

DEVELOPMENT OF THE THAI FAMILY CARE INVENTORY

by

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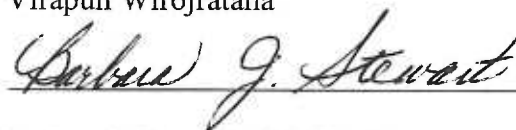
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ABSTRACT

TITLE: Development of The Thai Family Care Inventory

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The purpose of this study was to develop the Thai version of Archbold and Stewart's Family Care Inventory (FCI) and to evaluate its reliability and construct validity. The appropriateness of the FCI concepts for the Thai caregivers was confirmed. Back-translation was employed. Results showed that most scales met the .70 reliability criterion. Evidence of construct validity was strongly or moderately supported for most hypotheses, but not for mutuality and rewards of family care. Results indicated that caregiver role strain is a relevant concept for Thai caregivers. Preparedness and predictability were negatively related to caregiver role strain. Role transitions may be important times to target interventions. Conceptualization and measurement of mutuality and rewards of family care need further study.

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CHAPTER 1

INTRODUCTION

The population of Thai elders over the age 55 is projected to increase from 5.5 million in 1990 to 19.6 million by the year 2025. According to Frances and Kinellar (1992), this increase in the elders population from 9.7 % of the population to 21.7 % is a larger percentage increase than projected in the overall Thai population. Projections for the year 2020 indicate that 22% of the population will be age 55 and over, making Thai elders one of the fastest growing elderly populations in Asia.

Projections of increases in the numbers of elders in the population of Thailand has been influenced by reduced fertility rates and improved life expectancy, which are related to family planning policies, improvements in public health, urbanization, and a higher standard of living (Francese & Kinsella, 1992). The total fertility rates of Thailand in 1964-1965 and 1990-1995 were 6.3 and 2.2 respectively. It is expected to be 1.8 in 2015-2020 (Jitapunkul & Bunnag, 1997). The life expectancy at birth for the Thai population has been increasing, as a result of improvements in infant and childhood mortality, has been increasing. In 1974-1976 the life expectancy at birth of males and females was 58 and 63.6 years respectively. In 1985-1989, life expectancy was 65.6 years for males and 70.9 years for females. In 1991-1996, life expectancy had increased to 70 years for males and 75 years for females (National Statistical Office, 1998). Thus declining fertility rates and improving life expectancy have combined to increase the proportion of elders in the Thai population.

Thai elders have major health issues. Physical problems for Thai elders include cardiovascular disease, stroke, diabetes mellitus, fatigue, cancer, bone fractures and

paralysis. Mental health problems include depression, anxiety, mood disturbance and cognitive impairment (Institute of Geriatric Medicine, 1993). A survey of perceived health status in Thai elders found that 31.1% of elderly persons perceive their health status as fair and 29.3% reported their health status as poor (Choprapavan, Songkak, Chayovan, & Jiravatkul, 1995). These results indicate that the health of 60% elders is not good and they are moving toward a dependent status.

The history of Thailand stretches back more than 2,500 years. In recent year, Thailand has been changing from an agricultural economy to an industrial economy. One of the fundamental changes resulting from industrialization is the shift in the economy from family enterprises to wage-based employment. The rapid economic growth during the past two decades has resulted in dramatic socio-cultural changes (Chang, 1992). New employment patterns have created smaller households (Jitapunkul & Bunnag, 1997). Modernization is also changing a new generation's norms and values to individualism rather than interdependent relationships (Goldstein & Beall, 1981). In 1990, a national survey found that households in the municipal areas of the 75 provinces consisted 67% nuclear families, 21% extended families and 12% unrelated individuals. Households in non-municipal areas consisted of 68% nuclear families, 28% extended families, and 5% unrelated individuals (National Statistic Office, 1994). This study shows that the proportion of nuclear families is larger than that of extended families.

Despite this shift in family structure away from extended families in the general population, the picture for elders is somewhat different. According to Knodel, Amornsirisomboon and Khiewyoo (1997), a survey of elders in Thailand found that 4% live alone, 12% live with spouse only, 50% live with spouse and children or others, and

34% live with children or others. This survey also indicated that 72% of Thai elders live with their children. Those who do not live with their children generally receive frequent visits and/or substantial support from their children. Only a small proportion of elders live alone in residential homes. More commonly, neighbors take in elders without children. Thai families are primary resources in caring for elders. Several reasons have been given to explain this situation.

First, elders still need family members to take care of them. Choprapavan, et al., (1995) survey of the perspective of elders who need care found that 96.2% of elders have relatives to take care of them. Second, about 96% of Thai people are Buddhist. Thai Buddhists believe that the adult children are obligated to provide care for their parents and to respect elders (Payutto, 1997). Buddhist beliefs lead the people to feel responsible for care of elders.

Lastly, the problems encountered by Thai elders are with health care services, which are inadequate and insufficient to serve them. In Thailand, the health care system is comprised mainly of hospitals, which provide both acute care and long-term care. Currently, the number of beds is inadequate because of the population growth. Many hospitals have a policy of discharging patients early due to lack of beds and the increasing cost of health care. Therefore many families have to care for the elders at home (Maneewon, Sujinda, Panutas, & Pisansuthidad, 1994). Long-term facilities also have limited resources to serve elders. The government has not expanded the federal nursing home program because it is not considered appropriate in Thai culture. Sangtanchain's (1993) survey showed that Thai people have a negative attitude towards nursing homes. Thai people expect that elders must be taken care of by their child or

other family members. In addition, there is a high cost of this strategy over the long term. These reasons explain the increase in family responsibilities in caring for their elders.

The policy on health care of the aging was addressed in the eighth 5-year National Health Development Plan (1997-2001). This policy mandated extending the position description for community nurses to include home visits to elders. Nurses realized that home visits for elders are a new concept in Thailand. Because the Thai family is the primary caregiver (CG) for elders, nurses consider their focus should be the needs and health status of both elders and family CGs. Thai nurses have stated an interest in family caregiving and want to explore this area to increase the nursing knowledge base. Conceptual frameworks used by nurse researchers studying family caregiving in Thai culture have included Orem's Self-care Theory (Suwanno, 1998) as well as a combination of Roy's Adaptation Theory and Lazarus and Folkman's Stress and Coping Theory (Cheewapoonphon, 1998; Gasemgitvatana, 1994; Sakunhongsophon, 1997; Sithimongkol, 1998), and combination of Orem's Self-care Theory and Stress and Coping Theory (Choum, 1994; Phokudsai, 1997; Tirapatwong, 1997). Qualitative studies have explored the positive aspects of family caregiving using exchange theory (Caffrey, 1992) and using ethnography (Kespichayawattana, 1999).

Family caregiving situations are very complex. Given and Given (1991), suggested that family CG's reactions to the caregiving process have both negative and positive aspects. Studies in Thailand have a limited perspective in exploring the family caregiving phenomena. Studies should seek to balance the negative and positive aspects of family caregiving (Farran, Kaeane-Hagerty, Salloway, Kupferer, & Wilken, 1991; Motenko, 1989; Polit & Hugler, 1995). Stress and coping theory focuses on intra-

individual aspects which view caregiving as stressful. Therefore stress and coping theory provides information mainly on the negative aspects of caregiving (Inoue, 1995).

Exchange theory explains caregiving as activities that persons perform to pay back previous debts or because they experience a benefit from providing care (Caffrey, 1992).

The author's opinion from experiencing Thai culture and nursing practice is that exchange theory may not be appropriate to explore family caregiving phenomena in Thailand because the majority of CGs caring for elders do not perceive a reciprocal exchange between the CG and the elder. Rather the CGs have a role in caring for elders, which is a strong social norm. Furthermore, family studies in Thailand need to explore middle range theories, which may guide specific nursing practice.

Another theory to be considered in understanding family caregiving is role theory. Role theory as applied to caregiving is a middle range theory, focusing on interactions between an individual and others. One important aspect of this theory is that people fulfill roles based upon cultural, familial, and social expectations (Hardy & Conway, 1978). Such a theoretical view may broaden our understanding in the analysis of Thai family caregiving. In addition, caregiving is a strong social norm in Thai culture but the family CGs may not know how to enact the role and manage the complexity of the elder's health problems. The nurse researcher needs to be able to measure these aspects of care that are difficult for families and those aspects that go well so that interventions can be targeted to the aspects where CG's feel the most difficulty.

The Family Care Inventory (FCI) by Archbold and Stewart (1986), derived from Role Theory focuses on both negative and positive responses to family care. Their conceptual model of family care is shown in Figure 1. The FCI is a relatively

comprehensive measure of the phenomena of family care in the U.S and has shown good psychometric properties (Archbold, Stewart, Greenlick, & Harvath, 1990, 1992; Archbold, Stewart, Harvath, & Lucas, 1986; Archbold et al., 1995). However, it is important that concept equivalency and concept differences be established before attempting to use the same instrument to measure a concept in a different culture (Munet-Vilaro & Egan, 1990). If nurse researchers introduce the measurement techniques and instrumentation from the U.S. without sufficient consideration of their appropriateness for a different cultural setting, they may misunderstand phenomena and misinterpret the results of their studies. Such misinterpretations, if used to guide nursing practice, may have adverse effects. Therefore, prior to translating FCI scales from English to Thai, a review literature was done to evaluate the relevance of concepts measured in the FCI to Thai culture. The specific aims of this study are:

Aim 1. To evaluate the internal consistency of the Thai version of the FCI family care scales.

Aim 2. To present descriptive statistics on the FCI Scales for Thai family CGs.

Aim 3. To evaluate the construct validity of the Thai version of FCI scales by testing hypotheses about the relationship among concepts as shown in Table 1.

Aim 4. To evaluate internal consistency, descriptive statistics and construct validity of two new scales: Strain from feelings of guilt and rewards of spiritual fulfillment.

CHAPTER 2

REVIEW OF THE LITERATURE

In this section, the history of developing the FCI and the research projects using the FCI will be presented as well as preliminary work of the researcher. In addition, literature from the U.S., Canada and Thailand will be reviewed focusing on eight family care concepts as well as both the SF-36 Health Survey and the Center for Epidemiological Studies Depression Scale (CES-D).

Summary of the Family Care Inventory and Its Conceptual Framework

The conceptual framework for the Family Care Inventory (FCI), originally called the Family Caregiving Inventory is based in part on the qualitative work of Archbold, 1982, and in part on role theory. As a basis for exploring family care to frail elders, Archbold and Stewart developed a conceptual framework in the early to mid 1980's which postulated that selected characteristics of the CG, care receiver (CR), and the dyadic relationship between the two influence the nature of the caregiving role. The nature of caregiving role in turn influences the response to family care -- CG role strain and rewards of caregiving. These responses to family care influence the outcome of CG's health. Archbold and Stewart's team developed measures of seven key concepts in family care including mutuality, preparedness for family care, amount of family care, help from others in family care, predictability, CG role strain and rewards of caregiving. These measures were systematically reviewed by a panel composed of experts in the areas of gerontology, family caregiving and methodology (Archbold et al., 1986). Two measures of CG role strain, tension in the relationship between the CG and CR and the CG's feelings of being manipulated, which were developed by Montgomery and Borgatta

(undated), were used in the FCI (Archbold, 1991). The results of quantitative pretesting with 50 CGs and care-receivers indicated that nearly all measures had Cronbach's alpha $> .70$ and most hypotheses about the relationships between concepts being measured were supported (Archbold, 1991).

During 1985-1987, Archbold and Stewart conducted a longitudinal study to assess the relationships among the key family care concepts over a 9-month period following an older person's discharge from the hospital. High levels of mutuality were strongly associated with lower levels of most aspects of CG role strain, but mutuality declined over time as well (Archbold, 1991).

Between 1990 and 1995, the FCI was used in three studies to examine family care in Alzheimer's disease and Parkinson's disease, as well as in a pilot study of the PREP (Preparedness, Enrichment, and Predictability) intervention for families caring for elders referred for skilled home health services. In addition, the FCI was translated and modified by Inoue (1995) to become the Japanese Family Caregiving Inventory (JFCI).

Currently, there are three ongoing studies using the FCI: the Parkinson's Spouses Project, the African American Caregiving Study and the Family Care Study. In the Parkinson's Spouses Project (1992-present), the FCI was used to collect longitudinal family care data from spouses of persons with Parkinson's disease (Carter, Stewart & Archbold et al. 1998). From 1996 to the present, Waters, Stewart, Archbold, Miller and Li collaborated to explore the psychometric qualities of the FCI in African American families. The study is in progress. Archbold, Stewart, Hornbrook and their research team are currently conducting the family care study, which is designed to evaluate the PREP intervention as implemented by home health nurses.

Evaluating Content Validity

In order to determine that concepts measured in the FCI scales exist in Thai culture and that each item is appropriate and represented in Thai family caregiving, I reviewed the literature documenting family caregiving in Thailand including popular books, published personal journals, magazines, and research journals and reports. These sources provided both an emic perspective, focusing on meanings attributed to behavior within a particular culture, and an etic perspective, focusing on meanings which span diverse cultures as universals (Karno, Burnam, Escobar, Hough, & Eaton, 1983). In addition, as a part of a reading and conference course, I conducted interviews with three Thai home health nurses to explore whether or not each item in the FCI scales represented Thai caregiving phenomena.

Brislin (1986) suggested that researchers who use an existing instrument in another culture may need to modify some items and to add other new items. The items should capture additional aspects of a phenomenon in addition to those investigated by the original instrument. In this procedure, 'researchers use the emic-etic distinction to their benefit. Take the example of a two-culture comparison. 'Etic' refers to a phenomenon, or aspects of phenomenon, which have a common meaning across the culture under investigation' (p.140). Based on the literature reviewed and the nurse experts' experiences, the concepts measured by FCI scales do exist in Thai culture and most items seem to be appropriate and represent Thai family phenomena. However, two concepts were identified which were not measured by FCI scales; therefore, two new measures including strain from feelings of guilt and rewards from spiritual fulfillment were

were developed for the Thai FCI. Further, rewards from others, developed by Inoue (1995) for family CGs in Japan, was added to the Thai FCI.

Literature from the U.S., Canada and Thailand was reviewed, focusing on eight concepts including mutuality, preparedness, amount of care activities, amount of help from others, predictability, amount of negative life style change, CG role strain and CG rewards. The cultural appropriateness of these concepts and measures of family care of elders in Thailand was evaluated. The SF-36 health survey and the CES-D are also reviewed.

In evaluating the cultural appropriateness of each concept, five questions were considered. First, has the concept been studied in Thailand? Second, have Thai measures for the concept been developed? Third, what findings have been reported about the concept in the Thai literature? Fourth, what are the opinions of nurse experts about the concept and its relevance in Thailand? Finally, if there is a Thai measure for the concept, why has a scale from the FCI been chosen to measure the concept in this dissertation?

Mutuality

Many researchers have found that the quality of the relationship between the CG and CR is an important aspect of family caregiving (Archbold, 1991; Hirschfeld, 1983; Motenko, 1989; Mui, 1995; Peters-Davis, 1999; Pruchno, 1990; Townsend, 1995; Whitbeck, 1991). Mutuality is one concept that has been used to describe the quality of relationships. Hirschfeld's qualitative study (1983) of 30 demented elderly and family CG dyads described mutuality as: "the CG's ability to find gratification in relationship with the impaired person and meaning from caregiving situation" and "the CG's ability to perceive the impaired person as reciprocating by virtue of his or her existence" (p.26).

Lynch-Sauer's (1990) study of the experience of caring for a family member with Alzheimer's disease described mutuality as shared vision, goals or sentiments. "Mutuality occurs when the individual believes that others share their vision and perceptions. This results in a sense of acceptance and ability to develop rapport with others" (p.9).

Archbold, Stewart, Greenlick and Harvath's (1990) study defined mutuality as the positive quality of the relationship between a family CG and a CR. Based on qualitative data, mutuality has four dimensions including love and affection, shared pleasurable activities, shared values, and reciprocity.

Several researchers have used different concepts to explain the quality of CG and care-receiver relationships. Horowitz and Shindelman's (1983) study of 203 primary CGs caring for an older relative indicated that affection influences caregiving. Affection refers to "the quality of the CG-older relative relationship as perceived by the CG. It is the degree to which the latter has positive feelings towards the older person and experiences their relationship as close and enjoyable" (p.9). From the literature reviewed on later-life family relationships, Townsend and Franks (1995) developed 18 statements describing the quality of the CG's present relationship with the care recipient. Factor analysis was conducted and the researchers identified emotional closeness as a measure of the quality of a relationship. Emotional closeness includes feelings of affirmation and affection, and fundamental facets of intimate ties (as cited in Fearon, Donaldson, Burns, & Tarrier, 1998). Morrison, Morrison and Britton's (1988) study of spouse CGs of dementia sufferers identified intimacy as a characteristic of a marital relationship. This concept has five dimensions including affection, cohesion, expressiveness, compatibility and conflict resolution. Motenko (1989) used the concept of marital closeness. Allen, Goldscheider

and Ciambrone (1999) identified the concept of emotional closeness in marriage. This concept is operationalized as the nomination of the spouse as confidante.

Bengtson and Schrader (1989) studied the quality of the relationship between parent and child. They created the Positive Affect Index to assess general closeness, similarity in views about life, and getting along and doing things together (as cited in Yates, Tennstedt, & Chang, 1999). Carruth and colleagues (1996) studied 12 CGs of elderly parents to develop the CG reciprocity scale. Reciprocity was defined as an intergenerational exchange of assistance and support between an adult child and parent. Carruth and her colleagues conducted a factor analysis of 30-item scale with 303 adult children of elderly parents or in laws. They found four dimensions of reciprocity, including warmth and regard, intrinsic rewards of giving, love and affection, and balance within the family.

The quality of the relationship has been measured by a single item by asking the CG to rate the quality of his or her current relationship with the CR. This is used for assessing the quality of the relationship between the parent and child (Mui, 1995; Whitbeck, Simon, & Conger, 1991) and spouses (Pruchno, 1990).

An analysis of the Mutuality Scale developed by Archbold, Stewart, and colleagues (1986, 1990, 1992) found many reasons to support choosing this instrument for the Thai FCI. Mutuality is defined more broadly than other researchers' conceptualization of the CG/CR relationship. The concept of mutuality and the scale to measure it has four dimensions. These dimensions appear to capture the phenomena of the positive quality of relationships. In addition, the mutuality scale has scientific merit. Strong evidence for its content validity is apparent from the procedures used in its

development. Items were derived from qualitative interviews with CGs and CRs; therefore, these items are imbedded in the family's experiences. The questions and responses also use the CGs' and CRs' own words (personal communication, P. G. Archbold, 1990 as cited in Levine, 1993). Evidence of both construct validity and reliability was obtained in a longitudinal study of 78 older caregiving dyads. Support for construct validity was obtained by testing the hypothesized relationships between mutuality and CG role strain. As predicted, higher scores on mutuality were associated with lower strain from direct care, increased tension, feelings of being manipulated, mismatched expectations, role conflict and global strain. However, mutuality was not associated with strain from worry, lack of resources or economic burden. Cronbach's alpha for the mutuality scale was .91, and the stability over an 8 months was evidenced by a correlation of .79 (Archbold et al., 1990). In other studies the internal consistency reliability of mutuality was high; in spouses caring for a partner with Parkinson's disease (Carter et al., 1998), spouses of persons who had heart bypass surgery (Kneeshaw, Considine, & Jennings, 1999), and CGs of persons receiving parenteral nutrition (Smith, 1994) reliability estimates were .95, .93 and .94 respectively.

Cultural Appropriateness of Mutuality in Thailand

In Thailand, several authors have defined the quality of the family relationships. Sangtong (1983) characterized the positive quality of family relationships as harmony, love and coherence. Panitpan (1984) stated that the quality of family relationships includes love, attachment and closeness between parent and child, as well as with relatives and other people who live within the family. The quality of relationship has both positive and negative aspects that affect the family. Nuichan (1987) defined the

relationships of elders and family members as including shared activities, communication, an exchange of opinions and experiences, acceptance of each other, reciprocity, love, attachment and lack of conflict. Enz and Rongsopasakul (1998) conducted a qualitative study of 36 adult-child, spouse and relative CGs of elders, and defined the positive quality of the relationship between CG and CR as love, understanding, sympathy, willingness to help, and acceptance. The interviews indicated that the quality of relationship had changed since the caregiving relationship was established. More than half of the CGs reported that their relationships were the same as in the beginning of caring, but some CGs reported that the quality of their relationship with the CR was getting worse due to the burden from caring for the elderly relative. From the elderly CR's perspective, almost all reported the positive quality of relationship with the CG was the same. However, two of the elders perceived that their relationship got better. Only one of elders reported that their relationship was getting worse.

Pornteesud (1996) wrote about the experience of caring for her father who suffered renal failure. She described how difficult it was to care for him; however, it made her happy because she did not perceive caring for her father as a burden. She was willing to care for him with love and reciprocity. She said that, "Today, my father, my mom, me and my sister are still happy because of love and reciprocity, and we are happy to do everything for him without feeling like it is a burden. And also my father did not perceive that he is a burden to his family members because he knows that we do everything because of love" (p.59).

To evaluate the equivalence of the concept of mutuality in the U.S. and Thailand, interviews with three nursing experts in Thailand were conducted. One of the nurse

experts was a faculty member in the community department at the School of Nursing (Ramathibodi hospital), Mahidol University. She has more than 25 years experience in home visits and teaching. The other nurse experts included the head of an ambulatory care department and a visiting nurse, both of whom have experience in home visiting for more than 10 years. I discussed the mutuality scales with the nurse experts by reading each item and asking them to indicate which items represented the phenomena of the positive quality of relationships in Thailand. They indicated that most items did represent mutuality. However, item 4 (How much does he or she express feelings of appreciation for you and the things you do?) which is measure reciprocity, did not seem to match what Thai people might say because they commonly do not express feelings of appreciation by saying thank you directly but they may express this indirectly by using body language or other non verbal communication.

From the Thai literature reviewed, several researchers stated that the quality of family relationships is important. There is little known about the positive quality of the relationship between CG and CR. Although Enz and Rongsopasakul (1998) defined the positive quality of relationships as love, understanding, sympathy, willingness to help, and acceptance, the research did not report clearly that those definitions were based on data from CGs and CRs. Furthermore, a Thai measure of the positive quality of relationships has not been developed. However, the evidence in the literature reviewed and experts interviewed has shown that the concept of mutuality does exist in Thai culture. Although there is a Thai word for mutuality, it is not equivalent in meaning to mutuality as used by Archbold and colleagues. If “the positive quality of the relationship” is translated into the Thai language, Thai people understand it more clearly than they

would if the Thai word for mutuality were use. After evaluation of Thai CG words existing in the literature and the English words for each of the item, the mutuality scale appears to represent the positive quality of the relationship between the Thai CG and CR. However, some items need to be evaluated and adapted for cultural appropriateness including the reciprocity dimension, shared values, and shared pleasurable activities as shown in Table 2.

Preparedness

The concept of preparedness is defined as “The CG’s assessment of how ready he or she is to do needed caregiving activities and to handle the stress of caregiving” (Archbold & Stewart, 2000). The concept of preparedness is based on gaining knowledge of an anticipated role prior to experiencing the reality of life in that role. It is believed that by learning what will be needed in this new role first, the transition into it will be less problematical (Burr, Leigh, Day, & Constantine, 1979). However, from the early qualitative data, Archbold et al. (1992) found that CGs learned the caregiving role after entering into that role. Therefore, they have focused on “the CGs’ appraisal of how well-prepared they are, no matter when they learned the role” (p. 328). Preparedness has 6 dimensions that refer to domains of the CG role. These include the provision of physical and emotional support, the setting up of services, handle stress, making caregiving activities pleasant, handle emergencies, and getting help from health care system. (Schumacher, Stewart & Archbold 1998).

Few researchers have examined preparedness or any similar concepts. Lawton, Kleban, Moss, Rovine, and Glicksman (1989) defined caregiving mastery as “ a positive view of one’s ability and ongoing behavior during the caregiving process” (p. P62). This

concept is based on the cognitive appraisal theory of stress and coping. Lawton and colleagues reported results from the factor analysis of this instrument in two samples. Sample 1 included 632 CGs caring for patients with dementia in a respite care research project. Sample 2 included 239 CGs to persons with any type of impairment who were on a waiting list for institutionalization. In exploratory factor analysis of Sample 1 data, 6 items loaded on the mastery factor. However, in a confirmatory factor analysis with Sample 2, only two items were maintained and the researchers considered a two-item factor unsatisfactory. They noted that caregiving mastery clearly exists as a basis for people's appraisals of their caregiving effort; however, this measurement needs to be more developed to capture this phenomenon.

Pearlin, Mullan, Semple and Skaff (1990) sought to expand their understanding of the place of self in the stress process by including dimensions of self-concept that are anchored specifically in the caregiving situation and whose measurement reflects this context. They noted that CG competence is a component of self-concept. CG competence was defined as CGs' self rating of the adequacy of their performance as CG.

The other concept which is similar to the concept of preparedness is the concept of self-efficacy identified by Haley (1987). Self-efficacy is derived from cognitive appraisal theories of stress and coping. Self-efficacy was defined as CG confidence in how well they were managing problems. To determine whether or not the CG had confidence in managing the care-receiver dependencies and problems, Haley and colleagues asked CGs to rate their confidence on items from the activities of daily living scale, the instrumental activities of daily living scale, and the memory and behavior problems checklist.

The concept of preparedness was chosen to study the Thai family for several reasons. First, the concept of preparedness refers to specific aspects of each caregiving situation. The concept of CG mastery defined by Lawton and colleagues (1989) represents overall how CGs appraise their own competence in this role. CG mastery defined by Pearlin and colleagues (1990) is a "broad stance with respect to life situations or resource rather than an appraisal of one's behavior within a certain context" (Schumacher, et al., 1998, p. 65). CG competence defined by Pearlin and colleagues (1990) is also used to explore the overall CG situation.

Although the concept of self-efficacy as defined by Haley and colleagues (1987) is similar to the concept of preparedness, it is a more narrow definition than that the concept of preparedness. Self-efficacy assesses task-specific confidence while preparedness focuses on domain-specific preparedness (Archbold, et al., 1990).

Evidence of both construct validity and reliability was shown in a longitudinal study of 78 older caregiving dyads. Support for construct validity was obtained by testing the hypothesized relationships between preparedness and CG role strain. As predicted, higher scores on preparedness were associated with lower strain from direct care, increased tension, feelings of being manipulated, mismatched expectations and global strain. Thus, preparedness was not associated with strain from economic burden and role conflict. Cronbach's alpha for the preparedness scale was .72, and the stability over an 8-month period was evidenced by a correlation of .57 (Archbold et al., 1990). In other studies the reliability of preparedness was higher; in spouses caring for a partner with Parkinson's disease (Carter, et al., 1998), spouses of persons who had heart bypass

surgery (Kneeshaw, Considine, and Jennings, 1999), and CGs of persons receiving parenteral nutrition (Smith, 1994) reliability estimates were .92, .76 and .88 respectively.

Cultural Appropriateness of Preparedness in Thailand

In Thailand, the concept of preparedness has not been studied. However, the nurse experts reported that the concept of preparedness does exist in Thai family caregiving and they indicated that most preparedness items appear to be appropriate in Thai culture.

Care Activities

The amount of care activities consists of how many of a broad range of care activities that CGs actually perform in helping their CRs (Inoue, 1995). Many researchers limit their focus to Activities of Daily Living (ADL) and Instrumental Activities of Daily Living (IADL) as the care activities performed to explore the CG's stress (Fasion, Faria, & Frank, 1999; Fink, 1996; Marchi-Jones, Murphy, & Rousseau, 1996; Mathew, Mattocks, & Slatt, 1991; Tennstedt & Chang, 1998; Thompson, Futterman, Gallagher-Thompson, & Rose, 1994). CGs actually provide not only ADL and IADL help, but also medical/nursing treatments, protection, transportation, emotional support and managing behavior problems (Albert, 1991; Archbold et al., 1986; Oberst, Thomas, Gass, & Ward, 1989).

Archbold and Stewart (2000) consider the concept of care activities as one component of the nature of caregiving role. Their Care Activities Scale measure "the number and type of care activities the CG does for the CR" (p. 3). The dimensions of the amount of care include: (1) personal care, (2) mobility and protection, (3) illness-related care, (4) transportation, banking, and housekeeping, (5) little extras and emotional

support, and (6) dealing with the symptoms of dementia and difficult behavior, and (7) arranged care.

The Amount of Care Activities Scale developed by Archbold and Stewart (2000) was selected for this study because it appears to cover the range of family care activities better than other instruments. Evidence of reliability for an earlier version of the scale was shown in a longitudinal study of 78 caregiving dyads. Cronbach's alpha for the scale was .86, and the stability over an 8-month period was evidenced by a correlation of .73 (Archbold et al., 1990). The reliability of the Amount of Care Activities Scale in spouses caring for a partner with Parkinson's disease (Carter, et al., 1998) was .94.

Cultural Appropriateness of Caregiving Activities in Thailand

Care activities is an appropriate concept for Thai culture and has been studied more than other concepts of family care. In Thailand, there are several instruments used for determining the amount of care given to family members. ADL and IADL were translated into Thai and adapted for cultural appropriateness, and then used to investigate CG activities (Kaewraya, 1997). Gasemgitvatana (1994) used the CG Load Scale (CLS), developed by Oberst et al. (1989) to explore the CG activities of 104 wives of individuals who were chronically ill. The 13-item CLS includes medical and nursing treatment, personal care, assistance with mobility, emotional support, monitoring and reporting, provision of transportation, managing illness-related finances, additional household tasks, structuring activities, and managing behavior problems (Oberst et al., 1989). The CLS was translated into Thai and reviewed by four expert nurses who have experience in caring for chronically ill patients. Cronbach's alpha for the CLS scale was .72, and the stability over 4 weeks was evidenced by a correlation of .68. The CLS explored CG

burden as well as stress and coping in the Thai family CG (Cheewapoonphon, 1998; Phokudsai, 1997; Thepsiri, 1997; Tirapatwong, 1997).

Using Orem's theory as a conceptual framework, Boonyatulanon and Surapakapong (1996) conducted a study of CGs of persons who had chronic illness and developed a 36-item measure of CG agency, which they define as the CG's ability to assist a person with a stroke (as cited in Suwanno, 1998). CG agency has nine dimensions including maintaining sufficient intakes of air, water and food, provision of care associated with eliminative processes and excrements, personal care, promoting activities and exercise, protecting from accidents and complications, maintenance of rest, promoting privacy and social interaction, and providing medicine and treatment.

A qualitative study conducted by Enz and Rongsopasakul (1998), found that CGs assist elders with activities such as preparing meals, cooking, providing medical and personal care, making the bed, housekeeping, assisting with ambulation and exercise, massaging and emotional support. Kespichayawattana's qualitative study (1999) of 15 adult children who took care of their frail elderly parents identified three dimensions of caregiving including physical caregiving, psychological caregiving, and spiritual caregiving. There are five categories of physical caregiving which emerged from the data: a) maintaining parents' daily activities; b) nursing care activities; c) environmental modifications to promote parental function; d) obtaining assistance; and e) seeking alternative methods of treatment.

Sommanawan's (1994) study of 29 family CGs caring for a demented elderly relative at home used a case study, in-depth interview, as methodology. CGs described caregiving activities which they needed to provide to the demented elderly; these

activities included personal hygiene such as bathing and dressing, mealtime assistance, help with incontinence, sleep disturbances, immobility, and behavioral disturbance. Sommanawan's results also showed that CGs need to modify the environment of the demented elder. CGs described elders as having bladder accidents on the bed especially at night. CGs used plastic over the mattress; therefore, the CG can save money by not buying a new mattress to replace one damaged by urine. Other CGs described the problem of caring for elders who have bowel accident problems because the bathroom is outside the house or up stairs. CGs modified some areas for elders to solve such problems.

Several studies indicated that Thai family CGs combine western medical care with traditional Thai medical care. Sasat's (1998) qualitative study of 44 CGs caring for demented elders found nearly half (n=21, 47.7%) had sought help from traditional Thai medicine; the majority of CGs lived in a rural area. The types of traditional healer, which were found in this study, were herbalist, mediums, ritual and traditional massage. Kespichayawattana's qualitative study (1999) of 15 adult children who took care of their frail elderly parents identified seeking alternative methods of treatment as one category of physical caregiving. She stated that CGs "combine other alternative medicine as parts of caring regimens for their parents" (p.90). The study found that CGs tried herbs that were prepared by the Chinese traditional medical practitioner or Thai traditional medical practitioner. They also tried enlisting magic or holy water as an alternative method to help their parent. Hirunchunha's (1998) qualitative study of 15 primary CGs and 15 stroke patients was used to develop a care model for CGs of stroke patients at home. She found that all of the CGs believed that if the patient received the traditional massage, the

stroke patient would walk again. Therefore, all of the CGs in this study hired a professional massager to massage the stroke patient. They also used herbs as an alternative medicine.

From the Thai literature reviewed and interviews with nurse experts, the evidence supports that most of the Care Activities Scale developed by Archbold and Stewart (2000) is appropriate to assess care activities in Thailand. The scales seem to capture well the nature of the caregiving role in the Thai family. However, based on the literature review, items reflecting environmental modifications need to be added to the scale. In addition, Items 16, 40, 57, and 77 need to be adapted for cultural appropriateness (shown in Table 2). Items 16 and 40 are related to transportation and many families in Thailand do not have their own car. Thus, they use public transportation such as Tuk-Tuk, taxi and bus.

Item 57 is related to assisting the elder in filling out documents. The U.S. and Thailand are different in the type of document filled out. Thus, item 57 was reward. Item 77 is related to spiritual needs. There are three religions, including Buddhism, Christianity, and Islam. Most Thai are Buddhists. Therefore, Buddhist activities need to be reflected in this item. An item from the traditional healer also needs to be added (Table 2).

Predictability

Archbold and Stewart (2000) defined the predictability of family care as “the CG’s perception of the regularity and consistency in his or her family care situation” (p.4). The concept of predictability has links to the concept of control (Mirowsky & Ross, 1990; Rodin, 1986; Schulz, 1976; Schulz, Biegel, Morycz, & Visintainer, 1989). Control

refers to the degree to which individuals believe that they can control the good and bad things that happen in their lives. In other words, it reflects individual beliefs that one can obtain desired outcomes through one's action (Miller, Campbell, Farran, Kaufman, & Davis, 1995). Another concept that is similar to predictability is the concept of uncertainty. Mishel (1981) defined uncertainty as the perception of information as vague, having multiple meanings, as a probability, ambiguous, inconsistent, lacking information, unpredictable, or unclear.

The concepts of control and predictability are closely related. If people can control the outcome, they can also predict the outcome. However, the reverse is not always true, people may be able to predict an event while having little or no control over that event or outcome (Rodin, 1986; Schulz, 1976). In contrast to control and predictability, the concept of uncertainty suggests that the CGs cannot predict or have control over caregiving events and outcomes.

The concept of predictability and its corresponding measure developed by Archbold and Stewart (1986, 1993, 2000) was selected because it represents aspects of caregiving situations that vary in predictability such as regularity of activities. Four of seven items on the predictability scale represent specific aspects of caregiving situations that vary in predictability, with three items referring to the CG's general life situation. Evidence of moderate reliability $\alpha = .75$ was shown in a study of spouses caring for a partner with Parkinson's disease (Carter, et al., 1998).

Cultural Appropriateness of Predictability for Thailand

The concept of predictability has not been explored in Thai family caregiving situations. However, the nurse experts reported that the concept of predictability does

exist in the culture and they indicate that most predictability items seem to be appropriate.

Help from Other People

Archbold and Stewart (2000) defined help from other people as “the amount of help in family care from relatives, friends and neighbors, or professionals” (p.3). Other researchers have used similar concepts to measure help from others including informal care. Penrod, Kane, Kane, and Finch (1995) examined the informal network of 242 impaired older people in terms of help from other people but they combined primary and secondary CG. Informal care is provided by a network of helpers, that includes a primary CG plus secondary helpers who provide indirect help to the primary CG by helping the older person. Morrow-Howell, Proctor and Berg-Weger (1993) studied the discharge planner’s perspectives on the adequacy of informal care expected to be provided to older adults immediately following discharge from the hospital to home care. They defined adequacy of informal care as “the informal caregiving network, rather than a single CG, with the net work including all family and friends providing any type and amount of assistance, and focuses on the caregiving unit’s anticipated ability to provide the help expected, apart from formal services arranged” (p. 191).

The concept of help from others and its corresponding measure by Archbold and Stewart (2000) was selected because the concept’s definition is clearly described and the items separate out the care from a primary CG and other secondary helpers. The amount of help from others concept scale had a reliability of .69 in a sample of spouse of CG for a persons with Parkinson’s Disease (Carter, et al., 1998).

Cultural Appropriateness of Help from Other People for Thailand

Thai CGs get help from their relatives, friends and neighbors (Enz & Rongsopasakul, 1998). Kespichayawattana's qualitative study (1999) of 15 adult children who took care of their frail elderly parents showed that the CGs felt upset if they did not get help from persons who are expected to help in caring for elders. The nurse experts indicated that the CG might get help from professionals such as the home health nurse from Ramathibodi hospital. At the time of the study only one hospital in Thailand providing home health nurses. Home health aides were available from private agencies. Based on the literature reviewed and interviews with nurse experts, the evidence supports that most items on the amount of help from others scales are appropriate to assess the amount of help which the CG received from others caring for elders in Thai culture.

Amount of Negative Lifestyle Change

Archbold and Stewart (2000) defined the amount of negative life style change as "negative changes in the CG's lifestyle because of the CG role" (p.5). They used a scale developed by Montgomery and Borgatta (undated) to measure this concept. The concept of the amount of negative life style change and its measures were chosen because the concept's definition is clearly described and represents one characteristic that accompanies the assumption of the CG role. Cronbach's alpha reliability for Negative Lifestyle Change scale in the Japanese FCI was .84 (Inoue, 1995).

Several American studies showed that CGs' life style changed in many ways when CGs began to care for an ill family member (Enterlante & Kern, 1995; Periard & Ames, 1993; Silliman, Fletcher, Earp, & Wagner, 1986; Williamson, Shaffer, & Schulz, 1998). Some investigators have used social activity (Enterlante & Kern, 1995; Silliman,

Fletcher, Earp & Wagner 1986), life style change (Periard & Ames, 1993), CG activity restriction (Williamson, Shaffer & Schulz, 1998), and negative life style change (Archbold & Stewart, 2000) as a concept to describe this phenomena.

Silliman, Fletcher, Earp and Wagner (1986) defined social activity as the CG report of the frequency of visiting friends and family. Enterlante and Kern (1995) identified social activity as consisting of family gatherings, recreation, social gatherings, hobbies and organizational activities. Periard and Ames (1993) defined life style change as “a self- reported alteration (increase or decrease in amount or frequency), in any of nine categories: finances, instrumental activities of daily living (IADL), personal care, family relationships, relationships with friends, community activities, leisure activities, physical activities, and nutrition. CG activity restriction was defined as the CG’s reported extent to which nine areas of normal activity such as doing household chores, going shopping, visiting friends, participating in sports and recreation, and maintaining friendships were restricted by their caregiving responsibilities (Williamson, Shaffer & Schulz, 1998).

Cultural Appropriateness of Amount of Lifestyle Change for Thailand

In Thailand, several studies showed that the concept of the amount of negative life style change exists in the Thai family phenomena. Wongsit and Sririboon (1998) studied the problems of the CG caring elders. This study showed that the CG’s stress is both physical and mental. CGs who do not have help from others have greater emotional stress than CGs who have help form others. The time and freedom to go out or to do activities that they want to do was especially limited. Trirapaiwong’s (1997) study showed that caregiving affects their life style. A CG stated “I do not have freedom. When I go out, it

isn't convenient. I have to limit my social activities" (p.63). Another CG said that "Caregiving decreased my time for work, lowered my income, privacy and also decreased my time to sleep" (p.64).

Kespichayawattana (1999) identified social isolation as a negative consequence of the caregiving situation. Social isolation is defined as "the CG's feelings of being disconnected or a lack of social activities with their friends or groups because the caregiving responsibility consumed most of their time" (p. 146). A CG stated "I can not go anywhere. When my friends ask me to go out, I have to refuse them because no one will take care of my father" (p. 146). Another CG said, "My friend also asked why I did not find a job that can earn more than just washing and ironing clothes. She asked me to get out with her. But I couldn't do that. I told her that I couldn't leave my mother alone. Who will take care of her if I was not home? I have no time to go out. When I have to buy blue chux pads or stuff for her I went for 2 or 3 hours and hurriedly come back home. That is the only time that I left her alone" (p.146). Another CG said, "Even though people asked me to go out to make merit, I still could not do so. Thus, forget about going out for fun or travel. I could not go anywhere" (p.146).

Based on the literature reviewed, there is no negative lifestyle change instrument developed in Thai literature. Therefore, this instrument needs to be explored further. The nurse experts indicated that almost all items on of negative life style changes are culturally appropriate. Item 5 needs to be modified as shown in Table 2.

Caregiver Role Strain

Stress and coping theory (Lazarus & Folkman, 1984), role theory (Biddle & Thomas, 1966; Burr et al., 1979) and exchange theory (Burgess & Huston, 1979; Cook,

1987; Gergen, Green, & Willis, 1980) have been used to study the negative aspects of family caregiving.

Stress and coping theory focuses on the individual, and views caregiving as a negative experience. The concept of CG burden was developed from stress theory. This concept describes the phenomena of the amount of stress family CGs experience (Zarit, 1989). The Burden Interview (BI) was developed to measure the concept of CG burden. The BI was developed based on clinical experience in a senile dementia setting. The BI addressed areas most frequently mentioned by CGs as problems. These included the CG's health, psychological well-being, finances and social life (Zarit, Reever, & Bach-Peterson, 1980). Based on data from 184 CGs caring for dementia patients, the internal consistency reliability of the BI was .79 (Zarit, Anthony, & Boutselis, 1987). Anthony-Bergstone, Zarit & Gatz (1989) examined responses on the BI in a sample of 105 CGs caring for adult children with mental illnesses and 208 CGs caring for adult children suffering from mental retardation. Cronbach's alpha reliability coefficient for this sample was .87. Cox and Monk (Cox & Monk, 1993) examined the way cultural values and norms influenced the experiences of 86 Hispanic CGs. The reliability of the BI in this population was demonstrated by high values of Cronbach's alpha with a reliability of .91.

Validity assessment of the BI was performed with 184 CGs of dementia patients. Criterion-related validity was supported by correlations between the Brief Symptom Inventory, which measures depression, hostility and anxiety, and the BI, with a range of .42 to .52 (Anthony-Bergstone, Zarit and Gatz, 1989). The BI has been widely used in caregiving research.

