## HEALTH-RELATED QUALITY OF LIFE OF RURAL THAI FAMILY CAREGIVERS

By

Saowaluk Netchang

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#### ABSTRACT

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**Background/Purpose**: The number of older Thai people is projected to increase every year, and most of them experience problems, such as changes in mental and physical status. They also need help with activities of daily living. Increasing dependence of chronically ill elders results in a need for more family members to care for them. Studies have shown that family caregivers experience physical difficulties as a result of assisting with elders' increasing impairments and behavioral problems. Caregivers' functional status as an ability to perform their own daily life tasks was considered to be one of the important variables in the caregiving role that may influence caregiver health-related quality of life (HRQOL). The primary purpose of the study was to examine a model in which selected family caregiver and elderly care recipient (ECR) characteristics were hypothesized to predict HRQOL among rural Buddhist Thai family caregivers. Framework: The study was guided by the revised Wilson and Cleary model for HROOL, a conceptual model of client outcome assessing caregiver HROOL. Specific Aims: To examine (1) the relationships among the following variables: family caregiver characteristics (age, sex, relationship to ECR, religious activities, chronic health conditions, household income, and social support), ECR characteristics (age, sex, levels of physical disability, and ECRs' symptoms), length of caregiving, caregiver tasks of care, rewards of caregiving, and caregiver functional status; (2) the relationships among family caregiver characteristics, ECR characteristics, selected variables from Specific Aim 1, and overall HRQOL of rural Buddhist Thai family caregivers; and (3) whether the relationship between family caregiver functional

status and overall HRQOL of family caregivers is mediated by the rewards of caregiving, controlling for all other variables. **Methods**: This study was a cross-sectional, descriptive study conducted from October 2011 to January 2012 at two primary care units in two rural districts in the Uttaradit province of northern Thailand. The study sample included rural primary family caregivers of ECRs who had one or more chronic conditions and needed assistance for two or more ADLs at home for at least three months. A total of 201 family caregivers were included. **Results**: (1) Younger male caregivers with few chronic health conditions and caring for ECRs with fewer symptoms were more likely to have better functional status than were older female caregivers with more chronic health conditions and caring for ECRs more symptoms. (2). Older and spousal caregivers participating in more religious activities, who had few chronic health conditions, better functional status, higher perceived social support, and higher perceived rewards of caregiving were most likely to have a greater overall HRQOL. (3) Rewards of caregiving appear to significantly, partially mediate the relationship between caregiver functional status and overall HRQOL. Implications: Positive aspects of caregiving include religious activities, social support and rewards of caregiving, and are to be of concern for health care teams. Hospital and/or community health care providers are able to improve caregivers' overall HRQOL by offering training programs or discharge plans that include knowledge and skills suited to their elders' conditions. In addition, in wards or primary care units, private rooms with the Buddha image for praying or chanting and meditating would allow caregivers to participate in religious activities when their elders are admitted. Also, the Ministry of Public Health should request an annual budget to fund educational institutes of nursing for research and nursing education not only on elders, but also on family caregivers.

	This	dissertation	is	dedicated	to	my	famil	V
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To my beloved mother, Somsri Netchang, and father, Boonklue Netchang, for their inspiration, patience, and hard work, and to my sister, Taweevan, and brother, Komgrich, who have been taking good care of our mom and dad while I have been away; I could not have completed this dissertation or any of the doctoral program without their constant love, encouragement and support.

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### Chapter 1

#### Introduction

The ability of family members to continue to provide care for their elderly relatives in the context of the demographic and social changes of Thailand has been a critical concern for many researchers (Caffrey, 1992; Chan, 2005; Subgranon, 1999; Subgranon & Lund, 2000). While the number of elderly continues to rise, the increasing dependence of chronically ill elders results in a need for more family members to care for them. The more dependent the elderly are, the more difficulties family caregivers experience and the more help they need to provide proper care.

The purpose of this study was to examine a relationship in which selected family caregivers' and elderly care recipients' (ECR) characteristics, including the caregivers' task of care, are hypothesized to influence or be related to Heath-Related Quality of Life (HRQOL) among rural Buddhist Thai family caregivers of ECRs with one or more chronic conditions and who possessed at least two activity-of-daily living deficits. In chapter 1, the problem statement, significance, purposes, specific aims, and an overview of the study are discussed.

The number of older Thai people is projected to increase every year, and most of these people experience problems such as changes in mental status, immobility, sensory deficit, and sleep disorders; they also need help with personal activities of daily living (Chan, 2005; Sasat, 2006). Additionally, more elderly individuals in Thailand have been diagnosed with chronic, but manageable conditions such as stroke, cancer, dementia, congestive heart failure, and Alzheimer's disease due to improved medical therapies and technologies (Chan; Jordhoy et al., 2007; Moons, 2004; Plasqui, 2008). The majority of Thai elders live with family in rural areas where there is limited access to formal health care services (Ministry of Social Development and Human Security [MSDHS], 2007).

The dramatic increase in the chronically ill, elderly population in Thailand has a significant impact on families with ECRs and has resulted in the worsening physical and mental health of many family caregivers (Chatcheydang, 2005; Chung, Nsu, Wang, Lai, & Kao, 2007). The impact of caregiving on caregivers' HRQOL may be due to (a) the effect of physical exertion that produces muscle strain or pain; (b) negative changes on personal health-related activities, such as diet and exercise; or (c) physiological effects of psychological distress on their own chronic conditions, such as depression (Chatcheydang; Morimoto, Schreiner & Asano, 2003; Pinquart & Sorensen, 2007). Studies in Thailand have shown that family caregivers frequently experience physical difficulties from direct care, such as muscle strain, low back pain, and weakness of arms and legs as a result of assisting with ECRs' increasing impairments and behavioral problems (Chatcheydang). For this study, caregivers' functional status as an ability to perform their own daily self-care and household activities was considered an important variable in the caregiving role that may influence their HRQOL.

In this study, it was hypothesized that family caregivers who care for ECRs with physical disability tend to experience problems of caregiver functional status because of the degrees of ECR disability, age- and disease-related symptoms, and increased caregiver tasks of care.

Moreover, this study also investigated whether or not caregiver functional status was influenced by various characteristics of caregivers and ECRs, including environmental characteristics such as social support, length of care, and the rewards of caregiving perceived by the caregivers.

Similarly, in the United States and Thailand, more care recipients are elders with an average age of more than 60 years and are more often now diagnosed with one of these chronic illnesses: cancer, stroke, dementia, or heart disease (Foundation of Thai Gerontology Research and Development, FTGRD, 2009; National Alliance for Caregiving, NAC, 2004; 2009). Assistance

provided to elders with chronic diseases includes managing instrumental activities of daily living (IADLs), along with everyday living and activities of daily living (ADLs) personal care activities that may have an effect on caregivers' ability to care.

Moreover, age- and disease-related symptoms, such as weakness, pain, fatigue, insomnia, poor appetite, cognitive impairment, emotional and psychological behaviors, and so forth, are other factors predicting care demands of the elderly (Chan, 2005; Chatcheydang, 2005; Given, 1995; NAC, 2009; Pinquart & Sorensen, 2007). However, family involvement in tasks of care depends on elders' physical disability in daily self-care activities; each form of involvement demanding different skills and capacity, as well as psychological strengths, from family members (Given; Given & Sherwood, 2006). Although there have been some U.S. studies that have examined caregiver functional status and its relations in terms of physical function (Fredman, et al., 2009; Tong et al., 2002), there are few published studies that have specifically focused on caregivers' functional status, influenced factors, and the consequences of providing care for elders in Thailand.

The findings of this study will increase understanding about the relationship between caregivers, ECRs' characteristics, and caregivers' functional status, particularly in rural Thai family populations with few health care facilities. Moreover, the findings from this study should provide essential knowledge concerning specific characteristics of caregivers and ECRs—positive caregiving aspects in rural Buddhist Thai context—that can predict optimal caregivers' health outcome, HRQOL.

#### **HRQOL Among Family Caregivers**

In Thailand, most family members providing care scarcely know how to care for an elderly patient, regardless of the hospital or the institution in which care was given

(Chatcheydang, 2005; Jones & Peters, 1992; Subgranon, 1999). In some health care facilities in rural areas, family caregivers may not receive adequate information about caregiving at home because of insufficient time and a lack of knowledgeable health care professionals (Chatcheydang). Under such circumstances, Thai family caregivers of chronically ill elders have to find their own way to manage problems regarding the care they provide to their loved ones. Caregiving tasks include managing ADLs, administering medication, and providing for other needs, such as arranging everyday living -- housework, meal preperation, transportation, grocery shopping and financial tasks, for instance (Subgranon & Lund, 2000). In the United States, 1,480 caregivers reported that 72% of care recipients they cared for are older persons with conditions such as Alzheimer's disease or confusion, cancer, mental or emotional illness, heart disease, and stroke; long-term physical conditions are present in 69% of caregiving situations (NAC, 2009).

On average, caregivers spend 18 to 20 hours per week providing care, which includes helping the care recipient get into and out of bed and chairs, assisting with housework, preparing meals, administering medications, arranging transportation, shopping for groceries, arranging outside services, managing finances, and assisting with personal care tasks such as getting dressed, bathing or showering, toileting, dealing with incontinence, and feeding (FTGRD, 2009; NAC, 2004).

Caring for an older individual with chronic conditions such as stroke, cancer, diabetes mellitus, arthritis, or mental illness at home can place demands on a caregiver's physical and mental health (Caffrey, 1992; Chaoum, Intarasombat, & Putwatana, 1996; Frias, Tuokko, & Rosenberg, 2005) and result in negative consequences to his or her emotional and physical health (Barnes et al., 2006; Chatcheydang, 2005; Chung et al, 2007, Given & Sherwood, 2006). In 2005, Chatcheydang examined a model of relationships between caregivers' characteristics and

HRQOL of Thai female family caregivers of elder stroke survivors. The study found some negative health outcomes, such as anxiety, stress, depression, and fatigue, from providing long-term care at home. Kurtz, Kurtz, Given, and Given (2004) investigated the impact of cancer caregiving at home on caregivers' mental and physical health over a one-year period with a sample of 491 caregiver/ patient dyads. Results showed that caregivers' personal perceptions of three dimensions of their caregiving experience (impact on schedule, lack of family support, and social functioning) played a central role as determinants of caregivers' both mental and physical health (Kurtz et al.).

Consistently, Morimoto et al. (2003) examined the relationship between a caregiver's burden and HRQOL in family caregivers of older stroke patients in Japan. The study found that an increased burden from multiple caregiver tasks of care was significantly related to worsening HRQOL, particularly worsening mental health. Their results were consistent after controlling for caregiver age, sex, chronic illness, average caregiving hours per day, and functional dependence of the care-recipient.

Similarly, in relation to the overall HRQOL of caregivers, Kim and Given (2008) reviewed literature on the quality of life of cancer survivors' family caregivers during the acute phase (the period of diagnosis and treatment up to two years postdiagnosis), middle or long-term survivorship phases, and the bereavement phase (one year posttreatment). Their findings suggested that the quality of life of family cancer caregivers frequently varied along the illness trajectory, just as the various types and amounts of assistance provided by caregivers varied, indicating that further testing of family-based interventions across the trajectory of the illness was needed (Kim & Given). Authors have concluded that family caregivers frequently experience various problems from their caregiving experiences, including conflict within their

social roles, restrictions of activities, strain in marital and family relationships, psychological distress, and diminished physical health (Kim & Given; Haley, LaMonde, Han, Burton, & Schonwetter, 2003). Caring for the ECR with a positive attitude creates an overall sense of satisfaction toward the experience and may help family caregivers to recognize the rewards of caregiving. Rewards of caregiving may associate with the caregiver's ability to perform their daily life tasks and to care for the ECR. In addition, the caregivers' ability to provide care may also relate to their own quality of life, which is multidimensional and includes psychological, mental, social, physical, spiritual, and behavioral components, not only during the time that they are providing care but also throughout the trajectory of the illness.

Additional factors that may serve as either direct or indirect determinants of caregiver HRQOL can include ECR characteristics—such as the extent of their symptoms, their disability in personal care and everyday living, the severity of their health conditions, the types of treatments and comorbidity—and caregiver characteristics—such as relationship to the ECR, education, the length of care, and a positive aspect, the rewards of caregiving (Barnes et al., 2006; Blanes, Carmagnani, & Ferreira, 2007; Chatcheydang, 2005; Chung et al. 2007; Kurtz et al., 2004; Northhouse, Kershaw, Mood, & Schafenacker, , 2005; Rees, O'Boyle, & MacDonagh, 2001; Riedijket al., 2006). As shown in Chung et al.'s (2007) study, authors found elderly ADLs deficits, sex, marital status of caregivers, and the presence of a primary caregiver to be significant predictors of HRQOL of caregivers of chronically-ill elders. In the study of Chung et al., most Taiwanese caregivers were female spouses who professed having religion, shared good relationship with elders, had high functional status, and reported moderate HRQOL.

In Thailand and many other countries, caring for elderly persons with chronic illness has become increasingly complex because of the increased number of age-related, preexisting comorbid conditions many elders possess, which require more aggressive treatment protocols and prolonged survival periods after diagnosis (Chatcheydang, 2005; Chung et al, 2007; Given & Sherwood, 2006). Because more caregiving for chronic disease is now provided in home settings, increased involvement in managing medication and finances and in arranging outside services is frequently needed from family members. It is important for family members to coordinate and actively participate in providing assistance with everyday living and personal care for loved ones with chronic conditions (Chung et al.; Subgranon & Lund, 2000).

It has been demonstrated that a chronic illness experience can affect not only the individual but also his or her family and friends (Given & Sherwood; Markowitz, Gutterman, Sadik, & Papadopoulos, 2003; Morimoto et al., 2003; Pinquart & Sorensen, 2007). However, it remains largely unknown what most significantly influences HRQOL levels for Thai elderly caregivers (Chatcheydang; Sasat, 2006). Little is known about how ECRs' and caregivers' characteristics and other caregiving aspects subsequently influence caregivers' functional status and their HRQOL, particularly in rural Thailand settings where there are fewer health care facilities (Barnes et al., 2006; Blanes et al., 2007; Chatcheydang; Sasat).

In Thailand, there are few research and supportive services focused on family caregivers of chronically ill elders. Most prior studies have focused on caring for these elderly patients in hospital settings (Sasat, 2006; Subgranon, 1999). The family caregivers of chronically ill elders are briefly instructed on how to care of their relatives at home before hospital discharge (Subgranon). Since 1993, some stroke survivors have been visited by home health-care teams, including physicians, nurses, nutritionists, and social workers, every three months. However, these home health-care programs are mainly focused on the patients' needs and not those of the caregivers, with most programs in Bangkok and several big cities. No current, established

special-supportive programs are known that directly aim to reduce psychological and physical effects on rural family caregivers and/or enhance caregivers' functional status and HRQOL (Chatcheydang, 2005; Subgranon; Subgranon & Lund, 2000).

Regardless of whether or not family caregivers experience a positive or negative health outcome, caregiving influences the caregivers' overall life experiences. Because caregiving for chronically ill persons, particularly elders, is a long-term commitment for family caregivers and their loved ones, such commitment will likely influence the HRQOL of caregivers themselves.

### Caregiving of Chronically Ill Elders in Rural Thailand

In Thailand, the prevalence of chronic diseases in elders—including stroke, cancer, dementia, diabetes mellitus, heart failure, hypertension, and arthritis—is relatively high (Ministry of Social Development and Human Security [MSDHS], 2007; Puangwarin, 2001). In 2005, the Ministry of Information and Communication Technologies found that the group of individuals who are aged 60 and older has the largest proportion of those who suffer from chronic diseases or have personal unhealthiness (50% of all older persons). The northern part of Thailand, including Uttaradit province, the purposed setting of the study, has the largest proportion of chronically ill older persons at 59.2%. The statistical report of Uttaradit Hospital, a medical center of Uttaradit Province in northern Thailand, revealed that the number of the patients increased from 5,013 in 2009 to 7,085 in 2010 (Information Department of Uttaradit Hospital, 2010). It is therefore expected that the number of patients will continue to increase because of the growing elderly population, the group most affected by those chronic diseases.

ECRs symptoms and disabilities that affect caregiver tasks of care. At present, most Thai patients tend to be hospitalized for shorter lengths of stay than in the past because of the high cost of care, as well as limitations in budget, nurses, and hospital beds (MSDHS, 2007;

Puangwarin, 2001). Therefore, patients with stable and noncrisis conditions are discharged earlier from the hospital. However, the patients still need to have continuing care at home, so family members must take on the caregiving role for their relatives. Ninety percent of the Thai chronically ill elders who have been discharged from the hospital still have some disabilities requiring care at home (Lausawatchaikul, 2001; Lawang, Sunsern, & Rodjarkpai, 2005; Periard &Ames, 1993; Sasat, 2006), such as partial weaknesses, communication problems, cognitive impairment, memory loss, and swallowing problems. Because of their disabilities, many elders require help with IADL tasks, including housework, meal preparation, transportation, or grocery shopping, and ADLs, including providing help getting in and out of bed and chairs, bathing, or toileting. Moreover, ECRs' care demands are caused by age- and disease-related symptoms such as vision impairment, weakness, pain, fatigue, nausea, vomiting, insomnia, coordination problems, poor appetite, constipation, bed sores, inability to concentrate, and so forth. (NAC, 2004; FTGRD, 2009).

Christ & Diwan (2010) reported the bio-psychosocial health needs of chronically ill elders, who need information and education about illness, treatments, costs, health maintenance, and services available to them. Also, ECRs need help in managing illness throughout the different phases of the diseases—for example, prevention, diagnosis, treatment, remission and exacerbation—and advanced illness, as well as material and logistical resources, such as transportation and home care. Some elders need help in coping with the emotions that accompany illness and treatment. The majority of elders with chronic illness need assistance in changing their behaviors to minimize the impact of disease and increase the impact of treatment. They also need assistance with managing their medication side effects and administration, as well as coping with disruptions in their work, activities, family life, and social network. Finally,

financial assistance, including daily life expenses and managing and maintaining extra copay health insurance, is frequently another need. Family caregivers are frequently the most important people to help elders meet those needs.

Caregiver tasks of care from giving care for elders. ECRs' disabilities and symptoms increase their long-term dependency and needs, which demand some permanent care from other professional care providers or caregivers when the elderly patients are discharged to their home. ECRs' conditions can worsen when coupled with the ECRs' symptoms caused by the diseases, including (a) the patients' disabilities, as they are unable to help themselves because of weakness or pain, and so forth, and the caregivers have to make every decision on the patients' behalves; and (b) the patients' symptoms, such as frustration, irrationality, impatience, and bad temper or mood.

The person who assumes the caregiver's role will take more responsibility, which includes (a) managing everyday living, such as providing transportation, shopping for groceries, assisting with housework, managing finances, preparing meals, giving medication, and arranging outside services; (b) helping with personal care, such as getting in and out of beds and chairs, dressing, bathing, toileting, feeding, and dealing with incontinence; and (c) monitoring and assisting with symptoms management, such as weakness, pain, fatigue, insomnia, constipation, nausea, and vomiting, which may cause physical and psychological problems. Moreover, monitoring and assisting with age- and disease-related symptoms in elders is challenging in home care situations for family caregivers (Given & Sherwood, 2006), which may increase caregiving demands and tasks of care that could result in a decrease in a family caregiver's care ability.

### Caregiver functional status.

**Physical function.** The change in the caregiver's lifestyle results in a change in physical activities and behaviors. In other words, the caregiver's daily routine has to be adapted because of this new responsibility, including assisting the ECR with eating, exercising, and participating in recreational activities (Chung et al., 2007; Fredman et al. 2009). At the same time, caregivers must take time to maintain their own daily living activities. Family caregivers may be frustrated when they are forced to change their daily life activities. Their caregiving also might lead to feelings that they are not as strong as they used to be, and they could experience fatigue, insomnia, and fear that they may not be able to provide good enough care. Some caregivers may be afraid to be left alone with the ECRs (Caffrey, 1992; Chatcheydang, 2005; William, 1994). In addition, long-term care requiring a large commitment of energy, resources, and time may lead to changes in physical health. Caregivers may need to make decisions and carry out many activities on behalf of the ECRs, which can lead to stress. This can be observed in different physical symptoms, such as weight loss, headache, back pain, exhaustion, and lack of energy, which will impact a caregiver's ability to care for elders (Belasco et al., 2006; Blanes et al., 2007; Bull, 1990; Krach & Brooks, 1995; Teel, Duncan, & Lai, 2001).

Psychological function. Caregivers may suffer from stress, anxiety, or strain, which is caused by expanded and unprepared caregiving roles—including tasks of personal care and everyday living management for ECRs—which is a result of the ECRs' worsened conditions and behavioral problems. Furthermore, caregivers' psychological problems may result from the environment and family surroundings. For instance, caregivers have to do household work without the usual assistance, or financial problems could arise. Most importantly, psychological problems may be a result of the caregivers' own emotions, as they may feel that they cannot

provide appropriate care to the patients. They could not act to meet their own expectations and therefore put blame on themselves, because of an imbalance between care demands and the availability of resources to meet those demands (Belasco et al., 2006; Blanes et al., 2007; Given & Sherwood, 2006; Teel, et al., 2001).

Interestingly, Shaw et al. (1997), Patterson and Grant (2003), and Vitaliano et al. (2003) reported that psychological problems, such as burden and depression, may cause negative hormonal changes, increase susceptibility to infectious agents, and disrupt health habits, such as getting enough sleep and engaging in healthy eating patterns. In addition, depressed caregivers may over report physical problems (Frias et al., 2005), which could associate with caregivers' physical health and impact their ability to care for their elderly relatives.

Social function. When taking care of an elder at home, many caregivers may miss some other social activities they'd usually participate in. Social function is one domain of the ability to perform caregiving tasks (Wilson & Cleary, 1995; Ferrans, Serwic, Wilbur, & Larson, 2005) and is indicated as the ability of the individual to interact in society in a normal or usual way, which can be viewed from various perspectives (Ferrans et al.). As mentioned in physical and psychological function, caregivers spend most of their time caring for an elder with a chronic illness, resulting in a lack of time for their own social activities, such as maintaining relationships with other family members and friends or participating in rest and recreation (Caffrey, 1992; Northouse et al., 2002; Tang & Chen, 2002; William, 1994; Chatcheydang, 2005). Moreover, caregiving for chronically ill elders frequently has a strong influence on normal social activities, which is due to physical and psychological problems; therefore, caregivers cannot complete their social function needs. Similarly, for instance, Ebrahim and Nouri (1987), Caffrey (1992), William, Northouse et al., (2002), Tang and Chen (2002) and

Chatcheydang (2005) pointed out that two thirds of the families of elderly stroke survivors spent more time caring for the patients, and the provision of care affected their daily life activities. Caregivers had to spend less time on their social activities and were unable to cope with emotional problems, which created strain. Taking on the role of caring for elders with chronic illness may impact the ability of caregivers to interact in society in the normal or usual way (Belasco et al., 2006; Blanes et al., 2007).

Role function. By taking care of elders with chronic diseases, caregivers encounter problems that are results of the diseases' physical and mental effects on the elders. Caregivers must respond to the patients' constant needs, which require both time and effort and create different perceptions in caregivers (Bakas, Lewis, & Parsons, 2001; Fredman et al., 2009; Tong et al., 2002; Wilkins, Bruce, & Sirey, 2009). Hoyert and Seltzer (1992) studied underlying factors in happiness and family activities and found that there were differences between caregivers with responsibilities and caregivers without. In two studies, caregivers who had to take care of chronic patients had poorer health statuses, less self-satisfaction, and more depression (Nelson et al., 2008; Lu & Austrom, 2005). Additionally, when assessing the effects of caring, the researchers found that being a caregiver led to other negative aspects, including problems in household management, occupation, social activities, marital satisfaction, and health.

Caregivers have many roles to play in daily life, not only in caregiving. Caregivers may suffer from attempting to fulfill all their roles, including caregiver, wife or husband, and employee, as well as from attempting to perform those roles in line with expectations held by themselves or by others (Knodel & Chayavan, 2011; Wright, 2000). Thus, some problems with work or other daily activities can occur in family caregivers as a result of physical health or emotional problems that might result from taking on multiple roles.

**Environmental characteristic: social support.** Family caregivers may experience difficulties dealing with physical and emotional problems of chronically ill elders and strained relationships with potential support providers, and thus, may feel overwhelmed, isolated, or alone. They may experience difficulty communicating their needs to other family members and health professionals because of a perceived lack of support (Sammarco, 2001).

Social support is indicated as an environmental characteristic of caregiving because of its reported association with HRQOL in elderly caregiving (Northouse et al., 2002). Social support is the perception that leads individual caregivers to believe they are cared for, loved, esteemed, and valued, and that they belong to a network of communication and mutual obligation (Brandt & Weinert, 1981; Sammarco, 2001). Social support may positively affect caregivers' functional status by reducing their stressors, including assisting with care tasks (Chappell & Reid, 2002), helping to develop effective coping strategies (Losada, Montorio, Marquez, & Izal, 2005), and promoting positive health behaviors (Tang & Chen, 2002). Also, Uchino, Kiecolt-Glaser, and Cacioppo (1992) and Tong et al. (2002) reported that lower levels of social support were associated with worse physical function in caregivers, while caregivers reported better psychological well-being if they were highly satisfied with their social support in Ownsworth, Henderson, and Chambers's study (2010).

**Buddhist beliefs.** Buddhist beliefs that have been reported by rural Thai family caregivers have involved karma, the concepts of boon (merit or good deed) and babb (demerit or bad acts), which can be measured by the participation in religious activities (Sethabouppha & Kane, 2005; Subgranon & Lund, 2000). The majority (94.5%) of Thais is Buddhist (Wibulpolprasert, 2007), so, for this study, most caregivers were assumed to be Buddhist. According to Buddhist beliefs, karma means action performed with intention. The law of karma

means that good acts will lead to good consequences and bad acts will lead to bad results (Payomyong, 2000; Payutto, 1995, 1998). Thai Buddhist caregivers often strongly believed that the reason they had to take care of their ill family members was the result of the law of karma in their current and past lives. Accordingly, most of the caregivers performed boon, or good deeds for their ill elderly family members, to achieve a better life in their next rebirth. Caregivers followed Buddhism in caring for their chronically ill elders (Sethabouppha & Kane; Subgranon & Lund).

In summary, in the traditional Thai culture, children have to take care of their parents, and wives and husbands have to look after their spouses to show their love and feelings, as well as the prime responsibilities for the children. A qualitative study of caregiving at home in Thailand has confirmed that some caregivers believe caregiving of parents is a moral obligation for sons and daughters, and also believe caregiving of spouses shows love and attachment (Subgranon & Lund, 2000). Buddhist belief expressed as participation in religious activities has been shown to be a resource that people use when facing a problem or dealing with a difficult situation. Family caregivers of chronically ill elders may positively perceive their caregiving role, which is hypothesized to enhance their HRQOL in long-term care at home.

Positive impact: rewards of caregiving. A growing number of previous caregiver studies have reported that many caregivers could identify positive aspects of caregiving, such as personal uplifts, becoming closer to family spiritually (Kinney & Stephens, 1989), rewards (Picot, 1995; Picot, Debanne, Namazi, Wykle, 1997), gratifications (Motenko, 1989), or gains (Kramer, 1997). In nursing research, positive aspects of caregiving have been discussed using term such as rewards, uplifts of caregiving, caregiving esteem, caregiving satisfaction, gain in the caregiving experience, and caregiver appraisal (Hunt, 2003). Numerous terms used to

represent rewards of caregiving included an improved relationship with the care receiver or other family members (Kramer, 1993; Lawton et al., 1991; Picot), an increase in self-esteem (Karmer, 1993; Picot), a feeling of appreciation (Braithwaite, 1996; Picot; Stephens, Franks, Townsend, 1994), an enhanced sense of meaning or purpose (Karmer), and a feeling of pleasure (Picot).

Previously, it had been reported by Farran et al. (1991) that 90% of caregivers perceived rewards of caregiving in various areas, such as the positive growth in family and social relationships, the positive relationship they shared with the care recipient, the memories of an accomplishment with others, the feeling of appreciation from the care recipient, and the feeling of pride about the quality of care they provided. Also, rewards of caregiving have been reported in terms of self-satisfaction, increased interactions between the caregiver and the care receiver (Picot et al., 1997), and reduced feelings of difficulties for the caregiver (Riedel, Fredman, & Langenberg, 1998).

More recently, Cohen, Colantonio, and Vernich (2002) examined the positive aspect in caregiving and reported that 73% of the caregivers of seniors in rural communities could identify at least one specific positive aspect of caregiving, and 69% could identify more than one. In fact, some caregivers even reported significant gratification—such as satisfaction in life from caring for their loved ones—or positive gains from caregiving, such as a positive self-view and spiritual growth (Bacon, Milne, Sheikh, & Freeston, 2009; Cohen, Gold, Shulman, & Zucchero, 1994; Folkman, 1997; Lawton et al., 1991; Motenko, 1988; Picot, 1995; Pinquart & Sorensen, 2003).

Kim, Schulz, and Carver (2007) and Helgeson, Reynolds, and Tomich (2006) reported that positive effects result from traumatic events, including caregiving for chronically ill patients. Similarly, researchers identified that domains of benefit finding included an accepting attitude toward life, positive changes in self-view, a change in interpersonal relationships, and a deeper

sense of purpose in life with greater focus on important goals and priorities (Bower & Segerstrom, 2004; Kim et al., Helgesons et al.). A meta-analytic review of benefit finding and growth (Helgeson et al.) and other related studies (Kim et al.; Mock & Boerner, 2010) revealed that benefit findings including rewards of caregiving were associated with life satisfaction, depression, and positive well-being.

According to the positive experience of caregivers, the rewards of caregiving are one aspect that needs to be assessed and understood. In the United States, Rachick and Ingersoll-Dayton (2004) reported that a few studies have pointed to the positive experiences of caregiving, especially for men (e.g., Kramer, 1997), and husbands and wives (Fitting, Rabins, Lucas, & Eastham, 1986). The results showed a greater proportion of husbands reported their relationships with their spouses who had dementia had improved since they began providing care.

There is no unified or commonly accepted definition for those who mentioned positive caregiving experiences, but most definitions include feelings of satisfaction in the ability to meet challenges; an improved sense of self-worth; a sense of growing closer to the care recipient; and the experience of warmth, comfort, and pleasure in caregiving (Motenko, 1989).

Providing continuous long-term care, including helping with IADLs and ADLs for ECRs leads to some other benefit finding in elder caregiving experiences even in the midst of multiple caregiver tasks of care.

Other caregiver factors related to rewards of caregiving. Previous research studies both in Thailand and other countries have revealed that most of the caregivers of chronically ill elders were spouses, children, and kinship of the patients (Chatcheydang, 2005; Joolamate, 1997; Kasemkitwattana, 2006; Sasat, 2006; Pinquart & Sorensen, 2007). In Thailand, an estimated 90% of elders live with their children or relatives at home in rural areas, including most disabled

ECRs with chronic diseases (MSDHS, 2007; Subgranon & Lund, 2000). The major reasons for family members to take care of elders in rural Thailand include Buddhist beliefs that (a) older Thais should be offered a high status that demands care, respect, and obedience from their younger children or relatives; (b) one has an obligation to care for one's parents at home, causing most Thais to refuse to let their parents move into an institution; and (c) every act, word, or thought affects their later lives as they hope to receive good future care as a reward, according to the law of karma (Sethabouppha, & Kane, 2005).

Motenko (1988) found that husband caregivers experienced a sense of competence and pride from caring for their wives. Although few studies have explicitly examined relationship differences in caregiver benefits, some evidence suggests that adult children experience more rewards than spousal caregivers. For example, when comparing caregiving daughters and caregiving sons with caregiving wives, adult children caregivers were more likely to report an improvement in their relationship with the care recipient (Hinrichsen, Hernandez, & Pollack, 1992).

Similarly, in a study of husband and son caregivers, Harris (2002) concluded that sons were more likely than husbands to experience gratification from caregiving. That is, caregiving sons were particularly appreciative of the opportunity to pay back their parents for the nurturance they had received. It may be that adult children experience more rewards because of qualitative differences in caregiving responsibilities, with spousal caregivers having more intensive responsibilities than adult children.

In the context of parents caring at home for an adult child with mental illness, Schwartz and Gidron (2002) explored the positive aspects and rewards of caregiving. Specifically, the authors measured the extent to which parents perceived their ill child as providing assistance and

support—practical and emotional—and perceived their own caregiving as emotionally and mentally rewarding. In 2004, using a social exchange perspective and data from a national sample of 978 spouse and child caregivers of older family members, Raschick and Ingersoll-Dayton assessed the association between caregiver relationship and gender and the costs and rewards of caregiving. The authors also evaluated whether relationship and gender moderate the effects of helpfulness on caregiver costs and rewards. Results supported the hypotheses that women, whether wives or daughters, experience more caregiving costs than men, and that adult children experience more rewards than spousal caregivers. In addition, care recipient helpfulness was associated with a greater increase in rewards for spousal caregivers than for adult children caregivers.

In Thailand, there are few published studies focused on the positive experience of family caregiving, especially the rewards of caregiving. Researchers have seldom reported the factors in caregiving that influence rewards of caregiving in the context of rural Thai family caregivers of elders. However, some researchers found that caregiving for an older family member can also be a satisfying and rewarding experience despite the possible stress imposed from managing one's life (Kopachon, 2002; Playpetch, 2002; Sethabouppha, & Kane, 2005). Kopachon examined influences on preparedness, rewards of caregiving and factors in caregiver-role strain for those providing care to patients with strokes and found that almost all caregivers are Buddhists (99%). Caregivers had high scores in preparedness and rewards of caregiving, but had low scores in caregiver-role strain.

Similarly, the study of Playpetch (2002) aimed at investigating how self-transcendence and help from others influenced the rewards of caregiving among family caring for head-injured patients in the recovery stage. The results showed that 99% of caregivers were Buddhists, and

the scores of the rewards of caregiving were relatively high. Age and the duration of time spent being a caregiver were not related to the rewards of caregiving, but being a child of the patient, self-transcendence, and help from others had a positive relationship to the rewards of caregiving.

As specifically mentioned above, Buddhist beliefs toward elders may impart a sense of obligation on Thai caregivers to care for parents, and karma-based thought may create positive feelings from assuming the role of family caregiver, such as the rewards of caregiving (Sethabouppha, & Kane, 2005). In addition, Donprapeng (2006) and Kasemkitwattana, (2006) proposed that a caregiver's warm and supportive attitude toward the care recipient can sometimes help the individual cope with the caregiver role. However, the influences of religious activities resulting from Buddhist belief and karma-based thought on rewards of caregiving are not known. Perceived the role as a positive experience of caregiving, rewards of caregiving may positively influence caregivers' functioning that ultimately affect improved HRQOL.

### **Significance of Study**

As a result of the increase in the number of elderly Thais with chronic manageable illnesses, more elderly Thais require assistance at home that is due to age-related physical and mental deterioration (Sasat, 2006). More family members are now frequently required to assume daily caregiver roles for their elderly relatives.

In rural areas, most Thai elders live with their children or relatives at home because family members in rural Thailand believe in Buddhism. Buddhist beliefs dictate that older Thais should be offered a high status, respect, and obedience from younger Thais, and that children have an obligation to provide good care for their elders at home, leading most Thais to refuse to let their parents move into a day-care institution. Moreover, Thai people believe in karma, meaning that good acts, words, or thoughts affect their future lives as they wish to receive good

care in return when they are older (Payomyong, 2000; Payutto, 1995, 1998; Sethabouppha, & Kane, 2005). This Buddhist belief and karma thought may help caregivers to accept what happens in caregiving situations and roles, such that the rewards of caregiving are perceived. These domains of religious-related benefit finding in elder caregiving may be perceived by caregivers, and they are expected to be associated with caregivers' overall HRQOL.

In recent years, however, there has been a growing trend of business and economic changes, resulting in the migration of young people to urban areas for work (Choowattanapakorn, 1999; Pongpaichit & Baker, 1996; Warr, 1997). As a result, the economy has drawn large numbers of young adult Thai men and women from rural villages to larger cities and other countries. In 2005, the study of the MSDHS demonstrated that these dramatic economic and social changes have caused many elders to now live alone with their aged spouses at home. Those ECRs who do not have a family member or spouse living with them frequently live alone near other family relatives (MSDHS, 2007).

Consequently, rural Thai elders are frequently living at home with an elderly spouse, older daughter or son, or grandchildren, and have limited health care facilities or support (MSDHS; Subgranon & Lund, 2000). Because of the disabilities and bio-psychological needs of ECRs, the long-term dependency and need of care increases. ECRs require permanent caring from their family caregivers when they are discharged from the hospital. And so, the person who takes on the caregiver's role will take more responsible in an expanded role by helping with IADLs and ADLs, which may lead to physical and psychological problems. Buddhist beliefs might help the caregiver positively perceive existing phenomena of care as rewards of caregiving, which will help improve caregiver's HRQOL in the dimension of psychological adjustment for taking on the caregiver role.

The goal of caring for elders with chronic diseases is not only to maintain health and delay death of ECRs, but also to maintain or improve HRQOL of their caregivers. The concept of HRQOL has frequently been discussed as a key element of nursing practice and clinical outcome criteria (Ferrans, Serwic, Wilbur, & Larson, 2005; Wilson & Cleary, 1995). Although some studies have been conducted in Thailand focusing on caregivers, they have focused on other aspects (e.g., perceived burden, depression) of family caregivers, rather than the positive aspects of caregiving, caregivers' functional status, or HRQOL (Knodel & Saengtienchai, 1999; Namthamongkolchai, Makapat, Charupoonphol, & Munsawaengsub, 2007). Nursing researchers have increasingly attempted to clarify and measure relevant caregiving factors in order to examine influences affecting caregivers' HRQOL (Chan, 2005; Chung et al., 2007).

