). Nevertheless, the recipient's level of satisfaction with family care can be used as an indicator of how well that care is performed and provided. In the study, the participants' greater satisfaction with the family involvement in care was not necessarily associated with successful physical recovery or direct care, but might be focused on some other aspects of care involving family roles.

Participants assessed the quality of family care in different ways. Firstly, the assessment of quality was most often based on whether a sick individual could obtain support for the majority of their basic needs, for example being provided with meals and medicines, assisted with ADLs, being taken to the hospital when needed, being able to obtain good treatment, being visited, and respected as expected. Providing meals was one of the most explicit indicators.

People in the village all said that I was lucky because I didn't need to worry about things to eat as I had many children, and every one usually brings me some food when they come to visit. (Nui)

Secondly, since most wanted to relinquish control to family members, they viewed excellence in caregiving as protection and security. Finally, for three participants in the study, the ability to continue to function well as a family in the new situation contributed to the level of satisfaction with care and therefore with

family life. The ability of the family to balance the caregiving role with other family roles was appreciated by the sick individual, even though the actual care was not perfect. The ability to maintain family functions, especially the family business, was a source of pride for the participants and this could fulfil their psychological needs.

The quality of family care experienced by the participants was determined by a number of factors: the power of the sick individual, the relationship between the care provider and recipient, time available for caregiving, number of caregivers, health status of the primary caregiver, family economic status and family circumstances.

7.1. Power of the Sick Individual

Power is intricately linked with decision making and control. It was evident that participants with 'high power' (in term of influence in family decision making) were well served in respect to their physical needs, received more frequent visits by relatives and friends, and made more practitioner visits. Despite being sick and physically dependent, participants might try to maintain their power by trying to continue in their jobs if they could do so, or remain in control of the family finances. Normally, the older ones who were involved in managing the family finances, were able to direct the family functioning including their own treatment plan. Pirat, for example, was still able to maintain his power and was totally in control of his care needs.

I can still maintain my position in a small house construction company which is a co-investment business with my other two friends. My responsibility is managing the company budget and my friend is looking after the construction at the construction site.

In the study, most participants lost their control, authority or power after the stroke as they relied more and more on family members. Decisions relating to the care and rehabilitation plan, some satisfactory to the sick individual but others not, were mainly made by family members. Nui expressed his frustration at being powerless and dependent. He was not in a position to decide where to live or what kinds of care he would receive.

My wife, daughter and son decided to bring me back to this home because I can't be on my own. I have no basis from which to negotiate with them, everything is up to them really. They are all very busy and don't have time to deal with me. I sometimes can't get what I need. I feel very frustrated, you know, I used to cry very often. It hurts me terribly. I wish I would die, then everything would be over.

Winai also was unable to obtain his preferred treatment due to a lack of power in controlling his care and meeting his needs. He tried to deal with the problem through his social network. When he was informed that his blood pressure was extremely high (240/ 180 mmHg), he was very worried and tried to contact his family to take him to the hospital. His wife ignored his request and tried to shift the responsibility to his sons (her stepsons). Winai was in tears when talking about the experience. He asked me for medication but I explained to him that was beyond my capability because this type of medication required a prescription from the doctor. He told me that he had already been to the nurse in the village health centre in order to ask for some antihypertensive medicines but she was not in. He was aware that his condition was serious, so he asked for some tablets from another patient in the healing centre who also had high blood pressure. He was given four tablets which was only enough for two days. He eventually managed to go to the hospital with the hired carer about a week later, the same day the carer took his wife to the hospital for a follow-up appointment. They hired a car and shared the cost. That was the last visit to the hospital he was able to make.

However in the interdependent social context, good quality of family care may be more important to the individual than being overtly in control. As already mentioned, they might prefer to exercise power through other family members. The perceived quality of care partly depended on how successfully they could indirectly exercise their power while they were physically dependent.

7.2. Recipient-Provider Relationship

Satisfaction with care was greatly amplified by a good relationship between the recipient of care and the caregiver. The good relationship reflected how much love, concern, and concrete support the recipient had shown for the family and the caregiver in the past. The relationship contributed to a higher degree of commitment

from the family carer which increased the sense of security and protection, and thus the satisfaction with family care. In the study, three participants (Laap, Plup, and Pak) assessed the care they received from their spouses as excellent even though there were some limitations when care required the support of others, or was beyond the ability of the primary caregiver.

On the other hand, a poor relationship between the recipient of care and caregiver negatively affected the quality of caregiving and the caregiver's motivation to continue the caring role. One informant mentioned his father's bad parenting which resulted in him not getting involved in his father's care when he was sick. His father, Winai, left his first wife and four children to work in another province. He then married another woman and did not return to his family. His children were angry with him as he had not supported the family since he left. Consequently, they were unwilling to get involved in his care after his stroke.

Nui also considered he received a low quality of family care due to a poor relationship with the primary caregiver, even though he had worked very hard for his family. He had given a house together with a piece of land to each of his daughters and sons, including one of his grandsons who was raised by him from a young age. When Nui was sick, nobody paid much attention to him. Meals seemed to be the only thing that his sons and daughters took turns to bring him every day.

They always ask me if I have had something to eat yet. If not, they go to the kitchen and get something for me. If they know that there is no one with me, they will come to see me at the meal time and serve me food. (Nui)

The poor relationship might also be the result of the care recipient's demanding behaviour. The demanding behaviour not only affected the relationship but also further inhibited the caregiver's involvement and led to a perceived burden for the family.

The category of relationship, that is husband and wife, parent and daughter, or grandparent and grandchildren, contributed to variations in the participants' satisfaction with care. The care recipient was more likely to be satisfied with care by the spouse. However, in most cases, the male stroke victim's satisfaction was primarily linked to his wife's support whereas the woman's level of satisfaction was

linked with multiple sources of family support, especially the contributions from her husband and daughters. Female stroke victims who received regular partial support from their husbands enjoyed increased satisfaction with care at home.

7.3. Time Available for Caregiving

Time available for caregiving was closely associated with the caregiver's occupation. The time spent on the job was an important factor in determining the time available for the caregiving role. Carers who were employed full-time or in business had less time available for care, resulting in low satisfaction levels. On the other hand, caregivers who were farmers or housewives seemed to have more time and flexibility to deal with care requirements, and thus could satisfy the individual more.

Thai society emphasises the family as a unit, and values the characteristics of hardiness and ability to work. These characteristics and values influence both the family caregiver and also the recipient of care to give priority to work, a priority which places the sick person at risk. Time after work would be allocated to care. In other words, less priority is assigned to the care of the sick individual compared with the importance assigned to the family business which is for the benefit of the whole family.

7.4. Number of Caregivers

Participants who lived in an extended family environment were more likely to receive good care through the support of the family network. This was mainly due to the number of caregivers who could contribute to caring at different times to cover the needs of the whole day, and the sense of reciprocal support among family members. However, in most cases, the effective response of the family carers to the care of the sick family member tended to change over time from an initially overwhelming response from the immediate family members and relatives, to a reduced response from mainly the primary caregiver over the long-term as described by Suan.

I think now is more stressful than the initial period of her (the mother) discharge because at that time my mother had very good support from the family network. All my brothers, sisters, aunts, nieces, and

nephews came to visit and care for her. When she wanted anything, whoever who was close to her would help.

As time passed, the number of family members and relatives who were actively involved in caring decreased. They still came to visit but not as often.

They may think that we are all right now, so every one is back to their normal lives, leaving the caring tasks to the immediate family or the primary caregiver. (Choo)

Even though I've got many children and grandchildren, nobody can help me in this situation. It's unbelievable, isn't it? Every one has their own work to do. (Nui)

For the primary caregiver who provided care for a relatively long time without adequate family support, fatigue was a major reason for the lessening of the involvement in care and therefore the quality of care given.

7.5. Health Status of the Primary Caregiver

Since the quality of care depended mainly on the care given by the primary caregiver, the well-being of the caregiver was an important factor in determining how much care they could provide. Many of the older spouses had their own health problems because of their age, or their health deteriorated from long-term caring for the sick family member. Thus they were not able to handle some physical activities such as lifting, transferring and exercising.

7.6. Family Economic Status

In an extended family, usually the family is responsible for household expenses such as housing, gas, electricity, food, children's education and hospital fees for sick family members. A family in a good financial position can afford to buy more health services or hire a carer if they are not available to undertake the caring tasks themselves. Moreover, given no financial pressures, a family member can be assigned to undertake the caring tasks and received financial support from the family. On the other hand, for the low income family, every family member may need to work for the survival of the family and the caring role is viewed as secondary to the work commitment. Similarly, the caring role may be rejected by members of a family

which does not have the financial resources to support the carer. In this situation, the primary caregiver may be affected the most by the loss of their income, which leads to unwillingness to continue the caring role.

I don't know how my mother is going to cope with her care needs when I go out to work because I can't continue without money. (Kai)

7.7. Family Circumstances

The illness of an individual member in an extended family had a significant impact on the family functioning. Conversely, the sick individual's recovery and the quality of care given was also affected by the ability of the family to cope with family stresses. Families had a marked effect on the person's satisfaction with care by way of the physical and psychospiritual support they provided to the individual and through the family coping processes, such as successfully managing the family resources in response to the illness. Families might fail to cope because of the overload of stresses, with a consequent decrease in quality of care.

Choo's story sheds light on the relationship between family stresses, family coping ability and the quality of care. During the early stage of her illness, Choo (the mother) received very good support from her family, both immediate family members and relatives. Suan, the daughter, was the primary caregiver who lived with her and provided care for the majority of her needs. One year after the stroke, Choo's condition had not improved and it then dramatically deteriorated after Suan had a baby. Given the demands of a baby, Suan was no longer able to be a primary carer for her mother. Moreover, she needed the support of a full-time baby sitter for her baby as she and her husband worked full-time. The family's attention seemed to shift to the baby. Choo received the minimum of care and no assistance with exercises. Her condition was even worse after suffering a fractured femur from a fall when she was trying to get to the toilet one night. After discharge from the hospital, Choo became completely dependent and her quality of life deteriorated. She stayed in bed all the time. When I visited her, she was lying in bed. She looked very sick, pale and thin. Her hair was long and untrimmed, and her personal hygiene was very poor. Although the incision was healing well, her left hand looked worse, swollen and dry. There was severe shoulder subluxation and no finger movement at all. Choo had not

tried to stand up or walk since the operation as she had not yet returned to see the doctor and did not want to try to walk without getting the doctor's approval. After discharge, she could not manage to make a follow-up appointment or receive any other treatments except to complete the medicine she was discharged with, because of transportation difficulties.

In a situation with multiple stresses like this, support from family members was crucial. Suan expected her sister to take care of the baby but it was very difficult for the sister as the mother's care had also automatically shifted to her, while she still had an ambition to establish her own food business. A situation in which the need for care was far greater than that which could be provided by the family caregivers, could generate frustration in the family members, characterised by impatience and feelings of resentment. In these circumstances, the sick family member was usually left with minimum support.

8. Summary

In general, families took for granted that taking care of a sick member was a family obligation. Most of the primary caregivers for the stroke victims in this study were spouses and adult daughters. Other family members also contributed to the care by giving both direct and indirect care. It is obvious that after hospital discharge, participants relied heavily on the family caregivers for a wide range of care needs from personal to role activities both in the family and community. Caring for chronically ill or disabled persons who have significant care needs for a long period of time without adequate support from family members and health care agencies was the main reason for the caregiving burden felt by the primary caregivers. The quality of care perceived by the recipients was determined by many factors. The data demonstrated that the positive bond between the recipient of care and caregiver and the time available for care, outweighed other factors in determining the perceived quality of care. Participants who expressed more satisfaction with care at home were 1) more likely to be males who could exercise their power both directly and indirectly through their family members, 2) more likely to be cared for by spouses who were healthy, had a good marital relationship and did not work outside the home

(usually a housewife), and 3) more likely to be from a family with good extended family support, good financial resources and less family stresses.

CHAPTER 7 : COMMUNITY RESOURCES

1. Introduction

The main purpose of this chapter is to explore the health resources available in the community, which are an important factor in determining the treatments people choose when they are sick. Other factors contributing to the choice of treatments they make will be discussed. The discussion will cover four main domains of community resources: traditional medicine, Western medicine, mixed mode, and social networks. The emphasis will be on traditional medicine as it is the dominant source of health care used by the villagers after hospital discharge.

2. Traditional Medicine

In this section the participants' health practices relating to the use of traditional medicine and the rationale behind the selection of such services will be explored. Soon after the participants were discharged into the community, their use of various kinds of traditional medical practices both physical and psychospiritual became apparent. There were numerous treatments and remedies for stroke patients available in the community, as well as traditional healing centres where patients and their family members could reside while completing the course of treatment. These treatments included massage, walking training, compression, herbal medicines, prohibited foods, supplementary nutrients and tonics, and ritual activities. Most treatments were focused on correcting the body lines rather than dealing with the site of the damage caused by the stroke.

2.1. The Healing Centre

There were a number of healing centres where patients and their families were allowed to stay in order to obtain treatment. A popular healing centre that had attracted four participants from the study was examined in order to gain an understanding of the nature of the service from the participants' perspective. This centre attracted a lot of patients from the community.

The healing centre in question consisted of 30 residential huts for patients and family members and was located in the village, opposite the government village

health centre. A part of the healer's home was modified as a clinic for consultations and treatment. There was an altar to the original founder who was the father of the present healer, attached to one wall of the room. Next to the altar was a big bed where all the ritual activities relating to assessment and treatment, including massage, were conducted. Several chairs were placed on both sides of the treatment bed for family members, and other patients who were waiting to see the healer. This treatment environment allowed the family members to participate in the whole process of the investigation and treatment. Family members could express their concerns regarding the illness of their sick relatives, or ask questions. Other patients and their families often joined in the conversation and exchanged details of their experiences. Once a diagnosis was made, a massage would be given, along with a prescription for herbal medicines which were available in the herbal shops in the village centre, or the town.

The patients and their families had full control over the decision whether or not to stay in the centre when there was a place available. If all the existing accommodation was occupied, patients and their family were allowed to build a new hut on the healer's property. Usually, the request to stay in the centre was initiated by the patients and their families when they had difficulties in obtaining transportation, wanted to stay close to the healer, or sought company of others similarly affected.

