# Assessing Measures and Caregiving Experiences of Thai Caregivers of Persons with Dementia

Ву

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#### **ABSTRACT**

Background: The number of persons with dementia (PWD) has increased significantly. Informal caregivers form the major group to provide care for PWD. These caregivers can have perceived gains and burdens. Based on literature, caregivers who have had highly perceived gains may not only have less burdens but also experience a better health. Three main gaps were found from literature. First, some researchers did not report psychometric measures and define gains clearly. Second, most researchers did not use a theory to guide studies and conduct research in Eastern countries. Third, researchers have not fully described relationships among caregiving variables. Thus, I proposed to assess psychometric measures and relationships among caregiving variables with caregivers of PWD in Thailand guided by self-determination theory (SDT).

**Study Aims:** were to evaluate six measures for internal consistency reliability, four measures for content validity, and one measure for construct validity, and to examine relationships of variables: motivations, satisfaction with psychological needs, perceived gains and burdens, and caregiver health.

**Methods:** This study used a cross-sectional correlational descriptive design. I had two convenience samples by using self-report questionnaires. Sample 1 was five Thai experts and sample 2 was 146 Thai caregivers of PWD. Experts rated questionnaires for content validity. Caregivers answered questionnaires by interviewing or writing at clinics of four hospitals in Thailand. I analyzed data using descriptive statistics, bivariate analyses, and multivariate analyses, the composite indicator structural equation model (CISE), for controlling measurement errors.

**Results:** Most caregivers were middle age and daughter caregivers. They provided care on average of 15 hours/day for 4.6 years. The content validity indices of most items and all scales were .80 or higher for clarity, relevance, comprehensiveness, and cultural relevance. Experts

suggested for a few item revisions. Cronbach's alphas of six measures were .26 to .93. The gain scale had acceptable for construct validity. The satisfaction with needs and perceived support had significant positive relationships with caregiver health and a significant negative relationship with perceived burdens. The satisfaction with needs had significant positive relationships with each other. Five health subscales had significant positive relationships with each other and perceived burdens had significant negative relationships with caregiver health.

Discussion: Caregivers' characteristics were consistent with prior Thai studies. Four measures were valid and reliable but two measures were questionable for reliability. This was the first time of examining relationships among caregiving variables using SDT. This study provided breadth knowledge about relationships among caregiving variables. Cautious interpreting about relationships may be needed due to using the same sample to assess psychometrics.

Implications: Researchers could use fours measures with psychometric acceptability. Using a theory would help describe concepts and propositions and guide measure used. Researchers may examine satisfaction with psychological needs as mediators. Future studies by collecting data with caregivers in communities are needed to increase generalizability.

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#### **CHAPTER 1**

#### INTRODUCTION AND SPECIFIC AIMS

#### Introduction

Demands of care have increased, especially for older adults with chronic diseases and associated disabilities (Chan, 2011; Limpawattana et al., 2012; Schulz & Martire, 2004). Older adults need care from both formal caregivers that are paid professionals providing care and informal caregivers that are unpaid family members or friends providing care (Navaie-Waliser, Spriggs, & Feldman, 2002; Whitlatch & Noelker, 1996). Typically, informal caregivers often provide care for older adults at home (Bastawrous, 2013; Navaie-Waliser, Spriggs, & Feldman, 2002; Schulz & Sherwood, 2008). Informal caregiver refers to family members, relatives, partners, neighbors, or friends who have personal relationship with care recipients and provide unpaid care to these recipients with chronic diseases and associated disabilities at home (Blum & Sherman, 2010; Whitlatch & Noelker, 1996).

In this study, I focused on informal caregivers of persons with dementia (PWD). Informal caregivers form the major group who are providing care and assisting PWD at home (Chan, 2010). Dementia is an age-associated disease (Brodaty & Donkin, 2009). The number of people with dementia has significantly increased (Alzheimer's Disease International, 2013; Chan, 2010).

Informal caregivers of persons with dementia (PWD) can perceive caregiving as gains and burdens (Shim, Barroso, Davis, 2012). Because of long periods of time for providing care and changeable symptoms of PWD (Mohamed et al., 2010; Schulz & Martire, 2004), informal caregivers can have feelings of burden or depression (Etters, Goodall, & Harrison, 2008). At the same time, informal caregivers can feel good about themselves and strengthen family relationships because they are able to provide care competently with a closer relationship with other family members (Schulz & Sherwood, 2008).