This was one of the first studies to explore those relevant negative and positive caregiving aspects for specifically understanding caregivers' functional status and HRQOL, and for further research to develop appropriate interventions to improve Thai family caregivers' HRQOL. The results of the study examined the relationship among caregivers' clinical outcomes, functional status and HRQOL, which will further affect sustainability of caring for elders in the community.

Although it is especially challenging to support ECRs and family caregivers in Thai rural areas where there are fewer health care facilities, few researchers have previously studied the aspects of functional status and HRQOL including caregiving in rural settings. Most of the prior studies have focused on caring for chronically ill elders in hospital settings, and very few studies have focused on family caregivers (Chatcheydang, 2005; Knodel & Saengtienchai, 1999). In response, this study filled the ongoing knowledge gap by examining (a) the relationship among ECR and caregiver characteristics, ECRs symptoms, length of caregiving, social support,

caregiver tasks of care, caregivers' functional status, and rewards of caregiving and (b) whether rewards of caregiving mediate the relationship between Thai family caregiver functional status and family caregiver HRQOL. Such results will be particularly innovative, contributing to the understanding of factors that influence caregivers' HRQOL in a non-Western, rural context and furthering the investigator's research trajectory of caregiving for ECRs with Buddhist beliefs measured by caregivers' participation in religious activities. It will also be discussed whether or not the participation in religious activities such as praying, meditating, going to the temple, offering food and things for monks, or donation for others are shown to associate with family caregivers' perceived reward. Moreover, such results will lead to a new religion-related model of assessing caregiving consequences and will provide guidelines for the development of culturally appropriate intervention, including religious activities as resources of heightened caregiver rewards to enhance caregivers' functional status, further resulting in improved HRQOL.

### **Specific Aims**

Specific aims of this study were to examine:

- 1. The relationships among family caregiver characteristics (age, sex, relationship to ECR, religious activities, chronic health conditions, household income, social support), ECR characteristics (age, sex, levels of physical disability, ECRs' symptoms), length of caregiving, rewards of caregiving, caregiver tasks of care, and rural Buddhist Thai family caregiver functional status.
- 2. The relationships between family caregiver characteristics (age, sex, relationship to ECR, religious activities, chronic health conditions, household income, social support), ECR characteristics (age, sex, levels of physical disability, ECRs 'symptoms), length of caregiving, rewards of caregiving, caregiver tasks of care, family caregiver functional status, and overall

HRQOL of rural Buddhist Thai family caregivers.

3. Whether the relationship between family caregiver functional status and overall HRQOL of family caregivers were mediated by the rewards of caregiving, controlling for all other variables.

### **Purpose of Study**

The purpose of this study was to examine the relationship in which selected family caregiver characteristics (age, sex, relationship to ECR, religious activities, chronic health conditions, household income, social support), ECR characteristics (age, sex, levels of physical disability, ECRs' symptoms), length of caregiving, rewards of caregiving, caregiver tasks of care, and caregiver functional status are hypothesized to associate with HRQOL among rural Buddhist Thai family caregivers of ECRs who have one or more chronic conditions and possess at least two ADLs deficits. Furthermore, whether rewards of caregiving mediate the relationship between Thai family caregiver functional status and family caregiver HRQOL was tested.

Although many researchers attempted to define HRQOL in their studies, the wide variation in conceptual definitions still exists and challenges further research. This study was based on the Wilson and Cleary (1995) HRQOL conceptual model; HRQOL will be the ultimate outcome and will be discussed in chapter 2, along with conceptual definitions for each variable provided. In chapter 3, a review of the literature describing caregiver HRQOL, functional status, rewards of caregiving, and all caregivers' and ECRs' characteristics will be presented. Study design and methods, and planned data management and analysis will be described in chapter 4. Study findings and data interpretation will be presented in chapter 5. Nursing implication for clinical practice, future research, and policy based on this study will be discussed in chapter 6.

### Chapter 2

### **Conceptual Framework**

Originally, the concept of quality of life had its roots in classical Greek thought—the religious teaching that is concerned with an individual's personal satisfaction with life—and its academic roots in the discipline of psychology and sociology (Peterson& Bredow, 2009). Quality of life has been known as an interesting concept in multidiscipline professions, but the variety of perspectives from each discipline has caused little general agreement on defining the term.

Anderson and Burckhardt (1999) revealed the differences among philosophers concerned with the nature of human existence and with the definition of "the good life." Ethicists debate the shift in health care decision-making, while economists are concerned with the allocation of resources to achieve alternative goals. Physicians focus on health- and illness-related variables, while nurses have a holistic approach to the quality of life.

Quality of life measures are considered important in health care, and research implies that quality of life is the major focus. Wilson and Cleary (1995) indicated that HRQOL could be increasingly used as an outcome in clinical trials, effectiveness research, and research on quality of care. Moreover, Ferrans et al. (2005) and Murdaugh (1997) found that although quality of life research has increased in methodologic rigor and sophistication, progress has been hindered by the fact that the term *quality of life* has been used to mean a variety of different things, such as health status, physical functioning, symptoms, psychosocial adjustment, well-being, life satisfaction, and happiness. Thus, the term *health-related quality of life* was presented to narrow the focus of the broad quality of life to the effect of health, illness, and treatment on quality of life. Increasingly, HRQOL is used in many research areas of nursing—patient and caregiver (Blanes et al., 2007; Chatcheydang, 2005; Fang et al., 2004; Halvorsrud & Kalfoss, 2007;

Krethong, 2008; Markowitz et al., 2003; Morimoto et al., 2003; Richter, Schwarz, & Bauer, 2008; Osoba, 1994; Sandau, Lindquist, Treat-Jacobson, & Savik, 2008; Sousa, Holzemer, Henry, & Slaughter, 1999; Sprangers & Schwartz, 1999; Wang, Beyer, Gensichen, & Gerlach, 2008). In addition, the Food and Drug Administration addresses quality of life by imposing documentation on not only the safety and efficacy of new products, but also their effects on a user's quality of life (Spilker, 1996).

Wilson and Cleary (1995, p. 60) defined HRQOL as the aspects of quality of life that relate specifically to the person's health and developed a causal model to assess HRQOL consisting of five components: biological and physiological factors, symptom status, functional status, general health perception, and overall quality of life.

First, biological and physiological factors are commonly conceptualized, measured, and applied in routine clinical practice. The assessment of biological and physiological factors focuses on the function of cells, organs, and their systems—including diagnoses laboratory values, measures of physiological function, and physical examination findings. Second, symptom status focuses on a shift from specific cells and organs to the organism as a whole. It is defined as a patient's perception of an abnormal physical, emotional, or cognitive state. Symptom reports are described to be related to biological and physiological factors and as an important determinant of functioning. Third, functional status, or functioning, measures and assesses the ability of the individual to perform a particular defined task. Functioning is determined by patient-specific factors: personal ability and motivation, and many aspects of an individual's social environment. Also, functional status is measured in four domains: physical function, social function, role function, and psychological function.

Fourth, general health perceptions compose two outstanding characteristics: that they

represent an integration of all of the health concepts in earlier components, and they are, by definition, subjective ratings. This is a synthesis of all the various aspects of health in overall evaluation. Fifth, overall quality of life was characterized as subjective well-being relating to how happy or satisfied someone is with life as a whole.

In 2005, Ferrans, Zerwic, Wilbur, and Larson revised the Wilson and Cleary model of HRQOL to facilitate the use of HRQOL in nursing and health care. The revision of the model (see Figure 1) clearly indicates the elements of HRQOL; their determinants have been described explicitly, as have the theoretical grounding of characteristics of the individual and the environment. Characteristics of the individual in the revised model are categorized as demographic, developmental, psychological, and biological factors that influence health outcomes. Thus, an arrow from characteristics of the individual to biological function has been added. Biological factors include body mass index, skin color, and family history related to genetically linked disease and disease risk. Demographic factors that commonly have been linked to the incidence of illness are sex, age, marital status, and ethnicity.

Also, characteristics of the environment are categorized as either social or physical. Social environmental characteristics are the interpersonal or social influences on health outcomes, including the influence of family, friends, and health care providers. Ferrans et al. attempted to revise and clarify the model to focus on the identification of each domain, including characteristics of the individual and the environment, which was not clearly described in Wilson and Cleary's (1995) model. The revisions to the model have helped to define the scope of quality of life by making clear that the term of HRQOL refers to all of life, not just physical health status.

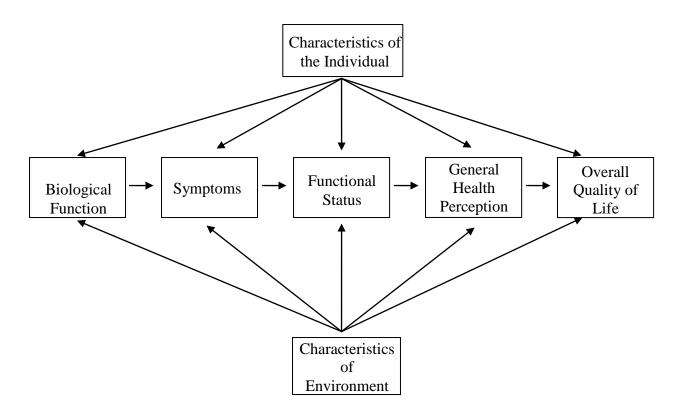


Figure 1. Revised Wilson and Cleary model for health-related quality of life. From "Conceptual Model of Health-Related Quality of Life," by C.E. Ferrans, J.J. Zerwic, J.E. Wilbur, & J.L. Larson, 2005, *Journal of Nursing Scholarship, Volume 37*(4), p. 338. Copyright by Sigma Theta Tau International. Reprinted with permission. (see Appendix E)

However, according to the Wilson and Cleary (1995, p. 62) causal model and Ferrans et al. (2005, p. 340), overall quality of life will be the ultimate outcome for this study, defined as "a multidimensional evaluation of a person's satisfaction with the areas of life that are important to him/her influenced by diverse factors in life." Wilson and Cleary identified causal relationships among the elements resulting in the overall quality of life. Similarly, Patrick and Chiang (2000) proposed the quality of life model with various individuals of internal and external concepts, but primarily used the same health elements as Wilson and Cleary's. Overall quality of life is not only affected by health-related factors but also influenced by other individual and environmental factors, including socially environmental and physically environmental characteristics, and other aspects in life. Thus, it is unavoidable for professionals to focus on overall quality of life in order

to maintain and improve patients' outcomes in all life aspects.

This study was based on a modified form of Wilson and Cleary's HRQOL theory (1995) and Ferrans et al. (2005), a causal model depicting a direct linear relationship between each of the following components: characteristics of the family caregiver (age, sex, religious, relationship to ECR, household income, and number of chronic health conditions) and the ECR (age, sex, physical disability, and symptoms related to age and diseases), which associate with how the caregiver tasks of care affect caregiver's functional status (Specific Aim 1). Simultaneously, one of the characteristics of environment, social support, is perceived by the family caregiver and directly influences the caregiver functional status. Then, family caregiver functional status—as an ability to perform their own daily activities—will be affecting family caregivers' overall quality of life, or how happy or satisfied caregivers are with their lives as a whole (Specific Aim 2). For rural Thai caregivers who believe in Buddhism, the relationship between caregiving factors—family caregiver characteristics, ECR characteristics, functional status, length of caregiving, and rewards of caregiving—and the levels of overall HRQOL of elderly rural family caregivers (Specific Aim 3) was examined, as shown in Figure 2. Buddhist beliefs and karma-based thoughts may create positive feelings from assuming the role of family caregiver, such as the rewards of caregiving. Buddhists believe that, out of a sense of obligation, children should provide good care at home for ill older Thais or parents and that karma—found in good acts, words, or thoughts—affects future lives, as everyone wishes to receive good care in return when they become older. These Buddhist beliefs can lead to a supportive attitude in Thai caregivers and may help them positively perceive the rewards in their caregiver role, influencing their performance and overall HRQOL. The following sections of this chapter will describe the conceptual schematic of this study and define concepts of each variable in the model.

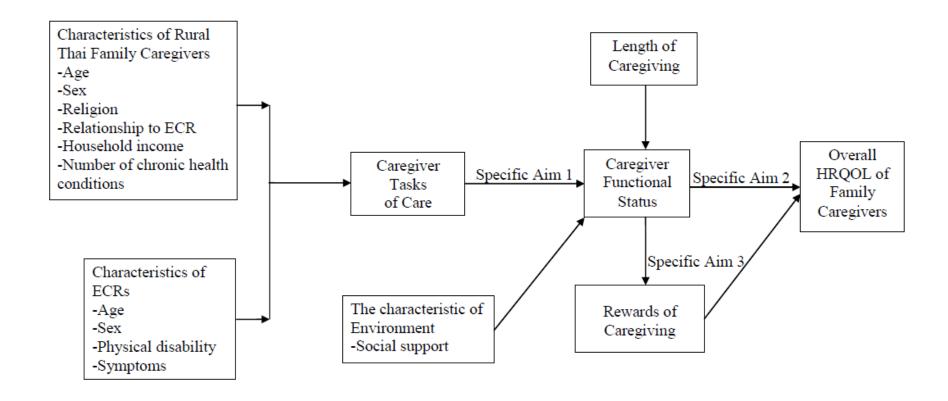


Figure 2. A modified model of the study: Caregiver health-related quality of life. From "Revised Wilson and Cleary Model for Health-Related Quality of Life," by Carol E. Ferrans, Julie J. Zerwic, Jo E. Wilbur, & Janet L. Larson, 2005, *Journal of Nursing Scholarship, Volume 37*(4), p. 338. Copyright by Sigma Theta Tau International. Adapted with permission (see Appendix E).

### **Characteristics of the Individual Caregiver**

In the modified model, characteristics of the individual were categorized as demographic, developmental, psychological, and biological factors that influence health outcomes.

Epidemiological evidence indicates links between individual characteristics and biological function by identifying attributes or behaviors that increase or decrease the likelihood of developing a given health problem (Ferrans et al., 2005). Biological factors include body mass index, skin color, and family history related to genetically linked disease and disease risk.

Demographic factors that commonly have been linked to the incidence of illness are sex, age, marital status, and ethnicity. For this study, selected characteristics were included in the model as caregivers' characteristics: age, sex, relationship to ECR, household income, number of chronic health conditions, and social support. Characteristics of the ECRs for whom those caregivers provided care are also included: age, sex and physical disability. Also, ECRs' symptoms, an essential care recipient factor for understanding the context of ECR health behavior and care needs, were included.

## **Characteristics of Rural Thai Family Caregivers**

Age. Age was conceptualized as having an effect on caregiving experiences, functional status, and HRQOL of family caregivers. The literature has been inconsistent with regard to the influence of age on family caregiver functional status (Lawang, Sunsern, & Rodjarkpai, 2005; Serrano-Aguilar, Lopez-Bastida, & Yanes-Lopez, 2006; Wongchantra, 1996). It is unclear whether or not age affects caregivers' performance during their provision of care, so age of family caregivers has been included in this study design. For this study, age was conceptually defined as the caregiver's chronological age in complete years at the time the questionnaire was administered.

**Sex**. Sex was conceptually defined as the distinction between male and female and is conceptualized as impacting caregiving experiences, functional status, and HRQOL. The sex of family caregivers was also included in this design because women are often socialized to be family caregivers and may be better prepared than men for the family caregiver role (Chaoum, Intarasombat, & Putwatana, 1996; Cheewapoonphon, 1998; Stoller, 1994).

Religious Activities. A definition for religious activity was derived from the previously used concept of religion which has been defined narrowly, focusing on personal feelings and attitudes (Heisel & Faulkner, 1982). A religious activity in this study was conceptually defined as the behaviors that reflect participation in religious activities, religious involvement, and the subject's reports of feelings of religiosity (Levin, Chatters, & Taylor, 1995; Picot et al., 1997). A religious activity resulting from Buddhist belief and karma thought, one of a caregiver's resources, may impact positive caregiving experiences. Religious activities were added in this design because it has been reported to lessen the effects of stress and heighten perceived caregiver rewards (Picot et al., 1997; Subgranon & Lund, 2000).

Relationship to ECR. Relationship to ECR was conceptualized as having an effect on caregiving experiences, functional status, and HRQOL of family caregivers and was conceptually defined as the particular type of connection existing between caregiver and ECR. Most previous research with Thai samples found that spouses are the primary family caregivers for ECRs (Cheewapoonphon, 1998; Belasco et al., 2006; Heru & Ryan, 2004). Because of their spousal role, the impact of caregiving tends to have ongoing negative effects on the health of elderly family-caregiver spouses (Pinquart & Sorensen, 2007).

**Household income.** Household income was defined as the total income of family caregivers and those living in the same place of residence and is conceptualized as having an

effect on caregiving experiences, functional status, and HRQOL of family caregivers. It has been found that caregivers with a higher household income were less likely to be affected by patient caregiving demands and more likely to have a better overall HRQOL (Ekwall, Sivberg, & Hallberg, 2004; Lawang, Sunsern, & Rodjarkpai, 2005). Caregivers with lower income levels frequently have to work harder to pay for living expenses, which may result in a decline in their functional status and health (Sasat, 2006).

Chronic health conditions. A caregiver's chronic health condition was conceptually identified as the total number of chronic health conditions that a family caregiver possesses (Chatcheydang, 2005; Pinquart & Sorensen, 2007) and is conceptualized as having an effect on caregiving experiences, functional status, and HRQOL of family caregivers. Many family caregivers experience one or more chronic illnesses, which have been shown to affect their health status (Blanes et al., 2007; Frias, Tuokko, & Rosenberg, 2005).

Caregiver tasks of care. Caregiver tasks of care were conceptually identified as the perception of time and difficulty of caregiving activities provided for the ECR during the day, at night, and on weekends, as well as on demand (Carey, Oberst, McCubbin, & Hughes, 1991; Oberst, 1990). Family involvement in care tasks depends on ECR physical disability and symptoms. Tasks of care cover those related to ADL, IADL, financial management, emotional support, and medication and symptom management (FTGRD, 2009; Girgis, Lambert, & Lecathelinais, 2011; Given, 1995; NCA, 2004; Sasat, 2006). A caregiver task of care was conceptualized as having an influence on caregiver functional status and HRQOL of family caregivers. Eighty percent of caregivers are helping with three or more IADLs and are more likely to be in fair or poor physical health (NCA, 2004; 2009; Sasat, 2006).

### **Characteristics of ECR**

Age. Age refers to the ECR's age in complete years. For this study, age of all ECRs was 60 years and older. The age of 60 is generally used in older-adult related research to define elderly samples, as the Thai government has previously used the age of 60 as a marker for reporting statistics describing older adult populations (MSDHS, 2007). Age-associated changes in physical and mental status and sensory deficits happen over time in elders (Jordhoy et al., 2007; Sasat, 2006). Thai elderly patients with chronic conditions have an appreciable decline in functioning and frequently need more help with personal ADLs (Sasat).

**Sex.** Sex was conceptually defined as the distinction between male and female. The sex of the ECRs has also been included in this design because the differences of sexes may result in differences in conditions, diseases, and overall well-being for ECRs (Sobieszczyk, Knodel, & Chayovan, 2002). Also, among Thai elder populations, there is a higher proportion of women than men with chronic disease (MSDHS, 2007).

Physical disability. Physical disability of ECR was defined as the limitation of performing ADL and is an indicator of the dependence and need of ECRs (Chatcheydang, 2005; Pinquart & Sorensen, 2007). Family caregivers must provide higher levels of care for more dependent ECRs. Physical disability is conceptualized as having an effect on the caregiving experiences, functional status, and HRQOL of family caregivers. Additional information regarding the Bathel Index (BI; Mahoney, & Barthel, 1965) measuring ECRs' physical disability will be presented in chapter 4.

ECRs' symptoms. Approximately 80% of older people live with chronic disease and experience about 3.9 symptoms per day (Lorig, 1993; Manton, Corder, & Stallard, 1997; Ory, Abeles, & Lipman, 1992). ECRs' symptoms for this study were defined as ECRs' present or

absent changes in physical, emotional, and psychological behaviors as perceived by family caregivers, including delusions, hallucinations, dysphoria, anxiety, agitation or aggression, euphoria, dis-inhibition, irritability orlability, apathy, aberrant motor activity, nighttime behavior disturbances, appetite changes and eating behaviors (Cummings et al., 1994). The ECRs' symptoms were also included in this design because the different number of symptoms may result in differences in ECR care needs, caregiver tasks of care that would associate with caregiver functional status, and HRQOL of family caregivers (Girgis et al., 2011; Osse, Vernooij-Dassen, Schade, & Grol, 2006; Pinquart & Sorensen, 2007).

#### **Characteristic of Environments**

Social support. Social support was defined as the level of support currently available to the caregiver. Social support originally included five relational dimensions: (a) provision for attachment or intimacy; (b) social integration—being an integral part of a group; (c) opportunity for nurturance behavior; (d) reassurance of worth as an individual and in role accomplishments; and (e) the availability of informational, emotional, and material assistance (Brandt & Weinert, 1981; Weinert, 1987; Weinert & Brandt, 1987). Additional information regarding the perceived social support measurement (Personal Resource Questionnaire; PRQ-85) will be presented in chapter 4. Social support is conceptualized as the caregivers' perception of supports and resources from others that may positively affect family caregivers' HRQOL by enhancing their rewards of caregiving (Chappell & Reid, 2002).

Length of caregiving. Length of caregiving was conceptually defined as the period of time in months or years that family caregivers have spent in the caregiver role for the current ECR. A longer time spent in the caregiving role was reported to be associated with negative health outcomes including physical health, burden, and depression (Pinquart & Sorensen, 2007).

Taking care of ECRs with chronic illness is a long-term care challenge for family caregivers, requiring both physical and psychological effort. Moreover, time has been reported as a significant predictor of positive well-being in instances when the time spent caregiving was more than two years, but caregivers reported less anxiety when the time spent was two years or less (Helgeson, Reynolds, & Tomich, 2006). Changes in functional status frequently occur over time in family caregivers with a chronic physical illness (Liedy, 1994) and might be associated with decreases in their overall HRQOL.

Rewards of caregiving. Rewards of caregiving were conceptually defined as levels of family caregiver's overall sense of satisfaction toward the experiences of caring for the ECR with a positive attitude during the period in which he or she performs the caregiving role (Raschick & Ingersoll-Dayton, 2004; Sasat, 2006; Stewart & Archbold, 1997), which can be measured by the Reward of Caregiving Form (Archbold & Stewart, 1986; Stewart & Archbold, 1993). Additional information regarding the Reward of Caregiving Form will be presented in chapter 4.

Caregiving for an older family member can also be a satisfying and rewarding experience, despite the possible stress imposed from managing one's life (Kramer, 1997; Davis, 2005). Buddhist beliefs toward elders of Thai caregivers may impart a sense of obligation to care for parents, and karma-based thought may create positive feelings from assuming the role of family caregiver, such as the rewards of caregiving (Sethabouppha, & Kane, 2005). The positive experience of caregiving, rewards, and relations to Buddhist beliefs might help caregivers understand and accept their roles, which may impact their ability to care for ECRs. Moreover, rewards of caregiving can be explained as the positive perceptions of caregivers, as well as the willingness to care for ECRs with chronic illness, which may impact the caregiver's desire to

perform a caregiving role.

# **Caregiver Functional Status**

The third element of the model, functional status or functioning, measures and assesses the ability of the individual to perform a particular defined task. Caregiver functional status is affected by previous elements of the caring situation for elders, including characteristics of the family caregiver and ECR, as well as characteristics of environments. Caring for older people living with chronic disease and experiencing various age- and disease-related symptoms has an impact on the caregiving tasks that caregivers perform. Caregiver functional status as an ability to perform daily activities is expected to affect caregivers' overall quality of life, or how happy or satisfied caregivers are with their lives as a whole. Functional status assessment originated in clinical rehabilitation practices for the purpose of determining caregivers' capacity to perform daily tasks in relation to expected performance and has been used in studies with chronically ill elder patient samples (Chung et al., 2010; Knight, 2000; Moons, 2004).

Functional status of family caregivers, for this study was conceptually defined as "the caregiver's ability to perform activities of daily living or the level of involvement in activities in multiple domains of function—physical, psychological, social, and role" (Acton, 1994; Wilson & Cleary, 1995, p. 61). A caregiver's functional status is affected by previous elements of the model, characteristics of the family caregiver and the ECR, and characteristics of the environment, as well as the social support. It was measured by the 12-item Short Form Survey (SF-12; Ware, Kosinski, & Keller, 1996), which will be discussed in detail more in chapter 4.

### **Overall HRQOL of Family Caregivers**

An ultimate outcome of the model, overall HRQOL was conceptually defined as subjective well-being related to how happy or satisfied someone is with life as a whole. It was an

integration of all of the concepts in earlier components of the model, and they are, by definition, subjective ratings. This was a synthesis of all the various aspects of health in an overall evaluation affected by previous components, including characteristics of family caregivers and ECRs, characteristics of environments, and caregiver functional status.

Overall HRQOL was characterized by Wilson and Cleary (1995, p. 62) as a subjective life quality related to "how happy or satisfied someone is with their life as a whole." The life domains selected by researchers have varied depending on the specific measures used in the studies. However, for this study, using both the Wilson and Cleary and Ferrans (2005) models, HRQOL dimensions were studied with Thai family caregivers and included four life domains: health, psychological or spiritual, social and economic, and family. HRQOL levels might also be influenced by various caregiving-related factors experienced in their current caring situations. Additional information regarding the HRQOL measuring by Quality of Life Index (QLI; Ferrans & Powers, 1985) will be discussed in chapter 4.

## **Summary**

The conceptual model for this study depicts a direct linear relationship among the following components: characteristics of the family caregiver (age, sex, relationship to ECR, religious activities, household income, and chronic health conditions) and the ECR (age, sex, and physical disability); characteristics of environments (social support); length of caregiving; rewards of caregiving; caregivers' functional status; and overall quality of life of caregivers. In this study, relationships between variables in each component and overall HRQOL were examined. Also, this study initially tested the mediating effect of a positive experience of care and rewards of caregiving, in the relationship of functional status and overall HRQOL. The findings showed the influence of Buddhist beliefs regarding elders in Thai family caregiver

populations.

Chapter 3 will provide a literature review as to what is known and what is unknown regarding the caregivers' HRQOL, functional status, rewards of caregiving, and other characteristics, as well as the relationship among these variables. The significance of and the need for research addressing caregivers' HRQOL will also be presented.

### Chapter 3

### **Literature Review**

The purpose of chapter 3 is to provide an overview and synthesis of the literature regarding the caregiver HRQOL, caregiver functional status, relationship between HRQOL and caregiver functional status, and influences on HRQOL of rural Thai family caregivers who are caring for elders with chronic illness. The developed conceptual schematic of the study (see Figure 3) serves as a guide for the following literature review. The model components, including characteristics of the family caregiver (age, sex, relationship to ECR, religious activities, household income, chronic health conditions), characteristics of the ECR (age, sex, physical disability, symptoms), and the characteristic of environments (social support), will be discussed as section headings. Also, other main components of the model, including caregiver tasks of care, length of caregiving, and the rewards of caregiving—which were expected to be supported by religious activities resulting from Buddhist beliefs—served as section headings.

The literature review here will begin with the ultimate outcome of this study, the HRQOL of the family caregiver, in order to specifically focus on a significant and critical caregiver health outcome. Maintaining HRQOL in the process of care is an essential component of a caregiver's psychological well-being (Chung et al., 2007; Morimoto et al., 2003), which, in turn, may affect the quality of the care provided (Riedijk et al., 2006).

Every year presents an increase in the number of elderly Thais. Most elders experience physical and psychological health problems that lead to behavioral changes and the need for help with ADLs and IADLs, as well as help managing symptoms (Chan, 2005; Sasat, 2006). Some Thai elders have been diagnosed with more than one age-related chronic condition or disease (Chan; Jordhoy et al., 2007; Moons, 2004; Plasqui, 2008). Additionally, they require a lot of

care, and because the majority of chronically ill Thai elders live with family in community dwelling areas where there is limited access to health care facilities they receive this care from family members.

## **HRQOL** of Caregiver

The impressive growth of chronically-ill elders has had a significant impact on families with ECRs and has demonstrated the negative outcomes for caregivers, including worsening physical and mental health, and an increase in caregiver burden and distress, which also relates to a decrease in mental and physical health, as well as lower HRQOL (Chatcheydang, 2005; Chung et al., 2007; Frias et al., 2005; Given & Sherwood, 2006; Jones & Peters, 1992; Morimoto et al., 2003; Northouse et al., 2002; Northouse et al., 2005; Osse et al., 2006; Pinquart & Sorensen, 2007; Subgranon, 1999; Subgranon & Lund, 2000). The impact of caregiving experiences on HRQOL may be due to factors from both sides: from the caregiver (the effect of physical exertion from providing care, negative health-related behavioral changes, and psychological distress on their own chronic conditions) and from the ECR's disabilities, symptoms, and needs (Chatcheydang; Chung et al.; Frias et al.; Morimoto et al.; Pinquart & Sorensen; Riedijk et al., 2006).

Studies in Thailand have shown that family caregivers frequently have physical difficulties from direct care dealing with ECRs' increasing impairments and behavioral problems, which impact caregivers' HRQOL (Chatcheydang, 2005; Subgranon & Lund, 2000). This chapter will also review and discuss caregiver functional status as another health outcome for caregivers during the process of care and its influence their HRQOL. Also, caregivers' functional status—as an ability to perform their own daily self-care and household activities, along with other relevant variables in relation to functional status—will be discussed to reveal

the relationship between them.

In this study, overall HRQOL was characterized by Wilson and Cleary (1995) as a subjective life-quality related to "how happy or satisfied someone is with his/her life as a whole" (p.62). The life domains selected by researchers have varied depending on the specific measures used in the studies. The domains have been characterized by Ferrans (1990) as health, psychological or spiritual, social and economic, and family. Smith, Avis, and Assmann (1999) posited that HRQOL is the subjective appraisal of one's current life based primarily on one's psychological functioning and, to a lesser degree, physical functioning. However, using both the Wilson and Cleary (1995) and Ferrans (2005) frameworks, HRQOL dimensions can be studied with Thai family caregivers by including four life domains: health, psychological or spiritual, social and economic, and family. HRQOL levels might also be influenced by various caregiving-related factors experienced in their current caring situations.

As previously mentioned, a number of elders in Thailand have been diagnosed with chronic, manageable diseases such as stroke, dementia, cancer, arthritis, congestive heart failure, diabetes mellitus, and Alzheimer's disease, because of an advance in medical therapies and technologies (Chan, 2005; Moons, 2004; MSDHS, 2007; Sasat, 2006). From such diseases, elders experience physical limitations, behavioral changes, and diseases-related symptoms and have an increased demand for long-term care from family members. Their disabilities and the severity of their symptoms could lead to an increase in the demands on their family caregivers. Responsibilities for decision-making or managing care situations, with regard to arrangements for long-term care, are often shared between the elderly and their family caregivers (McCullough et al., 1993; Chung et al., 2007; Wang, Chung, Lai, Chou, & Kao, 2004).

Taking the role of caregiver at home for chronically ill elders suffering from stroke,

cancer, diabetes mellitus, arthritis, or mental illness can place demands on one's physical and mental health (Caffrey, 1992; Chaoum et al., 1996; Frias et al, 2005; Jones & Peters, 1992; Wang et al., 2008) and result in negative consequences to the caregiver's emotional and physical health, as well as HRQOL (Barnes et al., 2006; Chatcheydang, 2005; Chung et al.; Frias et al.; Given & Sherwood, 2006; Jones & Peters; Moritomo et al., 2003; Northouse et al., 2002; Northouse et al., 2005; Osse et al., 2006; Pinquart & Sorensen, 2007; Subgranon & Lund, 2000). HRQOL of family caregivers of ECRs with chronic illness is influenced by various factors and can be impacted in different ways.

Some researchers have examined HRQOL and its influences on caregivers of elders with chronic illnesses. Chatcheydang (2005) examined a model of relationships between caregivers' characteristics and HRQOL of Thai female family caregivers of elder stroke survivors and found some negative health outcomes from providing long-term care at home, such as anxiety, stress, depression, and fatigue. Chung et al. (2007) and Wang et al. (2004) found elderly ADLs deficits, sex, marital status of caregivers, and family caregiver age to be significant predictors of HRQOL of caregivers of chronically ill elders. Moreover, there are numerous factors that can serve as either direct or indirect determinants of caregiver HRQOL, including ECR characteristics—such as number of symptoms, disability in personal care and everyday living, and severity of health conditions—types of treatments, and comorbidity. Caregiver characteristics are also factors and include relationship to ECR, education, and length of care, as well as a positive aspect: rewards of caregiving (Barnes et al., 2006; Blanes, Carmagnani, & Ferreira, 2007; Chatcheydang; Chung et al.; Kurtz et al.; Northhouse, et al., 2005; Rees, O'Boyle, & MacDonagh, 2001; Riedijk et al., 2006).

In addition, some researchers have examined caregiver-related experiences varying along

the illness trajectory and associated with caregiver HRQOL, such as the burden from tasks of care in caregivers of stroke patients, (Hughes et al., 1999; Morimoto et al., 2003), Alzheimer's disease patients (Markowitz et al., 2003; Riedijk et al., 2006; Watanabe, Araki, & Kurihara, 2003) and multiple sclerosis patients (Buchanan & Huang, 2010; Rivera-Navarro et al., 2009). These experiences require various types and amounts of assistance in caregivers (Bakas, Lewis, & Parsons, 2001; Kim & Given, 2008; Northouse et al., 2002; Northouse et al., 2005; Sammarco, 2001) and create conflict among their social roles, restrictions on activities, strain in marital and family relationships, psychological distress, and diminished physical health (Haley et al., 2003).

As shown in previous studies, caregiver HRQOL has been examined with some chronic diseases but not specifically in elders, particularly in Thai elderly populations. However, for this study, the recruited caregivers were not specifically caring for elders with only one particular chronic disease because the sample size would have been limited. The study instead focused on caregivers who were caring for elders with one or more chronic conditions and who possessed at least two ADL deficits.

In this study, HRQOL, as a subjective life-quality related to "how happy or satisfied someone is with his/her life as a whole," (p.62)—was examined using both the Wilson and Cleary (1995) and Ferrans (2005) frameworks—has dimensions including four life domains: health, psychological or spiritual, social and economic, and family. The degree to which family caregivers have an overall sense of satisfaction toward the experiences of caring for ECRs can result from various caregiving factors. One of the caregiving factors that is very important in providing care for the ECR is the caregiver's ability to perform his/her owns life tasks, or the level of involvement in the caregiver's activities, known as functional status. Taking caregiving roles may affect family caregivers' ability to perform their daily life tasks and to care for their

beloved ECRs. Caregivers' ability to perform life tasks is also expected to relate to their own HRQOL.

It has been shown that experiencing a chronic illness can affect not only the individual, but also family and friends, as above mentioned studies have shown (i.e., Chatcheydang, 2005; Chung et al., 2007; Given & Sherwood, 2006; Markowitz et al., 2003; Morimoto et al., 2003; Pinquart & Sorensen, 2007; Wang et al., 2004). An increase in chronically ill elders has increased the demand for long-term care; caregivers experience extra and unpredictable roles to assist ECRs with IADLs and ADLs, as well as to manage the ECR's symptoms, which may impact caregivers' ability to perform any other life tasks (Chan, 2005; Chatcheydang, 2005; Given, 1995; NAC, 2009; Pinquart & Sorensen).

The expanded role caring for ECRs at home can place demands on caregivers' physical and mental health (Caffrey, 1992; Chaoum, Intarasombat, & Putwatana, 1996; Frias, Tuokko, & Rosenberg, 2005) and can result in negative health outcomes for caregivers, including decreased emotional and physical health and lower HRQOL (Barnes et al., 2006; Chatcheydang; Chung et al.; Markowitz et al.; Morimoto et al.). Other studies revealed that HRQOL is influenced significantly by various variables, such as age, ECR condition, physical performance, and health behaviors (Casellas, Lopez-Vivancos, Casado, & Malagelada, 2002; Chung et al.; Kazis et al., 1998; Sullivan, Kempen, Van Sonderen, & Ormel, 2000).

Physical performance has the strongest impact on HRQOL in the physical domain (Lai et al., 2005). However, in Thailand, it remains largely unknown what most significantly influences HRQOL levels for Thai elderly caregivers (Chatcheydang; Sasat, 2006) and how caregivers' functional status influences their HRQOL. Sustaining caregiver HRQOL in the process of care is a necessary factor in a caregiver's psychological well-being, which, subsequently, may have an

effect on the quality of provided care (Chung et al.; Morimoto et al.; Subgranon & Lund, 2000).

## **Functional Status of Caregiver**

The care recipient's functional status or functional disability has been studied and shown to relate to the caregiver's health outcome, including HRQOL (e.g., Chung et al., 2007; Frias et al., 2005; Given & Sherwood, 2006; Jones & Peters, 1992; Morimoto et al., 2003; Mui, 1995; Northouse et al., 2002; Osse et al., 2006). Few investigators have studied the relationship of caregivers' functional status (Chung et al., 2010; Leidy, 1994; Newman, 1997; Spira et al., 2010). Caring for a loved one experiencing chronic diseases for an extended time challenges and disrupts family members' usual pattern of daily living (Newman; Lu & Austrom, 2005; Spira et al., 2010). Because of ECRs' symptoms, behavioral problems, and personal needs, taking on the caregiving role at home not only affects many family caregivers' health and well-being, but also increases their life tasks, limiting their participation in usual social, community, occupational, and other life activities (Chung et al., 2010; Newman). The ability to complete life tasks and other roles is considered necessary for caregivers of ECRs to provide long-term care and to meet the needs of both the ECRs and themselves. Maintaining caregiver functional status through the trajectory of the disease and the process of care is an important factor of the caregiver's physical well-being that may influence the quality of care the caregiver provides.