The centre's atmosphere was very like that of home in the village. Generally, residents were happy with the setting and arrangements in the centre even though there were limited facilities. For example the nearest public telephone was about six kilometres away. Therefore, those who did not have a family carer residing in the centre could be completely cut off from their outside ties. They would meet or learn about their family only when they came to visit. Two couples had lived there for many years (three and seven years) and saw the centre as their final home. The carers, wives of both patients, earned their living as dress makers in the centre, while taking care of their husbands at the same time. As one of the carers said:

We are too scared to live by ourselves and my husband can't stay alone, he is worried that something may happen while I'm away. Living here, I can ask other carers or residents to stay with him when I need to go out. I have been very happy staying here. We can get good support, regular and effective treatment for my husband, and I can also

work at the same time, so it is a perfect place for us. The Mhor is also very kind. He lets us live here as long as we want.

The husband (the patient) also shared his views on this point:

Well, before I came here, I used to live at home. Of course that is the best place because it is my own home but now my condition has changed, I can't go back to the way I used to be and here I think is perfect for me. I don't feel lonely, I have more friends and the most important thing is that I'm close to the Mhor.

Another resident was receiving treatment in the centre and also working as a 'Tuk Tuk driver' (taxi driver) while his wife worked as a carer for some other patients whose family members could not afford to care for them in the centre. This couple was also very happy with the place and seemed to regard the centre as their home.

Residents of the centre lived as members of one big family. They usually shared food, knowledge, experiences and medicines. They helped each other (carers-patient, patient-patient, and carer-carer) in providing care when needed or emergency assistance when required. Carers always got together to watch movies or dramas with those who had televisions in their huts. While many patients still kept in touch with the hospital, some of them who were alone might lose contact totally with the hospital and rely solely on the treatment at the centre.

Life in the centre

After having routine treatment early in the morning, residents went about their morning activities and had their morning meal. Some of them went to their huts, did walking exercises, or just leant on the walking rails in front of each hut and talked to people who were walking past. Some carers went to the village centre on their motorbikes to buy food for their sick relatives and other patients. Some patients, who were more independent, went to bathe and do their washing at the public well. In the afternoon, many of the residents passed the time by gathering together and smoking. Others stayed in their huts or friends' huts to watch their favourite programmes on television.

Support for the patients in the centre could come directly from the Mhor if an emergency arose, or the health personnel in the village health centre. One of the most typical forms of support was assistance from the other residents in the centre, with some being considered very supportive. If a patient was left alone by his/her family,

in an emergency situation others would help in some way, for instance trying to get in touch with their family, or sharing food and medicines if necessary.

Treatment in the centre started at about 4.00 a.m. Patients who were mobile were encouraged to walk to the clinic for treatment. Those who could not walk would get themselves ready in their huts and the Mhor would come to see them there, usually after he finished with the patients in the clinic. The Mhor normally finished patient rounds in the centre in the early morning and after that he would be available for out-patients who came from all over the country, including those who came every day to obtain treatment.

Services were provided four days a week except Thursday, and on the weekend. Thursday was regarded as a day of respect for the healer spirits (Wai-Kru). The day was set aside for those patients who were healed or had improved, to pay their respects to the spirit healer. People normally brought food and sweets to pay their respects at the altar of the healer spirit. Generally, traditional healers do not charge for treatment, but they readily accept donations.

About a hundred people came to visit the healer each day due to the healer's reputation for treating several diseases, especially paralysis, bone injuries, gynaecological, and psychological problems. There were also many other positive aspects that encouraged clients to stay with the service:

- the service was fast
- the Mhor was kind, and could be contacted anytime
- the Centre had a positive home like environment
- informal relationships existed between the healer and the residents
- good resident-resident relationships existed in the Centre
- carers could reside with a patient in the centre
- residents could be visited anytime

2.2. Attitudes towards Traditional Health Services

All participants in the study had received a large variety of traditional treatments since the initial stage of their illness. Traditional treatment was normally used as the second health resource after self and family, followed by Western medicine. When the illness became chronic participants usually used all health

resources simultaneously, with the belief that every treatment would help in some way to heal them. In certain circumstances, traditional health services might be considered as either a major source of treatment, complementary to Western health services, or as the last treatment option, depending on the individual's beliefs and experiences, and other factors influencing access to the services.

2.2.1. Traditional Medicine as a Major Source of Treatment

It was evident that most participants used traditional medicine as a major source of treatment, particularly after their hospital discharge. This was probably due to several reasons: disincentives to using Western health services such as no effective discharge and rehabilitation planning; difficulties in obtaining services; and the strong attraction to traditional health services, for example the patients' belief in the effectiveness of the traditional medicine, the availability of the services in the community, and low costs.

These factors did not seem to be influenced by the health service user's level of education. A caregiver explained how educated people could easily accept traditional practitioners who seemed to have a very vague training background. He told of several stroke patients who used to be teachers.

Both of them (stroke patients) were teachers. They are not poorly educated persons but they have been told by many people in the village that traditional treatments are good. Someone said that he was cured by a healer after being ill for 2 years, etc., etc., etc. These gradually pulled them to try and then stick to the treatments. (Nui's son-in-law)

The most important reason for the decision to seek traditional treatments was assumptions about the causes of the illness and the perceived effectiveness of the treatments.

I believed that the healer was very knowledgeable on body points and body lines. He knows exactly where the problem is and how to massage in order to correct the fault. I'm happy with the present treatment (massage, and Ya-Mor) which covers all effective treatments. I think that I'm on the right track now. (Pirat)

More practical reasons also contributed to the extensive utilisation of traditional health services. Because most hospitals did not provide patients with an effective rehabilitation plan after hospital discharge, many participants were left with no knowledge about their rehabilitation goals and planning for the future. This discouraged the participants from maintaining contact with the hospital. On the other hand, the patient's social network provided plenty of information relating to traditional treatments of which there were many and which were easily accessible within the community; thus it was not surprising that most participants moved to traditional services.

In addition, traditional medicine was cheap, simple and easy to understand because the same language was used, and the informal practitioner-patient relationship promoted two way communication and understanding. Furthermore, the service could be negotiated in terms of time and place - the healer's house or the patient's, depending on the patient's condition and the convenience of both parties. The contact time between practitioner-patient varied from five minutes to five hours. Most people preferred a longer treatment time as they thought that they could benefit more. The following statement reflects the close relationship between the healer and the patient.

He (the healer) does both Jubsen (massage along the body lines) and Guud-Juud (applying pressure to the body points). His treatment takes quite a long time, sometimes he takes nearly 5 hours to complete one treatment. He can take his time because we don't need to rush. He may start massaging me in the morning and he usually takes many short breaks in between. My wife may bring lunch for us to have in the hut and he may do more massage in the afternoon if he doesn't have other clients. (Pirat)

In cases of early hospital discharge when the participants' physical condition was still poor, some progress while receiving traditional treatments might be experienced after they returned home. Many of them believed that this progress was due entirely to the traditional treatment.

I started to move my leg after seeing the healer. (Pirat)

You know my improvement is mainly from Mhor-Beeb and Mhor-Baan, otherwise I don't think I could recover like this. Some time ago,

I couldn't manage to go to see the Mhor for about 5 days. I could feel something wrong with me. I couldn't walk well and didn't sleep well at night. Some nights, I felt like my muscles were in spasm...When I had been under hospital care, I complied strictly with the treatment. I tried to take the medicines at the right time and the correct dose, that sort of thing. I never missed a single dose of the medicines but my shoulder muscles still shrunk. I think my shoulder has been better since I started to have Ya-Mor. I felt that my scapular area has filled with muscle. (Pak)

Some participants, after spending some time and effort with modern medicine without seeing any obvious improvement, turned their back on it. Consequently, five of the participants rarely contacted or had no regular contact with the hospital after discharge. However, at the end of the study, only two from this 'non hospital contact' group reported that traditional medicine was effective, while the other three were not sure about its effectiveness as they could not see any real improvement over a longer period of time.

It was not uncommon to see patients going back and forth between traditional and Western medicine. Two of the three who were not sure about the effectiveness of the treatment, attempted to return to Western medicine but were unsuccessful in following the rehabilitation plan. They could not manage to see a physiotherapist on a day-to-day basis according to the doctor's advice, because of difficulties with transport. Since they could not gain admission to the hospital for rehabilitation, they lost contact with the hospital, and they finally accepted traditional medicine. The other participant (Prateep) who perceived no improvement from traditional treatment attributed the lack of success to the short treatment time the healer provided for each patient as a result of having too many patients. Prateep and his wife still believed that the treatment would have been effective if the healer could have provided a longer treatment time at each visit. Since he could not afford to go for other treatments, he had to accept the treatment available.

Some participants believed that both traditional and Western treatments were effective for treating stroke. The difference was that Western medicine was seen as being able to solve the problems more quickly, but with a high prospect of relapse, while traditional medicine was seen as providing a slow response but normally brought complete cure with no recurrences. On the basis of this belief, they relied mainly on traditional medicine which was easier to access and which cost less.

Herbal medicine is a sort of slow action treatment but it can provide a radical treatment. I meant that if you are given the right medicine for the disease, you can get cured without recurrence. (Pirat)

2.2.2. As a Complementary Treatment

Several participants viewed traditional medicine as a treatment complementary to Western medicine and they availed themselves of both systems, either simultaneously or sequentially. It was believed that each system has different strengths for treating stroke. Western medicine was suitable for the acute or emergency stage of the illness, whereas traditional medicine was beneficial for the rehabilitation period. Suree explained her thoughts about the two systems.

Someone suggested that I should go to the hospital first because there was modern equipment there. The doctor could investigate clearly whether there was something wrong in my brain. When I was better, I could come back to see the healer. My husband agreed with that idea because if I obtained only massage at home, we would never know what happened in the brain. (Suree)

I (the husband) think her condition has been improving fast because of both treatments: hospital and traditional treatments. The hospital deals with the problems in the brain and the traditional treatment helps with rehabilitation. (Chacrit)

Some believed that Western medicine was good for particular health problems such as blood pressure, seizures, headache and numbness, whereas traditional medicine was effective for diseases caused by a fault of the body lines which included slurred speech, facial palsy, paralysis, hand oedema, stiffness of joints and muscle tension.

I think both treatments (Western and traditional treatments) are beneficial for my illness in different ways. My blood pressure still needs Western medicine to control it, so I'll try to go to the hospital one day. I think the patient has to know what his/her real problems are. If I still feel numb in my hand or leg, that means it still needs treatment from the hospital and massage, which can stimulate the body lines to work from the healer. (Pirat)

Many of them just adopted all treatments because they believed that this approach would cure the disease.

Now I have received many treatments simultaneously. I have massage from a healer, herbal medicine from another healer and also Western medicine from the hospital. I think all are useful for helping me to get cured faster. (Pak)

The belief that the illness needs to be treated concurrently by both systems was based on a combination of Western and traditional understandings of causation. These two systems have different notions of the cause of stroke. In the Western medical model the cause is in the brain whereas the traditional is focused on the peripheries, in particular body points and lines. It also appeared that some traditional practitioners encouraged their patients to obtain concurrent treatment from the hospital to obtain the maximum benefit from all treatments.

I (the wife) was advised by our neighbours, other patients, and the Mhor (the healer) here to take my husband to have his health checked in the hospital. The Mhor told me that his Ya-Mor was safe to have with any hospital medicines. (Jop)

While in hospital, many participants brought in their own traditional healer to treat them in the ward without getting approval from the hospital. Some had initially asked permission to receive massage but were refused by the nurses. However, that did not stop the participants from using the healers. A healer might be brought into the hospital under the guise of being a relative who was to provide them with care. Alternatively the patient might decide to leave the hospital in order to receive traditional treatment. This negative response from health personnel towards traditional healers created some degree of tension and conflict between these two groups of health practitioners.

...he (the healer) normally was around in the hospital and if you wanted to see him, you just let him know. However one of the nurses in the hospital wasn't happy with his involvement in the hospital and she told him to stop providing treatment there. He was apparently very angry with that nurse. (Laap)

Despite the lack of co-operation between the traditional and Western health practitioners, participants who believed in both treatments would try to comply with both treatment regimens and would keep in touch with both services. However, efforts to continue receiving both treatments might be successful only in the initial phase of the illness. When they could not see any further obvious improvement from the Western treatment, and having experienced some difficulties in gaining access to the hospital services, the participants often finally came to rely completely on traditional medicine.

2.2.3. As a Last Treatment Option

Some traditional medicine was seen as unsound by some villagers because it was not based on a solid training system. Villagers, especially the more educated and Western-oriented tended to respond to illness with traditional medicine when their illness was either hopeless (when modern medicine could not help them), or when it was relatively minor. Community talk about harmful effects from the use of some traditional treatments increased their reluctance to utilise this type of treatment.

The daughter and son-in-law of one participant in the study did not trust the traditional treatment believing that it could cause harm and make the illness worse. The son-in-law expressed his ideas on this in the following statement:

I want my father-in-law to be in the hospital because I trust the services. I think doctors in the hospital have spent quite a long time to learning how to treat patients, so they must be very knowledgeable and keen on treating patients. I trust the ability of the doctors. There are many traditional healers in the community but I think I trust the Western practitioners. I'm not looking down on the traditional treatments but I have to give credit to the Western doctors as they have spent 5 to 6 years completing their degree. Certainly, they know more as they learn more. They have expertise in treating patients. However, we can't deny that traditional healers have been successful in curing many patients, but also that many patients can't be cured by them and may even get worse or die. If I'm as ill as my father, I won't see a traditional healer. I won't get a massage from the healer. I will never do that. I'll try the Western medicine until I've been told that they can do nothing further for my illness, and then I may come back to try the traditional medicine. That is what I think. You know people in the country, they think differently, many of them recommended many kinds of traditional treatments to my father. My father has heard

a lot and now he has started receiving some kinds of traditional treatment. (Nui's son-in-law)

Some people thought that massage could make their illness worse and might lead to some other health problems such as muscle injury, an abscess, or even damage to the hand or leg.

I have heard that a patient had lost his/her hand or leg, I can't remember, from the misuse of traditional medicine. (Nui)

Moreover, the concept of treating the body lines and stimulating them ("awakening them from sleep") by pinching was seen by some people as potentially harmful to the patient. Nui's son-in-law expressed his concerns in relation to this:

I don't want to take him to see a traditional healer. It's too risky. I think his hand muscles have been injured by the massage. The healer applied too much pressure on some points along his hand and leg and then the body lines in order to awaken them.