Caregiving outcomes may include perceived gains and perceived burdens (Liew et al., 2012; Pinquart & Sörensen, 2003b). Caregiving outcomes may influence physical, mental, and emotional health of caregivers (Hilgeman, Allen, DeCoster, & Burgio, 2007). Researchers have found that caregivers who have reported strong gains from caregiving may not only have less burdens and depression from caregiving but also experience a better caregiver health in physical and psycho-emotional (Cohen, Colantonio, & Vernich, 2002; Hilgeman et al., 2007; Pinquart & Sörensen, 2003b). Researchers have also found that perceived burdens of caregiving have had a strong relationship to poor mental and physical health of caregivers (Etters, Goodall, & Harrison, 2008; Knight & Losada, 2011; Pinquart & Sörensen, 2007). Most researchers have focused on perceived burdens rather than perceived gains of caregiving (Koerner et al., 2009; Shim et al, 2012). Although researchers have recently paid more attention to study perceived gains, the number of studies about perceived gains is limited.

## **Gaps in Caregiving Research**

To increase understanding about caregiving outcomes, I have reviewed 25 caregiving studies about influences on perceived gains and burdens and caregiver health. I found that five main gaps could impede understanding of caregiving experiences about caregiving variables and the relationships among these variables. First, researchers have not reported reliability of measures in 5 of 19 quantitative studies. Second, most researchers have not reported about validity of relevant measures used in caregiving research. Third, most researchers have not defined gains clearly, such as uplifts of caregiving and meaning in caregiving. Fourth, researchers have not used a conceptual framework or theory to guide their studies in 12 of 19 quantitative studies. Fifth, most studies have been conducted in Western countries except for four studies that were conducted in Eastern countries. These five gaps may cause researchers to not fully describe: (a) conceptual and operational definitions of caregiving variables and (b) the relationships among caregiving variables.

## Filling Gaps

Filling those gaps would be helpful to increase understanding of caregiving experiences about the relationships among caregiving variables. To fill the first two gaps of lacking psychometric properties of caregiving measures, I decided to evaluate psychometric properties such as content validity and internal consistency reliability of selected measures about caregiving. I chose to do this because changing the context in which a measure is used can influence reliability of measures (Polit & Beck, 2008). Second, to fill another gap about unclear defining perceived gains, I provided definition of terms in this study as below to decrease confusion about caregiving concepts and provide direction for the study (Hunt, 2003). Third, I believe that applying a conceptual framework or theory would help researchers describe relationships among caregiving variables in the caregiving context. Using a conceptual framework or theory in quantitative studies would also guide researchers to choose appropriate measures (Bastawrous, 2013). I proposed to apply self-determination theory (SDT) to guide this study. Finally, to increase understanding about caregiving experience in an Eastern country, I proposed to conduct a study with caregivers of PWD in Thailand.

#### **Definition of Terms**

In this study, I defined the caregiving variables as follows:

Perceived competence. Perceived competence refers to people's perceptions of their abilities to carry out caregiving activities with confidence. Perceived competence about caregiving may influence caregiving outcomes (Vansteenkiste & Sheldon, 2006).

Caregiver-care recipient relationships. Caregiver-care recipient relationships refer to the quality of the relationship between caregivers and care recipients both before and during providing care (Carbonneau, Caron, & Desrosiers, 2010; Quinn et al., 2010).

*Motivations of caregivers.* Motivations of Caregivers refer to the expressions and meaning that direct caregivers to provide care (Dilworth-Anderson et al., 2005; Romero-Moreno et al., 2011).

Motivations of caregivers consist of two types: autonomous motivations and controlled motivations (Deci & Ryan, 2000).

Perceived informal social support. Perceived informal social support refers to "assistance provided by family members or friends based upon feelings of affection or personal obligation toward the recipients of the assistance" (Kaufman, Kosberg, Leeper, & Tang, 2010 p. 252). Perceived gains of caregiving. Perceived gains of caregiving refer to caregivers' perceived psychosocial growth from their caregiving in three domains: personal, relationship, and spiritual (Koerner et al., 2009; Liew et al., 2010).