Some investigators who have criticized Zarit's work studied both subjective and objective burden (Montgomery, Gonyea, & Hooyman, 1985; Poulshock & Deimling, 1984). Poulshock and Deimling (1984) suggested that burden is a highly individualized response to specific caregiving issues, which is influenced by the type of the elder's impairment. CG burden was viewed as multidimensional, consisting of three parts: burden antecedents, burden and burden consequences. Burden antecedents included both cognitive burdens and physical burdens, which referred to the degree to which a CG believed the elder was cognitively and physically incapacitated. Burden included both social functioning burden and disruptive behavior burden. According to Poulshock and Deimling, the CG's feelings of oppression, discomfort, and distress arise both from the elder's disruptive behavior and from the elder's difficulties with social functioning. Therefore, social functioning burden and disruptive behavior burden result from the CG's perception of the elder's cognitive incapacity and physical impairments. Burden consequences consist of negative changes in the elderCG family relationships and also social activity restrictions, which refer to the effect on the CG's personal life and social life including decreased social activities, role strain, and financial problems.

Pearlin, Mullan, Semple, and Skaff (1990) suggested a conceptual model of Alzheimer's CG's stress that consists of four domains: 1) the background and social context of the caregiving situation, 2) stressors, 3) mediators of stress, and 4) stress outcomes. The background and social context of the caregiving situation includes age, gender, occupation, education, access to resources, and the history of the caregiving relationship. The model proposes two kinds of stressors. Primary stressors are those that arise from the illness condition that make caregiving necessary such as CRs' functional

and cognitive impairment, and also problematic behaviors. Secondary stressors are the role strain and intrapsychic strain generated by the primary stressors. Mediators of stress include coping mechanisms and social support. Stress outcomes refer to the CG's depression, anxiety and physical health.

Oberst, et al. (1989) used cognitive appraisal models of stress and coping as a conceptual framework. These models postulate that individual responses to a potentially stressful situation are mediated by an appraisal of the personal meaning of the situation, including one's ability to manage the situation. They developed the CG Load Scale (CLS) to measure caregiving. Carey, Oberst, McCubbin and Hughes (1991) modified the CLS to develop the CG Burden Scale (CBS). The CBS has a separate scale for caregiving demand and the amount of difficulty associated with caregiving tasks. A burden score is calculated for each item by multiplying the demand by the difficulty. A square root transformation is used to return the score to the original metric. Higher scores indicate higher caregiving demand, difficulty and burden. The reliability of caregiving demand and the amount of difficulty were .83 and .89 respectively. The correlation between the scales was .73.

Role theory has been used to conceptualize the negative aspects of caregiving. Role theory assumes that people fulfill roles based upon cultural, familial, and social expectations. These expectations may be conscious or unconscious; however, these expectations influence the person's feelings about their performance and their ability. In this way, the expectations that are embedded within the family role influence the degree of stress that the individual may feel (Hardy & Conway, 1978).

The concept of role strain, as derived from role theory, is defined as the felt difficulty in fulfilling role obligations. Burr, Hill, Leigh, Day and Constantine (1979) described Goode's definition of role strain as "the stress generated within a person when she/he either cannot comply or has difficulty complying with the expectation of the caregiving role or his/her set of roles" (p.57). They conceptualized role strain as a specific stressor.

Archbold and Stewart conceptualized CG role strain based on Goode's work (Archbold et al., 1986). CG role strain has been defined as the CG's felt difficulty in performing the CG role (Archbold, et al., 1990). CG role strain has 12 dimensions including strain from: care activities, communication problems, frustration due to communication problems, role conflict, worry, worry about safety, lack of resources, economic burden, feelings of being manipulated, increased tension, mismatched role expectations, and global strain (Carter, et al., 1998). Reliability evaluation of all but the strain due to communication problems, frustration due to communication problems and worry about safety scales was performed with 78 CGs (Archbold, et al., 1990). Cronbach's alpha reliability for seven of the nine strain scales ranged from .64 to .94; for two scales Cronbach's alpha was not computed because of legitimate missing responses. The correlational stability of these scales over an 8-month period ranged from .62 to .80. In 1995, Archbold and colleagues (1995) reported on the PREP system of nursing interventions. This was a pilot test with a sample of 22 families caring for older members. The internal consistency of the role strain scales was measured in this sample using Cronbach's alpha. Reliability for the strain scales ranged from .77 to .99. Carter et al.

(1998) studied 380 spouses of persons with Parkinson's disease. The reliability for CG role strain scales ranged from .57 to .98.

Obtaining evidence validity of the CG role strain scales began with content validity. Content validity of the scales was reviewed by three groups of experts: CGs, faculty and doctoral students in the field of gerontological nursing, and nurse practitioners (B. Stewart, personal communication, December 1, 1997). Construct validity evaluation of 9 of the 12 strain scales was performed with 78 CGs (Archbold, et al., 1990). Support for construct validity was obtained by testing the hypothesized inverse relationships between strain and mutuality and preparedness. CGs reported strain from direct care, increased tension and global strain appeared lower when higher levels of mutuality and preparedness. Strain from economic burden was not reduced by either mutuality or preparedness. Strain from worry and lack of resources were not related to mutuality.

According to Mui and Morrow-Howell (1993), role theory includes the concepts of role strain, role demand overload, and role conflict, and provides a useful framework for conceptualizing the experience of the CG. When people do not have enough resources to adequately fulfill their multiple role obligations, multiple role commitments produce role strain as a consequence of role demand overload and role conflict. CGs are likely to experience a sense of role strain because they may have limited financial and physical resources to cope with the caregiving situation (Mui, 1992). Role demand overload may be appropriate to describe the experience of the person who serves as the primary CG while they have multiple roles as parent, spouse, worker, and friend. Consequently, the increased demands of the CG role may force CGs to reduce other role obligations and

social activities. Another source of role strain is role conflict, which refers to incompatibilities of role expectations. A CG may need to deal with conflicting expectations from his or her elderly relative, spouse and children. Furthermore, an older CG is likely to experience role conflict if she/he has unrealistic expectations in the caregiving role. Mui (1992) defined CG role strain as the amount of emotional strain or stress that caring for the elderly person placed on the CG. Her CG role strain scale has 14 items, with an alpha of reliability of .77.

Exchange theory has been proposed as a model to use in examining relationships between elders and CGs. According to Dowd (1980), problems associated with the declining status of the aged are essentially due to a loss of valued resources. This causes a decrease in the power to gain respect of others. From this perspective, care is dependent on reciprocal exchange of the perceived equitable value between the elder and the CG (as cited in Caffrey, 1992). Walker, Martin & Jones (1992) studied the outcomes of caregiving for elderly mothers and their caregiving daughters based on exchange theory. They examined the data for both the positive and negative outcomes of caregiving (i.e., benefits and costs), but found only negative outcomes for caregiving in daughters. The results of this study showed the experience of costs for caregiving daughters including frustration, anxiety and insufficient time.

The concept of CG role strain was chosen to use as a tool to study the Thai family for several reasons. First, the concept of CG role strain is derived from role theory. Role theory, a middle range theory, is viewed as helpful, from a nursing perspective, in conceptualizing and measuring the difficult aspects of family caregiving. In contrast to stress and coping theory, a role theory perspective views family caregiving as interaction

between the CG and CR. Stress and coping theory focuses more on intra-individual responses of CGs and their view of caregiving as stressful. Second, negative aspects of family caregiving derived from exchange theory have not been well developed in the U.S. literature. In addition, it may be not appropriate for investigating Thai culture because almost all of Thai CGs do not expect to benefit from this situation. Third, although the concept of CG role strain developed by Mui was derived from role theory, her conceptualization of strain is not as comprehensive as that used by Archbold and colleagues (1990).

Evidence of strong validity and reliability of Archbold and Stewart's measures of CG role strain was described earlier.

Cultural Appropriateness of CG role strain for Thailand

Several investigators have studied the negative aspects of family caregiving in Thailand by using a combination of Roy's Adaptation Theory and either Stress and Coping Theory or Orem's Self Care Theory as conceptual frameworks. Gasemgitvatana (1994) examined the causal relationships among socioeconomic factors, past marital relationships, social support and caregiving demands, caregiving appraisal and caregiving role stress. This researcher translated the CG Burden Scale (CBS) developed by Oberst et al.(1989) into Thai and selected caregiving demands as a part of the CBS to explore CGs' activities. The researcher developed the CG role stress scales using content from Western literature including qualitative studies, a case study, phenomenology and the Role Strain Index developed by Whittset and Land (1992). The researcher also interviewed 3 spouses of individuals with chronic illnesses to tailor the CG role stress scales. The definition of CG role stress is unclear as described. CG role stress has three

dimensions including CG stress from role overload, role ambiguity, and role conflict. The content validity was supported from the agreement of 5 of 7 of experts. Cronbach's alpha reliability for CG role stress was .90. The correlational stability of this scale over a 4-month period was .86.

Kaewraya (1997) examined role stress in 210 CGs of elders in Petchaburi province. The researcher developed an assessment of CG role stress drawing on the work of Hardy and Conway (1988) and Robinson (1983), who developed the CG role strain Index. Kaewraya also defined CG role stress of as having three dimensions, including CG stress from role overload, role ambiguity and role conflict. The content validity was supported by Cronbach's alpha reliability of .90 for CG role stress.

The CBS, developed by Oberst et al. (1991) and translated and adapted for cultural appropriateness by Gasemgitvatana (1994), has been used to explore CG burden in Thailand. The reliability of the CBS was evaluated with CGs of dependent elderly (Chaoum, 1994), CGs of individual suffering from advanced cancer (Cheewapoonphon, 1998), spouses of persons who are waiting for kidney transplantation (Phokudsai, 1997), and CGs of stroke patients (Tirapiwong, 1997) and resulted in alpha values of were. .90, .78, .86, and .88 respectively.

The BI instrument has been also used in evaluating family CGs in Thailand. Monkong (1998) used the BI (Zarit, 1985) to explore CG burden in 33 CGs of Thai elderly with hip fractures. The BI, which was originally designed for CGs of persons with dementia, was translated into Thai but the scales were not adapted for individuals with fractured hips. The content validity was supported by the agreement of experts. Cronbach's alpha reliability for the BI interview was .90.

Several studies and interviews with nurse experts showed that the concept of CG role strain has equivalent concepts in Thai family caregiving.

Strain from care activities. Sommanawan (1994) interviewed 29 CGs who were caring for the demented elderly at home in Bangkok. The researcher found that 27% of the CGs reported that they felt burdened and had difficulty in providing personal care for the elderly in the advanced stages of dementia. One CG stated “She has memory loss that is all right for me but she cannot help herself in doing her personal care. I worry. I have to resign my job due to the fact that she is dependent and she cannot complete activities of daily living. I have to take care of her. I do not know what to do. I think this a lot. I cannot sleep. I am under stress. If she could help herself somewhat, I would feel better. It would easy to take care of her” (p.49). In addition, Sommanawan’s study (1994) found that CGs felt burdened by handling demented elderly patient symptoms from communication problems, toileting, feeding, memory loss, sleeping problems, wandering and getting lost, slow movement, accumulating things, and silence with no response. Sasat’s did a qualitative study of 44 CGs caring for demented elderly at home. She found that the majority of stress complaints were found among spouse CGs rather than younger relative CGs. These complaints almost always related to the demands of caring for the CR such as:

C20: “I have to help her walking upstairs and downstairs every day.”

C29: “I feel very stressed, because I have to look after her all the time.”

C39: “ I feel so tired from taking care of her, especially as she always struggles when I try to change her clothes.” (p.271).

This study also show that most CGs found it was difficult to handle physical symptoms related to the care-receivers' deterioration. These included sleep disturbance, balance problems, incontinence, constipation, and dysphasia. Half of the CGs reported that their caring problems and difficulties were associated with the CRs' behavior problems. There was a broad range of psychological symptoms, the most common being confusion and depression, hallucinations, mood swings, obsessive compulsive behavior, paranoid delusions and anxiety. CGs also noted the CR's memory loss. Memory problems described by CGs included the statement: "He is always forgetting where he keep his belongings and he's searching for them all the time. He's upset other family members by accusing them of stealing or moving his belongings" (p.272).

I discussed with the nurse experts the scales of strain from care activities including (1) personal care, (2) mobility and protection, (3) illness related care, (4) transportation, banking, and housekeeping, (5) little extras and emotional support, (6) dealing with the symptoms of dementia and difficult behavior, and (7) arranging care from others. They agreed that these items represented strain from care activities in the Thai family. However, some items needed to be modified to be appropriate in Thai culture; these were discussed in the care activities section.

Strain due to communication problem and frustration from communication problems. Sommanawan (1994) interviewed 29 CGs who were caring for demented elders at home in Bangkok. She found that more than half of the CGs reported that they had difficulties and were frustrated when they communicated with the CRs, especially dealing with the elder's complaints. Sometimes the elders used poor grammar and identified objects incorrectly, and they were unable to articulate their needs at all. Sasat's

qualitative study of 44 CGs caring for demented elders at home showed that CGs were upset at being unable to communicate with their CRs. In early dementia, CGs felt particularly frustrated about the lack of co-operation from CRs, for example (p. 271):

C4: "He never does anything that I ask him to do."

C6: "He always does what he want to. He never listens to us."

Such uncooperative behavior got worse when the CR went through a very confused state which rendered them unable to communicate. A CG said that "He's shouting and crying all day and all night long." By the time the CR got to the later stages of dementia they became more quiet so that one daughter said of her mother, "I can't communicate with her, so I don't know what she wants" (p. 271).

This evidence supported the premise that family CGs have difficulty in fulfilling the CG role due to strain from strain from communication problems and they are often frustrated. I also discussed with nurse expects the scales of strain from communication problems and frustration due to communication problems. They indicated that all items represented in the caregiving situations are appropriate to Thai culture.

Strain from lack of resources. Enz and Rongsopasakul study's (1998) found that the CGs were not getting enough rest and sleep. CGs reported the following:

Ms. Yongvadee: "I prepared everything in the morning including doing cooking. In the evening, I just warmed food up for her. I took a nap that lasted one or two hours. Then I woke up. Some days, I do not have time for sleeping. Sometimes, the elderly are just yelling when nothing's wrong with them" (p.29).

Ms. Thonguong: "Yesterday, I did not have time to sleep. I took a nap around 15-30 minutes. I was dizzy and felt uncomfortable" (p.29).

Ms Sumchit: "If the elderly have a fever at night, I need to stay awake all night long. I need to do a tepid sponge bath often for her" (p.29).

Ms. Sitichai: "I get little bit rest because the elderly do not have a normal sleep pattern. The elderly sleep during the day wake at night. Every family member goes to bed but the elderly are still awake" (p.29).

Sommanawan (1994) interviewed 29 CGs who were caring for demented elders at home in Bangkok. The study found that 51.7% of CGs reported that they could not sleep at night due to the demented elder waking up and their disruptive behaviors at night. Trirapaiwong (1997) studied patient-CG relationships and caregiving burden in family CGs of stroke patients. One CG reported that, "I have to do everything including house chores, taking care of the patient. I do not have anybody to consult when I have problems. I have to take on all responsibilities. My sleep and my privacy has decreased" p.(63). Another CG stated "I do not have free time, I work harder, am more tired and have less rest" (p.64).

In Hirunchunha's qualitative study of 15 primary CGs caring for stroke patients at home, one CG stated: "To be honest, I feel so fed-up with him, he never listens to me. All he wants to do is eat and sleep and he often says that he hasn't eaten when in fact he already has. He also wakes up many times at night and I have to wake up with him, so that I don't get enough sleep and feel tired because I have to work full-time outside the home"(p. 282). Kespichayawattana did a qualitative study (1999) of 15 adult children who took care of their frail elderly parents. She identified physical strain one of the dimensions of negative consequence of caregiving. Physical strain is defined as the CG's feeling of physical and mental exhaustion from the caregiving responsibilities. A CG

reported that “ I was irritable because I was so tired and exhausted. I sometimes felt very tired in the evening. I had no energy to do anything. I felt like I didn’t have even have energy to eat. I just want to lie down and sleep. If I layed down, I would easily fall asleep because of the tiredness”(p. 142). Another CG said, “The biggest problem that I faced is the feeling of tiredness. I am now aging and doing all this caregiving makes me very exhausted. I feel I could do nothing. I just sit and cry. I cried a lot during the first stage of being like this” (p. 142).

I discussed strain from lack of resources with nurse experts. They indicated that most items are represented in Thai family caregiving. From the literature reviewed and interviews with experts, this concept was supported. There are no items that need to be adapted for cultural appropriateness.

Strain from economic burden. Several studies showed that CGs have economic burden when they care for the ill elderly (Enz & Rongsopasakul, 1998); Kespichayawattana, (1999); Maneewon, et al., 1992). In Enz and Rongsopasakul study, the CG described that she felt good to be taking take care of elder; however, she has financial problems. She mentioned that “ I am used to living with the elderly. I felt good about taking take of her, but my standard of living decreased. I need to pay for my kids to go to school. My mom gets sick. I have to pay for her health services such as doctor appointments. I cannot make enough money to pay the bills” (p.19). Hirunchunha’s qualitative study of 15 primary CGs caring for stroke patients at home found that 33% of CGs had financial problems; therefore, they can not buy medical equipment or take the patient for treatment as much as the CG wants to. CGs have to pay extra money from their regular expenses when they are caring for patients with stroke. They have to take

responsibility to pay including the patient's food, taking the patient to go to massage, transportation, medical and other health services. This causes CG stress. In Kespichayawattana's qualitative study (1999) of 15 adult children who took care of their frail elderly parents, she found that there are some CGs who felt that financial support they received was inadequate for caregiving expenses. One CG said, "None of us can get welfare from the government. We are all poor. When my father was ill, there was no one to help. That's really my tough time" (p.116). Another CG described that, "I know that my elder sister who lives at Din Daeng also has a problem in her financial status. I rarely ask for help from her. When she visited our mother, sometimes she gave me 500 or 1000 baht helping for the expense of care for mother. Actually, that is not enough for the real expense for the care of mother" (p.116).

The evidence from literature supported that CG role strain from economic burden exists in Thai caregiving situations. The nurse experts also indicated that most items of the strain from economic burden scale are appropriate in Thai culture.

Strain from worry. In Enz and Rongsopasakul study's (1998), One CG said, "When I go to work, I worry about my mom. Is she all right?" (p.22). One CG reported "I worry about the progression of my mom's disease" (p.27). Another stated, "I feel an emotional burden. Whenever I go outside, I worry. I need to hurry back. Time for an injection.... Time to take medication" (p. 22). In Kespichayawattana's qualitative study (1999) she described CG stress as the CG's anticipatory concern about their parent's condition. A CG described, "I am worried about who is going to take care of her if I am not here with her. She (the mother) needs someone to be with her and take care of her all the time" (p.18). Another CG said, "I was not happy and also very worried while I was

out. I knew that he, (my father), was in a serious condition...my thoughts and my mind were always occupied with my worry about him and his condition” (p.144). Trirapaiwong (1997) studied patient-CG relationships and the caregiving burden in family caregiving of stroke patients. One of the CGs reported “taking care of the patient affects my mental state and my life. I am worried about debt, raising my kids, and also I sometimes have to leave work to take care of my parent ” (p.64).

From the Thai literature reviewed and interviews with nurse experts, the evidence supports the belief that the concept of worry does exist in Thai culture. I also discussed the worry scale with the Thai nurse experts. They indicated that some items which represent worry about the elder’s safety, (item 9 item 15), and the decision to send the patient to a nursing home (Item 13) need to be modified to be appropriate in the Thai culture (shown in Table 2).

Item 9, related to worry about traffic problems, needs to have more detail added so that it will be easy to understand. Item13 is related to worry about the CG’s decision making whether or not to put him or her into nursing home. Nursing homes do not currently exist in Thailand. There are assisted facilities for independent elders, but no care facilities for frail elders expect for hospitals that are used temporarily during acute illnesses. Item 15 need to be modified based on the literature and also the discussion with a Thai family researcher (S. Gasemgitvatana, personal communication, June 2, 2002). Intrarasuk (1990) wrote about how to care for the elderly at home. He suggested that CGs should watch out for elderly relatives’ safety when they use the stove, matches and electrical equipment. In addition, in Thailand, most Thai elderly do not use a lawnmower or a workshop: however, they may use sharp tools for many purposes (Table 4).

Strain from role conflict. Sommanawan (1994) interviewed 29 CGs who were caring for the demented elderly at home in Bangkok; 34.5 % of CGs reported that they could not join community activities such as religious activities, wedding ceremonies and other activities. Enz and Rongsopasakul (1998) conducted a qualitative study of 36 adult-child, spouse, and relative CGs caring for elders. The researcher interviewed CGs to describe what the consequences are of assuming the CG role. CGs reported that they feel burdened by taking care of elderly relatives. One CG stated that “ Sometimes I am head of the family. This is my mom. These are my kids. I feel stressed and then I express myself negatively in both words and actions” (p.21).

I discussed strain from role conflict with nurse experts. They indicate that most items discussed are represented in Thai family caregiving. From the literature reviewed and interviews with experts, this concept was supported as existing in Thai culture. There are items 11 and 12 that need to be adapted for cultural appropriateness.

Item 11 and 12 need to have more detail added so that it will be easy to understand as shown Table 2.

Strain from mismatched expectations. Sommanawan (1994) interviewed 29 CGs of the demented elderly at home in Bangkok. The study found that although 7% of the CGs felt that they wanted to give good care for the demented elderly, the elderly refused their care. This caused a conflict between CGs and care-receivers such as when a CG wanted the elderly to change to a bigger room; however, the elderly still wanted to stay in smaller room in a basement with no ventilation. The elderly then argued with the CG. In Gasemgitvatana's (1994) study of 104 caregiving wives of individuals who were chronically ill, the data indicated that CRs often feel uncomfortable when their children

are providing care because the CR is embarrassed specifically when bathing or being cleaned after elimination. One wife stated that “my kids help me to take care of my husband on the weekends. During the week my kids go to work. They are very tired. My husband hesitates to ask for help from the children for some activities such as cleaning up after elimination because he is embarrassed”(p.99). Puenchompoo (1997) did a qualitative study of 30 CGs caring for persons with continuous ambulatory peritoneal dialysis (CAPD). CGs were under stress because the patient was sometimes stubborn. A CG said “I take care of him. He has never had an infection, but the downside is that he is a little bit stubborn. He does not believe in me. He thinks that I am not a doctor, so he is not compliant. I get irritated and discouraged” (p.56).

From the literature reviewed and interviews with experts, the concept of CG role strain from mismatched expectation exist in Thai culture. There are no items that need to be adapted for cultural appropriateness.

Strain from increased tension. Trirapaiwong (1997) studied patient-CG relationships and caregiving burden in family CGs of stroke patients. CGs reported that they have to deal with CR changes in mood. These cause CG difficulty, stress, and discouragement in taking care of the person with a stroke. A CG stated:

“The patient gets irritated easily, often without reason. He also does not tell the truth and does not accept reality” (p.71).

“The patient gets upset very easily. Increasingly, he does not listen” (p.71).

“The patient gets irritated and I get irritated too. Then we argue a lot” (p.71).

Kespichayawattana (1999) studied 15 adult children who took care of their frail elderly parents. She explore the negative consequence of the caregiving situation. Negative

consequence of caregiving is defined as the CG' experience of having problems, difficulty or unpleasantness in their caregiving situation. She identified petty conflict with the CR as one of the dimensions of negative consequence of caregiving. One CG said, "My mother said something showed her sensitive feelings. That also made me upset. So I sometimes could not control my emotion and spoke out. I also felt hurt so I said to her please stop complaining! I did everything for you. I know that sometimes it's not exactly right as she wants. Actually I am not her favorite. She loves her sons most but never asks them to do anything. If anybody talked about sons in a bad way, she would protect them. Other people try to compromise by telling her not to scold me because I am the one who does everything for her! But she said that she did not scold, just complain" (p.141).

Puenchompoo (1997) did a qualitative study of 30 CGs caring for persons with continuous ambulatory peritoneal dialysis (CAPD). This study found that stress is one of the factors disturbing the quality of care. A CG stated " To be honest, sometimes I am bored and irritated. The patient is dependent and angry. I have to do many things. I am tired. I think that I am going to die before the patient does" (p.60).

From the literature reviewed and interviews with experts, CG role strain from increased tension was supported as existing in Thai culture. There are no items that need to be adapted for cultural appropriateness.

Strain from feelings of being manipulated. Enz and Rongsopasakul (1998) conducted a qualitative study of 36 adult-child, spouses and relative CGs caring for elders. The researcher interviewed CGs to describe what the consequences were from taking the CG role. One CG described that "Currently, I get bored when I leave my elderly relative because when I go outside just a short time, she complains that I abandon

her. When I want to go outside, it is difficult to decide whether or not I should go” (p. 20). Puenchompoo (1997) did a qualitative study of 30 CGs caring for persons with continuous ambulatory peritoneal dialysis (CAPD). This study found that the demanding of the patient disturbs the quality of care. A CG stated “ the patient is irritated, has a bad temper and is demanding. Sometimes, the patient wants to have this kind of food...that kind of food. I cooked the food that the patient wanted. Then the patient took one bite and complained that the food smelled bad. It is difficult to keep him happy” (P.59).

From the literature reviewed and interviews experts, this concept does exist in Thai family caregiving. However, Item 4 need to be adapted for cultural appropriateness as shown in Table 2.

Global strain. The cultural appropriateness of this concept is supported in several Thai Studies. For example, Puenchompoo (1997) did a qualitative study of 30 CGs caring for persons with continuous ambulatory peritoneal dialysis (CAPD). The study found that one of the negative effects of taking care of the patient with CAPD was CG burden. One CG described, “Sometime I get bored. It is very busy. I can not set my priorities. My child is very young. I have to cook. Especially in the evening, it is very busy. The patient needs to have help with dialysis” (p.53). Another negative effect is that caregiving is a difficult responsibility. One CG stated, “At the beginning, taking care of the patient was very complicated. I got headaches. I needed to follow every step as the health care provider taught me. It was too many steps. I told my daughter, oh man !! how I am going to do this? I am nervous. Everything is difficult. I needed to read the brochure and follow every step” (p.53). Kespichayawattana (1999) identified physical strain from no day off and defined it as the feeling of not having enough time to get a break from caregiving.

One CG stated, "I have been by her side every day! Never go any where or leave her (the mother) alone for nearly 6 months!" (p.142). Another CG said "I haven't been out of town for early 10 years. When I took vacation time, I still stayed here, being at home with him (the father). I told my children or others to enjoy the trip and just supported them with some pocket money. I was afraid that if something happened to him (my father) like he fell down, who is gonna take care of him if I were not home? That's why I decided not to go anywhere"(p.142). She also identified tension in the caregiving situation. The CGs also felt tense and pressure in their lives from their caregiving situation and responsibility. One CG stated, "I felt like everything in my life was so stressful. I even thought that I might break down some days because of this responsibility (caregiving). When the feeling of stress was nearly peaked, I thought I was going to be crazy. However, I could get through that tough time. That period of time was the most critical in my life. I was very tense and very discouraged" (p.144). Another CG stated that " Taking care of my mother and looking after my own family.. all are my responsibility. It's very heavy. I do not have someone to talk to. No one to consult with. My sisters also have their own family and responsibility. She has several children of her own so she could not help me. Now it's nearly the beginning of the school term for my son and I still do not know how to get money to pay for his school. Everything is tense for me" (p.144).

From the literature reviewed and interviews with experts, this concept was supported as existing in Thai family caregiving. There were no items that needed to be adapted for cultural appropriateness.

New Dimensions of CG role strain

Strain from Feelings of Guilt

Several Thai research studies showed that Thai family CGs reported feelings of guilt when caring for the CR. Kespichayawattana (1999) identified feelings of guilt as one dimension of the negative consequences of caregiving. She defined feelings of guilt as “the CG’s feelings of their own fault because of failing to give caregiving completely or behaving in an improper manner toward their parents” (p.145). A CG stated that “I realized that sometimes I also fell asleep and was remiss about changing his clothes. This does not occur very often. I realized that I must change his clothes and look after him more closely because I know he still perceives everything. For the chest tapping, I accept that I do not do it to him very often. Nurses had taught me how to do it. This is my fault. I accept. The tapping is rarely done, I skip it” (p.146). Another CG stated that “Like when I was so tired and feel that nobody helps or shares this caregiving responsibility, I said to my mother that I don’t want to take responsibility anymore. I will send her to live with my elder sister and won’t pay attention to her. I said this to mother because I get angry that she did not listen to me. She called names of other people all day and I felt irritable. But, would never do that to her. I just scold her because I want her to be quiet”(p.146). Sommanawan (1994) interviewed 29 CGs who were caring for demented elderly relative at home in Bangkok. All of the CGs reported that caring for the demented elderly was more difficult than caring for young children due to demented elderly wandered around and were stubborn. They cannot make them behave or punish them because of the CR’s age, and they were also afraid of losing merit. This situation lead to the CG’s feeling of frustration. In Gasemgitvatana’s (1994) study of wives caring for individuals who were

chronically ill, the data showed that the CG felt sorry for arguing with the CR. A CG stated that "He increased his demands. When I could not serve him immediately, he would yell at me. Sometimes, I cannot endure any more. I yelled at him. However, after that I felt sorry and sympathized with him" (p.98). Puntumajanda (1993) described the problems of CGs caring for individuals with Alzheimer's. CGs often felt both angry and guilty. As the CR's cognitive function declined, the CR repeated asking the CG the same question many time. The CG had to answer the same question over and over again. Sometimes, the CG felt annoyed or become angry, and CR has negative response such as crying. After this situation occurred, the CG felt guilty because CG cannot hold the care-receiver accountable for their temper. Since this situation continues to happen, CG feels increasing stress.

The literature showed that the concept of strain from feelings of guilt appears to exist in Thai family caregiving. Strain from feelings of guilt is defined as "the CG felt difficulty in fulfilling their CG role due to feelings of sorrow and unhappiness related to the caregiving situation". The scales of this concept are proposed as shown in Table 2.

Rewards of Family Care

The concept of positive aspects of family caregiving have been studied by using several theoretical perspectives and concepts. Archbold et al.(1995) studied the positive consequences or benefits of caregiving from the interactionist perspective of role theory. The positive aspects of caregiving was called rewards of caregiving. Rewards of caregiving were related to the CG's abilities to ascribe meaning and value to their own care situation (Archbold, 1990 as cited in Given & Given, 1991). Rewards of caregiving has three dimensions which are: rewards of being there for the CR, rewards of meaning

for oneself, rewards of learning, and financial rewards (Stewart, personal communication, July 13, 2000).

Picot (1995) studied the negative and positive perception, coping strategies and characteristics of African of America family CGs. She developed perceived CG rewards from social exchange theory. She defined perceived CG rewards as “the positive subjective feelings or objective changes, both internal and external, in the CGs’ lives, resulting from their caregiving situation. This reward could be presents or anticipated” (Picot, Debanna, Namazi and Wykle, 1997, p.90). Perceived CG Rewards (PCRS) have four dimensions, which are: CG perceived pleasures, satisfactions, good feelings and positive consequences. The PCRS inventory contains 24 items. The alpha coefficient in this study was .86. The content and construct validity for PCRS was supported. Perceived CG rewards were linked to stress theory as a caregiving appraisal.

Farran et al.(1991) conducted a qualitative study of family CGs caring for individuals with Alzheimer’s disease and explained how CGs might grow and find meaning through the caregiving experience. This study used existentialism as a theoretical perspective, which focused on finding meaning through suffering. They identified valuing positive aspects of the caregiving experience as a positive consequence of caregiving. Valuing positive aspects has two dimensions, which are the relational aspects and the caregiving aspects. CGs reported the relational aspects as valuing family and social relationships, love, memories of and accomplishment with others. CGs reported valuing aspects of caregiving as being appreciated, positive responses for caregiving, and valuing their own feelings of confidence that they were providing good care.

Hinrichsen, Hernanden and Pollack's (1992) study spouse and adult child caregiving of an older adult with major depressive disorder identified difficulties and rewards and explored the relationships among CG rewards, the clinical characteristics of the patient, the CG's emotional adjustment, and the course of the older patient's depressive illness. There is not a specified conceptual framework used in this study. The data for this study was obtained from 150 depressed older adults and their spouse or adult child CGs who took part in a larger longitudinal study. The CGs reported three dimensions of caregiving rewards. One dimension included their relationship with the patient, including whether their relationship with the patient improved or was enhanced since the CR became sick, a greater appreciation as a result of caregiving, and satisfaction in seeing the patient improve or seeing that they are able to help the CR. The second dimension included their relationship with themselves, including satisfaction over having fulfilled an obligation to the CR, feeling that they grew as a person as a result of caregiving; general satisfaction from helping another person and feeling strength as a result of caregiving. The third dimension included their relationship with others, including improving the relationship between CG and other family members and satisfaction from interactions with the health care system.

Motenko (1989) explored the concept of gratification. There is no specific theoretical framework. Gratification was defined as a CG's experience of warmth, comfort, and pleasure during caregiving. Gratification focused on relationship and gratification with social supports. There are four separate questions; one 4-point scale item regarding satisfactions about changes in relationships, and enjoyment experienced in husband's presence in home. Reliability was not reported in this study.

Lawton, Kleban, Moss, Rovine and Glicksman (1989) studied the appraisal of the caregiving process of caregiving of disabled older people. This study used a conceptual approach based on stress theory. They explained caregiving appraisal, which reflects all degrees of subjective response to the potential stressor including positive, neutral and negative responses. They found Lazarus' concept of uplifts to be relevant to the process of giving care to a loved family member. Based on the concept uplifts, they identified caregiving satisfaction as a positive aspect of caregiving. Caregiving satisfaction is defined as what one does or feels as a CG is a source of personal satisfaction. The items were scored on a 5-point frequency scale; alpha =.67 for the respite sample and .76 for nursing home applicant sample; retest reliability =.76. Finding indicated that satisfaction was associated with the quality of the relationship, burden, affect, and the relationship to CR.

Cultural Appropriateness of Rewards of Caregiving in Thailand

In Thailand, Caffery (1992) conducted a qualitative study in which she explored caregiving to the elderly in Northeast Thailand. Thirty-nine CGs caring for their parents were interviewed for their perspectives on the activities of caregiving, the impact of caregiving, support of family and the meaning of caregiving to the CG. She identified the primary motivations for caregiving as “ (1) fulfilling the expected cultural norm of filial obligation; (2) love or affection for the elder, (3) a desire to reciprocate for past services and to build up future merit for themselves. The difference between the first and third was an attitude of obligation versus an attitude of gratitude” (p.132).

Qualitative studies and interviews with nurse experts showed that the concept of rewards of caregiving has equivalent concepts in Thai family caregiving. Puenchompoo

(1997) did a qualitative study of CGs caring for persons with continuous ambulatory peritoneal dialysis (CAPD) using content analysis as methodology. The study finding showed that the caring process was perceived as having both positive and negative effects. The positive effect were: a proof of CGs' abilities, social admiration and increasing self esteem. Kespichayawattana (1999) explored the positive consequences of the caregiving situation. This concept was described as "the family CG's experience of having feelings of pleasure in the role of being a CG" (p.123). There were six categories: (a) happiness; (b) sense of self-pride; (c) recognition of the praise from others; (d) attaining merit; (e) warmth; and (f) the feeling of being lucky.

The research literature also shows that rewards of caregiving has equivalent concepts in Thai family caregiving as follows:

Rewards of meaning for oneself. Kespichayawattana (1999) identified that pride of the quality of care as the CG feeling pride in his or her ability in providing good care to parents which brings good outcome to parent's condition. CG stated, "My mother's friends came to visit her and they said that she (my mother) looked much better and happier than she had in the past. Her face was bright and she was smiling. Everyone notices the difference. I don't have to say anything. People know that she is happy because her face shows it" (p.128). She identified fulfillment of self is one sub-category of happiness. Fulfillment of self is defined as the CG's feelings of fulfillment in his or her own ability to achieve the caregiving duty from their own will. A CG stated "I do what I think is right. When I do this, (taking care of the mother), I feel happy...I feel like my heart wants me to do this. Really willing to do it from my heart"(p.126). Another CG stated "It's very difficult to express the feeling that I have. It's my delight and very

fulfilling to taking care of father” (p126). She also identified pride of being a CG is on sub-category of sense of self-pride. The pride of being a CG is defined as the CG’s feeling proud of having an opportunity to take care of parents. A CG stated, “Taking care of father gives me joy and is very fulfilling. I’m also proud of myself” (p.126). Another CG stated “I used to be very hot tempered person and very impatient. It surprises me that I can take care of my father and remain so calm. I feel that I am now more tranquil and mellow” (p.126). Suwanno (1998) studied of family CG caring for person with stroke. One CG stated “I take care of my father because I want to. I think that although I can hired someone to take care of him, my father might not feel as close as he could if a family member was taking care of him, he will feel happy in turn I feel happy too” (p.71).

The evidence from literature supported that rewards of meaning exist in Thai caregiving situations. I discussed the scale of rewards of meaning with a Thai family researcher (S. Gasemgitvatana, personal communication, July 22, 2000). Item 11 needs to be adapted to Thai culture as shown in Table 8.

Rewards of learning. Kespichayawattana (1999) identified that pride of the quality of care as the CG feeling pride in his/her ability in providing good care to parents which bring good outcome to parent’s condition. A CG stated “ My father has not had to go to the hospital for 3 years. I think I’ve learned to take care of most of my father’s health problems so that he has not needed to go to the hospital as often as he had to go in the past”(p.128). Enz and Rongsopasakul’s (1998) conducted a qualitative study of adult-child, spouses and relative CGs caring for elders. The researcher interviewed CGs to describe the burden from taking care elders. One CG described “It is normal now. I have

taken care of him at the beginningI feel that I now more understand about the elderly” (p.19).

The evidence from literature supported that rewards from learning consist in Thai caregiving situations. The nurse experts also indicated that most of rewards of learning are appropriated in Thai culture.

Rewards from being there for the CR. Kespichayawattana (1999) identified that feeling of joy happen when the CGs perceived improvement in their parents. CG stated “When I saw that my mother could walk and was becoming healthier, I felt good” (p.126). Another CG describe that “Since now she can void by herself, I feel very good” (p.126). Other CG stated “Yeah, I feel happy. It’s like when I was with him, I could sit down and talk with him. That’s really joyful” (p126). She also identified that satisfaction about what has been done is defined as the CG’s feelings of satisfaction about the quality of caregiving provided to his/her frail parents. A CG stated that, “When we all have learned how to care for him, we saw his condition and satisfied with our care. We realized that his condition was no longer critical’ (p.126).

From the Thai literature reviewed, the evidence supported the belief that the concept of rewards from being there for the care-receiver does exist in Thai culture. I also discussed the rewards from being there with a Thai family researcher (S. Gasemgitvatana, personal communication, July, 22, 2000).

Financial Rewards. There was no evidence of financial rewards for caregiving in the Thai family situation. I discussed with the nurse experts the scales of financial rewards. They indicated that item 4 and item 10 are not represented in Thai culture because health care in the U.S and Thailand are different. There were no nursing homes

or welfare systems for the elderly in Thailand. However, these items can be adapted for Thai culture as shown in Table 2.

New Dimensions of Rewards of Family Care

Rewards from Spiritual Fulfillment

According to history, the Buddhist philosophy of life was developed 543 years before Christ. Theravada Buddhism first appeared in South East Asia in the 11th century and was adopted by the Thai King as the national religion. Hence, the majority of the Thai population (96%) are Buddhist (Mulder, 1994 as cited in Sasat, 1998). Sheng-Yen (1991) stated that the goals of Buddhism are to foster the spiritual development of humanity and to resolve human suffering. The central concepts of Buddha's teaching are the Four Noble Truths and the law of Karma and rebirth. The Four Noble truths state that everything is a source of suffering and problems in life. The second truth identifies defilement as the cause of suffering. The mind is the most important because it is the root of all actions. If one acts with an impure mind or defilement, with thoughts such as with jealousy or hate, one would suffer. The third truth refers to the states of freedom from suffering or Nirvana. To attain Nirvana, defilement such as ignorance, craving and attachment must be completely eliminated from the mind (Ratanakul & Than, 1990 as cited in Tongprateep, 1998). The fourth truth presents the path for extinguishing desire, the solution to suffering. It consists of Right Understanding, Right Mindedness, Right speech, Right Action, Right Living, Right Effort, Right Attentiveness and Right Concentration.

The other central concept of Buddhist doctrine is the law of karma. Karma in Buddhism refers to every act performed intentionally or volitionally. Karma is also

known as the law of cause and effect or the correlation between action and consequence. These actions may be harmful or beneficial to self and others. Whether a person will become better or worse depends on one's own deeds or karma. When action based on good intentions, such as generosity, good will, and compassion, it is referred to as good karma (merit, bun) and will produce desirable results. On the other hand, if action is based on bad intentions such as greed, hatred, anger and selfishness, it is referred to as a bad karma (demerit, bad) and will produce undesirable results. Buddhists believed that each person's condition in life, including good or bad aspects, joy or sorrow, is result of one's own past actions (Payutto, 1994).

Rebirth takes place according to the nature of karma, both good and bad. Karma committed in people's previous lives have brought people into their present state. The conditions under which people are born, their present state and environment are the effects, the karma-results of their previous lives (Suriyabongs, 1955). Buddhist view birth or rebirth as a suffering state because, after that point, the human being must face pain, hunger, illness, fear, stress, separation from loved ones, and death. Nirvana is where rebirth ends, and is the goal of every Buddhist. One who has not practiced well enough will still be unable to break the cycle of birth and death (Payutto, 1994). As mentioned earlier, the ultimate goal of Buddhist is to eradicate all defilement or to attain Nirvana. Nirvana is recognized as a difficult state to achieve. Buddhists hope that by doing good deeds, they will get good results and finally that they will be able to eliminate the root of suffering in the future. Therefore, Thai people will try to extinguish defilements. The simplest way for each individual to accomplish this: (a) to do good by developing virtue (meritorious acts or merit making), such as practicing: loving, kindness, good will,

generosity, patience and altruistic thought towards others; (b) to avoid evil by observing five moral precepts, or avoiding harmful behaviors; and (c) to purify the mind or thinking process by practicing meditation (Payutto, 1994).

In caregiving situations, Thai CGs caring for older parents, in-laws, spouses or siblings are considered to be making-merit because they are doing good deeds which help prevent other people from suffering. These increase one's accumulation of merit which will lead to a better life in the future.