In this study, functional status was defined as "the person's ability to perform activities of daily living or the level of involvement in activities in multiple domains of function—physical, psychological, social, and role" (Acton, 1994; Wilson & Cleary, 1995, p. 61). The functional status assessment, originally invented in clinical rehabilitation practices for the purpose of determining caregivers' capacity to perform daily tasks in relation to expected performance, has been used in studies with chronically ill elder patient samples (Chung et al., 2007; Knight, 2000;

Liedy, 1994; Moons, 2004).

The caregiving role for chronically ill elders is often physically demanding. To maintain the caregiver's ability to provide care, it is important to identify modifiable risk factors for decline in the caregiver's functioning (Chung et al., 2007; Chung et al., 2010). The changes in the caregiver's lifestyle result in physical activity and behaviorial changes (Spira et al., 2010). While caregivers have to adapt their daily routines because of their new responsibilities—including assisting the ECR with eating, exercising, and participating in recreational activities, as well as managing their symptoms (Chung et al., 2007; Fredman et al. 2009)—they have to maintain their functioning of their own ADLs.

Moreover, caregivers' functional statuses may suffer from stress, anxiety, or strain caused by expanded and unprepared caregiving roles that result from the enduring worsened conditions of the ECRs and their behavioral problems (Caffrey, 1992; Chatcheydang, 2005; Chung et al.; William, 1994). Long-term care for ECRs with chronic illnesses, which requires a commitment of enormous energy, may lead to changes in physical functioning and/or psychological distress, which can be observed in different physical symptoms—such as sleeplessness, weight loss, headache, back pain, exhaustion, and lack of energy—and will impact caregivers' functional status and their ability to provide care for their elders (Belasco et al., 2006; Blanes et al., 2007; Bull, 1990; Krach & Brooks, 1995; Teel, et al., 2001). For instance, some researchers found that self-reported poor sleep in older adults has been linked to impairment in physical functioning and impairment in ADLs (Byles, Mishra, Harris, Nair, 2003; Motivala, Levin, Oxman, & Irwin, 2006). Spira et al. (2010) reported that the time increase in caregivers' total sleep was associated with an improvement in their physical functioning.

Functional status of the caregiver has been studied in association with various aspects of

caregiving situations, such as caregivers of patients with heart failure (Chung et al., 2010), of adult patients with memory impairment (Spira et al., 2010), and of patients with Alzheimer's disease (Lu & Austrom, 2005). Some researchers found that depressed caregivers and caregivers who spent more time and perceived difficulty in caregiving tasks had poor functional status (Chung et al.; Lu & Austrom; Spira et al.). Moreover, changes in physical performance in female caregivers were reported to associate with a high intensity (number of ADLs they performed for the care recipients) of caregiver task of care in an osteoporotic fracture sample (Fredman et al., 2009; Tong et al., 2002).

Multiple tasks of care resulting from ECRs' disabilities and symptoms, as well as dependency and needs, lead family caregivers to take more responsibilities in expanded roles, including managing everyday living, helping with personal care, and monitoring and assisting with symptoms management (Bakas et al., 2004; Bakas & Burgener, 2002; NAC, 2004; FTGRD, 2009). Such an increase in caregiving tasks may cause physical and psychological problems, as well as health behaviors. Also, monitoring and assisting with an ECR's symptoms was reported as time consuming, and physically demanding, and exhausting (Chung et al., 2010; Newman, 1997), which may increase caregiving demands and tasks of care, resulting in a possible decrease in the family caregiver's ability to provide care. Caregiver functional status is considered to be an important factor influencing a caregiver's ability to perform ADLs or the level of involvement in one's own activities, as well as the ECR's activities. There are few studies, particularly of Thai family caregivers, investigating predictors of caregiver functional status in relation to caregiver HRQOL.

## Relationships between Caregivers' HRQOL and Functional Status

HRQOL of a caregiver, interchangeably used with quality of life but similarly defined

and measured by the same instrument, has been investigated in general samples of elders (Chung et al., 2007; Jones and Peters, 1992) and in samples of elders with various specific chronic diseases, such as stroke (Chatcheydang, 2005; Morimoto et al., 2003; Subgranon & Lund, 2000), cancer (Given & Sherwood, 2006; Netchang et al., 2010; Northouse et al., 2002; Northouse et al., 2005), dementia and Alzheimer's (Arango-Lasprilla et al., 2010; Riedijk et al., 2006; Markowitz et al., 2003), heart failure (Chung et al., 2010), and multiple sclerosis (Buchanan & Huang, 2011). Authors reported and recommended that caregiver HRQOL was one of the essential components in a continuing caregiving situation, particularly in a home setting where most of the caregiving for chronically ill elders takes place (Chatcheydang; Chung et al.; Riedijk et al.; Subgranon). In addition, caregiver functional status, another caregiver health outcome indicative of a caregiver's ability to care for not only elderly relatives, but also themselves, is of concern in caregiving studies (Fredman et al., 2009; Lu & Austrom, 2005; Newman, 1997; Spira et al., 2010).

Caregiver's functional status or performance ability may be a crucial factor in accomplishing the caregiver role but has been discussed a result of long-term and physically exhausting care activities (Chung et al., 2010; Lee, Colditz, Berkman, & Kawachi, 2003; Mui, 1995; Schulz & Beach, 1999). Caregiver's functional status should be sustained in performing effective care through the trajectory of the disease and the process of care. Also, caregiver's functional status is expected to be an essential factor influencing HRQOL of the caregiver, which ultimately results in the continuous and desired care at home.

Most researchers have studied functional status as an ultimate outcome and have used it interchangeably with HRQOL because each of the concepts has lacked a clear definition (Patrick & Chiang, 2000; Siela, 2003; Wall, 2007). In this study, the functional status was explicitly

differentiated from HRQOL, and its relationships will be examined. There are no studies to date that could be found which have examined the relationship between functional status and HRQOL in Thai family caregivers of ECRs, particularly in rural settings and in the context of Buddhist beliefs. It is challenging to support Thai family caregivers of ECRs in rural areas so that they continue to provide care at home and have the optimal ability to perform care while maintaining their own HRQOL.

In this proposed study, family caregivers' functional status was measured to assess their functioning pertaining to their abilities to perform daily activities in eight domains: physical functioning, physical role functioning, bodily pain, general health, vitality, social functioning, emotional role functioning, and mental health. In addition, the association between Thai family caregivers' functional status and their overall HRQOL was systematically examined. In a study of 120 schizophrenic patients' caregivers, the rewards of caregiving and length of caregiving were suggested to influence the relationship between family caregiver functional status and overall HRQOL (Lueboonthavatchai & Lueboonthavatchai, 2006). However, whether or not the rewards of caregiving mediate the relationship of family caregiver functional status and overall HRQOL, as well as how it mediates, has not yet been examined.

The findings from this study were therefore required for the identification of the significance of the Buddhist-belief-related mediator, rewards of caregiving, enhancing overall HRQOL in rural Thai family caregivers. Moreover, the results will lead to a new religion-related model for assessing caregiving consequences and will provide guidelines for the development of culturally appropriate intervention, including religious activities, as resources for heightened caregiver rewards to enhance caregivers' functional status, further resulting in improved HRQOL. Caregiver functional status and HRQOL could be influenced by all preceding factors in

caregiving situations, including the ECR's symptoms and disability, caregiver task of care, as well as a positive aspect: namely, rewards of caregiving. All these relevant factors and their relationships will be discussed in the following sections.

## **Influences on Family Caregiver HRQOL**

## Family caregiver characteristics.

Age. Age refers to a family caregiver's age in complete years. The literature has been inconsistent with regard to the influence of age on family caregiver functional status (Lawang, Sunsern, & Rodjarkpai, 2005; Serrano-Aguilar et al., 2006; Wongchantra, 1996). Previous studies in Thailand have indicated that older family caregivers tend to consider the caring situations as something less serious and to adapt themselves to better accept the caregiving role than younger family caregivers do (Lawang et al.; Mui, 1995; Obert, et al., 1989; Sasat, 2006; Wongchantra, 1996). However, since these types of family caregivers are older, their health may more likely be affected, and they may suffer from underlying disease. Frais et al. (2005) and Serrano-Aguilar et al. (2006) found that being older related to experiencing greater health problems as family caregivers. As such, their health statuses during their provisions of care may be affected, so it is unclear whether or not age affects caregivers' performance during their provisions of care. Therefore, age of family caregivers has been included in this study design.

Sex. The sex of family caregivers was included in this design because women are often socialized to be family caregivers and may be better prepared than men for the family caregiver role (Chaoum, 1996; Cheewapoonphon, 1998; Stoller, 1994). As a result, associations between caregiving performance and health may be stronger in men than in women. Also, Mui (1995) and Ekwall et al. (2004) found that the ECR's functional impairments and the task of helping ECRs with ADL related to a worse caregiver health and HRQOL for male family caregivers, but not

female caregivers. Simultaneously, male family caregivers may be more likely to seek social support or to relinquish their family caregiver role when caregiving demands become too high (Pinquart & Sorensen, 2007). Because of inconsistent and ambiguous results, sex will be included in this study as a caregiver measure.

**Relationship to ECR.** The relationship to ECR is another relevant characteristic; most previous research with Thai samples found that spouses are the primary family caregivers for ECRs (Cheewapoonphon, 1998; Belasco et al., 2006; Heru & Ryan, 2004; Rashcick & Ingersoll-Dayton, 2004), and providing care tends to have ongoing negative effects on their health (Barnes et al., 1992; Pinquart & Sorensen, 2007; Pinquart & Sorensen, 2011). Similar to age, a spousal caregiver may report worse physical health than adult children do because they are usually older and more likely to show age-associated physical declines. Still, spouses may show a weaker relationship between family caregiver stressors and physical health of family caregivers because caregiving for a spouse is more normative than caring for other frail persons and helps positively appraise caregiving situation (Pinquart & Sorensen, 2007). Although Cantor (1983) and Barnes et al. (1992) found poorer physical health in caregiving spouses and a greater risk for health problems, Grasel (2002) demonstrated that health changes in family caregivers did not differ between spouses and adult children. Because of the likely significance of this caregiver characteristic associated with negative impact on caregivers' health changes, it will be included in this design.

Religious activities. The participation in religious activities is one of the internal characteristics available to people to manage the demands of a stressful situation (Kramer & Kipnis, 1995; Picot, 1997). The majority of Thais are Buddhist (94.5%; Wibulpolprasert, 2007). For this study, most caregivers are assumed to be Buddhist. Buddhist Beliefs described by rural

Thai family caregivers include karma, and the concepts of boon and babb, or merit and demerit, respectively (Sethabouppha & Kane, 2005; Subgranon, 1999; Subgranon & Lund, 2000).

According to Buddhist beliefs, karma means action performed with intention. Karma can be performed through three channels, including physical, verbal, and mental action. The law of karma means that good acts will lead to good consequences and bad acts will lead to bad results (Payomyong, 2000; Payutto, 1995, 1998). Thai Buddhist caregivers strongly believed that the reason they had to care for their ill family members was the result of the law of karma in their past and current lives. Some caregivers stated that, because of karma, they were repaying their elderly ill family members for being hurtful to them in the past (Subgranon & Lund, 2000).

Accordingly, most of the caregivers performed boon or good deeds for their elderly ill family members to achieve better lives in their next rebirth. Caregivers followed Buddhism in caring for their chronically ill elders (Sethabouppha & Kane; Subgranon & Lund).

A religious activity, in this study, was conceptually defined as the behaviors that reflect participation in religious activities, religious involvement, and subject reports of feelings of religiosity (Levin et al., 1995; Picot et al., 1997). The participation in religious activities, one of a caregiver's resources, may impact positive caregiving experiences. Religious activity was added in this design because it has been reported to lessen the effects of stress and heighten perceived caregiver rewards (Picot et al.; Subgranon & Lund, 2000).

Household income. Household income was defined as the total income of family caregivers and those living in the same place of residence (Chatcheydang, 2005; Pinquart & Sorensen, 2007). It has been found that those who had higher household income levels were less likely to be affected by patient caregiving demands and more likely to have a better overall HRQOL (Chatcheydang; Ekwall et al, 2004; Lawang et al., 2005; Pinquart & Sorensen).

Similarly, the investigator found that lower household income levels in an American sample ultimately correlate with caregiver HRQOL (Netchang, Corser, Given, Given, & Xie, 2010). In addition, those caregivers with greater financial stability had more opportunities to seek other things that benefit the ECR because they did not need to worry about earning their livings. Caregivers with lower income levels frequently have to work harder to pay for their daily living expenses (Chung et al. 2007; Lawang et al.). In addition, low-income family caregivers may have less interest in finding helpful information to improve their caregiving practices or to take care of their own health, which may result in a decline in their functional statuses and health (Chung et al.; Ekwall et al., 2004; Sasat, 2006).

Chronic health conditions. A caregiver's number of chronic health conditions was identified as the total number of chronic health conditions that a family caregiver possesses, such as high blood pressure, diabetes mellitus, stroke, cancer, heart disease, chronic bronchitis, low back pain, arthritis, and so forth (Chatcheydang, 2005; Pinquart & Sorensen, 2007). The number of chronic health conditions a caregiver possesses has been shown to affect the health status of the family caregiver (Cheewapoonphon, 1998; Pinquart & Sorensen).

Studies have shown that many family caregivers experience one or more chronic illnesses—such as hypertension, heart disease, low back pain, or arthritis—which have been shown to affect their health status (Blanes et al., 2007; Frias et al., 2005). Barnes et al. (2006) found that, when controlling for age, gender, and socioeconomic status, one of the significant predictors associated with caregivers' overall HRQOL is having two or more chronic health conditions. In this study, the number of chronic health conditions will be measured as objective indicators by using the number of medical and chronic illnesses, which will be counted in the total.

#### Characteristics of environments.

Social support. Social support was defined as the caregiver's level of perceived social support in regards to the current availability of functional supports, including (a) provision for attachment or intimacy; (b) social integration—being an integral part of a group; (c) opportunity for nurturance behavior; (d) reassurance of worth as an individual and in role accomplishments; and (e) the availability of informational, emotional, and material assistance (Brandt & Weinert, 1981; Weinert, 1987; Weinert & Brandt, 1987). Park and Lee (2007) and Oka, Szuba, Giacomini, and Cooke (2004) similarly found that social support is a potentially modifiable factor associated with functional status, particularly physical levels in older family caregivers. Moreover, social support may positively affect family caregivers' HRQOL by reducing their stressors, thereby enhancing their rewards of caregiving (Chappell & Reid, 2002; Cohen, Colantonio, & Vernich, 2002; Northouse et al., 2002; Picot, 1995), and helping to develop more effective forms of coping strategies, resulting in positive health behavior in relation to caregiving performance (Losada et al., 2005; Tang & Chen, 2002).

In Thailand, Lueboonthavatchai and Lueboonthavatchai (2006) found that social support was positively correlated to schizophrenic patient caregivers' HRQOL. Also, Morissey and colleagues (1990) and Uchino, Kiecolt-Glaser, and Cacioppo (1992) demonstrated that lower levels of social support were associated with worse physical functioning of family caregivers, but Mui (1995) did not find such a relationship. This study will include social support as one preceding caregiving factor, which is expected to be one of the predictors of caregivers' functional status.

#### ECR characteristics.

Age. Age refers to the ECR's age in complete years. Age-associated changes in physical

and mental status and sensory deficits happen over time in elders (Jordhoy et al., 2007; Sasat, 2006). That elderly patients with chronic conditions have an appreciable decline in functioning and frequently may need more help with personal ADLs (Choowattanapakorn, 1999; Jones & Peters, 1992). Some researchers found that an older age of the care recipient was associated with increased stress and age-related chronic diseases (Jones & Peters). However, the age of ECRs is one important variable to measure in order to classify them into different disease, severity, disability, limitation, or needs groups, which may help with studying the relationship of ECR age and family caregivers' functional status.

Sex. Sex of the ECRs was also included in this design because the differences between sexes may result in differences in conditions, diseases, and overall well-being for ECRs (Sobieszczyk, Knodel, & Chayovan, 2002). Also, among Thai elder populations, there is a higher proportion of women than men with chronic disease (MSDHS, 2007). Such evidence might further influence the dependencies and needs of ECRs that will affect caregivers' performance to meet ECRs' needs. The associations between sex of ECRs and caregiver performance or functioning are still knowledge gaps that need to be addressed.

ECR physical disability. ECR physical disability was defined as the limitation of performing ADLs and is an indicator of the dependence and need of ECRs (Chatcheydang, 2005; Pinquart & Sorensen, 2007). As ECRs experience more disabilities, family caregivers must provide higher levels of care. Some studies have demonstrated a negative relationship between levels of ECR disability and family caregiver's HRQOL (Alshubaili et al., 2008; Chatcheydang). However, Ekwall et al. (2004) proposed that family caregivers who reported that they helped with more ADLs may have better physical status. Since the relationship between ECRs' level of physical disability and caregivers' functioning remains unclear, it has been included in this study

design for substantiating its impact in predicting a caregiver's ability to perform life tasks.

ECR symptoms. Symptoms of ECRs were included in this study because the majority of older people living with chronic disease experienced about 3.9 symptoms per day (Lorig, 1993; Manton et al., 1997). ECRs' symptoms experiences are the most important determinants of the needs of care provided by family caregivers, resulting in caregiver tasks of care. Chronically ill elders who have been discharged from the hospital still have some disabilities (Lausawatchaikul, 2001; Lawang et al., 2005; Periard & Ames, 1993; Sasat, 2006) and need regular care for IADLs, ADLs, and age- and disease-related symptoms, including hearing loss, vision impairment, weakness, pain, fatigue, nausea, vomiting, insomnia, difficulty breathing, diarrhea, coordination problems, poor appetite, fever, cough, dry mouth, constipation, mouth sores, bed sores, inability to concentrate, and so forth (Chung et al., 2007; NAC, 2004; FTGRD, 2009).

The symptoms of ECRs with chronic diseases are associated with the number of caregiver tasks of care (Nijboer et al., 2000; Pinquart & Sorensen, 2003) and the degree of assistance required from the caregiver (Given & Sherwood, 2006). In turn, the caregiver's level of involvement in providing care has been associated with the functional status of the caregiver (Chung et al., 2010; Fredman et al., 2009). The ECRs' symptoms have been included in this study model to determine their effect on caregivers' functional status.

Length of caregiving. Length of caregiving refers to the period of time in months or years that a family caregiver has spent in the caregiver role. Changes in functional status frequently occur over time in family caregivers with chronic physical illnesses (Liedy, 1994) and might be associated with decreases in their overall HRQOL. Similar to Mui's (1995) study, the number of months of caregiving was correlated with decreased family caregiver health for women (Sasat, 2006). Alshubaili et al. (2008) have proposed that the available national welfare

supports in Thailand were not sufficient to lift HRQOL levels of family caregivers caring for patients with longstanding chronic illnesses because of the disproportions of elderly populations and the budget limitations.

Some studies have demonstrated that changes in caregiving over time are not only caused by the ECR's continued aging but also affected by the trajectory of chronic illnesses (Leidy). On the other hand, the longer family caregivers provide care, the more caregiving skills they may attain (Choowattanapakorn, 1999; Sasat, 2006). Family caregivers might have positive or negative feelings about caregiving that influence whether or not they are satisfied with their functional statuses and HRQOL (Mui; Pinquart & Sorensen, 2007). The effect of length or duration of caregiving on functional status is still questioned and has been included in this study design to answer the research questions.

Caregiver tasks of care. Caregiver tasks of care for elders were defined as care activities that often involve many aspects of care, dealing with the physical and psychological needs of an elder patient (Bakas et al., 2001; Chung et al., 2007; Jones & Peters, 1992; Oberst, Thomas, Gass, Ward, 1989; Sasat, 2006). Caregiver tasks of care included (a) managing IADLs; (b) helping with ADLs; and (c) monitoring and assisting with the ECR's symptoms experiences, which can be challenging for family caregivers in home care situations (Given & Sherwood, 2006). Multiple caregiver tasks of care may result in decreased care ability of the family caregiver (Bakas et al.; Caffrey, 1992; Chung et al.; Fredman et al., 2009; Oberst et al.). Moreover, the number and difficulty of caregiving tasks have been reported to be associated with caregiver burden in caregivers of patients with lung cancer (Bakas et al.; Chaoum et al., 1996) and were one of the predictors of family caregivers' HRQOL of chronically ill elderly (Chatcheydang, 2005; Chung et al.). Caregiver tasks of care has been included in this study to

examine whether or not multiple tasks of care will predict the caregiver's ability to perform his or her life tasks.

**Rewards of caregiving.** Rewards of caregiving refer to levels of the family caregivers' overall sense of satisfaction associated with performing their caregiving roles (Raschick & Ingersoll-Dayton, 2004; Sasat, 2006; Stewart & Archbold, 1997). Much of the earlier research on family caregivers has focused on the negative consequences of caregiving (e.g., Morimoto et al., 2003; Frias et al., 2005; Chatcheydang, 2005). However, caregiving for an older family member can also be a satisfying and rewarding experience, despite the possible stress imposed from managing one's life (Davis, 2005; Kramer, 1997; Picot, 1995; Raschick & Ingersoll-Dayton). Buddhist beliefs toward elders of Thai caregivers may impart a sense of obligation for them to care for parents, and karma-based thought may create positive feelings from assuming the role of family caregiver, such as the rewards of caregiving (Choowattanapakorn, 1999; Sasat, 2006; Sethabouppha, & Kane, 2005). Similarly, Heru and Ryan (2004), Donprapeng (2006), and Kasemkitwattana (2006) proposed that a caregiver's warm and supportive attitude toward his or her care recipient can sometimes help to cope with the caregiver role, which influences the caregiver's performance and overall HRQOL. This measure, therefore, will be a key in this study to investigate its effect on caregivers' functional status and HRQOL in Thai populations and whether or not rewards of caregiving can moderate or mediate the relationship between those two main caregiver outcomes: functional status and HRQOL.

#### **Summary**

Because of an increase in the number of elderly Thais with chronic, manageable illnesses, more elderly Thais require assistance at home to care for age-related physical and mental problems. Recently, more family members have been required to assume daily caregiver roles

for elderly relatives, particularly in rural areas (Chatcheydang, 2005; Subgranon, 1999). The majority of family members in rural Thailand believe in Buddhism—that older family members should receive obedience from the younger family members, parents should receive good care at home, and kids have a sense of obligation to provide care—leading most Thais to refuse to let elders or parents move into institutions. Buddhist beliefs have helped caregivers easily accept caregiving situations and the caregiver role. Also, Buddhist beliefs have facilitated caregivers to positively interpret and perceive the caring situation as rewards. These domains of benefit finding in elder caregiving have been perceived by caregivers, and they are expected to be associated with the caregivers' ability to perform care and their overall HROOL.

HRQOL measures have been developed to assess aspects of a family caregiver's subjective experience relating to health, disease, disability, and impairment. It is especially important for nursing researchers to more rigorously examine the relationship of family caregivers' functional status to their HRQOL. As an ability of the caregiver to functionally perform in daily life and to care for ECRs, functional status will be considered a very important influence in fulfilling a caregiver role. In this study, the HRQOL of elderly Thai family caregivers in rural settings was more rigorously explored to gain knowledge on how functional status might affect their HRQOL. This study also examined how other family caregiver and ECR factors are associated with HRQOL or functional status to fill the knowledge gap concerning the most culturally appropriate interventions for rural Thai family caregivers to enhance effectiveness and quality of their care for ECRs.

Even though Buddhist beliefs about elders in Thai family caregivers may create positive feelings in the caregiver from assuming this role, other family caregiver characteristics should be examined, such as age, sex, relationship to ECR, social support, and characteristics of ECRs. The

results of the study will examine the relationship among those caregivers' clinical outcomes, functional status, and HRQOL which will further affect the continuum of caring for elders at home. In addition, results will be particularly innovative in understanding how relevant caregiving variables impact caregivers' HRQOL in a rural, non-Western context.

Furthermore, the results of this study can be used to guide the future research trajectory of caregiving for ECRs in the rural Buddhist context. The results also revealed the association of caregivers' participation in religious activities and their perceptions of rewards. Such results will help create a new religion-related model of assessing caregiving consequences and provide guidelines for the development of appropriate religious intervention to enhance caregivers' ability to perform care for ECRs and themselves, which will impact on their HRQOL.

### Chapter 4

#### Methods

The purpose of chapter 4 is to present the methodology of the study. First, the design, subjects, and settings of the study are introduced. Then, the study's instrument operational definitions and measurement of variables (see Appendices A and B for Study Instruments) are presented. Finally, the proposed procedure of data collection, power and data analysis plan, data management, protection of human subjects and inclusion of women are described.

### **Research Design**

The cross-sectional, descriptive study was conducted from October 2011 to January 2012 by the investigator at two primary care units (PCUs) in two rural districts in the Uttaradit province of northern Thailand. The two selected PCUs were responsible for all aspects of population health in the small villages of each district. In every province of Thailand, the standard was one PCU per district, which typically houses the club for elders. The club's members participate in activities provided by staff nurses and health care professionals once or twice each month.

Purpose of the study. The purpose of this study was to examine which selected variables—family caregiver characteristics (age, sex, religious activities, relationship to ECR, chronic health conditions, household income, and social support), ECR characteristics (age, sex, levels of physical disability, and ECRs' symptoms), length of caregiving, rewards of caregiving, caregiver tasks of care, and family caregiver functional status—significantly influence the HRQOL levels of rural Buddhist Thai family caregivers caring for ECRs with one or more chronic conditions and at least two ADL deficits.

**Problem statement.** That family caregivers frequently have physical difficulties from

direct care dealing with chronically ill ECRs' impairments and behavioral problems (Chatcheydang, 2005). Assistance provided to elders with chronic diseases includes managing IADLs, helping with ADLs, and monitoring age- and disease-related symptoms, any of which may have a direct influence on the caregivers' ability to care for elders and for themselves. Caregivers' functional status as an ability to perform their own daily self-care and household activities will be considered an important variable in the caregiving role that may influence their HRQOL and the continuation of the caregiving role at home. This study examined the following research questions: What is the relationship between caregivers' functional status and the HRQOL of rural Thai family caregivers caring for chronically ill elders? Will the rewards of caregiving exert a mediating effect on the relationship between rural family caregiver functional status and overall caregiver HRQOL?

For the proposed study, the researcher hypothesized that Thai family caregivers, who care for ECRs with physical disabilities, tend to have problems with caregiver functional status because of the degrees of the ECRs' disabilities, their age- and disease-related symptoms, and increases in caregiver tasks of care. This was one of the first studies to explore those relevant caregiving aspects to specifically understand caregivers' functional status and HRQOL. The results will demonstrate the relationship among those caregivers' clinical outcomes affecting functional status and HRQOL, which will further affect the sustainability of caring for elders in the community.

#### **Subjects**

Sample respondents were community-dwelling, primary family caregivers of ECRs who had one or more chronic conditions (e.g., stroke, hypertension, osteoarthritis, Alzheimer's disease, and dementia) and have needed assistance for two or more ADLs at home for at least

three months. Family caregivers were unpaid for caring for an ECR, which is defined as a family member, such as a husband, wife, father, mother, son or daughter, sister or brother, and so forth.

All family caregivers taking care of chronically ill ECRs at home who met the inclusion criteria were invited to enroll in the study.

According to the G\*power for correlation and regression analyses and HRQOL outcome, a total of 201 family caregivers were recruited through purposive sampling using the study inclusion criteria. This minimal sample size of subjects provided an acceptable .80 power analysis of medium effect size and an alpha level of significance of .05 (Buchner, Erdfelder, & Faul, 1997; Faul et al., 2009; Walters et al., 2001).

The inclusion criteria for family caregiver eligibility included (a) being 18 years of age or older and living in rural area, (b) caring for a chronically ill ECR 60 years of age or older for at least three months, (c) acting as a primary caregiver at home and without pay for an ECR who has two or more ADL deficits, (d) being fluent in the Thai language, and (e) being Buddhist. The exclusion criteria included (a) being less than 18 years of age, (b) caring for elderly patients less than 60 years of age, (c) being paid to care for a chronically ill ECR, and (d) not living in the rural area (living in the municipal area).

# **Settings**

Family caregivers in the study were recruited by the investigator from two PCUs in rural regions of Northern Thailand. At each PCU, one elderly club provided monthly health-related activities for elderly members. There, older people had access to ongoing support from the staff of the PCU and engage in a wide-range of activities, such as praying, meditation, exercise, card games, other recreational activities, and health examinations. The two PCUs in this study were responsible for providing health care to residents of small villages where there is limited access

to health care facilities. Elders undergoing health examinations at the PCU were asked by the club staff if they are cared for by someone at home. Also, the caregivers accompanied the elders to the club were questioned by the PCU health professionals using the inclusion criteria for recruitment.

### **Sample Size**

The required sample size was calculated based on G\*power tests for correlation and regression analyses (Faul, Erdfelder, Bucher, & Lang, 2009). The choice of the sample size formulae depended on the way data will be analyzed, which, in turn, depended on specific characteristics of the data analyzed (Walters, 2004). Sample size was critically dependent on the purpose of the study, the outcome measure and how it is summarized, and the method of calculating the test statistic (Machin, Campbell, Favers, & Pinol, 1997; Walters, Campbell, & Lall, 2001).

Thus, according to the G\*power for correlation and regression analyses and HRQOL outcome, a minimal sample size of at least 150 subjects would provide an acceptable .80 power analysis of medium effect size, with 15 predictors and an alpha level of significance of .05 (Buchner et al., 1997; Faul et al., 2009; Walters et al., 2001).

#### **Instruments**

Sociodemographic and clinical characteristics. Socio-demographic and clinical characteristics were collected on the Thai study questionnaire developed by the investigator, as well as from self-reported information on family caregivers' characteristics: age in years, sex as male and female, participation in religious activities—including the religion caregivers believe in and activities they participated in, such as praying, meditating, offering food to monks, going to the temple, and so forth.—relationship to ECR as the types of connections existing between

caregiver and ECR, household income as the total monthly income of the family caregiver, and the chronic health conditions as the types and total number of the conditions that the family caregiver possesses. Also, ECRs' characteristics—age in years and sex as male and female—were reported by the family caregivers. Length of caregiving or duration of assuming a family caregiver role was measured using a question concerning the number of complete years as a family caregiver.

Religious activities. Religion is the participation in religious-related activities—including the activities they participated in, such as praying, meditating, offering food to monks, going to the temple, donating to others, and doing other good things for themselves and others as reported in previous religiosity-related literatures (Levin, Chatters, & Taylor, 1995; Picot et al., 1997). Religious activity was measured using the religious activity grid to rate how often caregivers do participate in those religious activities. Frequency scores were evaluated for each activity on 5-point Likert-type scales, where caregivers selected 0 (not at all), 1 (less than once a month), 2 (once a month), 3 (once a week), or 4 (once a day). Responses to the religious activity grid were summed such that high scores indicated a greater frequency of participating religious activities. Participation in religious activities, one of a caregiver's resources, may impact positive caregiving experiences and has been reported to lessen the effects of stress and heighten perceived caregiver rewards (Picot et al.; Subgranon & Lund, 2000).

All of the following instruments were used in many previous studies and were shown to be reliable and acceptable psychometric characteristics as shown in Table 1.

*HRQOL*. Overall HRQOL was measured using the Thai translation of Quality of Life Index (QLI; Ferrans, 2009; Petchprapai, 2007). The QLI was developed by Ferrans and Powers to measure quality of life in terms of a person's overall satisfaction with life (1985). The QLI

measures both satisfaction and importance regarding various aspects of life. The instrument consists of two parts: The first measured satisfaction with various aspects of life, and the second measures the importance of those same aspects. Scores were calculated for overall quality of life in total and in four domains: health, psychological, social and economic, and family (Ferrans, 1996; Ferrans & Powers; Ferrans, 1990).

The total score came from the 33 items which each rated on a 6-point Likert-type scale. Scores were calculated for HRQOL overall and in four domains: health and functioning, psychological and spiritual, social and economic, and family (Ferrans, 1996; Ferrans & Powers, 1985; Ferrans, 1990). The total score of the QLI ranged from 0 to30; a higher score indicating a better HRQOL. The instrument also had undergone formal psychometric testing for convergent and divergent validity, test–retest reliability, and internal consistency. Test–retest reliability of the measure is 0.87 with a 2-week interval and 0.81 with a 1-month interval and internal consistency, as measured by Cronbach's alpha, ranging from 0.73 to 0.99 (Ferrans & Powers, 1998; Katsuno, 2003) and 0.94 for the Thai version (Petchprapai, 2007).

Functional status. Caregiver functional status was measured using the 12-item Short Form Survey (SF-12). The SF-12 (Ware, Kosinski, & Keller, 1996), derived from the Thaitranslated version of SF-36, had been demonstrated to be reliable and valid in clinical and population-based applications (Hoffmann, 2005; Larson, 2002; Lim & Fisher, 1999; Lundberg, Johannesson, Isacson, & Borgquist, 1999). To reduce the respondent burden and the time needed for questionnaire administration, a short questionnaire had been used consisting of a single instrument of 12 items and has been tested within both adult and adolescent groups (McHorney, Ware, & Raczek, 1993; Nelson et al., 1994; Ware et al., 1995; Ware et al., 1996; Wasson et al., 1994). The SF-12 survey contained 12 categorical questions that assess ability in performing activities as a result of physical and emotional health and 3-, 5-, and 6-point Likert response

formats that assess limitations in physical activity and physical role functioning, pain, overall health, mental health, vitality, and social functioning. Higher total scores indicate better functioning status of caregivers.

All 12 items were used to calculate the physical- and mental-component summary scores and total scores by applying a scoring algorithm empirically derived from the data of a U.S. general population survey (Ware et al., 1995). Performance of the component summary scores had been studied in nine languages, and it has been recommended that the U.S.-derived summary scores, which yield a mean of 50 and a standard deviation of 10, be used in order to facilitate cross-cultural comparison of results (Chariyalertsak, Sirisanthana, Saengwonloey, & Nelson, 2001; Chariyalertsak et al., 2011; Gandek et al., 1998; Kontodimopoulos, Pappa, Niakas, & Tountas, 2007). Test-retest reliability coefficients greater than 0.70 were demonstrated (Resnick & Parker, 2001). Validity, discriminatory power, correlation with other measures, construct, and criterion had been rated as good (Larson et al., 2008; Lundberg et al.; Sanderson et al., 2001). The sensitivity to change was reported as adequate (Luo et al., 2001; Muller-Nordhorn et al., 2003). Similar to previous studies and some references to HRQOL measured by SF-36, a recent study by the investigator has indicated acceptable psychometric properties of the measure (Netchang et al., 2010). Moreover, many studies reported that the SF-12 summary measure replicates well the SF-36 summary measure and shows similar responsiveness to changes over time (Chariyalertsak et al. 2011; Lam et al., 2005; Larson; Muller-Nordhorn et al.; Wee, Davis, & Hamel, 2008).

Caregiver tasks of care. Caregiver tasks of care were measured by the Oberst Caregiving Burden Scale (OCBS; Carey, Oberst, McCubbin, & Hughes, 1991; Oberst, 1990; Oberst, Thomas, Gass, & Ward, 1989), assessing caregivers' perceptions of time and of difficulty

associated with tasks they performed in caring for their family members (Bakas et al., 2004; Carey et al., 1991). Among others, such tasks included providing personal care, assisting with medications, monitoring symptoms, managing the patient's emotions and behaviors, dealing with finances, and talking with health professionals. The time items on the OCBS were each rated on a 5-point scale ranging from 1 (*none*) to 5 (*a great amount*), and the difficulty items are rated on a 5-point scale ranging from 1 (*not difficult*) to 5 (*extremely difficult*). Total scores were separately generated for time and for difficulty, which range from 15 to75; higher scores represent more perceived time spent or more difficulty with tasks. The 15-item OCBS, as well as the Thai-translated version, has shown evidence of internal consistency reliability, unidimensionality, and content and construct validity in cancer, stroke, and heart failure caregivers (Bakas et al., 2004; Bakas & Champion, 1999; Boonluk, 2005; Carey et al., 1991; Chung et al., 2010; Oberst, 1990).

Social support. The social support questionnaire, Personal Resource Questionnaire 85 part II (PRQ85-II), was used for measuring social support. This instrument was developed by Brandt and Weinert (1981) and was modified and translated into Thai by Puttapitukpol (2001). The PRQ85-II is a 25-item questionnaire that measures the respondent's level of perceived social support (Brandt & Weinert; Weinert & Brandt, 1987). It includes five dimensions: intimacy, social integration, nurturance, worth, and assistance. These items each use a 7-point Likert rating scale, ranging from 1 (strongly disagree) to 7 (strongly agree) for positive statements, and from 7 (strongly disagree) to 1(strongly agree) for negative statements. The composite PRQ85-II score ranges from 25–175. The total scores were generated for this study; higher scores indicate higher levels of social support. The internal consistency of the Thaitranslated version was tested by Cronbach's alpha coefficient and was found to be good at 0.84

with the test-retest reliability shown to be 0.84 (Sreshthaputra, Sreshthaputra, & Vutyavanich, 2008; Tangkawanich, Yunibhand, Thanasilp, & Magilvy, 2008).

Rewards of caregiving. The rewards of caregiving were measured by the Thai-translated version of Archbold and Stewart's (1986, 1993) Rewards of Caregiving Form, which consisted of 27 items including five aspects: reward of meaning, reward of learning, financial reward, spiritual reward, and being there for the patient. This measure quantified levels of family caregivers' overall perceptions of reward from caring for the ECRs during the caring period.

Each statement has a 5-point Likert scale response, ranging from 0 (not at all) to 4 (a great deal). Responses to the Thai-translated version were summed such that high scores indicate a greater perceived reward of caregiving, with a range of 0 to 108 (Donprapeng, 2006; Kopachon, 2002; Plaipetch, 2002). The overall Cronbach's alpha of rewards of caregiving in previous studies ranged from 0.77 to 0.94 (Archbold et al., 1995) and, it has been reported, in Thai studies ranged from 0.80 to 0.93 (Chatcheydang, 2005; Donprapeng; Kopachon; Plaipetch; Subgranon & Lund, 2000).