Perceived burdens of caregiving. Perceived burdens of caregiving refer to caregivers' perceived physical, psychological, emotional, and social responses to their caregiving experiences (Bastawrous, 2013; Etters et al., 2008; Limpawattana et al., 2012).

Caregiver health. Caregiver health refers to caregivers' evaluations of their physical, mental, and emotional health when they are in the caregiving role (Huppert & So, 2013; Gitlin, Winter, Dennis, & Hauck, 2006).

#### Theory-Guided Study.

I used self-determination theory (SDT) to guide the study. SDT is described as essential elements of human nature on positive tendencies. These elements include motivations and psychological needs. People's motivations and satisfaction with psychological needs can direct their psychological growth, integrity, and well-being (Deci & Ryan, 2000). SDT authors have described type of motivations and satisfaction with psychological needs. SDT scholars have proposed that all people have three psychological needs: autonomy, competence, and relatedness. These variables with support of social environments can promote goal-direct behaviors, psychological growth, and well-being of people (Deci & Ryan, 2000).

SDT Researchers have applied motivations into two types as reasons of providing care: autonomous motivations and controlled motivations (Kim et al., 2008). Based on SDT,

researchers have studied satisfactions with autonomy, competence, relatedness and they have examined whether or not satisfactions with these needs were correlated with health and well-being of participants across four countries (Chen et al., 2015). Ng and colleagues did a meta-analysis of studies in which researchers had applied SDT in health contexts. They found that autonomous motivation and satisfactions with three psychological needs, that is, autonomy, competence, and relatedness, each had positive relationships with mental and physical health (Ng et al., 2012). If caregivers have autonomous motivation as a reason for providing care and this fulfills their satisfaction with the three psychological needs: autonomy competence and relatedness, they may be more likely to report perceived gains and have better health than caregivers with controlled motivations and low satisfaction with psychological needs (Kim et al., 2008; Quinn, Clare, McGuinnes, & Woods, 2012; Weinstein, DeHaan, & Ryan, 2010).

## **Assessing Psychometric Properties**

Before examining variables that may influence caregiving outcomes and their relationships, I proposed to fill gaps of lacking psychometric properties of caregiving measures. In this study, I proposed to use three groups of measures. First, because this study was guided by self-determination theory (SDT), SDT was used to describe concepts of type of motivations and satisfaction with psychological needs (Deci & Ryan, 2000). Relationships of these concepts directed to perceive gains and burdens and caregiver health based on SDT (Deci & Ryan, 2000; Ng et al., 2012). SDT was also guided to select two measures developed by SDT researchers. Two measures included a measure to assess caregivers' motivations and a measure to evaluate general caregivers' satisfactions with their psychological needs. The measure of assessing satisfaction with psychological needs was valid and reliable when researchers used it in Western countries (Gagne, 2003; Johnston & Finney, 2010). The measure of assessing caregivers' motivations was valid and reliable when researchers used with caregivers in the U.S. (Kim et al., 2008). Neither measures had been translated into Thai language nor reported

for psychometric properties in Thailand. Thus, I decided to do translation and back-translation of those measures, and then I evaluated those measures for content validity and internal consistency reliability.

Second, I proposed to use a measure to assess perceived gains of caregiving. There were a few studies about perceived gains of caregivers in Thailand (Ritteeveerakul, 2005). Thai researchers have only used a reward measure to assess perceived gains of caregiving. When comparing the reward measure with other measures to assess perceived gains, this measure did not focus on personal gains and gains in relationships. I proposed to use a measure to assess perceived gains. This measure was valid and reliable with caregivers of PWD when researchers used it with caregivers of PWD in Singapore (Yap et al., 2010). This measure was also more likely sensitive to assess perceived gains with Asian people than other measures. Additionally, the study of caregivers of PWD in Singapore was similar to caregivers in Thailand because both countries rely on daughter caregivers of a similar mean age (Liew et al., 2010). Although the perceived gain measure has been developed based on scientific methods and reported for psychometric properties differences in culture norms, religious beliefs, and language used may influence psychometric properties of measures. The perceive gain measure had not been translated into Thai language and reported for psychometric properties in Thailand. Thus, I decided to do translation and back-translation of the perceived gain measure and then I evaluated this measure for content validity and internal consistency reliability.