However, given the limitations of the Western health services, several participants were not able to keep in contact with the hospital and finally turned back to traditional medicine. When being discharged, Nui was told that his condition was stable and he should be able to recover at home. However, he thought that he had not improved, that all his problems were still there (he could not move his hand and leg). His son-in-law complained that:

I'm concerned about my father's condition, he is still sick and he wants to get cured. Why does the hospital refuse to give him treatment?

Nui's family was very frustrated that the hospital services that did not respond to Nui's health care needs.

Can you tell me where my father-in-law should go then? I want him to be cured. If he stays at home like this, should we take him to see a healer as has been suggested. That is so hopeless, you know. What he has done at home so far is try to walk. You can see how bad his walking is. I'm not sure if he can be healed at home, he may always walk like he is doing now.

In general, as participants were not sure of the specific causes of their illness, they tried all the treatments available for all possible purported causes of stroke. As a consequence, participants frequently adopted several different types of remedies or healers simultaneously, or in sequence. During some stages, they might accept only certain treatments or remedies and refuse others, or they might try remedies or treatments that they had previously rejected.

3. Western Medicine

Western medicine is the mainstream health service of the country. The ultimate goal of rehabilitation treatment in this model is to maximise the existing potential abilities of the patients and to enable them to resume their normal social roles and employment. This requires intensive co-operation between the patient and the multidisciplinary team. As services based on the Western medical model were mainly available in the cities and there was no public transportation system, many patients did not have the opportunity to access rehabilitation services. The health services were mainly used for serious or emergent illnesses.

The concepts of illness and treatment based on Western medicine differ from the folk or traditional ideology of illness, so it is not familiar to the villagers. Once a villager enters a Western health institution, decision making about conducting examinations, prescribing treatment and establishing a treatment plan is solely up to the practitioner, based on their professional judgement of the patient's best interests.

3.1. Attitudes towards Western Health Services

The experiences of using Western health services referred to here were mostly gained through contact with two types of government health service institutions: the hospital and the village health centre in the community. The users' attitudes towards the services of these government institutions are discussed.

3.1.1. Experiences with Hospital Services

Western medicine was believed to be effective in treating diseases and illnesses of various kinds, and providing professional care. This was the most important factor contributing to the high level of utilisation of Western health

services. It is very common to see a large crowd of patients and their relatives at the outpatient clinics of the government hospital, waiting to see the practitioners.

Given the combination of insufficient staff and cultural awareness of the effect of psychosocial and spiritual factors on health and human well-being, most hospitals in the area in which the study was conducted, allowed patients' relatives to stay with them in the hospital. They also had set aside areas for major ethnic groups to pray and perform ritual activities according to their own religious belief systems, for example providing a Buddha image or a small temple.

Although many attempts have been made by the government to overcome some of the limitations of Western medical model, they do not seem to have been successful, certainly not in Songkla. Participants in the study frequently referred to the difficulty of gaining access to Western health services and to the barriers between care providers and recipients. When mentioning hospital services, participants complained a great deals and giving many examples of their problems and frustrations in trying to receive treatment. The following complaint reflects a wide gap between hospital health personnel and health service recipients.

I realise that there are too many patients waiting for services in the hospital. However, I think that health personnel should communicate with patients and their families better than this. Patients and their relatives don't know much about the illness, and the hospital system. The problem with their illness is stressful enough. I want them to try to understand the patient's feelings. I also try to understand their situation where there are limited resources for a large population, which makes it very difficult to satisfy every patient's needs. (Nui's son-in-law)

The dissatisfaction with the hospital services resulted from four main causes: lack of resources, communication barriers, barriers related to health personnel, and difficulty in getting access.

3.1.1.1. Lack of resources.

Participants complained that they were not able to obtain hospital services when they were needed. Several of them were going from one hospital to another in the hope that they might be able to be admitted. The staff workloads, limited space and facilities of the public wards in the hospitals, especially for the relatives who

accompanied the patient, were factors which accelerated their early discharge, initiated by patients and their family in many cases.

The hospital is too busy and there is no space for family members who look after the patients. (Laap)

3.1.1.2. Communication barriers.

Little or no communication between a practitioner and a client leads to misunderstanding. A lack of detailed information or explanation about the patient's disabling conditions, the reasons for their symptoms and how to control or diminish them, treatment goals and the follow-up plan were the major causes of loss of hospital contact after discharge. The most common problem mentioned by the participants was the lack of a follow-up plan and appointment, leading them to believe that the doctor was no longer involved in their care. Suree for example still complained a lot about her left sided headache. She had nearly finished the medicines she got from the hospital. She was not sure whether or not she should go back to see the doctor.

.. the doctor didn't make a definite appointment with her. The doctor only told her to come back when she finished all the medicines.
(Chacrit)

Nui's son-in-law also mentioned a similar problem regarding the rehabilitation plan after hospital discharge.

When he was discharged from the hospital, he was given some medicines to take home. After finishing the medicines, there was no clear improvement. We now have to think about what we are going to do next, whether to install a walking rail for him to train to walk at home, or take him back to the hospital in order to receive comprehensive treatment, until the doctor says that he can do nothing further for him or it's impossible for him to be cured, that his hand and leg will never return to normal.

Some serious health problems were overlooked by the participants due to their lack of knowledge. Pirat was one of the participants who was not given clear advice about his blood pressure. He was informed on his first follow-up appointment after discharge that the doctor was very surprised at the rapid drop in his blood

pressure. The doctor was not planning to give him any more antihypertensive medicine but Pirat asked for a milder one just in case. From information obtained from a later home visit and interaction with the family, I questioned whether the rapid decrease in blood pressure may have been the result of having taken an overdose of antihypertensive medicines prescribed by different doctors he had visited at about the same time. Apparently, he had been to two western doctors and several traditional healers in the first few weeks after his hospital discharge. Pirat did not provide this information to either of these doctors because he did not want them to know that he had already seen other practitioners. His wife described the result:

Since being discharged from the hospital, he has been to many practitioners (private western and traditional clinics). Whichever doctor was said to be good, he would try to go to see them. He sometimes complained that he couldn't manage to take all the medicines. However, he tries to comply with every treatment. As a consequence, he normally has a handful of tablets, both western and herbal medicines, with each meal.

She showed me a basket full of western and traditional medicines. All the medicines prescribed by three western doctors were in one basket. Some of them had changed physically, which was probably due to the humidity or somebody spilling water on them.

Almost half of the participants knew that they still had high blood pressure. When discharged, they were told that their blood pressure had gone down to normal or was stable at a satisfactory level, and they were told to come back to see the doctor when they finished the medicines. Most of them thought that they were completely cured and did not need any further treatment for blood pressure. Unfortunately, as many of them had not had any visible negative symptoms of high blood pressure (that is they had asymptomatic hypertension) after losing hospital contact, they did not take any action to deal with the problem. Pirat developed his own rationale to deal with his high blood pressure as the following statement shows:

I didn't know my blood was still high (160/100 mmHg) so I didn't worry about it. I didn't go back to see the doctor in the hospital any more because I could control and treat my blood pressure myself by trying to keep my bowel movements normal.

In many cases, participants and their family were informed about the patient's illness and his/her prognosis with a sense of hopelessness, leaving the family without information about how to care for the patient.

On the day I took my husband to the hospital, after a series of investigations, including a brain scan, had been done, the doctor told us that my husband had bleeding in the brain. When he asked me if my husband used to drink and smoke, I said 'yes'. He didn't say anything. I then asked him if my husband could be cured. He said that we had to accept the fact that the possibility was very low, so we should be ready to face reality. After a week in the hospital, I was told to take my husband home to recover even though his condition was still very unsteady. I asked the doctor again if he would get better and I got a similar answer, that we just had to accept the facts. The doctor gave my husband some medicines and a follow-up appointment in a month's time. I was so frustrated and confused because I didn't know how to deal with my husband at home. (Jop)

I did want to go back to the hospital but there is no place for this sort of illness. We were told that I couldn't be cured, so I didn't need to come back to the hospital again. (Winai)

3.1.1.3. Barriers related to health personnel.

Most health personnel working in the Western system appeared to be distanced from their patients by socio-cultural background, economic status, education, world view and belief systems. These differences formed barriers between the health personnel and the patients, for example not being understood by the practitioner, lack of interest or attention from the practitioner.

One barrier which the participants commonly complained about was that 'the Mhor does not understand the patient's feelings'. These feelings include the desire to have a chance to talk more about their problems and concerns, and to incorporate their own concepts and beliefs into care. Negative actions or attitudes of the health personnel in the form of distrust, disrespect, lack of recognition or even opposition to the folk or traditional treatments participants employed for their illness, could create a gap between the health personnel and the patients and further cut off communication. Many participants were scared to tell the doctor the truth about their treatment history, especially the information relating to obtaining traditional services,

and behaviour which they themselves perceived as unco-operative, e.g. for example failure to follow the doctor's advice, or unhealthy behaviour such as drinking and smoking.

When I was asked about my smoking habit, I replied that I had stopped but in fact I hadn't, but I didn't want to be blamed, and I'm not sure whether I should tell the Mhor all the truth, that I have been to many traditional practitioners in the last two months. (Nui)

I'm afraid that if I go to the hospital again, the doctor may ask me about seeing the physiotherapist and he may get tired of me if I haven't followed his advice. He may not understand my difficulties in obtaining transportation to the hospital. (Suree)

Practitioners were usually busy and had limited time for each patient. Actions of the practitioner while the patient was talking, such as writing a prescription, having no eye contact, being ready to move along, a quick response and no time for the patient to ask questions, were perceived as negative and would shut down further communication. These actions could also be perceived as 'lack of attention from the practitioner'.

The doctor doesn't listen or care about the patients' problems. I tried to tell him my illness history but he didn't listen to me. (Prateep)

The doctor asked me what my problems were without watching my face. He was writing while talking to me. (Nui)

The doctor sometimes doesn't come to visit the patient at their bedside. He/she orders the treatment based on the patient's file at the desk. (Prateep)

3.1.1.4. Difficulty in getting access.

Difficulty in getting access to health services may be due to several reasons. These include the location of the hospital, which is normally situated in the city and outside the community where the villagers live, the time required, and the fact that specialised treatments are provided on a certain day.

It is very difficult to take my wife in a utz to the hospital in the town as the quality of the road is bad, so we prefer to take her to see the Mhor in our village which is more convenient. (Plup's husband)

Suree shared her concerns about the time required to obtain the hospital services and the limited availability of some specialised treatments.

My husband and I hate to go to the hospital. It takes at least half a day to see a doctor for 5 minutes.

I did go to the hospital once for my headache but unfortunately I didn't see a neurologist as the services were fully booked. I did manage to see a GP who gave me a prescription for some pain-killer tablets and told me to come back to see the neurologist on the following Wednesday when they have the specialised neurological clinic. I was told that I could only meet the neurologist on Wednesday morning which is quite difficult for me as I have to rely on others for transportation. I haven't been able to make it since then.

One participant, Pak believed that perceived social status was also a factor, with government employees finding it easier to access hospital services.

I told the Mhor that I'm covered by the government welfare benefit. I thought they wouldn't be interested in me if I didn't have a letter from my daughter's work place to show them. The first day that I went to the hospital, they told me that there was not a bed available but when they knew that I had the letter, they finally gave me a place. I meant the person who was at the counter of the clinic, not the doctor. (Pak)

He suggested several reasons for this social discrimination. Government employees were seen as middle class, the government welfare benefit was a secure source of payment and being in receipt of this benefit implied that the recipients were of the same social rank in society as those controlling admission to the hospital.

As a consequence of the numerous barriers to gaining access to Western medical services, patients were taken to the hospital only when they were in an emergency or acute situation, or when traditional medicine failed to treat the illness. Many turned their back on the Western health services and relied solely on traditional medicine and religious support which offered a wide range of services based on diverse beliefs.

3.1.2. Experiences with the Village Health Centre

In most villages, the main Western health service institution was the village health service centre. The services of the centre were not commonly used by the villagers due to a number of perceived disadvantages, for examples limited ability of the staff, low quality and range of services (could provide only first aid), shortage of equipment and medicines. Villagers normally went to the centre only for minor problems (like fever or flu), to receive vaccinations or family planning services. Besides, there were frequent complaints relating to the inappropriate behaviour of the health personnel in the centre, for example they were unreliable and sometimes dishonest. Participants also explained that the centre was occasionally left unattended, and that although the cost of the services was supposed to be cheap, they still cost more than they expected. When this matter was followed up with the health personnel, they responded that the centre sometimes was temporarily closed when they had school programmes or home visits and all the staff were required for the activity. Distrust of the personnel extended to the health volunteers, who seemed to be concerned more with their social activities than providing health services. Their activities seemed to be focused within their own group, rather than on the wider community.

In the study, none of the participants received regular rehabilitation services from their village health service centre. Staff of village health centres, who were usually local people sharing social values, beliefs and the culture with the villagers, agreed that patients with stroke or paralysis were more likely to be taken to healing centres as the Mhors were more skilful with these illnesses. Participants visiting a healing centre occasionally went to the village health centre for some particular purposes such as having a blood pressure check, a wound dressed, an injection, or seeking medications for their physical problems. An interesting observation was made of one of the healing centres located opposite a village health centre. There were hundreds of clients from within and outside the surrounding area, coming to see the healer each day, whereas only a small number of clients visited the village health centre.

4. Mixed Mode

A third treatment system is one that combines both Western and traditional medicine, which is referred to as 'mixed mode' in this study. The treatments usually incorporated in this approach are the use of injections and tablets (Western treatments), and some types of herbs and diets. The approach however is based predominantly on the traditional beliefs about the cause of the illness. The attractions of this approach are that the explanation of illness and treatment is congruent with the people's belief system, rapid results are expected from the injections and the services are cheap.

In the study, there were two mixed mode practitioners who were visited by the participants. One of them also worked full-time as some sort of assistant in a ward in a government hospital. The practitioner opened his private clinic after hours and on the weekend. The other practitioner also provided accommodation for the patients and their family members while undergoing treatment. The participants described their services as very effective because they incorporated both Western and traditional concepts into the treatment. They were willing to see any x-ray films that had been taken at the hospital, as well give an explanation of the cause of the illness according to Western concepts. However, they still viewed the cause of the stroke primarily within a framework of traditional concepts, that is the fault being in the body lines. The traditional treatments they incorporated, such as herbal medicine and prohibited food, successfully gained the patients' trust and motivated them to accept and continue the treatment.