Kespichayawattana's (1998) qualitative study supports the belief that the CG of parents perceived that they are making-merit. Data exemplar showed that "Taking care of one's parents is very important. It's also the best avenue of attaining merit. Although we do other kinds of merit, nothing else can compare to the merit obtained through the care taking of one's parent' (p.132).

Tongprateep's (1997) qualitative study also showed that taking care of older parents is considered to make merit. As the following data bit, "The last merit making of my father is the gratitude that I could do for my father. I still have my older sister who served as my mother. I am glad that I can take care of them when they get old and sick" (p.87).

Gasemgitvatana's (1994) study of wives caring for chronically ill spouses found that the CG believe that caregiving is making -merit. This is illustrated by the following data bit, "People said that if they were me, they would leave my husband. I can not leave him. I believe in the law of karma. Whenever, I take care him, I consider it to be making-merit" (p. 104).

Bun kun doing good deeds, is the cultural norm which is influenced by Buddhist doctrine. Bun Kun is described as any good thing, help or favors done by someone, which results in gratitude and obligation on the part of the beneficiary. Phra Buddhadasa Bhikul (1993), a leading Thai monk, stated that “no one in this world can survive or succeed without receiving help from other people. Everyone who raised, educated and successful, has received several sources of help from many people” (as cited in Sasat, 1998 p. 90). For instance, from birth they received help from their parents, then teachers educated them, and then they succeeded with help from their employers and colleagues. He further pointed out that if nobody recognized their reciprocal debt to each other, the world would be full of competition and desperation. Therefore, knowing and acknowledging one’s debt to beneficiaries is very important to keep peace in the world.

This Buddhist principle has become a traditional Thai culture ideology of “parent repayment” in which children are expected to repay their parents for having born and raised them. Parent repayment is called “Kathanyu Katawethi” in Thai culture. Katanyu refers to a constant sense of awareness of the benefits that another person has bestowed on him and Katawethi refers to doing something in return for them. Katawethi and return bun kun are interchanged term in Thai culture (Maniwan, communication, September 22, 1999). When caregiving situations take place, CGs consider that they have katawethi (return Bun Kun) to their parents. Katawethi extends equally to the parents in-law, as well as the parents. Tongprateep’s qualitative study (1998) also demonstrated this phenomena. As the following data bit, “All my gratitude I pay for my mother. At the end of my mother’s lifetime, I could show respect, take care and support my mother with

sincere love. I did not only take care of my mother but also my wife's parents. I think my wife and I are the same person, so her parents are my parents too" (p.86).

The author's clinical experiences demonstrated that many CGs care for siblings' spouses because they wanted to return bun kun or to show compassion for the care-receivers. In addition, the Thai family is bound together thought out the process of aging and dying as well as living. Whenever, the family members get sick, it is their right and duty to care for each other. Based on the literature reviewed, the tentative concept definition is "the CG performs caregiving to fulfill spiritual philosophy of Buddhism which includes accumulating good deeds or meritorious acts. Caregiving as a meritorious act leads to the prevention of suffering for the CR, positive feelings for the CG, and a peaceful mind". The scales of this concept are proposed as shown in Table 2.

Rewards from other people. Several studies showed evidence that CGs received admiration or approval from others such as relatives, friends, neighbors and health professionals because they take care of the care-receiver and also improve relationships with others. Kespichayawattana (1999) identified recognition of praise from others as a positive consequence of the caregiving situation. She defined this concept as "the CG's perception of being admired or approved by others because of their caregiving role" (p.129). A CG stated that " People usually praise me for being a good daughter and taking care of my parents" (p.132). Another CG said " People admired me. I know. Sometimes my neighbors walk past my house, they liked to talk and are very friendly and kind to me. They did not praise me directly, but I can feel from friendliness" (p.132). Another CG stated that "She's really good to her parents. She puts her father and mother as her first priority. She does everything for them, doing everything. All the money she

earned is spent for her parents. Her father even died in her arms. It's difficult to find people who are good such as this (a friend of ID 13)" (p.132). In addition, one CG described that taking care of her mother earned her merit. She believes that merit brings many good things to her. She said that "I now feel that many good things have happened to me. For example, my sister and others who used to think that I was a bad person, now realize and accept that I'm a good person. They know that I'm the only one who takes care of our mother" (p.133). Puenchompoo (1997) identified social admiration as a positive effect of the caring process. A data exemplar is that "When my husband was admitted to the hospital, the nurse told me that I am a good person. It seemed to her that I really love my husband. She observed that we stayed together in our old age, and that I took good care of my husband. She also observed that I never showed that I did not like taking care of him or was bored of taking care of him" (p.53).

In Japan, Inoue (1995) identified rewards from others as a new dimension of rewards of caregiving in the FCI. She defined reward from others as "the positive feeling and/or benefits that the CG receives because he or she fulfills the CG role, such as recognition and acceptance from other people and improvement of relationships with other people" (p.157). She developed the instrument of rewards from others, which consisted of 5 items. The content validity was supported. Cronbach's alpha for this scale was .92.

From the literature reviewed, the rewards from others scale, developed by Inoue (1995), seems to capture rewards of caregiving in the Thai family. However, some items need to be adapted for cultural appropriateness as shown in Table 2. Item 6 is specific for the immediate family members. In Thailand, a wide range of people including immediate

family members and relatives are involved in providing care to elderly. The CG who is providing good care for the elderly will be admired and approved of by others. In Item 8 the term “important person” may be too abstract for Thai family CGs. If you use the term “good person”, it will be easy to understand.

Item 19. Based on the literature review, this item should also designate health care professional.

The SF-36 Health Survey

The SF-36 is a 36-item instrument for measuring health status in eight general areas including: physical function, role physical, role emotional, bodily pain, general health, mental health, , social function, and vitality (Ware, 1998). Most SF-36 items have their roots in instruments that have been in use since the 1970s and 1980s, including the General Psychological Well-Being Inventory, various physical and role functioning measures, the Health Perceptions Questionnaire, and other measures that proved to be useful during the Health Insurance Experiment. In the Medical Outcomes Study (MOS), researchers selected and adapted questionnaire items from these and other sources and developed new measures for a 149-item Functioning and Well-being Profile (Stewart and Ware, 1992), which was the source for the SF-36 items (Ware, 2000, para. 1). The SF-36 items and instructions, which were first made available in a “developmental” form in 1988 and in “standard” form in 1990 (Ware & Gandek, 1998). From 1988 to 1996, the SF-36 has been documented in more than 400 publications and includes more than 140 studies of the translations and adaptations in countries outside the United States (Gandek et al., 1998).

The SF-36 has had extensive psychometric testing, and the results indicate that it is reliable and valid with both young and old adult patients. The reliability of eight scales has been estimated using both internal consistency and test-retest methods. With rare exception, published reliability statistics have exceeded the minimum standard of .70 recommended for measures used in group comparisons. In a summary of the 15 studies, most exceeded 0.80 (Ware, Snow, Kosinski, Gandek, 1993 as cited in Ware & Gandek, 1998). In addition, reliability of the SF-36 in eleven countries was greater than 0.70, for all scales except Social Functioning (Gandek et al., 1998).

Studies of validity are about the meaning of the score and whether or not they have their intended interpretations. The SF-36 is widely used across a variety of applications, and evidence of validity has been supported. Content validity of the SF-36 has been compared to that of other widely used generic health surveys. Systematic comparison indicated that the SF-36 includes eight of the most frequently represented health concepts (Ware, 2000, para. 15). The evidence supported the construct validity is based on the results of factor analyses of the SF-36. The findings showed that each scale has been shown to differ markedly from the other scales. The predictive validity studies have linked SF-36 scales and summary measures to utilization of health care services, loss of job within 1 year, and 5-year survival (Ware, Kosinski, Keller, 1994 as cited in Ware & Gandek, 1998).

The SF-36 was translated to Thai to be used for the evaluation of the quality of life in 212 Cardiac patients by Krittayaphong and Colleague (2000). Cronbach's alpha reliabilities for SF-36 subscales including: physical functioning, social functioning, role limitation due to physical problems, role limitation due to emotional problems, pain,

were .91, .82, .90, .81, .90, .75, .85, and .85

Depression Scale (CES-D)

(1977) is a 20-item self-report scale designed to measure the presence and severity of depressive symptomatology in the general population (National Institute of Mental Health, 1977). Although Radloff's initial analysis of the CES-D included four dimensions (i.e., somatic and retarded activity, depressed affect, positive affect, and interpersonal), the high internal consistency of the scale argues against the emphasis on separate factors, and a total scores is recommended as an estimate of the degree of depressive symptoms (Radloff, 1977 as cited in (Chapleski, Lamphere, Kaczynski, Lichtenberg, & Dwyer, 1997). McCallum, Mackinnon, Simons and Simons' (1995) cross-cultural study confirmed that the CES-D Scale is essentially unidimensional and recommended it for use in a large sample of elderly Australians.

The CES-D has high internal consistency and test-retest reliability and demonstrated good construct validity and concurrence on clinical and self-report criteria (Radloff, 1977; Roberts, 1983; Weissman, 1977). The CES-D has been noted as the most widely used measure of CG depression (Schulz, O'Brien, Bookwala, & Fleissner, 1995). Reliability of the CES-D was high; in adult daughter CGs of a parent with cancer (Reveis, Karus, & Siegel, 1998), CGs of post-surgical patients with cancer (Jepson, McCorkle, Adler, Nuamah, & Lusk, 1999), and CGs of Alzheimer victims (Schulz & Williamson, 1991), reliability estimates were .91, .90 and .90 respectively. In the study of the PREP system of nursing intervention reported that the CES-D was used to measure

CG depression at 2, 7 and 12 weeks after entry into the study and the Cronbach's alpha ranged from .82 to .86 (Archbold et al., 1995).

In Thailand, there are few studies of the CES-D, and this instrument has not been utilized to study the Thai family CG. However, studies have shown evidence of strong reliability of the CES-D in th few Thai samples. Vorapongsathorn, Pandii and Traimchaisri's (1990) study translated the CES-D into Thai and examined the reliability of a sample of 691 teacher's college students. Cronbach's alpha was .86. Kuptniratsaikul and Pekuman (1997) studied 99 individuals with and without depression. The reliability for the CES-D scale was .91.

CHAPTER 3

METHODS

Prior to addressing the study aims, the investigator evaluated the content validity and semantic equivalence of the Thai versions of the FCI.

The evaluation of content validity, based on a review of the CG literature in the U.S., Canada and Thailand, was summarized in Chapter 2. In general, there is strong evidence that the concepts being measured in the FCI are relevant for family CG in Thailand. Interviews with nurses in Thailand confirmed conclusion based on the literature reviews suggested revisions item wording improved content validity.

To ensure the quality of the translation and semantic equivalence of the Thai and English versions following steps were employed as shown in Figure 2. First, a bilingual translation committee translated the original English version of the FCI into Thai. This committee included the researcher and four nursing students who are studying in Ph.D. programs in the United States. The researcher translated the entire FCI, two Ph.D. students translated FCI scales of measuring six family care concepts, and two Ph.D. students translated FCI scales measuring two other family care concept as well as the concept of health (SF-36 health survey) (Appendix A). Therefore, three independent translators translated all sections of the FCI and SF-36 health survey into Thai. The CES-D Scale was previously translated into Thai by other researchers (Vorapongsathorn, et al, 1990). The advantage of the committee approach used in this dissertation is that the mistakes of one member can be caught by others (Brislin, 1970). The translators followed the suggestions of Karno (1983) and used the five most useful approaches for effective translation which are: (1) the use of short simple sentences of less than 16 words, (2) the

use of active rather than passive words, (3) the avoidance of metaphors and colloquialisms, (4) the avoidance of the subjunctive and conditional, and (5) the use of specific rather than general terms. The members of the translation committee translated the original English version into Thai working separately. After the translation into Thai was accomplished, the researcher examined the translations for apparent discrepancies. The researcher used individual communication or small group meetings to clarify words and meaning with apparent discrepancies. After the translators reached consensus, the researcher met with the dissertation committee to report on the translation. The dissertation committee and the researcher discussed and clarified any discrepancies of words or meaning in the two versions.

Second, because bilingual doctoral students may use phrases that are unfamiliar to the Thai CG, the Thai version of the FCI was reviewed and refined further by a family researcher who was accustomed to the language used by Thai CGs. This refinement resulted in a Thai version of the FCI that would be more easily understood by the target population (Brislin, 1986). After the Thai version of the FCI was completed, a professional Thai translator who has an M.A. in English (Appendix B), and who had not seen the original English version of the FCI then translated the Thai version of the FCI back to English. Back translation is the most common and highly recommended procedure for verifying the translation of an instrument (Brislin, 1970; Chapman, 1979). Researchers can examine the original and the back-translation versions to make judgments regarding the quality of the translation.

Third, the dissertation committee and the researcher examined the original English version and the back-translated English version of the Thai FCI. Items with

apparent discrepancies between the two versions were modified, and the back-translation cycle was repeated until the dissertation committee was satisfied with the equivalence of the Thai and English forms. This process is called “decentering” because neither language is the center of attention (Brislin, 1986; Chapman & Carter, 1979). If a concept survives the decentering procedure, it is assumed to be etic, referring to a phenomenon, or aspects of a phenomenon, which have a common meaning across the cultures under investigation, since there must be readily available words and phrases in the two languages which the translators could use. Although all original concepts and scales for the FCI were in the final back-translated version, sometimes a concept and its measure need to be deleted from the final back-translated version if a concept has emic aspects which are different in the two cultures. That is, the concept might be readily expressible in only one of the languages (Brislin, 1986).

Fourth, after the process of translation was finished, modified items and the new scales were added to the Thai version of the FCI. The researcher gave the final Thai version to Thai nursing students to read in order to determine how feasible it was to use the instrument. Then, the pilot test of the Thai version of FCI with 5 CGs was conducted. This also allowed the researcher to pilot test the recruitment procedures.

Design

Even though a researcher may accomplish the process of translating an instrument from the original language to a target language, it is not a guarantee that the measure will be valid in the new culture. Establishing the reliability and validity of instruments for the new culture is important in establishing the credibility of research findings based on the translated instrument (Erdman, Passchier, Kooijman, & Stronks, 1993). Therefore, a

cross sectional design was used to examine the reliability and validity of the final Thai version of the FCI in Thai family CGs.

Setting

Data gathering was conducted in the chronic illness outpatient department at Siriraj Hospital, Bangkok Thailand. The chronic illness department consisted of a general clinic and specialty clinics. The general clinic was open for service from 8:00 am to 12:00 pm from Monday through Friday. The specialty clinic included both medical and surgical clinics in neurology, cardiology, endocrinology, oncology, gastro-intestinal and orthopedic clinics. These clinics were open for service from 1:00 to 4:00 pm from Monday through Friday. The chronic illness department served 60 new, and 50 return elder patients per day.

Institutional Review Board (IRB) Procedures

The researcher submitted the dissertation proposal for approval to both the Thai IRB and the OHSU IRB (Appendix C). Documents were used in the process as following: (a) a brief proposal, (b) English and Thai versions of the consent form (Appendix D), and (c) English and Thai versions of the instruments (Appendix E). After the dissertation proposal received approval from the Thai IRB, the Thai IRB sent a letter of approval to the OHSU IRB, and the letter stated that: (a) the study was appropriate for the Thai Culture, (b) the study protocol followed Thai research regulations, (c) the consent form was appropriate for use in the Thai culture and represented an accurate translation of the English version submitted with it, (d) the instrument was appropriate for use in Thai culture, and (e) the manner in which the researcher had proposed to handle elder abuse, if detected, was appropriate and followed Thai law.

The researcher submitted the dissertation proposal to OHSU IRB. The submitted documents included: (a) a brief proposal including the back translator's resume, (b) the Proposed Project Questionnaire (PPQ), (c) the Initial Review Questionnaire (IRQ), (d) the consent form, (e) the Thai IRB letter, and, (f) the English and Thai instruments.

Sample Criteria

A purposive convenience sample of 80 family CGs was recruited. Inclusion criteria were: (a) the CG had been providing care for his or her elderly family member for at least 6 weeks, (b) the CR was 60 years of age or older, (c) the CR was frail and required help in at least one ADL or two or more IADLs. ADL refers to activities of daily living, such as dressing or bathing. IADL refers to instrumental activities of daily living, such as shopping or banking.

Sample

The demographic characteristics of CGs and their elderly CRs are summarized in Table 4, Table 5 and Table 6. CGs ranged in age from 23 to 78 years ($M = 47.7$, $SD = 11.7$) and most were female (78%). Most CGs were married (48%) or never married (36%). Half of CGs were the daughters of the CR, and nearly all (94%) lived with the CR. Although about half of CGs had attended college or gone to a higher level of education, about a third had completed junior high school or less. More than half of the CGs were working (59%), including 15% who were working part time. CGs' view of their income varied widely, with the most frequent response (34%) "enough with a little extra sometimes." Most of the CGs (88%) helped the CR 7 days a week ($M=6.7$) and about two-thirds of the CGs spent at least 5 hours a day helping the CR. The average length of time that they had been involved in caring was 3.29 years.

The age of elders being cared for ranged from 60 to 104 years ($M=77.5$). Most (77%) CRs were female. Over half (54%) of CRs were widowed and 40% were married. Most of CRs lived with other family members rather than with spouses only. Most of the CRs (82%) had completed grade school or less, only 8% had gone beyond grade school. Care-receivers needed most help in the ADLs of bathing or shower and dressing, and the least help in eating. CRs needed most help in the IADLs of preparing meals, doing light housework, doing heavy housework and driving or taking a bus or taxi to where the CR need to go and the least help in the telephone. The most prevalent medical diagnosis for the CR was heart disease (49%) followed by diabetes (36%), hypertension (31%) and stroke (31%).

Measures

The Family Care Inventory (Appendix D) consists of the scales and subscales shown in Table 3 and previously described in the literature review.

Procedures

Procedures for recruitment. A clinic nurse approached family CGs accompanying their elderly relatives to the chronic illness outpatient department at Siriraj hospital. The clinic nurse described the study and ascertained the family's interest in talking with the researcher. The clinic nurse introduced the CG to the researcher if the CG was interested in this study (Appendix F). The researcher explained the purpose of the study, the nature of the questionnaire, and the voluntary nature of participation and screened the family on inclusion criteria. If family CGs were eligible, they were invited to participate in the study. Family CGs expressing a willingness to participate were required to sign a consent form. The researcher made an appointment to interview the CG at home.

Procedures for data collection. The researcher or research assistant who was trained by the researcher (Appendix G) interviewed the family CG using the Thai version of the FCI in the CG's home. All interviews were audiotaped. The interview took about 2 hours and a break time was adjusted to the individual participant's availability and fatigue level.

Procedures for data management and assurance of confidentiality. The following efforts to assure the confidentiality of the participants were made. Each family member was assigned an identification number (ID). The quantitative data were entered, verified, and, if needed, corrections made using the Statistical Program for the Social Sciences (SPSS). CG's comments to specific items and responses to the open-ended questions were transcribed verbatim and identified by CG's ID number. The transcribed qualitative data were entered separately into FileMaker Pro. All data were entered into a personal password protected computer at the researcher's home. The data were available only to the researcher and members of the dissertation committee. A record of each CG's name, ID, address and telephone number was kept in a locked file in a separate location from the data. All data were stored in a locked file cabinet in Thailand and were accessible only to the researcher. All audiotapes will be destroyed when the project is finished.

Data Analysis

Quantitative were analyzed using SPSS. Descriptive statistics and histograms were used to evaluate the accuracy of data entry and the shape of the distribution of scores. Scale development for this study proceeded in 3 stages: (a) examination of internal consistency (Aim 1 and 4), and scale construction, and (b) review of scale

statistics (Aim 2), (c) correlational analysis of hypothesized relationships to obtain evidence for construct validity (Aim 3 and Aim 4).

Internal consistency reliabilities of all scales in this study were computed by using Cronbach's Alpha (Pedhazur & Schmelkin, 1991). In SPSS, Cronbach's alpha is computed using only subjects who have answered all items on the scale. For the scales of Strain from Caregiving Activities, Communication Problems, Role Conflict, Mismatched Role Expectation and Satisfaction with Help from Others, CGs answered "not applicable" if they did not do or have some of the listed roles or caregiving activities. Therefore, the standardized alpha was estimated based on the pairwise correlation matrix among items in these scales.

After the internal consistency reliability was examined, scales were constructed for each measure. The scores for most of scales in the TFCI were computed by averaging a CG's responses to all items on the scale (Archbold, et al., 1986). Average scores were computed as long as the CG had answered 75% or more of the items. For the Amount of Caregiving Activities, the computation procedure was different. Computation for these scales was based on a sum rather than on an average of the items. After constructing the scale, the descriptive statistics of each scale were reviewed.

Initial evidence of construct validity was examined by testing hypothesized relationships between variables which is the most common strategy for obtaining evidence for construct validity (Stewart & Peterson, 1982). The hypotheses tested in this study were based on role theory and the results of previous studies that were conducted in the U.S. using the FCI scales. To obtain evidence for construct validity, Pearson correlations were employed to test the hypothesized correlations among scales.

CHAPTER 4

RESULTS

Aim 1. To Evaluate the Internal Consistency of the Thai Version of the FCI Family Care Scales

The results of Cronbach's alpha and item analysis, including the summary of both inter-item and item-total correlations, are shown in Table 7. Because amount of help from other people (3 items) had low reliability (alpha = .22), it is not included in any further analyses or tables. Because there was a low item-total correlation ($r = .09$) for one financial rewards item about living more comfortably financially than if the CG hired a paid helper (Item 26, page 21 of FCI), it was dropped from the financial rewards scale.

According to Nunnally (1978), a Cronbach's alpha of .70 or greater for scale and subscales is an acceptable level for research purposes. In this study, Cronbach's alpha values for 22 of 29 scales and subscales were .70 or greater, however, 7 of the 29 scales and subscales did not meet the .70 criterion for research purposes (Tables 7 and 8).

High internal consistency, with alphas ranging from .90 to .99, was found for 6 of 29 scales: CR memory problems, mutuality, rewards from other people, amount of negative lifestyle change, strain from care activities and role conflict.

Moderately high internal consistency, with alphas ranging from .80 to .89, was found for 11 of 29 scales: CR ADL needs, CG physical health, CG mental health (SF-36), CG depressive symptoms (CES-D), preparedness for family care, amount of care activities, rewards of being there for the CR, rewards of meaning for oneself, and 3 CG

role strain scales (frustration due to communication problems, lack of resources and increased tension).

Moderate internal consistency, with alphas ranging from .70 to .79, was found for 5 of 29 scales: CG role strain from worry, worry about safety, economic burden, feelings of being manipulated, and global strain.

Marginal internal consistency, with alphas ranging from .55 to .69, was found for 5 of 29 scales: CR IADL needs, predictability, rewards of learning, financial rewards, and CG role strain from mismatched role expectations.

Low internal consistency, with alphas ranging from .33 to .54, was found for 2 of 29 scales: CR extent of communication problems and CG role strain from communication problems (see Table 7).

Aim 2. To Present Descriptive Statistics on the FCI Scales for Thai family CGs

Table 9 lists each scale and subscale with its mean, standard deviation, skewness, kurtosis, the potential and actual range of scores, and missing data. A visual inspection of the mean indicated that none of these scales or subscales had either extremely high or extremely low average scores, so it does not appear the scales or subscales have ceiling or floor effects. The lowest mean occurred for feelings of being manipulated ($M=0.45$). The ratio of the actual range of scores to the potential range of scores for all scales and subscales was more than .75, indicating that Thai CGs are using most of the response range for all scales.

Significantly positively skewed distributions occurred for 5 of the 29 scales and subscales (CR memory problems, CG role strain from role conflict, worry about safety, feelings of being manipulated and mismatched role expectations). The distribution of the

CR IADL needs was significantly and negatively skewed. Also, significantly leptokurtic distributions occurred for two scales--CG role strain from feelings of being manipulated and mismatched expectations (see Table 9). Most scores on CG role strain from feelings of being manipulated and mismatched role expectations were toward the low end of 0.00, and showed few responses at the higher end (2.00-4.00). Responses on these two scales were also concentrated in a narrow range. Because interviews were used to collect data from CGs, there was almost no missing data. Only 1 CG was missing a score on financial rewards.

Aim 3. To Evaluate the Construct Validity of the Thai Version of FCI scales by Testing Hypotheses About the Relationship Among Concepts

Table 10, Table 11 and Table 12 contain Pearson correlation coefficients to test Hypotheses 1 through 9.

Hypothesis 1: Mutuality will be negatively related to CG role strain, except for CG role strain from lack of resources, economic burden, and worry, which will not be related to mutuality. Mutuality was significantly negatively related to 2 of 8 CG role strain scales for which a negative correlation was hypothesized. Although mutuality was related to strain from care activities and global strain, it was not significantly related to CG role strain from communication problems, frustration due to communication problems, increased tension, role conflict, feelings of being manipulated, and mismatched expectations. Mutuality was not significantly related to 2 out of the 3 CG role strain for which we hypothesized no correlation (lack of resources and economic burden). However, mutuality scale was significantly positively related to strain from worry.

Hypothesis 2: Preparedness for family care will be negatively related to CG role strain, except for strain from economic burden and role conflict, which will not be related to preparedness. Preparedness for family care was significantly negatively related to 5 of 9 CG role strain scales for which a negative correlation was hypothesized. Preparedness for family care was correlated with strain from care activities, lack of resources, feelings of being manipulated, increased tension, and global strain. However, preparedness was not negatively related to strain from communication problems, frustration due to communication problems, worry and mismatched expectations as was hypothesized (Table 10). Finally, contrary to the hypotheses that the preparedness of family care would not be correlated with strain from role conflict and economic burden, preparedness was related significantly to strain from role conflict ($r = -.25$) and economic burden ($r = -.30$).

Hypothesis 3: Predictability of the caregiving situation will be negatively related to CG role strain, except for strain from care activities and mismatched expectation, which will not be related to predictability. Predictability of the caregiving situation was significantly negatively related to 7 of 9 CG role strain scales for which a negative correlation was hypothesized. Predictability of the caregiving situation was correlated with strain from communication problems, frustration due to communication problems, worry, lack of resources, economic burden, feelings of being manipulated and global strain. However, strain from increased tension and role conflict were not significantly correlated with predictability of the caregiving situation as was hypothesized. Predictability of the caregiving situation was not correlated with strain from mismatched expectations for which we hypothesized no correlation, but predictability correlated significantly with strain from care activities ($r = -.28$).

Hypothesis 4: Rewards of being there for the CR and meaning for oneself will be negatively related to CG role strain in a pattern similar to that hypothesized for mutuality. Rewards of being there for the CR was significantly negatively related to 2 of 8 CG role strain scales for which a negative correlation was hypothesized. Rewards of being there for the CR was correlated with strain from care activities and global strain. The other 6 subscales were not significantly correlated with rewards of being there for the CR. As hypothesized, rewards of being there for CR was not correlated with strain from worry and lack of resources, but it was correlated significantly with strain from economic burden ($r = -.28$).

Rewards of meaning for oneself was significantly negatively related to 3 of 8 CG role strain scales for which a negative correlation was hypothesized. Rewards of meaning for oneself was correlated with strain from care activities, frustration due to communication problems and global strain. The other 5 strain scales (strain from communication problems, role conflict, feelings of being manipulated, increased tension and mismatched expectations) were not significantly correlated with rewards of meaning for oneself (see Table 10). Rewards of meaning for oneself was not related to 1 of 3 CG role strain scales for which we hypothesized no correlation. As hypothesized, rewards of meaning for oneself was not related to strain from worry, but it was related significantly to strain from lack of resources ($r = -.21$) and economic burden ($r = -.23$).

Hypothesis 5: Mutuality, preparedness for family care, predictability, rewards of being there and rewards of meaning for oneself will be positively related to one another.

Mutuality, preparedness for family care, predictability, rewards of being there and rewards of meaning for oneself were significantly positively related to one another,

except that mutuality was not significantly correlated with predictability of family care (Table 11).

Hypothesis 6: Amount of care activities will be positively related to CG role strain. Amount of care activities correlated significantly and positively with 7 of 11 CG role strain scales, including strain from care activities, communication problems, role conflict, worry, feelings of being manipulated, increased tension and global strain. However, amount of care activities was not significantly related to strain from communication problems, frustration due to communication problems, lack of resources, economic burden, and mismatched expectations (Table 12).

Hypothesis 7: Amount of negative life style change will be positively related to CG role strain. Amount of negative lifestyle change was significantly and positively related to 10 of 11 CG role strain scales. Only 1 scale, mismatched expectations, was not significantly correlated with the amount of negative lifestyle change (see Table 12).

Hypothesis 8: CG health will be negatively related to CG role strain. CG physical health was significantly negatively related to 10 of 11 CG role strain scales. Only 1 scale, strain from mismatched expectations, was not significantly correlated with CG physical health.

CG mental health was significantly negatively related to 10 of 11 CG role strain scales. CG mental health was not significantly correlated with mismatched role expectations (see Table 12).

Hypothesis 9: CG depressive symptoms will be positively related to CG role strain. Hypothesis 9 was supported. The CES-D Depressive Symptoms correlated significantly and negatively with all 11 CG role strain scales.

Aim 4. To Evaluate Internal Consistency, Descriptive Statistics and Construct Validity of the New Scales: Rewards of Spiritual Fulfillment and Strain from Feelings of Guilt

The internal consistency of both rewards of spiritual fulfillment and strain from feelings of guilt are at an acceptable level (Table 13). As shown in Table 14, the means for the two scales indicate that neither of them had extremely high or extremely low average scores. The ratio of the actual range of scores to the potential range of scores for these scales was more than .75, indicating that Thai CGs are using most of the response range.

In order to validate and understand more about rewards of spiritual fulfillment and strain from feelings of guilt, these new scales were hypothesized to be correlated with selected FCI scales. Theoretically, it was hypothesized that rewards of spiritual fulfillment would be positively related to preparedness, predictability, rewards of being there for the CR, rewards of meaning for oneself and CG mental health. It was hypothesized that this new rewards scale was hypothesized to be negatively related to amount of negative lifestyle change, CG role strain, and CG depressive symptoms.

It was hypothesized that strain from feelings of guilt would be negatively related to preparedness, predictability, rewards of being there for the CR, rewards of meaning for oneself, rewards of spiritual fulfillment, CG physical and mental health. It was hypothesized that this new strain scale would be positively related to amount of care activities, amount of negative lifestyle change, CG role strain and CG depressive symptoms.

Rewards of spiritual fulfillment was significantly related to 9 of 21 the FCI scales for which a correlation was hypothesized. All of the significant correlations were in

expected direction (see Table 15). Rewards of spiritual fulfillment was related to few dimensions of CG role strain (strain from care activities, feelings of guilt and global strain). In addition, this scale was highly correlated with rewards of being there for the CR and rewards of meaning for oneself.

Strain from feelings of guilt was significantly related to 17 of 23 of the FCI scales for which a correlation was hypothesized (see Table 15). All the correlations were in expected direction. Strain from feelings of guilt was correlated with preparedness for family care, predictability and rewards of spiritual fulfillment. However, strain from feelings of guilt was not significantly correlated with mutuality, rewards of being there for the CR and rewards of meaning for oneself. Strain from feelings of guilt was significantly positively related to most dimensions of CG role strain except for strain from role conflict and worry about safety.

CHAPTER 5

DISCUSSION

The discussion focuses on the findings about the psychometric properties of FCI scales in Thai family CG. Issues of content validity of the study, the utility of the scales and limitation of this study are presented. Implications for theory, practice and research conclude this section.

Aim 1. Internal Consistency of the FCI scales

29 scales and subscales examined, 22 met the reliability criteria as described by Nunnally. The focus of those that demonstrated reliability measured the antecedent characteristics of the CG, the amount of care activities, and selected responses to family care. These 22 scales appear to reliability capture the Thai CG's experiences when caring for an elderly relative. These reliability results suggest that numerous family care concepts from the United States can be reliably measured in family CGs.

Seven scales and subscales demonstrated marginal or unacceptable reliability. These included CR IADL needs, CR extent of communication problems, predictability, rewards of learning, financial rewards, strain from communication problems and strain from mismatched role expectations. The low reliabilities may be related to the number of items comprising the scale or subscale (many consisted of fewer than 6 items) or the use of dichotomous response options in the scales measuring CR IADL needs. It is also possible that the issues surrounding differences between Thai and American cultures and inadequacies of the translation process lowered reliability.

The number of items in the scale or subscale influences its reliability and may account for the marginal and low reliabilities reflected in scales measuring CR extent of

communication problems, reward of learning, financial rewards, and strain from communication problems, each of which has 3 or 4 items. Since Cronbach's alpha can be low when the number of items in the scale is small and the range of the response options is small, lower internal consistency for these scales might be expected.

The low reliability of the CR IADL may reflect cultural differences that are accentuated by scale's dichotomous yes/no response format. Little variation in responses was found with its use in Thailand, although use in the United States found adequate variability. It may be that in Thai culture the younger and elder generations tend to be interdependent. That is, there is an expectation that the younger generation will provide help to elders. Because younger persons are willing to help elders, even though the elder still can do IADL tasks by him or herself and because the elder is happy to receive help, there are a high percentage of "yes" responses to most items. Thus, this scale may exhibit low internal consistency reliability for Thai CGs compared to U.S. CGs.

Translation difficulties are illustrated with the Predictability Scale. Although the back-translation of the Thai version appeared equivalent, the Thai word for 'predictable' is not commonly used. Thus, some CGs did not understand what the word meant in the context of caregiving and required the researcher to explain the meaning before responding to the question. This researcher felt that some CGs found her explanations ambiguous, leaving the researcher uncertain if the respondent truly understood what was being asked. The possibility that responses were based upon respect for the researcher's knowledge, saving face, or desire to continue the interview may present a source of confounding error.

Similar to the marginal reliability found with American CGs, the Strain from Communication Problems Scales had low reliability. In addition to only 3 items related to hearing, speaking and cognitive abilities, the items were not homogenous. The low Cronbach's alpha was not surprising. However, the scale is valuable for clinical purposes and possesses content validity for family caregiving.

Aim 2. Descriptive Statistics on the FCI scales

Aim 2 focused on the descriptive statistics of the scales when used with Thai CGs. This examination considered the variability and distribution of the scales and subscales. The scale means found with feelings of being manipulated and mismatched role expectations were low, and distributions were positively skewed and leptokurtic. These results may be explained by considering the focus and cultural appropriateness of the scale's items.

Each of the items of the Mismatched Role Expectation scale are broadly phrased questions. The CG was asked to think about the overall nature of caregiving situations. Some CG told the researcher that they could not remember or quickly replied "No." In addition, some CGs, generally those who were less educated, asked to have the question asked in reference to a particular type of situation. This approach seemed easy for the Thai CG to understand and respond accordingly. Their difficulty understanding the scale's questions may have contributed to their responses being skewed towards the lower end of the scale. Thus, the lack of correlation of the Mismatched Role Expectations Scale with other scales or subscales may be related to the CGs' difficulty understanding the question rather than the relevance of dimension in Thai culture.

One of the items contained in the Feeling of Being Manipulated Scale may not be culturally appropriate. Asking “Has assisting your family member added to your feelings that you are being taken advantage of?” consistently lead to denial of the feeling. Most CG and CR dyads in this study were parent and child. In Thailand, there is a tradition of obligation and the social norm to provide care for elderly parents remains strong. Thus, the common response “Not at all” to this item reflects the child’s obligation to the parent. The sole participant replying otherwise in a hushed voice - was the CR’s spouse. The intent of this item may be applicable to Thai culture, but best examined using another phrase that acknowledges the caregiving obligation.

Aim 3: Issues of Construct Validity of the Study

Aim 3 focused on construct validity by testing the correlations between concepts. A hypothesis-testing procedure was performed to assess construct validity of the TFICI. The hypotheses were based on the conceptual framework of the FCI, which was designed and implemented in the United States, translated to Thai, and then applied to Thai CGs. The results derived from the Thai CG study were compared with the results of studies with United States CGs. The correlations found with Thai CGs (see Table 10, 11 and 12) supported many of the hypotheses, although some correlations were not statistically significant.

The study findings indicated that the construct validity evidence was strong for Hypotheses 3, 5, 6, 7, and 8. Predictability and amount of negative lifestyle change were correlated with CG role strain. CG role strain was highly correlated with CG physical, mental health and depressive symptoms, which were the criterion measures in this study.

The study findings suggest the scales assessing predictability, amount of negative lifestyle change and CG role strain are valid measures for Thai CGs.

Mutuality, preparedness, predictability, rewards of being there and rewards of meaning for oneself were positively related to each other. This indicates that this set of concepts that define positive aspects of caregiving to the United States CG are pertinent to Thai CGs. However, rewards of being there for the CR and rewards of meaning of oneself were very highly correlated with each other, which may suggest that these two scales measure the same concept. This high correlation was not found in studies with United States CGs, and requires further examination with Thai CGs.

The analysis of construct validity for preparedness by examining its correlation with CG role strain provided moderate support for Hypothesis 2. In Thailand, willingness to care for elders is a cultural norm, which may motivate CGs to be ready to accept the caregiving role. However, it may be difficult for Thai CGs to enter the role without being prepared with information and resources to support role transition.

This study's findings indicated that Hypothesis 1 and 4 had weak evidence of construct validity. Mutuality, rewards of being there for the CR, and rewards of meaning for oneself were significantly correlated with few dimensions of CG role strain. When the scatter plots of correlations between mutuality and the various subscales of CG role strain were examined, no outliers in the scores were noted. Mutuality was not correlated with predictability. These findings suggest that mutuality and rewards of being there for the CR and meaning for oneself may be capturing some part of the Thai family care experience but are not as central concepts as in the U.S. This may be explained by the differences in Thai and U.S. cultural values.

The U.S and Thailand have different cultures. Individualism is highly regarded in the U.S. There is strong socialization for self-reliance and independence. In addition, the U.S. culture is very diverse. In Thailand, collectivism is highly regarded. There is strong socialization for obedience, duty and sacrifice for the group (Triandis, Mccusker, & Hui, 1990). Moreover, Thai culture has a specific cultural norm to care for elders that is influenced by Buddhism (Kespichayawattana, 1999). The attributes underlying the positive quality of relationships between the Thai CG and CR may be defined and operationalized differently than in the U.S. A more appropriate focus within Thai culture may be with hierarchy and harmony of the relationship between CG and CR. While love, shared pleasurable activities, shared values and reciprocity define and operationalize mutuality in the U.S., mutuality in Thailand may include components of love, reciprocity, and some other measures which operationalize the shared values surrounding family roles, respect, and duty. Additional exploration is needed to refine the definition of mutuality for Thai family care.

A cultural bias that may influence the results of this study is “Katanyu Katavedi” (Kespichayawattana, 1999) This belief says that one must care for family members when they get old. It also implies that caring for the elderly is not a burden. Therefore, when Thai study participants answered the questions, they may have downplayed the amount of strain they actually experienced. Another interesting cultural bias found among eastern Asian study participants was that they tended to respond to questions at the midpoint on a Likert scale (Chen, Lee, & Stevenson, 1995). These two phenomena may have affected the correlation results.

Aim 4. To evaluate internal consistency, descriptive statistics and construct validity of two new scales: Strain from feelings of guilt and rewards of spiritual fulfillment

The finding indicated that the two new scales have good psychometric properties. However, the correlation among rewards of being there for CR, meaning for oneself and spiritual fulfillment ($r = .67, .72, .77$) were higher than expected. The magnitude of these correlations was fairly close to the reliability of the scales (.89, .83, .82) This finding indicates that, within the Thai culture, the three concepts overlap and may measure the same concept. In the U.S., the concept of rewards of being there is distinctly different from the concept of rewards of meaning for oneself. However, in Thai culture, these rewards may be more similar to each other or the same as spiritual fulfillment. These findings may reflect the influence of cultural differences of individual versus collectivism between the U.S. and Thailand.

Strain from feelings of guilt was moderately positively related ($r = .24$ to $.42$, Median $r = .37$) to 10 of 12 dimensions of CG role strain. These results support the construct validity of the new Strain from Feelings of Guilt scale as a measure of a different dimension of CG role strain. Because the rewards from spiritual fulfillment and strain from feeling of guilt were newly developed for Thai family care, there are no previous data in the United States for comparison purposes. However, the study findings show that strain from feelings of guilt was not significantly related to spiritual fulfillment.

Utility of Measure

The average length of time for the interview was 2 hours. This was too long for the CGs. By the end of the interview, it was clear that their concentration and interest were diminished. The loss of concentration and interest may be partly attributed to the

fact that the tool was translated from English into Thai. There may have been some subtleties of meaning that were lost or difficult to understand. The tool should be refined and shortened so that it requires limited time and money, can be administered through the mail, is more culturally appropriate to identifies CG role strain in Thai family CG.

Limitations to the study

The study has several limitations. These include the sample bias and the method of data collection. The sample was biased because it is a convenience sample. The participants were recruited from an urban university setting, which could make it difficult to generalize the results to the rural population (Mertens, 1998).

The methodology used to interview was face-to-face interview at the participant's home. This may have produced bias because of social desirability, location of interview and distractions that extended the interview. Because of the researcher's position as a nurse and a PhD student who is studying at a university in the United States, the CGs may have felt more obligated to please her or to show that everything in their family was 'all right'. The interviews were conducted in the CG's home with the elder being cared for often present. This may have impeded the CG's ability to openly answer the questions. With the elder present, the CG had to continue caregiving during the interview, which often took attention away and/or added much time to the question session.

Implications for Theory, Practice and Research

Theory. The findings of this study contribute to the development of a framework for family care in Thailand. The FCI, which is derived from role theory, a middle range theory, provides an appropriate conceptual model for helping Thai nurses understand the

phenomena of family care. Scales on the FCI measure both positive and negative aspects of family care.

The study findings indicate that the theoretical concepts surrounding CG role strain are applicable to CGs in both Thai and TheU.S. cultures. However, the relationships between concepts are culturally specific. In Thailand, preparedness and predictability appear to have more salience for CG role strain than in the U.S. In contrast, mutuality an antecedent factor and one of the positive aspects of caregiving, captures only part of the quality of the relationship between CG and CR in Thai family care. Other positive aspect of family care include rewards of being there for the CR, meaning for oneself and spiritual fulfillment; these three scales appear to be a single concept Thai culture. These findings indicate that, for application to Thai CGs, the theory of family care needs to be refined. Qualitative studies, examining the phenomena of family care in Thailand, are needed to refine the FCI framework for relevance to Thai culture.

Practice. The findings suggest that, for Thai CGs, an important focus for nursing practice is to support the transition into the caregiving role. Those who felt better prepared in the caregiving role also reported greater predictability in caregiving situations and decreased CG role strain. Interviews with CGs revealed that they experienced more strain in the first 2 months following the CR's discharge from the hospital; CGs reported that over time, they became comfortable with the caregiving activities and routines, and no longer felt strained. Similar findings were reported by Subgranon and Lund (2000). Therefore, role transition may be an important time to target interventions for family care.