Third, because there were several studies of perceived burdens, perceived informal social support, and health status of people in Thailand. I proposed to use three valid and reliable measures. Two measures had been used with Thai people before: perceived informal social support and health status (Leurmarnkul & Meetam, 2005; Wongpakaran& Wongpakaran, 2012). The content validity of health status measure had been reported with Thai caregivers. But, researchers have not reported content validity of the perceived informal social support measure. This measure has not been used with Thai caregivers. The other measure was the short burden

scale. Although researchers have not used the short burden scale in Thailand before, they have often used the full burden scale. The short burden scale items were selected from the full burden scale. This measure was acceptable for validity with Thai caregivers. Thus, I decided to evaluate the perceived informal social support for content validity and internal consistency. The other two measures included the caregiver health and the short burden scale. I decided to evaluate those measures for internal consistency reliability.

## Assessing relationships among caregiving variables

From reviewing 25 caregiving studies, I have found that five main variables were significantly positively correlated with perceived gains and physical, mental, and emotional health of caregivers. These five variables were negatively correlated with perceived burdens. The five variables were: (a) the caregiver-care recipient relationship (Fauth et al., 2012), (b) motivations of caregivers (Quinn, Clare, McGuinnes, & Woods, 2012, (c) competence of caregivers (Cheng et al., 2012; Liew et al., 2010; Semiatin, & Connor, 2012) (d) perceived informal social support (Harwood et al., 2000; Koerner et al., 2009), and (e) cultural norms and religious beliefs (Coon et al., 2004; Haley et al., 2004; Roff et al., 2004). Although researchers have identified five main variables that may influence perceived gains and burdens and caregiver health, no researchers have studied relationships between these variables together and caregiving outcomes. Also, the relationships among five main variables and the relationships among outcome variables have not been examined. This may lead to the inability to fully describe the relationships among these variables and fully understand caregiving experiences. A better understanding about those relationships would be helpful for health professionals to increase understanding about caregiving experiences. With understanding caregiving experiences, health professionals would develop an effective intervention or future study to improve care for caregivers and their care recipients.

Cultural norms and religious beliefs may influence perceived gains and burdens and caregiver health. Researchers have found that caregivers who had more intact cultural norms and religious beliefs were likely to report high in perceived gains and low in perceived burdens and better health of caregivers (Haley et al., 2004; Roff et al., 2004; Parveen & Morrison, 2012; Tang, 2011). Based on cultural norms and religious beliefs, Thai people expect their children, especially daughters, to provide care for their parents (Limpawattana et al., 2013). These may influence motivations of Thai children to provide care for their parents. However, cultural norms and religious beliefs are complicated and specific issues (Dilworth-Anderson et al., 2005). The number of measures about cultural norms and religious beliefs are limited (Cohen & Lee, 2006; McCleary & Blain, 2013). Therefore, I did not examine cultural norms and religious beliefs as explanatory variables of this study. But, I chose to control for cultural norms and religious beliefs by only studying Thai caregivers.

I integrated caregiving variables of this study based on literature review and SDT. Three variables of prior caregiving literature: motivations, perceived competence, and caregiver-care recipient relationships were similar to SDT variables. The variable about perceived informal social support was from literature. These variables may influence perceived gains and burdens and physical and psycho-emotional health of caregivers. To evaluate psychometric properties of measure used and relationships among those variables, I categorized variables into two sets for clarity: (a) a set of explanatory variables and (b) a set of outcome variables. The set of explanatory variables included autonomous motivations, controlled motivations, satisfaction with autonomy, satisfaction with competence, satisfaction with relatedness, and perceived informal social support. The set of outcome variables included perceived gains of caregiving, perceived burdens of caregiving, and 5 variables of caregiver health: general health, bodily pain, role-emotional, vitality, and mental health. I chose to study these types of health because of literature support and those variables refer to physical, mental, and emotional health of caregivers.