Everyone is required to have their blood pressure checked and is given an injection on their first visit. This is followed by tablets for the fault in the body lines twice a day, in the morning and before bed. We are also given a list of foods to avoid. (Nui)

5. Social Network

5.1. Neighbours and Friends

Neighbours and friends, as part of the social support in the community, play an important role in sharing information and experiences about care and home remedies, and as a lay referral system. Information relating to all the therapeutic

options that people used in the community was informally passed on from one to another. Hence, the community members acted as a major source of health service information and folk remedies.

Most often, assistance from neighbours and friends was in the form of advice as to the folk diagnosis of the illness. They also advised where to get treatment, including folk remedies whose success had been confirmed by villagers' previous use. Each remedy had its own explanation and way of treating the illness. Usually there was no reluctance in accepting folk remedies, as most ingredients in the remedy were quite common to the villagers, and the remedies were usually available at little or no cost. Participants might take these remedies to supplement the primary treatment they had received from the hospital or traditional healers. The acceptance of folk remedies was based on trust in the person rather than a rationale explanation of their actions. Some participants appeared to readily accept some remedies without realising that there might be some harmful effects from their inappropriate use, for example from an excessive intake of some herbs or chemicals over a long period of time. The following folk remedy, dangerous in the light of Western scientific knowledge, contains a high concentration of salt which could disturb the electrolyte balance.

The remedy comprises 1 litre of water, 1 kilogram of sugar, 1 kilogram of salt and as many limes as the age of the patient. Each lime was cut in half. All the ingredients were put into a clay pot and boiled until the solution was well mixed. The pot containing the mixture was then placed in a mound of paddy husks for a week. Then it would be ready to drink. The patient was told to drink half a glass of the mixture three times a day. This remedy requires 24 pots of the mixture. (Pirat)

Pirat accepted this remedy as it was simple and he thought that nothing was wasted if the treatment was not successful. The remedy was suggested by one of his neighbours who used it to treat his father who had also suffered a stroke. The neighbour claimed his father was completely cured by the treatment.

Participants would consult neighbours and friends about problems with which they might be able to help. It depended on whom and what they knew. The neighbours might have experience from seeing similar patients before, if not direct experience as a carer. The involvement of neighbours and friends undoubtedly

provided the patient and family with great psychological support. This is one example of suggestions from neighbours and friends that were perceived as providing significant reassurance or emotional support.

Try to think in a positive way in order to cheer yourself up. You should believe that you can get cured and pay attention only to the treatment. I have a friend who has been sick from a stroke, he has got atrophic leg but you haven't. He is still trying hard to get cured and now he is staying in a temple to receive massage. This kind of illness must be massaged regularly...You should be patient about getting massage, but you should stop taking the medicine from the hospital because it is usually tranquillisers, which are not necessary for your illness. But you shouldn't stop getting massage. (Suree's neighbour)

Neighbours and friends might provide assistance to the patient and his/her family when necessary, such as baby-sitting and essential assistance in an emergency situation. Jop, as a butcher, normally started her work after midnight and finished trading in the afternoon. As she had a young daughter, it was impossible for her to handle the job without any support. In this situation, she left her daughter with her neighbour, just before she went to work and came to collect her after work the next afternoon. In return, she offered to look after her neighbour's children when required. She said she also tried to maintain the good relationship with her neighbours by giving them gifts, usually food and fruit, which worked well in her case. She also used the same strategy with the residents in the healing centre where her husband was staying, so that they would help when necessary.

Suree described the important role her neighbours played when she suffered the stroke, in helping her and her family with the crisis. That day she suddenly felt numb and weak in her left hand and leg. She then sat on the floor and called her daughter to help. Her daughter had never experienced anything like this before. She was frightened and did not know how to deal with the problem.

Luckily, my neighbours noticed that something wrong had happened in my house. They then came in and lifted me off the floor. They gave me initial assistance and advice about what to do next and where to get treatment, which was very useful because in that situation we were in a state of shock and couldn't think properly. (Suree)

The help from the neighbours meant a lot to the patient and family.

For the participants who were still of working age (less than 60 years) and who worked for the government prior to their stroke, support from friends and colleagues at work was critical for the patient and his/her family. According to workforce regulations, government officials are allowed to take sick leave of up to three months. In the case of a stroke, patients often need more than three months to recover, or they may have some disabilities after their illness, resulting in difficulties with remaining in the workforce. With the generosity and kindness of friends and colleagues, it was not uncommon for these people to keep their employment status without working for months, years, or even until they were due to retire and were eligible to receive superannuation. The patient might try to contribute to his/her job but feelings of ambiguity and frustration might occur over whether they were 'contributing' or 'disturbing'. Prateep expressed his ambiguous feelings about his role in the workplace after the illness.

I feel ashamed that I am still being paid without working. I think I can still be useful to my workplace, at least to be a consultant mechanic which is my area of expertise, but no one can give me a lift to the office. My boss told me to call him if I wanted to go to the office and he would send someone to pick me up, but he didn't really expect me to go. Since I can't be independent, I'm not sure whether if I try to make it, it would be 'contributing' or 'disturbing'. It is a really frustrating feeling. (Prateep)

5.2. Self-Help Groups

Self-help groups are not as popular in Thailand as in Western countries. In the community the closest approximation to the Western self-help group in the study was identified in the healing centre. In the centre, informal self-help groups were naturally formed by the gathering of a group of patients who were experiencing similar symptoms or illnesses, and also their family carers. There was no clear structure in the group, but the activities and mutual support of the residents in the centre were comparable to self-help groups in Western literature. People who were facing similar misfortunes would try to get in touch with others to provide mutual support (physically and psychologically), exchange information, share medicines, folk remedies and food.

The residents in the healing centre usually considered each other as members of a big family - brothers, sisters, etc. This home-like environment promoted the establishment of the informal self-help group which benefited both patients and their caregivers. The most significant benefit obtained from the group was psychological support. Nui shared his story about the informal self-help group he had experienced when he was residing in a healing centre. He was very impressed by the mutual assistance and support, care, love and understanding that the patients and carers gave to each other in the centre. He wished to go back there when he could find a family carer to reside with him in the centre.

I just realised that there were many people suffering from stroke when I was there. Some of them were very old but some were still very young. Some had right sided paralysis, whereas the others had left sided paralysis. Many of them had facial palsy and slurred speech. We were all facing similar problems and difficulties, so we understood and supported each other well. Everyone there had left home to stay in the centre in order to get cured. It could be very lonely, hence we tried to arrange some activities to get together such as birthday parties. I was really impressed by the generosity, care and concern I received from people there and if I could have helped them in any way, I would certainly have done so.

6. Summary

The four main domains of health resources in the community - traditional medicine, Western medicine, mixed mode and social network - provided a wide variety of health services and support to patients in the community. Each domain had its strengths and weaknesses. When there were very limited government health services available in the community, people tended to consult their own social network (relatives, friends and neighbours), or use traditional and mixed mode health services where more information was available and which were much easier to access. This finding indicates that lay networks, traditional and mixed mode health services still play a very prominent role in providing care and support for people with chronic health problems and disabilities in the community. Hence it is essential to facilitate the generation of culturally effective models of care that integrate formal and informal health services in community-based, long-term care.

CHAPTER 8 : INTEGRATING THE DOMAINS

1. Introduction

In the three previous chapters, the experiences of individuals who had suffered a stroke and their family's experiences in caring for them within the community context in Thailand were presented. In this chapter, all these experiences are combined to describe the reality of lay caring practice in the Thai context. To help understand the phenomenon of lay caring practices in this cultural context, a comparison of the important features of these practices to the concept of 'self-care' as defined in Western literature, is made. Differences and similarities between Thai and Western practices as portrayed in mainstream American nursing self-care theories, are identified.

2. Lay Caring Practice in the Thai Culture

Results from this study demonstrate that lay caring practices in Thai society are based on personal and social interdependence. Reflection on the pattern of interdependence provides opportunities to explore the relationships between the individual, the family and the wider social network that develop in response to illness. This pattern of interdependence is basically generated from ties of kinship, friendship and neighbourhood and is shaped by cultural beliefs and values. Its role in maintaining mutual relationships among community members goes a good deal of the way toward explaining the lay caring practices in this cultural context.

Within a family unit, every family member contributes support to the family as well as receiving support from other members. However, the interdependent relationship within a family is not an equal 'give-and-take' relationship at any one time. The amount and type of support a family member gives and receives at a certain stage of family life vary with their roles, which are dynamic and changeable according to age, gender and position in the family. The interdependent relationship of family members in this cultural context is a process of reciprocity operating over one's lifetime.

Various components of lay caring practice are illustrated in Figure 2. Each component of this practice will be discussed in detail in the following sections.

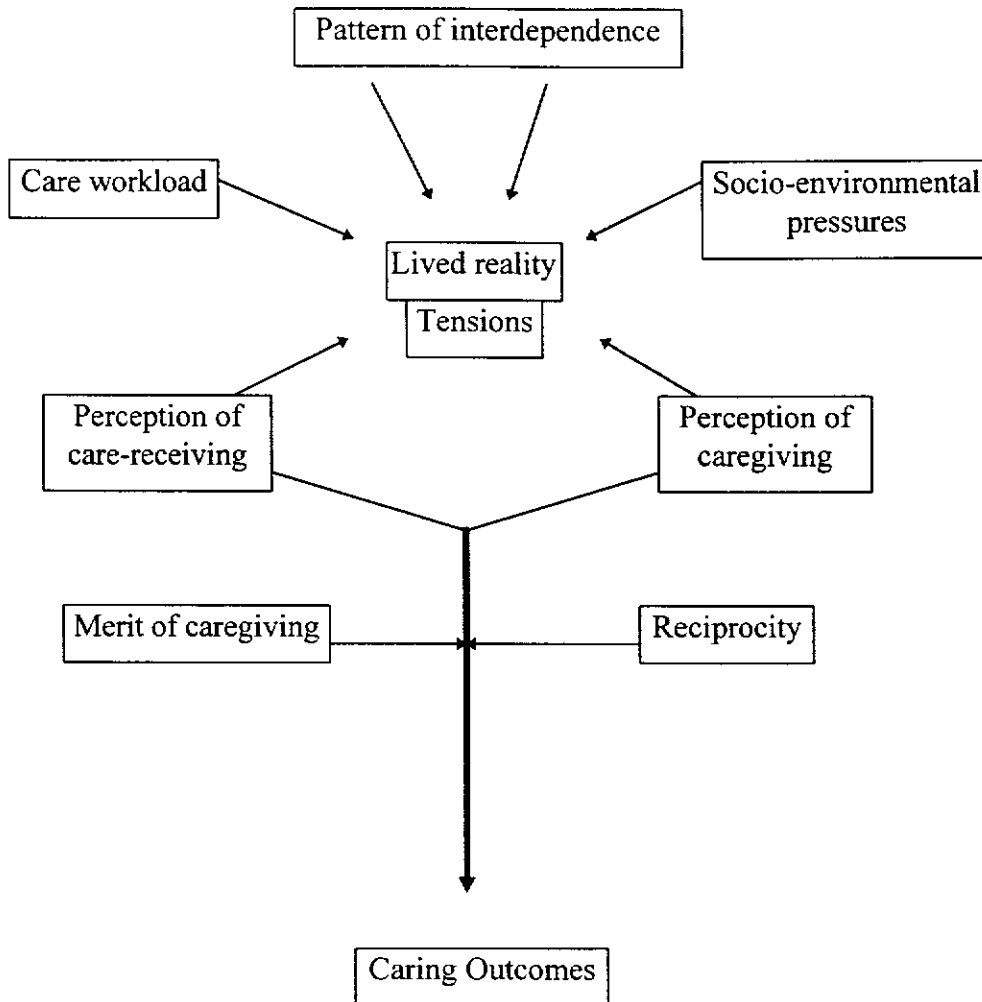


Figure 2: Lay Caring Practice

This interdependence prompts family members to discharge their roles and responsibilities. Chronically ill or disabled persons such as those suffering a stroke, who usually require a considerable amount of care for an extended period of time, may create tensions in the life of the family when family members try to meet their obligations. The reality of caring for a chronically ill person or persons with disability is conditioned by four main factors: socio-environmental pressures, care workload, perception of care-receiving and caregiving. The caring outcome is usually a balance between benefits for an individual and benefits for the family as a whole.

2.1. Socio-Environmental Pressures

This factor includes economic and socio-political pressures. These factors place pressure on lay caring practice in the community. The impacts of poor socio-economic status on lay caring practice have been well-documented in the literature. Ell and Northen (1990) reported that the poor have higher rates of most illnesses and higher mortality rates, less access to health services, and are more likely to postpone seeking care outside the family until the illness is at an advanced stage. The family's financial constraints are recognised as limiting use of external health resources. As a consequence caring for a sick member falls entirely to family members.

The country's socio-political structure is the most prominent factor in determining health services and their allocation in the country (Roemer, 1977). For example, the lack of priority assigned to public health services, especially in the area of rehabilitative and geriatric services, is a result of the country's health policy. Thailand's public health system is primarily focused on Western medicine and the social welfare benefit for health care expenses covers only these services. However, the scarcity of these services, particularly in rural areas, means they are used a lot less than alternative care services which are more accessible. Thai government policies also strongly encourage the elderly to live with their family. The government nursing homes project targets mainly the poor who do not have adequate support at home. Nursing homes are therefore viewed as a place of charity rather than a health service for the frail elderly. These policies, and the lack of rehabilitation services and respite care, combine to deny Western medicine options for the family.

In addition to the lack of formal health services, the difficulties in getting access to the existing hospital services together with the perceived barriers created by communication and personnel, result in low levels of utilisation by the villagers. These disadvantages reduce the possible choices for those who are keen to use Western health services. Thus, the clients and their family are left to solve their problems by themselves.

2.2. Care Workload

The caring workload depends on the degree of physical impairment and the previous role responsibilities of the individual. This study demonstrates that the

workload generated by the care needs is in many cases heavy and creates significant tensions in the family, especially when the illness becomes chronic and the person requires significant amounts of physical assistance. The caring workload is increased because of the attachment to the 'sick role' by both the individual and the family caregivers, coupled with a lack of formal support. Care after discharge from the hospital is almost completely dependent on the family, their social network and informal resources in the community. Formal health services provide very little support to the patients and their family. This lack of resources contributes to tensions affecting both the sick person and other family members.