Transition into new roles is associated with less role strain if the individual is provided with programs designed to facilitate modification and expansion of existing attitudes, knowledge, values, and behaviors appropriate for their new roles (Hardy, 1978; Burr, Leigh, Day & Constantine, 1969). Such preparation allows roles to be assumed with ease and an increased likelihood of success. In the Thai family, the motivation and willingness to assume the CG role is strong. However, the new CG usually has no experience caring for elders with a chronic illness.

Nurses can facilitate the transition by sharing knowledge about elder's illnesses and approaches to providing care, and providing a support system for the CG's ongoing needs and concerns. Ideally, this intervention begins prior to discharge and continues via home visits. The CG role is both individually desired and socially mandated, thus the new CG is receptive to learning. Nursing can have a strong impact on the transition by helping to create a sense of satisfaction and pride with caregiving role.

The FCI provides a tool to systematically assess family strengths and difficulties from the perspective of the CG. The tool, after it is refined for Thai culture, will assist Thai nurses to understand the experiences of individual CGs. This information will enable the nurse to provide targeted interventions to minimize CG role strain.

Research. The results of this study suggest that future research is needed for the FCI to be culturally appropriate for the Thai family care. First, a qualitative study will increase the understanding of the phenomena of family care in Thailand. Such methodology would help to identify other concepts important to Thai family care, may not be as relevant for family care in the U.S, especially concepts related to the positive aspects of caregiving.

Following this study, the TFCI should be revised. New subscales should be created to address the newly identified Thai concepts. Other items, as identified in these findings, should be refined to increase cultural appropriateness. Additionally, the instrument should be made shorter --especially the sections surrounding care activity.

After the refinement, the current study should be replicated. Factor analysis should be run with these results to further explore construct validity; and confirmatory factor analysis should be done with a second sample. The future studies should be done with a larger sized, heterogeneous sample, and examine reliability using a test-retest approach.

For all future studies, the method of data collection needs to be revised so that the limitations of this study are not repeated. Data collection should include the researcher and a research assistant. While the researcher is interviewing the CG, the assistant is available to assess the CR's needs and provide care as needed. This allows the CG to be interviewed apart from the CR, decreasing social desirability, while also enabling the CG to focus on the interview with fewer distractions, thus increasing the quality of data.

Finally, a longitudinal study will allow the nature of caregiving in Thailand to be further examined. This will provide additional information about the relationship between the concepts of preparedness and other concepts with in family care. Such an approach would be similar that that used by Archbold and colleagues when examining mutuality and preparedness (Archbold, et al, 1990).

Combined, findings from such a series of studies will lay the foundation for appropriate nursing interventions with Thai families.

Table 1

Hypotheses to be Tested About Concepts Measured by Family Care Inventory Scales and Subscales

H₁: Mutuality will be negatively related to caregiver role strain, except for caregiver role strain from lack of resources, economic burden, and worry, which will not be related to mutuality.

H₂: Preparedness for family care will be negatively related to caregiver role strain except for strain from economic burden and role conflict, which will not be related to preparedness.

H₃: Predictability of the caregiving situation will be negatively related to caregiver role strain, except for strain from care activities and mismatched expectations, which will not be related to predictability.

H₄: Rewards of being there for the care receiver and rewards of meaning for oneself will be negatively related to caregiver role strain in a pattern similar to that hypothesized for mutuality.

H₅: Mutuality, preparedness for family care, predictability, rewards of being there and rewards of meaning for oneself will be positively related to one another.

H₆: Amount of care activities will be positively related to caregiver role strain.

H₇: Amount of negative life style change will be positively related to caregiver role strain.

H₈: Caregiver health will be negatively related to caregiver role strain.

H₉: Caregiver depressive symptoms will be positively related to caregiver role strain.

Table 2

The Items of Family Caregiving Inventory Adapted for Cultural Appropriateness

Scale or Subscale	Original Items	New or Modified Items
Mutuality		
Shared Values	<p><u>Item 1.</u> To what extent do the two of you see eye to eye?</p> <p><u>Item 9.</u> To what extent do the two of you share the same values?</p>	<p>How much do the two of you agree on things?</p> <p>How much do you and your family member think the same things are important in life?</p>
Shared Pleasurable Activities	<p><u>Item 11.</u> How much do the two of you laugh together?</p>	<p>How much do you and family member spend time talking and laughing together?</p>
Reciprocity	<p><u>Item 4.</u> How much does he or she express feelings of appreciation for you and the thing you do?</p> <p><u>Item 10.</u> When you really need it, how much does he or she comfort you?</p> <p><u>Item 13.</u> How much emotional support does he or she give you?</p> <p><u>Item 15.</u> How often does he or she express feelings of warmth toward you?</p>	<p>How much does your family member show his or her appreciation for your taking care of him or her?</p> <p>When you are suffering, how much does he or she comfort you?</p> <p>How much does he or she encourage you and being sympathetic?</p> <p>How often does he or she express feeling of "auarthon" toward you?</p>

(table continues)

Table 2 (continued)

The Items of Family Caregiving Inventory Adapted for Cultural Appropriateness

Scale or Subscale	Original Items	New or Modified Items
Amount of Care Activities		
	<p><u>Item 16.</u> Do you do any of the driving for your family member?</p> <p><u>Item 40.</u> Do you have to deal with his or her unsafe driving?</p> <p><u>Item 57.</u> Do you assist him or her in filling out forms such as taxes, Medicare, Social Security, or insurance?</p> <p><u>Item 77.</u> Do you help to meet his or her spiritual needs ? (For example, do you arrange for a priest/minister/rabbi to come, or arrange to watch religions programs on TV, or read religious books to him or her?)</p>	<p>Keep Item 16, but add:</p> <p>Do you assist your family member in using public transportation such as taxi, tuk-tuk or bus?</p> <p>Keep Item 40, but add:</p> <p>Do you have to deal with safety issues when her or she uses public transportation?</p> <p>Delete Item 57 and add:</p> <p>Do you assist him or her filling out legal or health forms?</p> <p>Delete Item 77 and add:</p> <p>Do you Thom Boon for your family member? For example, Do you prepare food or a gift for your family member give to monks? Do you arrange for monks/ a priest /a mullah to visit?</p> <p>Do you set up a place for praying, or watch religions programs on TV or radio, or read religious books to him or her?</p> <p>Add environment modification item: Have you modified the household environment for your family member? (For example, setting up a specific area for your family member, installing hand rails or modifying the bath room)</p>

(table continues)

Table 2 (continued)

The Items of Family Caregiving Inventory Adapted for Cultural Appropriateness

Scale or Subscale	Original Items	New or Modified Items
		<p>Add item about help from a traditional healer:</p> <p>Have you ever sought an alternative method of treatment such as using Chinese medicine, herbs, massage, holy water or magic in order to alleviate the family member's health problems?</p>
Amount of Negative Lifestyle Change		
	<u>Item 5.</u> Has assisting your family member decreased the time you have to spend in recreational activities?	Has assisting your family member decreased the time you have to spend in entertaining activities?
Caregiver Role Strain		
Strain from Care Activities	Items 16, 40, 57 and 77	See items for Amount of Care Activities
Strain from Worry	<p><u>Item 9.</u> How much do you worry about his or her safety because of traffic problems?</p> <p><u>Item 13.</u> How much you worry about having to make the decision about whether to put him or her into a nursing home?</p> <p>Item 15. How much do you worry about safety when he or she uses lawn, shop, or other equipments?</p>	<p>How much do you worry about his or her vulnerability to cars motorcycles, tuktuks, tricycles or bicycles when he or she goes outside?</p> <p>Deleted</p> <p>How much do you worry about safety when he or she uses sharp tools such as knife or use electrical equipments?</p>

(table continues)

Table 2 (continued)

The Items of Family Caregiving Inventory Adapted for Cultural Appropriateness

Scale or Subscale	Original Items	New or Modified Items
Strain from Role Conflict	<p><u>Item 11.</u> To what extent does caring for your family member interfere with your ability to be active in your church in the way you think you should be?</p> <p><u>Item 12.</u> To what extent does caring for your family member interfere with your ability to be active in the community in the way you think you should be?</p>	<p>To what extent does caring for your family member interfere with your ability to involved in religion activites such as ability going to the temple on important religious day, joining other merit making ceremonies in the way you should be?</p> <p>To what extent does caring for your family member interfere with your ability to be involved in social activities such as marriage ceremonies, funerals and Nean Boon Roi Wan in the way that you think you should be?</p>
Strain from Feelings of Being Manipulated	<u>Item 4.</u> Has assisting your family member increased attempts by him or her to manipulate you?	Has assisting your family member increased his or her try to make you do thing that you don't want to do?
Strain from Feelings of Guilt (New dimension)		<ol style="list-style-type: none"> 1) How often do you blame yourself about a behavior you have directed towards your family member? 2) How often do you feel guilt or feel that you are not taking a good care of your family member when your family member's symptom getting worse? 3) How often do you feel sorry that you have failed to give care completely or have been remiss in some caregiving activities?

(table continues)

Table 2 (continued)

The Items of Family Caregiving Inventory Adapted for Cultural Appropriateness

Scale or Subscale	Original Items	New or Modified Items
Positive Aspects of Family Care		
Rewards of Meaning for Oneself	<u>Item 11</u> . Have you personally grown as a result of being a caregiver?	Has caring for him or her changed you in a positive way such as making you feel more tranquil?
Financial Rewards	<p><u>Item 4</u>. To what extent does caring for him or her help you financially (such as by providing you a place to live or giving you his/her Social Security check to cover expenses related to caregiving)?</p> <p><u>Item 10</u>. To what extent does caring for your family member help you live more comfortably financially than if you put him or her in a nursing home?</p>	<p>To what extent does caring for him or her help you financially such as relatives giving you some money to cover expenses related to caregiving?</p> <p>To what extent does caring for your family member help you live more comfortably financially than if you hired a paid helper to care for him or putting her or him in a private hospital?</p>
Rewards from Spiritual Fulfillment (New Scale)		<ol style="list-style-type: none"> 1. How much does caring for you family member help you accumulate merit which will bring you to a better situation in this life or next life? 2. How much does caring for you family member fulfill bon kun? 3. How much does caring for your family help you feel "Pi Tee"? 4. How much does caring for you family member help you have a better life in the future?

(table continues)

Table 2 (continued)

The Items of Family Caregiving Inventory Adapted for Cultural Appropriateness

Scale or Subscale	Original Items	New or Modified Items
		5.How much does caring your family member giver you good Karma?
Rewards from Other People	<p><u>Item 6.</u> Do you feel glad to be a caregiver because immediate family members look at you as important person?</p> <p><u>Item 7.</u> Does caring him or her help you show others the importance of caregiving?</p> <p><u>Items 8.</u> Do you feel glad to be a caregiver because other relatives look at you as an important person</p> <p><u>Item 19.</u> Do you feel glad to be a caregiver because your neighbors and friends look at you as an important person?</p>	<p>Are you happy to be a caregiver because family members praise you for taking good care of him or her?</p> <p>By giving good care to family member, are you being a good example?</p> <p>Are you happy to be a caregiver because other relatives look at you as a good person?</p> <p>Are you glad to be a caregiver because your neighbors, friends, or health professionals look at you as a good person?</p>

(table continues)

Table 3

List of 14 Concepts Measured by Scales on Family Care Inventory, Number of Items, Response Format, and Reliability

Concepts	Number of Items	Description of Scale	Reliability
Antecedent Factors: Care Receiver			
CR ADL Needs	6 items	Self-report items use response options of yes (1) or no (0); total score is computed by summing the <u>yes</u> answers.	.80
CR IADL Needs	9 items	Self-report items use response options of yes (1) or no (0); total score is computed by summing the <u>yes</u> answers.	.74
CR Memory Problems	8 items	Self-report items use a 5-point response format ranging from 0 (not at all difficult) to 4 (can't do at all). Higher score reflect higher CG's memory impairment.	.93
CR Extent of communication problems	3 items	Self-report items use response options of yes (1) or no (0); total score is computed by summing the <u>yes</u> answers. Higher score indicated that CR has higher communication problems.	.60
Antecedent Factors: Caregiver			
CG Physical and Mental Health	36 items	<p>The SF-36 Health Survey Self-report items use a Likert response format. The total scale measures general health including:</p> <ul style="list-style-type: none"> • Physical Functioning • Role-Emotional • Role-Physical • Bodily Pain • General Health • Vitality • Social Functioning • Mental Health <p>Scale scores are computed and then transformed to a 0-to-100 scale in which a higher score indicates better health.</p>	.80 (Ware & Gendek, 1998)
CG Depressive Symptoms	20 items	<p>The Center for Epidemiological Studies Depression Scale (CESD)</p> <p>Self-report items use a 4-point response format. Response categories range from "Rarely or None of the time" to "Most or All of the time". The total score ranges from 0-60 and the higher the score the more depressed.</p>	.82-.91 (Archbold et al., 1995; Jepson et al., 1999; Reveis et al., 1998;. Schulz & Williamson, 1991)

(table continues)

Table 3 (continued)

List of 14 Concepts Measured by Scales on Family Care Inventory, Number of Items, Response Format, and Reliability

Concepts	Number of Items	Description of Scale	Reliability
Mutuality	15 items	Self-report items use a 5-point response format ranging from 0 (not at all) to 4 (a great deal). CGs who have high scores on the mutuality scale report their relationship with the CR is characterized by a great deal of love, shared pleasurable activities, shared values and reciprocity.	.91-.95 (Archbold & Stewart, 1999)
Preparedness for Family Care	8 items	Items have a 5-point response format ranging from 0 (not at all prepared) to 4 (very well prepared). Higher scores reflect higher preparedness.	.86-.92 (Archbold & Stewart, 1999)
Family Care			
Amount of Care Activities	87 items	Items employ response options of yes (1) or no (0); the total score is computed by summing the <u>yes</u> answers seven subscales include: (1) personal care, (2) mobility and protection, (3) illness-related care, (4) transportation, banking, and housekeeping, (5) little extras and emotional support, (6) dealing with the symptoms of dementia and difficult behavior, (7) arrange care. Scales employ response option of yes (1) or no (0); the score is computed by summing the <u>yes</u> answers.	.86-.91 (Archbold & Stewart, 1999)
Amount of Help from Others	10 items	Items have a 5-point response format ranging from 0 (not at all or very unhappy) to 4 (a great deal or very happy). The potential range for the scale is 0.00 to 4.00, with higher scores reflecting more help from others and more happiness with that care.	.69 (Archbold & Stewart, 1999)
Responses to Family Care: Positive Aspects			
Predictability	7 items	Items have a 5-point response format ranging from 0 (not at all or never) to 4 (very or always). The potential range for the scale is 0.00 to 4.00, with higher scores reflecting more predictability	.71 (Archbold & Stewart, 1999)

(table continues)

Table 3 (continued)

List of 14 Concepts Measured by Scales on Family Care Inventory, Number of Items, Response Format, and Reliability

Concepts	Number of Items	Description of Scale	Reliability
Rewards of Caregiving	15 items	<p>Items have a 5-point response format ranging from 0 (not at all) to 4 (a great deal). The potential range for the scale is 0.00 to 4.00, with higher scores reflecting more rewards from caregiving.</p> <p>Rewards of Caregiving include:</p> <ul style="list-style-type: none"> • Rewards of Being There for the Care-receiver (5 items). • Rewards of Meaning for Oneself (5 items). • Rewards of Learning (4 items). • Financial Rewards (3 items). • Rewards of Spiritual Fulfillment (6 items)- New scale\ 	.67-.94 (Archbold & Stewart, 1999)
Responses to Family Care: Negative Aspects			
Amount of Negative Life Style Change	6-items	<p>Items have a 5-point response format ranging from 0 (not at all) to 4 (a great deal). The potential range for the scale was 0.00 to 4.00, with higher scores reflecting that more negative life style change occurred as a result of caregiving.</p>	.84 (Inoue, 1995)
CG Role Strain	143 items	<p>Items on the CG role strain scales use a 5-point response format and usually include the response options (not at all) 0, (a little) 1, (some) 2, (quite a bit) 3, and (great deal) 4.</p> <p>The CG Role Strain include:</p> <ul style="list-style-type: none"> • Strain from care activities (80 items). • Strain from Arranging Care (6items). • Strain from Mismatched Expectations (7 items). • Strain from Role Conflict (12 items). • Strain from Communication Problems (4items). • Strain from Frustration due to communication problems (3 items). • Strain from Lack of Resources (6 items). • Strain from Worry (17 items). • Strain from Increased Tension (4 items). • Strain from Feelings of Being Manipulated (4 items). • Strain from Economic Burden (4 items). • Global Strain (4 items). • Strain from Feelings of Guilt (3 items).-New scale 	.64-.80 (Archbold et al., 1990)

Note. CG = caregiver; CR = care receiver; ADL = Activities of Daily Living; IADL = Instrument Activities of Daily Living.

Table 4

Age of Caregivers, Amount and Duration of Their Care (N=80) and Age of Their Care Receivers

Characteristic	Mean	SD	Range
Caregiver			
Age	47.7	11.7	23-78
Days providing care per week	6.7	.9	2-7
Hour providing care per day	7.8	5.2	1-24
Years of caregiving	3.3	3.8	0.2-22.1
Care Receiver			
Age	77.5	9.3	60-104

Table 5

Gender, Marital Status, Education and Occupation of Caregivers (N=80) and Their Care Receivers

Characteristic	Caregiver Percent	Care Receiver Percent
<u>Gender</u>		
Female	78	77
Male	22	23
<u>Marital Status</u>		
Married	48	40
Widowed	5	54
Divorced	5	1
Separated	6	2
Never Married	36	2
<u>Education</u>		
No formal education	1	39
Completed grade school	28	42
Completed junior high school	4	4
Completed high school	8	2
Completed associate degree	11	2
Attended college	4	0
Completed college	34	1
Graduate professional training	11	1
<u>Occupational Categories</u>		
1. Higher executives of large concerns, proprietors, and major professionals	4	4
2. Business manager, proprietors of medium-sized businesses, and lesser professionals	24	11
3. Administrative personal, owners of small businesses, and minor professionals	9	0
4. Clerical and sale workers, technicians, and owners of little businesses	19	5
5. Skilled manual employees	2	2
6. Machine operators and semiskilled employees	14	21
7. Unskilled employees	26	56

Table 6

Caregiver's Employment, Income Adequacy, and Relationship to Care Receiver, and Care Receiver's Living Situation, Need for Help, and Medical Diagnoses

	Percent		Percent
<u>Employment Status</u>		<u>Care Receiver Needs Help with</u>	
Employed	59	<u>Activities of Daily Living</u>	
Not employed	41	Bathing or shower	75
		Dressing	75
<u>Income Adequacy</u>		Using the toilet, including	68
Can't make ends meet	16	getting to the toilet	
Just enough, no more	26	Getting in and out of bed or	67
Enough with a little extra	36	chairs	
sometimes		Walking	63
Always left over	22	Eating	56
<u>Relationship to Care Receiver</u>		<u>Care Receiver Needs Help with</u>	
Wife	8	<u>Instrumental Activities of Daily</u>	
Husband	4	<u>Living</u>	
Daughter	49	Preparing meals	96
Son	15	Doing light housework	95
Daughter-in-law	8	Doing heavy housework	95
Other relative	16	Driving or taking a bus or taxi to	95
Neighbor or friend	1	where care receiver needs to go	
		Managing money	91
<u>Care Receiver's Living Situation</u>		Taking medication	91
With spouse	2	Shopping for personal items	88
With children	30	Getting around outside	59
With other relatives	10	Using the telephone	58
Spouse and children	19		
Children and other relatives	20	<u>Care Receiver Medical Diagnoses</u>	
Spouse and children and other	14	Heart disease	49
relatives		Diabetes	36
Others	5	Hypertension	31
		Stroke	31
<u>Care Receiver Living with</u>		Alzheimer's disease or other	25
<u>Caregiver</u>		dementia	
Yes	94	Arthritis	16
No	6	Parkinson's disease or other	12
		movement disorder	
		Cancer	8
		Depression	6
		Osteoporosis	6
		Chronic renal failure	6
		Other diseases	19

Table 7

Summary of Item Analysis and Cronbach's Alpha on Family Care Inventory Scales and Subscales

Scale or Subscale	No. of items	Inter-Item Correlation		Item-Total correlation		Cronbach's Alpha
		Mean	Range	Mdn	Range	
Antecedent Factors: Care Receiver						
1. CR ADL Needs	6	.50	.19 to .73	.70	.36 to .77	.85
2. CR IADL Needs	9	.16	-.07 to .47	.27	.14 to .47	.57
3. CR Memory Problems	8	.70	.55 to .85	.81	.71 to .88	.95
4. CR Extent of Communication Problems	3	.14	.02 to .31	.23	.06 to .30	.34
Antecedent Factors: Caregiver						
5. Health						
a. CG Physical Health: SF 36	21	.22	-.15 to .79	.46	.08 to .63	.85
b. CG Mental Health: SF 36	14	.38	.09 to .72	.59	.45 to .70	.89
6. CG Depressive Symptoms CES-D	20	.22	-.30 to .70	.41	-.00 to .68	.80
7. Mutuality	15	.50	.24 to .79	.69	.58 to .80	.94
8. Preparedness for Family Care	8	.37	.01 to .62	.56	.42 to .65	.82
Family Care						
9. Amount of Care Activities	90	.06	-.39 to .86	.23	-.18 to .60	.86
Responses to Family Care: Positive Aspects						
10. Predictability	6	.19	-.09 to .62	.37	-.00 to .63	.58
11. Rewards of Family Care						
a. Being There for the CR	5	.61	.51 to .75	.77	.63 to .79	.89
b. Meaning for Oneself	5	.50	.39 to .60	.64	.57 to .71	.83
c. Learning	4	.37	.16 to .53	.50	.29 to .60	.67
d. Financial Rewards	2	.48	.48 to .48	.48	.48 to .48	.65
f. Other people	4	.76	.72 to .79	.82	.80 to .85	.93

(table continues)

Table 7 (continued)

Summary of Item Analysis and Cronbach's Alpha on Family Care Inventory Scales and Subscales

Scale or Subscale	No. of items	Inter-Item Correlation		Item-Total Correlation		Cronbach's Alpha
		Mean	Range	Mdn	Range	
Responses to Family care: Negative aspects						
12. Amount of Negative Life style Change	6	.62	.46 to .79	.76	.59 to .84	.91
13. Caregiver Role Strain from Care Activities	90	-	-	a	a	.99
14. Caregiver Role Strain from the caregiving situation:						
a. Communication Problems	3	.15	.01 to .40	.32	.04 to .34	.39
b. Frustration due to Communication Problems	3	.57	.42 to .67	.62	.57 to .76	.80
c. Role Conflict	14	.58	-.08 to 1.0	a	a	.95
d. Worry	11	.22	-.00 to .53	.44	.21 to .60	.76
e. Worry About Safety	4	.40	.16 to .67	.65	.22 to .73	.75
f. Lack of Resources	5	.44	.31 to .64	.59	.47 to .67	.80
g. Economic Burden	4	.39	.05 to .81	.70	.12 to .78	.77
h. Feelings of Being Manipulated	4	.43	.05 to .68	.63	.33 to .75	.74
i. Increased Tension	4	.55	.39 to .66	.53	.54 to .74	.83
j. Mismatched Role Expectations	5	.25	.13 to .35	.38	.29 to .48	.61
k. Global Strain	4	.41	.22 to .56	.57	.36 to .65	.74

Note. Mdn = Median; CG = caregiver; CR = care receiver; ADL = Activities of Daily Living Scale; IADL = Instrument Activities of Daily Living Scale; SF 36 = Health Survey Scale; CES-D = the Center for Epidemiological Studies Depression Scale.

a = Item total correlations were not computed because of legitimate missing responses. Because a caregiver's score on this scale is based on only the applicable subset of items, each caregiver has legitimate "missing responses" to some items on this scale. The extent and pattern of missing data for this scale made it impossible to use the usual SPSS computer procedure for estimating alpha because a listwise deletion of cases is employed.

Table 8

Frequency Distribution of Cronbach's Alpha Values for Scales on the Thai Version of Family Care Inventory

Cronbach's Alpha		Number of Scales
High reliability	.95 to .99	3
	.90 to .94	3
Moderately high reliability	.85 to .89	5
	.80 to .84	6
Moderate reliability	.75 to .79	3
	.70 to .74	2
Marginal reliability	.65 to .69	2
	.60 to .64	1
	.55 to .59	2
Unacceptable reliability	.50 to .54	0
	Below .50	2
Total		29

Table 9

Descriptive Statistics for Scales on the Thai Version of Family Care Inventory

Scales	# of items	# of Resp Options	Potential Range of Scores	Descriptive Statistics					
				Mean	SD	Actual Range of Scores	Skewness (SE) * p < .001	Kurtosis (SE) * p < .001	% Missing
Antecedent Factors: Care Receiver									
1. CR ADL Needs	6	2 (0-1)	0-6	3.93	2.16	0.00-6.00	-0.71 (0.27)	-0.88 (0.53)	0
2. CR IADL Needs	9	2 (0-1)	0-9	7.39	1.40	3.00-9.00	-0.97* (0.27)	0.96 (0.53)	0
3. CR Memory Problems	8	5 (0-4)	0.00-4.00	1.07	1.26	0.00-4.00	1.05* (0.27)	-0.08 (0.53)	0
4. CR Extent of Communication Problems	3	5 (0-4)	0.00-4.00	1.16	0.82	0.00-4.00	0.62 (0.27)	0.64 (0.53)	0
Antecedent Factors: Caregiver									
5a. CG Physical Health: SF36	21	3, 5 & 6 (1-3) (1-5) (1-6)	0.00-100.00	77.20	13.64	40.53-97.62	-0.70 (0.27)	-0.10 (0.53)	0
5b. CG Mental Health: SF36	14	5 (1-5)	0.00-100.00	72.06	16.56	28.57-100.00	-0.47 (0.27)	-0.20 (0.53)	0
6. CG Depressive symptoms	20	4 (1-4)	0-60	11.31	7.76	0-31	1.14 (0.27)	0.70 (0.53)	0
7. Mutuality:	15	5 (0-4)	0.00-4.00	2.23	0.86	0.33-3.93	-0.22 (0.27)	-0.73 (0.53)	0
8. Preparedness for Family Care	8	5 (0-4)	0.00-4.00	2.33	0.63	1.25-3.75	0.29 (0.27)	-0.82 (0.53)	0

(table continues)

Table 9 (continued)

Descriptive Statistics for Scales on the Thai Version of Family Care Inventory

Scales	# of items	# of Resp options	Potential Range of Scores	Descriptive Statistics					
				Mean	SD	Actual Range of Scores	Skewness (SE) * p < .001	Kurtosis (SE) * p < .001	% Missing
Family Care									
9. Amount of Care Activities	90	2 (0-1)	0.00-90.00	46.09	10.96	25-73	0.31 (0.27)	-0.27 (0.53)	0
Responses to Family Care: Positive Aspects									
10. Predictability	6	5 (0-4)	0.00-4.00	2.46	0.59	1.00-4.00	.15 (0.27)	-.45 (0.53)	0
11a. Rewards of Being There for the CR	5	5 (0-4)	0.00-4.00	2.96	0.69	0.40-4.00	-0.81 (0.27)	1.44 (0.53)	0
11b. Rewards of Meaning for Oneself	5	5 (0-4)	0.00-4.00	2.90	0.69	0.60-4.00	-0.56 (0.27)	0.49 (0.53)	0
11c. Rewards of Learning	4	5 (0-4)	0.00-4.00	3.05	0.55	1.75-4.00	0.02 (0.27)	-0.61 (0.53)	0
11d. Financial Rewards	2	5 (0-4)	0.00-4.00	0.65	0.89	0.00-3.00	1.2 (.30)	-.36 (.58)	1
11e. Rewards Other People	4	5 (0-4)	0.00-4.00	2.08	1.12	0.00-4.00	-0.29 (0.27)	-0.79 (0.53)	0
Responses to Family Care: Negative Aspects									
12. Amount of Negative Life style Change	6	5 (0-4)	0.00-4.00	1.14	0.88	0.00-3.67	0.66 (0.27)	-0.24 (0.53)	0
13. CG Role Strain from CG Activities	90	5 (0-4)	0.00-4.00	0.87	0.49	0.03-2.18	0.72 (0.27)	0.01 (0.53)	0

(table continues)

Table 9 (continued)

Descriptive Statistics and Reliability for Scales on the Thai Version of Family care Inventory

Scales	# of items	# of Resp Options	Potential Range of Scores	Descriptive Statistics					
				Mean	SD	Actual Range of Scores	Skewness (SE) * p < .001	Kurtosis (SE) * p < .001	% Missing
14. CG role strain from caregiving situation:									
a. Commun Problems	3	5 (0-4)	0.00-4.00	1.58	0.85	0.00-2.67	0.76 (.27)	.01 (0.53)	12
b. Frustration due to Commun Problems	3	5 (0-4)	0.00-4.00	0.91	0.85	0.00-2.67	0.55 (0.27)	-0.98 (0.53)	0
c. Role Conflict	14	5 (0-4)	0.00-4.00	0.80	0.85	0.00-3.56	1.25* (0.27)	0.89 (0.53)	0
d. Worry	11	5 (0-4)	0.00-4.00	1.84	0.64	0.00-3.00	-0.68 (0.27)	0.26 (0.53)	0
e. Worry About Safety	4	5 (0-4)	0.00-4.00	0.78	0.97	0.00-3.25	1.07* (0.27)	0.01 (0.53)	0
f. Lack of Resources	5	5 (0-4)	0.00-4.00	1.26	0.80	0.00-3.40	0.57 (0.27)	-0.25 (0.53)	0
g. Economic Burden	4	5 (0-4)	0.00-4.00	0.90	0.83	0.00-3.00	0.80 (0.27)	-0.05 (0.53)	0
h. Feelings of Being Manipulated	4	5 (0-4)	0.00-4.00	0.43	0.56	0.00-2.50	1.47* (0.27)	2.10* (0.53)	0
i. Increased Tension	4	5 (0-4)	0.00-4.00	0.90	0.74	0.00-3.00	0.63 (0.27)	-.37 (0.53)	0
j. Mismatched Role Expect	4	5 (0-4)	0.00-4.00	.87	0.70	0.00-3.40	1.19* (0.27)	2.19* (0.54)	0
k. Global Strain	4	5 (0-4)	0.00-4.00	1.00	0.63	0.00-2.75	0.44 (0.27)	-0.09 (0.53)	0

Note. CG = caregiver; CR = care receiver; ADL = Activities of Daily Living Scale; IADL = Instrument Activities of Daily Living Scale.

Table 10

Hypotheses 1, 2, 3, and 4: Correlations of Mutuality, Preparedness, Predictability, Rewards of Being There for the Care Receiver, and Rewards of Meaning for Oneself with Caregiver Role Strain (N=80)

Caregiver Role Strain from . . .	7. Mutuality	8. Preparedness for Family Care	9. Predictability of Family Care	11a. Rewards of Being There for Care Receiver	11b. Rewards of Meaning for Oneself
13. Care Activities	-.37**	-.41**	-.28**	-.21*	-.29**
14a. Communication Problems	-.17 ^a	-.18 ^a	-.31**^a	-.04^a	-.12^a
14b. Frustration due to Commun Problems	-.16	-.15	-.27**	-.16	-.30**
14c. Role Conflict	.07	-.25*	-.18	.04	-.01
14d. Worry	.19*	-.14	-.19*	.13	.07
14f. Lack of Resources	-.10	-.52**	-.43**	-.16	-.21*
14g. Economic Burden	-.08	-.30**	-.19*	-.28**	-.23*
14h. Feelings of Being Manipulated	.01	-.29**	-.20*	-.06	-.10
14i. Increased Tension	-.06	-.36**	-.13	.02	-.05
14j. Mismatched Expectations	.10 ^b	-.03 ^b	-.10 ^b	.13 ^b	.08 ^b
14k. Global Strain	-.31**	-.57**	-.36**	-.36**	-.41**
# significant r_s / # hypothesized r_s	2 / 8	5 / 9	7 / 9	2 / 8	3 / 8
# nonsignificant r_s / # hypothesized zero r_s	2 / 3	0 / 2	1 / 2	2 / 3	1 / 3

Note. Shaded areas are hypotheses that were supported. Dark shading is for directional hypotheses that were supported. Light shading is for hypothesized zero correlations that were supported.

^a n= 68. ^b n= 77. ** p < .01. * p < .05.

Table 11

Hypotheses 5: Correlations among Mutuality, Preparedness, Predictability, Rewards of Being There for the Care Receiver, Rewards of Meaning for Oneself

	7. Mutuality	8. Preparedness for Family Care	9. Predictability of Family Care	11a. Rewards of Being There for the Care Receiver	11b. Rewards of Meaning for Oneself
7. Mutuality	1.00**				
8. Preparedness for Family Care	.33**	1.00**			
9. Predictability of Family Care	.17	.50**	1.00**		
11a. Rewards of Being There for the Care Receiver	.42**	.45**	.41**	1.00**	
11b. Rewards of Meaning for Oneself	.46**	.48**	.55**	.77**	1.00**
# significant rs / # hypothesized rs: 9 / 10					
# nonsignificant rs / # hypothesized zero rs: 0 / 0					

Note. Shaded areas are hypotheses that were supported.

** p < .01.

Table 12

Hypotheses 6, 7, 8 and 9: Correlations of Amount of Care Activities, Amount of Negative Lifestyle Change, Caregiver Health, and Caregiver Depressive Symptoms with Caregiver Role Strain.

Caregiver Role Strain from . . .	9. Amount of Care Activities	12. Amount of Negative Life style Change	5a. Caregiver Physical Health: SF-36	5b. Caregiver Mental Health: SF-36	6. Caregiver Depression Symptoms CES-D
13. Care Activities	.24*	.32**	-.42**	-.37**	.20*
14a. Communication Problems	.30* ^a	.31* ^a	-.33** ^a	-.39** ^a	.25* ^a
14b. Frustration due to Communication Problems	.15	.22*	-.28**	-.26*	.24*
14c. Role Conflict	.21*	.57**	-.29**	-.47**	.33**
14d. Worry	.21*	.26**	-.32**	-.49**	.34**
14f. Lack of Resources	.02	.43**	-.39**	-.54**	.47**
14g. Economic Burden	.14	.32**	-.36**	-.36**	.27**
14h. Feelings of Being Manipulated	.24*	.38**	-.35**	-.38**	.43**
14i. Increased Tension	.24*	.69**	-.27**	-.54**	.48**
14j. Mismatched Role Expectations	.01 ^b	.18 ^b	-.07 ^b	-.21 ^b	.29* ^b
14k. Global Strain	.19*	.62**	-.27**	-.46**	.44**
Hypotheses supported	7 of 11	10 of 11	10 of 11	10 of 11	11 of 11

Note. SF 36 = Health Survey Scale; CES-D = the Center for Epidemiological Studies Depression Scale;

Shaded areas are hypotheses that were supported.

^a n= 68. ^b n= 77.

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

Table 13

Summary of Item Analysis, Cronbach's Alpha on Rewards of Spiritual Fulfillment and Strain From Feelings of Guilt

Scale or subscale	No. of items	Inter-Item Correlation		Item-Total correlation		Cronbach's Alpha
		Mean	Range	Median	Range	
11f. Rewards of Spiritual Fulfillment	5	.54	.34 to .71	.67	.57 to .75	.82
14l. Strain from Feelings of Guilt	3	.48	.38 to .63	.60	.45 to .64	.74

Table 14

Descriptive Statistics for Scales on Rewards of Spiritual Fulfillment and Strain from Feelings of Guilt

Scales	# of items	# of Resp Options	Potential Range of Scores	Descriptive Statistics					
				Mean	SD	Actual Range of Scores	Skewness (SE) * p < .001	Kurtosis (SE) * p < .001	% Missing
11f. Rewards of Spiritual Fulfillment	5	5 (0-4)	0.00-4.00	2.70	0.87	0.00-4.00	-0.88 (0.27)	0.66 (0.53)	0
14l. Strain from Feelings of Guilt	3	5 (0-4)	0.00-4.00	1.16	0.78	0.00-3.00	0.56 (0.27)	0.22 (0.53)	0

Table 15

Correlations of Rewards of Spiritual Fulfillment and Strain From Feelings of Guilt with Family Care Inventory Scales

Scales and Subscales	Rewards of Spiritual Fulfillment	Direction of Correlation Hypothesized	Feelings of Guilt	Direction of Correlation Hypothesized
Antecedent Factors : Care Receiver				
1. CR ADL Needs	.18	No Hypothesized	-.03	No Hypothesized
2. CR IADL Needs	-.00	No Hypothesized	-.31	No Hypothesized
3. CR Memory Problems	.02	No Hypothesized	-.10	No Hypothesized
4. CR Extent of Communication Problems	-.00	No Hypothesized	.20	No Hypothesized
Antecedent Factors : Caregiver				
5. Health		No Hypothesized		No Hypothesized
a. CG Physical Health: SF 36	.11	No Hypothesized	-.40**	Negative
b. CG Mental Health: SF 36	.03	Positive	-.53**	Negative
6. CG Depressive Symptoms CES-D	-.20*	Negative	.48**	Positive
7. Mutuality	.36**	Positive	-.13	Negative
8. Preparedness for Family Care	.38**	Positive	-.33**	Negative
Family Care				
9. Amount of Care Activities	.06		.14	Negative
Responses to Family Care: Positive Aspects				
10. Predictability	.28**	Positive	-.25**	Negative
a. Rewards of Being There for the Care Receiver	.72**	Positive	-.14	Negative
b. Meaning for Oneself	.67**	Positive	-.18	Negative
c. Learning	.39**	No Hypothesized	.13	No Hypothesized

Table 15 (continued)

Correlations of Rewards of Spiritual Fulfillment and Strain From Feelings of Guilt with Family Care Inventory Scales

Scales and Subscales	Rewards of Spiritual Fulfillment	Direction of Correlation Hypothesized	Feelings of Guilt	Direction of Correlation Hypothesized
d. Financial Rewards	.19*	No Hypothesized	.30**	No Hypothesized
e. Other People	.32**	No Hypothesized	.20*	No Hypothesized
f. Spiritual Fulfillment			-.16	Negative
Responses to family Care: Negative Aspects				
12. Amount of Negative Life style Change	.04	Negative	.27**	Negative
13. Strain from Care Activities	-.23*	Negative	.36**	Positive
14. Caregiver Role Strain from..				
a. Communication Problems	-.20	Negative	.24*	Positive
c. Frustration due to Communication Problems	-.15	Negative	.28**	Positive
c. Role Conflict	.03	Negative	.16	Positive
d. Worry	.10	Negative	.41**	Positive
e. Worry About Safety	.16	Negative	.08	Positive
f. Lack of Resources	-.11	Negative	.40**	Positive
g. Economic Burden	-.20	Negative	.35**	Positive
h. Feelings of Being Manipulated	-.13	Negative	.38**	Positive
i. Increased Tension	-.01	Negative	.42**	Positive
j. Mismatched Role Expectations	.01	Negative	.27*	Positive
k. Global Strain	-.26**	Negative	.42**	Positive

(table continues)

Table 15 (continued)

Correlations of Rewards of Spiritual Fulfillment and Strain From Feelings of Guilt with Family Care Inventory Scales

Scales and Subscales	Rewards of Spiritual Fulfillment	Direction of Correlation Hypothesized	Feelings of Guilt	Direction of Correlation Hypothesized
I. Feelings of Guilt	-.16*	Negative		

Note. CG = caregiver; CR = care receiver; ADL = Activities of Daily Living; IADL Scales = Instrument Activities of Daily Living Scale; SF 36 = Health Survey Scale; CES-D = the Center for Epidemiological Studies Depression Scale.