This study is built from literature on caregiving and on SDT. To fill gaps about psychometric properties of caregiving measures and examine caregiving variables and their relationships, I conducted a study with a cross-sectional design with two main purposes. The primary purpose was to evaluate the psychometric properties of measures that I proposed to be relevant to caregiving. The secondary purpose was to examine the relationships among caregiving variables.

#### **Specific Aims**

The specific aims of this study were:

- 1. To evaluate the content validity of four measures: (a) the Reason for Providing Care Questionnaire, (b) the Basic Needs Satisfaction Scale in General, (c) the Gain in Alzheimer Care Questionnaire, and (d) the Multidimensional Scale of Perceived Social Support Questionnaire.
- 2. To assess the internal consistency reliability of six measures: (a) the Reason for Providing Care Questionnaire, (b) the Basic Needs Satisfaction Scale in General, (c) the Gain in Alzheimer Care Questionnaire, (d) the Multidimensional Scale of Perceived Social Support Questionnaire, (e) the Short Form of the Zarit Burden Questionnaire, and (f) 5 subscales: general health, bodily pain, role-emotional, vitality, mental health of the SF-36 (Thai version).
- 3. To investigate the construct validity of the measure of the Gain in Alzheimer Care Questionnaire.
- 4. To describe informal caregivers' characteristics, caregiving factors, care recipients' characteristics, as well as the degree of; motivations, autonomous and controlled; satisfaction of psychological needs, autonomy, competence, and relatedness; perceived informal social support; perceptions of caregiving, gains and burdens; health in 5 dimensions: general health, bodily pain, role-emotional, vitality, and mental health of Thai caregivers of PWD at home.

## 5. To examine relationships as follows:

5a. the relationships between a set of explanatory variables (autonomous motivations, controlled motivations, satisfaction with autonomy, satisfaction with competence, satisfaction with relatedness, and perceived informal social support) and a set of outcome variables (perceived gains of caregiving, perceived burdens of caregiving, and 5 dimensions of health: general health, bodily pain, role-emotional, vitality, and mental health).

5b. the relationships among the explanatory variables (autonomous motivations, controlled motivations, satisfaction with autonomy, satisfaction with competence, satisfaction with relatedness, and perceived informal social support)

5c. the relationships among the outcome variables (perceive gains of caregiving, perceived burdens of caregiving, and 5 variables of caregiver health: general health, bodily pain, role-emotional, vitality, and mental health).

#### **CHAPTER 2**

#### **BACKGROUND AND LITERATURE REVIEW**

#### **Overview of Caregiving**

Because of advanced technologies in health care and increased life expectancy (Schulz & Martire, 2004), the number of older adults has significantly increased (Bedini & Gladwell, 2014). In the U.S., older adults were about 61 million with age 60 or over in 2012. By 2030, there will be 77 million American older adults (Administration on Aging, 2012). We have known that age is associated with disability (Spillman et al., 2014). This leads to increased demands of care of older adults. At least 90 % of American older adults age 65 or older receive some caregiving about assisting of daily activities such as household activities, mobility, and transportation (Spillman et al., 2014).

Caregiving is a broad concept that refers to providing assistance or care to a relative, friend, or other who is unable to do for oneself (Pearlin, Mullan, Semple, & Skaff, 1900; Whitlatch & Noelker, 1996). This assistance comes from formal caregivers and informal caregivers (Navaie-Waliser, Spriggs, & Feldman, 2002). In the U.S., 18 million informal caregivers provided care for older adults about 1.3 billion hours of care per month in 2011 (Spillman et al., 2014). In Thailand, informal caregivers are the major source to provide care for older people (Chunharas, 2007).

## **Persons with Dementia (PWD)**

The number of dementia sufferers around the globe has dramatically increased. In 2010, these people were about 35.6 million. By 2030, the number of PWD will be 65.7 million (Alzheimer's Disease International, 2013; Chan, 2011). In the United States, 5.4 million Americans had Alzheimer's disease in 2012. By 2050, American people with that disease will be 16 million (Alzheimer's Association, 2012). In Thailand, the number of Thais with dementia

is estimated to increase to 450,000 by 2020 and 1.2 million by 2050 (Chunharas, 2007). Dementia not only influences the health of persons with dementia but also influence their caregivers in health, social, and financial dimensions (World Health Organization (WHO), 2012). To encourage global preparedness to care PWD, the WHO raised dementia as a public health priority in 2012. Additionally, the WHO have recommended researchers to conduct further studies with considering specific content and cultural relevance about dementia (WHO, 2012).