2.3. Perception of Care Receiving

An individual's view of caring for themselves and receiving care from others determines the degree to which they actively or passively participate in their care when they are no longer independent. Socio-cultural factors and complex interpersonal relationships between an individual, their family and their social network shape the ways individuals view their health status and their expectations. Social views and expectations about an individual's self-caring and care-receiving roles can also shape an individual's health care behaviours. What is viewed as normal in one culture may be seen as quite aberrant in another. All participants in the study perceived their post-stroke conditions involving residual disability, as 'being sick' or at least being 'abnormal' to some degree. Behaviours enacted in this state were therefore those of a sick person. The acceptance of this new role influences an individual's perception of caring for themselves and expectations of care from their family members. The individual's acceptance of the sick role and the expectation to be cared for by the family can inhibit the potential ability to resume their own care.

There were many dependent or sick elders who considered receiving support from their children as a part of family obligation. These participants believed that it was time for them to realise the benefits of their hard work during the early part of their life. Additionally, they believed that providing care to parents gave the children an opportunity to 'do merit'. This group of participants assumed little or no responsibilities for their own care and expected to be cared for by family members. In general, these participants saw their responsibilities as seeking beneficial treatment and complying with these treatments.

Participants who were more self-reliant adapted themselves to their situation by trying to limit their desires as well as trying to help themselves as much as possible. Being unable to be independent in ADLs and unable to perform their normal roles made them feel useless and frustrated. They did not feel comfortable asking for help or directly expressing their desires. However they still expected assistance from family members with tasks perceived to be too difficult and beyond their existing capability.

In the study, participants identified the boundary between caring tasks performed themselves and those performed by family caregivers as being based on their remaining physical abilities. Since all participants had one non-functioning hand due to paralysis, assistance was needed with activities requiring two hands, for example bathing, dressing especially with a 'Sarong' (traditional lower garment), toileting (cleaning after bowel movement), preparing and cooking food, and washing clothes. Although half of the participants could walk with a walking stick, some of them were still totally mobility-dependent on family caregivers due to their refusal to use walking aids or to their fear of falling. Without mobility aids, their care needs were significant. Therefore, most of the individual's physical needs required their family caregiver(s) to assist in part or in total.

The participants' notion of self-caring' and 'care-receiving' roles appeared to be congruent with the family caregivers' ideas. These were linked to the 'sick role'. According to this belief, the sick person was exempted from normal roles and responsibilities while the family was obliged to take care of the sick individual's previous roles as well as the caring role. The sick individual's normal responsibilities and caring tasks were allocated to family members according to age, gender, position and role. The major goal of the family was for all family members to work together to maintain normal family functioning as well as provide the sick member with quality care.

The data clearly indicated that, in this particular context, the active involvement of an individual's family is always required to meet an individual's self-care requisites. In another words, an individual's health care needs are less likely to be met without support from the family. Thus self-care in this cultural context is not

an individual responsibility as it is in Western culture. It is regarded as one of the family functions that the whole family has to participate in, in some way.

2.4. Perception of Caregiving

This is taken for granted that they have to assume the caregiving role for their parents in their old age or when they are sick. Caring is considered as a family obligation regardless of whether the care is good or bad, the family caregivers are willing or unwilling to care of the sick relative, or the caregivers are able or unable to handle the caring tasks. Contributing to caring for the sick family member is strongly influenced by motivations which are deeply grounded Thai culture. Caregiving was seen as a burden by the majority of family caregivers in this study, however they still kept on providing care. Personal commitment to the caring role developed from filial affection and a sense of responsibility was an important motivation among the family primary caregivers caring for their frail elders. Factors such as social norms, cultural values and traditions also influenced the family's response to the caring role. These factors influence behaviours, roles, relationships, understandings and consequently, the way caregiving is defined by family members (Phillips et al., 1996).

Two key concepts which are religiously influenced - reciprocity (Tob-Taan-Khun) and merit (Bun) - motivated family members to take on this caring role and underpinned their commitment and attitudes.

2.4.1. Tob-Taan-Khun (Reciprocity)

Reciprocity (Tob-Taan-Khun) is critically important to the maintenance of the pattern of interdependence among family members and outsiders in the community. The word 'Khun or Bunkhun' is described as goodness generated from meritorious actions such as a mother giving love and care to a child, a teacher giving knowledge and wisdom to students, favours given to relatives, friends and others in the social network. The Bunkhun that one receives imposes a moral obligation that must be repaid. The greatest obligation occurs in the close personal relationship with one's mother and the obligation becomes less as one moves from central family members to more remote (Mulder, 1994). People learn to reciprocate Bunkhun by being grateful, showing recognition, and giving gifts and moral support.

The unconditional support from parents for their children invites the children's role towards their parents. They are expected to provide help and care to their parents when they become old, ill or physical dependent. This caring obligation is developed within the family and sustained through family interaction. The young generation will learn and absorb this value from the previous generation (Mulder, 1994). It is believed that if children give good care to their older family members, they will in turn be given the same thing from their younger family members. This may be considered as another form of health insurance in this cultural context.

In this study, parents expressed their ideas of raising a child in expectation of an explicit return. A daughter may repay the debt to her parents by remaining in the parental household to care for them in their old age, while a son may become a Buddhist monk or provide them with support such as care probably through his wife or daughter, or financial support if needed. When things do not turn out as expected, parents simply interpret this as a consequence of previous Karma.

In a community characterised by close family networks, villagers may regard their friends and neighbours as their relatives. Support from outside the family is effective especially in an emergency and the initial phase of an illness. However, in some situations, the individual and family may feel uncomfortable receiving support from their social network if they are not sure they will have the opportunity and energy to reciprocate.

2.4.2. Merit of Caregiving

One of the prominent teachings of the Buddha is to encourage people to 'do merit'. A merit is a performance of good deeds which purifies and cleanses the mind of evil tendencies of greed, hatred and delusion, which give rise to more suffering. The importance of doing merit is grounded in the belief of reincarnation or rebirth and the law of Karma. It is believed, according to the law of Karma, that what we are now is a consequence of past acts; doing good brings good to life. The benefit of doing merit is therefore happiness now and in the future - maybe tomorrow, later in this life or in a world beyond. It is said that merit is the gateway to a fortunate life by increasing one's chances of a good education, good health and possessing or obtaining wealth, preferably in this life. Merit is derived from the

performance of all positive actions whether they can be cognitive, verbal or involve the body in their principal expression. Doing merit can be achieved in several ways such as giving (food, material items, money, emotional support and physical help), moral conduct, revering others, sharing merit with others, rejoicing in the merit of others, preaching and teaching the Dhamma, and listening to the Dhamma (Dhammananda, 1987).

As mentioned earlier, Thais strongly emphasise the goodness of the parents, especially the mother who gives life to a child and expends a great deal of effort raising and supporting the child to the best of her ability. This goodness results in a great debt on the part of the child, a debt that can never be repaid (Mulder, 1994). Caring for the elderly or dependent parents is a very meritorious deed. On the other hand, failure to fulfil this obligation results in committing the sin of ‘Neerakhun’ (failure to reciprocate the goodness received) which is believed to be an extremely censurable act (Mulder, 1994, p. 84). Being ‘Neerakhun child’ not only results in experiencing bad Karma but also in being blamed by the society. Cultural expectations of the family members to enact the role of caregiver create social pressures on the family to perform that role. While this study has shown that the family well-being is one of the main goals of family functioning, there is a tendency for the family to experience stress and strain as a result of these cultural expectations.

2.5. Caring Outcome

From the individual’s perspective, satisfaction with care might not be necessarily related only to the excellence of physical care but also to the ability of the family to maintain family functioning. The individual’s perception of ‘well-being’ or ‘health’ is tied to the well-being of the family as a whole. The participants’ perception of ‘well-being’ or ‘health’ approximated the definition of ‘holistic health’ proposed by Steiger and Lipson (1985, p. 11) as “a process in which physical, emotional, socio-cultural, and spiritual aspects of the individual are integrated and functioning in harmony with the environment”. The ‘environment’ in this case would need to include the family as the primary component.

The outcome of care, whether good or bad, was therefore determined by two main factors: the individual’s level of functioning and the family functioning. These

two components were major contributors to the physical and psycho-spiritual well-being of the individual as well as the other family members. A positive outcome of the individual's level of physical functioning relied mostly on input from health practitioners. Family caregivers took the role of assisting the individual to obtain services and in providing direct care. The sick expected the family to care for their physical needs and role responsibilities both within and outside the family. As family functioning was also incorporated into the goal of the lay caring practice, issues of maintaining family well-being while coping with a sick member also needed to be addressed. Success in maintaining the well-being of the whole family depended on the competency of the family. This competency was based on appropriate allocation of roles and responsibilities among family members, interdependent relationships and financial stability.

These findings indicate that the major difference between the lay concept of health and the scientific model of health is that the lay concept includes the social as well as the personal component, with the explanation of health being intimately linked with the wellness of the family.

This section has described the reality of lay caring practice which shows the intimate relationship between the individual and family members within the family context. Here the ultimate goal of lay caring practice is to achieve health or well-being of an individual as well as the family as a whole. Therefore, both the individual and the family members are expected to contribute to restoring the health of the individual. The focus of personal health is on normal physical functioning and contentment while that of the family is on family functioning. These data reinforce the view that the family is a primary resource for health and well-being of its members. The care within the family is well supported by informal health services in the community. These sources of care spring from ties of kinship, friendship and neighbourhood, and they are irreplaceable. The next section will compare the lay caring practice of Thai society to that of Western countries.

3. Comparison of Self-Care in Thai Culture with Western Culture

3.1. Individual Versus Family-Based Care

In Western society people value individualism. Care is focused on individuals meeting their needs. In this regard, locus of control, self-esteem, self-efficacy or mastery have recently been the focus of research on individual coping. Family members will get involved only when an individual is unable to be independent.

Both older Americans and their children value independence (Lim et al., 1996). Thompson and Sobolew-Shubin (1993) reported that older adults who received home-delivered meals were depressed and helpless when they felt overprotected by their caregivers. Lim et al. (1996) found that even though children believed that families should be responsible for their parents when they can no longer be independent, they regarded the parents as demanding if they requested assistance more frequently than considered necessary.

Western literature supports the significance of autonomy in health and quality of life of older people. The issue of how to maintain the personal autonomy of older adults, especially those who live with chronic illnesses and disabilities, is a growing concern for an ageing society. Because the culture values individualism, the loss of autonomy can be very threatening to the older person's identity and self-esteem (David, 1990). The more they depend on others for their health care needs, the more vulnerable to depression they can become.

Autonomy is associated with issues of individual rights, privacy and control over one's life. All the meanings given to 'autonomy' imply independence and freedom from influence by others (David, 1990). Research has demonstrated a strongly positive effect of autonomy on health outcomes. Kobasa (1979) noted that when people are actively taking care of themselves, have the power to make decisions and have a sense of control over their lives, their health outcomes are better. In Spitzer's study (Spitzer, Bar-Tal & Ziv, 1996) the elderly subjects' sense of control was influenced positively by caring for themselves and the satisfaction that stemmed from this self-care. On the other hand this sense of control was negatively influenced by the severity of symptoms and being cared for by others. The sense of autonomy of the frail elderly is disrupted when they are unable to maintain their

independence. Caregivers may ignore or override their choices because of competing concerns for the elderly's safety and well-being, organisational efficiency and accountability, resource limitations, or caregivers' own needs or interests (Agree, Steven, Laurence. & Beth, 1988). In summary the research in Western cultures indicates that autonomy is crucial for maintaining elders' well-being and can be promoted by self-care activities.

Within the Thai society, interdependence rather than independence, is valued. This does not mean that Thai people are not self-reliant. Thai people are familiar with the Buddhist teaching that persons ultimately rely on themselves in order to reach enlightenment. According to the Law of Karma, one is responsible for the consequences of one's acts, or in another words an individual is responsible for their own life. However this concept has different connotations to the Western concept of individualism. Benjamin (1973, pp. 191-192) defined 'individualism' as a strong personal attitude or actions exhibiting independence from a group standard, and that the individual is of paramount importance and should take precedence over other concerns e.g. for others. The Thai concept does not correspond to independence from the group and the individual is not of paramount importance, rather that people are interdependent with others in their daily life.

In general, family interaction in Thai society is interdependent in nature. As indicated earlier every family member has been ascribed a certain set of roles in order to maintain family functioning, with its system of exchange and reciprocity. The family's involvement in care is not necessarily confined to when an individual is no longer independent. The family may contribute care-related actions such as health maintenance and health promotion of elderly members by providing them with a healthy home environment (both physically and psychologically), food, or encouraging them to participate in elderly health promotion programmes which are available in the community. When they are old or sick and dependent, the family is obliged to provide more support in various forms, both direct and indirect nursing care. Both the family caregivers and the family elders share the same value of interdependence.

In summary, the results of this study differ in two ways from those reported for Western health contexts. In the Western studies there is a clear boundary between

care by self and care by others. Individuals will try their best to stay independent and they will move from being a self-care agent to being a patient receiving care from others only when there is a deficit in the self-care domain (Whetstone, 1987). In contrast, in this Thai study health maintenance and caring for a sick family member are family affairs that require contributions from the whole family to maintain the family well-being or solve the problem.

In regard to the issue of the autonomy, findings from this study are congruent with studies from Western countries that indicate the elderly's power or sense of control diminishes with the degree of physical disabilities and level of dependence. However, in Western studies, despite diminished abilities and need for assistance, many clients attempt to maintain a myth of control and independence (Dubler, 1988). In contrast, Thai participants in this study preferred to shift or delegate their authority or decision making to their family members.

3.2. The Use of Community Support Systems

The idealised Western family is nuclear in nature. Family members tend to live apart once they have reached maturity, in some cases at a considerable distance. Having left the natal home, they rely heavily on their spouses or formal community support systems. Community health services provide a wide range of support, for example home help, domiciliary nursing, transport and respite care. In these circumstances, formal providers sometimes substitute for family, as when a live-in companion becomes as close as kin (Luna et al., 1996). As well, home-help facilities and independence aids are popularly used to maximise the frail elderly's ability to be independent. However, despite the formal health system being the main source of support, the family is still considered as an important source of care when available.

Thai elders prefer to rely on family rather than the outside social networks or formal support systems. Good family support is a source of pride for both the caregiver and the care-recipient. The pride of the younger family caregiver is derived from the ability to meet the expectations of the family and society whereas that of the care-recipient stems from having good children who reflect the positive way they have been raised.