ECR physical disability. The physical disability of the ECR was measured by the family caregivers using the Barthel Index (BI; Mahoney, & Barthel, 1965). The BI was developed as a measure to assess disability in patients and has been recommended by the Royal College of Physicians for routine use in the assessment of older people (Sainsbury et al., 2005). The index was an ordinal scale comprising of 10 ADLs: transferring, walking, stairs, toilet use, dressing, feeding, bladder, bowel, grooming, and bathing. The scores range from 0 to 100; the healthy score is 100, and lower scores indicate greater disability. Interrater reliability was reported as high percentage agreement (> 0.70) for the total score. The reliability of the Thai version of the BI has been investigated in the major clinical settings relevant to older people and has been

found to be reliable (> 0.80; Senanarong, et al., 2003).

*ECR symptom.* The symptom of the ECR was measured by the Memorial Symptom Assessment Scale (MSAS:Portenoy et al., 1994). The MSAS was originally developed to provide multidimensional information about a diverse group of common symptoms and first tested in the cancer population. The MSAS consisted of subscales that describe (a) psychological symptom distress (PSYCH), which includes feeling sad, worrying, feeling irritable, feeling nervous, difficulty sleeping, and difficulty concentrating; (b) physical symptom distress (PHYS), which includes lack of appetite, lack of energy, pain, feeling drowsy, constipation, dry mouth, nausea, vomiting, change in taste, weight loss, feeling bloated, and dizziness; and (c) global symptom distress (Global Distress Index; GDI). The GDI included the frequency scores for feeling sad, worrying, feeling irritable, and feeling nervous, and it includes the distress scores for lack of appetite, lack of energy, pain, feeling drowsy, constipation, and dry mouth. Severity, frequency, and distress were evaluated for 24 symptoms, along with severity and distress for eight symptoms, on 4- and 5-point Likert-type scales. Higher scores indicated more severity, greater frequency, and higher distress. The scores range from 0 -128, with a score of zero indicating the caregiver did not perceive that the ECR experienced the symptom in the past four weeks. All reporting of symptoms was completed by caregivers, the individual symptom score was the average of all the completed dimensions. The total MSAS score is the average of the scores for all 32 symptoms. The scoring of the MSAS also yields three subscales.

Internal consistency was found to be moderate to high (0.58 - 0.88; Portenoy et al., 1994). The MSAS was tested to determine whether or not it could serve as a feasible, reliable, and valid tool for use in assessing family caregivers on the symptoms experiences of advanced cancer patients. The author found that the internal consistency was high in the PHYS ( $\alpha = 0.84$ ),

PSYCH ( $\alpha$  = 0.82), and GDI ( $\alpha$  = 0.84) subscales (Lobchuk, 2003). The Thai-translated version of MSAS was reported as high (0.78 - 0.91) in cancer patients (Malangpoothong et al., 2009; Sumdaengrit, 2008; Suwisith, 2007).

#### **Procedure for Data Collection**

The rights of the caregiver subjects enrolled in this study were respected by the investigator throughout the study period through various measures. Also, the study was guided by principles of the Health Insurance Portability and Accountability Act (HIPAA) of 1996 (HIPAA, 1996). After the Institutional Review Boards (IRB) of Michigan State University (MSU) approved the study (see Appendix D for IRB Approval Letter), the investigator contacted the PCU directors, who had already completed training in research ethics and human rights. The investigator explained the objectives and procedures of the study to the PCU nurses and asked for their assistance in identifying eligible family caregivers. Each of the PCUs provided a letter of approval allowing the investigator to conduct the study at the facility. Then, information was gathered using the following steps (see Figure 3):

- 1. Screening for eligible subjects was first completed by the club staff nurses at the PCUs based on the specified inclusion criteria. The ECRs had been diagnosed for their conditions and diseases by the specialists at Uttaradit hospital once they were admitted to or visited the emergency department.
- 2. All eligible subjects were approached by the investigator after they asked to obtain more information about the study. Eligible subjects were asked to provide their informed consent (see Appendix C for Study Consent Form) after the investigator had explained the study objectives, the data collection processes, and the subject's right to not participate in the study.
  - 3. Separate from the ECRs, the investigator asked consented family caregivers to

complete a questionnaire at the elderly club in approximately 45 to 60 minutes. The investigator read the questionnaires for those family caregivers who requested assistance or reported having difficulty completing the questionnaires.

Figure 3 shows the sequence that was used for collecting data. This study was conducted by the investigator at the PCUs and elderly clubs in two rural districts in the Uttaradit province of Northern Thailand. Eligible family caregivers were first identified by the club staff, who searched census registration lists and patient records. At the PCUs, participants attending health examinations and elderly club activities were asked by club staff whether they are care for elders in need of assistance for two or more ADLs. A total of 127 family caregivers were recruited from the initial contact at PCUs, and a total of 74 family caregivers were recruited from census searching. The investigator approached family caregivers at the PCU who agreed to receive more information on the study. Participants who were not caring for an elderly family member at home or did not intend to participate in the study were thanked for answering before they left. Few family caregivers refused participation in this study because their elders needed no help with two or more ADLs. Family caregivers who agreed to talk with the investigator were provided information about the study objectives, along with a copy of the informed consent form.

After consent was obtained by the investigator, the investigator administered the translated questionnaires (see Appendix A) to family caregivers at the elderly clubs. Using the study questionnaire, the investigator collected study data from enrolled family caregivers regarding all study variables: family caregiver and ECR sociodemographic and clinical characteristics, length of caregiving, caregiver tasks of care, rewards of caregiving, family caregiver functional status, and overall HRQOL.

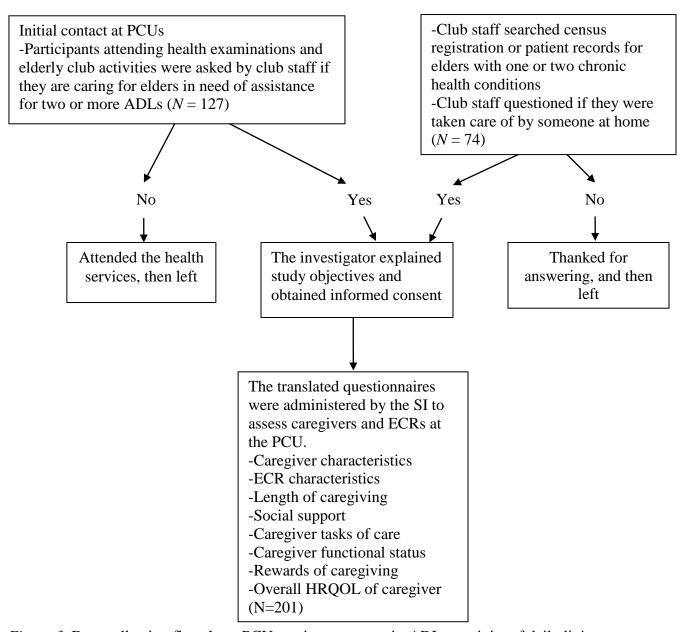


Figure 3. Data collection flowchart. PCU = primary care unit; ADL = activity of daily living; ECR = elderly care recipient; HRQOL = health related quality of life.

## **Plan for Data Management**

A total of 201 family caregivers were asked to complete a questionnaire by the SI at the PCU, and the SI read the questionnaires for those family caregivers who requested assistance or report having difficulty completing the questionnaires. The questionnaires included family caregivers' and ECRs' sociodemographic and clinical characteristics, QLI, SF-12, PRQ85-II, BI,

MSAS, OCBS, and rewards of caregiving. All completed study questionnaires were kept confidentially by the investigator and housed separately from the signed consent form. The data were entered daily by only the investigator using the Predictive Analytics Software 18 (PASW 18.0) in the SI's personal computer and saved in a password-protected file. A codebook was developed that linked the study variables to variable names in PASW.

The codebook was used as a guide for entering, cleaning, checking, and analyzing all the data. The questionnaires were coded anonymously by a designated study ID number, which corresponded with the subject ID variable in the PASW data set. Missing data were to be carefully coded and managed to prevent an analysis error as planned, but there were no missing data because the investigator was at the PCU to answer all the questions the caregivers asked when experiencing problems completing the study questionnaire. Also, every questionnaire was carefully checked right after the caregiver returned it to the investigator. The investigator asked the caregiver to review and complete the questionnaire if there were any incomplete items. Random checks were made to ensure that data was entered completely and correctly by the investigator.

Only the investigator, major professor, and study statistician were allowed to access the information. All study questionnaires were stored in a locked cabinet at the investigator's office in Thailand or at West Fee Hall on MSU's campus, and the electronic data were kept in a password-protected file on the investigator's personal computer. The investigator's personal computer had a backup file system to restore data, had any problems arisen with the hard drive, and the data were kept separately in a password-protected external hard drive. Because the electronic data were kept in the investigator's personal computer and external hard drive, the personal computer and the external hard drive were carried in a backpack kept by the

investigator's side when traveling internationally.

## **Plan for Data Analysis**

Data from all participants were analyzed by the investigator using the PASW 18.0 Statistic for Windows (IBM SPSS Statistics, 2010). The specific analysis plan for each aim is outlined in the following section.

Descriptive statistics were calculated for the categorical variables of sociodemographic and clinical characteristics of family caregivers and ECRs, including frequencies and percentages. The mean, range, and standard deviation of the continuous variables' scores for family caregivers and ECR sociodemographic and clinical characteristics, length of caregiving, caregiver tasks of care, rewards of caregiving, family caregiver functional status, and overall HRQOL of family caregivers were computed.

A series of Pearson's product moment correlation procedures was used to explore relationships between family caregiver and ECR characteristics, as well as other selected caregiving-related variables for rural Thai family caregiver functional status (Specific Aim 1). Correlation tests of the associations among study variables were executed by setting the significance level at .05.

Multiple regression procedures were used to examine the relationships between family caregiver and ECR characteristics, length of caregiving, caregiver tasks of care, rewards of caregiving, family caregiver functional status, and overall HRQOL of family caregivers (Specific Aims 2 and 3), setting the significance level at .05 (Tabachnick, & Fidell, 2007; see Figure 3). Analyses to determine the mediating effect of the rewards of caregiving on the relationship between family caregiver functional status and HRQOL of family caregiver were based on the principles published by Baron and Kenny (1986). To test a potential mediating effect of rewards

of caregiving on the relationship between caregiver functional status and HRQOL, three regression equations were performed, controlling for other family caregiver and ECR characteristics. The three regression equations were (a) caregiver functional status as a significant predictor of rewards of caregiving, (b) caregiver functional status as a significant predictor of overall HRQOL, and (c) caregiver functional status and rewards of caregiving entered simultaneously with the overall HRQOL.

Hypotheses of the study were that:

- 1. That the limitation of rural family caregivers' functional status would have a negative influence on their overall HRQOL.
- 2. That the rewards of caregiving would exert a mediating effect on the relationship between rural family caregivers' functional status and caregivers' overall HRQOL.

# **Human Subjects Protection**

The rights of the caregiver subjects who were enrolled in this study were respected by the investigator throughout the study period. Also, the study was guided by principles of HIPAA of 1996 (HIPAA, 1996). After the study had been approved by the IRB of MSU and the PCUs, the investigator contacted the PCUs' nurse director and department heads who had already completed training in research ethics and the protection of human subjects. The investigator explained the objectives and procedures of the study to four PCU nurses and asked for their assistance in identifying eligible family caregivers. Eligible family caregivers were first identified by the club staff, who searched census registration lists and patient records. The investigator approached family caregivers at the PCU who had agreed to receive more information about the study. Only the investigator enrolled family caregivers.

Family caregivers who agreed to talk with the investigator were informed of the study via

an information sheet and were provided with a consent form. The consent form included information about the study, study objectives, rights of participants, and contact information for the investigator and IRB. A consent form and an information sheet were translated and back translated by a PhD-educated translator in Thailand to ensure that the study materials were equivalent in Thai and English. Family caregivers read and signed the consent form prior to answering the questionnaires. If family caregivers were unable to read, the investigator is applied for a waiver of documentation of written consent to the MSU IRB.

After consent was obtained by the investigator, the investigator administered translated questionnaires—QLI, SF-12, PRQ85-II, BI, MSAS, OCBS, and rewards of caregiving—to family caregivers at the PCUs or their homes. They had the right to stop participating in the study at any time. No study data were collected before IRB and PCU permission approval.

Participants were asked to complete the study questionnaire, which contained no identifiers, such as names or phone numbers. Data–including family caregivers' and ECRs' sociodemographic and clinical characteristics, QLI, SF-12, PRQ85-II, BI, MSAS, OCBS, and rewards of caregiving–then were entered daily by only the investigator using PASW 18.0. All completed study questionnaires were kept confidential and separate from the signed consent forms. The data were coded anonymously by a designated study ID number. The research findings did not associate subjects with specific questionnaires or findings. Only the investigator, major professor, and study statistician were allowed to access the family caregivers' information. All study questionnaires were stored in a locked cabinet at the investigator's office in Thailand or at Fee Hall on MSU's campus, and the electronic data were kept in a password-protected file on the investigator's personal computer. The hard copies of consent forms and the electronic data were brought separately and confidentially to MSU's College of Nursing for potential audit.

Because the electronic data were kept in the investigator's personal computer and external hard drive, the personal computer, the external hard drive, and consent forms were separately carried in the investigator's locked carry-on luggage and the backpack and kept with the investigator when traveling from Thailand back to the United States.

### Women and Minority Inclusion in Clinical Research

As the National Institutes of Health (NIH) policy and guidelines on the inclusion of women and minorities as subjects in clinical research—amended October, 2001—require, female and minority (if there are any) caregivers were recruited representing the subjects of the proposed study. A breakdown in sex and religious activities in the dataset for the proposed research was expected, and descriptive statistics regarding sex and religious activities are reported in chapter 5.

The purpose of this chapter was to present the design and methods that were used for this study, as well as human subject protection and data safety. Chapter 5 will describe the result of the study analyses. Chapter 6 will present contributions to science and implications for policy, clinical practice and research.

Table 1
Summary of Study Measures

Measure	Number of items	Data source	Admin.	Time (min.)		Psychom	etric property		Thai- translated
				` ,	Reliability	Validity	Sensitivity to change	Respon- siveness	version
Overall QOL: QLI	33	Family caregiver	Self- administered	10	0.73 - 0.99	High	Acceptable	Demonstrated	Yes
Functional status: SF-12	12	Family caregiver	Self- administered	5	> 0.76	Good	Adequate	Demonstrated	Yes
Social support: PRQ85-II	25	Family caregiver	Self- administered	10	0.84	High	Adequate		Yes
Rewards of caregiving	27	Family caregiver	Self- administered	2	> 0.80	Moderate	Acceptable		Yes
Physical disability: BI	10	Family caregiver	Self- administered/ interviewed	5	0.80, 0.89	High	Adequate	High	Yes
ECR symptoms: MSAS	32	Family caregiver	Self- administered/ interviewed	10	0.78 - 0.91	High	Adequate		Yes
Caregiver tasks of care: OCBS	15	Family caregiver	Self- administered	5	> 0.80	High	Adequate	Demonstrated	Yes

Table 1 (cont'd)

Measure	Number of items	Data source	Admin.	Time (min.)		Psychometric	c property		Thai- translated
				_	Reliability	Validity	Sensitivity to change	Respon- siveness	version
Family caregiver sociodemographic & clinical characteristic	7	Family caregiver	Self- administered	5					Yes
ECR socio- demographic & clinical characteristic	3	Family caregiver	Self- administered/ interviewed	5					Yes

Note. Admin. = method of administration; QOL = quality of life; QIL = Quality of Life Index; SF-12 = 12-item Short Form Survey; PRQ85-II = Personal Resource Questionnaire 85 part II; BI = Barthel Index; ECR = elder care recipient; MSAS = Memorial Symptom Assessment Scale; OCBS = Oberst Caregiving Burden Scale.

### Chapter 5

#### **Results**

The primary purpose of this study was to examine which selected variables—family caregiver characteristics (age, sex, religious activities, relationship to ECR, chronic health conditions, household income, and social support), ECR characteristics (age, sex, levels of physical disability, and ECRs' symptoms), length of caregiving, perceived rewards of caregiving, caregiver tasks of care, and family caregiver functional status—significantly influence the HRQOL levels of rural Buddhist Thai family caregivers caring for ECRs with at least two ADL deficits. This study sought to address the following specific aims, to examine:

- 1. The relationships among family caregiver characteristics (age, sex, religious activities, relationship to ECR, chronic health conditions, household income, social support), ECR characteristics (age, sex, levels of physical disability, ECRs' symptoms), length of caregiving, rural Thai family caregiver tasks of care, rewards of caregiving, and functional status.
- 2. The relationships among family caregiver characteristics (age, sex, religious activities, relationship to ECR, chronic health conditions, household income, social support), ECR characteristics (age, sex, levels of physical disability, ECRs' symptoms), length of caregiving, rewards of caregiving, caregiver tasks of care, family caregiver functional status, and overall HRQOL of rural Buddhist Thai family caregivers.
- 3. Whether the relationship between family caregiver functional status and overall HRQOL of family caregivers is mediated by the rewards of caregiving, controlling for all other variables.

The following sections will present the results from this study. Sample characteristics and descriptive analyses will be presented. In addition, reliability of study instruments and

scoring information will be presented. Interpretation and discussion of the results and implications will be presented in chapter 6.

#### **Study Measures**

Operational definitions for all study variables were provided in chapter 4. The following section will discuss the actual measurement, scoring, and descriptive analyses results of the sample response to study variables. Reliability coefficient for each of the study instruments will be presented. Reliability data for each instrument for this study can be found in Table 2.

#### **Predictors/Covariates**

## Caregiver characteristics.

Age. Each caregiver reported his or her age in years based on the age at the date of enrollment into the study and treated as a continuous variable for analysis.

Sex. Each caregiver self-reported his or her sex as either male or female. They were scored as 1 for male and 2 for female in PASW 18.0. Sex was treated as a categorical variable for analysis.

**Religion.** Each caregiver was asked to select the category which best fit his or her religion. Categories were Buddhist, Christian, Islam, and other. Religion was treated as a categorical variable for analysis.

**Religious activities.** Each caregiver was asked to report the frequency of participation in religious-related activities, which were, praying, meditating, going to the temple, offering food and things for monks, donating for others and other. Participation in religious activities was measured using the religious activity grid to rate how often caregivers do participate in those religious activities. Frequency scores were evaluated for each activity on 5-point Likert-type scales, in which participants selected 0 (not at all), 1 (less than once a month), 2 (once a month),

3(once a week), or 4 (once a day). A total score of the religious activity was developed by summing all activities with total number for other, such that higher scores indicate a greater frequency of participating religious activities. This variable was treated as a continuous variable analysis.

Relationship to ECR. Each caregiver was asked to report his or her relationship to the ECR. They were instructed to choose the category best described the particular type of connection existing between the caregiver and ECR. Categories were wife, husband, daughter, son, niece, nephew, sister (younger), brother (younger), son-in-law, daughter-in-law, and other relatives. Relationship to ECR was treated as a categorical variable for analysis.

Chronic health conditions. Caregivers were asked to respond "yes" or "no" when questioned whether they possessed chronic health conditions. Chronic health conditions included hypertension, diabetes mellitus, heart disease, chronic obstructive pulmonary disease, back pain, arthritis, and others. Each condition was coded 1 (yes) or 0 (no). For the other category, the study investigator reviewed what was written to ensure that the participant reported a chronic condition different from what had already been reported in the list. A score for chronic health conditions was developed by summing all chronic health conditions. This variable was treated as a continuous variable for analysis.

Household income. Income was a self-reported variable. Caregivers were asked to select the total household income which best reflected them. Income was divided into four different categories ranging from less than or equal to 2000 Baht (\$65) per month to greater than or equal to 10,000 Baht (\$325) per month. Income was treated as a categorical variable for analysis.

#### Elderly care recipient characteristics.

Age. Each caregiver was asked to report the age in completed years of the elderly

recipient in the individual's care. The ECR's age in years was based on the age at the date of caregiver enrollment into the study and treated as a continuous variable for analysis.

Sex. Each caregiver was asked to report the ECR's sex either male or female. They were scored as 1 (male) or 2 (female) in SPSS. Sex of the ECR was treated as a categorical variable for analysis.

Levels of physical disability. The BI (Mahoney, & Barthel, 1965) was used to measure the limitation of performing ADLs as an indicator of the dependence and need of the ECR. This instrument was described in chapter 4. This instrument was administered by the individual caregiver reporting the ADLs limitation of the ECR. The index is an ordinal scale comprising of 10 ADLs: transferring, walking, stairs, toilet use, dressing, feeding, bladder, bowel, grooming, and bathing. Each caregiver was asked to rate the limitation with scores ranging from 0 to100. The highest score is 100, indicating no disability, and lower scores indicate greater disability. The mean scores of 51-75 were reported as moderate disability in the previous study (Supervia, Aranda, Marquez, Aguirre, Skaf, & Cutierrez, 2008). The limitation score for each index was summed to create a total ADL limitation score for each ECR. A level of physical disability was treated as a continuous variable for analysis. A Cronbach's alpha for this instrument was administered and determined to be .82. This is consistent with the reported reliability of the instrument both in English and Thai-translated version of the BI (Sainsbury et al., 2005; Senanarong, et al., 2003).

*ECRs' symptoms*. The MSAS (Portenoy et al., 1994) was used to collect data on 32 different symptoms common in elders. This instrument was described in chapter 4. To administer the MSAS, Individual caregivers selected the frequency, severity, and distress for symptoms. Severity, frequency, and distress were evaluated and reported for 24 symptoms, as were severity

and distress for 8 symptoms, on 4- and 5-point Likert-type scales. Higher scores indicated more severity, greater frequency, and higher distress. All symptoms were reported by caregivers. The individual symptom score was the average of all the completed two or three dimensions (frequency, severity, and distress) divided by the number of dimensions for each item. The total dimension scores for each item were summed to create a total symptom score. The scores range from 0 -128, with a score of zero indicating the caregiver did not perceive the ECRs' symptoms in the past four weeks. The score of each dimension was reported as low when it was lower than 14.8 in the previous study (Portenoy et al., 1994). The variable, ECRs' symptoms, was treated as continuous for analysis. A Cronbach's alpha for this instrument was administered and determined to be .81. This is consistent with the reported reliability of the instrument both in English and Thai-translated version of the MSAS (Portenoy et al.; Suwisith, 2007).

#### **Environmental characteristics.**

Social support. The PRQ85-II (Brandt & Weinert, 1981) was used for measuring social support. This instrument was described in chapter 4. Caregivers were asked to rate their levels of perceived social support regarding provision for attachment or intimacy, social integration, opportunity for nurturance behavior, reassurance of worth as an individual and in role accomplishments, and the availability of informational, emotional, and material assistance. These items each use a 7-point Likert rating scale, ranging from 1 (strongly disagree) to 7 (strongly agree) for positive statements and from 7 (strongly disagree) to 1 (strongly agree) for negative statements (item numbers 4, 7, 10, 16, and 24). For this study, all items were summed to create a total social support score for each caregiver. The total score ranges from 25–175; higher scores indicate higher levels of social support. The score of social support was reported as high in the previous study when it was higher than 120 (Sreshthaputra, Sreshthaputra, & Vutyavanich,

2008). Social support was treated as a continuous variable for analysis. A Cronbach's alpha for this instrument was administered and determined to be .91. This is consistent with the reported reliability of the instrument both in English and Thai-translated version of the PRQ85-II (Brandt & Weinert, 1981; Sreshthaputra et al., 2008).

**Length of caregiving.** The total number of caregiving months was determined by computing the total number of months from the caregiver's start in the role of primary caregiver, to the month caregiver enrolled into the study. The length of time of caregiving was reported in total months, and was treated as a continuous variable for analysis.

Rewards of caregiving. The Rewards of Caregiving Form (Archbold & Stewart, 1986, 1993) was used to measure rewards of caregiving. This instrument was described in chapter 4. The instrument consisted of 27 items which assessed the levels of family caregivers' overall perceptions of the rewards of caregiving for the ECRs during the caring periods. It is scored by using a 0 to 4 response scale response, and then all items are summed for a total score ranging from 0 to 108 such that high scores indicate a greater perceived reward of caregiving. Rewards of caregiving scores were reported as high above the cut-off point of 70 in Kopachon's (2002) and Plaipetch's (2002) studies. Rewards of caregiving were treated as a continuous variable for analysis. A Cronbach's alpha for this instrument was administered and determined to be .97. This is consistent with the reported reliability of the instrument both in English and Thaitranslated version of the Rewards of Caregiving Form (Archbold et al., 1995; Chatcheydang, 2005).

Caregiver tasks of care. The OCBS (Carey, Oberst, McCubbin, & Hughes, 1991; Oberst, 1990; Oberst, Thomas, Gass, & Ward, 1989) was used to assess caregivers' perceptions of time and difficulty associated with tasks they performed in caring for their ECRs. This instrument was

described in chapter 4. Tasks included were providing personal care, assisting with medications, monitoring symptoms, managing the patient's emotions and behaviors, dealing with finances, and talking with health professionals. Caregivers were asked to rate the time spent on these tasks ranging from 1 (*none*) to 5 (*a great amount*), and the difficulty of these tasks ranging from 1 (*not difficult*) to 5 (*extremely difficult*). Total scores were generated separately for time and for difficulty, which ranged from 15-75; higher scores represent more perceived time spent or more perceived difficulty with tasks. Both the time spent on and the difficulty of tasks were reported as low when the scores were less than 35 in previous studies (Boonluk, 2005; Carey et al., 1991). Caregiver tasks of care were treated as a continuous variable for analysis. A Cronbach's alpha for this instrument was administered and determined to be .96. This is consistent with the reported reliability of the instrument both in English and Thai-translated version of the OCBS (Bakas et al., 2004; Boonluk, 2005). Reliability coefficients were also calculated for the instrument subscales of time and difficulty. The time and difficulty subscale was the same ( $\alpha = .95$ ).

Family caregiver functional status. The SF-12 (Ware, Kosinski, & Keller, 1996) was used to calculate total scores of physical and mental components by applying a scoring algorithm. This instrument was described in chapter 4. The SF-12 survey contains 12 categorical questions that assess limitations in performing activities as a result of physical and emotional health. Caregivers were asked to rate the items in 3-, 5-, and 6-point Likert response formats to assess limitations in physical activity and physical role functioning, pain, overall health, mental health, vitality, and social functioning. The instrument was scored in two steps. First, the response for each item was recoded with a value from 0 to 100. Second, an average value was calculated for all items scored by each individual caregiver, which ranged from 0-100. Higher

total scores indicate better functioning status of caregivers. Functional status scores reported higher than the standard mean scores (50) indicated good abilities to perform daily activities (Chariyalertsak et al., 2011; Ware, Kosinski, & Keller, 1996). Caregiver functional status was treated as a continuous variable for analysis. A Cronbach's alpha for this instrument was administered and determined to be .89. This is consistent with the reported reliability of the instrument both in English and Thai-translated version of the SF-12 (Resnick & Parker, 2001; Chariyalertsak et al.).

#### **Dependent Variable**

Caregiver overall HROOL. Overall HROOL was measured with the QLI (Ferrans & Powers, 1985; Ferrans, 2009; Petchprapai, 2007). The QLI was developed to measure quality of life in terms of a person's overall satisfaction with life. The QLI measures both satisfaction and importance regarding various aspects of life. This instrument was described in chapter 4. This instrument consisted of 33 items which measure satisfaction and importance. Responses were scored by recoding the satisfaction raw score in order to center the scale at zero, done by subtracting 3.5 for each item and then weighting it by multiplying with the importance raw score. The weighted scores were summed to generate the preliminary total score. To prevent bias due to missing data, the primary investigator divided each sum-obtained score by the number of items answered by individual caregiver. Lastly, to eliminate negative numbers for the final score, 15 were added to every score; this produced the final overall total QLI score which ranged from 1 to 30. The total score ranged from 0 to 30; a higher score indicating a better HRQOL. Caregivers were reported as having slightly satisfied HRQOL when the QLI scores were lower or equal to 20 in some previous studies (Katsuno, 2003; Petchprapai, 2007). Overall HRQOL was treated as a continuous variable for analysis. A Cronbach's alpha for this instrument was administered and determined to be .98. This was consistent with the reported reliability of the instrument both in

English and Thai-translated version of the QLI (Ferrans & Powers, 1998; Petchprapai).

Table 2

Reliability Coefficients for Study Instruments

Instrument	N of items	μ	SD	α
Quality of Life Index (QLI)	33	20.71	3.75	.98
12-item Short Form Survey (SF-12)	12	64.36	14.73	.89
Personal Resource Questionnaire (PRQ85-II)	25	122.47	15.05	.91
Rewards of Caregiving Form	27	74.85	16.27	.97
Memorial Symptom Assessment Scale (MSAS)	32	10.33	7.14	.81
Oberst Caregiving Burden Scale (OCBS) Time Difficulty	15 15	33.86 28.23	9.97 9.31	.95 .95
Barthel Index (BI)	10	75.10	13.87	.82

*Note.*  $\mu$  = mean; SD = standard deviation;  $\alpha$  = Cronbach's alpha.

## Sample

Once IRB approval was obtained from MSU (see Appendix C for IRB approval letter) a total of 201 family caregivers who met the inclusion criteria were enrolled in this study. A criteria checklist was used to ensure that subjects were Buddhist primary caregivers who were not being paid to care for a chronically ill ECR and who were not living in the municipal area, in alignment with the specific objectives of this study.

Sociodemographic characteristics of caregivers (N = 201) and elders are presented in Table 3. Of the caregivers who were eligible and enrolled in the study, 61.7% (n = 124) were female and 39.3% (n = 79) were daughters, and there was mean age of 40 years old (SD = 13). A

full 100% were Buddhist who pray (chant) daily (52.2%, n = 105), offer food and things for monks each day (33.3%, n = 67), and go to the temple monthly (39.8%, n = 80; see Table 4). The majority had moderate to high household incomes of 5,001-10,000 baht per month (54.7%, n = 110). Most of the caregivers had no chronic health conditions (55.7%, n = 112), and some caregivers reported one chronic health condition (25.9%, n = 52). Family caregivers were found to have some chronic health conditions, such as back pain (30.3%, n = 61), hypertension (20.4%, n = 41), arthritis (12.4%, n = 25), and diabetes mellitus (7%, n = 14; see Table 5).

For ECRs, the majority were female (62.7%, n = 126), with the mean age of 71.65 (SD = 7.67) and with an average of two chronic health conditions (48.8%, n = 98). Most chronic health conditions reported in ECRs included hypertension (72.1%, n = 145), diabetes mellitus (53.2%, n = 107), arthritis (18.9%, n = 38), stroke (7.5%, n = 15), and congestive heart failure (7.5%, n = 15). In addition, the averages of ECR symptoms were reported as low in three dimensions of the MSAS included frequency, severity, and distress. ECRs had an average physical disability score of 75.07 (SD = 14.06) indicating a moderate physical disability of the ECRs in performing ADLs (see Table 6).

Moreover, Tables 6 and 7 present further sample information, the means and standard deviations for continuous variables, which included total religious activities, length of caregiving, social support (PRQ85-II), rewards of caregiving, caregiver tasks of care (OCBS), caregiver functional status (SF-12), and caregiver overall HRQOL (QLI).

Caregivers had an average of three years (mean = 38.56 months, SD = 39.9 months) in taking the role of caregiving, but they reported the amount of time mean score of 33.86 (SD = 9.97) and the difficulty mean score of 28.22 (SD = 9.31). That is, caregivers in this study reported low total scores representing low perceived time spent and low perceived difficulty with

tasks. Also, caregivers reported the mean social support score of 122.47 (SD = 15.05) and mean rewards of caregiving score of 74.85 (SD = 16.27) indicating caregivers perceived social support and rewards of caregiving as high. Although most of the caregivers had relatively good functional status with the mean scores of 64.36 (SD = 14.93), some older caregivers reported lower scores indicating poor functional status (see Table 7). However, caregivers reported a slightly satisfied HRQOL (20.71, SD = 3.75; see Table 6 and 7).

Table 7 shows that male caregivers reported higher functional status than female caregivers did, with mean scores of 65.55 and 63.61 (SD = 13.49 and 15.76), respectively. However, female caregivers reported slightly higher HRQOL than male caregivers did, with the mean scores of 21.05 and 20.16 (SD = 3.95 and 3.36), respectively. For age of caregivers, older caregivers were more likely to report worse functional status, but they were more satisfied their lives than younger caregivers. In the relation to age, spousal caregivers reported lower functional status than younger daughters, sons, and others did.

Table 3
Sample Characteristics of Caregivers and Elderly Care Recipients, N and % for Categorical Variables

Characteristic	Variable	N	%
Caregiver			
Sex	Male	77	38.3
	Female	124	61.7
Relationship to elderly	Wife	13	6.5
care recipient	Husband	7	3.5
-	Daughter	79	39.3
	Son	42	20.9
	Niece	23	11.4
	Nephew	21	10.4
	Others	16	8
Household income	Less than 2000	5	2.5
(reported in Baht)	2,001-5,000	59	29.4
	5,001-10,000	110	54.7
	10,001 or more	27	13.4
Elderly care recipient			
Sex	Male	75	37.3
	Female	126	62.7

Table 4

Caregiver Religion and Religious Activities, N and %

Characteristic	Variable	N	%
Religion	Buddhist	201	100
Religious activities	Praying Meditating	105 17	52.2 8.5
	Going to the temple	80	39.8
	Offering food and things for monks	67	33.3
	Donating	97	48.3

Table 5

Clinical Characteristics of Caregivers and Elderly Care Recipients, N and % for Categorical Variables

Characteristic	Variable	N	%
Caregiver			
Chronic health condition	No	112	55.7
	Hypertension	41	20.4
	Diabetes mellitus	14	7.0
	Heart diseases	1	.5
	Back pain	61	30.3
	Arthritis	25	12.4
	Others	3	1.5
Total chronic health conditions	0	109	54.2
	1	52	25.9
	2	27	13.4
	3	13	6.5
Elderly Care Recipient			
Diagnosis (chronic health condition)	Hypertension	145	72.1
	Diabetes Mellitus	107	53.2
	Arthritis & gouty arthritis	38	18.9
	Cardiovascular accident	15	7.5
	Congestive heart failure	15	7.5
	Back pain	7	3.5
	Alzheimer's	4	2.0
	Hyper-lipidemia	4	2.0
	Others	8	4.0
Total chronic health conditions	1	81	40.3
	2	98	48.8
	3	22	10.9

Table 6  $Sample\ Characteristics\ of\ Caregivers\ and\ Elderly\ Care\ Recipients\ (ECRs),\ \mu,\ and\ SD\ for\ Continuous\ Variables\ (N=201)$ 

Variable	Description	Description Range M		Max.	μ	SD
Caregiver						
Age	Age of caregiver		18	80	40.70	13.00
Religious activities	Total number of religious activities of caregiver	0-20	1	15	7.74	3.66
ECR	Ç					
Age	Age of elderly care recipient		60	92	71.65	7.67
Length of caregiving	Caregiving period in months		2	252	38.56	39.9
BI	Elder physical disability	0-100	10	90	75.07	14.06
PRQ85-II	Social support of caregiver	25-175	84	169	122.47	15.05
Rewards of caregiving	Rewards of caregiving	0-108	36	108	74.85	16.27
MSAS	Elder symptom	0-128	1.20	36.20	10.33	7.14
Frequency	Symptom frequency	0-96	1.00	43.00	8.88	6.12
Severity	Symptom severity	0-128	1.00	33.00	9.42	6.68
Distress	Symptom distress	0-128	1.60	36.80	11.62	8.01
OCBS time	Caregiver task of care: Time spent in caregiving	15-75	15	61	33.86	9.97

Table 6 (cont'd)

Variable	Description	Range	Min.	Max.	μ	SD
OCBS difficulty	Caregiver task of care: Difficulty of caregiving	15-75	15	58	28.22	9.31
SF-12	Caregiver functional status	0-100	25	93.75	64.36	14.93
QLI	Caregiver overall HRQOL	1-30	12.89	28.98	20.71	3.75

*Note*. μ= mean; *SD* = standard deviation; BI = Barthel Index; PRQ85-II = Personal Resource Questionnaire 85 part 11; MSAS = Memorial Symptom Assessment Scale; OCBS = Oberst Caregiving Burden Scale; SF-12 = 12-item Short Form Survey; QLI = Quality of Life Index; HRQOL = health-related quality of life.

Table 7

Categorical Sociodemographic Characteristics of Caregivers, Caregiver Functional Status, and Overall HRQOL

		Caregiver	Caregiver
		functional status	overall HRQOL
	N	$\mu$ (SD)	$\mu$ (SD)
Sex			
Male	77	65.55 (13.49)**	20.16 (3.36)
Female	124	63.61 (15.76)	21.05 (3.95)
Age			
18-24	13	74.78 (8.88)**	21.40 (3.01)
25-34	61	65.96 (13.38)	19.85 (3.32)
35-49	77	68.63 (12.58)	20.73 (3.45)
50-64	37	56.19 (15.42)	20.81 (4.58)
65+	13	44.32 (11.69)	23.57 (4.28)*
Relationship to elder			
Wife	13	45.96 (17.07)	24.10 (4.09)**
Husband	7	57.66 (12.52)	23.35 (4.06)
Daughter	79	65.41 (14.60)	20.72 (3.79)
Son	42	67.44 (13.34)	20.10 (3.17)
Niece	23	70.83 (11.89)	20.80 (3.41)
Nephew	21	68.02 (11.38)	19.78 (2.45)
Others	16	54.86 (13.27)	19.39 (4.77)

*Note.* HRQOL = health-related quality of life;  $\mu$ = expected value; SD = standard deviation. \*p < .05. \*\*p < .01

## **Results and Analysis**

**Specific Aim 1.** As stated previously, Aim 1 was to examine the relationships among the following variables: family caregiver characteristics (age, sex, religious activities, relationship to ECR, chronic health conditions, household income, social support), ECR characteristics (age, sex, levels of physical disability, ECRs' symptoms), social support, length of caregiving, rural Thai family caregiver tasks of care, and functional status.