In Thailand, there were a few studies about caregiving experiences of caregivers of PWD. However, researchers have paid attention to developing and strengthening the long-term care system for the elderly population. Researchers have also needed to increase understanding traditional care of families for older adults (Sasat, 2012; Srithamrongsawat, Bundhamcharoen, Sasat, Odton, & Ratkjaroenkhajorn, 2009). To increase a better understanding about caregiving, research on caregivers of dependent older adults has been increased (Wongsawang, Lagampan, Lapvongwattana, & Bowers, 2013). If we understood more about caregiving experiences, this would help researchers improve care for care recipients and their caregivers in the future.

As the number of PWD increases, informal caregivers form the major group who are providing care and assisting PWD at home (Chan, 2011). Informal caregivers refer to family members, relatives, partners, neighbors, or friends who have personal relationships with and provides unpaid care to assist persons with dementia at home (Blum & Sherman, 2010; Whitlatch & Noelker, 1996). Providing care for PWD is a long trajectory for caregivers because PWD has gradually had memory and other cognitive function declines (Huang et al., 2015; Shim et al., 2012). Also, symptoms and behaviors of PWD may change throughout time of providing care in different stages on dementia (Huang et al., 2015; Kaplan & Berkman, 2011). Caregivers may need to provide care closely with a long period of time when care recipients are in advanced stages of dementia (Shim et al., 2012).

## **Informal Caregivers**

In this study, I focus on informal caregivers of persons with dementia (PWD). Informal caregivers usually provide direct hands-on care for the instrumental activities of daily living (IADL) such as preparation of food and housekeeping in the mild stages of dementia, and for IADL and activities of daily living (ADL) such as bathing and toileting in advance stages of dementia (Ciro, 2014; Huang et al., 2015). Other family members can assist to provide care in 4 types: (a) being with, (b) organizing care, (c) monitoring care, and (d) supporting care (Wongsawang et al., 2013).

Caregivers who provide care for PWD can perceive caregiving as burdens and gains (Shim et al., 2012). On the one hand, caregivers may be likely to report perceived burdens and a poor physical and mental health (Huang et al., 2015; Ciro, 2015). In the other hand, caregivers may report perceived gains because of a sense of fullfilment in the caregving role and an increased feeling of closeness with care recipients (Peacock et al., 2009). Researchers have found that perceived gains had a negative relationship with perceived burdens (Liew et al., 2012; Quinn et al., 2012). Based on the negative realtionship between perceived gains and burdens, caregivers who report high in perceived gains may report low in perceived burdens. In contrast, informal caregivers who provide direct hands-on care may be likely to perceived burdens because of dealing with behavioral problems of care recipients (Etters et al., 2008). The behavior problems of care recipients and caregiving workload had positive relationships with perceived burdens and poor mental and physical health of caregivers (Knight & Losada, 2011). Thus, caregivers who provide direct hands-on care may be likely to report perceived burdens rather than perceived gains.

Thai informal caregivers may provide care because of cultural norms and religious beliefs. Cultural norms about family obligations can influence family members to provide care for care recipients at home in both Eastern and Western countries ((Cohen & Lee, 2006; McCleary & Blain, 2013; Limpanichkul & Magilvy, 2003; Ritteeveerakul, 2005). To take on the caregiving

role, Thai adult children may also hold strong cultural norms about family obligations, reciprocity, and dedication to provide care for their parent when needed (Limpanichkul & Magilvy, 2003; McCleary & Blain, 2013; Ritteeveerakul, 2005; Sasat, Bryar, & Newens, 2000; Sethabouppha & Kane, 2005). In particular, Thai daughters or daughters-in-law are expected to be the caregivers (Ritteeveerakul, 2005; Sasat et al., 2000). Other Thai family members may provide informal social support based on cultural norms about a sense of duty and obligation (Rosenberg, Jullamate, & Azeredo, 2009; Sethabouppha & Kane, 2005). Informal social support provided by family members is a main resource for Thai caregivers who provide care for PWD at home (Chunharas, 2007; Ritteeveerakul, 2005). However, because of the smaller family sizes in the Thai population and more adult children are working outside home today (Knodel & Chayovan, 2008), adult caregivers can be challenged. They may perceive demands from working outside home and providing care for care recipients. These caregivers may manage their responsibilities by hiring someone or asking other family members to help provide care at home.