The lack of popularity of mobility and functional aids in Thailand may be associated with lack of knowledge about their existence, lack of public sources supplying these aids, and the valuing of 'contentment'. Many Thai people tend to accept life as it is and try to adapt themselves.

While people in Western society rely mainly on formal health services for their care needs, Thais depend heavily on informal health services. It is clear that the informal health services in the community fit well with the Thai people's way of life, their attitudes and beliefs, and meet most of the care needs which are not met by the government health services. The availability and accessibility of the services in the community allow the villagers more control over the choice of treatments they make to suit their culture, belief system and health care needs. The strength of traditional medicine lies within the psychological and spiritual domains of the approach. Those that trust in the effectiveness of the treatment together with the ability of the healer, believe that the treatment can successfully heal their illness. Today it is accepted that the psychological component plays an important role in the healing process by facilitating natural healing potential (Bushy, 1992). This probably contributes to a healer's success. The informal health care system played a most important role in sustaining the participants' health and giving them hope.

Since the traditional conceptualisation of illness, treatment and care is different from the Western medical model, incongruence between care practices of the two systems may occur and the villagers have to decide which to accept or reject. This indicates a need on the part of care providers to understand the recipients' cultural background, use of other sources of care, and include these modalities of care in the process of restoring health based on the clients' needs.

4. Summary

This study was conducted primarily among participants living a rural lifestyle where the traditional way of life still could be observed. In this lifestyle, family members are still greatly dependent on each other for a wide range of supports. However life in contemporary rural Thai society is changing due to socio-economic pressures. These pressures are affecting family structures and relationships. The social welfare system in Thailand, including the health care system, has not changed to accommodate new needs arising from the socio-economic restructuring currently

underway. The health services are still focused on hospital care for patients with emergency and acute health problems. Government health services at the community level are even more limited, and cannot meet the health care needs of the people. The demand for health services, in particular in the rural areas, is far more than the supply. The reliance on the family carers to meet the ongoing care needs for family members with chronic illness and/or disabilities is placing more strain on these carers as the socio-economic changes accelerate. These problems must be taken into consideration, and policies and strategies developed to address the country's health problems.

Family-based care is essential in the community given the current and future pressures on the health care system. A challenge for nurses and health professionals is how to keep families continuing to act as the primary source of care, thus preserving the traditional culture of Thai family relationships and meeting needs that cannot be met within the financial constraints of government funding. It is crucial that we understand the real situation of care and the influence of culture and beliefs that govern that care, to ensure that we can provide the community with culturally appropriate support. The burden of caring for extended periods of time without any support from health care agencies can be a tremendous load for the family carers. This caregiving burden can be reduced by providing public home-based services.

The new generation who are under economic stress in the modern society may use these pressures as an excuse for not getting involved with the care of the elderly which may lead to a change in attitude to family based care in the future. Ell (1990) noted that failure to give equal attention to the health services required by families results in an excessive emphasis on family responsibility. Families' success in promoting and maintaining the health of their members is undoubtedly a product of their ability to obtain the social resources vital to maintaining family well-being and the extent to which a family's social environment is supportive or non-supportive. Use of family care resources is relatively cheap and also a source of pride for both caregivers and care-recipients. The major aim of health care services should be to encourage, facilitate and provide partial support to patients and families in order to allow family members to perform other roles in the family and community.

As mentioned above, one reason for the popularity of traditional medicine in contemporary Thai society is the scarcity and maldistribution of modern medical resources, which are concentrated in the big cities. This combines with communication problems with providers associated with these health care institutions. In contrast, there are a wide range of traditional medicines and mixed mode health services available in the community. These health services incorporate a family focus into their treatment programmes. Family involvement in the process of treatment and caring is widely encouraged by traditional practitioners. Within these modes, families can exercise their right to choose the services and design the treatment and caring plan for the sick family member. The popular use of traditional medicine in the community also stems from its key characteristics: it is understandable, negotiable and easily accessible.

5. Recommendations

Findings from this study have specific implications for both nursing practice and education. These will be discussed in the final chapter in relation to the model of practice that has been developed, rather than providing separate recommendations. However two recommendations relating to the health care service system more generally will be included in this chapter.

First, additional health resources need to be allocated to rural areas. Improving and upgrading the existing government health services at the village level by supplying the health centre with adequate medical equipment and qualified health personnel is a key to gaining the trust of the villagers and providing them with more effective health service options. In particular, services in the area of rehabilitation should be identified as one of the major health services in the community in response to the increase of people with disabilities and/or chronic illnesses and who are being cared for at home.

Second, there is an urgent need to establish home-based care especially for the long-term care needs of people with chronic illnesses and disabilities, and the dependent elderly. A lack of rehabilitation programmes for these people inhibits the development of their potential ability to regain independence, and thus to be able to resume their normal social roles including employment. The services should be

staffed by nurses qualified in rehabilitation. The most appropriate means of achieving this goal is to upgrade the level of nursing services in the community and modify the nurses' roles by adding this modality of care to their job description. Roles of community nurses should include these activities:

- liaising with the hospital for information, especially about rehabilitation plans and goals
- providing home visiting services as a means to keep in touch with the clients, particularly with those who have difficulties with obtaining transportation to the hospital, and as a means of providing nursing care in the clients' home more sensitive to environmental and cultural factors.
- providing skilled rehabilitation care in the community
- facilitating continuity of care

The final chapter of this thesis will present a self-care model applicable to this Thai cultural context, together with the implications of the model for nursing practice.

CHAPTER 9 : SELF-CARE MODEL

1. Introduction

In the previous chapters, data have been presented which illustrate how the participants and their families view and participate in caring for themselves and for other family members. The factors influencing this caring practice have been identified. In this chapter, these factors are brought together in a model describing the self-care phenomenon in Thai culture, that is a family oriented self-care model. This model is informed by contextual and experiential data from the study, and related literature in this area. Rationales supporting the various aspects of the proposed model are discussed.

The benefits of self-care are being increasingly recognised as especially important in chronic and long-term care for reasons of cost and availability. Steiger and Lipson (1985) noted that the philosophy and practices of self-care are valid for a range of socio-economic and cultural groups, if the values of each group are taken into consideration. To support this notion, a model of self-care within the Thai culture has been developed to stimulate discussion as to the most appropriate means for nurses and health professionals to implement the self-care strategy in a more culturally appropriate way.

2. Presuppositions

The proposed self-care model is based on the following definitions and presuppositions within the Thai cultural context:

1. Definitions of terms:

1.1. A family is a group of people who are related to each other by blood, marriage, or adoption; living together; sharing some aspects of their emotional lives, such as happiness and sadness; and having the same family goal, that is the maintenance of the well-being of the family.

The most common type of family grouping in Thai society is the extended family. This is defined as a gathering of several generations under one roof, or at least under several roofs within the same compound. Family members usually interact frequently and exchange mutual aid. It is the primary place where Thai

children learn and absorb the cultural values that will guide them throughout much of their later lives (Thailand Office of the Prime Minister, 1991).

1.2. Self-care is defined as one of several family functions. All family members contribute to self-care activities in order to promote, maintain, and restore the well-being or health of the individuals and the whole family.

1.3. Health is a state of wellness resulting from the balance of the physical, social, emotional and spiritual aspects of an individual, that are intimately linked with the well-being of the family to which he/she belongs.

2. Individuals and family members are ultimately responsible for caring for themselves to the best of their ability.

3. A family obligation is to maintain the well-being of family members (health promotion, maintenance and prevention), and to care for sick members. The family has the following functions concerning health management in the family (modified from Muttigo, 1987, pp. 120-121):

3.1. The family has the right to decide and choose types of treatment and care for sick family members.

3.2. Family members work together in making decisions regarding the plan of care, allocating caring responsibilities including the previous responsibilities of the sick member, and managing family resources to meet the health care needs of the family member.

3.3. The family is responsible for caring for the sick family members by gaining health knowledge and caring skills from resources available in the community, e.g., books, radio and television.

4. The family is considered the primary unit of self-care for the Thai elderly as most of the elderly still live with their extended family, and the response to illness in the elderly is family based rather than individually based.

3. The Model

The self-care model in this study is based on the family context for several reasons. Firstly, the data collected from stroke patients show that most lived and shared their lives with their extended family and that the notion of self-care is interwoven with family and societal expectations. Secondly, the data illustrate that the well-being of the family members is a result of family interaction. Thai society

can be characterised as an 'interdependent' society in which people depend upon each other and thus find their security in dependence and patronage rather than individualism (Wichiarajote, no date - cited in Mulder, 1994). This pattern of family interaction underpins the care model in which family members work together to promote their well-being and participate in caring for those who are sick. Since most of the participants who provided information for this study were elderly, the model is best suited for application to Thai families with older members living with them.

This model has two prime functional referents. First, the Thai family functions to 'promote normalcy' in the well family, that is to say in health promotion and maintenance. Secondly, it functions in 'caring' for sick members, that is health restoration (see Figure 3). Families move over time between these two functional emphases. The self-care practices are the family processes aiming to promote, maintain or restore the 'well-being' or 'health' of the family. These practices are influenced by four main factors: the family (individual and other family members), support from their social network, the health care system and socio-cultural factors. The two functional referents will now be discussed in detail.

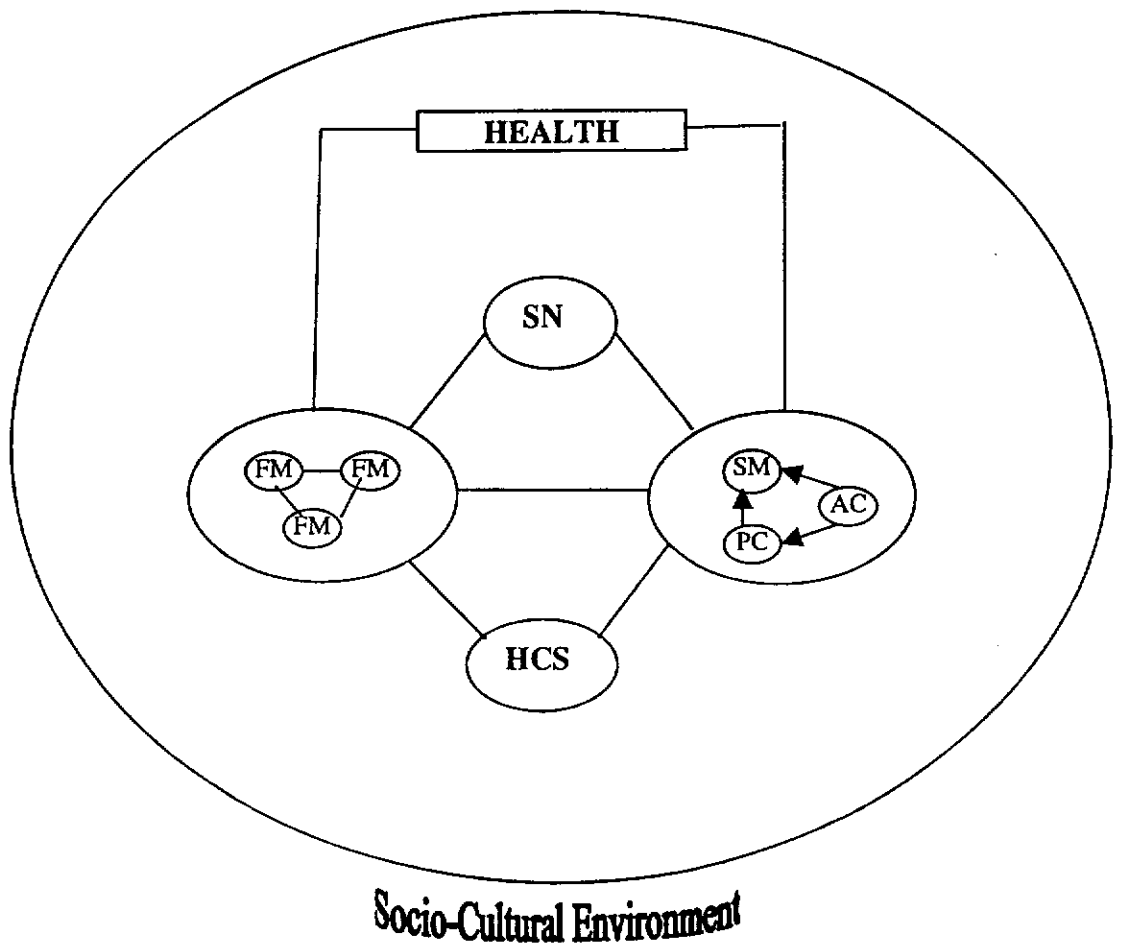
3.1. The Well Family

In this model, the family is a primary resource for maintaining the well-being of its members. If the whole family is functioning well, the well-being of the family will be promoted, including the physical health of its members. The ability of the family to promote and restore the well-being of the family depends on the capability of the individuals and the family system to carry out health related actions, including the all-important task of accessing external expertise and support. The ability of an individual to perform self-care activities is conditioned by many factors such as age, gender, marital status, level of education, health state and cognitive ability (Hanucharunkul, 1988; Vithayachockitikhun, 1991) whereas the family system is shaped by the family's structure, lifestyle, values, economic status and socio-cultural practices.

In contributing to the well-being of the family, members have an obligation to assume their expected responsibilities as a part of the family. Each member is ascribed a set of family roles which provide a connectedness between individuals and

the family unit. Family members' positions are usually described as those of mother/father, husband/wife, sibling by gender and age, grandparents and other relatives (Ell & Northen, 1990). The roles attached to these positions contribute to the well-being of family members. The women contribute most to the health, safety and well-being of the family. For example the mother is usually the person who looks after the family meals, safety and cleanliness of the home environment, and the health care needs of family members including advice to and guidance of her children about health related issues (Tongtae, 1992). Elderly parents, especially the grandmother, may help with some of these domestic activities if able. Men usually are the breadwinners of the family. At home they may help with tasks involving transport and labour such as shopping, watering plants, looking after livestock. In respect to health matters, they also give advice and contribute to decision making. Each child may be assigned certain duties according to age and ability, such as feeding livestock or taking care of younger brothers or sisters while the parents are at work or in the fields (Thailand Office of the Prime Minister, 1991). They are taught to help with family projects as well as to be self-reliant. Therefore, the well-being of family members in the extended family environment is maintained by two different means: the direct contribution of each family member to their own wellness and that of other family members; and family socialisation.