** $p < .01$. * $p < .05$.

PREP and the Family Care Process

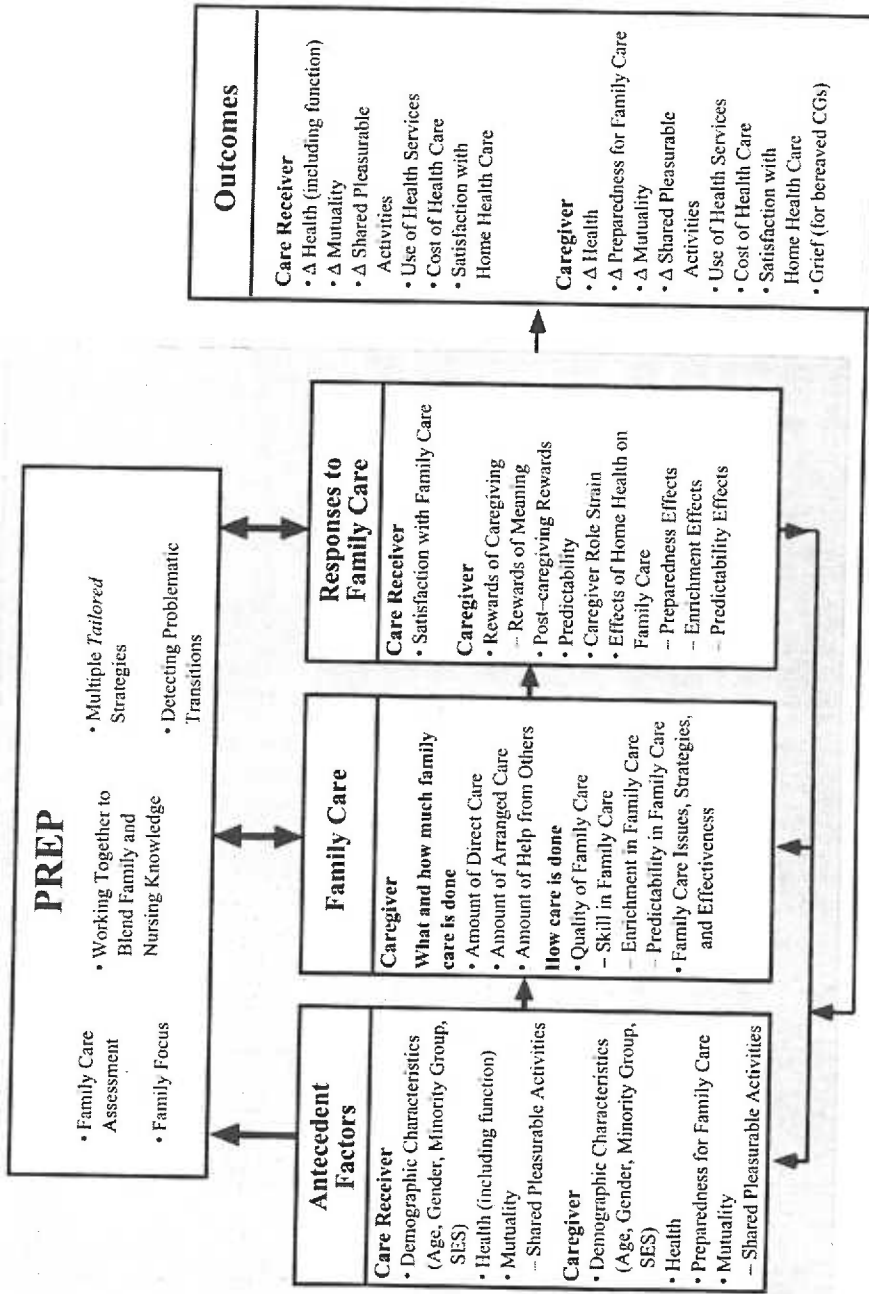


Figure 1. The Family Care Conceptual Framework

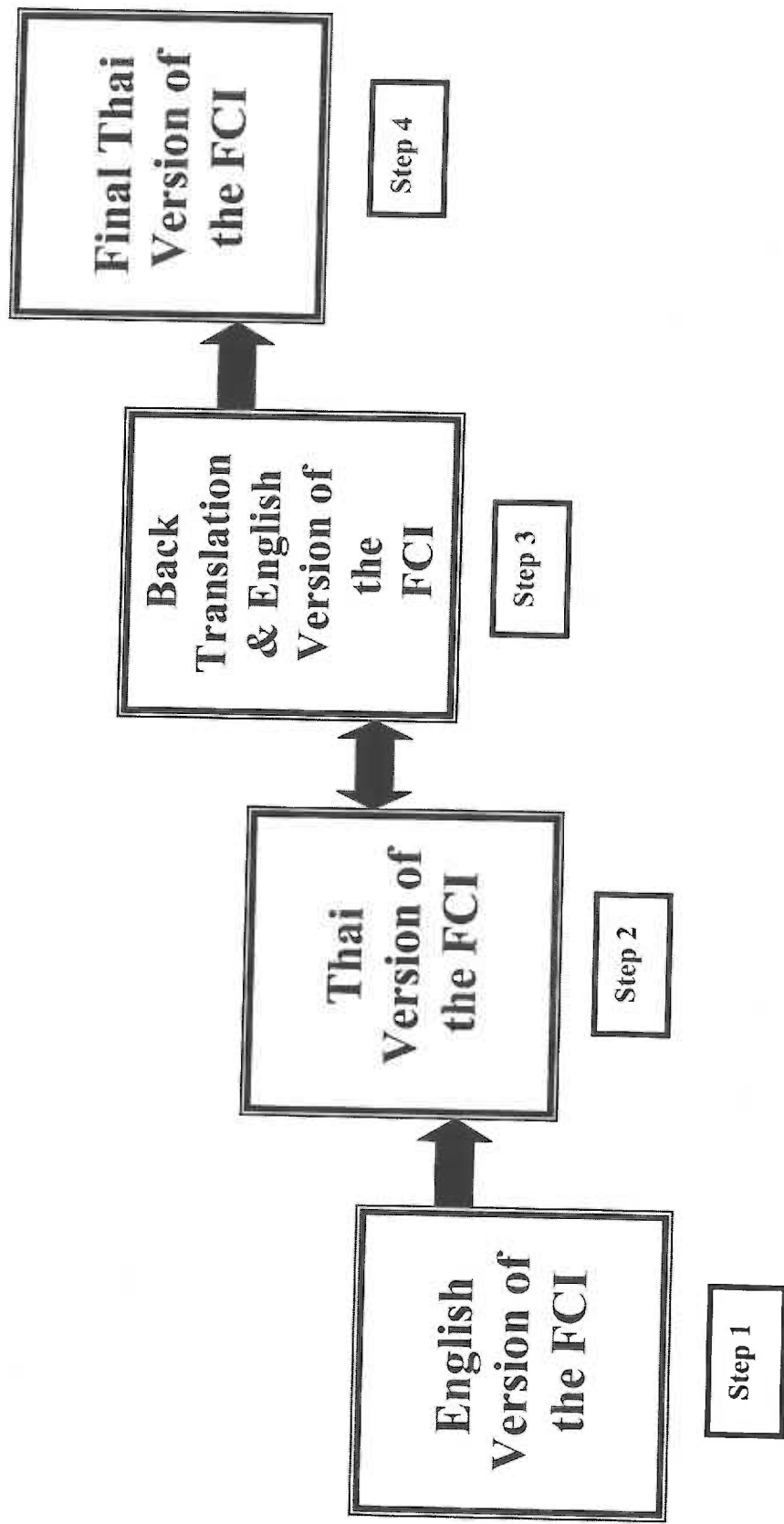


Figure 2. To Ensure the Quality of the Translation

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Appendix A

Summary of the Scales Translated by Each Translator

Summary of the Scales Translated by Each Translator

	Translator A	Translator B	Translator C	Translator D	Translator E
Mutuality	√	√	√	-	-
Preparedness	√	√	√	-	-
Caregiving Activities	√	√	√	-	-
Predictability	√	-	-	√	√
Help form Other People	√	√	√	-	-
Amount of Negative Life Style Change	√	√	√	-	-
Caregiver Role Strain	√	√	√	-	-
Rewards of Caregiving	√	-	-	√	√
SF-36	√	-	-	√	√

Appendix B

The Curriculum Vitae of the Back-Translator

Junnaree Atchaneeyasakun Edwards
 3215 Princess Lane, Dallas, TX 75229-5021
 Tel. (214) 357-6306
 e-mail <lek@wt.net>

EDUCATION:

6/1978 – 10/1981 B.A. in Economics, Thammasart University, Bangkok, Thailand
 9/1984 – 8/1985 Certificate in General Business, University of California,
 Los Angeles, California
 9/1985 – 3/ 1987 M.A. in English with TESL concentration, California State
 University, Dominguez Hill, California

EXPERIENCE:

10/1981 – 9/1984 General Manager, Tasanai Medical Clinic, Bangkok Thailand
 1/1987 – 3/1987 Tutor, Learning Assistance Center, California State University,
 Dominguez Hill, California
 12/1987 – 12/1988 English Teacher at Phanas Nikom Refugee Camp, The
 Consortium, Chonburi, Thailand
 8/1988 – 3/1993 Teaching English to students ages range from 4-20 years old,
 Bangkok, Thailand
 1/1989 – 3/1990 Art Editor for Khunka Children Magazine, Khun 39, Co., Ltd.,
 Bangkok, Thailand
 4/1990 – 12/1991 English Teacher, Siam Language Institute, Bangkok, Thailand
 1/1992 – 3/1993 Manager, Language Department, Siam Language Institute,
 Bangkok, Thailand
 1/1993 – 4/1995 Intensive English Language Program Director, Infinix Idea, Co.,
 Ltd., Bangkok, Thailand
 1/1993 – present Freelance Writer
 1. English Usage & Grammar Book 1:
 First print published in September 1995
 Second print published in November 1996
 Third print published in November 1998
 Fourth print published in September 1999
 2. English Usage & Grammar Book 2:
 First print published in September 1995
 Second print published in November 1996
 Third print published in January 1998

3. 99 Tips for Better English Grammar:
First print published in June 1997
Second print published in July 1999
 4. English Grammar: Practical lessons and exercises:
First print published in August 1997
Second print published in July 1999
 5. English Conversation, in print
- 3/1993 – 6/1995 Translator for Nestle (Thailand) Quarterly Journal, Nestle, Bangkok, Thailand
- 3/1993 – present Translator, Seubnakasathien Foundation, Bangkok, Thailand
- 5/1994 – 5/1996 Committee Member and Interpreter, The Amateur Softball Association of Thailand, Bangkok, Thailand
- 5/1996 – present Translator, The Amateur Softball Association of Thailand, Bangkok, Thailand

REFERENCES: Upon request.

Appendix C

The Approval of Thai and OHSU IRB



ASHLAND • KLAMATH FALLS • LA GRANDE • PORTLAND

OREGON HEALTH SCIENCES UNIVERSITY
 PORTLAND CAMPUS
 3181 S.W. SAM JACKSON PARK
 PORTLAND, OR 97201-31
 503-494-7

February 16, 2001

Faculty of Medicine
 Siriraj Hospital, Mahidol University
 2 Prannok Rd.
 Bangkoknoi, Bangkok 10700
 Thailand

To Whom It May Concern:

As a Professor at the Oregon Health Sciences University (OHSU), I am writing this letter on behalf of Ms. Virapun Wirojratana, who is a Ph.D. student in the School of Nursing at OHSU, Portland, Oregon, U.S.A. I am serving as Ms. Virapun Wirojratana's Ph.D. dissertation advisor.

The purpose of this letter is to request approval for Ms. Virapun Wirojratana's dissertation study from the Ethical Clearance Committee on Human Rights Related to Research Involving Human Subjects at Siriraj Hospital.

The title of Ms. Virapun Wirojratana's dissertation is "**Development of the Thai Family Care Inventory.**" Her dissertation research has already involved the translation and back-translation of the English version of the Family Care Inventory into the Thai language. She is now proposing to evaluate the reliability and validity of the Inventory to evaluate its appropriateness for use with family caregivers in Thailand. This dissertation research on family care for frail elders is very important because of the increasing number of elders in Thailand. It is important to find ways for health care providers to help families who are taking care of frail and ill elders. Following completion of her dissertation, Ms. Virapun Wirojratana will be able to return to Thailand with great strength in research skills that can be used to study health issues in Thailand.

Now, Ms. Virapun Wirojratana is ready to use the Thai version of the Family Care Inventory to collect data for her dissertation from 100 family caregivers for frail elders who live in Thailand. She would like to recruit these 100 family caregivers from the Chronic Illness Outpatient Department in Siriraj Hospital.

We would like for you to review Ms. Virapun Wirojratana's proposed research and give approval for her to recruit family caregivers from Siriraj Hospital. Before she begins her data collection, the Institutional Review Board (IRB) at OHSU would like a formal letter of approval from your Ethical Clearance Committee. Specifically, they would like for your committee to give your opinion about the following issues:

1. Does the study, which proposes to use the Family Care Inventory to examine the experience of caregivers of frail elders in Thailand, focus on a topic that is appropriate and relevant in Thai culture?
2. Does the proposed study follow Thai research regulations?
3. Is the consent form appropriate for Thai culture and represent an accurate translation of the English version submitted with it?

4. Does the Family Care Inventory meet the Thai requirements for human subjects?
5. Has the researcher proposed to handle elder abuse, if detected, using a procedure that is appropriate and follows Thai law?

Ms. Virapun Wirojratana will be submitting to your Ethical Clearance Committee:

1. A brief proposal describing the study aims and method.
2. English and Thai versions of the consent form.
3. English and Thai versions of the Family Care Inventory.
4. A copy of the required application form for the Ethical Clearance Committee.

Thank you very much for considering this request. Please feel free to contact me at 503-494-3835 in the U.S.A. or by email at: stewartb@ohsu.edu.

Sincerely,



Barbara J. Stewart, Ph.D.
Professor, School of Nursing
Oregon Health Sciences University
Portland, Oregon
U.S.A.

๒ ถนนพรานนก บางกอกน้อย กรุงเทพฯ ๑๐๗๐๐
 โทร. ๔๑๑-๑๔๒๘, ๔๑๑-๓๒๕๓
 โทรสาร. ๖๖-๒-๔๑๒-๑๓๗๑



2 PRANNOK Rd., BANGKOKNOI, BANGKOK 10700
 TEL. 411-1429, 411-3253
 FAX : 66-2-412-1371

Faculty of Medicine Siriraj Hospital
 Mahidol University

March 19, 2001

Dear Sir or Madam :

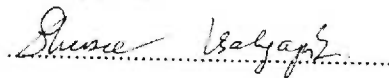
We have reviewed Ms. Wirojratanana's research proposal entitled, "Development of the Thai Family Care Inventory," and have given our approval for her to begin the data collection phase of this research project.

Given Dr. Stewart's letter of February 16, 2001, we have carefully considered the questions concerning the regulatory, legal, cultural, and social appropriateness of the inventory for the Thai culture. We will address each one of her concerns as follows:

1. As we reviewed this proposal, it became very clear that this study is both timely and potentially important. Thai people care deeply for their elderly, yet we do not have enough research into the positive and negative effects of caregiving. This research study will provide such information.
2. Based on our review of this study's design, the data collection plan and analysis, we feel that Ms. Wirojratanana's proposal meets the generally established research requirements and standards used in Thailand.
3. We evaluated the Thai translation of the consent form against the English version and believe that the Thai version accurately captures the intent and meaning of the English document. The consent form employs sensitive and culturally appropriate language and we approve it for use.
4. The Family Care Inventory has been reviewed and we find it satisfactorily meets the Thai review board's requirements for human subjects.
5. While the United States research institutions have strong protocols for issues related to child and elder abuse, Thailand does not, as yet, have established abuse protocols. Given this difference in our cultures, we have evaluated Ms. Wirojratanana's plan of action and should these events arise during the course of her study, we feel her intervention plan is both appropriate and fair.

We appreciated this opportunity to work collaboratively with the Oregon Health Sciences University School of Nursing and the Oregon Health Sciences University Institutional Review Board.

Sincerely yours,



Prof. Shusee Visalyaputra
 Chairman of the Ethical Committee



Prof. Piyasakol Sakolsatayadorn
 Dean, Faculty of Medicine Siriraj Hospital

To: Kathryn Campbell
From: Barbara Stewart
Subject: Re: Initial Approval
CC: Pat Archbold ; Lois Miller; Virapun Wirojratana

Kathrynn,

Thank you so much for your email. Based on this approval, Virapun will begin collecting data for her dissertation.

Barbara J. Stewart, PhD
Professor
Population Based Nursing Dept.
OHSU, Mail Code SN-5S
3181 SW Sam Jackson Park Road
Portland, OR 97201-3098

W: 503-494-3835
email: stewartb@ohsu.edu

>>> Kathryn Campbell - 7/20/01 10:46 AM >>>

This is to inform you that Virapun Wirojratana's study titled,
Development of the Thai Family Care Inventory, has been approved by the Oregon Health & Science University's
Initial Review Board.

Kathrynn Campbell
IRB Analyst
Research Compliance & Assurance
Oregon Health & Science University
Phone: 494-9504
Fax: 494-7787
Mailcode: L106
Email: campbeka@ohsu.edu

Appendix D

The Consent Form (English and Thai)

IRB# 6527
Approved: 07/20/2001

OREGON HEALTH & SCIENCE UNIVERSITY

Consent Form

Title: Development of the Thai Family Care Inventory

Principal Investigator: Virapun Wirojratana, RN, MS,

Doctoral Student, School of Nursing

Oregon Health Sciences University

Phone: 001(662) 2411724 (Bangkok, Thailand)

E-mail: Wirojrat@ohsu.edu

Advisor in the USA: Barbara J. Stewart, Ph.D.

Professor, School of Nursing

Oregon Health Sciences University

Portland, Oregon, U.S.A

Phone: (503) 494-3835

E-mail: stewartb@ohsu.edu

Advisor in Thailand: Saipin Gasemgitvatana, Ph.D.

Associate Professor, Faculty of Nursing

Mahidol University

Bangkok, Thailand

Phone: (662) 411-0264

E-mail: nssgs@mahidol.ac.th

Purpose:

You have been invited to participate in this research study because you are a caregiver of a family member who has a chronic illness. The purpose of this study is to

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develop and test a series of questions to understand caring for chronically ill elderly relatives. Results from this study will be used to develop a better questionnaire to be used in future studies.

Procedures:

If you agree to participate in this study, you will be interviewed at your home. The interview needs to be conducted in private. If you are comfortable having the interview audiotaped and agree to this, the interview will be audiotaped so that the researcher will not miss any of your comments. The interview will take approximately 2 hours.

Risk and Discomforts:

It is possible that some of the questions could make you feel mildly anxious or uncomfortable. There are no other anticipated risks of participating in this study.

Benefits:

You may or may not personally benefit from participating in this study. However, your participation in this study will provide knowledge and understanding of the experience of Thai family caregivers. Your responses will contribute to the development and modification of the instrument. This instrument can then be used in future research and may benefit Thai family caregivers in the future.

Alternative:

You may choose not to participate in this study.

Confidentiality:

The information that you give is confidential. Neither your name nor your identity will be used for publication or publicity purposes. The questionnaires will have a code number that can be linked to you. However, only the principal investigator, Virapun

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Wirojratana, will have access to your name and to the list that links your name and number. The questionnaires will be kept in a locked cabinet. The audio-tapes will be erased after the transcription is complete.

In the event that the researcher observes physical abuse or need of an elder for health care services such as referral to in-service care, the researcher is required by her school's (Oregon Health & Science University) policies to report this to the social worker at Siriraj hospital.

Costs:

There are no financial costs to you for participating in the study.

Liability:

It is not the policy of the U.S. Department of Health and Human Services, or any federal agency funding the research project in which you are participating to compensate or provide medical treatment for human subjects in the event the research results in physical injury.

The Oregon Health & Science University is subject to the Oregon Tort Claims Act (ORS 30.260 through 30.300). If you suffer any injury and damage from this research project through the fault of the University, its officers or employees, you have the right to bring legal action against the University to recover the damage done to you subject to the limitations and conditions of the Oregon Tort Claims Act. You have not waived your legal right by signing this form. For clarification on this subject, or if you have further questions, please call the OHSU Research Support Office at 503-494-7887.

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Approved: 07/20/2001

Participation:

Participation in this study is completely voluntary. You may refuse to participate or may withdraw from this study at any time without penalty or loss of benefits. If you have any questions regarding your rights as a research participant or questions about this research, you may contact, the principal investigator, Virapun Wirojratana at (02) 2221414. The investigator has offered to answer any questions that you may have.

I have read the above statement and have been able to ask questions and express concerns, which have been satisfactorily responded to by the investigator. I understand the purpose of the study as well as the potential benefits and risks that are involved. I hereby give my informed and free consent to be a participant in this study. I have been given a copy of this consent form.

Your signature below indicates that you have read the foregoing and agree to participate in this study.

1. I agree to complete the questionnaire and be interviewed by the researcher.

No Yes

2. I agree to have my interview audiotaped

No Yes

Caregiver's signature

Date

Person obtaining caregiver's signature

Date

IRB# 6527
Approved: 07/20/2001

มหาวิทยาลัย โอเรกอน
แบบยินยอมเข้าร่วมการศึกษา

ชื่อโครงการวิจัย: การพัฒนาแบบสอบถามการดูแลครอบครัวที่บ้าน

ชื่อหัวหน้าโครงการวิจัย: น.ส. วิราพรรณ วิโรจน์รัตน์

นักศึกษาระดับปริญญาเอก, คณะพยาบาลศาสตร์
มหาวิทยาลัย โอเรกอน, พอร์ตแลนด์, โอเรกอน, ประเทศสหรัฐอเมริกา
โทร. 2411724 อีเมล : wirojrat@ohsu.edu

ผู้ควบคุมวิทยานิพนธ์ในประเทศสหรัฐอเมริกา:

ดร. บาบารา สจวต
ศาสตราจารย์ ประจำคณะพยาบาลศาสตร์
มหาวิทยาลัยพอร์ตแลนด์, โอเรกอน, ประเทศสหรัฐอเมริกา
โทร. (503) 494-3835 อีเมล : stewartb@ohsu.edu

ผู้ควบคุมวิทยานิพนธ์ในประเทศไทย:

ดร. สายพิน เกษมกิจวัฒนา
รองศาสตราจารย์, คณะพยาบาลศาสตร์
มหาวิทยาลัยมหิดล, บางกอกน้อย, กรุงเทพฯ 10700
โทร. (02) 4197466-80 ต่อ 1216 อีเมล : nssgs@mahidol.ac.th

วัตถุประสงค์:

ท่านได้รับเชิญเข้าร่วมการศึกษาคั้งนี้เพราะท่านเป็นผู้ดูแลสมาชิกในครอบครัวที่เจ็บป่วยเป็นโรคเรื้อรังการวิจัยคั้งนี้มีวัตถุประสงค์เพื่อที่จะพัฒนาและทดสอบแบบสอบถามให้เข้าใจถึงกระบวนการ การดูแลผู้สูงอายุที่เจ็บป่วยเป็นโรคเรื้อรัง ผลจากการศึกษาคั้งนี้จะนำไปสู่การพัฒนาและปรับปรุงแบบสอบถามเพื่อที่จะใช้ในการศึกษาต่อไปในอนาคต
ขั้นตอนวิธีวิจัย:

หากท่านตกลงที่จะเข้าร่วมการศึกษานี้ ผู้วิจัยจะไปสัมภาษณ์ท่านที่บ้านระหว่างสัมภาษณ์ผู้วิจัยจะขออนุญาตอัดเทป ถ้าท่านไม่ขัดข้องผู้วิจัยจะอัดเทปเพื่อความแน่ใจว่าผู้วิจัยไม่ตกหล่นความคิดเห็นของท่าน การสัมภาษณ์คั้งนี้จะใช้เวลาประมาณ 2 ชั่วโมง

ความเสี่ยงและความไม่สะดวก:

ผู้ดูแลผู้สูงอายุไม่มีความเสี่ยงใดๆจากการเข้าร่วมการศึกษาคั้งนี้ แต่ บางข้อคำถามอาจทำให้ผู้ดูแลผู้สูงอายุมีความกังวลหรืออึดอัดใจเล็กน้อย นอกเหนือจากนี้แล้วผู้ดูแลผู้สูงอายุจะไม่มี

IRB# 6527
Approved: 07/20/2001

ความเสี่ยงอื่นได้อีก

ประโยชน์ที่จะได้รับ:

ท่านเข้าร่วมในโครงการวิจัยครั้งนี้อาจจะไม่ได้รับประโยชน์เป็นการส่วนตัว แต่อย่างไรก็ตามที่ข้อมูลที่ได้จากผู้ดูแลผู้สูงอายุนี้จะให้ความรู้และเข้าใจเกี่ยวกับการดูแลผู้สูงอายุที่บ้านซึ่งสามารถนำมาพัฒนาและปรับปรุงแบบสอบถามเพื่อให้เกิดประโยชน์ต่อผู้ดูแลผู้สูงอายุต่อไปในอนาคต

ทางเลือกของผู้ร่วมการศึกษา:

ท่านอาจจะเลือกไม่ เข้าร่วมในโครงการวิจัยนี้

ความลับส่วนบุคคล:

ข้อมูลที่ท่านให้สัมภาษณ์จะเก็บไว้เป็นความลับ ชื่อ นามสกุล และข้อมูลส่วนตัวจะไม่มี การเปิดเผยไม่ว่าโดยการพิมพ์เผยแพร่หรือเปิดเผยต่อสาธารณชน แบบสอบถามที่ท่านตอบนั้น ผู้วิจัยจะใส่รหัสเป็นตัวเลขซึ่งสามารถเชื่อมโยงถึงตัวท่าน แต่อย่างไรก็ตามผู้วิจัย, วิชาพรณ วิโรจน์รัตน์, เพียงผู้เดียวที่จะสามารถเชื่อมโยงรหัสเป็นตัวเลขถึง ชื่อ นามสกุล และข้อมูล ส่วนตัวของท่านแบบสอบถามที่ท่านตอบนั้นผู้วิจัยจะจัดเก็บใส่ตู้และใส่กุญแจ หลังจากผู้วิจัย เสร็จสิ้นการถอดเทป เทปบันทึกเหล่านั้นจะถูกลบทิ้ง

ในกรณีที่หากผู้วิจัยพบกรณีผู้สูงอายุเจ็บป่วยต้องส่งต่อเพื่อการรักษาพยาบาล, การทำธุรกรรม หรือปัญหาถูกละเลยซึ่งอาจเกิดขึ้นตรงต่อผู้สูงอายุ ผู้วิจัยจะทำการส่งต่อนักสังคมสงเคราะห์ของโรงพยาบาลศิริราช จากนั้นนักสังคมสงเคราะห์ จะทำการดำเนินการให้ถูกต้องและเหมาะสมตามสถานะการณ่นั้นต่อไป

ค่าใช้จ่ายในการร่วมวิจัย:

ท่านไม่ต้องเสียค่าใช้จ่ายใดๆ

ผู้รับผิดชอบ:

กระทรวงสาธารณสุขหรือสถาบันที่สนับสนุนโครงการวิจัยของประเทศสหรัฐอเมริกาไม่มีนโยบาย ตอบแทนค่าเสียหายหรือให้การรักษาในกรณีที่ท่านได้รับบาดเจ็บทางร่างกาย การทำวิจัยครั้งนี้ขึ้นอยู่กับความรับผิดชอบของ มหาวิทยาลัยโอเรกอนตามกฎหมายของรัฐ โอเรกอน (ORS30.260 through 30.300) หากท่านได้รับความเสียหายหรือเจ็บป่วยจากการเข้าร่วมงานวิจัยครั้งนี้ ท่านสามารถเรียกร้องค่าเสียหายที่เกิดขึ้นได้ ถ้าท่านมีข้อสงสัย กรุณาสอบถาม ที่หน่วยบริการทางการค้นคว้าวิจัยของมหาวิทยาลัยโอเรกอน (The OHSU Research Support Office) ที่หมายเลขโทรศัพท์ 001-503-494-7887

IRB# 6527
Approved: 07/20/2001

การเข้าร่วมวิจัย:

การเข้าร่วมวิจัยครั้งนี้ถือว่าเป็นความสมัครใจของท่าน ท่านสามารถปฏิเสธต่อการเข้าร่วมวิจัย หรือหยุดในระหว่างการทำวิจัยโดยจะไม่มีผลเสียหายใดๆต่อท่าน ถ้าท่านมีคำถามเกี่ยวกับสิทธิของท่านในการเข้าร่วมวิจัย หรือคำถามเกี่ยวกับการวิจัย ท่านสามารถติดต่อผู้วิจัย, วิชาพรณ วิโรจน์รัตน์, หมายเลขโทรศัพท์ (02) 2221414 ผู้วิจัยยินดีจะตอบคำถามของท่านทุกคำถาม

ข้าพเจ้าได้อ่านข้อความข้างต้นและถามคำถามที่สงสัย ข้าพเจ้าได้รับคำตอบที่พึงพอใจจากผู้วิจัย ข้าพเจ้าเข้าใจ วัตถุประสงค์, ประโยชน์ที่จะได้รับ และความเสี่ยงที่จะได้รับ ข้าพเจ้ายินดีที่จะเข้าร่วมการวิจัยครั้งนี้ ข้าพเจ้าได้รับสำเนาของแบบยินยอมเข้าร่วมการศึกษานี้

ลายเซ็นของท่านที่ปรากฏข้างล่างนี้บ่งบอกให้ทราบว่าท่านได้อ่านข้อความข้างบนและยินดีที่จะเข้าร่วมการวิจัยครั้งนี้

1. ข้าพเจ้ายินดีที่จะตอบแบบสอบถามและให้สัมภาษณ์

ไม่ใช่ ใช่

2. ข้าพเจ้ายินดีที่จะให้บันทึกเทปในการสัมภาษณ์

ไม่ใช่ ใช่

ลายเซ็นของผู้ดูแล

วัน เดือน ปี

พยาน

วัน เดือน ปี

Appendix E

The Family Care Inventory (English and Thai)

Family Care Inventory

The Caregiver's View

ID#					
<table border="1"><tr><td> </td><td> </td><td> </td><td> </td><td> </td></tr></table>					
Date of Interview: _____					
Time interview started: _____					
Time interview ended: _____					
Name of Interviewer: _____					

DATE AND TIME YOU BEGIN QUESTIONNAIRE _____ DATE _____ TIME _____

YOU AND YOUR FAMILY MEMBER

The elder refers to your relative or friend who has health or memory problems. Please tell us about you and the elder. For all questions, fill in the blank or **CIRCLE** the answer that best describes you and the elder.

1. How are you related to the elder you are helping?

Are you his or her _____?

- Wife 1
- Husband 2
- Daughter 3
- Son 4
- Daughter-in-law 5
- Son-in-law 6
- Other relative 7
- Neighbor or friend 8
- Other: _____

2. About how many years have you and the elder known each other?

_____ years _____ months

3. How many years, if any, have you lived with the elder while you were an adult (age 18 or over)?

_____ years _____ months

4. At this time, do you and the elder live in the same household?

Yes 1

No 0



4a. If **NO**, how far away do you live from the elder?

_____ kilometer

Because of health or memory problems, does the elder **NEED** help with any of the following activities? (**CIRCLE** the number next to **ALL** that apply.)

- 5. Bathing or showering?
- 6. Dressing?
- 7. Eating?
- 8. Getting in and out of bed or chairs?
- 9. Walking?
- 10. Getting around outside?
- 11. Using the toilet, including getting to the toilet?
- 12. Preparing meals?
- 13. Shopping for personal items (such as toilet items or medicines)?
- 14. Managing money (such as keeping track of expenses or paying bills)?
- 15. Using the telephone?
- 16. Doing light housework (like doing dishes, straightening up, or light cleaning)?
- 17. Doing heavy housework (like scrubbing floors or washing windows)?
- 18. Taking medication?
- 19. Driving or taking a bus or taxi to where the elder needs to go?
- 20. Others: _____
- 21. None of the above

YOUR FAMILY MEMBER

Please tell us about the elder. (Fill in the blank or **CIRCLE** the answer that describes the elder.)

1. How old is the elder?

Age: ____ years

Date of birth ____/____/____
mm dd yy

2. Is the elder female or male?

Female 1

Male 2

3. What is the highest grade in school that the elder completed?

No formal education 1

Completed grade school 2

Completed junior high school 3

Completed high school 4

Completed associate degree 5

Attended college 6

Completed college 7

Graduate professional training 8

Other _____ 9

4. What kind of work has the elder done most of his or her working life?

5. What is the elder's current marital status?

Married 1

Widowed 2

Divorced 3

Separated 4

Never married 5

Partnered 6

6. With whom does the elder usually live? (Circle **ALL** that apply.)

No one, lives alone 0

With spouse or partner 1

With child(ren) 2

With other relative(s) 3

With friend(s) that are "just like a family" 4

With other friend(s), housemate(s) 5

In a nursing home or care facility 6

Paid live-in helper 7

7. Altogether, counting the elder, how many people live in your family member's household?

_____ people

8. Who manages the money in the elder's household? (For example, managing health care expenses)

THE ELDER

(Fill in the blank or **CIRCLE** the answer that describes the elder.)

9. Is the elder Thai?

No 0

Yes 1

If not, what race is the elder?

10. Which part of Thailand are you and the elder from?

Bangkok 1

Central 2

North 3

Northeast 4

South 5

East 5

THE ELDER'S CURRENT SITUATION

We'd like to ask you some questions about the elder's memory and the difficulty the elder may have doing some things. (**CIRCLE** your answer.)

How difficult is it for the elder to:	Not At All Difficult	Just A Little Difficult	Fairly Difficult	Very Difficult	Can't Do At All
1. Remember recent events?	0	1	2	3	4
2. Know what day of the week it is?	0	1	2	3	4
3. Remember his or her home address?	0	1	2	3	4
4. Remember words?	0	1	2	3	4
5. Understand simple instructions?	0	1	2	3	4

CAREGIVING ACTIVITIES

This set of questions is very long. However, your answers are very important to us because we want to have a really good idea about what you are now doing to take care of the elder. Sometimes helping someone is no problem, but for a number of people, giving this help is very difficult to do, both physically and emotionally.

Below is a list of types of help that may be given to a person who has health or memory problems. We would like for you to tell us whether you do each type of help and, if so, how it goes for you.

For each question, Circle **(NO)** if you do NOT do that type of help or if the elder doesn't have that problem. Circle **(YES)** if you do that type of help. If you circled **YES**, indicate how hard it is for you to do that type of help.

Please circle **Very Hard 4**, **Pretty Hard 3**, **Somewhat Hard 2**, **Not Too Hard 1** or **Easy 0**.

Do you do this type of help for the elder?	If YES, how hard is it for you to do this.						
	NO	YES	Very Hard	Pretty Hard	Somewhat Hard	Not Too Hard	Easy
1. Do you do shopping and errands for the elder?	NO	YES	4	3	2	1	0
2. Do you have to assist the elder with walking around the house? For example, do you have to give the elder your arm or get your elder a walker?	NO	YES	4	3	2	1	0
3. Do you have to assist the elder with getting around outside the house?	NO	YES	4	3	2	1	0
4. Do you have to keep one eye on the elder to make sure he or she is safe?	NO	YES	4	3	2	1	0
5. Do you assist the elder with his or her medications or shots?	NO	YES	4	3	2	1	0
6. Do you have to help the elder with eating?	NO	YES	4	3	2	1	0
7. Do you protect the elder from falls?	NO	YES	4	3	2	1	0
8. Do you help make major decisions about the elder's health care -- such as surgery or a change in treatment?	NO	YES	4	3	2	1	0

CAREGIVING ACTIVITIES (cont.)

If YES, how hard is it for you to do this.

Do you do this type of help for the elder?	NO	YES	If YES, how hard is it for you to do this.				
			Very Hard	Pretty Hard	Some-what Hard	Not Too Hard	Easy
9. Do you try to keep the elder active and involved in activities that he or her enjoys?	NO	YES	4	3	2	1	0
10. Do you keep the doctor informed about changes in the elder's health?	NO	YES	4	3	2	1	0
11. Do you keep nurses and other health care workers informed about changes in the elder's health?	NO	YES	4	3	2	1	0
12. Do you lift or transfer the elder from one place to another? For example, do you lift the elder out of a chair, or transfer him or her from a bed to a chair? ...	NO	YES	4	3	2	1	0
13. Do you have to go with the elder as he or she does shopping or errands?	NO	YES	4	3	2	1	0
14. Do you have to make sure the elder gets the right amount of liquids? (Circle NO if the elder can do that on his or her own.)	NO	YES	4	3	2	1	0
15. Do you assist the elder with bathing, washing, or taking a shower?	NO	YES	4	3	2	1	0
16. Do you do any of the driving for the elder?	NO	YES	4	3	2	1	0
17. Do you have to handle the elder's paranoia or suspiciousness? (Circle NO if the elder does not have that problem.)	NO	YES	4	3	2	1	0
18. Do you take part in leisure activities with the elder, such as watching TV, playing games, or listening to music?	NO	YES	4	3	2	1	0
19. Do you have to handle the elder crying spells? (Circle NO if the elder does not have that problem.)	NO	YES	4	3	2	1	0
20. Do you have to make sure the elder eats the right amount or types of food? (Circle NO if the elder can do that on his or her own.)	NO	YES	4	3	2	1	0
21. Do you have to clean up if the elder has a bladder accident?	NO	YES	4	3	2	1	0

CAREGIVING ACTIVITIES (cont.)

If YES, how hard is it for you to do this.

Do you do this type of help for the elder?

NO YES Very Hard Pretty Hard Some-what Hard Not Too Hard Easy

22. Do you do writing for the elder? (Circle NO if your elder can do that on his or her own.)	NO	YES	4	3	2	1	0
23. Do you have to handle the elder's yelling? (Circle NO if the elder does not have this problem.)	NO	YES	4	3	2	1	0
24. Do you have discussions with the elder about the future, the meaning and purpose of life, or how the elder has lived his or her life?	NO	YES	4	3	2	1	0
25. Do you cook or help prepare meals for the elder?	NO	YES	4	3	2	1	0
26. Do you apply lotions to the elder's skin?	NO	YES	4	3	2	1	0
27. Do you have to listen to, and answer, questions that the elder asks over and over again?	NO	YES	4	3	2	1	0
28. Do you have to help the elder on stairs?	NO	YES	4	3	2	1	0
29. Do you take care of the elder's dentures or brush his or her teeth?	NO	YES	4	3	2	1	0
30. Do you handle or manage medical equipment or machines, such as oxygen, a feeding tube, IV equipment, or catheters?	NO	YES	4	3	2	1	0
31. Do you the elder get legal matters taken care of?	NO	YES	4	3	2	1	0
32. Do you have to deal with the elder's problems with fatigue?	NO	YES	4	3	2	1	0
33. Do you have to watch the elder in case he or she wanders off?	NO	YES	4	3	2	1	0
34. Do you assist the elder with dressing or undressing?	NO	YES	4	3	2	1	0
35. Do you keep other family members informed about the elder's health?	NO	YES	4	3	2	1	0
36. Do you sit and spend time with the elder?	NO	YES	4	3	2	1	0

CAREGIVING ACTIVITIES (cont.)

If YES, how hard is it for you to do this.

Do you do this type of help for your elder?

NO YES Very Hard Pretty Hard Some-what Hard Not Too Hard Easy

37. Do you have to get up at night to help the elder?	NO	YES	4	3	2	1	0
38. Do you have to help the elder with emotional ups and downs?	NO	YES	4	3	2	1	0
39. Do you assist the elder with banking or paying bills?	NO	YES	4	3	2	1	0
40. Do you have to deal with the elder unsafe driving? (Circle NO if the elder does not have that problem.)	NO	YES	4	3	2	1	0
41. Do you have to handle situations when the elder doesn't remember who or where he or she is?	NO	YES	4	3	2	1	0
42. Do you have to check on or treat skin problems that the elder has?	NO	YES	4	3	2	1	0
43. Do you check in on the elder to make sure your elder is OK?	NO	YES	4	3	2	1	0
44. Do you have to handle the elder's hallucinations? (Circle NO if the elder does not have this problem.)	NO	YES	4	3	2	1	0
45. Do you take the elder to see the doctor?	NO	YES	4	3	2	1	0
46. Do you have to protect the elder from being poisoned such as taking too much medication or being exposed to poisons used in the house?	NO	YES	4	3	2	1	0
47. Do you take the elder out such as to the temple, relatives' or friends' homes or eating out?	NO	YES	4	3	2	1	0
48. Do you have to clean up when the elder has a bowel accident?	NO	YES	4	3	2	1	0
49. Do you have to help the elder with bowel problems like constipation or diarrhea?	NO	YES	4	3	2	1	0
50. Do you have to manage the elder's nausea?	NO	YES	4	3	2	1	0
51. Do you fix things and do odd jobs to maintain the elder's house?	NO	YES	4	3	2	1	0

CAREGIVING ACTIVITIES (cont.)

If YES, how hard is it for you to do this.

Do you do this type of help for the elder?

NO YES Very Hard Pretty Hard Some-what Hard Not Too Hard Easy

52.	Do you have to help the elder in getting to the bathroom?	NO	YES	4	3	2	1	0
53.	Do you change the elder's bed linens?	NO	YES	4	3	2	1	0
54.	Do you have to watch out for and treat the elder's infections?	NO	YES	4	3	2	1	0
55.	Do you help the elder use the toilet or bedpan?	NO	YES	4	3	2	1	0
56.	Do you have to deal with the elder because of problems related to keys and locks for doors?	NO	YES	4	3	2	1	0
57.	Do you assist the elder in filling out legal or health forms?	NO	YES	4	3	2	1	0
58.	Do you have to make sure the elder gets enough rest?	NO	YES	4	3	2	1	0
59.	Do you do things for the elder like hold hands or rub his or her back?	NO	YES	4	3	2	1	0
60.	Do you have to help with the elder breathing problems?	NO	YES	4	3	2	1	0
61.	Do you help the elder make major financial decisions?	NO	YES	4	3	2	1	0
62.	Do you have to help the elder with tasks that require fine motor control such as to cut, to button, or to open jars?	NO	YES	4	3	2	1	0
63.	Do you have to handle the elder's physical pain?	NO	YES	4	3	2	1	0
64.	Do you have to handle the elder's hitting or pushing people? (Circle NO if the elder does not have that problem.)	NO	YES	4	3	2	1	0
65.	Do you do light housekeeping for the elder?	NO	YES	4	3	2	1	0
66.	Do you have to watch out for problems that the elder has with swelling?	NO	YES	4	3	2	1	0

CAREGIVING ACTIVITIES (cont.)

→ If YES, how hard is it for you to do this.

Do you do this type of help for the elder?

NO YES Very Hard Pretty Hard Some-what Hard Not Too Hard Easy

67. Do you assist the elder with hair care or shampooing?	NO	YES	4	3	2	1	0
68. Do you help the elder to get going in an activity?	NO	YES	4	3	2	1	0
69. Do you help the elder use the phone?	NO	YES	4	3	2	1	0
70. Do you have to handle the elder's hiding things and forgetting where he or she put them?	NO	YES	4	3	2	1	0
71. Do you have to deal with the elder's agitation or restlessness? (Circle NO if the elder does not have that problem.)	NO	YES	4	3	2	1	0
72. Do you have to deal with the elder's showing sexual behavior in appropriately?	NO	YES	4	3	2	1	0
73. Do you read to the elder?	NO	YES	4	3	2	1	0
74. Do you have to monitor the number of people who come to see the elder?	NO	YES	4	3	2	1	0
75. Do you have to handle emergencies related to the elder's illness?	NO	YES	4	3	2	1	0
76. Do you help trim and take care of the elder's fingernails or toenails?	NO	YES	4	3	2	1	0
77. Do you set up place for praying, or watch religions programmes on T.V, or radio, or read religious books to the elder?	NO	YES	4	3	2	1	0
78. Do you have to handle the elder's swearing or foul language? (Circle NO if the elder does not have that problem.)	NO	YES	4	3	2	1	0
79. Do you have to help the elder because of problems with his or her eyesight?	NO	YES	4	3	2	1	0
80. Do you have to help the elder because of his or her slowness in moving?	NO	YES	4	3	2	1	0

CAREGIVING ACTIVITIES (cont.)

→ If YES, how hard is it for you to do that.

Do you do this type of help for the elder?

NO YES Very Hard Pretty Hard Some-what Hard Not Too Hard Easy

81. Do you Thom Boon for the elder? (For example, prepare food or a gift for the elder give to monks, arrange for monks/ a priest/ a mullah to visit)	NO	YES	4	3	2	1	0
82. Have you modified the household environment for the elder? (For example, setting up a specific area for the elder, installing hand rails or modifying the bath room).....	NO	YES	4	3	2	1	0
83. Do you assist the elder in using public transportation such as taxi, tuk-tuk or bus?.....	NO	YES	4	3	2	1	0

CAREGIVING ACTIVITIES (cont.)

Do you do this type of help for the elder?

→ If YES, how hard is it for you to do that.

NO YES Very Hard Pretty Hard Some-what Hard Not Too Hard Easy

Sometimes people who take care of the elder get extra help from a health or social service agency.