Religious beliefs about the gratitude system about Buddhist principles may influence
Thai caregivers' reasons for providing care and caregiving outcomes. About 95% of Thai people
are Buddhists (Ministry of Pubic Health Thailand, 2005). Buddhist principles include such as the
law of Karma and the Bunkhun. The law of Karma refers to action by intention (Sethabouppha &
Kane, 2005). Bunkhun refers to "good things, favors, or help that is meritorious" (Subgranon &
Lund, 2000, p.169). These principles may influence Thai informal caregivers' beliefs to provide
care for care recipients, especially for their parents (Limpanichkul & Magilvy, 2003;
Ritteeveerakul, 2005). While providing care, Thais' Buddhist beliefs about Buddhist principles
always help caregivers generate compassion in caregiving, manage and sustain caregiving, and
accept their caregiving role (Sethabouppha & Kane, 2005). These beliefs may help Thai
caregivers to continue to provide care and perceive gains rather than burdens (Limpanichkul &
Magilvy, 2003; Ritteeveerakul, 2005). Because Thai caregivers' religious beliefs may be

antecedents to their perceived reasons for providing care and acceptance of caregiving outcomes, controlling or examining influences of religious beliefs on caregiving would be needed of caregiving studies in Thailand.

## **Caregiving outcomes**

In this study, I proposed perceived burdens and gains of caregiving and caregiver health as caregiving outcomes. On the one hand, researchers have found that informal caregivers of PWD have often reported perceived burdens of caregiving. This results from several reasons:

(a) caring for PWD involves a long duration of providing care, (b) a trajectory of functioning decline of care recipients, and (c) unexpected behaviors of care recipients (Pinquart & Sörensen, 2003b; Tremont, 2011). Researchers have also found that informal caregivers of PWD are more likely to experience physical, mental, emotional, and social problems compared to other caregivers and non-caregivers (Pinquart & Sörensen, 2003a, 2003b; Schulz & Martire, 2004).

Researchers have found that burdens of caregiving have negatively correlated to subjective well-being and health outcomes of caregivers (Spillman et al., 2014). Using a longitudinal, randomized controlled trial design, Mohamed and colleagues (2010) studied the relationships caregivers' characteristics, clinical problems, perceived burdens of caregiving, and quality of life of care recipients with a secondary analysis of 421 dyads of caregivers. They found that care recipients who had changes in symptoms, behavioral problems, and quality of life were moderately positive correlated with perceived burden of caregivers. This was consistent with the findings in a meta-analysis, behavioral problems of care recipients were strongly correlated with perceived burden of caregivers (Pinquart & Sörensen, 2003a).

Perceived burdens of caregivers had correlated with poor mental and physical health of caregivers (Knight & Losada, 2011). Caregivers were more likely to report perceived burdens and health problems than non-caregivers (Pinquart & Sörensen, 2003a). Although caregivers

may be likely to report perceived burdens they may have perceived gains such as increasing personal strengths and relationships with care recipients (Parveen & Morrison, 2012; Peacock et al., 2009).

Researchers have paid more attention to study perceived gains of caregiving in the past two decades. Researchers have found that caregivers have expressed not only negative consequences but also positive consequences of caregiving such as personal and spiritual growth in their lives (Koerner et al., 2009; Parveen & Morrison, 2012; Peacock et al., 2009; Sanders, 2005; Semiatin & O'Connor, 2012). Shim et al. (2012) conducted a qualitative study to describe in caregiving experiences of 21 spouse caregivers of PWD with a secondary analysis of 57 interviews from a longitudinal study. They found that caregivers perceived caregiving as negative, ambivalent, or positive experiences. In addition, by using national study of caregiving in 2011 of 17,949 American caregivers for older adults, Spillman and team (2014) reported that 67% of caregivers shared substantial positive consequences of caregiving, such as, feeling closer to the care recipients. Nearly 63% of caregivers expressed little or no negative consequences of caregiving. In addition, nearly 25% of caregivers of PWD have reported substantial negative consequences of caregiving.