Correlation analysis was utilized to determine if the caregiver's and ECR individual characteristics and other independent factors were either positively or negatively related to the

caregiver's functional status. A series of Pearson's product moment correlation procedures were used to explore relationships among family caregiver and ECR characteristics, as well as other selected caregiving-related variables, and their associations with rural Thai family caregiver functional status. Correlation tests of the associations among study variables were executed by setting the significance level at .05 (see Table 8 for correlation results). Caregiver age, caregiver chronic health conditions, length of caregiving, elder chronic health conditions, elder symptoms, and caregiver task of care were all negatively correlated with caregiver functional status. As caregiver age, caregiver chronic health conditions, length of caregiving, elder chronic health conditions, elder symptoms, and caregiver task of care increased, the caregiver functional status decreased. Simultaneously, social support, rewards of caregiving, and elder's physical disability were all positively correlated with caregiver functional status. As social support, rewards of caregiving, and elder's physical ability increased so did the caregiver functional status.

A linear regression model was also run to assess for possible significant predictors of caregiver functional status. In order to run this model, categorical variables (sex of caregiver and elder, and relationship to elder) were recoded to dummy variables (male = 1 and female = 0; daughter = 1 and others = 0) and all selected variables were entered. The highest nonsignificant probability variable in each iteration was trimmed until the model was stable with a highest correlation coefficient. A total of eight iterations were completed before the final model was achieved. The final model had a correlation coefficient (R) of .797, correlation coefficient squared ( $R^2$ ) of .635, correlation coefficient squared change of .635, and an R distribution of 29.735 with a probability of .000. That is, all final variables included caregiver age, sex, chronic health conditions, and elder symptoms significantly influenced caregiver functional status with the P-value less than .001. The adjusted correlation coefficient squared for the final model was

.614, indicating that the model explained approximately 61% of the variance. Caregiver age, sex, chronic health conditions, and elder symptoms were noted to be significant predictors of caregiver functional status (see Table 9 for regression coefficients). Younger male caregivers with few chronic health conditions who were taking care of ECRs with fewer symptoms were most likely to have better functional status than those who were older female with more chronic health conditions who were taking care of elders with more symptoms.

Table 8 Correlation Estimates of Caregivers' and Elderly Care Recipients' Characteristics and Caregiver Functional Status (N = 201)

Characteristics	Caregiver age Caregiver chronic health condition	Length of caregiving	Elder chronic health condition	Social support	Rewards of caregiving	Elder disability	Elder symptoms	Caregiver task of care (Difficulty)	Caregiver functional status
Caregiver age	1 .757**	.326**	.228*	*083	.127	256**	.294**	443**	451**
Caregiver chronic health condition	1	.205**	.235*:	*086	.077	297**	.284**	* .369**	·419**
Length of caregiving		1	.136	.051	.063	102	.170*	.134	138*
Elder chronic health condition			1	032	.084	174*	.212**	' .195**	·199**
Social support				1	.567**	* .094	040	099	.334**
Rewards of caregiving					1	.090	036	009	.157*
Elder physical						1	.576**	· .299**	: .170*
disability Elder symptoms							1	.436**	213**
Caregiver task of care (Difficulty)								1	239**
Caregiver functional status									1

<sup>\*</sup> p < .05. \*\*p < .01.

Table 9

Coefficients for Final Linear Regression Model Indicating Significant Predictors of Caregiver Functional Status

Predictor	Unstandardized coefficient		Standardized coefficient			
	Beta	Std. error	Beta	t	Significance	
Constant	75.967	9.548		7.956	.000	
Caregiver age	493	.087	415	-5.653	<.001	
Caregiver sex; male	4.378	1.742	.138	2.513	.013	
Relationship to ECR; daughter	2.409	1.700	.076	1.417	.158	
Household income	1.429	1.075	.064	1.330	.185	
Caregiver chronic health condition	-4.130	1.152	248	-3.584	<.001	
Length of caregiving	.019	.019	.049	1.012	.313	
Elder symptoms	447	.114	206	-3.923	<.001	
Caregiver tasks of care (difficulty)	141	.091	085	-1.548	.123	

*Note.* Std. error = standard error; t = t distribution.

**Specific Aim 2.** The purpose of Aim 2 was to examine the relationships between the following variables: family caregiver characteristics (age, sex, religious activities, relationship to ECR, chronic health conditions, household income, and social support), ECR characteristics (age, sex, levels of physical disability, and ECRs' symptoms), length of caregiving, rewards of caregiving, caregiver tasks of care, family caregiver functional status, and overall HRQOL of rural Buddhist Thai family caregivers.

Correlation analysis was utilized to determine if the caregiver's and ECR's individual characteristics and other independent factors were either positively or negatively related to the caregiver overall HRQOL. A series of Pearson's product moment correlation procedures were used to explore relationships between family caregiver and ECR characteristics, as well as other selected caregiving related variables, and their associations with rural Thai family caregiver

overall HRQOL, setting the significance level at .05 (see Table 10 for correlation results).

Caregiver age, religious activities, household income, social support, rewards of caregiving, and caregiver functional status were all positively correlated with caregiver overall HRQOL. As caregiver age, religious activities, household income, social support, rewards of caregiving, and caregiver functional status increased, so did the caregiver's overall HRQOL. Simultaneously, relationship to elder was negatively correlated with caregiver overall HRQOL. When caregivers were not daughters, but were spouses or others, caregiver overall HRQOL was higher

A linear regression model was also run to determine what predictors contributed significantly to caregiver overall HRQOL (see Table 11 for regression coefficients). In order to run this model, categorical variables (sex of caregiver and elder and relationship to elder) were recoded to dummy variables (male = 1 and female = 0; daughter = 1 and others = 0), and all selected variable were entered. The highest nonsignificant probability variable in each iteration was trimmed until the model was stable with a highest correlation coefficient. A total of 12 iterations were completed before the final model was achieved. The final model had a correlation coefficient of =.857, a correlation coefficient squared of .735, a correlation coefficient squared change of .735, an F distribution of 47.54 with a probability of .000. That is, all final variables included caregiver age, total religious activities, relationship to elder, caregiver chronic health condition, social support, rewards of caregiving, and caregiver functional status significantly influenced caregiver overall HRQOL with the p-value less than .001.

Table 10

Correlation Estimate of Caregivers' and Elderly Care Recipients' Characteristics, Other Selected Caregiving Factors, and Overall HRQOL (N=201)

	age	activities	lincome	port	Rewards of caregiving	functional	RQOL
Characteristics	Caregiver age	Religious activities	Household income	Social support	Rewards o	Caregiver functional status	Overall HRQOL
Caregiver age	1	.351**	076	083	.127	451**	.183*
Religious activities		1	.202**	.466**	.807**	.037	.735**
Household income			1	.244**	.186**	.138	.255**
Social support				1	.567**	.334**	.582**
Rewards of caregiving					1	.157*	.801**
Caregiver functional status						1	.250**
Overall HRQOL							1

*Note.* HRQOL = health-related quality of life.

The adjusted correlation coefficient squared for the final model was .719, indicating that the model explained approximately 72% of the variance. Caregiver age, total religious activities, relationship to elder, caregiver chronic health condition, social support, rewards of caregiving, and caregiver functional status were noted to be significant predictors of caregiver overall HRQOL. Older, nondaughter (spouses and others) caregivers participating in more religious activities, who had few chronic health conditions and better functional status and perceived higher social support and higher rewards of caregiving, were most likely to have the greatest overall HRQOL. Simultaneously, younger daughter caregivers participating in fewer religious

p < .05. \*\*p < .01.

activities, who had more co-morbid conditions and worse functional status and perceived lower levels of social support and rewards of caregiving, tended to have a low overall HRQOL.

Table 11

Coefficients for Final Linear Regression Model Indicating Significant Predictors of Caregiver Overall HRQOL

	Unstandardized coefficient		Standardized coefficient		
Predictor	Beta	Std. error	Beta	t	Significance
Constant	949	2.049	_	463	.644
Caregiver age	.064	.018	.221	3.518	.001
Caregiver sex; male	190	.367	025	517	.806
Religious activities	.203	.075	.198	2.695	.008
Relationship to elder; spouse	648	.295	085	-2.200	.029
Household income	.303	.218	.056	1.391	.166
Caregiver chronic health condition	475	.239	117	-1.986	.048
Length of caregiving	002	.004	024	589	.557
Social support	.034	.012	.137	2.796	.006
Rewards of caregiving	.117	.017	.509	7.057	<.001
Elder symptoms	025	.023	047	-1.072	.285
Caregiver functional status	.042	.012	.165	3.564	<.001

*Note.* HRQOL = health-related quality of life; Std. error = standard error; t = t distribution.

**Specific Aim 3.** The purpose of Aim 3 was to determine whether the relationship between family caregiver functional status and overall HRQOL of family caregivers is moderated or mediated by the rewards of caregiving, controlling for all other variables.

Analyses to determine the mediating effect of the perceived reward of caregiving on the relationship between family caregiver functional status and HRQOL of family caregiver was based on the principles proposed by Baron and Kenny (1986). To test a potential mediating effect of rewards of caregiving on the relationship between caregiver functional status and

HRQOL, three regression equations were performed, controlling for other family caregiver and ECR characteristics. Three regression equations were (a) caregiver functional status as a significant predictor of rewards of caregiving, (b) caregiver functional status as a significant predictor of overall HRQOL; and (c) caregiver functional status and rewards of caregiving entered simultaneously with the overall HRQOL.

To test rewards of caregiving as a potential mediating variable, the three regression equations were completed for caregiver functional status (see Table 12, 13, and 15 and Figure 4). The analyses indicated a partial mediating influence of rewards of caregiving on caregiver overall HRQOL. Data from the first equation showed that, when controlling for other variables, caregiver functional status influenced (p < .05) rewards of caregiving, meaning that caregivers who had greater functional status tended to report higher perceptions of rewards of caregiving.

Table 12

Coefficients for Linear Regression Model Indicating Caregiver Functional Status as a Significant Predictor of Rewards of Caregiving

	Unstandardized Coefficient		Standardized Coefficient	_	
Predictor	Beta	Std. Error	Beta	t	Significance
Constant	63.867	5.040		12.673	.000
Caregiver functional status	.171	.076	.157	2.236	.026

*Note.* Std. error = standard error; t = t distribution.

The second equation showed that caregiver functional status positively influenced caregiver overall HRQOL (p < .01; see Table 13). That is, caregivers who had better functional status were most likely to have greater overall HRQOL.

Table 13

Coefficients for Linear Regression Model Indicating Caregiver Functional Status as a Significant Predictor of Overall HRQOL

		ndardized ficients	Standardized Coefficients	_	
Predictor	Beta	Std. Error	Beta	t	Significance
Constant	16.668	1.140		14.624	.000
Caregiver functional status	.063	.017	.250	3.640	.000

*Note.* Std. error = standard error; t = t distribution.

The final test for mediation was to enter both rewards of caregiving and caregiver functional status into a regression equation and evaluate whether: (a) rewards of caregiving was a significant influence on caregiver overall HRQOL and (b) the strength of the relationship between caregiver functional status and caregiver overall HRQOL decreased when rewards of caregiving was included. When both caregiver functional status and rewards of caregiving were included as predictors of caregiver overall HRQOL, controlling for all other variables, the model had a correlation coefficient of .811, a correlation coefficient squared of .658, a correlation coefficient squared change of .658, and an F distribution of 190.459 with a probability of .000 (see Table 14). The adjusted correlation coefficient squared for the final model was .655, indicating that the model explained approximately 65% of the variance. Caregiver functional status (p = .003) and rewards of caregiving (p = .000) were noted to be significant predictors of caregiver overall HRQOL, satisfying the first criterion as a mediating influence (see Table 15).

Table 14

Model Summary for Multiple Regression Indicating the Variance of Caregiver Functional Status and Rewards of Caregiving in Predicting Caregiver Overall HRQOL

				Change Statistics				
	2	Adjusted		2	F			Sig. F
R	$R^2$	R <sup>2</sup>	SE	R <sup>2</sup> Change	Change	df1	df2	Change
.811	.658	.655	2.20635	.658	190.459	2	198	.000

*Note*. HRQOL = health-related quality of life; R = multiple correlation;  $R^2 =$  multiple correlation squared; SE = standard error of the estimate; F = F distribution; df = degrees of freedom; Sig. F Change = significance F distribution change

Table 15

Coefficients for Multiple Regression Model Indicating Caregiver Functional Status and Rewards of Caregiving as Significant Predictors of Overall HRQOL

	Unstandardized Coefficients		Standardized Coefficients		
Predictors	Beta	SE	Beta	t	Significance
Constant	5.156	.928		5.557	.000
Caregiver functional status	.032	.011	.128	3.030	.003
Rewards of caregiving	.180	.010	.781	18.568	.000

Note. HRQOL = health-related quality of life; SE = standard error; t = t distribution.

Considering the second criterion, the t-value representing the relationship between caregiver functional status and caregiver overall HRQOL decreased (see Figure 4) when rewards of caregiving was included. Sobel's test to determine whether this change was statistically significant was performed, and the results (p = .02) indicated a significant difference. The effect of caregiver functional status on caregiver overall HRQOL, however, did not disappear when rewards of caregiving was entered into the model, indicating that a partial mediation effect had occurred. Therefore, rewards of caregiving appears to have significantly, partially mediated the relationship between caregiver functional status and overall HRQOL.

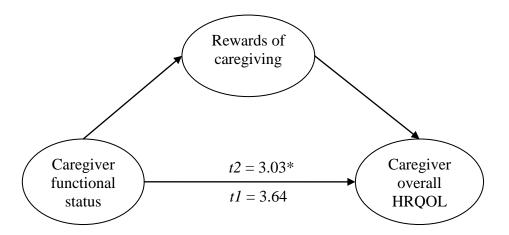


Figure 4. Summary model of the partial mediation of rewards of caregiving in the relationship between caregiver functional status and overall health-related quality of life (HRQOL). t1 = t distribution of the relationship between solely caregiver functional status and caregiver overall HRQOL; t2 = t distribution of the relationship between caregiver functional status and caregiver overall HRQOL when rewards of caregiving was simultaneously entered in the model.

# **Additional Analysis**

As shown in the findings, the relationship between family caregiver functional status and overall HRQOL of family caregivers was partially mediated by the rewards of caregiving. In order to assess influences associated with rewards of caregiving, correlation analysis was utilized to determine if any of the caregiver's and ECR's individual characteristics and other independent factors were either positively or negatively related to rewards of caregiving. Furthermore, whether or not behaviors reflecting participation in religious activities were shown to associate with family caregivers' perceived rewards had been tested. Religious activities were praying, meditating, going to the temple, offering food and things for monks, or donation of money, food and things for others.

Pearson's product moment correlation procedures was used to explore relationships between family caregiver and ECR characteristics, as well as other selected caregiving related variables, and their associations on rewards of caregiving. Correlation tests of the associations among study variables were executed by setting the significance level at .05 (see Table 16 for correlation results and Table 17 for the mean of rewards of caregiving in each categorical group).

Caregiver sex, religious activities, household income, and social support were all positively correlated with rewards of caregiving. If the caregivers were female, as religious activities, household income, and social support increased, so did the rewards of caregiving. Simultaneously, relationship to elder was negatively correlated with rewards of caregiving. When the caregivers were spouses, rewards of caregiving were reported as higher than other kinds of relationship to elder with the mean score of 86.85 (SD = 16.18) in wives and the mean score of 90.00 (SD = 8.12) in husbands. Mean rewards of caregiving for each sex and relationship to elder are shown in Table 17, which indicates that female caregivers reported higher rewards of caregiving and spousal caregivers reported higher rewards of caregivers than the others.

Table 16  $\begin{tabular}{ll} \hline Correlation Estimate of Significant Caregiver's Characteristic, Other Selected Caregiving \\ Factor,s and Rewards of Caregiving (N = 201) \\ \hline \end{tabular}$ 

Characteristic	w w	plc		s of ng
	Total religious activities	Household	Social	Rewards o caregiving
Total religious activities	1	.202**	.466**	.807**
Household income		1	.244**	.186**
Social support			1	.567**
Rewards of caregiving				1

<sup>\*\*</sup>p < .01

Table 17

Categorical Sociodemographic Characteristics of Caregivers and Rewards of Caregiving

		Rewards of caregiving	
Characteristic	N	$\mu$ (SD)	
Sex			
Male	77	71.61 (16.11)	
Female	124	76.86 (16.10) *	
Relationship to elder			
Wife	13	86.85 (16.18)	
Husband	7	90.00 (8.12)	
Daughter	79	77.18 (14.82) **	
Son	42	68.90 (14.84)	
Niece	23	77.00 (11.11)	
Nephew	21	72.62 (14.74)	
Others	16	62.85 (23.19)	

*Note.*  $\mu = \text{mean}$ ; SD = standard deviation.

A linear regression model was also run to assess for possible significant predictors of rewards of caregiving. In order to run this model, categorical variables (sex of caregiver and elder and relationship to elder) were recoded to dummy variables (male = 1 and female = 0; daughter = 1 and others = 0) and all selected variable were entered. The highest nonsignificant probability variable in each iteration was trimmed until the model was stable with a highest correlation coefficient. A total of two iterations were completed before the final model was achieved. The final model had a correlation coefficient of .840, a correlation coefficient squared of .705, a correlation coefficient squared change of .705, an F distribution of 93.351 with a probability of .000. The adjusted correlation coefficient squared for the final model was .698, indicating that the model explained approximately 69.8% of the variance. Total religious activities, social support, and relationship to elder were noted to be significant predictors of rewards of caregiving (see Table 18 for regression coefficients). Daughter caregivers who participated in more religious activities and perceived greater social support were most likely to

<sup>\*</sup>p < .05. \*\*p < .01

have higher perception of rewards of caregiving than those who were not a daughter, but were participating in few religious activities and perceiving lower social support.

Table 18

Coefficients for Final Linear Regression Model Indicating Significant Predictors of Rewards of Caregiving

	Unstand Coeffi		Standardized Coefficients		
Predictors	Beta	Std. error	Beta	t	Significance
Constant	16.358	5.684		2.878	.004
Caregiver sex; male	2.518	1.594	.075	1.580	.116
Religious activities	3.116	.202	.702	15.455	.000
Relationship to elder; daughter	3.259	1.553	.098	2.099	.037
Household income	411	.941	018	436	.663
Social Support	.272	.048	.251	5.612	.000

*Note.* Std. error = standard error; t = t distribution

#### **Power**

A post hoc analysis utilized the program G\*power (Faul, Erdfelder, Bucher, & Lang, 2009) in order to determine the study's power. This analysis was run for the linear regression model predicting caregiver functional status and overall HRQOL and determining rewards of caregiving as a potential mediating variable. The linear regression model revealed an effect size of .35 and a power (1-β error probability) of .99. Because the required sample size has been calculated based on G\*power Tests for correlation and regression analyses, this sized sample provided an acceptable power analysis of a large effect size.

### **Summary**

This chapter presented the results from quantitative analysis. Based on the results, some

caregiver sociodemographic characteristics, health condition, and elder symptoms had an impact on caregiver abilities to perform ADL and functional status. Moreover, religious activities caregiver participate in and other positive aspects in caregiving—such as social support and rewards of caregiving—are noted significantly influence caregiver overall HRQOL. Rewards of caregiving were found to have a partial mediating effect in the relationship between caregiver functional status and overall HRQOL. Finally, family caregivers' rewards of caregiving were found to be significantly predicted by religious activities—such as praying, meditating, going to the temple, offering food and things for monks, or donation for others— as well as social support, and relationship to elder. Further interpretation and discussion of these results will be presented in chapter 6.

### Chapter 6

### **Discussion & Implications**

The focus of this study was on the relationship among individual caregivers' elders' clinical characteristics, positive and negative caregiving aspects, family caregiver functional status, and overall HRQOL of rural Buddhist Thai family caregivers caring for chronically ill ECRs. A discussion of the results with interpretation, as well as how they support or differ from existing research literature, and limitations of the study will be presented in this chapter. Also, this final chapter will present the implications for nursing practice, research, and policy.

## **Discussion of Sample**

The study results of sociodemographic characteristics of caregivers as female and daughters were consistent with the previous reports and other caregiver studies in Thailand (Chatcheydang, 2005; Lawang et al., 2006). The majority of the caregivers were female (61.7%, n = 124) and daughters (39.3%, n = 79), a caring situation whereby one generation cared for the other. Social belief and the Thai culture inculcated the expectation that the role of primary care was a female function. Daughters assumed this role to show gratitude to their parents because they have concern for their loved ones and a good attitude toward care through the love, bonding, and closeness with the patients, including fathers, mothers, grandfathers, and grandmothers (Chatcheydang; Sethabouppha & Kane, 2005; Subgranon & Lund, 2000).

Most of the caregivers had no chronic health conditions (55.7%, n = 112); because the mean age of caregivers was 40, perhaps they were middle-aged adults who had no occurrence of many chronic health conditions. Studies have shown that many older family caregivers experience one or more chronic illnesses, such as hypertension, heart disease, low back pain, or arthritis (Chatcheydang, 2005; Blanes et al., 2007; Frias et al., 2005).

For ECRs, the majority were female (62.7%, n = 126), the mean age was 71.65, and roughly half had two chronic health conditions (48.8%, n = 98), which included hypertension, diabetes mellitus, and so forth. The results were consistent with the report of the Ministry of Social Development and Human Security (MSDHS, 2007) and other studies that report that the number of older Thai people is projected to increase, female elders have longer life expectancies, and most of these people experience chronic health problems (Caffrey, 1992; Chan, 2005; Sasat, 2006; Subgranon, 1999; Subgranon & Lund, 2000).

The study results serve to clarify the associations between family caregiver characteristics, ECR characteristics, caregiving-related independent variables, caregiver functional status, and caregivers' overall HRQOL. A discussion of the results with interpretation for each aim, as well as the additional results, will be presented in the following sections.

# **Discussion of Results for Specific Aim 1**

**Specific Aim 1.** The purpose of Specific Aim 1 was to examine the relationships among the following variables: family caregiver characteristics (age, sex, religious activities, relationship to ECR, chronic health conditions, household income, and social support), ECR characteristics (age, sex, levels of physical disability, and ECRs' symptoms), social support, length of caregiving, rural Thai family caregiver tasks of care, and functional status.

Initially, correlations were computed, and caregiver age, caregiver chronic health conditions, length of caregiving, elder chronic health conditions, elder symptoms, and caregiver task of care were found to be negatively correlated with caregiver functional status. Also, social support, rewards of caregiving, and elder's physical disability were found to be positively correlated with caregiver functional status. That is, caregiver functional status was expected to decrease when caregivers get older, have more chronic health conditions, spend more time in the

caregiving role, and have more care tasks, as well as when elders have more chronic health conditions and more symptoms. Simultaneously, caregiver functional status is assumed to increase when caregivers perceive higher social support and rewards of caregiving, and when elders have more physical disability.

A linear regression model was also computed. Caregiver age, sex, chronic health conditions, and elder symptoms were found to be predictors of caregiver functional status. Younger male caregivers with few chronic health conditions and caring for elders with few symptoms were found to have better functional status.

Age. The younger caregivers were, the more they were to perform their daily activities and tasks. Previous studies have also noted age to be a predictor of caregiver functional status (Lawang et al, 2005; Serrano-Aguilar et al., 2006; Wongchantra, 1996). Wongchantra and Lawang et al. noted that older caregivers' functioning may be deteriorating and older caregivers may suffer from their underlying disease more than younger caregivers. This causes the older caregiver to experience decreased ability to perform daily tasks compared to the younger caregiver. However, the mean age of caregivers in the present study was 40, which shows that caregivers were mid-adult and most likely have an above average functional status (64.36, SD = 14.93).

*Sex.* For sex of caregivers, being male predicted a higher score of functional status. The study results show that male caregivers reported slightly higher scores of functional status than did female caregivers (65.55 and 63.61, respectively). Although women are often socialized to be family caregivers and may be better prepared than men for the family caregiver role, associations between performing their daily tasks and caregiving may be physically stronger in men than in women (Chaoum, 1996; Cheewapoonphon, 1998; Pinquart & Sorensen, 2007;

Stoller, 1994). The male caregivers may have more physical strength than female caregivers and, in relation to age, the mean age of male caregivers in current study is 38.66 (SD = 11.70) years old, which shows that male caregivers were likely younger than their female counterparts.

Chronic health conditions. Caregivers with few chronic health conditions are more likely to have better functional status because they have fewer physical and mental symptoms and limitations related to those chronic health conditions. Although the study results show that caregivers are middle-age adults with few instances of chronic health conditions (1 condition; 25.9%, n = 52), the number of chronic health conditions was still found to be one of the significant predictors of caregiver functional status. The results were similar to the previous studies, which have shown that many family caregivers experience one or more chronic illnesses, such as hypertension, heart disease, low back pain, or arthritis. These chronic conditions have been shown to affect a caregiver's ability to perform daily tasks (Blanes et al., 2007; Cheewapoonphon, 1998; Chatcheydang, 2005; Frias et al., 2005; Pinquart & Sorensen 2007). More chronic health conditions may negatively impact the physical and mental health status of caregivers, leading the caregivers to perform fewer abilities in their life tasks.

ECRs' symptoms. Caregivers who are taking care of elders with fewer symptoms were more likely to have better functional status than those who were taking care of elders with more symptoms. The results of this study are consistent with previous studies that have shown that the symptoms of ECRs with chronic diseases are associated with the number of caregiver tasks of care (Girgis et al., 2011; Osse et al., 2006; Nijboer et al., 2000; Pinquart & Sorensen, 2003, 2007) and the degree of assistance required from the caregiver (Given & Sherwood, 2006). In turn, the level of involvement in providing care has been associated with the functional status of the caregiver (Chung et al., 2010; Fredman et al., 2009). ECRs with more symptoms required

caregivers to perform more tasks, which, consequently, worsen caregivers' functional status in achieving their own daily tasks.

Interpretation based on the finding for Specific Aim 1. Caregivers who were younger, male, have few chronic health conditions, and taking care of elders with fewer symptoms are more likely to have greater functional status. That is, the older caregivers' functioning may have been deteriorating, and older caregivers may have suffered from their own comorbid diseases. Because they may be physically weaker than male caregivers, the female caregiver's functioning may decrease, especially as it's associated to age. Moreover, consistent with the earlier literature (Chatcheydang, 2005; Frias et al., 2005; Pinquart & Sorensen 2007), caregivers' possessing more chronic health conditions negatively influence caregivers' health and ability. In addition, ECRs who had more symptoms require more time, more difficult care which in turn interferes with caregivers' functioning. Nurses and other health care providers who are caring for chronically ill elders need to understand this relationship and pay more attention to these caregiving factors in order to assist caregivers and elders in caring. The younger male with few chronic health conditions may have a better functional status, but he may need more supportive information and skills to continually care at home for an elder with more symptoms. The symptom management or extra support for managing symptoms and treatment of elders should be of concern.

## **Discussion of Results for Specific Aim 2**

**Specific Aim 2.** The purpose of Aim 2 was to examine the relationships among the following variables: family caregiver characteristics (age, sex, religious activities, relationship to ECR, chronic health conditions, household income, and social support), ECR characteristics (age, sex, levels of physical disability, and ECRs' symptoms), length of caregiving, rewards of caregiving, caregiver tasks of care, family caregiver functional status, and overall HRQOL of

rural Buddhist Thai family caregivers.

A correlation analysis and linear regression model were computed to determine the relationship among caregivers' and ECRs' individual characteristics, as well as other independent factors that were related to the caregiver overall HRQOL. The results show that caregiver age, religious activities, household income, social support, rewards of caregiving, and caregiver functional status are positively correlated with caregivers' overall HRQOL. Also, relationship to elder is negatively correlated with caregivers' overall HRQOL.

Age. Older caregivers are more likely to be happy and satisfied with their lives as a whole. Although older caregivers reported lower functional status, they reported higher overall HRQOL. Previous studies in Thailand have indicated that older family caregivers tend to consider the caring situations as something less serious and to adapt themselves to better accept the caregiving role than do younger family caregivers, because older caregivers could more readily accept the changes of elders' condition (Lawang et al., 2005; Mui, 1995; Obert, et al., 1989; Sasat, 2006; Wongchantra, 1996). In other words, when caregivers are older, they had experienced many life events, which enabled them to solve caregiving problems more effectively. The caregivers would be able to make decisions and cope with problems and would possess the skills necessary in providing care to elders. This is unlike Frais et al. (2005) and Serrano-Aguilar et al. (2006) findings that being older relates to greater health problems, possibly worsening older caregivers' physical health and their overall HRQOL more so than younger caregivers.

*Religious activities.* Caregivers who participated in more religious activities were more likely to have a greater overall HRQOL. The mean of total religious activities was 7.74, indicating a moderate to high level of caregiver religious participation. As religion in this study

was conceptually defined as the behaviors that reflect participation in religious activities, religion is expected to be the one of a caregiver's resources that may impact positive caregiving experiences. In this study, 100% of family caregivers were Buddhists who believed in the law of karma. The law of karma means that good acts will lead to good consequences (Payomyong, 2000; Payutto, 1995, 1998); caregivers perform good deeds for their elderly ill family members to achieve better lives in their next rebirths. Caregivers followed Buddhism in caring for their chronically ill elders (Sethabouppha & Kane, 2005; Subgranon & Lund, 2000). Consistent with Picot et al.'s (1997), Sethabouppha and Kane's, and Subgranon's studies, caregivers' overall HRQOL is predicted by a positive resource, religion, as total of religious activities. The more religious activities caregivers participate in, the more positive resources and benefit finding they perceive, which further affects their happiness or satisfaction of life as a whole, and thus a effects higher overall HRQOL.

Relationship to ECR. Spousal and other kinds of relationships to elders are more likely to associate with higher overall HRQOL then daughter-caregiver relationships. Although most of the caregivers in this study are daughters and they have greater functional status than spousal caregivers, daughters report lower overall HRQOL than husbands and wives do (20.72, 23.35, and 24.10, respectively). This is unlike previous studies with Thai samples, which found that spouses are the primary family caregivers for ECRs (Cheewapoonphon, 1998; Belasco et al., 2006; Heru & Ryan, 2004) and that providing care tends to have ongoing negative effects on their health (Barnes et al., 1992; Pinquart & Sorensen, 2007; Pinquart & Sorensen, 2011). However, this study focuses on the overall HRQOL as a subjective aspect related to how happy or satisfied the caregiver is with life as a whole, which may differ from other studies using physical health measures. Consequently, spousal relationships may show stronger associations

with overall HRQOL of family caregivers because caregiving for a spouse is more normative than caring for other persons and helps caregivers positively appraise caregiving situations (Pinquart & Sorensen, 2007).

Chronic health conditions. Similar to the relationship to functional status, caregivers who have fewer chronic health conditions are more likely to have better overall HRQOL. Many family caregivers reported experiencing one or more chronic illnesses, which has been shown to affect their health and might worsen their overall HRQOL (Blanes et al., 2007; Frias et al., 2005). Similarly, Barnes et al. (2006) found that, when controlling for age, gender, and socioeconomic status, one of the significant predictors associated with caregivers' overall HRQOL is having two or more chronic health conditions. Also, the physical conditions were reported to have the strongest impact on HRQOL in Lai et al.'s study (2005). Caregivers' physical health may be deteriorating and interfering with daily life, because of their underlying diseases or chronic health conditions as mentioned above. Besides, because caregivers are middle-aged adults, they may have some chronic health conditions and may not be able to take appropriate care of the elders for long, or they may face more barriers in performing as a care provider because of their own health status limitation. All of these reasons may lead a caregiver to appraise his or her life as one of not being satisfied.

Social support. Social support was one predictor of greater overall HRQOL. In this study, perceived social support is defined as the level of support currently available to the caregiver. Also, others have conceptualized social support as a resource that may positively affect family caregivers' HRQOL (Chappell & Reid, 2002; Lueboonthavatchai and Lueboonthavatchai, 2006). Social support may have positively affected family caregivers' overall HRQOL by reducing their stressors, enhancing their rewards of caregiving (Chappell &

Reid, 2002; Cohen, Colantonio, & Vernich, 2002; Northouse et al., 2002; Picot, 1995), and helping them to develop more effective forms of coping strategies, all of which result in positive health behaviors in relation to caregiving performance (Losada et al., 2005; Tang & Chen, 2002). However, functional status was not predicted by social support. This is unlike the studies of Park and Lee (2007), and Oka et al. (2004), which found that social support was a modifiable factor associated with functional status, particularly physical levels, in family caregivers. More caregiver support from family, friends, and others positively affects caregiver satisfaction. Even though they have to deal with difficult caring situations, caregivers perceive those circumstances with the happiness needed to continue their caregiving roles when they have more resources and support.

Rewards of caregiving. Rewards of caregiving was a significant predictor of caregiver overall HRQOL. Caregivers who perceive higher rewards are more likely to have high overall HRQOL while taking care of chronically ill elders. Similar to Karmer's (1997) and Davis's (2005) studies, caregiving for an older family member can also be a rewarding experience, despite the possible stress imposed from managing one's life. Buddhist beliefs toward elders of Thai caregivers may have imparted a sense of obligation to care for parents, and karma-based thoughts may create positive feelings and rewards from assuming the role of family caregiver (Sethabouppha, & Kane, 2005). The positive experience of caregiving, its rewards, and its relation to Buddhist beliefs might have helped caregivers understand and accept their roles.

Moreover, rewards of caregiving can be explained as the positive perceptions of caregivers, as well as their willingness to care for ECRs with chronic illness, which may impact the caregivers' appreciation to perform caregiving roles. Besides, Heru and Ryan (2004), Donprapeng (2006), and Kasemkitwattana, (2006) found that a caregiver's warm and supportive attitude toward the

care recipient can sometimes help him or her cope with the caregiver role, which influences the caregiver's performance and overall HRQOL. In this study, caregivers reported the high rewards of caregiving with the mean score of 74.85 (SD = 16.27; ranged from 0-108), and 100% are Buddhist. It is assumed that caregivers positively perceive experiences of care as the happiness in their lives as a whole.

Caregiver functional status. Caregiver functional status was another predictor of caregivers' overall HRQOL. In this study, caregivers with greater functional status are more likely to have higher overall HRQOL. As relation to age, some older caregivers reported poor functional status but they were found to perceive higher overall HROOL. In this study, the relationship of caregiver functional status and overall HRQOL was found to be mediated by rewards of caregiving, which might explain the high overall HRQOL in the poor functional status caregivers. Similar to some previous studies (Bakas & Burgener, 2002; Chung et al., 2010; NAC, 2004; FTGRD, 2009), HRQOL levels might also be influenced by various caregivingrelated factors experienced in the current caring situations. Multiple tasks of care for ECRs, as well as dependency and needs of ECRs, lead the family caregiver to take more responsibility in expanded roles (Bakas et al., 2004; Bakas & Burgener, 2002; NAC, 2004; FTGRD, 2009). Such an increase in caregiving tasks may cause physical and psychological problems, as well as problematic health behaviors. Moreover, monitoring and assisting with an ECR's symptoms was reported as time consuming, physically demanding, and exhausting (Chung et al., 2010; Newman, 1997), which may increase caregiving demands and tasks of care, resulting in a possible decrease in the family caregiver's ability to perform his or her own life tasks and to provide care. An ability to perform daily tasks of care may be a crucial factor in accomplishing the caregiver role, which can influence the caregiver's overall HRQOL as shown in the study

results, consistently with some previous studies (Chung et al., 2010; Fredman et al., 2009; Lee et al., 2003; Lu & Austrom, 2005; Spira et al., 2010).

Interpretation based on the finding for Specific Aim 2. Older spouses and other caregivers participated in more religious activities, who have few chronic health conditions and better functional status have higher levels of overall HRQOL. Furthermore, caregivers who perceive higher social support and rewards of caregiving have greater overall HRQOL. Positive aspects of caregiving—including religious activities, social support, and rewards of caregiving—and functional status are significant predictors which may be enhanced by nurses and health care teams either in hospitals or communities. Moreover, caregiver's functional status should be sustained in performing effective care through the trajectory of the disease and the process of care. Caregiver's functional status can be expected to be an essential factor influencing HRQOL of the caregiver, which ultimately results in the continuous and desired care at home. In other words, caregivers will be more happy or satisfied with their lives as a whole when they are able to perform daily life tasks even during caregiving periods.

## Discussion of Results for Specific Aim 3

**Specific Aim 3.** The purpose of Aim 3 was to determine whether the relationship between family caregiver functional status and overall HRQOL of family caregivers is mediated by the rewards of caregiving, controlling for all other variables.

To test rewards of caregiving as a potential mediating variable, the three regression equations were performed for caregiver functional status. The analyses indicated a partial mediating influence of rewards of caregiving on the relationship of caregiver functional status and his or her overall HRQOL. Results from the first equation show that, when controlling for other variables, caregiver functional status influences rewards of caregiving, meaning that

caregivers who have greater functional status tended to report higher perceptions of the rewards of caregiving.

Rewards of caregiving in this study were defined as levels of family caregivers' overall sense of satisfaction toward the experiences of caring with a positive attitude during the periods of care (Raschick & Ingersoll-Dayton, 2004; Sasat, 2006; Stewart & Archbold, 1997). Most of the caregivers in this study report relatively high scores of functional status (56 -74), which were higher than the standard mean scores (50), indicating that most caregivers have good abilities to perform their daily activities. Due to age-related physical changes, older caregivers were found to report lower scores of functional status, which mean they had poorer abilities to perform their life tasks, particularly in the group of above 65-year-old caregivers (44). Although much of the earlier research on family caregivers has focused on the negative consequences of multiple tasks of care (e.g., Morimoto et al., 2003; Chatcheydang, 2005), caregiving for an older family member can also be a rewarding experience, despite the physical and psychological stress imposed from managing one's life (Davis, 2005; Kramer, 1997; Picot, 1995; Raschick & Ingersoll-Dayton, 2004). The results of this study initially showed that a reward of caregiving was significantly predicted by a greater functional status of caregivers. This finding will be useful for further investigating the relationship between physical and psychological aspects of caregiving.