84. Have you helped the elder by getting information from a doctor or other health care staff?	NO	YES	4	3	2	1	0
85. Have you contacted a hospital, a health care center, or a private health service agency to find out if they had a service that might assist in caring for the elder?.....	NO	YES	4	3	2	1	0
86. Have you ever arranged for someone from a hospital, a health care center, or private health service agency to take care the elder?.....	NO	YES	4	3	2	1	0
87. Have you had to make sure whether people from a hospital, health care center, or private health service agency has continued to take care of the elder?	NO	YES	4	3	2	1	0
88. Have you had to check and make sure people from those agencies take care of the elder with skill?	NO	YES	4	3	2	1	0
89. Have you tried to get help for the elder but were not able to find anybody?	NO	YES	4	3	2	1	0
90. Have you ever sought an alternative method of treatment such as using Chinese medicine, herbs, massage, or holy water in order to alleviate the elder's health problems?	NO	YES	4	3	2	1	0
91. Do you help the elder in other ways? Please explain							
a) _____?	NO	YES	4	3	2	1	0
b) _____?	NO	YES	4	3	2	1	0
c) _____?	NO	YES	4	3	2	1	0

EXTENT OF HELP

1. Altogether, how long has the elder needed extra help from you or someone else because of health or memory problems?

_____ years _____ months _____ days

2. How long have you **personally** been involved in providing the needed extra help to the elder because of his or her health or memory problems?

_____ years _____ months _____ days

3. How many days in the past week did you spend time helping the elder? _____ days

4. On the days you help the elder, about how many hours per day (including time you get up at night) do you spend in helping him or her? _____ hours

MEDICAL DIAGNOSES

What main medical diagnoses has the elder received? (Please **CIRCLE** all that apply.)

Diagnosis	<u>NO</u>	<u>YES</u>
1. Heart Disease (e.g., congestive heart failure)	0	1
2. Cancer	0	1
3. Stroke	0	1
4. Alzheimer's Disease or other dementia	0	1
5. Parkinson's Disease or other movement disorder	0	1
6. Arthritis	0	1
7. Diabetes	0	1
8. Other: _____	0	1

HELP FROM OTHERS IN CARING FOR THE ELDER

On pages 4 through 10, researcher asked you questions about the kinds of things you do to help the elder. Now we would like to know if other people have helped out in these activities.

HELP FROM RELATIVES

1. How much help have relatives given to the elder?
 - None at all 0 **(Go to Q. 4)**
 - A little 1
 - Some 2
 - Quite a bit 3
 - A great deal 4

2. About how many relatives have helped out?
 _____ *(Number of relatives)*

3. How satisfied are you with the help given by relatives?
 - Very satisfied 4
 - Quite satisfied 3
 - Somewhat satisfied, Somewhat dissatisfied 2
 - Quite unsatisfied 1
 - Very unsatisfied 0

HELP FROM PEOPLE WHOSE JOB IT IS

7. How much help do you have from health care staff such as doctors, nurses, nurse assistant, or some one you hire to take care of the elder?
 - None at all 0 **(Go to Q. 10)**
 - A little 1
 - Some 2
 - Quite a bit 3
 - A great deal 4

8. About how many paid people have helped out?
 _____ *(Number of people)*

9. How happy are you with the help given by paid people?
 - Very satisfied 4
 - Quite satisfied 3
 - Somewhat satisfied, Somewhat dissatisfied 2
 - Quite unsatisfied 1
 - Very unsatisfied 0

HELP FROM FRIENDS AND NEIGHBORS

4. How much help have friends and neighbors given to the elder?
 - None at all 0 **(Go to Q. 7)**
 - A little 1
 - Some 2
 - Quite a bit 3
 - A great deal 4

5. About how many friends and neighbors have helped out? _____ *(Number of friends and neighbors)*

6. How satisfied are you with the help given by friends and neighbors?
 - Very satisfied 4
 - Quite satisfied 3
 - Somewhat satisfied, Somewhat dissatisfied 2
 - Quite unsatisfied 1
 - Very unsatisfied 0

HELP NOT RECEIVED

10. Is there anybody who you think should help you more to take care of the elder, but has **not** helped?
 - No 0
 - Yes 1

- 10a. If **YES**, how upsetting has it been for you that this person has **not** helped as you expected?
 - Not at all upsetting 0
 - A little upsetting 1
 - Somewhat upsetting 2
 - Quite upsetting 3
 - Extremely upsetting 4

AREAS OF CONCERN

Researcher would like to know how much you worry about each of the items listed below.

How much do you worry about . . .	Not at all	A little	Some	Quite a bit	A great deal
1. the elder's health condition?.....0	1	2	3	4	5
2. obtaining enough help for the things you can't do for the elder?0	1	2	3	4	5
3. the elder's mood or state of mind?0	1	2	3	4	5
4. financial problems related to the elder's care? .0	1	2	3	4	5
5. your ability to continue taking care of the elder because of your own health?0	1	2	3	4	5
6. safety when the elder uses the stove?.....0	1	2	3	4	5
7. how you can go on if the elder gets worse?0	1	2	3	4	5
8. having to leave the elder alone when you go out? (If you never leave the elder alone, if you had to go out and leave the elder alone, how much would you worry?)0	1	2	3	4	5
9. the elder's vulnerability to cars, motorcycles, tuktuks, tricycles, or bicycles when he or she goes outside?.....0	1	2	3	4	5
10. your own future?0	1	2	3	4	5
11. who will take care of the elder if something happens to you?0	1	2	3	4	5
12. safety because guns or other weapons are present in the home?0	1	2	3	4	5
13. whether the care and advice you receive from doctors and nurses are adequate?0	1	2	3	4	5
14. safety when the elder uses sharp tools such as knife or use electrical equipments?0	1	2	3	4	5
15. the negative effects of taking care of the elder on the rest of your family?.....0	1	2	3	4	5
16. the progression of his or her disease?.....0	1	2	3	4	5

AREAS OF CONCERN

We would like to know how much you worry about each of the items listed below.

How much do you worry about ...	Not at all	A little	Some	Quite a bit	A great deal
17. Are there any other things you worry about?					
_____ 0	1	2	3	4	
_____ 0	1	2	3	4	

HEARING, SPEECH, AND MEMORY PROBLEMS

The next questions focus on communication between you and the elder. People sometimes have hearing, speech, or memory problems that can interfere with how well they can understand or talk with others.

1. To what extent does the elder have difficulty hearing?

- Not at all 0 (Go on to Q. 2) . .
 A little 1
 Some 2
 Quite a bit 3
 A great deal 4

} **Answer Q. 1a**

3. To what extent does the elder have difficulty with remembering or understanding what is said?

- Not at all 0 (Go on to Q. 4)
 A little 1
 Some 2
 Quite a bit 3
 A great deal 4

} **Answer Q. 3a**

1a. To what extent does the elder's hearing problem make it hard for you to provide care to him or her?

- Not at all 0
 A little 1
 Some 2
 Quite a bit 3
 A great deal 4

3a. To what extent does the elder's problem with remembering or understanding what is said make it hard for you to provide care to him or her?

- Not at all 0
 A little 1
 Some 2
 Quite a bit 3
 A great deal 4

2. To what extent does the elder have difficulty with speech?

- Not at all 0 (Go on to Q. 3)
 A little 1
 Some 2
 Quite a bit 3
 A great deal 4

} **Answer Q. 2a**

4. To what extent do **you** have difficulty hearing?

- Not at all 0 (Go on to next page)
 A little 1
 Some 2
 Quite a bit 3
 A great deal 4

} **Answer Q. 4a**

2a. To what extent does the elder's speech problem make it hard for you to provide care to him or her?

- Not at all 0
 A little 1
 Some 2
 Quite a bit 3
 A great deal 4

4a. To what extent does **your** hearing problem make it hard for you to provide care to the elder?

- Not at all 0
 A little 1
 Some 2
 Quite a bit 3
 A great deal 4

HEARING, SPEECH, AND MEMORY PROBLEMS (continued)

To what extent do any of these hearing, speech or memory problems...	Not at all	A little	Some	Quite a bit	A great deal
5. create feelings of frustration in you?	0	1	2	3	4
6. make it hard for you to talk with your family member?	0	1	2	3	4
7. create feelings of impatience in you?	0	1	2	3	4

CAREGIVING PROBLEMS

Sometimes caregivers find that the following problems make it harder to give care to their the elder.

Have any of the following been a problem for you?	Not a problem	A small problem	A moderate problem	A big problem	A very big problem
8. Not having enough money?	0	1	2	3	4
9. Your being too tired emotionally?	0	1	2	3	4
10. Your being too tired physically?	0	1	2	3	4
11. Not having enough time?	0	1	2	3	4
12. Not having enough help from other people? ..	0	1	2	3	4
13. Not having enough space in the home?	0	1	2	3	4
14. Not having a separate room for the elder?	0	1	2	3	4
15. Decreased time you have for sleep?	0	1	2	3	4

YOUR PREPARATION FOR CAREGIVING

Reseacher know that people may feel well prepared for some aspects of giving care to another person, and not as well prepared for other aspects. We would like to know how well prepared you think you are to do each of the following, even if you are not doing that type of care now.

	Not at all prepared	Not too well prepared	Somewhat well prepared	Pretty well prepared	Very well prepared
1. How well prepared do you think you are to take care of your the elder's physical needs?	0	1	2	3	4
2. How well prepared do you think you are to take care of the elder's emotional needs?	0	1	2	3	4
3. How well prepared do you think you are to find out about and set up services for the elder?	0	1	2	3	4
4. How well prepared do you think you are for the stress of caregiving?	0	1	2	3	4
5. How well prepared do you think you are to make caregiving activities pleasant for both you and the elder?	0	1	2	3	4
6. How well prepared do you think you are to respond to and handle emergencies that involve the elder?	0	1	2	3	4
7. How well prepared do you think you are to get the help and information you need from hospitals or health care center?	0	1	2	3	4
8. Overall, how well prepared do you think you are to care for the elder?	0	1	2	3	4

YOUR EVERYDAY LIFE

Now we are interested in your everyday life and how predictable it is.

1. How predictable are the elder's needs?

- Not at all predictable 0
- Not too predictable 1
- Somewhat predictable 2
- Pretty predictable 3
- Very predictable 4

2. How predictable is your caregiving routine, or the activities that you do for the elder?

- Not at all predictable 0
- Not too predictable 1
- Somewhat predictable 2
- Pretty predictable 3
- Very predictable 4

3. How often is your routine unexpectedly interrupted because of the elder's problems?

- Never 0
- Rarely 1
- Sometimes 2
- Usually 3
- Always 4

4. How often does your day go pretty much as you planned it or as you expected it to go?

- Never 0
- Rarely 1
- Sometimes 2
- Usually 3
- Always 4

5. How much do you currently feel in control of your life?

- Not at all in control 0
- In control a little 1
- Somewhat in control 2
- Pretty much in control 3
- Very much in control 4

6. How predictable is your current life situation?

- Not at all predictable 0
- Not too predictable 1
- Somewhat predictable 2
- Pretty predictable 3
- Very predictable 4

7. When you think about your overall family care situation, would you say...

- You would like your family situation to be more predictable 1
- The predictability is about right 2
- Things are too predictable and routine, and you would like some more change in your everyday life 3

REWARDS OF CAREGIVING

Researcher 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 the elder. There are no right or wrong answers to these questions.

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

REWARDS OF CAREGIVING (cont.)

To what extent...	Not at all	A little	Some	Quite a bit	A great deal
15. does caring for the elder help you accumulate merit which will bring you to a better situation in this life or next life?	0	1	2	3	4
16. does caring for the elder fulfill Bon Kun?	0	1	2	3	4
17. does caring for the elder help you feel Pi Tee?	0	1	2	3	4
18. does caring for the elder help you have a better life in the future?	0	1	2	3	4
19. does caring for the elder give you good karma?	0	1	2	3	4
20. are you happy to be a caregiver because family members praise you for taking good care of the elder?	0	1	2	3	4
21. by giving good care to the elder, are you being a good example?	0	1	2	3	4
22. are you happy to be a caregiver because other relatives look at you as a good person?	0	1	2	3	4
23. are you glad to be a caregiver because your neighbors, friends, or health professionals look at you as a good person?	0	1	2	3	4
24. does caring for the elder help you financially such as relatives giving you some money to cover expenses related to caregiving?	0	1	2	3	4
25. will caring for the elder help you financially in the future?	0	1	2	3	4
26. does caring for the elder help you live more comfortably financially than if you hired a paid helper to care for him or her or putting her or him in a private hospital?	0	1	2	3	4

YOUR ROLES

These questions focus on the different roles you may have and the extent to which your caregiving interferes with these other roles. If the role listed does **not** apply to you, check the box at the right.

To what extent does caring for the elder interfere with your ability to be . . .	Not at all	A little	Some	Quite a bit	A great deal	Check <input checked="" type="checkbox"/> If not applic.
1. the kind of spouse or partner you think you should be?	0	1	2	3	4	<input type="checkbox"/>
2. the kind of parent you think you should be? ...	0	1	2	3	4	<input type="checkbox"/>
3. the kind of daughter/son you think you should be?	0	1	2	3	4	<input type="checkbox"/>
4. the kind of sister/brother you think you should be?	0	1	2	3	4	<input type="checkbox"/>
5. the kind of grandparent you think you should be?	0	1	2	3	4	<input type="checkbox"/>
6. the kind of relative you think you should be to people other than those listed in Q1-Q5? ..	0	1	2	3	4	<input type="checkbox"/>
7. the kind of friend you think you should be to other people?	0	1	2	3	4	<input type="checkbox"/>
8. the kind of worker you think you should be outside the house?	0	1	2	3	4	<input type="checkbox"/>
9. the kind of worker you think you should be around or in the house?	0	1	2	3	4	<input type="checkbox"/>
10. the kind of student you think you should be? .	0	1	2	3	4	<input type="checkbox"/>
11. involved in religious activities such as ability going to the temple on important religious day, joining other merit making ceremonies in the way you should do?	0	1	2	3	4	<input type="checkbox"/>
12. involved in social activities such as marriage ceremonies, funerals and Nean Boon Roi Wan in the way you think you should be?	0	1	2	3	4	<input type="checkbox"/>

YOUR ROLE (cont.)

To what extent does caring for the elder interfere with your ability to be . . .	Not at all	A little	Some	Quite a bit	A great deal	✓ Check if not applic.
13. good to yourself?	0	1	2	3	4	
14. To what extent do your other responsibilities interfere with your ability to care for the elder in the way you would like to?	0	1	2	3	4	

YOU AND THE ELDER

Now we would like you to let us know how you and the elder feel about each other at the current time.

	Not at all	A little	Some	Quite a bit	A great deal
1. How much do the two of you agree on agree on things?	0	1	2	3	4
2. How close do you feel to the elder?	0	1	2	3	4
3. How much do you enjoy sharing past experiences with the elder?	0	1	2	3	4
4. How much does the elder show his or her appreciation for your taking care of him or her? ..	0	1	2	3	4
5. How attached are you to the elder?	0	1	2	3	4
6. How much does the elder help you?	0	1	2	3	4
7. How much do you like to sit and talk with the elder?	0	1	2	3	4
8. How much love do you feel for the elder?	0	1	2	3	4
9. How much do you and the elder think the same things are important in life?	0	1	2	3	4
10. When you are suffering, how much does the elder comfort you?	0	1	2	3	4
11. How much do you and the elder spend time talking and laughing together?	0	1	2	3	4
12. How much do you confide in the elder?	0	1	2	3	4
13. How much does the elder encourage you and being sympathetic?	0	1	2	3	4
14. How happy are you when you spend time with the elder?	0	1	2	3	4
15. How often does he or she express feelings of "aarthon" toward you?	0	1	2	3	4

YOUR REACTIONS TO HELPING THE ELDER

1. Is there some kind of help you think you **should** give to the elder that you are not able to give him or her?

No 0 (Go to Q. 2)
Yes 1
↓ Unsure -8 (Go to Q. 2)

1a. If **YES**, what is it? _____

- 1b. If **YES**, how much does this bother you?

Not at all 0
A little 1
Somewhat 2
Quite a bit 3
A great deal 4

2. Are there things you do for the elder, but after you've done them, you think "you should not have done so"?

No 0 (Go to Q. 3)
Yes 1
↓ Unsure -8 (Go to Q. 3)

2a. If **YES**, what are they? _____

- 2b. If **YES**, how much does this bother you?

Not at all 0
A little 1
Somewhat 2
Quite a bit 3
A great deal 4

3. Are there things that the elder tries to do for him or herself, but you think he or she should let you help with?

No 0 (Go to Q. 4)
Yes 1
↓ Unsure -8 (Go to Q. 4)

3a. If **YES**, what are they? _____

- 3b. If **YES**, how much does this bother you?

Not at all 0
A little 1
Somewhat 2
Quite a bit 3
A great deal 4

4. Are there things that you do for the elder, but you think he or she should try to do it by him or herself?

No 0 (Go to Q. 5)
Yes 1
↓ Unsure -8 (Go to Q. 5)

4a. If **YES**, what are they? _____

- 4b. If **YES**, how much does this bother you?

Not at all 0
A little 1
Somewhat 2
Quite a bit 3
A great deal 4

YOUR REACTIONS TO HELPING THE ELDER

5. How often do you feel the elder expects too much from you?

- Never 0
- Rarely 1
- Sometimes 2
- Much of the time 3
- Always 4

6. Is there some help that the elder needs that is difficult for you to provide because it is embarrassing for either you or him or her?

No 0 (Go to Q. 7)

Yes 1

6a. If YES, how much stress does this embarrassment cause you?

- Not at all 0
- A little 1
- Some 2
- Quite a bit 3
- A great deal 4

7. How much family conflict has occurred because of the elder's health situation and need for help?

- No conflict 0
- A little conflict 1
- Some conflict 2
- Quite a bit of conflict 3
- A great deal of conflict ... 4

8. At this time, do you provide care for one or more ill persons other than the elder?

No 0 (Go on to next page)

Yes 1



8a. If YES, could you please describe this situation and the kind of help you give?

YOUR REACTIONS TO HELPING THE ELDER

Now researcher would like to know whether assisting and having other contact with the elder has negatively affected your life.

How often...	Not at all	A little	Moderately	A lot	A great deal
1. do you blame yourself about a behavior you have directed towards the elder?	0	1	2	3	4
2. do you feel guilt or feel that you are not taking a good care of the elder when the elder's symptom getting worse?	0	1	2	3	4
3. do you feel sorry that you have failed to give care completely or have been remiss in some caregiving activities?	0	1	2	3	4

YOUR REACTIONS TO HELPING THE ELDER

Now researcher would like to know whether assisting and having other contact with the elder has negatively affected your life.

Has assisting the elder. . .	Not at all	A little	Moderately	A lot	A great deal
1. decreased the time you have to yourself?	0	1	2	3	4
2. increased the stress in your relationship with the elder?	0	1	2	3	4
3. restricted personal privacy?	0	1	2	3	4
4. increased the elder try to make you do thing that you don't want to do?	0	1	2	3	4
5. decreased the time you have to spend in recreational activities?	0	1	2	3	4
6. increased the number of unreasonable requests made of you?	0	1	2	3	4
7. added tension to your life?	0	1	2	3	4
8. restricted the vacation activities and trips you take?	0	1	2	3	4
9. increased the nervousness and depression you have concerning your relationship with the elder	0	1	2	3	4
10. added to your feelings that you are being taken advantage of?	0	1	2	3	4
11. reduced the time you have to do your own work and daily chores?	0	1	2	3	4
12. increased the elder tendency to become self-centered which has increased unnecessary help?	0	1	2	3	4
13. increased your anxiety about things?	0	1	2	3	4
14. decreased the time you have for friends and other relatives?	0	1	2	3	4
15. decreased the money available to meet the rest of your expenses?	0	1	2	3	4

YOUR OVERALL EXPERIENCE

1. From talking with many caregivers, we know some of them feel that caring for their elders is like being restricted, while some of them do not feel that way. For you, how much do you feel that caring for your family member is like being restricted?

- Not at all restricted 0
- A little restricted 1
- Somewhat restricted 2
- Pretty much restricted 3
- Extremely restricted 4

2. How often do you feel caring for the elder is very difficult?

- Never 0
- Rarely 1
- Sometimes 2
- Much of the time 3
- Always 4

3. How much stress do you feel because of all your obligations, including taking care of the elder?

- No stress 0
- Very little stress 1
- Some stress 2
- A lot of stress 3
- Overwhelming stress 4

4. How much of the time do you feel you are patient in caring for the elder?

- Never 0
- Rarely 1
- Sometimes 2
- Most of the time 3
- Always 4

5. Do you feel that caring for the elder beneficial to you or detrimental to you?

- Definitely more beneficial than detrimental 4
- Somewhat more beneficial than detrimental 3
- As beneficial as detrimental 2
- Some what more detrimental than beneficial 1
- Definitely more detrimental than beneficial 0

6. The needs of the elder can change continuously. In your case, as time passes, taking care of the elder:

- Become much easier for you 4
- Become somewhat easier for you 3
- Stayed about the same for you 2
- Become somewhat more difficult for you.. 1
- Become much more difficult for you 0

7. If the elder needs more help, how confident are you that you can provide more care than what you are doing now?

- Not at all confident 0
- A little confident 1
- Somewhat confident 2
- Pretty confident 3
- Very confident 4

YOUR HEALTH

1. In general, would you say your health is
(Circle One Number):

- Excellent 1
- Very Good 2
- Good 3
- Fair 4
- Poor 5

2. Compared to one year ago, how would you
rate your health in general now ?

- Much better now than one year ago 1
- Somewhat better now than one year ago 2
- About the same 3
- Somewhat worse now than one year ago 4
- Much worse now than one year ago 5

The following items are about activities you might do during a typical day. Does your health now limit YOU in these activities? If so, how much?

Activities	Yes, I am Limited A Lot	Yes, I am Limited A Little	No, Not Limited At All
3. Vigorous activities , such as running, lifting heavy objects, participating in strenuous sports 1	1	2	3
4. Moderate activities , such as moving a table, pushing a vacuum cleaner, bowling, or playing golf 1	1	2	3
5. Lifting or carrying groceries 1	1	2	3
6. Climbing several flights of stairs 1	1	2	3
7. Climbing one flight of stairs 1	1	2	3
8. Bending, kneeling or stooping 1	1	2	3
9. Walking more than a mile 1	1	2	3
10. Walking several blocks 1	1	2	3
11. Walking one block 1	1	2	3
12. Bathing or dressing yourself 1	1	2	3

YOUR HEALTH (cont.)

During the **past month**, have you had any of the following problems with your work or other regular daily activities **as a result of your physical health**?

	All of the time	Most of the time	Some of the time	A little of the time	None of the time
13. Cut down the amount of time you spent on work or other activities	1	2	3	4	5
14. Accomplished less than you would like	1	2	3	4	5
15. Were limited in the kind of work or other activities	1	2	3	4	5
16. Had difficulty performing the work or other activities (for example, it took extra effort).....	1	2	3	4	5

During the **past month**, have you had any of the following problems with your work or other regular daily activities **as a result of any emotional problems** (such as feeling depressed or anxious)?

	All of the time	Most of the time	Some of the time	A little of the time	None of the time
17. Cut down the amount of time you spent on work or other activities	1	2	3	4	5
18. Accomplished less than you would like	1	2	3	4	5
19. Did work or activities less carefully than usual	1	2	3	4	5

YOUR HEALTH (cont.)

20. During the **past month**, to what extent have your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors, or groups?

- Not at all 1
- A little bit 2
- Moderately 3
- Quite a bit 4
- Extremely 5

21. How much **daily** pain have you had during the **past month**?

- None 1
- Very mild 2
- Mild 3
- Moderate 4
- Severe 5
- Very severe 6

22. During **past month** 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

YOUR HEALTH (cont.)

These questions are about how you feel and how things have been with you **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 month ...	All of the Time	Most of the Time	Some of the Time	A little of the Time	None of the Time
23. Did you feel full of pep?	1	2	3	4	5
24. Have you been a very nervous person?	1	2	3	4	5
25. Have you felt so down in the dumps that nothing could cheer you up?	1	2	3	4	5
26. Have you felt calm and peaceful?	1	2	3	4	5
27. Did you have a lot of energy?	1	2	3	4	5
28. Have you felt downhearted and blue?	1	2	3	4	5
29. Did you feel worn out?	1	2	3	4	5
30. Have you been a happy person?	1	2	3	4	5
31. Did you feel tired?	1	2	3	4	5

32. During the **past month**, how much of the time have your **physical health or emotional problems** interfered with your social activities (like visiting with friends, relatives, etc.)?

- 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

YOUR HEALTH (cont.)

How true or false is each of the following statements for you?

	Definitely True	Mostly True	Don't Know	Mostly False	Definitely False
33. I seem to get sick a little easier than other people	1	2	3	4	5
34. I am as healthy as anybody I know	1	2	3	4	5
35. I expect my health to get worse	1	2	3	4	5
36. My health is excellent.....	1	2	3	4	5

YOUR FEELINGS DURING THE PAST WEEK

Listed below are some statements. We would like you to tell me how often you felt or behaved this way — **DURING THE PAST WEEK.**

- 1 = Rarely or none of the time (less than 1 day)
- 2 = Some or a little of the time (1-2 days)
- 3 = Occasionally or a moderate amount of time (3-4 days)
- 4 = Most or all of the time (5-7 days)

During the PAST WEEK, on how many days did you feel or behave this way?	Rarely or None less than 1 day	Some or A Little 1-2 days	Occasionally or Moderate 3-4 days	Most or All 5-7 days
1. I was bothered by things that usually don't bother me.....	1	2	3	4
2. I did not feel like eating; my appetite was poor.	1	2	3	4
3. I felt that I could not shake off the blues even with help from my family or friends.	1	2	3	4
4. I felt that I was just as good as other people.	1	2	3	4
5. I had trouble keeping my mind on what I was doing.	1	2	3	4
6. I felt depressed.	1	2	3	4
7. I felt that everything I did was an effort.	1	2	3	4
8. I felt hopeful about the future.	1	2	3	4
9. I thought my life had been a failure.	1	2	3	4
10. I felt fearful.	1	2	3	4
11. My sleep was restless.	1	2	3	4
12. I was happy.	1	2	3	4
13. I talked less than usual.	1	2	3	4
14. I felt lonely.	1	2	3	4
15. People were unfriendly.	1	2	3	4
16. I enjoyed life.	1	2	3	4
17. I had crying spells.	1	2	3	4
18. I felt sad.	1	2	3	4
19. I felt that people disliked me.	1	2	3	4
20. I could not get "going."	1	2	3	4

TELL US ABOUT YOU

1. How old are you?
Age: _____ years

Date of birth / /
 mm dd yy
2. Are you female or male?
Female 1
Male 2
3. What is the highest grade in school that you completed?
No formal education 1
Completed grade school 2
Completed junior high school 3
Completed high school 4
Completed associate degree 5
Attended college 6
Completed college 7
Graduate professional training 8
Other _____ 9
4. What kind of work have you done most of your working life?

5. What is your current marital status ?
Married 1
Widowed 2
Divorced 3
Separated 4
Never married 5
10. Counting yourself, how many people live in your household?
_____ people
16. Which of the following four statements describes your ability to get along on your income?
I can't make ends meet 1
I have just enough, no more 2
I have enough, with a little extra sometimes 3
I always have money left over 4
8. What is the total amount of your income per month?
Below 1,000 baht 1
1,001-5,000 baht 2
5,001-10,000 bath 3
10,001-\$15,000 bath 4
15,001-\$20,000 bath 5
Above 20,000 bath 6
19. Do you pay other people out of your own pocket to take care of your family member?
No 0
Yes 1
↓
- 19a. If YES, how much of a financial burden is it? Would you say:
Not a burden 0
A little burden 1
Some burden 2
A lot of burden 3
Overwhelming burden 4
10. Are you currently employed?
1 No, I am retired
2 No, I am looking for employment
3 No, I never have been employed
4 No, I quit work because of the elder's health condition
5 Yes, part-time or on-call
6 Yes, full-time
11. Approximately how many hours per week do you work? _____ hours/week

YOUR VIEW

1. In your experience, does caregiving affect the interpersonal relationship between you and the elder?

No 0
Yes 1

1a. If **Yes**, please tell me how does caregiving make it better? Does make it worse? _

1b. If please give me the example of the positive quality of the relationship between you and care receiver? _____

2. Do you have any quilt or sorry about the things that have happened during the time you have been caring for the elder?

No 0
Yes..... 1

2a. If **YES**, what are they? _____

3. Do you think caring for your family member give you any financial advantage or disadvantage ?

No 0
Yes..... 1

3a. If **YES**, Would you describe you thought? _____

YOUR VIEW (cont.)

4. In your experience, what do you find rewarding in helping the elder? please explain.

5. Do you ever have both good and bad feelings about the caregiving situation?

No 0
Yes 1

5a. If **YES**, please tell me about these feeling and what kind of situations lead to these feelings occurring? _____

6. Please tell us any other questions that we should have asked you in order to have a good picture of your situation. _____

แบบสอบถามการดูแลครอบครัว

ในมุมมองของผู้ดูแล

ID#	<input type="text"/>
วันที่สัมภาษณ์:	<input type="text"/>
เริ่มเวลา:	<input type="text"/>
จบเวลา:	<input type="text"/>
ชื่อผู้สัมภาษณ์:	<input type="text"/>

วัน และ เวลาที่สัมภาษณ์

วัน

เวลา

ท่าน และ ผู้สูงอายุ

ผู้สูงอายุ หมายถึง ผู้สูงอายุที่มีปัญหาทางสุขภาพและความจำ
กรุณาตอบคำถามเกี่ยวกับตัวท่านและผู้สูงอายุดังต่อไปนี้

1. ท่านมีความเกี่ยวข้องกับอย่างไรกับผู้สูงอายุ?

ท่านเป็น...

- ภรรยา 1
- สามี 2
- ลูกสาว 3
- ลูกชาย 4
- ลูกสะใภ้ 5
- ลูกเขย 6
- ญาติ 7
- เพื่อนบ้านหรือเพื่อน 8
- อื่นๆ: _____

2. ท่านกับผู้สูงอายุรู้จักกันนานเท่าไร?

_____ ปี _____ เดือน

3. ตั้งแต่เริ่มเป็นผู้ใหญ่ (อายุ 18 ปีหรือมากกว่า)

ท่านอยู่กับผู้สูงอายุนานเท่าไร?

_____ ปี _____ เดือน

4. ขณะนี้ท่านพักอาศัยอยู่บ้านเดียวกัน
กับผู้สูงอายุ?

ใช่ 1

↓
ไม่ใช่ 0

4 ก. ถ้าไม่ใช่, ท่านพักอยู่ไกลจากผู้สูงอายุเป็นระยะ
ทางกี่กิโลเมตร?

_____ กิโลเมตร

เนื่องจากผู้สูงอายุมีปัญหาทางสุขภาพ

หรือความจำ, ท่านได้ช่วย ผู้สูงอายุ
ทำกิจกรรมดังต่อไปนี้หรือไม่?

- 5. อาบน้ำ?
- 6. แต่งตัว?
- 7. รับประทานอาหาร?
- 8. ช่วย ผู้สูงอายุ ขึ้น/ลงเตียงหรือเก้าอี้?
- 9. เดิน?
- 10. เดินรอบๆบ้าน?
- 11. พาไปห้องน้ำ?
- 12. เตรียมอาหาร?
- 13. พาไปซื้อของใช้ส่วนตัว (เช่นของใช้ในห้องน้ำ
หรือ ซักผ้า)?
- 14. จัดการเกี่ยวกับการเงิน (เช่น ดูแลค่าใช้จ่าย
หรือ การจ่ายเงินต่างๆ)?
- 15. การใช้โทรศัพท์?
- 16. การทำงานบ้านเล็กน้อย
(เช่นล้างจาน, จัดเก็บของ หรือ ทำความ สะอาด
เล็กน้อย)?
- 17. การทำงานบ้านที่หนักๆ (เช่น ทำความ
สะอาดพื้น หรือ หน้าต่าง)?
- 18. รับประทาน ยา?
- 19. ขับรถหรือใช้รถเมล์, รถแท็กซี่หรือรถตุ๊กตุ๊กพา
ผู้สูงอายุไปที่ผู้สูงอายุอยากไป?
- 20. อื่นๆ: _____
- 21. ไม่เคยต้องช่วยในสิ่งที่กล่าวไว้ข้างบนนี้

ผู้สูงอายุ

กรุณาเล่าข้อมูลเกี่ยวกับผู้สูงอายุ (วงกลม คำตอบที่ตรงกับลักษณะของผู้สูงอายุ)

1. ผู้สูงอายุอายุเท่าไร?

อายุ: _____ ปี

เกิดเมื่อ ____/____/____

2. ผู้สูงอายุเพศ?

ผู้หญิง 1

ผู้ชาย 2

3. ผู้สูงอายุจบการศึกษาชั้นสูงสุด
ชั้นอะไร?

ไม่ได้เรียนหนังสือ 1

ประถมศึกษา 2

มัธยมศึกษาตอนต้น 3

มัธยมศึกษาตอนปลาย 4

ประกาศนียบัตร 5

เรียนไม่จบมหาวิทยาลัย 6

ปริญญาตรี 7

ปริญญาโท 8

อื่นๆ _____ 9

4. เมื่อก่อน ผู้สูงอายุทำงานอะไร?

5. สถานะภาพสมรสของผู้สูงอายุ?

คู่ 1

หม้าย 2

หย่า 3

แยกกันอยู่ 4

ไม่เคยแต่งงาน 5

6. ผู้สูงอายุอาศัยอยู่กับใคร?
(วงกลมทั้งหมดตรงกับผู้สูงอายุ)

อยู่คนเดียว 0

อยู่กับสามี/ภรรยา 1

อยู่กับลูก 2

อยู่กับญาติ 3

อยู่กับเพื่อนที่สนิทเหมือนคน

ในครอบครัว 4

อยู่กับเพื่อน, เข้าบ้านอยู่ด้วยกัน 5

7. สมาชิกในครอบครัวทั้งหมดมีกี่คน?

_____ คน

8. ใครเป็นผู้จัดการกับค่าใช้จ่ายภายในบ้าน? (เช่น
จัดการกับค่าใช้จ่ายการรักษาพยาบาล)

ผู้สูงอายุของท่าน

กรุณาตอบคำถาม เกี่ยวกับผู้สูงอายุ

9. ผู้สูงอายุสัญชาติไทยใช่หรือไม่?

ไม่ใช่ 0

ใช่ 1

ถ้าไม่ใช่ ผู้สูงอายุ สัญชาติอะไร

10. ท่านและผู้สูงอายุของท่านภูมิลำเนาเดิม
อยู่ที่

กรุงเทพมหานคร 1

ภาคกลาง..... 2

ภาคเหนือ 3

ภาคตะวันออกเฉียงเหนือ..... 4

ภาคใต้ 5

ภาคตะวันออก..... 6

ในปัจจุบันนี้ผู้สูงอายุ

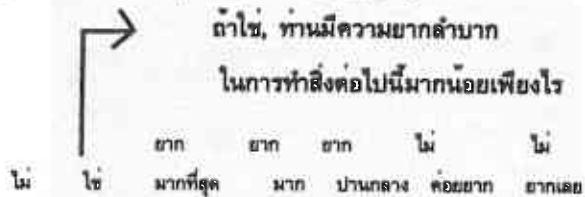
ผู้วิจัยต้องการถามคำถามเกี่ยวกับความจำ และ ความลำบากในการทำบางสิ่งบางอย่างของผู้สูงอายุ

	ไม่	มี	มี	มี	ไม่
	มีความ	ความลำบาก	ความลำบาก	ความลำบาก	สามารถ
ผู้สูงอายุของท่านมีความลำบาก	ลำบากเลย	เล็กน้อย	ปานกลาง	มาก	ทำได้เลย
ในการทำสิ่งเหล่านี้มากนักน้อยเพียงใด					
1. จำสถานการณ์ในปัจจุบัน?	0	1	2	3	4
2. รู้ว่าวันนี้เป็นวันอะไร?	0	1	2	3	4
3. จำบ้านเลขที่ไว้ได้?	0	1	2	3	4
4. จำคำศัพท์ไว้ได้?	0	1	2	3	4
5. เข้าใจคำอธิบายที่ง่าย ๆ?	0	1	2	3	4
6. รู้ว่าอะไรอยู่ตรงไหนภายในบ้าน?	0	1	2	3	4
7. พุดเป็นประโยค?	0	1	2	3	4
8. จำบุคคลที่เคยรู้จักไว้ได้?	0	1	2	3	4

กิจกรรมการดูแล

ผู้วิจัยต้องการทราบเกี่ยวกับการดูแล ผู้สูงอายุ ผู้ดูแลบางท่านอาจไม่มีปัญหา แต่บางท่านมีความ
 ยากลำบากในการดูแลทั้งด้านร่างกาย และอารมณ์ ข้อคำถามข้างล่างนี้จะเกี่ยวข้องกับความช่วยเหลือที่ท่านให้กับ
 ผู้สูงอายุ ผู้วิจัยต้องการทราบว่าท่านได้ให้การดูแลผู้สูงอายุใน สิ่งเหล่านี้หรือไม่
 ถ้าให้ท่านมีความยากลำบากมากน้อยเพียงไร ในแต่ละข้อคำถาม ขอให้ ให้ตอบ **ไม่** ถ้าท่านไม่ได้ให้ความช่วย
 เหลือในสิ่งนั้น หรือ ผู้สูงอายุไม่มีปัญหาเหล่านั้นเลย ขอให้ท่านตอบ **ใช่** ถ้าท่านได้ให้ความช่วยเหลือในสิ่งนั้น
 และ กรุณาบอกถึง ความยากลำบากในการให้ความช่วยเหลือ โดยผู้วิจัย มีคำตอบให้เลือก 5 ระดับคือ
 ยากมากที่สุด 4 , ยากมาก 3 , ยากปานกลาง 2 , ไม่ค่อยยาก 1 , หรือ ไม่ยากเลย 0

ท่านได้ช่วยผู้สูงอายุทำสิ่งดังต่อไปนี้...



1. ท่านไปจ่ายตลาดซื้อของใช้หรือทำธุระให้ ผู้สูงอายุหรือไม่?.....	ไม่	ใช่	4	3	2	1	0
2. ท่านต้องช่วยผู้สูงอายุในการเดิน ภายในบ้าน เช่น เจน ขน หรือ นำที่หัด เดินมาให้ผู้สูงอายุหรือไม่ ?.....	ไม่	ใช่	4	3	2	1	0
3. ท่านต้องช่วยผู้สูงอายุ ออกเดินรอบๆ นอกบ้านหรือไม่ ?	ไม่	ใช่	4	3	2	1	0
4. ท่านต้องคอยดู ให้อยู่ ในสายตา เสมอเพื่อให้แน่ใจว่าผู้สูงอายุปลอดภัย หรือไม่?.....	ไม่	ใช่	4	3	2	1	0
5. ท่านช่วยผู้สูงอายุในการรับประทานยาหรือ ฉีดยาหรือไม่?.....	ไม่	ใช่	4	3	2	1	0
6. ท่านช่วยผู้สูงอายุในการรับประทานอาหาร หรือไม่?.....	ไม่	ใช่	4	3	2	1	0

กิจกรรมการดูแล (ต่อ)

ท่านได้ช่วยผู้สูงอายุทำสิ่งดังต่อไปนี้...



ถ้าใช่, ท่านมีความยากลำบาก

ในการทำสิ่งต่อไปนี้มากน้อยเพียงไร

ยาก ยาก ยาก ไม่ ไม่
มากที่สุด มาก ปานกลาง ค่อนข้าง ยากเลย

ไม่

ใช่

7.	ท่านระวังไม่ให้ผู้สูงอายุหกล้ม หรือไม่?	ไม่	ใช่	4	3	2	1	0
8.	ท่านช่วยผู้สูงอายุตัดสินใจเกี่ยวกับการดูแลรักษาสุขภาพที่สำคัญ เช่น การผ่าตัดหรือการเปลี่ยนการรักษา หรือไม่?	ไม่	ใช่	4	3	2	1	0
9.	ท่านพยายามให้ผู้สูงอายุยังคงทำกิจกรรมและทำสิ่งต่างๆ ที่ผู้สูงอายุชอบ หรือไม่?	ไม่	ใช่	4	3	2	1	0
10.	ท่านเล่าถึงอาการเปลี่ยนแปลงต่างๆ ของผู้สูงอายุให้หมอที่ตรวจรักษาทราบหรือไม่?	ไม่	ใช่	4	3	2	1	0
11.	ท่านเล่าถึงอาการเปลี่ยนแปลงทางด้านสุขภาพของผู้สูงอายุให้พยาบาล หรือเจ้าหน้าที่ที่มสุขภาพรับทราบ หรือไม่?	ไม่	ใช่	4	3	2	1	0
12.	ท่านอุ้มหรือช่วยพยุงผู้สูงอายุจากที่หนึ่งไปยังอีกที่หนึ่งเช่นช่วยอุ้มหรือพยุงผู้สูงอายุจากเตียงลงนั่งเก้าอี้ หรือไม่? (ตอบ ไม่ ถ้าสมาชิกในครอบครัวของท่านสามารถทำได้เอง)	ไม่	ใช่	4	3	2	1	0
13.	ท่านต้องไปเป็นเพื่อนผู้สูงอายุ เมื่อผู้สูงอายุไป ซื้ของหรือทำธุระหรือไม่?	ไม่	ใช่	4	3	2	1	0
14.	ท่านดูแลให้ผู้สูงอายุได้รับน้ำเพียงพอหรือไม่?(ตอบ ไม่ ถ้าผู้สูงอายุท่านไม่มีปัญหา)	ไม่	ใช่	4	3	2	1	0
15.	ท่านช่วยผู้สูงอายุอาบน้ำ หรือไม่?	ไม่	ใช่	4	3	2	1	0
16.	ท่านขับรถให้ ผู้สูงอายุหรือไม่?	ไม่	ใช่	4	3	2	1	0

กิจกรรมการดูแล (ต่อ)

ท่านได้ช่วยผู้สูงอายุทำสิ่งดังต่อไปนี้...