The direct health related actions of an individual for their own health and the well-being of other family members, depend on the arrangement of family role responsibilities and the member's ability to undertake these responsibilities. Family socialisation influences members' health by shaping their health practices and health service use, influencing psychological health and providing access to external resources (Ell & Northen, 1990). The family is assumed to play a vital role in directly and indirectly shaping members' beliefs and attitudes about health related practices and lifestyle, conveying family norms about what constitutes illness and what are appropriate illness behaviours. Health related issues such as weight, dieting,



Well family

Health Promotion

- Within the family: Interdependent health promotion practices
- Family-health care providers: health promotion relationship

Family with a sick member

Health Restoration

- Within the family: Interdependent self-care practices
- Family-health care providers: care provider-care recipient relationship

FM= Family member; SM= Sick member; PC= Primary caregiver;

AC= Associate caregiver; HCS= Health care system; SN= Social support network

Figure 3: Family-Oriented Self-Care Model

exercise, smoking, alcohol use, psychological and social development of an individual in the family are all part of the dynamic of family interaction and relationships (Ell & Northen, 1990).

3.2. Family with a Sick Member

The normal role pattern in the family is disturbed when one or more members are sick or disabled. While patients may lose numerous roles in the family and community, they must also learn to assume their new roles as a 'sick person'. Family members need to understand and help them in this adjustment. In the interdependent Thai society, the role responsibilities of the sick member and the caregiving workload are distributed among family members according to age, gender and family function. Adult women are usually the primary caregivers, responsible for the majority of caring tasks, while other family members may act as associate carers providing both direct and indirect care (to free up the primary caregiver for the caring tasks). The relationship between the sick person and family members can take any form ranging from complete dependency, to partnership or facilitator (by guiding, supporting, and teaching) depending on the individual's degree of dependence and the family situation.

3.2.1. Patterns of Family Interaction

The degree and nature of family involvement vary with an individual's condition and assumption of various roles. Three general patterns of individual-family interaction were identified in the study: individual-focused, family-focused and resource-focused. Although the family may demonstrate one of these patterns of interaction at a particular point of time, they may move to another pattern over time.

3.2.1.1. Individual-Focused.

The focus of this interaction pattern is on the sick person. Family life revolves around the sick person in an effort to provide the best possible care, with the potential problem of over-involvement or over-protection. Arrangements are often made for a family member to look after the sick person or to allocate the caring tasks among family members. This arrangement usually causes tremendous changes in family members' roles and responsibilities. A family member may need to resign

from their job or leave school to take care of the sick member. Others may take leave of absence from work in order to contribute to the care. This type of response is more likely to occur at the acute or initial stages of the illness, or in a family with no financial difficulties. This is the ideal pattern of family care for their elderly. The quality of care is usually considered to be good from the care recipient's point of view.

3.2.1.2. Family-Focused.

In the family-focused pattern of interaction, caring is considered as one family matter that needs to be balanced with other family functions or roles such as nurturing young family members, farming and other work commitments. The primary focus is on maintaining a functioning family. This mode of caring is very common in families caring for an elderly member with a chronic illness. Family members need to contribute their time to the caring role as well as to other family roles. In some situations, the majority of caring activities are provided outside working hours. Elders can be satisfied with the care given even though only basic health care needs are met, provided the family continues to function well. This is because the elders' goals relate to the well-being of the whole family and they perceive that the family members have done their best.

3.2.1.3. Resource-Focused.

In the resource-focused family, caring is based on the resources available to the family. This pattern of response is often employed by families caring for a sick member for an extended period of time and encountering multiple stresses such as financial difficulty, multiple responsibilities or poor health of the family caregivers. It is also common in families who perceive the patient's condition as hopeless. Both the sick person and the family may come to terms with and accept the situation as a result of previous Karma (Taam-Bun-Taam-Kum). Although there is no active seeking of beneficial treatment by either party, at least the provision of basic care needs is ensured.

The pattern of family interaction reflects what the family circumstances determine in relation to the mode of caring and the degree of family involvement in providing that care. A sick person is less likely to contribute to self-care in the

individual-focused mode and more likely to assume a greater degree of responsibility for individual self-care in the family-focused and resource-focused modes. For example, a sick elder may not perform self-care tasks even though he/she is still capable, when this is perceived as a family carer's role and the carer is able to assume that role.

4. Factors Influencing Self-Care

In addition to the personal characteristics of an individual and family support, self-care behaviour and illness response are influenced by social support networks, health care services and socio-cultural factors.

4.1. Social Support Network

Friends, neighbours and the wider social support network (other patients and health personnel in the village health centre who are also members of the community) are part of the network of informal carers surrounding the family unit. Support and help from the social network include the offering of food, herbs, massage, advice, companionship, and health service and resource information. Peer support in the form of informal self-help groups appears to be useful and a valued resource for patients and their families in settings such as healing centres. These support networks substantially shape the way patients and their families respond to illness, care, and selection of treatment modalities and health services through direct interaction and communication.

4.2. Health Care System

As discussed earlier, from the villagers' perspective the health care system in Thailand can be divided into three subsystems: Traditional Medicine (Mhor-Baan), Western Medicine (Mhor-Luang), and Mixed Mode (Mhor-Cheetya). Their availability and accessibility influence health care practices and the use of services. For example, at some stage patients and their families may have required Western health services, but could not access them because of limited services, difficulties in transportation, and barriers between service users and providers. Therefore, people are more likely to benefit from traditional and mixed mode health services which are available and easy to access in the community. As a consequence, it is important to

incorporate these modes of service when planning nursing interventions relating to self-care and care at home.

4.3. Socio-Cultural Environment

The influence of the social environment on family health related functions and tasks includes socio-economic, socio-political and socio-cultural (religious beliefs, social values) factors. These environmental factors are powerful, pervasive, and have potentially negative as well as positive effects on the individual and family in terms of their ability to carry out the necessary health care tasks.

5. Implications for Nursing

Although the findings are limited by sample size and group (Buddhist, especially elderly), they provide directions for nursing practice, education and research relating to family care.

5.1. Implications for Practice

The proposed model of self-care has implications for nursing practice, in particular the care of elderly Thais suffering from chronic illness in a home setting. The involvement of health personnel, including nurses, in maintaining well-being, promoting health and preventing disease should not be limited to when an individual encounters self-care deficit, but should also occur in the well-being phase. Consequently, this model allows for the application of the self-care concept to both well families and families with sick members.

The results from this study regarding the family with a sick member(s) are compatible with the model of family care described by Taylor (1989) when viewing the family as a dependent unit of care, or as a unit of service. Taylor (p. 134) defined a dependent unit of care as a unit within the family, of two or more persons, one of whom is dependent on the others for assistance with self-care. The unit may be the whole family or subunit of the family. It may be a stable unit, that is, the same two or three persons are involved over time, or the number of family members may fluctuate on a regular or irregular basis. In Taylor's model, nurses may be engaged in the direct care of the dependent family member or may assist the caregiver in providing the care to that person.

When the family is a unit of service, nursing intervention is not only focused on the sick member and 'dependent care unit' but also on the whole family. This approach is based on the belief that the family is a unit that is more than the sum of its parts (Taylor, 1989). Families have their ways of meeting the health care needs of the sick member as well as the well-being of the family as a whole. Knowledge about family roles and responsibilities regarding self-care, health service use (especially folk or traditional medicine), and the family's culture and belief systems should be included in the planning of nursing interventions. It is important for health personnel to include the family caregiver in the process of rehabilitation especially in the decision-making process. The rehabilitation plan is more likely to be translated into action when the caregiver gives a commitment to do so.

The elderly-family relationship in Thai society is interdependent in nature. Within this cultural context, nursing interventions that only focus on the elderly as a 'self-care agent', or alternatively the family members as a 'dependent care agent' providing care to that sick person, are inappropriate, even counterproductive. The enhancement of only the self-care agency of the individual who is 'sick' may disrupt the reciprocal relationship within the family. Similarly, targeting the family ('dependent care agent') without providing support from government health services, may cause this relationship within the family to deteriorate, in particular when caring for family members with chronic illness or disabilities. Since the meeting of the sick person's care needs relies on both the individual and the family members, the target of intervention therefore must be both the individual and the family.

From the above discussion, it is clear that promotion of self-care in the Thai society requires family members to be included as a unit of dependent care or of service. Whereas the well family acts to prevent disease and promote health, the behaviour of the family with a sick member is directed towards the well-being of the family and caring for the sick member. The model emphasises the importance of the family in the process of encouraging self-care. This model is applicable to both community and institutional settings in promoting self-care by a sick individual and family members. However, it is suggested that the model may be best used in the community where the family belongs. Within the clients' natural environment in

their own community, the clients have more control over the care and service needs. Additionally this environment allows more family members to participate in the care. In this setting health providers can gain more understanding of the clients' reality and thus facilitate self-care more appropriately. Applying this model in an institutional setting where health providers are more likely to dominate decision making in respect to care, they should be aware of the reality of the clients' post-discharge care environment. They also need to recognise and include family members in the process of promoting self-care.

Another feature of the participants' use of health services in the community was the extensive use of traditional medicine and self-remedies. These care resources need to be recognised and considered when planning care. Loss of hospital contact after discharge or 'noncompliant behaviours' as judged by health professionals, does not always mean clients are not looking after themselves. Actual self-care practices need to be assessed in the home context in order to identify the efforts expended by individuals and their family seeking for services outside the formal health care system.

Another implication for practice relates to self-care assessment tools and educational programmes. Most self-care educational programmes or self-care assessment tools are developed from theoretical frameworks that are grounded in a particular socio-cultural background. These are applied and evaluated in another socio-cultural context without adaptation to or cognisance of the reality of that context. For example pre and post testing of an educational programme may not measure the actual self-care practices in the participants' real life. Thus the evaluation results may be falsely positive with a misleading conclusion being drawn that the theory is appropriate for that society. For example, researchers may use Orem's self-care theory as a theoretical framework to construct their self-care educational packages based on a one way interaction from nurses to patients. They then evaluate the programme by completion of a post-test questionnaire or monitoring the improvement of a certain caring skill without assessing the actual self-care activities in the participants' day to day life at home. The evaluation has actually measured the learning process rather than the achievement in self-care practice.

Similarly, standard assessment tools designed to assess self-care ability and achievement in self-care need to be sensitive to cultural differences. For example the self-care assessment tools developed for Western health care emphasise individual responsibilities. The unmodified use of these in an interdependent society where family members rely on each other can be problematic. For example, an older member of a Thai family who is asked to respond to the following statement: 'I always keep my house and environment clean', may answer 'no' because this task is ascribed to another member of the family. In this situation the person does not perform this task even though they have the ability to do so. However they may be responsible for other tasks which are not included in the tool such as baby-sitting. In this case the individual may be assessed as having less self-care agency than they actually have, the result being distorted by the sharing of these self-care tasks among family members in the interdependent society.

5.2. Implications for Education and Research

The proposed model of self-care has particular implications for community-based nursing education. Nursing education in Thailand has been traditionally focused on the individual, not family and community oriented. Students' clinical learning experiences mainly take place in government health institutions where the focus is on the care of individuals with acute illnesses. Confined to institutions, nursing students do not have the opportunity to learn about the realities of patients' lives in their natural context. The current clinical learning experiences not only limit interaction between students and families but also confine the spectrum of patients' care needs to acute care. This limitation is particularly telling in respect to the chronically ill elderly, most of whom remain in their community and are cared for by their family. Their needs, conditioned by their own beliefs, values and cultural systems, are too complex for students to understand outside the patients' community context. Improving the quality of care particularly in the area of health promotion and restoration of chronically ill patients requires a reforming of nursing curricula to one that is more community-based. The curriculum must emerge from the community environment. With community-based education, the focus is shifted from the individual to the family or group living in the community. The focus is on the

well-being of the group, i.e. the family or the community. Therefore community-based education encourages students to know and understand the client's reality, and use this knowledge to effectively strengthen self-care in the community.

The model also has implications for research. This model emphasises the family as the unit of analysis for research in the area of self-care. The results indicated that an individual as well as all the family members contribute to self-care and therefore the 'health' or 'well-being' of the family. People's conceptualisations of health and self-care have a profound influence on the research aims. The model emphasises family role responsibilities, family socialisation, family interdependence, social support network, utilisation of community health resources, and the influence of the socio-cultural environment. These factors should be considered when researching issues relating to self-care in this cultural context. Further research is needed to gain more understanding of the meaning of 'health' or 'well-being' of the family from the perspective of family caregivers. Gender issues also need further research as this exploration may provide a greater understanding of the socio-cultural dynamics that shape the role of individuals within the family, thereby adding valuable information to the model of self-care. Self-care strategies can then be based on the needs of the family. Research and training in home-based services is also needed to facilitate self-care, as well as to decrease the family caregiving burden. The current model contributes to our understanding of self-care within the family context despite the limitation imposed by the primary age group of the study population. It is still questionable if the model is appropriate for the wider population. It will be useful to test if this model of self-care is applicable for other age groups, e.g. young or adult members who live in an extended family, families with differing cultural or religious beliefs, e.g. Muslims.

6. Summary

This model of 'self-care' has been developed in order to address the situation of stroke victims in rural home settings in southern Thailand. The model was informed by contextual and experiential data gathered from ten individuals who had suffered a stroke and from their families, related documents and literature.

The self-care family based model identifies two main aspects of family health care: the well family and the family with a sick member. The focus of the well family is on health promotion and the maintenance of health. The emphasis of the family with a sick member is on health restoration. The self-care practices in both situations are conditioned by three main factors: the social network, health care services and socio-cultural environment. This model has implications for nursing practice for clients in an interdependent society, especially those living in an extended family in Thailand. The focus of nursing intervention must be on individuals and their family as an interrelated client unit of care.

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APPENDICES

APPENDIX 1: ASSESSMENT FORM FOR ACTIVITIES OF DAILY LIVING (ADLs)

	With Help	Independent
1. Feeding (if food needs to be prepared to eat = help)	5	10
2. Moving from wheelchair to bed and return (includes sitting up in bed)	5-10	15
3. Personal toilet (wash face, comb hair, shave, clean teeth)	0	5
4. Getting on and off toilet (handling clothes, wipe, flush)	5	10
5. Bathing self	0	5
6. Walking on level surface (or if unable to walk, propel wheelchair)	10	15
score only if unable to walk	0	5*
7. Ascend and descend stairs	5	10
8. Dressing	5	10
9. Controlling bowels	5	10
10. Controlling bladder	5	10

Total score is 100. 100 BI (Barthel Index) means a patient is continent, feeds himself, dresses himself, gets up out of bed and chairs, bathes himself, walks at least a block, and can ascend and descend stairs.