The second equation shows that caregiver functional status positively influenced caregiver overall HRQOL. That is, caregivers who have better functional status are most likely to have greater overall HRQOL. As discussed in Specific Aim 2, caregiver overall HRQOL was influenced by caregiver functional status. Caregivers with greater abilities to perform their daily life tasks are more likely to be happier or more satisfied with their lives as a whole. Although

caregivers take more responsible in expanded roles of caring (Bakas et al., 2004; Bakas & Burgener, 2002; NAC, 2004; FTGRD, 2009), including monitoring and assessing ECRs' symptoms (Chung et al., 2010; Newman, 1997), their overall HRQOL are not worsened if they can maintain good functional status.

The results are consistent with some previous studies (Chung et al., 2010; Fredman et al., 2009; Lee et al., 2003; Lu & Austrom, 2005; Spira et al., 2010) revealing that an ability of caregivers to perform daily tasks is a crucial factor influencing their overall HRQOL. That is, caregivers are more satisfied with their life and are happier if they can complete their daily life activities, even though they also have expanded roles caring for chronically ill elders at home.

The final test for mediation was to enter both rewards of caregiving and caregiver functional status into a regression equation and evaluate whether: (a) rewards of caregiving was a significant influence on caregiver overall HRQOL and (b) the strength of the relationship between caregiver functional status and caregiver overall HRQOL decreased when rewards of caregiving was included. When both caregiver functional status and rewards of caregiving were included as predictors of caregiver overall HRQOL controlling for all others related variables, the model accounted for 65% of variance in predicting caregiver overall HRQOL. Both caregiver functional status and rewards of caregiving were significant influences on caregiver overall HRQOL, satisfying the first criterion as a mediating influence. Sobel's test was performed to determine the statistically significant changes of the *t*-value. The *t*-value representing the relationship between caregiver functional status and caregiver overall HRQOL decreased when the rewards of caregiving was included, satisfying the second criteria as a partial mediating influence. Rewards of caregiving significantly, partially mediate the relationship between caregivers' functional status and their overall HRQOL. That is, functional status still appears to

have a positive impact on overall HRQOL, but the degree of the effect decreases when a reward of caregiving takes its role to affect overall HRQOL. Caregivers are satisfied with their lives when they are able to complete their own daily life tasks. Caregivers would be much happier if they also positively perceived their caregiving role as a reward, similarly reported in Lu and Austrom's (2005) and Spira et al.'s (2010) studies.

The results show a partial mediation: both a direct effect of caregiver functional status on caregiver overall HRQOL and an indirect effect through rewards of caregiving. An ability to perform life tasks has a direct positive impact on caregivers' happiness and still has influences on overall HRQOL when the caregivers have positive appraisals of caregiving. Concerning the indirect effect, caregiver functional status leads to higher rewards of caregiving, which further leads to higher overall HRQOL in caregivers. As discussed above, a caregivers who has a good functional status is more likely to perceive positive or reward experiences (Davis, 2005; Kramer, 1997; Picot, 1995; Raschick & Ingersoll-Dayton, 2004) and tends to have a better overall HRQOL (Chung et al., 2010; Fredman et al., 2009; Lee et al., 2003; Lu & Austrom, 2005; Spira et al., 2010). Not only does caregiver functional status need to be enhanced, but caregivers' overall sense of satisfaction toward the experiences of caring with a positive attitude could also be increased. That is, the happier the life of a caregiver, overall HRQOL, is encouraged by both better physical capability and superior mental appraisal. In other words, caregivers' overall HRQOL results from both their physical and emotional factors of caregiving.

Interpretation based on the finding for Specific Aim 3. In summary, Specific Aim 3 examined whether the relationship between family caregiver functional status and overall HRQOL of family caregivers is mediated by the rewards of caregiving, controlling for all other variables. Interpretively, rewards of caregiving not only highly correlated to caregiver overall

HRQOL, but also partially mediated the relationship between caregiver functional status and overall HRQOL. That is, caregivers who had e the capacity to complete their life tasks are more likely to be happy or satisfied with their lives as a whole, increasing overall HRQOL. Caregivers would be even happier if they also positively perceived their caregiving roles as rewards. However, comparing caregiver overall HRQOL between groups with low and the high functional status when both groups have had high rewards of caregiving is of further concern. The results of such comparison would lead nurses and health care providers to assess how rewards of caregiving can improve overall HRQOL in the group with low functional status. The appropriate interventions or programs for enhancing rewards of caregiving, such as improving caregiver overall HRQOL, are needed.

### **Discussion of Additional Analysis**

As the findings show, rewards of caregiving significantly, partially mediates the relationship between family caregiver functional status and overall HRQOL of family caregivers. The results also reveal that rewards of caregiving is a crucial factor influencing caregiver overall HRQOL. In order to assess influences associated with rewards of caregiving, correlation analysis was performed among caregivers' and ECRs' individual characteristics, other independent factors, and rewards of caregiving. Furthermore, whether the number of religious activities—such as praying, meditating, going to the temple, offering food and things for monks, or donation for others—positively associate with family caregivers' rewards of caregiving has been tested.

The mean scores of rewards of caregiving indicate that female caregivers report higher rewards of caregiving and spousal caregivers report higher rewards of caregivers than did other elder relations. Caregiver sex, religious activities, household income, and social support are positively correlated with rewards of caregiving. Rewards of caregiving increase for female

caregivers and as caregivers participate in religious activities, report higher household income, and perceive more social support. Simultaneously, caregivers' relationship to elder negatively correlated with rewards of caregiving. If the caregivers were spouses, rewards of caregiving scores were higher than daughter caregivers' scores. Rewards of caregiving are the positive resources or benefit findings for caregivers, and appear to have an encouraging impact on overall HRQOL, as discussed above. Such results help pave the way to improve caregivers' HRQOL through supporting constructive perception in caring situations, such as motivating or encouraging participation in the desired religious activities. A private room with a Buddha image for praying, chanting, or meditating is a simple way to support and enhance some religious activities could be created by nurses in a ward.

Some previous studies in Thailand (Chaoum, 1996; Chatcheydang, 2005;

Cheewapoonphon, 1998; Stoller, 1994) have revealed that women are often socialized to be family caregivers and may be better prepared than men for the family caregiver role. Similarly, the results in this study show that female caregivers experience higher rewards of caregiving.

The results in Aim 3 show that caregivers who have better functional status tend to perceive higher rewards of caregiving and better HRQOL. Such findings may support the association between caregiving performance and health in men, which is stronger for men than for women. However, Pinquart and Sorensen (2007) found that male family caregivers had some positive attitudes in caregiving because they may be more likely to seek social support for their family caregiver roles when caregiving demands become too high. Even though sex correlates with rewards of caregiving, it is not a significant predictor of rewards of caregiving when entered into the linear regression model. That is, although male caregivers may have been stronger and able to complete more tasks than females can, female caregivers may have positive feelings about

caregiving. Female caregivers may be more prepared for caring roles and may report higher perceptions of positive view points. So, sex is not considered to have a significant impact on rewards of caregiving in this study.

Caregiver household income was found to be correlated with rewards of caregiving in this study. Similar to previous studies, those with higher household income levels are less likely to be affected by patient caregiving demands and more likely to have positive experiences of caregiving (Chatcheydang, 2005; Ekwall et al, 2004; Lawang et al., 2005; Pinquart & Sorensen, 2007). Caregivers with lower income levels frequently have to work harder to pay for their daily living expenses and tend to perceive caregiving as a burden (Chung et al. 2007; Lawang et al.; Sasat, 2006). Although, in this study, caregiver household income correlated with rewards of caregiving, it is not a significant predictor of rewards of caregiving when entered into the regression model. Higher household income may have helped caregivers perceive caregiving roles positively; however, their financial status alone does not impact rewards of caregiving in this study. This might be due to the fact that because most of caregivers in this study (68.1%, n = 137) have moderate to high household income.

When performing a linear regression model to assess for possible significant predictors of rewards of caregiving, total religious activities, social support, and relationship to elder were found to be significant predictors of rewards of caregiving. Daughter caregivers participating in more religious activities and perceiving greater social supports are more likely to have higher perceptions of rewards of caregiving.

*Religious activity.* Religious activity has the highest correlation with rewards of caregiving (see Table 16) and is the most significant predictor (see Table 18) of rewards of caregiving. The results show that all of the caregivers in the study were Buddhist. Buddhist

beliefs dictate that older Thais should be offered a high status, respect, and obedience from children and younger members of society. Children have an obligation to provide good care for their elders at home. Moreover, Thai people believe in the law of karma, meaning that good acts, words, or thoughts affect their future lives, and they wish to receive good care in return when they are older (Payomyong, 2000; Payutto, 1995, 1998; Sethabouppha, & Kane, 2005). Buddhist beliefs toward elders may impart a sense of obligation on caregivers to care for parents, and karma-based thought may create positive feelings, such as the rewards of caregiving, from assuming the role of family caregiver (Sethabouppha, & Kane, 2005). Following the law of karma, caregivers reported moderate to high religious activities, and the findings reveal that caregivers participated in more activities are more likely to perceive higher rewards of caregiving. That is, the caregivers who believe in Buddhism and the law of karma participate in good activities and responsibly care for their elders, easily accepting their roles and positively appraising their caregiving role as a one with rewards.

Relationship to ECR. Daughters comprised the majority of caregivers in this study, and daughter-elder relationships significantly predict rewards of caregiving. Inconsistently, previous research both in Thailand and other countries revealed that most of the caregivers of chronically ill elders were spouses of the patients (Chatcheydang, 2005; Joolamate, 1997; Kasemkitwattana, 2006; Sasat, 2006; Pinquart & Sorensen, 2007). In Thailand, an estimated 90% of elders live with their children or relatives at home in rural areas (MSDHS, 2007; Subgranon & Lund, 2000) because of these Buddhist belief-related reasons mentioned above (Sethabouppha, & Kane, 2005). As females, daughters are often socialized to be family caregivers and may be better prepared than men for the family caregiver role, as found in some previous studies (Chaoum, 1996; Chatcheydang, 2005; Cheewapoonphon, 1998; Stoller, 1994). Similarly, in Raschick and

Ingersoll-Dayton's (2004) study, they assessed the association between caregiver relationship and gender, and the costs and rewards of caregiving in a national sample of 978 spouse and child caregivers of older family members. Results supported studies' hypotheses that women, whether wives or daughters, experience more caregiving costs than men, and that adult children experience more rewards than spousal caregivers. For this study, daughters, the majority of caregivers (61.7%, n = 124), have positive rewards of caregiving because of generational caring situations, resulting from social beliefs and Thai culture which inculcates that the expected role of primary care is a female function. Daughters are taught to assume this role to show gratitude to their parents, and because daughters have more concern and better attitudes of care through the love, strong bonds, and closeness with the elders.

Social support. Perceived Social support, one of the most important resources for family caregivers, significantly predicts rewards of caregiving. Many caregivers could identify positive aspects of caregiving, such as rewards (Picot, 1995; Picot et al., 1997), gratifications (Motenko, 1989), or gains (Kramer, 1997) through support from family members, friends, and others. Similar to Chappell and Reid's (2002) study, social support was conceptualized as the caregivers' perceptions of support and resources from others and was found to positively affect rewards of caregiving (Chappell & Reid, 2002). Park and Lee (2007) and Oka et al. (2004) similarly found that social support might be a potentially modifiable factor associated with positive aspects in caregiving, particularly psychological levels in older family caregivers. Moreover, social support has been found to positively affect family caregivers' HRQOL by reducing their stressors and enhancing their rewards of caregiving (Chappell & Reid, 2002; Cohen, Colantonio, & Vernich, 2002; Northouse et al., 2002; Picot, 1995). Nurses and health care providers should appropriately assess caregivers' needs and help support and provide

sufficient resources required to enhance confidence in knowledge and skills for caregiving roles. As social support also included the provision for attachment, the social integration, and the availability of informational, emotional, and material assistance, training programs and discharge plans are needed to develop caregivers' knowledge and to build caregiving skill for enhancing caregivers' perceived social support. Nurses can offer and support some parts of the informational, emotional, and material assistance regarding elder conditions or diseases and their needs with those conditions and caregiving skills to perform care with those specific conditions. Having sufficient knowledge and skills would lead caregivers to assertively comprehend their roles as rewarding and benefit finding.

In conclusion, a reward of caregiving was a crucial factor influencing HRQOL and partially mediates the relationship between caregivers' functional status and their overall HRQOL.

Interpretation for additional results. Greater rewards of caregiving are significantly influenced when caregivers participate in more religious activities, perceive higher levels of social support, and have a daughter-elder relationship. Even though the relationship to elder can't be changed, other relations can be motivated to have higher perceptions of rewards of caregiving. Also, religious activities and social support are important caregiver resources which can be enhanced and promoted by nurses and health care providers both in hospitals and communities. Nurses and health care providers not only provide knowledge and skills in caring to enhance caregivers' resources, but also maintain and increase positive perceptions of rewards by supporting and encouraging caregivers to join religious activities.

#### **Study Limitations**

This study may have been subject to some limitations which related to threats to validity.

Threats to validity are reasons the conclusion or the inference of the study might be incorrect (Trochim & Donnelly, 2007). First, there may have been an inadequate number of relevant factors in the model or too many overlapping components of each concept to explore the full impact on caregiver overall HRQOL or predict it. Second, a relatively small convenience sample of rural Thai family caregivers and ECRs were enrolled; the generalizability of the study results to other Thai or Asian settings may be limited. Third, the cross-sectional study design limits the interpretation of study findings to the relationships among selected variables over time. That is, the descriptive nature of the design does not allow for a strong causal relationship between study measures. Because subjects were not selected randomly and the inclusion criteria were relatively broad, the findings cannot be generalized. Nonprobability sampling (convenience and purposive sampling) of the subjects and the fact that the study only applies to Buddhist also somewhat limit the heterogeneity of the sample characteristics.

Finally, although measures used in the study were self-administered questionnaires, the researcher read the questionnaires for those family caregivers who requested assistance or reported having difficulty completing the questionnaires. Thus, a social threat of researcher expectancy bias may exist. But the investigator carefully, informally communicated with the caregivers, so as not to create stressful situations, which might have made caregivers answer with the desired outcomes for study. In addition, the bias may have occurred if the caregivers' desired to look good, and might have lead them to react or respond in a very good way. This may be especially true with the rewards of caregiving; a bias may have caused high levels of rewards for some individuals. However, a mono-method bias in the future may be caused by using the same method, self-report, for all operationalization.

### **Implications for Nursing Practice**

The results of this study show that, in general, caregivers of ECRs reported good functional status and moderate to high rewards of caregiving, as well as overall HRQOL. However, this does not mean that caregivers were not vulnerable in their caregiving roles. Based on the relationships between variables found in this study, nurses and health care providers are able to maintain and enhance caregiver functional status by improving caregivers' abilities and skills to effectively deal with all of the elders' symptoms, even though they cannot reduce those symptoms. Older caregivers should have regular health checks and receive appropriate treatments if they have chronic health conditions. A caregiver's functional status as the ability to perform daily life tasks should be sustained in performing effective care through the trajectory of the disease and the process of care at home and in the community.

Moreover, findings show that older caregivers participating in more religious activities, had few chronic health conditions and better functional status, and perceived greater social support and rewards of caregiving have greater overall HRQOL. Positive aspects of caregiving—including religious activities, social support, and rewards of caregiving—as well as functional status are of concern for nurses and health care providers. Caregivers require not only physical ability and support in caregiving situation, but also sufficient positive or psychological support. Hospital and/or community health care providers may be able to improve caregivers' overall HRQOL by offering desired information and caregiving skills suited to their elders' conditions. In addition, in wards or primary care units, there could be a private room with the Buddha image for praying or chanting and meditating, where caregivers can participate in religious activities when their elders are admitted.

Also based on results from mediation testing, increasing the rewards of caregiving will

further enhance caregiver functional status, which positively impacts caregiver overall HRQOL. Nurses can help maintain and encourage caregivers' functional status by providing sufficient knowledge and training for the specific skills each caregiver needs, such as transferring elders and assisting with exercising, preparing meals, rehabilitating, or providing transportation. When caregivers are confident in caring and perform appropriate and effective care, they are not exhausted and do not negatively appraise their caring situations. In doing so, caregivers have better functional statuses and are empowered to positively perceive caring situations as rewards. Combined with additional results, the more religious activities caregivers participated in, the higher they appraised the rewards of caregiving. Nurses and health care providers can also offer more than a private room with the Buddha image. On the occasion of important days of Buddhism, monks could be invited to the hospital or care unit to give the Dharma talk, at which time the caregivers are able to offer food and things for monks, or to donate some money if they so desire. Developing a special unit in the community would help to counsel caregivers to manage all the symptoms and problems they experience at home if they cannot go to the hospital in the city. Training programs or discharge plans for caregivers of chronically ill elders are needed to support all the above mentioned issues, and to promote caregivers' functional status, which is expected to maintain and improve their HRQOL.

#### **Implications for Research**

Measuring HRQOL of the Thai family caregivers taking care of ECRs over time would be incredibly advantageous in order to reveal the effect of caregiving on caregiver overall HRQOL over time and to provide nursing interventions relevant to longitudinal experiences based on empirical findings. This study provided results of factors influencing caregiver overall HRQOL of chronically ill elders. It would be more useful in developing knowledge of family

caregivers if it investigated overall HRQOL of Thai caregivers taking care of elders with certain chronic diseases, such as cancer, stroke, dementia, or Alzheimer's disease. In future research, the negative aspect of caregiving or psychological health— such as depressive symptoms, anxiety, worry, or burden—of caregivers may be included to predict overall HRQOL. For example, the research question could be, "what is the relationship between worry of caregiving and overall HRQOL in caregivers of elder stroke survivors?" Whether or not rewards of caregiving are mediated, the relationship between worry of caregiving and overall HRQOL is of concern. Whether the rewards of caregiving can mediate the relationship between a negative aspect and overall HRQOL should be examined. Also, if the rewards of caregiving will be negatively or positively influence those relationships should also be investigated.

Moreover, this study highlights the need for further research to investigate the relationship between other negative consequences of caregiving and overall HRQOL. Some researchers have examined HRQOL and its influences on caregivers of elders with chronic illnesses and have found some negative health outcomes from providing long-term care at home, such as anxiety, stress, depression, and fatigue. All those negative outcomes should be added to predict HRQOL of caregivers of chronically ill elders. The rewards of caregiving should also be tested as a mediating effect in those relationships.

As a multidimensional outcome, nursing interventions for overall HRQOL might be approached in various ways. Also, HRQOL is defined as a subjective life quality related to how happy or satisfied someone is with his or her life as a whole, and is measured as subjective or psychosocial-related outcome. Therefore, because psychosocial variables have been linked to morbidity and mortality, the examination of non-pharmacological nursing interventions that guide clinical practice and improve patient outcomes are of interest and should be a focus.

Before conducting the intervention research, much more correlational and causal research, including longitudinal studies, is needed to confirm certain predictors, such as caregiver sex, functional status, social support, or religious activities, and the relationship between those existing predictors and caregiver HRQOL, cause and effect, and relevant influences of HRQOL, such as caregiver age and religious activities. Previous intervention research was conducted to maintain and improve patients' HRQOL in a variety of diseases, and such research should be developed for caregivers of those patients as well.

#### **Implications for Policy**

This study provided results which highlight the need for the development of policies and protocols to improve outcomes for caregivers of chronically ill elders. The increase in the chronically ill elderly population in Thailand has had a significant impact on families with ECRs and has resulted in worsening physical and mental health of many family caregivers. Currently, in Thailand all of the policy focuses on the patients, not the caregivers. As the results in this and previous studies show, caregivers should be taken care of in the same way. Caregivers are key persons continuing to take on the roles of caring for their chronically ill elders at home. The aim of caring for elders with chronic illnesses is not only to maintain health and delay death of ECRs, but also to maintain or improve HRQOL of their caregivers. In doing so, government and the Ministry of Public Health should promote policies that expand the elderly care workforce and policies to provide adequate funding for programs that assist family caregivers.

The concept of HRQOL has frequently been discussed as a key element of nursing practice and clinical outcome criteria. The evaluation of caregivers' overall HRQOL of chronically ill patients may enable health care providers to evaluate the impact of medical and nursing interventions on caregivers' lives and, ultimately, to produce information that may

improve health care and the quality of the population's lives. However, HRQOL is a complex concept that does not have a universal definition or a standard for its measurement. It must be defined clearly in order for it to be clinically useful, especially in HRQOL measurement. In Thailand, the Ministry of Public Health may propose the identification of key stages in HRQOL measurement for policy decisions, included selecting the salient descriptive characteristics relevant to health; choosing an operational definition and categorization of the selected characteristics; and standardizing an appropriate type of measurement. These stages would guide researchers to conduct productive research properly using HRQOL as an outcome. For this part, the Ministry of Public Health should request an annual budget and fund educational institutes of nursing for research not only on elders but also on family caregivers. Moreover, in a nursing student courses that focus on the elderly, the content of caregivers' problems and needs should not be ignored. Thus, funding would be provided for creating appropriate training programs to assist caregivers in continuing their home care with sufficient knowledge and skills supported and managing by nurses and health care providers.

The conceptual model of this study was based on the revised Wilson and Cleary model for HRQOL by Ferran et al. (2005). The results of this study did show that some of caregivers' and elders' characteristics and selected caregiving aspects were related to and had an influence on caregiver functional status and their overall HRQOL. The model worked well in predicting caregiver overall HRQOL, however, due to the small sample size and the low levels of elders' symptoms, disabilities, and caregiver tasks of care, it may possibly not detect all relationships as revealed in the model. More research for testing the model with more caregiving-related variables, including positive and negative aspects, should be done to confirm the significant factors influencing caregiver overall HRQOL.

#### **Conclusion/Summary**

The primary purpose of this study was to examine factors which may influence overall HRQOL levels of rural Buddhist Thai family caregivers caring for ECRs aged 60 and older who had one or more chronic conditions and at least two ADL deficits. Additionally, rewards of caregiving was tested to determine whether it exerts a mediating effect on the relationship between rural family caregiver functional status and overall caregiver HRQOL. Caregiver age, total religious activities, relationship to elder, caregiver chronic health conditions, social support, rewards of caregiving, and caregiver functional status were significant influences of better caregiver overall HRQOL. This is in comparison to younger caregivers who participated in fewer religious activities, were not daughters of the ECRs, had more chronic health conditions, experienced less social support, perceived lower rewards of caregiving, and reported worse functional status. Moreover, rewards of caregiving partially mediated the relationship between family caregiver functional status and overall HRQOL.

Additional analysis was performed in order to examine factors which may influence rewards of caregiving. Greater rewards of caregiving were significantly predicted by more religious activities in which the caregivers participated, higher social support, and daughter-elder relationships. Rewards of caregiving is one important resources predicting HRQOL and can be enhanced by those factors which relate to religious activities. This study contributes to the science by adding knowledge regarding what can make caregivers perceive more positive aspects, rewards, in Thai family caregiving which ultimately impacts overall HRQOL.

Supportive protocols and interventions need to be developed and provided in order to improve care for caregivers of chronically ill elders, done by improving caregivers' overall HRQOL.

**APPENDICES** 

## APPENDIX A

Study Instrument (Thai-Translated Version)

# ข้อมูลส่วนบุคคลของผู้ดูแล

โปรดตอบคำถามข้อมูลส่วนบุคคลต่อไปนี้ โดยเติมคำในช่องว่างและทำเครื่องหมายกากบาท หน้าข้อความที่เหมาะสมกับท่าน

1. อายุของผู้ดูแลปี (เติมตัวเล	ิจขอายุเป็	<b>่</b> นปี)				
2. เพศของผู้ดูแล (เลือกหนึ่งคำตอบ)	ชาย			หญิง		
3. ศาสนา (เลือกหนึ่งคำตอบ) พุทธคริสต์อิส	ลาม	อื่นๆ (โ	ปรดระบ)			
	านและพิ	จารณาว่าห	ที่ผ่านมา <sup>๊</sup> ท่	่านได้ปฏิบัติ	 iกิจกรรมเหล บสิ่งที่ท่านไ	ง่านี้ ด้ปฏิบัติ
Table A1						
Caregiver Religious Activities Questi	ions (Tha	ui)				
กิจกรรมทางศาสนา	วันละ ครั้ง	สัปดาห์ ละครั้ง	เดือน ละครั้ง	น้อยกว่า หนึ่งครั้ง ต่อเดือน	ไม่เคย ปฏิบัติ เลย	
สวดมนต์ไหว้พระ (เลือกหนึ่ง						
คำตอบ)						
นั่งสมาธิ์ (เลือกหนึ่งคำตอบ)						
ไปทำบุญที่วัด (เลือกหนึ่งคำตอบ)						
ตักบาตรทำบุญ (เลือกหนึ่งคำตอบ)						
บริจาคสิ่งของ (เลือกหนึ่งคำตอบ)						
อื่นๆ (โปรดระบุ)						
4. ความสัมพันธ์กับผู้สูงอายุ (เลือกหนึ่	<u> </u> เงคำตลาเ	)				
คู่สมรส (ภรรยา/สามี)						
		ง ≀ง ⁄ ב ≀ธ ว/ชาย น้อง	าสาว/ชาย			
บุตรเขย /สะใภั		าง 5 เอ ฆอง โ (โปรดระบ				
		1 ( 611 901 901	<del> </del>  /			
5. รายได้ของครอบครัว (บาท/เดือน) (	้เลือกหนึ่	งคำตอบ)				
ต่ำกว่า 2000 ิ	_	2001-5	000			
5001-10000	_	10000	และมากก	ว่า		
			ı	v		
6. โรคประจำตัว (จำนวนโรคที่เป็นทั้งเ	หมด) (เลื	อกทุกคำต	อบทีเกิดร	ขึ้น)		
ไม่มี						
ความดันโลหิตสูง						
เบาหวาน						
โรคหัวใจ						

โรคหลอดลมอักเสบเรือรัง	
ปวดหลัง	
โรคกระดูกเสื่อม	
(อื่นๆ) โปรดระบุ	
7. ระยะเวลาในการดูแลผู้สูงอายุ	เดือน (เติมตัวเลขระยะเวลาเป็นเดือน)
8. อายุของผู้สูงอายุปี (เติมตัวเล	งขอายุเป็นปี)
9. โรคที่เป็น	(เติมชื่อโรคที่ผู้ป่วยได้รับการวินิจฉัย)
10. เพศของผู้สูงอายุ (เลือกหนึ่งคำตอบ	)ชายหญิง
แบบวัดความสามา	เรถในการปฏิบัติกิจกรรมของผู้ดูแ <b>ล</b>
แบบสอบถามนี้ถามความคิดเห็นของคุณ	เกี่ยวกับสุขภาพของคุณ ข้อมูลนี้จะช่วยในการ
บันทึกว่าคุณรู้สึกอย่างไร และคุณสามาร	ถุทำกิจกรรมต่างๆ ได้ดีแค่ไหน ในแต่ละคำถาม ต่อไปนี้
โปรดทำเครื่อ๊งหมาย✔์ ลงหน้าข้อความท์	≀ี่ตรงกับความสามารถของท่านมากที่สุด
1.โดยทั่ว ๆ ไปสุขภาพของท่านเป็นอย่าง	งไร
ดีมากที่สุด (1)	
ดีมาก (2)	
ดี (3)	
พอใช้ (4)	
แย่ (5)	
	ว่าภาวะสุขภาพของท่านใน <u>ปัจจุบัน</u> ส่งผลให้ท่านม <u>ีข้อจำกัด</u>
	ำกัดมากน้อยเพียงใดโดยทำ เครื่องหมาย ✔ลง
หน้าข้อความที่ตรงกับระดับความจำกัดข	
2.กิจกรรมที่ออกแรงปานกลาง เช่น เลื่อเ	มโต๊ะ, กวาดบ้าน, ถูบ้าน
ใช่ จำกัดมาก (1)	
ใช่ จำกัดเล็กน้อย (2	2)
ไมู่จำกัดเลย (3)	
3.เดินขึ้นบันไดหลายขั้น (1 ชั้นหรือมาก <i>เ</i>	רֹכו)
ใช่ จำกัดมาก (1)	
ใช่ จำกัดเล็กน้อย (2	2)
ไม่จำกัดเลย (3)	
	เาว่า <u>ในช่วง 1 เดือนที่ผ่านมา</u> ท่านมีปัญหาเกี่ยว กับการ
	งเป็นผลมาจากสุขภาพกายของท่านหรือไม่ถ้ามีบ่อยครั้ง
เพียงใดโดยทำเครื่องหมาย✓ลงหน้าข้อ	
4.ทำงานหรือปฏิบัติกิจวัตรประจำวันได <u>้ส</u> ์	<u>าเร็จน้อยกว่า</u> ที่อยากทำ
ตลอดเวลา (1)	
เป็นส่วนมาก (2)	
เป็นบางครั้ง (3)	
นานๆครั้ง (4)	
ไม่เลย (5)	

5.ถูกจำกัด <u>ชนิด</u> ของงาน หรือ ทำกิจกรรมบางที่สามารถทำได้
ตลอดเวลา (1)
เป็นส่วนมาก (2)
เป็นบางครั้ง (3)
นานๆครั้ง (4)
ไม่เลย (5)
กรุณาอ่านข้อความต่อไปนี้แล้วพิจารณาว่า <u>ในช่วง 1 เดือนที่ผ่านมา</u> สภาพทางด้าน <u>อารมณ์</u> ของท่าน
เช่นรู้สึกซึมเศร้าหรือกังวลทำให้ท่านมีปัญหาเกี่ยวกับการทำงาน หรือการปฏิบัติกิจวัตรประจำวัน
บ่อยครั้งเพียงใด ให้ทำเครื่องหมาย√ลงหน้าข้อความที่ตรงกับระดับปัญหาข้องท่าน
6.ทำงานหรือทำกิจวัตรประจำวันได <u>้สำเร็จน้อยกว่า</u> ที่ท่านอยากจะทำ
ตลอดเวลา (1)
เป็นส่วนมาก (2)
เป็นบางครั้ง (3)
นานๆครั้ง (4)
ไม่เลย (5)
7.ทำงานหรือกิจกรรมอื่นๆ ด้วย <u>ความระมัดระวังน้อย</u> กว่าปกติ
ตลอดเวลา (1)
เป็นส่วนมาก (2)
เป็นบางครั้ง (3)
นานๆครั้ง (4)
ไม่เลย (5)
8. <u>ในช่วง 1เดือนที่ผ่านมา</u> ท่าน <sup>์</sup> มีอาการเจ็บปวดในร่างกาย มากน้อยเพียงใด
ไม่มีเลย (1)
เล็กน้อย (2)
ปานกลาง (3)
มาก (4)
มากที่สุด (5)
กรุณาอ่านข้อคำถามต่อไปนี้ ซึ่งถามเกี่ยวกับความรู้สึกของท่านและสิ่งที่เกิดขึ้นใน <u>ช่วง 1 เดือนที่</u>
<u>ผ่านมา</u> แล้วทำเครื่องหมาย ✔ ลงในหนาข้อความที่ตรงหรือใกล้เคียงกับความรู้สึกของท่านให้มาก
ที่สุด
9.ท่านมีความรู้สึกสงบและเป็นสุข
ตลอดเวลา (1)
เป็นส่วนมาูก (2)
เป็นบางครั้ง (3)
ุนานๆครั้ง (4)
ไม่เลย (5)
10.ท่านมีพละกำลังเป็นอย่างมาก
ตลอดเวลา (1)
เป็นส่วนมาก (2)
เป็นบางครั้ง (3)
นานๆครั้ง (4)
ไม่เลย (5)

11.ท่านรู้สึกท้อแท้ใจและซึมเศร้า
ตลอดเวลา (1)
เป็นส่วนมาก (2)
เป็นบางครั้ง (3)
ุนานๆครั้ง (4)
ไม่เลย (5)
12. <u>ในช่วง 1 เดือนที่ผ่านมา</u> ปั๊ญหาทางสุขภาพและอารมณ์ของท่านเป็นอุปสรรคในการทำกิจกรรม
ทางด้านสังคม เช่น ไปเยี่ยมเพื่อน/ ญาติ มากน้อยเพียงใด
ตลอดเวลา (1)
เป็นส่วนมาก (2)
เป็นบางครั้ง (3)
นาน ๆ ครั้ง (4)
ไม่เลย (5)
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**แบบประเมินการได้รับการสนับสนุนส่วนบุคคล** <u>คำชี้แจง</u> ข้อความต่อไปนี้ บางท่านอาจจะเห็นด้วย บางท่านอาจจะไม่เห็นด้วย โปรดอ่าน ข้อความ ในแต่ละข้อ และวงกลมในข้อที่ท่านเห็นว่าเป็นข้อที่ตรงกับความคิดเห็นของท่าน มากที่สุด ไม่มี คำตอบถูกหรือผิด

Table A2 Personal Resource Questionnaire Part II (PRQ85-II; Thai)

	ไม่เห็นด้วยอย่างยิ่ง	ไม่เห็นด้วย	ค่อนข้างที่จะไม่เห็น ด้วย	เสยา	ค่อนข้างเห็นด้วย	เห็นด้วย	เห็นด้วยอย่างยิ่ง
1.ฉันมีคนที่ฉันรู้สึกใกล้ชิดสนิทสนมซึ่งทำให้ฉันรู้สึก	1	2	3	4	5	6	7
อบอุ่นปลอดภัย 2.ฉันมีกลุ่มเพื่อนหรือเพื่อนบ้านซึ่งทำให้ฉันรู้สึกว่าฉันมี ความสำคัญในกลุ่ม	1	2	3	4	5	6	7
3.คนรอบข้างหรือเพื่อนร่วมงานบอกหรือแสดงให้ฉันรู้ ว่า ฉันทำงานได้ดี (งานบ้านหรือที่ทำงาน)	1	2	3	4	5	6	7
4.ฉันไม่สามารถพึ่งพาญาติและเพื่อนที่จะช่วยเหลือฉัน เมื่อฉันมีปัญหา	1	2	3	4	5	6	7
5. ฉันรู้สึกว่าฉันเป็นคนมีค่าสำหรับญาติและหรือเพื่อนๆ	1	2	3	4	5	6	7
6.ฉันใช้เวลาพูดคุยหรือทำกิจกรรมร่วมกับคนที่มีความ สนใจในเรื่องคล้ายๆกัน	1	2	3	4	5	6	7
7.ฉันไม่ค่อยได้เป็นผู้ให้ หรือช่วยเหลือผู้อื่น	1	2	3	4	5	6	7
8.คนรอบข้างหรือเพื <sup>่</sup> อนๆ แสดงให้ฉันรู้ว่ <sup>า</sup> เขาชอบที่ได้ ทำงานร่วมกับฉัน	1	2	3	4	5	6	7
9.ถ้าฉันต้องการความช่วยเหลือที่ต้องใช้เวลานานพอ สมควร มีคนพร้อมที่จะสละเวลาช่วยเหลือฉัน	1	2	3	4	5	6	7
10.ฉันไม่รู้จะระบายความรู้สึกกับใครเมื่อฉันมีปัญหา หรือไม่สบายใจ	1	2	3	4	5	6	7
11.ฉันและเพื่อนจะช่วยเหลือซึ่งกันและกัน	1	2	3	4	5	6	7
12.ฉันได้มีส่วนช่วยให้เพื่อนหรือคนรู้จักสามารถทำงานได้ ดีขึ้น	1	2	3	4	5	6	7
13.ครอบครัวของฉันแสดงให้ฉันทราบว่าฉันมีความ สำคัญกับเขา	1	2	3	4	5	6	7

Table A2 (cont'd)

Table A2 (cont'd)							
	ไม่เห็นด้วยอย่างยิ่ง	นให้นด้วย	ค่อนข้างที่จะไม่เห็นด้วย	ធ្វេច	^ <u>ค่อนข้างเห็นด้วย</u>	0 เห็นด้วย	^ เห็นด้วยอย่างยิ่ง
14.ฉันมีญาติหรือเพื่อนที่พร้อมที่จะช่วยเหลือฉันถึง แม้ว่า	1	2	3	4	5	6	7
ฉันจะไม่สามารถตอบแทนเขาได้		_	_		_	_	_
15 เมื่อฉันรู้สึกไม่สบายใจฉันมีคนใกล้ชิดที่เข้าใจฉัน และ	1	2	3	4	5	6	7
ทำให้ฉันรู้สึกเป็นตัวของตัวเอง							
16.ฉันรู้สึกว่าไม่มีใครมีปัญหามากเท่าฉัน	1	2	3	4	5	6	7
17.ฉันรู้สึกมีความสุขที่จะทำสิ่งพิเศษเล็กๆน้อยๆ ที่ทำให้	1	2	3	4	5	6	7
ผู้อื่นพอใจ							
18.ฉันรู้สึกว่ามีคนชื่นชมฉัน	1	2	3	4	5	6	7
19.ฉันมีคนที่รักและห่วงใยฉัน	1	2	3	4	5	6	7
20.ฉันมีเพื่อนที่จะคุย เที่ยว หรือทำอะไรด้วยกัน	1	2	3	4	5	6	7
21 ฉันมีความรับผิดชอบในการช่วยเหลือผู้อื่น	1	2	3	4	5	6	7
22.ถ้าฉันต้องการคำแนะนำ มีคนพร้อมที่จ <sup>ะ</sup> ช่วยฉัน	1	2	3	4	5	6	7
23.ฉันมีความรู้สึกว่าฉันเป็นที่ต้องการของเพื่อน ญาติ หรือ	1	2	3	4	5	6	7
คนที่รู้จัก							
24.มีค <sup>ื</sup> นคิดว่าฉันไม่ได้เป็นเพื่อนที่ดีอย่างที่ฉันควรจะเป็น	1	2	3	4	5	6	7
25.ถ้าฉันป่วย มีคนที่จะให้คำแนะนำฉันในการดูแลตนเอง	1	2	3	4	5	6	7