ถ้าใช่, ท่านมีความยากลำบาก

ในการทำสิ่งต่อไปนี้มากน้อยเพียงไร

ยาก ยาก ยาก ไม่ ไม่
มากที่สุด มาก ปานกลาง ค่อนข้าง ยากเลย

	ไม่	ใช่	มากที่สุด	มาก	ปานกลาง	ค่อนข้าง	ยากเลย
17. ท่านต้องจัดการกับความหวาดระแวงหรือข้าง สงสัยของผู้สูงอายุหรือไม่? ไม่	ใช่	4	3	2	1	0	
18. ท่านมีส่วนในการทำกิจกรรมร่วมกับ ผู้สูงอายุ เช่น ดูโทรทัศน์หรือฟังวิทยุ หรือไม่? ไม่	ใช่	4	3	2	1	0	
19. ท่านต้องจัดการเมื่อผู้สูงอายุร้องให้ หรือไม่? (ตอบ ไม่ ถ้าผู้สูงอายุ ท่านไม่มีปัญหานี้)..... ไม่	ใช่	4	3	2	1	0	
20. ท่านดูแลให้ผู้สูงอายुरับประทานอาหาร ตามชนิด หรือปริมาณที่ผู้สูงอายุ ควร จะได้ หรือไม่? (ตอบ ไม่ ถ้าผู้สูงอายุ ของท่านสามารถทำตัวเอง)..... ไม่	ใช่	4	3	2	1	0	
21. ท่านต้องทำความสะอาดเมื่อผู้สูงอายุ ปัสสาวะรดหรือไม่? ไม่	ใช่	4	3	2	1	0	
22. ท่านช่วยเขียนหนังสือให้ผู้สูงอายุ หรือไม่? (ตอบ ไม่ ถ้าผู้สูงอายุของท่าน สามารถทำตัวเอง) ไม่	ใช่	4	3	2	1	0	
23. ท่านต้องจัดการกับการที่ผู้สูงอายุส่ง เสียงดังหรือไม่? (ตอบ ไม่ ถ้าผู้สูงอายุ ท่านไม่มีปัญหานี้)..... ไม่	ใช่	4	3	2	1	0	
24. ท่านพูดคุยกับผู้สูงอายุในเรื่องอนาคต การดำรงชีวิตหรือเป้าหมายชีวิตของผู้สูงอายุ หรือไม่? ไม่	ใช่	4	3	2	1	0	

กิจกรรมการดูแล (ต่อ)

ท่านได้ช่วยผู้สูงอายุทำสิ่งดังต่อไปนี้...

ถ้าใช่, ท่านมีความยากลำบาก
ในการทำสิ่งต่อไปนี้มากน้อยเพียงไร

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	ไม่	ใช่	มากที่สุด	มาก	ปานกลาง	ค่อยยาก	ยากเลย
25. ท่านทำอาหารหรือเตรียมอาหารให้ผู้สูงอายุหรือไม่?	ไม่	ใช่	4	3	2	1	0
26. ท่านดูแลผิวหนังและทาโลชั่นให้ผู้สูงอายุหรือไม่?	ไม่	ใช่	4	3	2	1	0
27. ท่านต้องรับฟังและตอบคำถามของผู้สูงอายุที่ถามท่านซ้ำแล้วซ้ำอีก หรือไม่?	ไม่	ใช่	4	3	2	1	0
28. ท่านต้องช่วยเหลือผู้สูงอายุขึ้น และ ลงบันไดหรือไม่?	ไม่	ใช่	4	3	2	1	0
29. ท่านช่วยผู้สูงอายุแปรงฟันหรือทำความสะอาดฟันปลอม หรือไม่?	ไม่	ใช่	4	3	2	1	0
30. ท่านดูแล อุปกรณ์การแพทย์ที่ใช้กับผู้สูงอายุหรือช่วยผู้สูงอายุ ติดตั้งอุปกรณ์การแพทย์ เช่น ออกซิเจน, ท่ออาหารสายยาง, สายน้ำเกลือ, และสายสวนปัสสาวะ หรือไม่?	ไม่	ใช่	4	3	2	1	0
31. ท่านช่วยผู้สูงอายุทำกิจวัตรทางด้านกฎหมายหรือไม่?	ไม่	ใช่	4	3	2	1	0
32. ท่านต้องจัดการกับปัญหาเหนื่อยล้าไม่มีแรงของผู้สูงอายุหรือไม่?	ไม่	ใช่	4	3	2	1	0
33. ท่านต้องเผื่อระวังผู้สูงอายุไม่ให้ออกนอกบ้านเนื่องจากกลัวผู้สูงอายุ พลัดหลงทางหรือกลับบ้านไม่ถูก หรือไม่?	ไม่	ใช่	4	3	2	1	0
34. ท่านช่วย ผู้สูงอายุสวมเสื้อผ้า หรือถอดเสื้อผ้าหรือไม่?	ไม่	ใช่	4	3	2	1	0
35. ท่านต้องคอยเล่าอาการของผู้สูงอายุให้คนในครอบครัว ทราบหรือไม่?	ไม่	ใช่	4	3	2	1	0

กิจกรรมการดูแล (ต่อ)

ท่านได้ช่วยผู้สูงอายุทำสิ่งดังต่อไปนี้...

ถ้าใช่, ท่านมีความยากลำบาก

ในการทำสิ่งต่อไปนี้มากน้อยเพียงไร

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36. ท่านนั่งเป็นเพื่อนผู้สูงอายุหรือไม่?	ไม่	ใช่	4	3	2	1	0
37. ท่านต้องตื่นกลางดึกเพื่อดูแล ผู้สูงอายุ หรือไม่?	ไม่	ใช่	4	3	2	1	0
38. ท่านต้องช่วยดูแลผู้สูงอายุเมื่อผู้สูงอายุมี ภาวะอารมณ์ขึ้นๆลงๆ หรือไม่?	ไม่	ใช่	4	3	2	1	0
39. ท่านช่วยผู้สูงอายุในการเบิกเงินหรือฝาก เงินกับธนาคาร หรือ การจ่ายเงินค่าใช้จ่ายต่างๆ หรือไม่?	ไม่	ใช่	4	3	2	1	0
40. ท่านต้องจัดการกับปัญหาเรื่องความไม่ ปลอดภัย ในการขับรถของผู้สูงอายุหรือไม่? (ตอบ ไม่ ถ้าผู้สูงอายุท่านไม่มีปัญหานี้)	ไม่	ใช่	4	3	2	1	0
41. ท่านต้องจัดการกับการที่ผู้สูงอายุมีความ จำละเลือน, จำคนหรือสถานที่ไม่ได้ หรือไม่?	ไม่	ใช่	4	3	2	1	0
42. ท่านต้องคอยตรวจตรา ดูแลและรักษาปัญหา เกี่ยวกับผิวหนังของผู้สูงอายุ หรือไม่?	ไม่	ใช่	4	3	2	1	0
43. ท่านตรวจตราว่า ผู้สูงอายุยังอยู่ดี หรือไม่?	ไม่	ใช่	4	3	2	1	0
44. ท่านต้องจัดการกับอาการประสาทหลอนของ ผู้สูงอายุหรือไม่?(ตอบ ไม่ ผู้สูงอายุไม่มีปัญหานี้)	ไม่	ใช่	4	3	2	1	0
45. ท่านพาผู้สูงอายุไปหาหมอ หรือไม่?	ไม่	ใช่	4	3	2	1	0
46. ท่านคอยระวังไม่ให้ผู้สูงอายุได้รับอันตราย จากสารพิษ เช่น กินยาเกินขนาด หรือ ได้รับ สารพิษที่ใช้ในบ้าน หรือไม่?	ไม่	ใช่	4	3	2	1	0

กิจกรรมการดูแล (ต่อ)

ท่านได้ช่วยผู้สูงอายุทำสิ่งดังต่อไปนี้...



ถ้าใช่, ท่านมีความยากลำบาก

ในการทำสิ่งต่อไปนี้มากน้อยเพียงไร

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ไม่ ใช่

47. ท่านพาผู้สูงอายุ ออกนอกบ้าน เช่น ไปวัด, เยี่ยมญาติหรือเพื่อน หรือรับประทานอาหารนอกบ้าน หรือไม่?	ไม่	ใช่	4	3	2	1	0
48. ท่านต้องทำความสะอาดเมื่อผู้สูงอายุ อุจจาระราด หรือไม่?	ไม่	ใช่	4	3	2	1	0
49. ท่านต้องช่วยเหลือผู้สูงอายุ ไปปัญหาเรื่อง ท้องผูกหรือท้องเดิน หรือไม่?	ไม่	ใช่	4	3	2	1	0
50. ท่านต้องจัดการกับอาการคลื่นไส้ของ ผู้สูงอายุ หรือไม่?	ไม่	ใช่	4	3	2	1	0
51. ท่าน ซ่อมแซมสิ่งของเครื่องใช้หรือทำงานบ้าน เล็กๆ น้อยๆ ให้ผู้สูงอายุ หรือไม่?	ไม่	ใช่	4	3	2	1	0
52. ท่านต้องช่วยพาผู้สูงอายุ เข้าห้องน้ำหรือไม่?	ไม่	ใช่	4	3	2	1	0
53. ท่านเป็นคนเปลี่ยนผ้าปูที่นอนให้ผู้สูงอายุ หรือไม่?	ไม่	ใช่	4	3	2	1	0
54. ท่านต้องระวังหรือดูแลรักษาการติดเชื้อของ ผู้สูงอายุ หรือไม่หรือไม่?	ไม่	ใช่	4	3	2	1	0
55. ท่านช่วยผู้สูงอายุ ไข่ต้ม หรือ หม้อเอน (กระโถน) หรือไม่?	ไม่	ใช่	4	3	2	1	0
56. ท่านต้องจัดการกับปัญหาของ ผู้สูงอายุ เกี่ยวกับการใส่กุญแจ หรือ ล็อคกลอนประตู หรือไม่?	ไม่	ใช่	4	3	2	1	0

กิจกรรมการดูแล (ต่อ)

ท่านได้ช่วยผู้สูงอายุ ทำสิ่งดังต่อไปนี้...



ถ้าใช่, ท่านมีความอยากลำบาก
ในการทำสิ่งต่อไปนี้มากน้อยเพียงไร

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คำถาม	ไม่	ใช่	4	3	2	1	0
57. ท่านต้องช่วยผู้สูงอายุ ในการกรอกแบบฟอร์ม ต่างๆ เช่น กรอกแบบฟอร์ม ทางด้านกฎหมาย, ทางด้านสุขภาพ หรือไม่?.....	ไม่	ใช่	4	3	2	1	0
58. ท่านต้องดูแลผู้สูงอายุ ให้พักผ่อนอย่าง เพียงพอ หรือไม่?	ไม่	ใช่	4	3	2	1	0
59. ท่านได้ทำสิ่งเหล่านี้ เช่น จับมือ หรือลูบหลัง ผู้สูงอายุ หรือไม่?	ไม่	ใช่	4	3	2	1	0
60. ท่านต้องช่วย ผู้สูงอายุ ในปัญหาด้านการหายใจ หรือไม่?	ไม่	ใช่	4	3	2	1	0
61. ท่านช่วย ผู้สูงอายุตัดสินใจด้านการเงิน ที่สำคัญๆหรือไม่?	ไม่	ใช่	4	3	2	1	0
62. ท่านต้องช่วยผู้สูงอายุ ในการทำกิจกรรม ที่ต้องใช้ความละเอียด เช่น การตัด, ใส่กระดุม หรือ เปิดฝากระป๋อง หรือไม่?	ไม่	ใช่	4	3	2	1	0
63. ท่านต้องช่วยจัดการกับอาการเจ็บปวดทางด้าน ร่างกายของ ผู้สูงอายุ หรือไม่?.....	ไม่	ใช่	4	3	2	1	0
64. ท่านต้องจัดการกับการที่ผู้สูงอายุ หุบติหรือผลักคนอื่น หรือไม่?	ไม่	ใช่	4	3	2	1	0
65. ท่านช่วยผู้สูงอายุ ทำงานบ้านที่เบาๆ หรือไม่?	ไม่	ใช่	4	3	2	1	0
66. ท่านต้องเฝ้าระวังไม่ให้ผู้สูงอายุมีอาการบวมเกิดขึ้น หรือไม่?	ไม่	ใช่	4	3	2	1	0

กิจกรรมการดูแล (ต่อ)

ท่านได้ช่วยผู้สูงอายุ ทำสิ่งดังต่อไปนี้...



ถ้าใช่, ท่านมีความยากลำบาก
ในการทำสิ่งต่อไปนี้มากน้อยเพียงไร

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67. ท่านช่วยผู้สูงอายุ ตูแถมหรือสระผม หรือไม่?	ไม่	ใช่	4	3	2	1	0
68. ท่านช่วย บอกผู้สูงอายุ ริเริ่มทำกิจกรรมในแต่ละวัน หรือไม่?	ไม่	ใช่	4	3	2	1	0
69. ท่านช่วยผู้สูงอายุ ไขโทรทัศน์ หรือไม่?	ไม่	ใช่	4	3	2	1	0
70. ท่านต้องจัดการกับการ ที่ผู้สูงอายุ ชอบสิ่งของและลืมว่าซ่อนไว้ที่ไหน หรือไม่?	ไม่	ใช่	4	3	2	1	0
71. ท่านต้องจัดการกับการอยู่ไม่สุขหรือ กระวนกระวายของผู้สูงอายุ หรือไม่?	ไม่	ใช่	4	3	2	1	0
72. ท่านต้องจัดการกับอาการที่ผู้สูงอายุ แสดงพฤติกรรมทางเพศไม่เหมาะสม หรือไม่?	ไม่	ใช่	4	3	2	1	0
73. ท่านอ่านหนังสือให้ผู้สูงอายุ หรือไม่?	ไม่	ใช่	4	3	2	1	0
74. ท่านคอยดูแลจำนวนคนที่มาเยี่ยม ผู้สูงอายุ หรือไม่?	ไม่	ใช่	4	3	2	1	0
75. ท่านต้องจัดการกับอาการป่วยฉุกเฉินของผู้สูงอายุ หรือไม่?	ไม่	ใช่	4	3	2	1	0
76. ท่านดูแลและตัดเล็บมือเล็บเท้าให้กับ ผู้สูงอายุ หรือไม่?	ไม่	ใช่	4	3	2	1	0
77. ท่านจัดสถานที่ให้ ผู้สูงอายุ สวดมนต์, ดูรายการธรรมะทางโทรทัศน์ หรือวิทยุ, หรืออ่านหนังสือธรรมะให้ผู้สูงอายุ หรือไม่?	ไม่	ใช่	4	3	2	1	0

กิจกรรมการดูแล (ต่อ)

ท่านได้ช่วยผู้สูงอายุ ทำสิ่งดังต่อไปนี้...

ถ้าใช่, ท่านมีความยากลำบาก

ในการทำสิ่งต่อไปนี้มากน้อยเพียงไร

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78. ท่านต้องจัดการกับการที่ผู้สูงอายุ ใช้คำพูดที่รุนแรง และก้าวร้าวหรือไม่?	ไม่	ใช่	4	3	2	1	0
79. ท่านต้องช่วยเหลือผู้สูงอายุ เนื่องจาก มีปัญหาเกี่ยวกับสายตา หรือไม่?	ไม่	ใช่	4	3	2	1	0
80. ท่านต้องช่วยเหลือผู้สูงอายุ เนื่องจาก การเคลื่อนไหวช้า หรือไม่?	ไม่	ใช่	4	3	2	1	0
81. ท่านช่วยผู้สูงอายุ ในการทำบุญ เช่น เตรียมอาหารใส่บาตร, ทำบุญเลี้ยงพระ, เชิญบาทหลวง, พระอิสลาม มาเยี่ยมสมาชิกใน ครอบครัว ที่บ้าน หรือไม่?	ไม่	ใช่	4	3	2	1	0
82. ท่านปรับเปลี่ยนสิ่งแวดล้อมในบ้านเพื่อให้เหมาะสมกับ ผู้สูงอายุ เช่น จัดสถานที่เฉพาะให้, ติดตั้งราวไม้ หรือปรับเปลี่ยนห้องน้ำหรือไม่?	ไม่	ใช่	4	3	2	1	0
83. ท่านช่วยเหลือผู้สูงอายุ ในการใช้บริการรถแท็กซี่, รถเมล์, หรือ รถตุ๊กๆ หรือไม่?	ไม่	ใช่	4	3	2	1	0

กิจกรรมการดูแล (ต่อ)

ท่านได้ช่วยผู้สูงอายุ ทำสิ่งดังต่อไปนี้...

ไม่

ใช่

ถ้าใช่, ท่านมีความยากลำบาก

ในการทำสิ่งต่อไปนี้มากน้อยเพียงไร

ยาก ยาก ยาก ไม่ ไม่

มากที่สุด มาก ปานกลาง ค่อยยาก ยากเลย

ผู้วิจัยอยากทราบว่า ท่านได้รับความช่วยเหลือ จากแหล่งใดบ้าง

84. ท่านเคยเสาะหาข้อมูลจากหมอหรือเจ้าหน้าที่ที่มสุขภาพให้กับผู้สูงอายุ หรือไม่?.....	ไม่	ใช่	4	3	2	1	0
85. ท่านเคยติดต่อหาข้อมูลจากโรงพยาบาล, ศูนย์อนามัยหรือศูนย์เฝ้าไข้เอกชนว่าทางหน่วยงานเหล่านี้มีบริการที่จะช่วยท่านในการดูแล ผู้สูงอายุ หรือไม่?.....	ไม่	ใช่	4	3	2	1	0
86. ท่านเคยจัดหาเจ้าหน้าที่จากโรงพยาบาล, ศูนย์อนามัยหรือศูนย์เฝ้าไข้เอกชนมาช่วยดูแลผู้สูงอายุหรือไม่?.....	ไม่	ใช่	4	3	2	1	0
87. ท่านเคยต้องคอยตรวจตราเจ้าหน้าที่จากโรงพยาบาล, ศูนย์อนามัยหรือศูนย์เฝ้าไข้เอกชนให้การดูแลผู้สูงอายุอย่างต่อเนื่อง หรือไม่?.....	ไม่	ใช่	4	3	2	1	0
88. ท่านเคยต้องคอยตรวจตราเจ้าหน้าที่หรือคนที่ช่วยดูแลว่าได้ให้ การดูแลผู้สูงอายุด้วยความชำนาญหรือไม่?.....	ไม่	ใช่	4	3	2	1	0
89. ท่านได้พยายามที่จะหาคนมาช่วยดูแล ผู้สูงอายุ แต่ท่านไม่สามารถหาใครมาช่วยได้?.....	ไม่	ใช่	4	3	2	1	0
90. ท่านเคยเสาะแสวงหาแหล่งรักษาอื่นๆ เช่น ยาจีน, สมุนไพร, นวดแผนโบราณ, หรือน้ำมันตรีเพื่อบรรเทาปัญหาทางสุขภาพของ ผู้สูงอายุหรือไม่?	ไม่	ใช่	4	3	2	1	0

กิจกรรมการดูแล (ต่อ)

ท่านได้ช่วย ผู้สูงอายุทำสิ่งดังต่อไปนี้...



ถ้าใช่, ท่านมีความยากลำบาก
ในการทำสิ่งต่อไปนี้มากน้อยเพียงไร

ยาก ยาก ยาก ไม่ ไม่
มากที่สุด มาก ปานกลาง ค่อยยาก ยากเลย

91. ท่านได้ช่วยเหลือ ผู้สูงอายุนอกเหนือจาก
กิจกรรมที่กล่าวมาข้างต้น หรือไม่?
กรุณาเล่าให้ผู้วิจัยทราบ

ก) _____ ?ไม่	ใช่	4	3	2	1	0
ข) _____ ?ไม่	ใช่	4	3	2	1	0
ค) _____ ?ไม่	ใช่	4	3	2	1	0

การให้ความช่วยเหลือ

1. ผู้สูงอายุ ต้องการความช่วยเหลือจากท่านและบุคคลอื่นเนื่องจากผู้สูงอายุ มีปัญหาทาง ด้านร่างกาย และความจำมานานเท่าไร ?

_____ ปี _____ เดือน _____ วัน

2. ท่านได้ให้ความช่วยเหลือผู้สูงอายุเนื่องจากผู้สูงอายุ มีปัญหาทาง ด้านร่างกาย และความจำมานานเท่าไร ?

_____ ปี _____ เดือน _____ วัน

3. ท่านได้ให้ความช่วยเหลือผู้สูงอายุเป็นเวลากี่วันในช่วงหนึ่งอาทิตย์ที่ผ่านมา? _____ วัน

4. วันที่ท่าน ให้ความช่วยเหลือผู้สูงอายุท่านใช้เวลากี่ชั่วโมง ในการดูแล (รวมทั้งเวลาที่ท่านต้องลุกมากกลางดึก) ?
_____ ชั่วโมง

การวินิจฉัยโรค

ผู้สูงอายุท่านป่วยเป็นโรคอะไร? (ตอบได้มากกว่า 1) ...

การวินิจฉัยโรค	ไม่	ใช่
1. โรคหัวใจ	0	1
2. โรคมะเร็ง.....	0	1
3. อัมพาต	0	1
4. ปัญหาเกี่ยวกับความจำ (Alzheimer, dementia)	0	1
5. โรค พากินสัน หรือความผิดปกติทางการเคลื่อนไหว	0	1
6. โรคข้ออักเสบ	0	1
7. โรคเบาหวาน	0	1
8. โรคอื่นๆ: _____	0	1

การได้รับการช่วยเหลือจากผู้อื่นในการดูแลผู้สูงอายุ

จากหน้า 4 ถึง หน้า 15 ผู้วิจัยได้ถามถึงกิจกรรมการดูแลที่ท่านได้ช่วยผู้สูงอายุ ต่อไปนี้ผู้วิจัยต้องการรู้ว่าใครบ้างที่ได้ช่วยเหลือท่านในการทำกิจกรรมเหล่านี้

การได้รับการช่วยเหลือจากญาติ

1. ญาติพี่น้องให้การดูแลผู้สูงอายุ
 มากน้อยเพียงใด?
 ไม่เลย..... 0 (ไปตอบข้อ4)
 น้อยครั้ง..... 1
 บางบางครั้ง..... 2
 มาก..... 3
 มากที่สุด..... 4
2. ญาติพี่น้องที่ให้ความช่วยเหลือผู้สูงอายุ
 มีกี่คน? _____ (คน)
3. ท่านพึงพอใจกับความช่วยเหลือที่ได้รับจาก
 ญาติพี่น้องมากน้อยเพียงใด?
 พึงพอใจมาก..... 4
 พึงพอใจค่อนข้างมาก..... 3
 พึงพอใจปานกลาง..... 2
 ค่อนข้างไม่พึงพอใจ..... 1
 ไม่พึงพอใจมาก..... 0

การได้รับความช่วยเหลือจากเจ้าหน้าที่

7. ท่านได้รับความช่วยเหลือจากเจ้าหน้าที่ที่มสุขภาพ
 เช่น หมอ พยาบาล ผู้ช่วยพยาบาล
 หรือคนรับจ้างดูแลผู้สูงอายุมากน้อยเพียงใด?
 ไม่เลย..... 0 (ไปตอบข้อ10)
 น้อยครั้ง..... 1
 บางบางครั้ง..... 2
 มาก..... 3
 มากที่สุด..... 4
8. เจ้าหน้าที่ที่มสุขภาพหรือคนรับจ้างดูแลมีกี่คน?
 _____ (คน)
9. ท่านรู้สึกพึงพอใจกับความช่วยเหลือจากบุคคลเหล่านี้
 นี้น้อยเพียงใด?
 พึงพอใจมาก..... 4
 พึงพอใจค่อนข้างมาก..... 3
 พึงพอใจปานกลาง..... 2
 ค่อนข้างไม่พึงพอใจ..... 1
 ไม่พึงพอใจมาก..... 0

การได้รับการช่วยเหลือจากเพื่อนและเพื่อนบ้าน

4. เพื่อนและเพื่อนบ้านให้ความช่วยเหลือ ผู้สูงอายุ
 มากน้อยเพียงใด?
 ไม่เลย..... 0 (ไปตอบข้อ7)
 น้อยครั้ง..... 1
 บางบางครั้ง..... 2
 มาก..... 3
 มากที่สุด..... 4
5. เพื่อนหรือเพื่อนบ้านที่ให้ความช่วยเหลือมีกี่คน?
 _____ (คน)
6. ท่านพึงพอใจกับความช่วยเหลือที่ได้รับจากเพื่อน
 หรือเพื่อนบ้านมากน้อยเพียงใด?
 พึงพอใจมาก..... 4
 พึงพอใจค่อนข้างมาก..... 3
 พึงพอใจปานกลาง..... 2
 ค่อนข้างไม่พึงพอใจ..... 1
 ไม่พึงพอใจมาก..... 0

ไม่ได้รับความช่วยเหลือจากคนอื่น

10. คนที่ท่านคิดว่าควรมาช่วยท่านดูแลผู้สูงอายุ
 ให้มากกว่านี้แต่ไม่ได้ช่วยท่านดูแลผู้สูงอายุ
 มีหรือไม่?
 ไม่มี..... 0
 มี..... 1
- 10ก. หากท่านตอบว่ามี ท่านรู้สึกเสียใจ เพียงใดที่คนง
 นั้นไม่ได้ให้ความช่วยเหลือตามที่ท่านคาดหวังไว้?
 ไม่เสียใจเลย..... 0
 เสียใจ เล็กน้อย..... 1
 เสียใจ ปานกลาง..... 2
 เสียใจ มาก..... 3
 เสียใจ มากที่สุด..... 4

ความเป็นห่วง

ผู้วิจัยต้องการทราบว่าท่านกังวลใจเกี่ยวกับข้อคำถามเหล่านี้มากน้อยเพียงไร

ท่านมีความกังวลเกี่ยวกับเรื่องต่างๆ ต่อไปนี้มากน้อยเพียงใด	ไม่ เลย	น้อย ครั้ง	บ้าง บางครั้ง	มาก มาก	มาก ที่สุด
1. สุขภาพของผู้สูงอายุ?	0	1	2	3	4
2. การได้รับความช่วยเหลืออย่างเพียงพอในสิ่งที่ท่าน ไม่สามารถทำให้กับ ผู้สูงอายุได้?	0	1	2	3	4
3. อารมณ์ หรือสภาวะจิตใจของ ผู้สูงอายุ ?	0	1	2	3	4
4. ปัญหาทางการเงินอันเนื่องมาจากการ ดูแลผู้สูงอายุ มากน้อยเพียงใด?	0	1	2	3	4
5. ความสามารถของท่านที่จะให้การดูแลผู้สูงอายุ ในอนาคต เนื่องจากสุขภาพของตัวท่านเอง ?	0	1	2	3	4
6. ความปลอดภัยเมื่อผู้สูงอายุ ไข้เตา ในการหุงต้ม?	0	1	2	3	4
7. ถ้าผู้สูงอายุมีอาการเลวลง ท่านจะให้การดูแลผู้สูงอายุ ได้อย่างไร?	0	1	2	3	4

ความเป็นห่วง

ผู้วิจัยต้องการทราบว่าท่านกังวลใจเกี่ยวกับข้อคำถามเหล่านี้มากน้อยเพียงไร

	ไม่ เลย	น้อย ครั้ง	บ้าง บางครั้ง	มาก มาก	มากที่สุด
8. การทิ้งผู้สูงอายุ ไว้ตามลำพังเมื่อท่าน ต้องออกไปทำธุระนอกบ้าน (ถ้าท่านไม่เคยทิ้ง ผู้สูงอายุ ไว้ตามลำพัง ให้สมมุติว่าถ้า ท่านต้องไปทำธุระนอกบ้านและต้องทิ้งผู้สูงอายุ ไว้ตามลำพัง ท่านจะมีความกังวลมาก น้อยเพียงใด)?	0	1	2	3	4
9. ความปลอดภัยของผู้สูงอายุ เนื่องจาก ปัญหาที่จะถูกรถยนต์, รถมอเตอร์ไซด์, ตู้ๆ, สามล้อหรือจักรยานชน เมื่อผู้สูงอายุ ออกนอกบ้าน?	0	1	2	3	4
10. อนาคตของตัวเอง?	0	1	2	3	4
11. ใครจะดูแลผู้สูงอายุ หากท่านเป็นอะไรไป?	0	1	2	3	4
12. ความปลอดภัยของผู้สูงอายุเนื่องจากมีปืน หรืออาวุธอื่นๆ ในบ้าน?	0	1	2	3	4
13. การช่วยเหลือ หรือ คำแนะนำที่ได้รับจากแพทย์ และพยาบาลนั้นเพียงพอในการดูแลผู้สูงอายุ?	0	1	2	3	4

ความเป็นห่วง

ผู้วิจัยต้องการทราบว่าท่านกังวลใจเกี่ยวกับข้อคำถามเหล่านี้มากน้อยเพียงไร

ท่านมีความกังวลเกี่ยวกับเรื่องต่างๆ ต่อไปนี้มาก น้อยเพียงใด	ไม่ เลย	น้อย ครั้ง	บ้าง บางครั้ง	มาก มาก	มากที่สุด
14. ความปลอดภัยเมื่อผู้สูงอายุ ใช้นั่งของ มีคมเช่น มีด หรือ เครื่องใช้ไฟฟ้าต่างๆ?	0	1	2	3	4
15. การที่ท่าน ดูแลผู้สูงอายุ ที่เจ็บป่วย นั้นส่งผล เสียต่อ คนในครอบครัวคนอื่น?	0	1	2	3	4
16. ผู้สูงอายุ จะมีอาการของโรครุนแรงมากขึ้น?	0	1	2	3	4
17. มีสิ่งใดบ้างที่ท่านมีความกังวลนอกเหนือจากนี้					
ก) _____	0	1	2	3	4
ข) _____	0	1	2	3	4
ค) _____	0	1	2	3	4

ปัญหา การได้ยิน, การพูด, และความจำ

คำถามต่อไปนี้จะเน้นถึงการติดต่อสื่อสารระหว่างท่านและผู้สูงอายุคนที่มีปัญหาเกี่ยวกับ การได้ยิน, การพูด และ ความจำ มักจะเป็นอุปสรรคต่อความเข้าใจ หรือ การสื่อสารกับคนอื่น ๆ.

1. ผู้สูงอายุมีปัญหาเรื่องการได้ยิน
น้อยเพียงใด?

- | | | | |
|-----------------|-----------------|---|------------|
| ไม่เลย | 0 (ไปตอบ ข้อ 2) | } | ตอบ ข้อ 1ก |
| น้อยครั้ง | 1 | | |
| บางครั้ง | 2 | | |
| มาก | 3 | | |
| มากที่สุด | 4 | | |

1ก. ปัญหาการได้ยินของผู้สูงอายุ
ทำให้ท่านมีความลำบากในการดูแล
มากน้อยเพียงใด?

- | | |
|-----------------|---|
| ไม่เลย | 0 |
| น้อยครั้ง | 1 |
| บางครั้ง | 2 |
| มาก | 3 |
| มากที่สุด | 4 |

2. ผู้สูงอายุมีปัญหาในการพูดมาก
น้อยเพียงใด?

- | | | | |
|-----------------|-----------------|---|------------|
| ไม่เลย | 0 (ไปตอบ ข้อ 3) | } | ตอบ ข้อ 2ก |
| น้อยครั้ง | 1 | | |
| บางครั้ง | 2 | | |
| มาก | 3 | | |
| มากที่สุด | 4 | | |

2 ก. ปัญหาการพูดของผู้สูงอายุ
ทำให้ท่านมีความลำบากในการดูแลมาก
น้อยเพียงใด?

- | | |
|-----------------|---|
| ไม่เลย | 0 |
| น้อยครั้ง | 1 |
| บางครั้ง | 2 |
| มาก | 3 |
| มากที่สุด | 4 |

3. ผู้สูงอายุมีปัญหาในด้านการจำหรือ
เข้าใจสิ่งที่ท่านพูดมากน้อยเพียงใด?

- | | | | |
|-----------------|-----------------|---|------------|
| ไม่เลย | 0 (ไปตอบ ข้อ 4) | } | ตอบ ข้อ 3ก |
| น้อยครั้ง | 1 | | |
| บางครั้ง | 2 | | |
| มาก | 3 | | |
| มากที่สุด | 4 | | |

3ก. ปัญหาเรื่องความจำหรือความเข้าใจของ
ผู้สูงอายุ ทำให้ท่านมีความลำบากในการ
ดูแลผู้สูงอายุมากน้อยเพียงใด?

- | | |
|-----------------|---|
| ไม่เลย | 0 |
| น้อยครั้ง | 1 |
| บางครั้ง | 2 |
| มาก | 3 |
| มากที่สุด | 4 |

4. ท่านมีปัญหาเรื่องการได้ยินมากน้อยเพียงใด?

- | | | | |
|-----------------|---------------------|---|------------|
| ไม่เลย | 0 (ไปตอบ หน้าต่อไป) | } | ตอบ ข้อ 4ก |
| น้อยครั้ง | 1 | | |
| บางครั้ง | 2 | | |
| มาก | 3 | | |
| มากที่สุด | 4 | | |

4ก. ปัญหาการได้ยินของท่านทำให้ท่านมีความลำบาก
ในการดูแลผู้สูงอายุมากน้อยเพียงใด?

- | | |
|-----------------|---|
| ไม่เลย | 0 |
| น้อยครั้ง | 1 |
| บางครั้ง | 2 |
| มาก | 3 |
| มากที่สุด | 4 |

ปัญหาการได้ยิน, การพูด, และ ความจำ

ปัญหาการได้ยิน, การพูด และ ความจำ	ไม่ เลย	น้อย ครั้ง	บาง ครั้ง	มาก	มาก ที่สุด
5. สร้างความคับข้องใจให้ท่านมากน้อยเพียงใด?	0	1	2	3	4
6. ทำให้ท่านลำบากในการพูดคุยกับผู้สูงอายุ มากน้อยเพียงใด?	0	1	2	3	4
7. ทำให้ท่านขาดความอดทนมากน้อยเพียงใด?	0	1	2	3	4

ปัญหาการดูแล

บางครั้งผู้ดูแลจะประสบปัญหาดังต่อไปนี้ ซึ่งทำให้การดูแลมีความยากลำบากมากขึ้น

สิ่งต่อไปนี้ เป็นปัญหากับท่านมากน้อยเพียงใด	ไม่เป็น ปัญหา	เป็นปัญหา เล็กน้อย	เป็นปัญหา ปานกลาง	เป็นปัญหา มาก	เป็นปัญหา มากที่สุด
8. ปัญหาเกี่ยวกับการขาดแคลนการเงินหรือไม่?	0	1	2	3	4
9. ท่านรู้สึกอ่อนล้าด้านอารมณ์?	0	1	2	3	4
10. ท่านรู้สึกเหน็ดเหนื่อยด้านร่างกาย?	0	1	2	3	4
11. การไม่มีเวลาเพียงพอ?	0	1	2	3	4
12. การไม่ได้รับความช่วยเหลืออย่างเพียงพอจากผู้อื่น? ...	0	1	2	3	4
13. การไม่มีพื้นที่เพียงพอภายในบ้าน?	0	1	2	3	4
14. การไม่มีห้องแยกให้ผู้สูงอายุ?	0	1	2	3	4
15. มีเวลานอนน้อยลง?	0	1	2	3	4

ความพร้อมในการดูแล

ผู้วิจัยทราบว่าผู้ดูแลบางคนอาจความพร้อมในการดูแลในตำแหน่งใดตำแหน่งหนึ่ง ผู้วิจัยต้องการทราบว่าท่านมีความพร้อมในข้อคำถามต่อไปนี้เพียงใด ในช่วงแรกที่ท่านหาที่ดูแล ถึงแม้ว่าในปัจจุบันท่านจะไม่ได้ทำสิ่งเหล่านี้ก็ตาม

	ไม่มี ความพร้อมเลย	มี ความพร้อม เล็กน้อย	มี ความพร้อม ปานกลาง	มี ความพร้อม มาก	มี ความพร้อม มากที่สุด
1. ท่านคิดว่าท่านมีความพร้อมในการดูแลความต้องการด้านร่างกายของผู้สูงอายุ มากน้อยเพียงใด?	0	1	2	3	4
2. ท่านคิดว่าท่านมีความพร้อมในการดูแลความต้องการทางด้านอารมณ์ของผู้สูงอายุ มากน้อยเพียงใด?	0	1	2	3	4
3. ท่านคิดว่าท่านมีความพร้อมที่จะหาข้อมูลเกี่ยวกับการบริการและจัดหาบริการการดูแลให้กับ ผู้สูงอายุ มากน้อยเพียงใด?	0	1	2	3	4
4. ท่านคิดว่าท่านมีความพร้อมในการจัดการกับความเครียดที่เกิดขึ้นระหว่างดูแล ผู้สูงอายุ มากน้อยเพียงใด?	0	1	2	3	4
5. ท่านคิดว่าท่านมีความพร้อมในการดูแลผู้สูงอายุ ให้เกิดความพึงพอใจทั้งตัวท่านเองและ ผู้สูงอายุมากน้อยเพียงใด?	0	1	2	3	4
6. ท่านคิดว่าท่านมีความพร้อมในการจัดการกับ ภาวะฉุกเฉินที่เกิดขึ้นกับผู้สูงอายุ มากน้อยเพียงใด?	0	1	2	3	4
7. ท่านคิดว่าท่าน มีความพร้อมในการขอความช่วยเหลือและขอข้อมูลที่จำเป็นจากทางโรงพยาบาล หรือศูนย์สาธารณสุขได้มากน้อยเพียงใด?	0	1	2	3	4
8. โดยรวม ท่านคิดว่าท่านมีความพร้อมในการดูแล ผู้สูงอายุมากน้อยเพียงใด?	0	1	2	3	4

ชีวิตประจำวันของท่าน

ผู้วิจัยต้องการทราบถึงชีวิตประจำวัน และ ความสามารถในการคาดการณ์ของท่าน.

1. ท่านสามารถคาดการณ์ถึงความต้องการของ

ผู้สูงอายุ มากน้อยเพียงใด?

ไม่สามารถคาดการณ์ได้เลย 0

คาดการณ์ได้บ้างเล็กน้อย 1

คาดการณ์ได้ปานกลาง 2

คาดการณ์ได้มาก 3

คาดการณ์ได้มากที่สุด 4

2. ท่านสามารถคาดการณ์ถึงกิจกรรมการดูแลที่

ท่านทำอยู่เป็นประจำหรือกิจกรรมการดูแล

ที่ท่านต้องทำให้กับผู้สูงอายุได้

มากน้อยเพียงใด?

ไม่สามารถคาดการณ์ได้เลย 0

คาดการณ์ได้บ้างเล็กน้อย 1

คาดการณ์ได้ปานกลาง 2

คาดการณ์ได้มาก 3

คาดการณ์ได้มากที่สุด 4

3. บ่อยครั้งเพียงใดที่กิจกรรมที่ท่านปฏิบัติอยู่เป็นประจำต้องหยุดชะงักลงอย่างไม่ได้คาดคิดเนื่องจาก

ปัญหาของผู้สูงอายุ?

ไม่เคยเลย 0

นานๆครั้ง 1

บางครั้ง 2

ค่อนข้างบ่อย 3

เป็นประจำ 4

4. บ่อยครั้งเพียงใดที่ท่านสามารถดำเนินกิจวัตร

ประจำวันของท่านได้ตามแผนที่วางไว้?

ไม่เคยเลย 0

นานๆครั้ง 1

บางครั้ง 2

ค่อนข้างบ่อย 3

เป็นประจำ 4

5. ในขณะที่ท่านรู้สึกว่าคุณสามารถควบคุม

ชีวิตของท่านได้ มากน้อยเพียงใด?

ควบคุมไม่ได้เลย 0

ควบคุมได้เล็กน้อย 1

ควบคุมได้ปานกลาง 2

ควบคุมได้มาก 3

ควบคุมได้มากที่สุด 4

6. ในขณะที่ท่านสามารถคาดการณ์สถานการณ์ชีวิต

ของท่านได้มากน้อยเพียงใด?

ไม่สามารถคาดการณ์ได้เลย 0

คาดการณ์ได้บ้างเล็กน้อย 1

คาดการณ์ได้ปานกลาง 2

คาดการณ์ได้มาก 3

คาดการณ์ได้มากที่สุด 4

7. เมื่อท่านคิดถึงสถานการณ์ของการดูแลผู้สูงอายุ โดยรวมท่านคิดว่า...