Reference: Mahony, F. I., & Barthel, D. W. (1965). Functional evaluation: The Barthel Index. *Maryland State Medical Journal*, 4, 61-65.

	1	2	Discharge	3	4	5
Date	9/03/95	26/03/95	3/04/95	8/04/95	9/04/95	11/04/95
Time	11:30 AM	3:00 PM		6:00 PM	3:00 PM	5:00 PM
Place	hospital	hospital		home	home	home
Plan	-Case assessment -Introduction	-Establish relationship -Data collection from pt's file		-Get to know the pt's environment -Informal interviews	-Get to know the pt's environment -Informal interviews	-Get to know the pt's environment -Informal interviews
Event & Settings	<i>The pt was in her private room with her husband and nineteen year old daughter. They were sitting together on a sofa. I went into her room with the head nurse. The head nurse introduced me to them. The pt seemed to be very friendly towards me but the husband wasn't. The head nurse told me that they had family problems and the husband didn't want other people to get involved in them.</i>	<i>The pt was sitting in a wheel chair talking to her daughter and son. Her husband was sleeping on a sofa. She looked happy. I spent about 30 mins talking mainly about her illness as I tried to avoid discussing her personal life.</i>		<i>Yesterday I called the pt to ask to visit her at home. She told me to feel free to come anytime. When I arrived at her home today, nobody was in. The door was locked. The house was in the residential area in Hatyai. It was a small two storey house. I asked a neighbour for the pt. She said the pt might have gone to see Mhor Beeb.</i>	<i>Only the son was at home. The son told me that his mother, father and sister had gone to see his grand mother in Suratthani province and didn't know exactly when they would be back.</i>	<i>I rang to check and made an appointment before I went to visit the pt today. They arrived back from Suratthani yesterday. Every body was at home. The husband was massaging the pt with herbs. There was a stove with a piece of stone on it in order to heat a wrap for the herb. The house used to be a grocery and food shop as there were shelves for goods and a noodle counter at the front of the house.</i>

APPENDIX 2: HOME VISIT RECORD

APPENDIX 3: INTERVIEW GUIDE

INTERVIEW GUIDE (PATIENTS)

The following areas will be explored with the patients over the period of field work.

Aspects of self care and the patient's experiences since discharge from the hospital

- The daily life of the patients and their families; how life has changed after the stroke
- The activities that they can do by themselves and those needing help from others
- Persons who help the patient at home, what activities they help with, what has been most helpful and least helpful
- The ease with which they are able to ask their relatives for help
- The amount and adequacy of support they receive from family members in order to meet their needs
- The manner in which they are given support to facilitate self care behaviours
- Ability to make decisions about care and perform self care at home
- Factors that inhibit or facilitate self care
- Factors that help them make decisions and to play an active role in their own care
- Use of community resources and facilities

INTERVIEW GUIDE (FAMILY CARERS)

The following areas will be explored with the carers.

Aspects of self care and care provided by the family carers and their experiences

- The detailed activities / support that the family provides for the patient
- Ability to make decisions about care and provide care at home
- Factors that inhibit or facilitate self care
- The manner in which the family provides support to assist the patient perform his/her own care
- The amount and adequacy of support they can provide to their sick relative at home
- The amount of involvement they wish to have in the individual's care
- The availability of community resources and facilities to assist the patient live independently at home
- The utilisation of community resources and facilities

INTERVIEW GUIDE (KEY INFORMANTS)

- Factors that inhibit or facilitate self care
- Availability of community resources and facilities to assist patients live independently at home
- The utilisation of community resources and facilities
- Cultural aspects relating to self care

APPENDIX 4 : DEMOGRAPHIC AND MEDICAL INFORMATION

DEMOGRAPHIC INFORMATION: PATIENTS

Researcher's use only _____
Date of interview _____
Interview code number _____
Ward code number _____
Admission date _____
Discharge date _____
Type of stroke _____
Date of the onset of stroke _____
Patient's condition _____

The following information will be collected from the patients' files or by interviewing the patients.

Gender: 1) Male
 2) Female

Age _____
Marital status _____
Highest level of education _____
Occupation _____
Religion _____
Average income/month _____
Address _____
Telephone no _____
Family members with whom the patient lives _____

Primary family carer(s) _____

Other health problems _____
Patient's condition when discharged from the hospital _____
Number of readmissions after stroke _____

DEMOGRAPHIC INFORMATION: FAMILY CARER(S)

Researcher's use only

Interview code number _____

Date of interview _____

The following information will be collected by interviewing primary family carers.

Gender: 1) Male
 2) Female

Age _____

Marital status _____

Highest level of education _____

Occupation _____

Religion _____

Average income/month _____

Address _____

Telephone no _____

Relationship to the patient _____

APPENDIX 5: CONSENT FORM

THESIS TITLE: SELF CARE OF STROKE PATIENTS IN THAI CULTURE

My name is Urai Hatthakit, I am a nurse and I am currently enrolled to complete doctoral studies at a university in Australia. The purpose of this research project is to increase nurses' understanding of the roles and ways in which stroke patients and their family members participate in care after being discharged from hospital. The knowledge gained from this study will be important as it will provide nurses with information which will help us to assist people who have suffered from a stroke to care for themselves.

I invite you to participate in this study which will be conducted using observations and interviews. This will involve me visiting you at home a number of times over a period of months. Both formal interviews and discussions will take place during my visits. The formal interviews, which will last approximately one hour, will be tape recorded. During the interview, you may decline to answer any questions, and request that the tape recorder be turned off. No names will appear on the transcribed interviews. Extracts of interviews may be used in the research report, but you will not be identified in any way. Participation is voluntary and consent can be terminated at any time. There are no health risks associated with your participation.

If there are any questions or concerns you have regarding this project, please do not hesitate to contact me.

School of Nursing, Prince of Songkla University, Phone no: 212-901

PARTICIPANT'S CONSENT

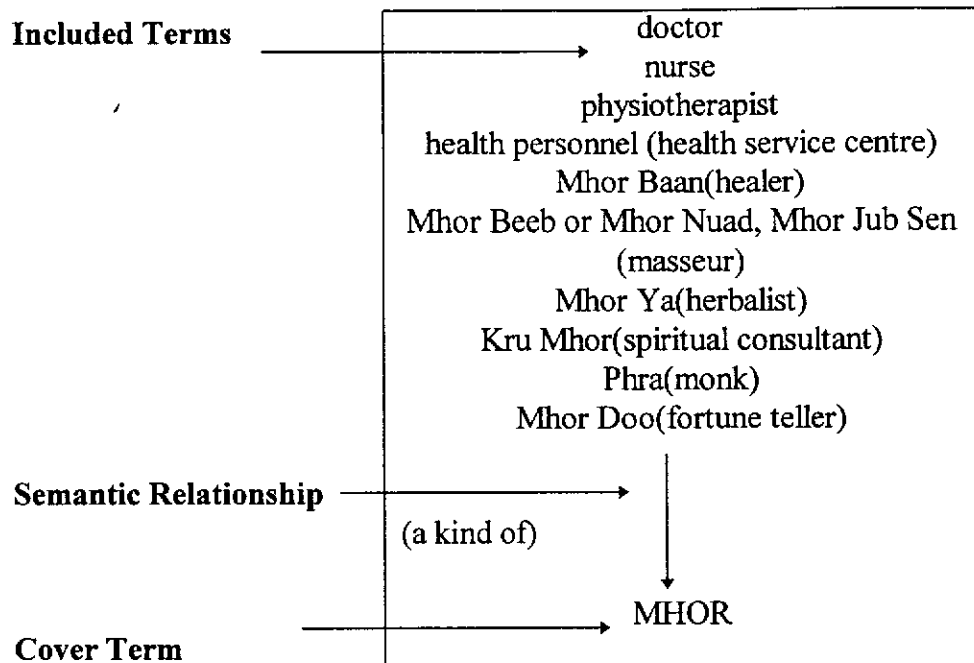
I, _____, have read the above information on the study. I understand the nature and intent of the study and have the opportunity to ask questions. I understand where to direct any future questions that I may have. I have received a copy of the consent form. I hereby give permission to be interviewed and for the interviews to be tape recorded. I understand that my participation is voluntary and I may withdraw my consent and terminate my participation at any time without incurring any penalty.

Signed _____ Patient/family member Date _____

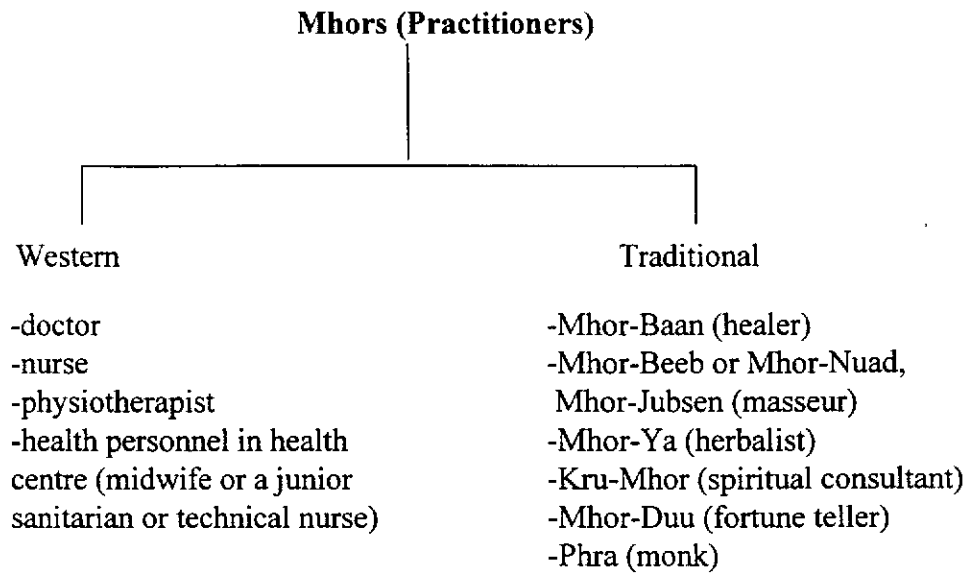
Signed _____ Researcher Date _____

APPENDIX 6: DEVELOPMENT OF DOMAIN

DOMAIN: "Mhor" (Practitioner)



APPENDIX 7: TAXONOMIC ANALYSIS



APPENDIX .8: COMPONENTIAL ANALYSIS
(Paradigm for kinds of Mhor)

Contrast Set	Dimensions of contrast										
	Place	Fee	Contact time	Number of participants	Practitioner-Pt Relationship	Communication	Accessible	Pt's attitudes	Expected services	Satisfaction	Reasons
Western -Hospital	hospital)	expensive	short	only a Pt or with a carer if necessary	formal	formal doctor: -restricted -didn't listen to Pts -Pt was afraid to tell the doctor the truth nurse: -nurses spoke politely	difficult: -not enough services -too many Pts -specific time and place to get Px:	1. more effective 2. good for Px in the acute stage 3. good for dealing with problems in the brain; dissolving the clot in the brain	effective in treating some symptoms; -headache -high BP -numbness -constipation	No	1. short contact time 2. lack of explanation 3. didn't understand the pts' feelings 4. couldn't negotiate 5. couldn't get the service when wanted 6. difficult to get access to the services
-Village Health Centre	Village Health Center	cheap	flexible	Pt or with carers (more flexible)	less formal	less formal -local language	not sure: -easy to get access to the center bec. it is located in the community but difficult to find a staff member (the center always left unattended)	1. poor quality of care and limited skill 2. limited ability of staff 3. short of equipment and medicines 4. health volunteers didn't do their jobs	normally Pts went to see for: 1. monitoring BP 2. minor health problems e.g. first aid or dressing wounds 3. family planning 4. immunisation	No	1. didn't trust the services 2. difficult to find the health personnel
Traditional	home/ temple	vary from free of charge to expensive	vary from 5 mins to 5 hours	Pt and family	informal	informal: -local language -openly express -no emotional distance	easy: 1. can see the practitioner any time 2. services can be provided at home 3. many varieties of treatments available for selection	1. take time to be cured 2. good for rehabilitation	treating some symptoms by: 1. correcting the body lines by massaging: -slurred speech -facial palsy -high BP -paralysis -stiffness of joints -muscle tension 2. herbal medicines and hot compress -edema -constipation	Yes	1. long contact time 2. happy with the explanation 3. understanding the Pt's feelings 4. the Px was negotiable 5. cheap 1. uncertain about the effectiveness of treatment as they don't have good training system

Contrast Set	Dimensions of contrast											
	training	systemic training	W. med.	PT	exercises	walking training	massage	herbs	compress	prohibited foods	nutrient and tonic	rituals
Western -hospital	Yes	Yes	Yes	Yes	Yes	Yes	No	No	No	No	No	No
-village health centre	Yes	Yes	No	No	No	No	No	No	No	No	No	No
Traditional	No	No	No	No	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes

PT: Physiotherapist

APPENDIX 9: COMPONENTIAL ANALYSIS (Paradigm for kinds of Mhor, Part 2)

APPENDIX 10: Examples of statements demonstrating negative emotion or feeling

Negative emotion or feeling	Example
<ul style="list-style-type: none"> • Anger (Groge) • Disappointment (Ped-Wong) • Feeling of being hurt by a very close person (Noy-Jai), • Concern that they were annoying others (Tum-Hai-Kon-Aern-Rum-Kaan), irritating them (Tum-Hai-Kon-Aern-Ngud-Ngid), or disturbing them (Rob-Koan-Kon-Aern) • Not wishing to disturb or inconvenience others (Grang-Jai) 	<p>“Nobody understand me. I don’t mean I don’t try to help myself but I really can’t do it, otherwise I wouldn’t disturb them”</p> <p>“I was so disappointed that my children rarely responded to my requests. When I was well, I did everything for them”</p> <p>“I feel very Noy-Jai when my daughter is unwilling to help me”</p> <p>“When I ask my daughter for help and she is not in a good mood, she responds by asking me why I didn’t try to help myself. This made me very Noy-Jai”</p> <p>“I don’t want to ask my daughter too much, because she has been very tired with me and with her own children and so on”</p> <p>“I felt that I had disturbed my daughter and son-in-law too much, so I decided to terminate the treatments and go home”</p> <p>“If I go socialising, I may disturb others or make them worry about me”</p>