**แบบวัดรางวัลที่ได้รับจากการดูแล** (Rewards of Caregiving) จากหัวข้อแต่ละหัวข้อต่อไปนี้ โปรดพิจารณาเลือกคำตอบที่บ่งชี้ถึงระดับความคิดเห็น ของท่านต่อ สถานการณ์การดูแลผู้สูงอายุด้านต่างๆ คำตอบแต่ละข้อไม่มีความหมายว่า ถูกหรือผิดอย่างแท้จริง หากคำตอบที่มีใม่ตร<sup>ง</sup>กั๊บความรู้สึกของท่านทีเดียว กรุณาวงกลม ตัวเลขที่ใก<sup>้</sup>ล้เคียงกับระดับความ คิดเห็นของท่านมากที่สุดและโปรดตอบข้อคำถามทุกข้อ

Table A3 Rewards of Caregiving (Thai)

	ไม่ เลย	เล็ก น้อย	ปาน กลาง	ค่อน ข้าง มาก	มาก ที่สุด
1.การดูแลผู้ป่วยช่วยให้ท่านรู้สึกว่าท่านได้ทำความดี มากน้อยเพียงใด	0	1	2	3	4
2.การดูแลผู้ป่วยช่วยให้ท่านเข้าใจตัวท่านเองเมื่อ ต้อง เจ็บป่วยมากน้อยเพียงใด	0	1	2	3	4
3.การดูแลผู้ป่วยช่วยให้ท่านรู้สึกว่าท่านได้สร้างกุศล ผลบุญมากน้อยเพียงใด	0	1	2	3	4
4.การดูแลผู้ป่วยช่วยให้ท่านรู้สึกว่าท่านได้ทำในสิ่งที่ มี ความ สำคัญมากน้อยเพียงใด	0	1	2	3	4
5.การดูแลผู้ป <sup>ั</sup> ้วยช่วยให้ท่านรู้สึกปลื้มปิติมากน้อย เพียงใด	0	1	2	3	4
6.การดูแลผู้ป่วยช่วยให้ท่านรู้สึกว่าเป็นการแสดง ความ กตัญญู/ร่วมทุกข์ร่วมสุขต่อผู้ป่วยมากน้อย เพียงใด	0	1	2	3	4
7.ท่านคิดว่าการดูแลผู้ป่วยช่วยให้ท่านมีชีวิตที่ดีใน ชาติ นี้หรือชาติหน้ามากน้อยเพียงใด	0	1	2	3	4
8.การดูแลผู้ป่วยช่วยฐานะทางการเงินของท่านโดย ที่ไม่ คาดคิดมาก่อน เช่น ได้รับมรดกหรือเงินรางวัล จากญาติ ที่มาเยี่ยม	0	1	2	3	4
9.การดูแลผู้ป่วยช่วยให้ท่านมีความรู้สึกที่ดีต่อตัวท่าน เอง มากน้อยเพียงใด	0	1	2	3	4

Table A3 (cont'd)

Table A3 (cont d)	ไม่	เล็ก	ปาน	ค่อน	มาก
	เลย	น้อย	กลาง	ข้าง	ที่สุด
				มาก	,
10.การดูแลผู้ป่วยช่วยให้ผู้อื่นเห็นความสำคัญของ	0	1	2	3	4
การ ดูแล้มาก๊น้อยเพียงใด ้					
11.ก ้ารดูแลผู้ป่วยช่วยให้ชีวิตของท่านมีความหมาย	0	1	2	3	4
มากขึ้นมากน้อยเพียงใด					
12.การดูแลผู้ป่วยที่บ้านช่วยให้ท่านมีความคล่องตัว	0	1	2	3	4
ด้าน การเงินมากกว่าการให้ผู้ป่วยไปอยู่โรงพยาบาล					
หรือสถาน พยาบาลมากน้อยเพียงใด					
13.การดูแลผู้ป่วยช่วยให้คนในครอบครัวของท่าน	0	1	2	3	4
ใกล้ชิด สนิทสนมกันมากน้อยเพียงใด					
14.การดูแลผู้ป่วยช่วยให้ท่านรู้สึกประสบความสำเร็จ	0	1	2	3	4
ในบทบาทของการเป็นผู้ดูแลมากน้อยเพียงใด					
15.การดูแลผู้ป่วยช่วยให้ท่านรู้สึกว่าได้ตอบแทน	0	1	2	3	4
บุญคุณ ผู้ป่วยมากน้อยเพียงใด					
16.การดูแลผู้ป่วยช่วยให้ท่านรู้สึกว่าท่านได้ช่วยชีวิต	0	1	2	3	4
ของผู้ป่วยให้ดีขึ้นมากน้อยเพียงใด					
1ฺ7.ท่านรู้สึกภูมิใจมากน้อยเพียงใดที่ท่านเป็นคนหนึ่ง	0	1	2	3	4
ที่ให้การดูแลผู้ป่วย					
18.การดูแลผู้ป่วยเป็นประสบการณ์ที่ท่านพึงพอใจ	0	1	2	3	4
มาก น้อยเพียงใด					
19.การดูแลผู้ป่วยทำให้ท่านมีความสุขมากน้อย	0	1	2	3	4
เพียงใด					
20.การดูแลผู้ป่วยช่วยให้ท่านรู้สึกว่าท่านมี	0	1	2	3	4
คุณประโยชน์ ต่อผู้ป่วยมากน้อยเพียงใด					
21.การดูแลผู้ป่วยช่วยให้ทู่านและผู้ป่วยมีความ	0	1	2	3	4
ใกล้ชิด สนิทสนมกันมากขึ้นมากน้อยเพียงใด					
22.การดูแลผู้ป่วยช่วยให้ท่านเรียนรู้เกี่ยวกับการดูแล	0	1	2	3	4
สุขภาพมากน้อยเพียงใด					

Table A3 (cont'd)

Table A3 (cont d)					
	ไม่ เลย	เล็ก น้อย	ปาน กลาง	ค่อน ข้าง มาก	มาก ที่สุด
23.การดูแลผู้ป่วยช่วยให้ท่านปรับตัวเองไปในทางที่ดี ขึ้น เช่น ใจเย็นมากขึ้น ,อดทนมากขึ้น ,มีความ อ่อนโยนมากขึ้น มากน้อยเพียงใด	0	1	2	3	4
24.การที่ผู้ป่วยหรือบุคคลอื่นแสดงความชื่นชมหรือ ซาบซึ้งที่ท่านให้การดูแล ถือเป็นรางวัลสำหรับท่าน มากน้อยเพียงใด	0	1	2	3	4
25.การดูแลผู้ป่วยช่วยให้ท่านรักหรือรู้สึกดีกับผู้ป่วย มากน้อยเพียงใด	0	1	2	3	4
26.การดูแลผู้ป่วยช่วยให้ท่านดูแลสุขภาพของตนเอง ดีขึ้นมากน้อยเพียงใด	0	1	2	3	4
27.การดูแลผู้ป่วยช่วยให้ท่านชื่นชมหรือภาคภูมิใจคน ในครอบครัวมากน้อยเพียงใด	0	1	2	3	4

# แบบประเมินสมรรถภาพผู้สูงอายุ

จากหัวข้อแต่ละกิจกรรมต่อไปนี้ โปรดพิจารณาเลือกคำตอบที่บ่งชี้ถึงระดับความสามารถของ ผู้สูงอายุในการปฏิบัติกิจกรรมนั้นๆ โดยใส่ตัวเลข (0, 5, 10, หรือ 15) ลงในช่องว่าง

<u>กิจกรรม</u>	<u>คะแนนการประเมิน</u>
การรับประทานอาหาร	
0=ทำไม่ได้เลย	
	บางส่วน หรือต้องการอาหารพิเศษ/ อาหารเฉพาะโรค
10 = ทำได้เอง	
การอาบน้ำ	
0=ทำไม่ได้เลย	
5 = ทำได้แต่ต้องการความช่วยเหลือง	<u></u>
การดูแลสุขลักษณะส่วนตัว	
0=ต้องการความช่วยเหลือในการดูแ	ลสุขลักษณะส่วนตัว
5 = ทำได้เอง (ล้างหน้า หวีผม แปรงท์	งัน โกนหนวด โดยมีผู้เตรียมอุปกรณ์ให <i>้</i> )
การใส่เสื้อผ้า	
0=ทำไม่ได้เลย	
5= ทำได้แต่ต้องการความช่วยเหลือเ	<u> </u>
10 = ทำได้เอง (รวมถึงการติดกระดุม,	รูดซิบ, ผูกเชือกรองเท้า และอื่นๆ)
การควบคุมการขับถ่ายอุจจาระ	
0 = ควบคุมการูขับถ่ายอุจจาระไม่ได้ (	
$5=$ ควบคุม/กลั้นอุจจาระไม่ได้เป็นบา $\cdot$	งครั้ง
10= ควบคุมการขับถ่ายอุจจาระได้	
การควบคุมการขับถ่ายปัสสาวะ	
	(กลั้นไม่ได้) หรือใส่สายสวนปัสสาวะค้างไว้
5= ควบคุม/กลั้นปัสสาวะไม่ได้เป็นบา	งครั้ง
10=คูวบคุมการขับถ่ายปัสสาวะได้	
การใช้ห้องน้ำ	
0=ทำไม่ได้เลย	
5 = ทำได้ด้วยตัวเองแต่ต้องการความ	ช่วยเหลือบางส่วน
10=ทำได้ด้วยตัวเอง (เปิดและปิด, แ	ต่งตัว, ทำความสะอาด)
การเคลื่อนย้าย (ระหว่างเตียงและเก้าอี้)	
0=ทำไม่ได้เลย, ไม่สามารถนั่งได้	
5 = สามารถนั่งได้, ต้องการความช่วยเ	เหลือเป็นส่วนใหญ่ (ต้องการผู้อื่นช่วยในระหว่างการ
เคลื่อนย้าย)	
10=ต้องการความช่วยเหลือเล็กน้อย	
15 = สามารถเคลื่อนย้ายได้ด้วยตัวเอ <sub>ง</sub>	<u></u>
การเคลื่อนที่ (เคลื่อนที่ในแนวราบ)	
0= ไม่สามารถเคลื่อนที่ได้ด้วยตัวเอง	
	าั้งเข็นรถเลี้ยวได้, เคลื่อนที่ได้มากกว่า 45 เมตร
10 – เดินได้ด้วยตนเองนากกว่า 45 เน	ตรแต่ต้องการผ้าว่าเมหลือ 1 คม

15 = เดินได้ด้วยตนเองหรือร่วมกับอุปกรณ์ช่วยเดินโดยไม่ต้อง	งมีผู้ดูแลได้มากกว่า 45 เมตร
<b>การขึ้นลงบันได</b> 0 = ไม่สามารถขึ้นลงบันไดได้เลย	
5 = สามารถขึ้นลงบันไดได้แต่ต้องการความช่วยเหลือ 10 = สามารถขึ้นลงบันไดได้เอง	
คะแนนรวม (0–100):	
สลรักเสองการี การสลากร์กรับใกละโรกการการกี่ การสามา การการกิ	

สนับสนุนโดยศูนย์ผู้ป่วยโรคหลอดเลือดสมองทางคอมพิวเตอร์ - www.strokecenter.org

# แบบประเมินอาการของผู้สูงอายุ (MSAS)

ส่วนที่ 1. มีอาการทั้งหมด 24 อาการให้ท่านอ่านและพิจารณาว่าในหนึ่งเดือนที่ผ่านมาผู้สูงอายุมี อาการเหล่านี้หรือไม่ ถ้ามี <u>เกิดขึ้นบ่อยครั้งเพียงใด</u> <u>รุนแรงเพียงใด</u> และอาการเหล่านี้<u>รบกวนผู้สูงอายุ มากน้อยเพียงใด</u> โปรดวงกลมตัวเลขที่เหมาะสมกับอาการที่เกิดขึ้น ถ้าไม่เกิดขึ้นให้ทำเครื่องหมาย X ลงในช่อง "ไม่มีอาการ"

Table A4

Memorial Symptoms Assessment Scale – Section 1 (Thai)

ระหว่างหนึ่งเดือนที่ผ่าน		<u>ถ้ามี</u> เกิดขึ้นบ่อย เพียงใด			<u>ถ้ามี</u> อาการรุนแรง เพียงใด				<u>ถ้ามี</u> อาการที่เกิดขึ้น รบกวนผู้สูงอายุ มากน้อยเพียงใด					
<u>มา</u> ผู้สูงอายุมีอาการเหล่านี้ เกิดขึ้นหรือไม่?	ใม่มีอาการ	แทบจะไม่เกิดขึ้น	เป็นบางครั้ง	บ่อย	เกือบจะสม่าเสมอ	เล็กน้อย	ปานกลาง	iniso	รุ่นแรงมาก	ใม่รบกวน	รบกวนเล็กน้อย	รบควนปานคลาง	รบกวนค่อนข้างมาก	รบควนมาค
มีปัญหาในการมุ่งจุด		1	2	3	4	1	2	3	4	0	1	2	3	4
สนใจทำสิ่งใดสิ่งหนึ่ง														
ความเจ็บปวด		1	2	3	4	1	2	3	4	0	1	2	3	4
หมดกำลัง, อ่อนเพลีย		1	2	3	4	1	2	3	4	0	1	2	3	4
ไอ		1	2	3	4	1	2	3	4	0	1	2	3	4
ประหม่า/กระวนกระวาย		1	2	3	4	1	2	3	4	0	1	2	3	4
ปากแห้ง		1	2	3	4	1	2	3	4	0	1	2	3	4
คลื่นใส้		1	2	3	4	1	2	3	4	0	1	2	3	4
รู้สึกเซื่องซึม		1	2	3	4	1	2	3	4	0	1	2	3	4
ชามือและเท้า		1	2	3	4	1	2	3	4	0	1	2	3	4
มีปัญหาในการนอนหลับ		1	2	3	4	1	2	3	4	0	1	2	3	4
อึดอั๊ดแน่นท้อง		1	2	3	4	1	2	3	4	0	1	2	3	4
มีปัญหาการขับถ่าย		1	2	3	4	1	2	3	4	0	1	2	3	4
ปัสสาวะ														
อาเจียน		1	2	3	4	1	2	3	4	0	1	2	3	4
หายใจสั้น		1	2	3	4	1	2	3	4	0	1	2	3	4
ท้องเสีย		1	2	3	4	1	2	3	4	0	1	2	3	4
รู้สึกเศร้า		1	2	3	4	1	2	3	4	0	1	2	3	4
เหงื่อออกมาก		1	2	3	4	1	2	3	4	0	1	2	3	4
วิตกกังวล		1	2	3	4	1	2	3	4	0	1	2	3	4

Table A4 (cont'd)

Table A4 (cont d)														
ระหว่างหนึ่งเดือนที่ผ่าน			<u>มี</u> าขึ้นา บงใด			อาก	<u>ถ้ามี</u> อาการรุนแรง อาการที่เ <i>ก</i> ็ เพียงใด รบกวนผู้สู มากน้อยเ				ผู้สูง	สูงอายุ		
<u>มา</u> ผู้สูงอายุมีอาการเหล่านี้ เกิดขึ้นหรือไม่?	ใม่มีอาการ	แทบจะใม่เกิดขึ้น	เป็นบางครั้ง	บ่อย	เกือบจะสม่าเสมอ	เล็กน้อย	ปานกลาง	innes	รุนแรงมาก	ใม่รบกวน	รบกวนเล็กน้อย	รบควนปานกลาง	รบกวนค่อนข้างมาก	รบควนมาก
มีปัญหาเกี่ยวกับการมี เพศสัมพันธ์		1	2	3	4	1	2	3	4	0	1	2	3	4
อาการคัน		1	2	3	4	1	2	3	4	0	1	2	3	4
ความอยากอาหารลดลง		1	2	3	4	1	2	3	4	0	1	2	3	4
เวียนศีรษะ		1	2	3	4	1	2	3	4	0	1	2	3	4
กลืนลำบาก		1	2	3	4	1	2	3	4	0	1	2	3	4
รู้สึกหงุดหงิดโมโหง่าย		1	2	3	4	1	2	3	4	0	1	2	3	4

ส่วนที่ 2. มีอาการทั้งหมด 8 อาการให้ท่านอ่านและพิจารณาว่าในหนึ่งเดือนที่ผ่านมาผู้สูงอายุมี อาการเหล่านี้หรือไม่ ถ้ามี อาการเหล่านั้นรุนแรงเพียงใดและรบกวนผู้สูงอายุมากน้อยเพียงใด โปรด วงกลมตัวเลขที่เหมาะสมกับอาการที่เกิดขึ้น ถ้าไม่มีอาการ ให้ทำเครื่องหมาย X ลงในช่อง "ไม่มี อาการ"

Table A5

Memorial Symptoms Assessment Scale – Section 2 (Thai)

<u>ระหว่างหนึ่งเดือนที่ผ่านมา</u>	lo.	<u>ถ้ามี</u> อาการรุนแรง เพียงใด				ผู้สูง	ารที่เ	รที่เกิดขึ้นรบกวน วายุมากน้อย ใด				
ผู้สูงอายุมีอาการเหล่านี้เกิดขึ้น หรือไม่?	ใม่มีอาการ	เล็กน้อย	ปานกลาง	esint	ษะเรงมาก	ไม่รบกวน	รบกวนเล็กน้อย	รบควนปานคลาง	รบกวนค่อนข้างมาก	รบกวนมาก		
แผลในปาก		1	2	3	4	0	1	2	3	4		
การรับรสอาหารเปลี่ยนแปลง		1	2	3	4	0	1	2	3	4		
น้ำหนักลด		1	2	3	4	0	1	2	3	4		
ผมร่วง		1	2	3	4	0	1	2	3	4		
ท้องผูก		1	2	3	4	0	1	2	3	4		
แขนหรือขาบวม		1	2	3	4	0	1	2	3	4		
''ฉันรู้สึกไม่ชอบตัวเอง''		1	2	3	4	0	1	2	3	4		
มีการเปลี่ยนแปลงของผิวหนัง		1	2	3	4	0	1	2	3	4		
ถ้าผู้สูงอายุมีอาการอื่นๆ ในระหว่างหนึ่งเดือนที่ผ่านมา โปรดเติมลงในช่องด้านล่าง และระบุว่า อาการเหล่านั้นรบกวนผู้สูงอายุมากน้อยเพียงใด												
อาการอื่นๆ:	•					0	1	2	3	4		
อาการอื่นๆ:						0	1	2	3	4		

## แบบประเมินภาระหน้าที่ในการดูแล (OCBS)

คำถามเหล่านี้ถามเกี่ยวกับภาระหน้าที่และกิจกรรมที่ท่านทำเพื่อช่วยเหลือผู้สูงอายุ ในแต่ละข้อ คำถามให้ท่านระบุว่าท่าน<u>ใช้เวลาในการทำกิจกรรม</u>เหล่านั้นมากน้อย เพียงใด และการปฏิบัต<u>ิแต่ละ</u> กิจกรรมมีความยากมากน้อยเพียงใด

เวลา 5 = 2 ใช้เวลามากที่สุด ความยาก 5 = 2 ยากมากที่สุด 4 = 2 ใช้เวลาค่อนข้างมาก 4 = 2 ยากมาก 3 = 2 ใช้เวลาปานกลาง 2 = 2 ใช้เวลาเล็กน้อย 2 = 2 ยากเล็กน้อย 2 = 2

Table A6

Oberst Caregiving Burden Scale (Thai)

		เวล	ลาที่'	ใช้		ความยาก					
ภาระหน้าที่และกิจกรรมที่ท่านทำเพื่อ ช่วยเหลือผู้สูงอายุ:	ไม่มาก	เล็กน้อย	เานกลาง	ค่อนข้างมาก	มากที่สุด	ใม่ยาก	ยากเล็กน้อย	ยากปานกลาง	ยะเลก	ยากมากที่สุด	
1. กิจกรรมการรักษาทางการแพทย์และการ พยาบาล (ให้ยา, ดูแลผิวหนัง, ทำแผล	1	2	3	4	5	1	2	3	4	5	
୩ <b>ର</b> ୩):	1	2	2	4		1	2		4		
2. กิจกรรมส่วนบุคคล (อาบน้ำ, ขับถ่าย, แต่งตัว, ให้อาหาร, ฯลฯ):	1	2	3	4	5	1	2	3	4	5	
3. ช่วยเหลือในการเดิน ลุกออกและ กลับ เข้าเตียง, ออกกำลังกาย, ฯลฯ:	1	2	3	4	5	1	2	3	4	5	
4. การสนับสนุนด้านอารมณ์, การอยู่กับ     ผู้สูงอายุ:	1	2	3	4	5	1	2	3	4	5	
5. เฝ้าดูและรายงานอาการของผู้สูงอายุ, เฝ้าดูว่าเป็นอย่างไร และดูความก้าวหน้า ของอาการต่างๆ:	1	2	3	4	5	1	2	3	4	5	
6. ช่วยเหลือในการเดินทางหรือร่วมทำ กิจกรรม (ขับรถ, ขี่จักรยานด้วัยกัน, การ นัด หมาย และขับรถให้ในงานที่ผู้สูงอายุขอ:	1	2	3	4	5	1	2	3	4	5	
7. จัดการเกี่ยวกับค่าใช้จ่ายเกี่ยวกับ ความ เจ็บป่วยของผู้สูงอายุ:	1	2	3	4	5	1	2	3	4	5	
8. งานในบ้านอื่นๆ (ซักผ้า, ทำอาหาร, ทำ ความสะอาด, ทำสวน, ซ่อมบ้าน, ฯลฯ):	1	2	3	4	5	1	2	3	4	5	

Table A6 (cont'd)

Table A6 (cont d)		เวล	ลาที่'	ใช้			คว	ามย	าก	
ภาระหน้าที่และกิจกรรมที่ท่านทำเพื่อช่วย เหลือผู้สูงอายุ:	ใม่มาก	เล็กน้อย	ปานกลาง	ค่อนข้างมาก		ใม่ยาก	ยากเล็กน้อย	ยากปานกลาง	ยากมาก	
9. งานนอกบ้านอื่น (ซื้ออาหารและเสื้อผ้า, ไปธนาคาร, จัดการงานอื่นๆที่ร้องขอ, ฯลฯ:	1	2	3	4	5	1	2	3	4	5
10. วางแผนเกี่ยวกับกิจกรรมสำหรับผู้สูง อายุ (งานอดิเรก, การพักผ่อน, อาหาร, และ อื่นๆ ที่ผู้สูงอายุควรทำ):	1	2	3	4	5	1	2	3	4	5
11. จัดการกับปัญหาพฤติกรรมของผู้สูงอายุ (อารมณ์เสีย, หงุดหงิด, สับสน, หลงลืม, ฯลฯ):	1	2	3	4	5	1	2	3	4	5
12. จัดหาและจัดการบุคคลเพื่อดูแลผู้สูง อายุเมื่อท่านจะไม่อยู่บ้าน:	1	2	3	4	5	1	2	3	4	5
13. กิจกรรมการติดต่อสื่อสาร (ช่วยเรื่อง โทรศัพท์, เขียนหรืออ่าน, อธิบายสิ่งต่างๆ, พยายามเข้าใจสิ่งที่ผู้สูงอายุพูด, ฯลฯ):	1	2	3	4	5	1	2	3	4	5
14. ประสานงาน, จัดการ, และบริหารเกี่ยว กับบริการและสิ่งสนับสนุนต่างๆ (นัดแพทย์, จัดยานพาหนะ, อำนวยความสะดวกในการ จัดสิ่งของและอุปกรณ์ต่างๆ, และจัดหา สิ่ง สนับสนุนภายนอก):	1	2	3	4	5	1	2	3	4	5
15. หาข้อมูลและพูดคุยกับแพทย์, พยาบาล และบุคลากรสุขภาพอื่นๆ เกี่ยวกับ สภาพ ของผู้สูงอายุและแผนการรักษา:	1	2	3	4	5	1	2	3	4	5

#### ดัชนีคุณภาพชีวิต (Quality of Life Index) ชุดที่หนึ่ง แบบประเมินระดับความพึงพอใจ

จากหัวข้อแต่ละหัวข้อต่อไปในี้ โปรดพิจารณาเลือกคำตอบที่บ่งชี้ถึงระดับความพึงพอใจ ของท่านใน ชีวิต ด้านต่างๆ คำตอบแต่ละข้อไม่มีความหมายว่าถูกหรือผิดอย่างแท้จริง หากคำตอบที่มีไม่ตรงกับ ความรู้สึกของท่านทีเดียว กรุณาเลือกคำตอบที่ใกล้เคียง กับระดับความพึงพอใจของท่านมากที่สุด และโปรดตอบข้อคำถามทุกข้อ

Table A7

Ferrans and Powers Quality of Life Index, Part 1 (Thai)

ท่านมีความพึงพอใจในสิ่งต่อไปนี้เพียงใด	ใม่พึ่งพอใจอย่างมาก	ใม่พึงพอใจปานกลาง	ใม่พึงพอใจเล็กน้อย	พึงพอใจเล็กน้อย	พึงพอใจปานกลาง	พึงพอใจอย่างมาก
1. สุขภาพของท่าน	1	2	3	4	5	6
2. การดูแลทางด้านสุขภาพที่ท่านได้รับอยู่	1	2	3	4	5	6
3. ความรุนแรงของอาการเจ็บปวดที่ท่านมีอยู่	1	2	3	4	5	6
4. พละกำลังในการประกอบกิจวัตรประจำวัน	1	2	3	4	5	6
5. ความสามารถในการทำสิ่งต่าง ๆ ได้ด้วยตนเอง	1	2	3	4	5	6
6. ความสามารถควบคุมและชี้นำชีวิตของ ตนเอง	1	2	3	4	5	6
7. โอกาสที่จะมีชีวิตยืนยาว	1	2	3	4	5	6
8. สุขภาพของสมาชิกในครอบครัวของท่าน	1	2	3	4	5	6
9. ลูกหลานของท่าน	1	2	3	4	5	6
10. ความสุขในครอบครัวของท่าน	1	2	3	4	5	6
11. การมีเพศสัมพันธ์	1	2	3	4	5	6
12. ความสัมพันธ์กับคู่ครอง / บุคคลที่มี ความหมายต่อ	1	2	3	4	5	6
ท่าน						
13. เพื่อน ๆ ของท่าน	1	2	3	4	5	6
14. ความช่วยเหลือ ความเห็นอกเห็นใจ หรือ กำลังใจที่ ท่านได้รับจากครอบครัว	1	2	3	4	5	6

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Table A7 (cont'd)

ท่านมีความพึงพอใจในสิ่งต่อไปนี้เพียงใด	ใม่พึ่งพอใจอย่างมาก	ใม่พึ่งพอใจปานกลาง	ไม่พึงพอใจเล็กน้อย	พึงพอใจเล็กน้อย	พึงพอใจบานกลาง	พึงพอใจอย่างมาก
15. ความช่วยเหลือ ความเห็นอกเห็นใจ หรือ กำลังใจที่	1	2	3	4	5	6
ท่านได้รับจากผู้อื่น						
16. ความสามารถที่จะทำหน้าที่ต่อครอบครัว	1	2	3	4	5	6
17. ความมีประโยชน์ หรือมีคุณค่าต่อผู้อื่น	1	2	3	4	5	6
18. ระดับความเครียด หรือความกังวล ในชีวิตของท่าน	1	2	3	4	5	6
19. เพื่อนบ้านของท่าน	1	2	3	4	5	6
20. บ้านของท่านหรือที่อยู่อาศัย	1	2	3	4	5	6
21. งานของท่าน (หากทำงาน)	1	2	3	4	5	6
22. การไม่มีงานทำ (หากไม่ได้ทำงาน ออกจากงาน	1	2	3	4	5	6
หรือทุพลภาพ)						
23. การศึกษาของทุ่าน	1	2	3	4	5	6
24. ความสามารถพึ่งตนเองด้านการเงิน	1	2	3	4	5	6
25. งานอดิเรก หรือกิจกรรมยามว่างของท่าน	1	2	3	4	5	6
26. โอกาสที่จะมีความสุขในวัยชรา เกษียณ อายุ	1	2	3	4	5	6
27. ความสงบทางใจของท่าน	1	2	3	4	5	6
28. ความเชื่อของท่านเกี่ยวกับพระเจ้า และ ศาสนา	1	2	3	4	5	6
29. ความสำเร็จตามเป้าหมายในชีวิต	1	2	3	4	5	6
30. ความสุขโดยทั่วไปของท่าน	1	2	3	4	5	6
31. ชีวิตโดยทั่วไปของท่าน	1	2	3	4	5	6
32. รูปร่างหน้าตา สภาพร่างกายของท่าน ตามที่ปรากฏ	1	2	3	4	5	6
33. ตัวของท่านเองโดยทั่วไป	1	2	3	4	5	6

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## ชุดที่สอง แบบประเมินระดับความสำคัญ

จากหัวข้อแต่ละหัวข้อต่อไปนี้ โปรดพิจารณาเลือกคำตอบที่บ่งชี้ถึงระดับความสำคัญ ที่ท่านให้กับ ชีวิตในด้านต่าง ๆ คำตอบแต่ละข้อไม่มีความหมายว่าถูกหรือผิดอย่างแท้จริง หากคำตอบที่มีไม่ตรง กับความรู้สึกของท่านทีเดียว กรุณาเลือกคำตอบที่ใกล้เคียงกับ ระดับความพึงพอใจของท่านมาก ที่สุด และโปรดตอบข้อคำถามทุกข้อ

Table A8

Ferrans and Powers Quality of Life Index, Part 2 (Thai)

ท่านให้ความสำคัญต่อสิ่งต่อไปนี้เพียงใด	ไม่สำคัญต่อท่านเลย	ใม่สำคัญต่อท่านปานกลาง	ไม่สำคัญต่อท่านเล็กน้อย	สำคัญต่อท่านเล็กน้อย	สำคัญต่อท่านปานกลาง	สำคัญต่อท่านอย่างมาก
1. สุขภาพของท่าน	1	2	3	4	5	6
2. การดูแลทางด้านสุขภาพที่ท่านได้รับอยู่	1	2	3	4	5	6
3. ความรุนแรงของอาการเจ็บปวดที่ท่านมื้อยู่	1	2	3	4	5	6
4. พละกำลังในการประกอบกิจวัตรประจำวัน	1	2	3	4	5	6
5. ความสามารถในการทำสิ่งต่าง ๆ ได้ด้วย ตนเอง	1	2	3	4	5	6
6. ความสามารถควบคุมและชี้นำชีวิตของ ตนเอง	1	2	3	4	5	6
7. โอกาสที่จะมีชีวิตยืนยาว	1	2	3	4	5	6
8. สุขภาพของสมาชิกในครอบครัวของท่าน	1	2	3	4	5	6
_9. ลูกหลานของท่าน	1	2	3	4	5	6
_10. ความสุขในครอบครัวของท่าน	1	2	3	4	5	6
_11. การมีเพศสัมพันธ์	1	2	3	4	5	6
12. ความสัมพันธ์กับคู่ครอง / บุคคลที่มีความหมาย	1	2	3	4	5	6
ต่อท่าน						
_13. เพื่อน ๆ ของท่าน	1	2	3	4	5	6
14. ความช่วยเหลือ ความเห็นอกเห็นใจ หรือ กำลังใจ ที่ท่านได้รับจากครอบครัว	1	2	3	4	5	6

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Table A8 (cont'd)

ท่านให้ความสำคัญต่อสิ่งต่อไปนี้เพียงใด	ไม่สำคัญต่อท่านเลย	ื่ใม่สำคัญต่อท่านปานกลาง	ไม่สำคัญต่อท่านเล็กน้อย	สำคัญต่อท่านเล็กน้อย	สำคัญต่อท่านปานกลาง	สำคัญอย่างมาก
15. ความช่วยเหลือ ความเห็นอกเห็นใจ หรือ กำลังใจ	1	2	3	4	5	6
ที่ท่านได้รับจากผู้อื่น						
16. ความสามารถที่จะทำหน้าที่ต่อครอบุครัว	1	2	3	4	5	6
17. ความมีประโยชน์ หรือมีคุณค่าต่อผู้อื่น	1	2	3	4	5	6
18. ระดับความเครียด หรือความกังวล ในชีวิตของ	1	2	3	4	5	6
ท่าน						
19. เพื่อนบ้านของท่าน	1	2	3	4	5	6
20. บ้านของท่านหรือที่อยู่อาศัย	1	2	3	4	5	6
21. งานของท่าน (หากทำงาน)	1	2	3	4	5	6
22. การไม่มีงานทำ (หากไม่ได้ทำงาน ออก จากงาน	1	2	3	4	5	6
หรือทุพลภาพ)						
23. การศึกษาของทุ่าน	1	2	3	4	5	6
24. ความสามารถพึ่งตนเองด้านการเงิน	1	2	3	4	5	6
25. งานอดิเรุก หรือกิจกรรมยามว่างของท่าน	1	2	3	4	5	6
26. โอกาสที่จะมีความสุขในวัยชรา เกษียณ อายุ	1	2	3	4	5	6
27. ความสงุบทางใจของุท่าน	1	2	3	4	5	6
28. ความเชื่อของท่านเกี่ยวกับพระเจ้า และ ศาสนา	1	2	3	4	5	6
29. ความสำเร็จตามเป้าหมายในชีวิต	1	2	3	4	5	6
30. ความสุขโดยทั่วไปของท่าน	1	2	3	4	5	6
31. ชีวิตโดยทั่วไปของท่าน	1	2	3	4	5	6
32. รูปร่างหน้าตา สภาพร่างกายของท่าน ตามที่	1	2	3	4	5	6
ปรากฏ						
33. ตัวของท่านเองโดยทั่วไป	1	2	3	4	5	6

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# <u>บัดนี้ท่านได้ทำแบบสอบถามเสร็จสมบูรณ์แล้ว</u> ขอขอบพระคุณในความร่วมมือเป็นอย่างสูง

## APPENDIX B

Study Instrument (English Version)

## **Caregiver Socio-Demographic Questionnaire**

Please complete the following personal information by writing in the blank and making a check mark in front of the most appropriated items.

1. Caregiver ageyears (w	rite the i	number of	age in ye	ears)		
2. Caregiver sex (check one)	Male		Fem	ale		
3.Religion (check one)						
Buddhist						
Christian						
Islam						
Others (specify)						
We have listed religious activities	below.	Read each	n one care	fully. If you	have bee	n participated
those activities, let us know how						-
rate for each activity.		. 1	•		•	
·						
Table B1						
Caregiver Religious Activities Qu	estions					
	T -	T _	Г	Γ	T	ı
	Once	Once a	Once a	Less than	Not at	
Religious activities	a day	week	month	once a	all	
				month		
Praying (check one)						
Meditating (check one)						
Going to the temple (check one)						
Offering food and things for						
monks (check one)						
Donation (check one)						
Others (specify)						
4 D 1 1 1 EGD ( )						
4. Relationship to the ECR (chec		<b>.</b> 1. /	a		11	1, / 1
Spouse	I	Daughter/	Son	G	randdaug	hter/ grandson
Sister/ Brother		2.1 1	.• (	• • •		
Daughter-in-law		Other rela	tives (spe	cify)		
5. Household income/ monthly (E			5001	10000	100	00 1
	2001-50		5001	-10000	100	00 and over
6. Co-morbid conditions (check a	II that ap	ppiy)				
No						
High blood pressure						
Diabetes Mellitus						
Heart disease						
Chronic bronchitis						
Low back pain						
Arthritis						

Others (specify)
7. Length of caregivingmonths (write the number of length in months)
8. ECR ageyears (write the number of age in years)
9. Diagnosis (write the diagnosed disease)
10. Sex (check one)MaleFemale
SF-12® Questionnaire
This survey asks for your views about your health. This information will help keep track of
how you feel and how well you are able to do your usual activities. For each of the following
questions, please mark on the line in front of the appropriate answer.
1. In general, would you say your health is:
Excellent (1)
Very Good (2)
Good (3)
Fair (4)
Poor (5)
The following two questions are about activities you might do during a typical day. Does YOUR
HEALTH NOW LIMIT YOU in these activities? If so, how much?
2. MODERATE ACTIVITIES, such as moving a table, pushing a vacuum cleaner, bowling, or
playing golf:
Yes, Limited A Lot (1)
Yes, Limited A Little (2)
No, Not Limited At All (3)
3. Climbing SEVERAL flights of stairs:
Yes, Limited A Lot (1)
Yes, Limited A Little (2)
No, Not Limited At All (3)
During the PAST 4 WEEKS have you had any of the following problems with your work or
other regular activities AS A RESULT OF YOUR PHYSICAL HEALTH?
4. ACCOMPLISHED LESS than you would like:
All of the Time (1)
Most of the Time (2)
Some of the Time (3)
A Little of the Time (4)
None of the Time (5)
5. Were limited in the KIND of work or other activities:
All of the Time (1)
Most of the Time (2)
Some of the Time (3)
A Little of the Time (4)
None of the Time (5)
During the PAST 4 WEEKS, were you limited in the kind of work you do or other regular
activities AS A RESULT OF ANY EMOTIONAL PROBLEMS (such as feeling depressed or
anxious)?