ท่านอยากให้สามารถคาดการณ์ได้มากกว่านี้ 1

ท่านชอบความสามารถคาดการณ์ของท่านในขณะนี้ 2

สิ่งต่างๆสามารถคาดการณ์ได้อย่างง่ายดายและเป็นกิจวัตรและอยากให้

มีการเปลี่ยนแปลงในชีวิตประจำวันได้มากกว่านี้ 3

ความรู้สึกที่ดีที่ได้รับจากการดูแล

ผู้วิจัยทราบว่า ผู้ดูแลบางท่านพบว่า การดูแลผู้สูงอายุ นั้น ก่อให้เกิดความรู้สึกที่ดี แต่ผู้ดูแลบางท่านไม่รู้สึกเช่นนั้น คำถามต่อไปนี้อาจจะตรงหรือไม่ตรงกับความรู้สึกของท่าน คำตอบที่ท่านให้ไม่มีถูก หรือผิด

	ไม่ เลย	เล็ก น้อย	ปาน กลาง	มาก	มาก ที่สุด
1. การดูแลผู้สูงอายุช่วยให้ท่านเข้าใจถึงความแก่ชรา ของตัวท่านเอง มากน้อยเพียงใด?	0	1	2	3	4
2. การดูแลผู้สูงอายุช่วยให้ท่านรู้สึกที่ท่านกำลังทำใน สิ่งที่มีความสำคัญ มากน้อยเพียงใด?	0	1	2	3	4
3. การดูแลผู้สูงอายุช่วยให้ท่านเข้าใจสภาพของคน ชราโดยทั่วไป มากน้อยเพียงใด?	0	1	2	3	4
4. การดูแลผู้สูงอายุช่วยให้ท่านมีความรู้สึกที่ดีเกี่ยวกับ ตัวของตนเอง มากน้อยเพียงใด?	0	1	2	3	4
5. ท่านมีความรู้สึกที่ดีเนื่องจากท่านรู้สึกว่าท่าน ช่วยให้ชีวิตของผู้สูงอายุดำเนิน ไปได้ง่ายขึ้น มากน้อยเพียงใด?	0	1	2	3	4
6. การที่ท่านดูแลผู้สูงอายุทำให้ชีวิตของท่านมีความหมาย มากขึ้น มากน้อยเพียงใด?	0	1	2	3	4
7. ท่านเรียนรู้เกี่ยวกับภาวะสุขภาพ และความเจ็บป่วย จากการดูแลผู้สูงอายุ มากน้อยเพียงใด?	0	1	2	3	4
8. การดูแลผู้สูงอายุทำให้ ท่านรู้สึกว่า ท่านได้ทำในสิ่งที่ท่าน ตั้งใจไว้ มากน้อยเพียงใด?	0	1	2	3	4

ความรู้สึกที่ดีที่ได้รับจากการดูแล

ผู้วิจัยทราบว่า ผู้ดูแลบางท่านพบว่าการดูแลผู้สูงอายุนั้น ก่อให้เกิดความรู้สึกที่ดี แต่ผู้ดูแลบางท่านไม่รู้สึกเช่นนั้น คำถามต่อไปนี้อาจจะตรงหรือไม่ตรงกับความรู้สึกของท่าน คำตอบที่ท่านให้ไม่มีถูก หรือผิด

	ไม่ เลย	เล็ก น้อย	ปาน กลาง	มาก	มาก ที่สุด
9. ท่านมีความรู้สึกดีใจ ที่ได้ช่วยเหลือเมื่อผู้สูงอายุต้องการความช่วยเหลือ มากน้อยเพียงใด?	0	1	2	3	4
10. การดูแลผู้สูงอายุช่วยให้ท่านเปลี่ยนแปลงไปในทางที่ดีขึ้น เช่น ใจเย็น หรือ อึดทนขึ้น มากน้อยเพียงใด?	0	1	2	3	4
11. ท่านรู้สึกดีใจที่ท่านได้เป็นคนดูแลผู้สูงอายุ มากน้อยเพียงใด?	0	1	2	3	4
12. การดูแลผู้สูงอายุช่วยให้ ท่านเข้าใจมากขึ้นถึงกระบวนการของความแก่ชรา มากน้อยเพียงใด?	0	1	2	3	4
13. การดูแลผู้สูงอายุช่วยให้ ท่านมีความรู้สึกปลื้มใจ เนื่องจากท่านดูแลผู้สูงอายุแล้วทำให้ผู้สูงอายุมีความสุข มากน้อยเพียงใด?	0	1	2	3	4
14. การดูแลผู้สูงอายุช่วยให้ท่านมีความรู้สึกที่ดี เนื่องจากรู้ว่าท่านได้ทำประโยชน์ให้กับผู้สูงอายุ มากน้อยเพียงใด?	0	1	2	3	4
15. การดูแลผู้สูงอายุช่วยให้ท่านมีความรู้สึกว่าคุณได้ทำบุญกุศล ซึ่งอาจจะ ทำให้ท่าน มีชีวิตที่ดีในชาตินี้ หรือชาติหน้า มากน้อยเพียงใด?	0	1	2	3	4
16. การดูแลผู้สูงอายุช่วยให้ท่านมีความรู้สึกว่าคุณได้ตอบแทนบุญคุณผู้สูงอายุ มากน้อยเพียงใด?	0	1	2	3	4
17. การดูแลผู้สูงอายุช่วยให้ท่านมีความรู้สึกปิติ ยินดี มากน้อยเพียงใด?	0	1	2	3	4

ความรู้สึกที่ดีที่ซึ่งได้รับการดูแล

ผู้วิจัยทราบว่า ผู้ดูแลบางท่านพบว่า การดูแลผู้สูงอายุ นั้น ก่อให้เกิดความรู้สึกที่ดี แต่ผู้ดูแลบางท่านไม่รู้สึกเช่นนั้น คำถามต่อไปนี้ อาจะตรงหรือไม่ตรงกับความรู้สึกของท่านคำตอบที่ท่านให้ไม่มีถูก หรือผิด

	ไม่ เลย	เล็ก น้อย	ปาน กลาง	มาก	มาก ที่สุด
18. การดูแลผู้สูงอายุช่วยให้ท่านมีความรู้สึกที่ท่าน จะมีชีวิตที่ดีในอนาคต มากน้อยเพียงใด?	0	1	2	3	4
19. การดูแลผู้สูงอายุช่วยให้ท่านมีความรู้สึกดี เนื่องจากว่าท่านทำกรรมดี มากน้อยเพียงใด?	0	1	2	3	4
20. ท่านมีความสุขเพราะคนในครอบครัว ชมว่าท่านให้การดูแล ผู้สูงอายุเป็นอย่างดีมากน้อยเพียงใด?	0	1	2	3	4
21. ท่านได้รับคำชมว่าเป็นตัวอย่างที่ดีเพราะ ท่านให้การ ดูแลผู้สูงอายุ มากน้อยเพียงใด?	0	1	2	3	4
22. ท่านมีความสุขเพราะญาติพี่น้องของท่าน มองเห็นท่าน เป็นคนดี จากการดูแลผู้สูงอายุมากน้อยเพียงใด?	0	1	2	3	4
23. ท่านรู้สึกดีใจเนื่องจากเพื่อน, เพื่อนบ้าน หรือ หมอ พยาบาล มองเห็นว่าท่านเป็นคนดี มากน้อยเพียงใด?	0	1	2	3	4
24. การดูแลผู้สูงอายุช่วยภาวะทางการเงินของท่าน เช่น การได้เงินจากญาติพี่น้อง หรือ ได้เงินบำนาญของ ผู้สูงอายุ มากน้อยเพียงใด?	0	1	2	3	4
25. การดูแลผู้สูงอายุจะช่วยฐานะการเงินของ ท่านในอนาคต มากน้อยเพียงใด?	0	1	2	3	4
26. การดูแลผู้สูงอายุช่วยให้ท่านประหยัดมากกว่า การจ้างคนอื่นมาดูแลหรือส่งผู้สูงอายุไปฝากดูแลที่ สถานรับดูแลคนชรา มากน้อยเพียงใด?	0	1	2	3	4

บทบาทของท่าน

คำถามต่อไปนี้เน้นถึง บทบาทต่างๆของท่าน การที่ท่านให้การดูแลผู้สูงอายุ อาจทำให้เป็นอุปสรรค ต่อ การ ทำบทบาทอื่นๆ, กรุณา บอกผู้วิจัย, ถาท่านไม่มีบทบาทนั้น,

การดูแลผู้สูงอายุมีอุปสรรคต่อ ความสามารถของท่านในการ . . .	ไม่ เลย	เล็ก น้อย	ปาน กลาง	มาก	มาก ที่สุด	ไม่ มีบทบาท นี้.
1. ทำหน้าที่ของภรรยา/สามีที่ท่านคิดว่าควรจะเป็น เป็นมากน้อยเพียงใด?.....	0	1	2	3	4	<input type="checkbox"/>
2. ทำหน้าที่ของพ่อหรือแม่ที่ท่านคิดว่าควรจะเป็น มากน้อยเพียงใด?.....	0	1	2	3	4	<input type="checkbox"/>
3. ทำหน้าที่ของลูกสาว/ลูกชายที่ท่านคิดว่าควร จะเป็นมากน้อยเพียงใด?.....	0	1	2	3	4	<input type="checkbox"/>
4. ทำหน้าที่ของพี่หรือน้องที่ท่านคิดว่าควรจะเป็น เป็นมากน้อยเพียงใด?.....	0	1	2	3	4	<input type="checkbox"/>
5. ทำหน้าที่ของการเป็นปู่ย่า/ตายายที่ท่านคิดว่าควรจะเป็น เป็นมากน้อยเพียงใด?.....	0	1	2	3	4	<input type="checkbox"/>
6. ทำหน้าที่ของการเป็นญาติซึ่งนอกเหนือจากที่ กล่าวมาในข้อ 1 ถึง 5 มากน้อยเพียงใด?	0	1	2	3	4	<input type="checkbox"/>
7. ทำหน้าที่ของการเป็นเพื่อนที่ท่านคิดว่าควรจะเป็น เป็นมากน้อยเพียงใด?.....	0	1	2	3	4	<input type="checkbox"/>
8. ทำหน้าที่ของการเป็นคนทำงานนอกบ้านอย่างที่ท่าน คิดว่าควรจะเป็นมากน้อยเพียงใด?.....	0	1	2	3	4	<input type="checkbox"/>
9. ทำหน้าที่ของการเป็นคนทำงานในบ้านที่ท่านคิด ว่าควรจะเป็นมากน้อยเพียงใด?.....	0	1	2	3	4	<input type="checkbox"/>

บทบาทของท่าน

คำถามต่อไปนี้เน้นถึง บทบาทหน้าที่ต่างๆของท่าน การที่ท่านให้การดูแลผู้สูงอายุ อาจทำให้เป็นอุปสรรค ต่อ การทำบทบาทอื่นๆ. กรุณา บอกผู้วิจัย. ถ้าท่านไม่มีบทบาทนั้น,

การดูแลผู้สูงอายุมีอุปสรรคต่อ ความสามารถของท่านในการ . . .	ไม่ เลย	เล็ก น้อย	ปาน กลาง	มาก	มาก ที่สุด	ไม่ มีบทบาท นี้.
10. ทำหน้าที่ของการเป็นนักศึกษาที่ท่านคิดว่าควร จะเป็นมากน้อยเพียงใด?.....0		1	2	3	4	<input type="checkbox"/>
11. เข้าร่วมกิจกรรมทางศาสนา เช่นไปวัดใน วันสำคัญต่างๆ ทางศาสนา, การไปร่วมทำบุญใน โอกาสต่างๆ มากน้อยเพียงใด?	0	1	2	3	4	<input type="checkbox"/>
12. เข้าร่วมงานสังคม เช่น งานแต่งงาน, งานศพ, งานบุญร้อยวัน มากน้อยเพียงใด?	0	1	2	3	4	<input type="checkbox"/>
13. ทำสิ่งดี ๆ ให้กับตัวเอง เช่น การดูแลตัวเอง มากน้อยเพียงใด?	0	1	2	3	4	<input type="checkbox"/>
14. ความรับผิดชอบอื่นๆที่ท่านมีอยู่มีผลรบกวน การดูแลผู้สูงอายุให้เป็นไปตามที่ท่านคิดว่าควร จะเป็นมากน้อยเพียงใด ?	0	1	2	3	4	<input type="checkbox"/>

ท่านและผู้สูงอายุ

ผู้วิจัยต้องการทราบว่า ในปัจจุบันนี้ท่านมีความรู้สึกอย่างไรต่อผู้สูงอายุ

	ไม่ เลย	เล็ก น้อย	บางครั้ง	มาก	มาก ที่สุด
1. ท่านและ ผู้สูงอายุ มีความเห็นตรง กันในเรื่องต่างๆ มากน้อยเพียงใด?	0	1	2	3	4
2. ท่านมีความใกล้ชิดสนิทสนมกับผู้สูงอายุ มากน้อยเพียงใด?	0	1	2	3	4
3. ท่านมีความสุขที่ได้ร่วมพูดคุยหรือฟังถึงความหลังกับ ผู้สูงอายุมากน้อยเพียงใด?	0	1	2	3	4
4. ผู้สูงอายุแสดงออกถึงความรู้สึกซาบ ซึ้งในตัวท่านและสิ่งที่ท่านปรารถนาต่อผู้สูงอายุ มากน้อยเพียงใด?	0	1	2	3	4
5. ท่านรู้สึกผูกพันกับผู้สูงอายุ มากน้อยเพียงใด?	0	1	2	3	4
6. ผู้สูงอายุให้ความช่วยเหลือ ท่านมากน้อยเพียงใด?	0	1	2	3	4
7. ท่านชอบนั่งและพูดคุยกับผู้สูงอายุ มากน้อยเพียงใด?	0	1	2	3	4
8. ท่านมีความรักในตัว ผู้สูงอายุมากน้อยเพียงใด?	0	1	2	3	4
9. ท่านและ ผู้สูงอายุให้ความสำคัญ (คุณค่า) กับสิ่งหนึ่งสิ่งใดในชีวิต พ้องกันมากน้อยเพียงใด?	0	1	2	3	4

ท่านและสมาชิกในครอบครัวท่าน

ผู้วิจัยต้องการทราบว่า ในปัจจุบันนี้ท่านมีความรู้สึกอย่างไรต่อผู้สูงอายุ

	ไม่ เลย	เล็กน้อย	บางครั้ง	มาก	มากที่สุด
10. เมื่อท่านมีความทุกข์ ผู้สูงอายุ ช่วยปลอบ ใจท่านทำให้ท่านรู้สึกสบายใจมากน้อยเพียงใด?	0	1	2	3	4
11. ท่านกับ ผู้สูงอายุ พุดคุยกันอย่างสนุกสนาน บ่อยครั้งเพียงใด?	0	1	2	3	4
12. ท่านปรับทุกข์กับ ผู้สูงอายุ มากน้อยเพียงใด?	0	1	2	3	4
13. ผู้สูงอายุ ให้กำลังใจและเห็นใจท่าน มากน้อยเพียงใด?	0	1	2	3	4
14. ท่านมีความสุขที่มีเวลาอยู่ด้วยกันกับผู้สูงอายุ มากน้อยเพียงใด?	0	1	2	3	4
15. ผู้สูงอายุ แสดงออกถึงความเอื้ออาทร ต่อท่านมากน้อยเพียงใด?	0	1	2	3	4

ความรู้สึกของท่านที่มีต่อการช่วยเหลือผู้สูงอายุ

1. มีความช่วยเหลือใดบ้างที่ท่านคิดว่าท่านควรให้กับผู้สูงอายุ แต่ท่านไม่สามารถให้ความช่วยเหลือ?

ไม่มี 0 (ไปตอบข้อ2)

มี 1

ไม่แน่ใจ -8 (ไปตอบข้อ2)



1ก. ถ้ามี, กรุณาบอกวาส่งนั้นคืออะไร?

1ข. ถ้ามี, สิ่งนั้นรบกวนจิตใจท่านมากน้อยเพียงใด?

ไม่เลย 0

เล็กน้อย 1

ปานกลาง 2

มาก 3

มากที่สุด 4

2. มีสิ่งใดบ้างที่ท่านทำเพื่อผู้สูงอายุแต่หลังจากที่ทำแล้วท่านคิดว่าท่านไม่น่าจะทำสิ่งนั้น?

ไม่มี 0 (ไปตอบข้อ3)

มี 1

ไม่แน่ใจ -8 (ไปตอบข้อ3)



2ก. ถ้ามี, กรุณาบอกวาส่งนั้นคืออะไร?

2ข. ถ้ามี, สิ่งนั้นรบกวนจิตใจท่านมากแค่ไหน?

ไม่เลย 0

เล็กน้อย 1

ปานกลาง 2

มาก 3

มากที่สุด 4

3. มีสิ่งใดบ้างที่ผู้สูงอายุพยายามทำด้วยตัวเอง แต่ท่านคิดว่าผู้สูงอายุควรที่จะให้ท่านช่วยเหลือในสิ่งนั้น?

ไม่มี 0 (ไปตอบข้อ. 4)

มี 1

ไม่แน่ใจ -8 (ไปตอบข้อ. 4)



3ก. ถ้ามี, กรุณาบอกวาส่งนั้น คืออะไร? _____

3ข. ถ้ามี, สิ่งเหล่านั้นรบกวนจิตใจท่านมากน้อยเพียงใด?

ไม่เลย 0

เล็กน้อย 1

ปานกลาง 2

มาก 3

มากที่สุด 4

4. มีบางสิ่งบางอย่างที่ท่านต้องทำให้ผู้สูงอายุ แต่ท่านคิดว่าผู้สูงอายุควรทำสิ่งเหล่านั้นเองมีหรือไม่?

ไม่มี 0 (ไปตอบข้อ5)

มี 1

ไม่แน่ใจ -8 (ไปตอบข้อ 5)



4ก. ถ้ามี, กรุณาบอกวาส่งนั้นคืออะไร? _____

4ข. ถ้ามี, สิ่งนั้นรบกวนจิตใจท่านมากแค่ไหน?

ไม่เลย 0

เล็กน้อย 1

ปานกลาง 2

มาก 3

มากที่สุด 4

ความรู้สึกละอายใจของท่านที่มีต่อการช่วยเหลือผู้สูงอายุ

5. ท่านรู้สึกกับผู้สูงอายุ มีความ
คาดหวังในตัวท่านมากเกินไปบ่อยครั้งเพียงใด?

- ไม่เคยเลย 0
- นานๆครั้ง 1
- บางครั้ง 2
- บ่อยครั้ง 3
- เสมอ 4

6. มีความช่วยเหลือบางอย่างที่ผู้สูงอายุ
ควรต้องการให้ท่านช่วยแต่เป็นความลำบาก
ของท่าน และผู้สูงอายุ เนื่องจากเป็นสิ่งที่
เหนื่อย?

- ไม่มี 0 (ไปตอบข้อ 7)
- มี 1

6ก. ถ้ามี, ท่านมีความเครียดจากความรู้สึก
อายแค่ไหน?

- ไม่เลย 0
- เล็กน้อย 1
- ปานกลาง 2
- มาก 3
- มากที่สุด 4

7. ครอบครัวยุคใหม่มีความขัดแย้งเกิดขึ้นเนื่อง
จากภาวะสุขภาพ และความต้องการ
การช่วยเหลือของผู้สูงอายุ?

- ไม่มีความขัดแย้ง 0
- มีความขัดแย้งเล็กน้อย 1
- มีความขัดแย้งปานกลาง 2
- มีความขัดแย้งมาก 3
- มีความขัดแย้งมากที่สุด 4

8. นอกเหนือจากการดูแล ผู้สูงอายุแล้ว
ท่านต้องการการดูแล คนอื่นๆ ที่มีการเจ็บป่วย
ด้วยหรือไม่?

- ไม่มี 0 (ตอบหน้าถัดไป)
- มี 1



8ก.

ถ้ามี, กรุณาให้รายละเอียดเกี่ยวกับสถานการณ์
และชนิดของ การช่วยเหลือที่ท่าน
ให้การดูแล?

ความรู้สึกของท่านที่มีต่อการช่วยเหลือผู้สูงอายุ

1. บ่อยครั้งแค่ไหนที่ท่านดำเนินตัวเองในพฤติกรรมบางอย่างที่ท่านแสดงออกต่อผู้สูงอายุ?

ไม่เคยเลย.....0

น้อยครั้งมาก.....1

บางครั้ง.....2

บ่อยครั้งมาก.....3

เป็นประจำ.....4

2. บ่อยครั้งแค่ไหนที่ท่านรู้สึกผิด หรือท่านรู้สึกว่าท่านไม่ได้ดูแลผู้สูงอายุเป็นอย่างดีเมื่อผู้สูงอายุมีอาการเลวลง?

ไม่เคยเลย.....0

น้อยครั้งมาก.....1

บางครั้ง.....2

บ่อยครั้งมาก.....3

เป็นประจำ.....4

3. บ่อยครั้งแค่ไหนที่ท่านรู้สึกเสียใจที่ท่านไม่สามารถให้การดูแลอย่างครบถ้วนหรือต่ากิจกรรมการดูแลบางอย่างให้กับผู้สูงอายุ?

ไม่เคยเลย.....0

น้อยครั้งมาก.....1

บางครั้ง.....2

บ่อยครั้งมาก.....3

เป็นประจำ.....4

ความรู้สึกของท่านที่มีต่อการช่วยเหลือผู้สูงอายุ

ผู้วิจัยต้องการทราบการดูแลผู้สูงอายุหรือการที่ติดต่อกับคนอื่น นั้นมีผลกระทบในทางลบต่อชีวิตของท่าน

การช่วยเหลือผู้สูงอายุ. . .	ไม่ เลย	เล็ก น้อย	ปานกลาง	มาก	มาก ที่สุด
1. ทำให้ท่านมีเวลาให้กับตัวเองน้อยลงหรือไม่?	0	1	2	3	4
2. เพิ่มความตึงเครียดในความสัมพันธ์ระหว่างท่านและผู้สูงอายุ?	0	1	2	3	4
3. ทำให้ความเป็นส่วนตัวของท่านลดน้อยลง?	0	1	2	3	4
4. ผู้สูงอายุพยายามเรียกร้องให้ท่าน ทำในสิ่งที่ท่านไม่อยากทำ?	0	1	2	3	4
5. ทำให้ท่านมีกิจกรรมเพื่อความเพลิดเพลินลดน้อย ลงหรือไม่?	0	1	2	3	4
6. ผู้สูงอายุเรียกร้องให้ช่วยเหลือในสิ่งที่ ไม่สมเหตุสมผลมากขึ้น?	0	1	2	3	4
7. เพิ่มความตึงเครียดให้กับชีวิตของท่าน?	0	1	2	3	4
8. ทำให้การหยุดพักผ่อนหรือการไปเที่ยวของท่าน ลดลงหรือไม่?	0	1	2	3	4
9. เพิ่มประสาตึงเครียดและซีจี้จากการที่ท่านพะวง ถึงความสัมพันธ์ของท่านกับผู้สูงอายุ?	0	1	2	3	4
10. ท่านรู้สึกว่าผู้สูงอายุเอาเปรียบท่าน?	0	1	2	3	4
11. ทำให้การทำงานส่วนตัวหรืองานบ้านของท่าน ลดลงหรือไม่?	0	1	2	3	4
12. ผู้สูงอายุเอาแต่ใจตัวเองซึ่งทำให้เพิ่มความ ช่วยเหลือนอกเหนือความจำเป็น?	0	1	2	3	4

ความรู้สึกของท่านที่มีต่อการช่วยเหลือผู้สูงอายุ

ผู้วิจัยต้องการทราบการดูแลผู้สูงอายุหรือการที่ติดต่อกับคนอื่น นั้นมีผลกระทบในทางลบต่อชีวิตของท่าน

การช่วยเหลือผู้สูงอายุ. . .	ไม่ เลย	เล็ก น้อย	ปานกลาง	มาก	มาก ที่สุด
13. เพิ่มความกังวลในเรื่องต่างๆ มากขึ้น?	0	1	2	3	4
14. ทำให้เวลาในการพบปะเพื่อนฝูงและญาติพี่น้อง ลดน้อยลง?	0	1	2	3	4
15. ทำให้ท่านมีเงินน้อยลงสำหรับค่าใช้จ่ายที่อื่นๆ?	0	1	2	3	4

ประสบการณ์โดยทั่วไปของท่านในการดูแลผู้สูงอายุ

- | | |
|--|---|
| <p>1. จากการพูดคุย กับผู้ดูแลบางคนเราทราบว่า ผู้ดูแลบางคนรู้สึกว่าการดูแล ผู้สูงอายุ ทำให้ขาดอิสระ ในขณะที่บางคนไม่รู้สึกเช่นนั้น สำหรับตัวท่านเอง ท่านรู้สึกว่าการดูแลผู้สูงอายุ ทำให้ขาดอิสระ มากน้อยเพียงใด?</p> <p>ไม่รู้สึกเลยว่าขาดอิสระ 0
 รู้สึกบ้างเล็กน้อย 1
 รู้สึกขาดอิสระปานกลาง 2
 รู้สึกขาดอิสระค่อนข้างมาก 3
 รู้สึกขาดอิสระมากที่สุด 4</p> <p>2. บ่อยครั้งเพียงใด ที่ท่านรู้สึกว่า การดูแล ผู้สูงอายุ มีความยากลำบาก?</p> <p>ไม่เคยเลย 0
 นานๆ ครั้ง 1
 บ้างครั้ง 2
 บ่อยครั้งมาก 3
 เป็นประจำ 4</p> <p>3. ท่านรู้สึกเครียด ต่อการรับผิดชอบในสิ่งต่างๆ รวมทั้งการดูแล ผู้สูงอายุ มากน้อยเพียงใด?</p> <p>ไม่เครียดเลย 0
 เครียดเล็กน้อย 1
 เครียดปานกลาง 2
 เครียดมาก 3
 เครียดมากที่สุด 4</p> <p>4. บ่อยครั้งแค่ไหนที่ท่านรู้สึกว่า ท่านขาดความอดทน ในการดูแลผู้สูงอายุ?</p> <p>ไม่เคยเลย 0
 น้อยครั้งมาก 1
 บ้างครั้ง 2
 บ่อยครั้งมาก 3
 เป็นประจำ 4</p> | <p>5. ในการดูแล ผู้สูงอายุ ท่านรู้สึกว่าท่านได้รับผลดี และผลเสียอย่างไร?</p> <p>มีผลดีมากกว่าผลเสียอย่างมาก 4
 ค่อนข้างไปทางด้านผลดีมากกว่าผลเสีย 3
 มีผลดีและผลเสียเท่ากัน 2
 ค่อนข้างไปทางมีผลเสียมากกว่าผลดี 1
 มีผลเสียมากกว่าผลดีมาก 0</p> <p>6. ความต้องการของผู้สูงอายุเปลี่ยนแปลงไปเรื่อยๆ ในกรณีของท่านเมื่อเวลา ผ่านไป การดูแลผู้สูงอายุ นั้น:</p> <p>ง่ายขึ้นมาก 4
 ค่อนข้างง่ายขึ้น 3
 เหมือนเดิม 2
 ค่อนข้างยากขึ้น 1
 ยากมาก 0</p> <p>7. ถ้าผู้สูงอายุ มีความต้องการการดูแล เพิ่มมากขึ้น ท่านมีความมั่นใจ เพียงใด ที่จะให้การดูแลผู้สูงอายุ มากกว่าที่ท่านทำอยู่ ในขณะนี้?</p> <p>ไม่มั่นใจเลย 0
 มั่นใจเล็กน้อย 1
 มั่นใจปานกลาง 2
 มั่นใจมาก 3
 มั่นใจมากที่สุด 4</p> |
|--|---|

ภาวะสุขภาพของผู้ดูแล

1. โดยทั่วไป, สุขภาพของท่าน:

- ดีมากที่สุด 1
 ดีมาก 2
 ดี 3
 พอใช้ 4
 แย่ 5

2. เปรียบเทียบกับเมื่อปีที่แล้ว,

ท่านประเมินภาวะสุขภาพของท่านโดยทั่วไป
 ในปัจจุบันนี้

- ดีมากกว่าปีที่แล้วมาก 1
 ค่อนข้างดีกว่าปีที่แล้ว 2
 เหมือนปีที่แล้ว 3
 ค่อนข้างแย่กว่าปีที่แล้ว 4
 แย่กว่าปีที่แล้วมาก 5

ข้อคำถามดังต่อไปนี้ ถามเกี่ยวกับกิจกรรมประจำวันของท่าน ภาวะสุขภาพของท่านในปัจจุบันนี้ มีความจำกัด
 การทำกิจกรรม ต่อไปนี้ หรือไม่ ถ้าใช่ มีความจำกัดมากน้อยเพียงใด?

กิจกรรม	ใช่ จำกัด มาก	ใช่ จำกัด เล็กน้อย	ไม่ จำกัด เลย
3. กิจกรรมที่ออกแรงมาก เช่น การวิ่ง, การยกของหนัก, การเล่นกีฬาอย่างหนัก	1	2	3
4. กิจกรรมที่ออกแรงปานกลาง เช่น เดินโต๊ะ, กวาดบ้าน, ถูบ้าน	1	2	3
5. การหิ้วของจาก การจ่ายตลาด หรือ ซุปเปอร์มาเก็ต	1	2	3
6. เดินขึ้นบันไดมากกว่าชั้น (ชั้นที่ 1 ไปชั้นที่ 3 หรือมากกว่า)	1	2	3
7. เดินขึ้นบันได 1 ชั้น (ชั้นที่ 1 ไปชั้นที่ 2)	1	2	3
8. งอตัว, ก้มตัว หรือ ก้มตัว	1	2	3
9. เดินมากกว่าหนึ่งกิโลครั้ง	1	2	3
10. เดินหลายร้อยเมตร	1	2	3
11. เดินร้อยเมตร	1	2	3
12. อาบน้ำ หรือ แต่งตัว	1	2	3

ภาวะสุขภาพของผู้ดูแล (ต่อ)

ในระหว่างหนึ่งเดือนที่ผ่านมา, ท่านมีปัญหาเกี่ยวกับการทำงานหรือ การปฏิบัติกิจวัตรประจำวัน ซึ่งเป็นผลมาจากสุขภาพทางด้านร่างกายของท่าน บ่อยครั้งเพียงใด

	ตลอด เวลา	เป็น ส่วนมาก	เป็นบาง ครั้ง	นานๆ ครั้ง	ไม่ เลย
13. ลดปริมาณเวลาในการทำงานหรือ กิจกรรมอื่นๆลง?	1	2	3	4	5
14. ทำงานหรือปฏิบัติกิจวัตรประจำวัน ได้สำเร็จน้อยกว่าที่อยากจะทำ?	1	2	3	4	5
15. ทำงาน หรือ ทำกิจกรรมบางอย่างไม่ได้?	1	2	3	4	5
16. มีความลำบากที่จะทำงาน หรือ กิจกรรมอื่นๆ (เช่น ต้องใช้ความพยายามมากขึ้นกว่าเดิม)?	1	2	3	4	5

ระหว่าง หนึ่งเดือนที่ผ่านมา, ท่านมีปัญหา การทำงานหรือ การปฏิบัติกิจวัตรประจำวัน ซึ่งเป็นผลมาจากสภาพอารมณ์ ของท่าน เช่น รู้สึกซึมเศร้า หรือ กังวล บ่อยครั้งเพียงใด

	ตลอด เวลา	เป็น ส่วนมาก	เป็นบาง ครั้ง	นานๆ ครั้ง	ไม่ เลย
17. ลดปริมาณเวลา ในการทำงานหรือ กิจกรรมอื่นๆลง?	1	2	3	4	5
18. ทำงานหรือทำกิจวัตรประจำวันได้สำเร็จ น้อยกว่าที่ท่านอยากจะทำ?	1	2	3	4	5
19. ทำงานหรือกิจกรรมอื่นๆ ด้วยความระมัด ระวังน้อยลง?	1	2	3	4	5

ภาวะสุขภาพของผู้ดูแล (ต่อ)

20. ในระหว่างหนึ่งเดือนที่ผ่านมา, ปัญหาทางภาวะสุขภาพ ทางร่างกาย และอารมณ์ ของท่านมีอุปสรรคต่อการเข้าร่วม กิจกรรมทางด้านสังคมตามปกติ กับครอบครัว, เพื่อน, เพื่อนบ้าน หรือ กลุ่มต่างๆ มากน้อยเพียงใด?

- ไม่เลย..... 1
- เล็กน้อย..... 2
- ปานกลาง 3
- ค่อนข้างมาก 4
- มากที่สุด..... 5

21. ท่านมีภาวะการเจ็บปวด ของร่างกาย ในระหว่างหนึ่ง เดือนที่แล้ว มากน้อยเพียงใด?

- ไม่มีเลย 1
- น้อยมาก 2
- เล็กน้อย..... 3
- ปานกลาง 4
- มาก 5
- มากที่สุด..... 6

22. ในระหว่างหนึ่งเดือนที่ผ่านมา, ภาวะการเจ็บปวดนั้นกระทบต่อการทำงานตามปกติของท่าน (รวมทั้ง การทำงานภายในบ้าน และ นอกบ้าน)?

- ไม่มีเลย 1
- เล็กน้อย..... 2
- ปานกลาง 3
- มาก 4
- มากที่สุด..... 5

ภาวะสุขภาพของผู้ดูแล (ต่อ)

ข้อคำถามต่อไปนี้ เกี่ยวกับความรู้สึกของท่าน และสิ่งที่เกิดระหวางหนึ่งเดือนที่ผ่านมาในการตอบคำถามในแต่ละขอ กรุณาตอบให้ใกล้เคียงกับความรู้สึกของท่านให้มากที่สุด

บ่อยครั้งเพียงใดในระหว่าง หนึ่งเดือนที่ผ่านมา.....	ตลอด เวลา	เป็น ส่วน มาก	เป็น บาง ครั้ง	นานๆ ครั้ง	ไม่ เลย
23. ท่านรู้สึกมีชีวิตชีวา หรือไม่?	1	2	3	4	5
24. ท่านเคยรู้สึกกังวลเป็นอย่างมาก หรือไม่?	1	2	3	4	5
25. ท่านเคย รู้สึกหดหูใจซึ่งไม่มี สิ่งใดที่ทำให้จิต ท่านดีขึ้นได้?	1	2	3	4	5
26. ท่านเคยมีความรู้สึกสงบและเป็นสุข หรือไม่?	1	2	3	4	5
27. ท่านมี พละกำลังเป็นอย่างมาก?	1	2	3	4	5
28. ท่านเคยรู้สึกท้อแท้ใจ และซีเมเศร้าหรือไม่?	1	2	3	4	5
29. ท่านรู้สึกหมดแรง หรือไม่?	1	2	3	4	5
30. ท่านรู้สึกมีความสุข?	1	2	3	4	5
31. ท่านรู้สึกอ่อนเพลีย?	1	2	3	4	5

32. ในระหว่าง หนึ่งเดือนที่ผ่านมา, ปัญหาทางภาวะสุขภาพทางร่างกาย และอารมณ์ของท่านมีอุปสรรค
ในการทำกิจกรรมทางดานสังคม เช่น ไปเยี่ยมเพื่อน, ญาติ มากน้อยเพียงใด?

- ตลอดเวลา 1
- เป็นส่วนมาก 2
- เป็นบางครั้ง 3
- นานๆ ครั้ง 4
- ไม่เลย 5

ภาวะสุขภาพและผู้ดูแล (ต่อ)

ประโยคต่อไปนี้ ถูกหรือผิด?

	ถูกต้อง ทุกประการ	ถูกต้อง เป็นส่วนใหญ่	ไม่ทราบ	ไม่ถูกต้อง เป็นส่วนใหญ่	ไม่ถูก ตongเลย
33. ฉันเจ็บป่วย น้อยกว่าคนทั่วไป	1	2	3	4	5
34. ฉันสุขภาพดีเหมือนคนอื่นที่ฉันรู้จัก	1	2	3	4	5
35. ฉันคิดว่าสุขภาพของฉันแย่มาก	1	2	3	4	5
36. ฉันรู้สึกว่าคุณภาพของฉันดีเยี่ยม	1	2	3	4	5

ความรู้สึกของผู้ดูแลในหนึ่งอาทิตย์ที่ผ่านมา

ความรู้สึกต่อไปนี้อาจเกิดขึ้นกับผู้ดูแลได้ กรุณาตอบให้ตรงกับ ความรู้สึกของท่านมากที่สุดในรอบสัปดาห์ที่ผ่านมา

- 1 = ความรู้สึกนั้นเกิดขึ้นน้อยกว่า 1 วัน
- 2 = ความรู้สึกนั้นเกิดขึ้น 1-2 วัน
- 3 = ความรู้สึกนั้นเกิดขึ้น 3-4 วัน
- 4 = ความรู้สึกนั้นเกิดขึ้น 5-7 วัน

	ไม่เลย น้อยกว่า 1 วัน	นานๆ ครั้ง 1-2 วัน	ค่อนข้าง บ่อย 3-4 วัน	บ่อย ครั้ง 5-7 วัน
1. ฉันรู้สึกหงุดหงิดง่าย.....	1	2	3	4
2. ฉันรู้สึกเบื่ออาหาร.....	1	2	3	4
3. ฉันรู้สึกว่าฉันไม่สามารถจัดการความหม่นหมองออกไป แม้ว่าจะมีคนในครอบครัว หรือ เพื่อนคอยช่วยเหลือ. .	1	2	3	4
4. ฉันรู้สึกว่าตนเองมีความดีดัดเทียมคนอื่น ๆ.....	1	2	3	4
5. ฉันรู้สึกลำบากในการตั้งสมาธิ เพื่อทำสิ่งใดสิ่งหนึ่ง.....	1	2	3	4
6. ฉันรู้สึกหดหู่ใจ.....	1	2	3	4
7. ฉันรู้สึกว่าทุกๆสิ่งๆที่ฉันกระทำต้องฝืนใจทำ.....	1	2	3	4
8. ฉันมีความหวังเกี่ยวกับอนาคต.....	1	2	3	4
9. ฉันคิดว่าชีวิตฉันมีแต่ความล้มเหลว.....	1	2	3	4
10. ฉันรู้สึกหวาดกลัว.....	1	2	3	4
11. ฉันนอนไม่ค่อยหลับ.....	1	2	3	4
12. ฉันมีความสุข.....	1	2	3	4
13. ฉันพูดน้อยกว่าปกติ.....	1	2	3	4
14. ฉันรู้สึกอ้างว้างเดียวดาย.....	1	2	3	4
15. ผู้คนทั่วไปไม่มีความเป็นมิตร.....	1	2	3	4
16. ฉันรู้สึกว่าชีวิตนี้มีแต่ความสนุกสนาน.....	1	2	3	4
17. ฉันมีกรองใจ.....	1	2	3	4
18. ฉันรู้สึกไม่มีความสุข.....	1	2	3	4
19. ฉันรู้สึกว่าผู้คนรอบข้างไม่ชอบฉัน.....	1	2	3	4
20. ฉันรู้สึกท้อถอยในชีวิต.....	1	2	3	4

กรุณาให้รายละเอียดเกี่ยวกับข้อมูลส่วนตัวของผู้ดูแล

1. ท่านอายุเท่าไร?
อายุ: _____ ปี
เกิดเมื่อ ____/____/____
2. เพศ?
ผู้หญิง 1
ผู้ชาย 2
3. ท่านจบการศึกษา ชั้นสูงสุดชั้นอะไร?
ไม่ได้เรียนหนังสือ 1
ประถมศึกษา 2
มัธยมศึกษาตอนต้น 3
มัธยมศึกษาตอนปลาย 4
ประกาศนียบัตร 5
เรียนไม่จบมหาวิทยาลัย 6
ปริญญาตรี 7
ปริญญาโท 8
อื่นๆ 9
4. ท่านมีอาชีพอะไร?

5. สถานะภาพสมรส ?
คู่ 1
หม้าย 2
หย่า 3
แยกกันกันอยู่ 4
ไม่เคยแต่งงาน 5
6. สมาชิกในครอบครัวทั้งหมดมีกี่คน?
7. กรุณาให้รายละเอียดเกี่ยวกับ ภาวะทางด้านการเงินของท่าน?
รายจ่ายมากกว่ารายรับ 1
ใช้เดือนชนเดือน 2
พอใช้และบางครั้งเหลือเก็บ เล็กน้อย .. 3
มีเงินเก็บในแต่ละเดือนอยู่เป็นประจำ .. 4
8. รายได้ของครอบครัวต่อเดือน
ต่ำกว่า 1,000.....1
1,001-5,000.....2
5,001-10,000.....3
10,001-15,000.....4
15,001-20,000.....5
20,000 ขึ้นไป.....6
9. ท่านจ้างคนอื่นมาดูแลด้วยผู้สูงอายุเงินส่วนตัวของท่านเองหรือไม่?
ไม่ 0
ใช่ 1
- 9ก. ถ้าตอบว่า ใช่, เป็นภาระกับท่านมากน้อยเพียงใด?
ไม่เป็นภาระ 0
เป็นภาระเล็กน้อย 1
เป็นภาระปานกลาง 2
เป็นภาระค่อนข้างมาก 3
เป็นภาระมากที่สุด 4
10. ขณะนี้ท่านทำงานหรือไม่?
1. ไม่, วางงาน
2. ไม่, เกษียณ
3. ไม่, กำลังหางานทำ
4. ไม่, หยุดทำงาน เพราะผู้สูงอายุ มีปัญหาทางสุขภาพ
5. ทำ, ทำเป็นบางวัน
6. ทำ, เป็นงานประจำ
11. ท่านทำงานประมาณกี่ชั่วโมง ต่อสัปดาห์?
_____ ชั่วโมง/สัปดาห์
12. กรุณาเล่าเกี่ยวกับภาวะสุขภาพของท่าน?

มุมมองของผู้ดูแล

1. ในประสบการณ์ของท่าน, การที่ท่าน ให้การดูแลผู้สูงอายุ มีผลทำให้ความสัมพันธ์ระหว่างท่านและผู้สูงอายุ เปลี่ยนแปลงไปจากเดิมหรือไม่

ไม่มี.....0

มี.....1

- 1ก. ถ้ามี, กรุณาบอกผู้วิจัยว่าการดูแลให้ความสัมพันธ์ระหว่างท่านและผู้สูงอายุ นั้นดีขึ้นได้อย่างไร หรือ มีเหตุการณ์ อะไรบ้างที่ทำให้ความสัมพันธ์ระหว่างท่านและผู้สูงอายุ นั้นแย่ลงกว่าเดิม?

- 1ข. กรุณา ยกตัวอย่างถึงลักษณะ คุณภาพความสัมพันธ์ที่ีระหว่างท่านและผู้สูงอายุ?

2. ท่านรู้สึกผิด หรือ เสียใจเกี่ยวกับ เหตุการณ์ที่เกิดขึ้น ในระหว่างที่ท่านให้การดูแลผู้สูงอายุหรือไม่?

ไม่มี..... 0

มี..... 1

- 2ก. ถ้ามี, ยกตัวอย่าง เหตุการณ์นั้น? _____

3. ท่านคิดว่า การดูแลผู้สูงอายุ ทำให้เกิดผลเสีย หรือผลดีต่อภาวะการเงินของท่านหรือไม่?

ไม่มี..... 0

มี..... 1

- 3ก. ถ้ามี, กรุณาเล่าถึงรายละเอียด? _____

มุมมองของผู้ดูแล

4. ในประสบการณ์ของท่าน, ท่านได้รับความรู้สึกที่ดีทางด้านจิตใจ จากการดูแลผู้สูงอายุอย่างไร? กรุณา
เล่ารายละเอียด

5. ท่าน เคยมีความรู้สึกที่ดี และไม่ดีในเวลาเดียวกัน ในขณะที่ให้การดูแลผู้สูงอายุ หรือไม่?
ไม่มี.....0

มี.....1

- 5ก. ถ้ามี, กรุณาเล่าถึงสถานการณ์เช่นใดที่ทำให้ท่านมีความรู้สึกเช่นนั้น? _____

6. กรุณาแสดงความคิดเห็น ว่าคำถามในลักษณะใดที่ผู้วิจัย ควรถาม ซึ่งจะช่วยให้ผู้วิจัยได้เข้าใจสถานการณ์
การดูแลผู้สูงอายุ มากขึ้น _____

Appendix F

The Script for the Clinical Nurse

The Script for the Clinical Nurse introducing the family caregiver to the researcher

Ms. Virapun Wirojratana is a graduate student at the Oregon Health Science University. She is interested in interviewing family caregivers who help an older family member with bathing, dressing, mobility, toileting, eating, cooking, shopping, cleaning house, managing money, or taking medication.

I would like to know if you are interested in talking to Virapun about participating in her research, and answering questions.

Appendix G

Training the Research Assistant

Procedures for Training the Research Assistant

The research assistant who had a master's degree in nursing education was trained for data collection as follows.

1. The researcher described the study to the research assistant. The researcher and research assistant then went through questionnaire. The researcher answered any questions that the research assistant had.
2. The researcher and research assistant practiced interviewing each other by using the Thai version of the FCI.
3. The research assistant went on a home visit with the researcher and observed the researcher conducting an interview.
4. In the next interview, the research assistant conducted the interview with the family caregiver and the researcher observed the interview. The researcher and research assistant discussed if there were any problems.
5. The researcher and research assistant met once a week to discuss any coding problems.