6. ACCOMPLISHED LESS than you would like:
All of the Time (1)
Most of the Time (2)
Some of the Time (3)
A Little of the Time (4)
None of the Time (5)
7. Didn't do work or other activities as CAREFULLY as usual:
All of the Time (1)
Most of the Time (2)
Some of the Time (3)
A Little of the Time (4)
None of the Time (5)
8. During the PAST 4 WEEKS, how much did PAIN interfere with your normal work (including
both work outside the home and housework)?
Not At All (1)
A Little Bit (2)
Moderately (3)
Quite a Bit (4)
Extremely (5)
The next three questions are about how you feel and how things have been DURING THE PAST
4 WEEKS. For each question, please give the one answer that comes closest to the way you have
been feeling. How much of the time during the PAST 4 WEEKS –
9. Have you felt calm and peaceful?
All of the Time (1)
Most of the Time (2)
Some of the Time (3)
Some of the Time (3) A Little of the Time (4)
None of the Time (5)
10. Did you have a lot of energy?
All of the Time (1)
Most of the Time (2)
Some of the Time (3)
Some of the Time (3) A Little of the Time (4)
None of the Time (5)
11. Have you felt downhearted and blue?
All of the Time (1)
Most of the Time (2)
Some of the Time (3)
Some of the Time (3) A Little of the Time (4)
None of the Time (4)
12. During the PAST 4 WEEKS, how much of the time has your PHYSICAL HEALTH OR
· · · · · · · · · · · · · · · · · · ·
EMOTIONAL PROBLEMS interfered with your social activities (like visiting with friends, relatives, etc.)?
All of the Time (1)
An of the Time (1) Most of the Time (2)
Some of the Time (2)
DOING OF THE LITTLE STATE

A Little of the Time (4) None of the Time (5)
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## Personal Resource Questionnaire Part II (PRQ85-II)

Below are some statements with which some people agree and others disagree. Please READ EACH STATEMENT AND CIRCLE the response most appreciate for you. There is no right or wrong answer.

Table B2

Personal Resource Questionnaire Part II (PRQ85-II)

	STRONGLY DISAGREE	DISAGREE	SOMEWHAT DISAGREE	NEUTRAL	SOMEWHAT AGREE	AGREE	STRONGLY AGREE
a.There is someone I feel close to who makes me feel secure	1	2	3	4	5	6	7
b.I belong to a group in which I feel important	1	2	3	4	5	6	7
c.People let me know that I do well at my work (job,	1	2	3	4	5	6	7
homemaking)	_	_					.
d.I can't count on my relatives and friends to help me	1	2	3	4	5	6	7
with my problem							
e.I have enough contact with the person who makes me	1	2	3	4	5	6	7
feel special							
f.I spend time with others who have the same interest	1	2	3	4	5	6	7
that I do							
g. There is little opportunity in my life to be giving and	1	2	3	4	5	6	7
caring to another person		2	2	4	_	_	_
h.Others let me know that they enjoy working with me	1	2	3	4	5	6	7
(job, committees, projects)	1		2				7
i.There are people who are available if I needed help	1	2	3	4	5	6	7
over an extended period of time	1	2	2	4		-	7
j. There is no one to talk to about how I am feeling	1	2	3	4	5	6	7
k.Among my group of friends we do favors for each other	1	2	3	4	3	O	/
1.I have the opportunity to encourage others to develop	1	2	3	4	5	6	7
their interests and skills	-		-	•	-	-	-

Table B2 (cont'd)

Table B2 (cont'd)							
	STRONGLY DISAGREE	DISAGREE	SOMEWHAT DISAGREE	NEUTRAL	SOMEWHAT AGREE	AGREE	STRONGLY AGREE
m.My family lets me know that I am important for	1	2	3	4	5	6	7
keeping the family running							
n.I have relatives or friends that will help me out even	_	_			_	_	_
if I can't pay them back	1	2	3	4	5	6	7
o.When I am upset there is someone I can be with who	1	2	3	4	5	6	7
lets me be myself							
p.I feel no one has the same problems as I	1	2	3	4	5	6	7
q.I enjoy doing little "extra" things that make another person's life more pleasant	1	2	3	4	5	6	7
r.I know that others appreciate me as a person	1	2	3	4	5	6	7
s. There is someone who loves and cares about me	1	2	3	4	5	6	7
t.I have people to share social events and fun activities with	1	2	3	4	5	6	7
u.I am responsible for helping provide for another person's needs	1	2	3	4	5	6	7
v.If I need advice there is someone who would assist me to work out a plan for dealing with the situation	1	2	3	4	5	6	7
w.I have a sense of being needed by another person	1	2	3	4	5	6	7
x.People think that I'm not as good a friend as I should be	1	2 2	3	4	5	6	7
y.If I got sick, there is someone to give me advice about caring for myself	1	2	3	4	5	6	7

#### **Rewards of Caregiving**

We know that some people find aspects of their caregiving situation rewarding and others do not. These questions are about things that you may or may not find rewarding because of caring for your family member. Please READ EACH STATEMENT AND CIRCLE the response most appreciate for you. There are no right or wrong answers.

Table B3

Rewards of Caregiving

To what extent	Not at all	A little	Some	Quite a bit	A great deal
1. does caring for him or her help you understand your own aging?	0	1	2	3	4
2. does caring for him or her help you feel like you are doing something important?	0	1	2	3	4
3. does caring for him or her help you understand the situation of older people in general?	0	1	2	3	4
4. is caring for your family member rewarding for you because it keeps him or her out of a nursing home?	0	1	2	3	4
5. does caring for him or her help you feel good about yourself?	0	1	2	3	4
6. is it rewarding because you feel you make life a little easier for him or her?	0	1	2	3	4
7. does caring for him or her add meaning to your life?	0	1	2	3	4
8. have you learned a lot about health and illness because of caregiving?	0	1	2	3	4
9. does caring for him or her give you a sense of accomplishment?	0	1	2	3	4
10. is just "being there" for him or her rewarding to you?	0	1	2	3	4
11. have you personally grown as a result of being a caregiver?	0	1	2	3	4
12. do you feel glad that <b>you</b> are the one who is providing care to him or her?	0	1	2	3	4
13. do you understand more about the aging process because of caregiving?	0	1	2	3	4
14. is caring for your family member rewarding because it makes him or her happy?	0	1	2	3	4
15. is it rewarding to know that you are helpful to him or her?	0	1	2	3	4

#### THE BARTHEL INDEX

This list of indexes is about the record of what an elder does. For each of the following index, please write in the number (0, 5, 10, or 15) to score the dependency of the elder you cared for.

Activity Score	
FEEDING	
0 = unable	
5 = needs help cutting, spreading butter, etc., or requires modified diet	
10 = independent	
BATHING	
0 = dependent	
5 = independent (or in shower)	
GROOMING	
0 = needs to help with personal care	
5 = independent face/hair/teeth/shaving (implements provided)	
DRESSING	
0 = dependent	
5 = needs help but can do about half unaided	
10 = independent (including buttons, zips, laces, etc.)	
BOWELS	
0 = incontinent (or needs to be given enemas)	
5 = occasional accident	
10 = continent	
BLADDER	
0 = incontinent, or catheterized and unable to manage alone	
5 = occasional accident	
10 = continent	
TOILET USE	
0 = dependent	
5 = needs some help, but can do something alone	
10 = independent (on and off, dressing, wiping)	
TRANSFERS (BED TO CHAIR AND BACK)	
0 = unable, no sitting balance	
5 = major help (one or two people, physical), can sit	
10 = minor help (verbal or physical)	
15 = independent	
MOBILITY (ON LEVEL SURFACES)	
0 = immobile or < 50 yards	
5 = wheelchair independent, including corners, > 50 yards	
10 = walks with help of one person (verbal or physical) > 50 yards	
15 = independent (but may use any aid; for example, stick) > 50  yards	
STAIRS	
0 = unable	
5 = needs help (verbal, physical, carrying aid)	
10 = independent	
<b>TOTAL</b> (0–100): (for researcher)	
Provided by the Internet Stroke Center — www.strokecenter.org	

## **Memorial Symptoms Assessment Scale**

Section 1. We have listed 24 symptoms below. Read each one carefully. If the elder you cared for has had the symptom during this past month, let us know how OFTEN the elder had it, how SEVERE it was usually and how much it DISTRESSED or BOTHERED the elder by circling the appropriate number. If the elder DID NOT HAS the symptom, make an "X" in the box marked "DID NOT HAVE."

Table B4

Memorial Symptoms Assessment Scale – Section 1

During the past month	VE	How OFTEN did you have				Ho	IF YES How SEVERE was it usually?				IF YES How much did it DISTRESSED or BOTHER you?					
Did the elder have any of the following symptoms?	DID NOT HAVE	Rarely	Occasionally	Frequently	Almost Constantly	Slight	Moderate	Severe	Very Severe	Not at all	A Little Bit	Somewhat	Quite a Bit	Very Much		
Difficulty concentrating		1	2	3	4	1	2	3	4	0	1	2	3	4		
Pain		1	2	3	4	1	2	3	4	0	1	2	3	4		
Lack of energy		1	2	3	4	1	2	3	4	0	1	2	3	4		
Cough		1	2	3	4	1	2	3	4	0	1	2	3	4		
Feeling nervous		1	2	3	4	1	2	3	4	0	1	2	3	4		
Dry mouth		1	2	3	4	1	2	3	4	0	1	2	3	4		
Nausea		1	2	3	4	1	2	3	4	0	1	2	3	4		
Feeling drowsy		1	2	3	4	1	2	3	4	0	1	2	3	4		
Numbness/ tingling in hands/feet		1	2	3	4	1	2	3	4	0	1	2	3	4		
Difficulty sleeping		1	2	3	4	1	2	3	4	0	1	2	3	4		
Feeling bloated		1	2	3	4	1	2	3	4	0	1	2	3	4		
Problems with urination		1	2	3	4	1	2	3	4	0	1	2	3	4		
Vomiting		1	2	3	4	1	2	3	4	0	1	2	3	4		
Shortness of breath		1	2	3	4	1	2	3	4	0	1	2	3	4		
Diarrhea		1	2	3	4	1	2	3	4	0	1	2	3	4		

Table B4 (cont'd)

rable D4 (cont u)														
		If Y	<u> YES</u>			<u>IF</u>	YES			<u>IF</u>	YES	<u> </u>		
		Ho	w Ol	FTE	N	Ho	w SE	EVE	RE	Но	w m	uch	did	it
	[7]	did	you	have	9	was	s it u	sual	ly?	DI	STR	ESS	ED	or
During the past month	M	it?								BC	TH	ER y	ou?	
Did the elder have any of the following symptoms?	DID NOT HAVE	Rarely	Occasionally	Frequently	Almost Constantly	Slight	Moderate	Severe	Very Severe	Not at all	A Little Bit	Somewhat	Quite a Bit	Very Much
Feeling sad		1	2	3	4	1	2	3	4	0	1	2	3	4
Sweats		1	2	3	4	1	2	3	4	0	1	2	3	4
Worrying		1	2	3	4	1	2	3	4	0	1	2	3	4
Problems with sexual		1	2	3	4	1	2	3	4	0	1	2	3	4
interest or activities														
Itching		1	2	3	4	1	2	3	4	0	1	2	3	4
Lack of appetite		1	2	3	4	1	2	3	4	0	1	2	3	4
Dizziness		1	2	3	4	1	2	3	4	0	1	2	3	4
Difficulty swallowing		1	2	3	4	1	2	3	4	0	1	2	3	4
Feeling irritable		1	2	3	4	1	2	3	4	0	1	2	3	4

Section 2. We have listed 8 symptoms below. Read each one carefully. If the elder has had the symptom during this past month, let us know how SEVERE it was usually and how much it DISTRESSED or BOTHERED the elder by circling the appropriate number. If the elder DID NOT HAS the symptom, make an "X" in the marked "DID NOT HAVE." Table B5

Memorial Symptoms Assessment Scale – Section 2

During the past month	HAVE		<u>/ES</u> w SE` it us			DIS	ZES v mu TRE ΓΗΕ	SSE	D or	
Did you have any of the following symptoms?	DID NOT	Slight	Moderate	Severe	Very Severe	Not at all	A Little Bit	Somewhat	Quite a Bit	Very Much
Mouth sore		1	2	3	4	0	1	2	3	4
Change in the way food tastes		1	2	3	4	0	1	2	3	4
Weight loss		1	2	3	4	0	1	2	3	4
Hair loss		1	2	3	4	0	1	2	3	4
Constipation		1	2	3	4	0	1	2	3	4
Swelling of arms or legs		1	2	3	4	0	1	2	3	4
"I don't like myself"		1	2	3	4	0	1	2	3	4
Changes in skin		1	2	3	4	0	1	2	3	4
If the elder had any other symptoms during the past month, please list below and indicate how much the symptom has distressed or bothered the elder.										
Other:						0	1	2	3	4
Other: 0 1 2 3							4			

## **Oberst Caregiving Burden Scale**

This group of questions is about the tasks and activities that you do to help the elder. For each of the following activities, please mark HOW MUCH TIME you spend and HOW DIFFICULT each activity is for you to do

Time 5 = A great amount Difficulty 5 = Extremely difficult 4 = A large amount 4 = Very difficult 3 = A moderate amount 2 = A small amount 2 = S lightly difficult 1 = None 1 = Not difficult

Table B6

Oberst Caregiving Burden Scale

		7	Time	e			D	iffic	ılty	
Tasks and activities that you do to help the elder:	None	A small amount	A large amount	A moderate amount	A great amount	Not difficult	Slightly difficult	Moderately difficult	Very difficult	Extremely difficult
1. Medical or nursing treatment (giving	1	2	3	4	5	1	2	3	4	5
medications, skin care, dressing, etc.):										
2. Personal care (bathing, toileting, getting	1	2	3	4	5	1	2	3	4	5
dressed, feeding, etc.):										
3. Assistance with walking, getting in and out of	1	2	3	4	5	1	2	3	4	5
bed, exercises, etc.:										
4. Emotional support, "being there" for the elder:	1	2	3	4	5	1	2	3	4	5
5. Watching for and reporting the elders'	1	2	3	4	5	1	2	3	4	5
symptoms, watching how the elder is doing, monitoring the elder's progress:										
6. Providing transportation or "company"	1	2	3	4	5	1	2	3	4	5
(driving, riding along with elder, going to	1	_	5	•	5	1	_	3	•	5
appointments, driving elder around for errands,										
etc.):										
7. Managing finances, bills, and forms related to	1	2	3	4	5	1	2	3	4	5
the elder's illness:										
8. Additional household tasks for elder (laundry,	1	2	3	4	5	1	2	3	4	5
cooking, cleaning, yard work, home repair, etc.):										
9. Additional tasks outside the home for the elder	1	2	3	4	5	1	2	3	4	5
(shopping for food and clothes, going to the										
bank, running errands, etc.):										

Table B6 (cont'd)

Table Bo (cont d)		7	Γim	е			D	iffic	ulty	
Tasks and activities that you do to help the elder:	None	A small amount	A large amount	A moderate amount	A great amount	Not difficult	Slightly difficult	Moderately difficult	Very difficult	Extremely difficult
10. Structuring/planning activities for the elder (recreation, rest, meals, things for the elder to do, etc.):	1	2	3	4	5	1	2	3	4	5
11. Managing behavior problems (moodiness, irritability, confusion, memory loss, etc.):	1	2	3	4	5	1	2	3	4	5
12. Finding and arranging someone to care for the elder while you are away:	1	2	3	4	5	1	2	3	4	5
13. Communication (helping the elder with the phone, writing or reading, explaining things, trying to understand what the elder is trying to say, etc.):	1	2	3	4	5	1	2	3	4	5
14. Coordinating, arranging, and managing services and resources for the elder (scheduling appointments, arranging transportation, locating equipment and services, and finding outside help):	1	2	3	4	5	1	2	3	4	5
15. Seeking information and talking with doctors, nurses and other professional health care workers about the elder's condition and treatment plans:	1	2	3	4	5	1	2	3	4	5

# Ferrans and Powers Quality of Life Index©Generic Version – III

PART 1. For each of the following, please choose the answer that best describes HOW SATISFIED you are with that area of your life. Please mark your answer by circling the number. There are no right or wrong answers.

Table B7

Ferrans and Powers Quality of Life Index, Part 1

HOW SATISFIED ARE YOU WITH:	Very Dissatisfied	Moderately Dissatisfied	Slightly Dissatisfied	Slightly Satisfied	Moderately Satisfied	Very Satisfied
1. Your health?	1	2	3	4	5	6
2. Your health care?	1	2	3	4	5	6
3. The amount of pain that you have?	1	2	3	4	5	6
4. The amount of energy you have for everyday	1	2	3	4	5	6
activities?						
5. Your ability to take care of yourself without help?	1	2	3	4	5	6
6. The amount of control you have over your life?	1	2	3	4	5	6
7. Your chances of living as long as you would like?	1	2	3	4	5	6
8. Your family's health?	1	2	3	4	5	6
9. Your children?	1	2	3	4	5	6
10. Your family's happiness?	1	2	3	4	5	6
11. Your sex life?	1	2	3	4	5	6
12. Your spouse, lover, or partner?	1	2	3	4	5	6
13. Your friends?	1	2	3	4	5	6
14. The emotional support you get from your family?	1	2	3	4	5	6
15. The emotional support you get from people other than your family?	1	2	3	4	5	6
16. Your ability to take care of family responsibilities?	1	2	3	4	5	6

Table B7 (cont'd)

HOW SATISFIED ARE YOU WITH:	Very Dissatisfied	Moderately Dissatisfied	Slightly Dissatisfied	Slightly Satisfied	Moderately Satisfied	Very Satisfied
17. How useful you are to others?	1	2	3	4	5	6
18. The amount of worries in your life?	1	2	3	4	5	6
19. Your neighborhood?	1	2	3	4	5	6
20. Your home, apartment, or place where you live?	1	2	3	4	5	6
21. Your job (if employed)?	1	2	3	4	5	6
22. Not having a job (if unemployed, retired, or	1	2	3	4	5	6
disabled)?						
23. Your education?	1	2	3	4	5	6
24. How well you can take care of your financial needs?	1	2	3	4	5	6
25. The things you do for fun?	1	2	3	4	5	6
26. Your chances for a happy future?	1	2	3	4	5	6
27. Your peace of mind?	1	2	3	4	5	6
28. Your faith in God?	1	2	3	4	5	6
29. Your achievement of personal goals?	1	2	3	4	5	6
30. Your happiness in general?	1	2	3	4	5	6
31. Your life in general?	1	2	3	4	5	6
32. Your personal appearance?	1	2	3	4	5	6
33. Yourself in general?	1	2	3	4	5	6

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PART 2. For each of the following, please choose the answer that best describes HOW IMPORTANT that area of your life is to you. Please mark your answer by circling the number. There are no right or wrong answers.

Table B8

Ferrans and Powers Quality of Life Index, Part 2

HOW IMPORTANT TO YOU IS:	Very Unimportant	Moderately Unimportant	Slightly Unimportant	Slightly Important	Moderately Important	Very Important
1. Your health?	1	2	3	4	5	6
2. Your health care?	1	2	3	4	5	6
3. The amount of pain that you have?	1	2	3	4	5	6
4. The amount of energy you have for everyday	1	2	3	4	5	6
activities?						
5. Your ability to take care of yourself without help?	1	2	3	4	5	6
6. The amount of control you have over your life?	1	2	3	4	5	6
7. Your chances of living as long as you would like?	1	2	3	4	5	6
8. Your family's health?	1	2	3	4	5	6
9. Your children?	1	2	3	4	5	6
10. Your family's happiness?	1	2	3	4	5	6
11. Your sex life?	1	2	3	4	5	6
12. Your spouse, lover, or partner?	1	2	3	4	5	6
13. Your friends?	1	2	3	4	5	6
14. The emotional support you get from your family?	1	2	3	4	5	6
15. The emotional support you get from people other than	1	2	3	4	5	6
your family?						
16. Your ability to take care of family responsibilities?	1	2	3	4	5	6
17. How useful you are to others?	1	2	3	4	5	6

Table B8 (cont'd)  HOW IMPORTANT TO YOU IS:	Very Unimportant	Moderately Unimportant	Slightly Unimportant	Slightly Important	Moderately Important	Very Important
18. The amount of worries in your life?	1		3	4	5	6
19. Your neighborhood?	1	2	3	4	5	6
20. Your home, apartment, or place where you live?	1	2	3	4	5	6
21. Your job (if employed)?	1	2	3	4	5	6
22. Not having a job (if unemployed, retired, or disabled)?	1	2	3	4	5	6
23. Your education?	1	2	3	4	5	6
24. How well you can take care of your financial needs?	1	2	3	4	5	6
25. The things you do for fun?	1	2	3	4	5	6
26. Your chances for a happy future?	1	2	3	4	5	6
27. Your peace of mind?	1	2	3	4	5	6
28. Your faith in God?	1	2	3	4	5	6
29. Your achievement of personal goals?	1	2	3	4	5	6
30. Your happiness in general?	1	2	3	4	5	6
31. Your life in general?	1	2	3	4	5	6
32. Your personal appearance?	1	2	3	4	5	6
33. Yourself in general?	1	2	3	4	5	6

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THANK YOU VERY MUCH FOR YOUR PARTICIPATION.

# APPENDIX C

Study Consent Form (Thai-Translated and English Versions)

## รายละเอียดการยินยอมมีส่วนร่วมในการศึกษา

เรื่อง คุณภาพชีวิตที่เกี่ยวข้องกับสุขภาพของผู้ดูแลผู้สูงอายุที่เจ็บป่วยด้วยโรคเรื้อรัง เรียน ผู้ดูแลผู้สูงอายุที่เจ็บป่วยด้วยโรคเรื้อรัง

การศึกษาเรื่องคุณภาพชีวิตที่เกี่ยวข้องกับสุขภาพของผู้ดูแลผู้สูงอายุที่เจ็บป่วยด้วยโรคเรื้อรังนี้ จัดทำขึ้นโดย นางสาวเสาวลักษณ์ เนตรชัง นักศึกษาระดับปริญญาเอก ในสาขาการพยาบาล (PhD in Nursing) ณ มหาวิทยาลัย แห่งรัฐมิชิแกน (Michigan State University) ประเทศสหรัฐอเมริกา โดยความดูแลของ ศาสตราจารย์เกียรติคุณ ดร.บาร์บาร่า กีฟเว่น (Distinguished Professor Barbara Given, PhD, RN, FAAN) โดยมีวัตถุประสงค์เพื่อ ศึกษาถึงคุณภาพชีวิตที่เกี่ยวข้องกับสุขภาพของผู้ดูแลผู้สูงอายุ ที่เจ็บป่วยด้วยโรคเรื้อรัง โดยการ ตอบแบบสอบถามนี้จะใช้ เวลาประมาณ 45-60 นาทีในการตอบคำถามทั้งหมด ความเสี่ยงทางด้านสุขภาพ อาจที่เกิดจากการที่ท่านได้เข้าร่วมในการ วิจัยครั้งนี้มีน้อยมากเนื่องจากท่านเพียงแต่ตอบแบบสอบถามเกี่ยวกับสถานการณ์ และความรู้สึก ในการดูแลผู้สุงอายุและท่าน อาจรู้สึกไม่สบายใจในการตอบบางข้อคำถาม ถ้าท่านรู้สึกเช่นนั้นท่านสามารถไม่ตอบคำถามนั้นๆได้

ท่านอาจไม่ได้รับผลประโยชน์ต่อตัวท่านโดยตรงจากการเข้าร่วมในการวิจัยแต่ผลของการวิจัยจะเป็นประโยชน์ในการ เพิ่มพูนความรู้และความเข้าใจเกี่ยวกับคุณภาพชีวิตที่เกี่ยวข้องกับสุขภาพของผู้ดูแลผู้สูงอายุและเป็นข้อมูลเบื้องต้นในการ พัฒนา กิจกรรมที่เหมาะสมสำหรับส่งเสริม ความรู้สึกในด้านบวกในการดูแลผู้สุงอายุที่บ้านในชุมชนของท่าน

การมีส่วนร่วมในการวิจัยนี้ขึ้นอยู่กับความสมัครใจของท่านและท่านอาจจะยุติการตอบแบบสอบถามเมื่อใดก็ได้หรือ ยกเว้นที่จะไม่ตอบคำถามข้อใดข้อหนึ่งได้โดยไม่มีโทษใดๆเกิดขึ้นภายหลัง หากท่านมีความยินดีที่จะมีส่วนร่วมในการศึกษา ครั้งนี้ โปรดทราบว่าข้อมูลต่างๆ ของท่านจะถูกเก็บเป็นความลับสูงสุดตามกฎหมายและนำไว้ใช้ประโยชน์สำหรับการวิจัย โดยผู้ที่เกี่ยวข้องโดยตรงกับการศึกษานี้เท่านั้น อีกทั้งจะไม่มีการระบุหรือเชื่อมโยงถึงตัวท่านกับข้อมูลที่ท่านได้ตอบไว้ใน แบบสอบถาม การตัดสินใจเข้าร่วมหรือไม่เข้าร่วมในงานวิจัยจะไม่มีผล ต่อการรับการรักษา ณ สถานพยาบาลแห่งนี้ และเจ้าหน้าที่ทุกท่านในสถานพยาบาลแห่งนี้จะไม่มีส่วนรับรู้การตัดสินใจเข้าร่วมหรือไม่เข้าร่วม ในงานวิจัยของท่าน

ผู้ตอบแบบสอบถามจะต้องเป็นผู้ที่มีอายุไม่ต่ำกว่า18 ปีบริบูรณ์ เป็นผู้ดูแลผู้สูงอายุที่เจ็บป่วยด้วยโรคเรื้อรังที่บ้าน โดยไม่ได้รับค่าตอบแทนและสามารถสื่อสารได้ด้วยภาษาไทย

ข้อมูลจากการวิจัยจะถูกเก็บรักษาไว้อย่างดีในตู้ที่ล็อคกุญแจหรือในคอมพิวเตอร์ที่ใส่ระหัสลับที่มหาวิทยาลัยมิชิแกน เป็นระยะเวลาสามปีหลังจากเสร็จสิ้นงานวิจัย ผู้ที่สามารถเข้าถึงข้อมูลได้คือผู้วิจัย อาจารย์ที่ปรึกษาและเจ้าหน้าที่ส่วนงานพิทักษ์งานวิจัยอันเกี่ยวข้องกับมนุษย์ เท่านั้น

11111111111111111111111111111111111111	
ลายมือชื่อผู้ให้ความยินยอม	วันที่
ลายมือชื่อผู้ได้รับความยินยอม	 วันที่

ขอของ เพร~อกเอย่างสง

"ให้สำเนาเอกสารกับผู้ดูแลผู้สูงอายุ"

หากท่านมีข้อสงสัยหรือคำถามเกี่ยวกับการวิจัย เช่น ประเด็นทางวิทยาศาสตร์, ต้องทำอย่างในในการเข้าร่วมงานวิจัย, หรือ ต้องการที่จะได้รับข้อมูลหรือให้ข้อมูลใดๆ หรือต้องการที่จะร้องทุกข์เกี่ยวกับการศึกษาในครั้งนี้ ท่านอาจติดต่อผู้วิจัยตาม ที่อยู่ดังต่อไปนี้

รายละเอียดผู้วิจัย:

ชื่อ: Distinguished Professor Barbara Given, PhD, RN, FAAN

(ผู้วิจัยหลักและอาจารย์ที่ปรึกษา)

ที่อยู่ที่ประเทศสหรัฐอเมริกา:

B510 West Fee Hall College of Nursing, Michigan State University East Lansing, MI 48824-1315 Phone (517) 355-6526 Fax (517) 353-8612

Email: barb.given@hc.msu.edu; cindy.espinosa@hc.msu.edu

ชื่อ: เสาวลักษณ์ เนตรชัง (Ms. Saowaluk Netchang)

(ผู้วิจัยรอง)

ที่อยู่ที่ประเทศไทย:

35 หมู่ 5 ต. ป่าเช่า อ. เมือง จ. อุตรดิตถ์ 53000 โทรศัพท์: 081-532-5427

ที่อยู่ที่ประเทศสหรัฐอเมริกา:

1625 Spartan Village, Apt J Michigan State University East Lansing, Michigan 48823-5933, U.S.A

โทรศัพท์: +1(517) 355-9901

อีเมล์แอดเดรส: netchang@msu.edu

หากท่านมีคำถามข้อสงสัยเกี่ยวกับสิทธิของผู้ตอบแบบสอบถาม ต้องการที่จะได้รับข้อมูลหรือให้ข้อมูลใดๆ
หรือต้องการที่จะร้องทุกข์ เกี่ยวกับการศึกษาในครั้งนี้ ท่านอาจติดต่อส่วนงานพิทักษ์งานวิจัยอันเกี่ยวข้องกับมนุษย์
(Michigan State University Human Research Protection Program) โดยไม่จำเป็นต้องเปิดเผยนามได้ที่
Michigan State University Human Research Protection Program
207 Olds Hall, MSU East Lansing, MI 48824-1034, U.S.A

โปรดเก็บเอกสารแผ่นนี้ไว้กับท่านเพื่อใช้เป็นข้อมูลอ้างอิง

Informed Consent This consent form was approved by the Biomedical and Health Institutional Review Board (BIRB) at Michigan State University. Approved 05/06/11 – valid through 05/05/12. This version supersedes all previous versions. IRB# 11-462.

# Study Title: Health-Related Quality of Life of Rural Thai Family Caregivers

To: Family Caregiver

This research is a study conducted by Ms. Saowaluk Netchang, a doctoral student in the PhD Nursing program at Michigan State University, United States, under supervision of Distinguished Professor Barbara Given, PhD, RN, FAAN. This study aims to examine the key factors influencing the overall Health-related Quality of Life (HRQOL) of rural Thai family caregivers of elderly care recipients (ECR) with one or more chronic conditions who possess at least two activity of daily living (ADL) deficits. The questionnaire should take about 45-60 minutes to complete. There are no foreseeable risks associated with your participation in this study. Although it may be possible that you would feel mildly uncomfortable answering some of the questions, you will never be obligated to answer any questions that may make you feel uncomfortable.

This research is voluntary and you can withdraw or refuse to answer any particular question without penalty. Your responses will be released only as summaries in which no individual's answer can be identified. In addition, only those directly involved in this study will be allowed to access the research data. Your decision on whether or not to join this study is entirely your own decision. Your usual medical care provided at the Primary Care Unit (PCU) will not change if you do, or do not decide to enroll in this study. None of the healthcare professionals at the PCU will be capable of knowing whether you decided to participate in this study or not. Your confidentiality will be protected to the maximum extent allowable by law.

You will not **specifically benefit from** your participation in this study. Your participation in this study may contribute to the understanding of predictors of caregivers' HRQOL leading to initiate appropriate interventions to enhance positive aspect of providing care for elders in rural setting.

To participate, you must be at least 18 years old, caring for chronically-ill ECR who has two or more ADLs deficits at home without payment, and be fluent and functionally literate in the Thai language.

The research data will be kept on the campus of Michigan State University in a locked file cabinet or password protected computer for three years after the close of the research and only the appointed researchers and the Institutional Review Board (IRB) will have access to the data.

Thank you very much

Your signature below means that you voluntarily agree to participate in this research study.

Signature	Date
Person Obtaining Consent	Date

"PROVIDE COPY TO CAREGIVER"

If you have any concerns or questions about this study, such as scientific issues, how to do any part of it, or to report an injury, please contact the researchers.

### **Investigator contact information:**

Name: Distinguished Professor Barbara Given, PhD, RN, FAAN

(Principal Investigator and Major Advisor)

#### Address in U.S.A:

B510 West Fee Hall College of Nursing, Michigan State University East Lansing, MI 48824-1315 Phone (517) 355-6526 Fax (517) 353-8612

Email: barb.given@hc.msu.edu; cindy.espinosa@hc.msu.edu

Name: Saowaluk Netchang, PhD(c), RN

(Secondary Investigator)

#### **Address in Thailand:**

35 M. 5 Pasao, Muang

Uttaradit 53000

Phone: (081)-532-5427

#### Address in U.S.A:

1625 Spartan Village, Apt J

Michigan State University

East Lansing, Michigan 48823-5933, U.S.A

Phone: +1(517) 355-9901

Email: netchang@msu.edu

If you have any questions or concerns about your role and rights as a research participant, would like to obtain information or offer input, or would like to register a complaint about this research study, you may contact, anonymously if you wish, Michigan State University Human Research Protection Program at 517-355-2180, FAX 517-432-4503, or email irb@msu.edu, or regular mail at:

207 Olds Hall, MSU East Lansing, MI 48824-1034, U.S.A

## Please keep this sheet for your reference

Informed consent This consent form was approved by the Biomedical and Health Institutional Review Board (BIRB) at Michigan State University. Approved 05/06/11 – valid through 05/05/12. This version supersedes all previous versions. IRB# 11-462

# APPENDIX D

IRB Approval Letter

Renewal Application Approval

April 9, 2012

To: Barbara A. Given B510 W. Fee Hall MSU

Re: INB# 71-462 Category: EXPEDITED 2-7

Renewal Approval Date: April 6, 2012 Project Expiration Date: April 5,2A13

Title: Health-Related Quality of life of Rural Thai Family Caregivers

The Institutional Review Board has completed their review of your project. I am pleased to advise you that the renewal has been approved.

This letter notes approval for data analysis only (contact with subjects and data collection is complete). Any further recruitment, data collection or contact with subjects will require IRB review and approval via a revision before implementation.

The review by the committee has found that your renewal is consistent with the continued protection of the rights and welfare of human subjects, and meets the requirements of MSU's Federal Wide Assurance and the Federal Guidelines (45 CFR 46 wrd2l CFR Pa\* 50). The protection of human subjects in research is a partnership between the IRB and the investigators. We look forward to working with you as we both fulfill our responsibilities.

Renewals: IRB approval is valid until the expiration date listed above. If you are continuing your project, you must submit an Application for Renewal application at least one month before expiration. If the project is completed, please submit an Application for Permanent Closure.

Revisions: The IRB must review any changes in the project, prior to initiation of the change. Please submit an Application for Revision to have your changes reviewed. If changes are made at the time of renewal, please include an Application for Revision with the renewal application.

Problems: If issues should arise during the conduct of the research, such as unanticipated problems, adverse events, or any problem that may increase the risk to the human subjects, notify the IRB office promptly. Forms are available to report these issues.

Please use the IRB number listed above on any forms submitted which relate to this project, or on any correspondence with the IRB office.

Good luck in your research. If we can be of further assistance, please contact us at 517-355-2180 or via email at irb@msu.edu. Thank you for your cooperation.

Sincerely'

Ashir Kumar' M'D' BIRBChair

c:SaowalukNetchang

## APPENDIX E

Permission for Models

Date: Fri, 6 Apr 2012 11:59

From: Carol Ferrans <a href="mailto:cferrans@uic.edu">cferrans@uic.edu</a>
To: netchang@msu.edu < netchang@msu.edu>

Subject: RE: Introducing Thai Scholar and requesting for instrument use

#### Hello Saowaluk,

Thank you for my email. I am happy t grant you permission to use the figure referenced in your email below, as well as any other figures I have published, for your dissertation. Of course, you will need to credit the figures appropriately with citations in your dissertation, but I'm sure you were already planning on that.

Because this is a dissertation, this permission should be sufficient. When you move forward to publish reports from your dissertation, you would need permission from the journal also, in addition to my permission.

Thanks and good luck with your work.

Sincerely,

Carol Estwing Ferrans, PhD, RN, FAAN
Professor and Associate Dean for Research
Co-Director, UIC Center of Excellence in Eliminating Health Disparities
Co-Director, Community Engagement and Research Core, UIC Center for Clinical and
Translational Science
University of Illinois at Chicago
College of Nursing
845 S. Damen Avenue (M/C 802)
Chicago, IL 60612
phone 312-996-8445; fax 312-996-497 9
email cferrans@uic.edu
QLI website www. uic.ed u/orgs/q li

From: netchang@msu.edu fmailto:netchang@msu.edu]

Sent: Tuesday, April 03, 2OL2 7:44 PM

To: Carol Ferrans

Subject RE: Introducing Thai Scholar and requesting for instrument use

#### Dear Dr.Ferrans,

I'm now done collecting and analyzing data. The QLI has a good reliability coefficient (alpha=.98).

I have another question to ask about the permission to use your revised Wilson & Cleary {1995) model in your article "Conceptual model of health-related quality of life," (Journal of Nursing Scholarship, 2005;37(4):336-42). I have both original model and your revised model in my dissertation. What should I do to ask for the permission to use that model? Do I have to contact the journal or ask form the owner? Please give me some suggestions.

Thank you very much.

Regards,

Saowaluk Netchang

Quoting Carol Ferrans < cferrans@uic.edu>: Dear Ms. Netchang,

Thank you for your email. I am happy to grant you permission to use the Quality of Life Index for your study, and there is no charge for this use. You may download copies of the instrument from our website for your IRB application, and all other uses for your study, including copies within your proposal and final dissertation.

I wish you all success with your work.

Sincerely,

Carol Estwing Ferrans, PhD, RN, FAAN

Professor and Associate Dean for Research

Co-Director, UIC Center for Excellence in Eliminating Health Disparities

Co-Director, Community Engagement and Research Core, Center for

Clinical and Translational Science

University of Illinois at Chicago

College of Nursing (M/C 802), Room 606

845 S. Damen Avenue

Chicago, IL60612

phone 312-996-8445

fax 312-996-4979

email cferrars@uic

Q Ll website www. uic. ed u/orgs/qli< lrttp: //www. uic. ed u/orgs/qli>

From: netchang@msu.edu [netcharg@msu.edu]

Sent: Thursday, February 10, 3:45 PM

To: Carol Ferrans

Subject: Introducing Thai Scholar and requesting for instrument use

Dear Dr . Carol Ferrans,

I am Saowaluk Netchang, Thai scholar, studying PhD in Nursing at Michigan State University, College of Nursing. According my research interest, health-related quality of life of rural Thai caregivers taking care of chronically-ill elders, I am looking for the effects of caregivers and elders key factors on caregivers' health-related quality of life. I am going to use the Thaitranslated version of Quality of Life Index in my study, collecting data in rural Thai caregivers. I am, now, working on my IRB process and would like to have the copy of the instrument to attach

with the IRB application. I would like to ask for the permission of using the QLI; please let me know what should I process next or if you have any other questions about my future study. I am looking forward to hear from you very soon.

Regards, Saowaluk Netchang REFERENCES

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