Informal caregivers of PWD can experience perceived gains and burdens of caregiving. Caregivers can perceive burden or depression of caregiving but some caregivers can expressed their gains from caregiving for example, personal and spiritual growth in their lives (Peacock, et al., 2010; Sanders, 2005; Semiatin & Conner, 2012). Researchers have found that caregivers who had perceived high gains of caregiving may not only have had low burden and depression of caregiving but also have a better health (Cohen et al., 2002; Hilgemen et al., 2007; Pinquart &Sörensen, 2003a).

Perceived gains of caregiving may help balance burdens of caregiving (Spillman, et al., 2014). This may lead to a better physical and psychological health of caregivers by reducing the impacts of the burden of caregiving (Cohen et al., 2002; Hilgeman et al., 2007). Researchers

have found that gains from caregiving may correlate to better mental health (Hodge & Sun, 2012; Liew et al., 2010; Netto, Jenny, & Philip, 2009) and physical health (Cohen et al., 2002). From two meta-analyses, researchers have reported that gains were positively associated with the subjective well-being of caregivers (e.g., positive affect, life-satisfaction, perceived quality of life) (Pinquart & Sörensen, 2004) and negatively correlated to caregiver burden and depression (Pinquart & Sörensen, 2003a). If caregivers have better physical and mental health, the caregivers could continue to provide care for care recipients over a longer duration of time. This could support a delay in time for nursing home placement of the care recipients and decrease the cost of long-term care services (Alzheimer's Association, 2012). Because the knowledge about perceived gains of caregiving is relatively new when comparing with the knowledge of perceived burdens of caregiving. I reviewed literature to increase a better understanding about perceived gains of caregiving.

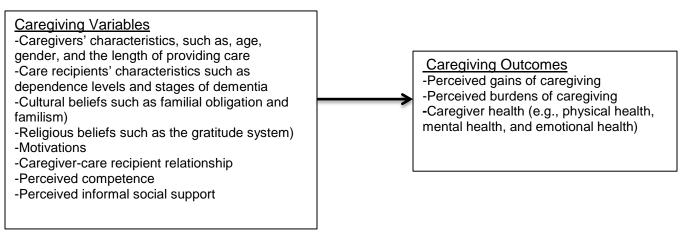
## **Strengths of Prior Research**

I reviewed 25 caregiving studies about variables that may influence caregiving outcomes. There are three strengths of prior research about perceived gains, burdens, and caregiver health. First, researchers have generated knowledge about major variables that may influence caregiving outcomes (Fauth et al., 2012; Quinn et al., 2010). These variables included: caregivers and care recipients' characteristics such as age, cultural norms, religious beliefs, motivations, caregiver-care recipient relationships, perceived competence, and perceived informal social support (see figure 1). No researchers have conducted a study by examining relationships of all these variables together and caregiving outcomes. Second, most researchers who studied caregiving experiences examined both negative consequences, such as perceived burdens or depression, and positive consequences of caregiving, such as perceived gains or meaning in caregiving, in 17 from 19 quantitative studies (Liew et al., 2012; Quinn et al., 2012; Roff et al., 2004). Third, because researchers have more studied the

relationships between variables that may influence perceived gains of caregiving (e.g., motivations and self-efficacy) and caregiving outcomes (e.g., perceived burdens and caregiver health), the findings have lead researchers to conduct further studies regarding research questions (Cohen et al., 2002; Hilgeman et al., 2007; Pinquart & Sörensen, 2004): what are relationships of possible variables that may influence caregiving outcome together? What are relationships among caregiving outcomes? How do perceived gains influence perceived burdens and caregiver health? To answer those questions may help increase caregiving knowledge in breadth about variables that may influence caregiving outcomes and in depth about relationships among outcome variables. Understanding caregiving knowledge would help researchers develop further studies to improve care for caregivers and their care recipients.

Figure 2.1.

A Summary of Variables that May Influence Caregiving Outcomes Based on Literature Review



#### **Gaps of Prior Research**

From reviewing literature, there are four gaps of prior research about caregiving outcomes. First, some researchers have not reported psychometric properties of measures about reliability when using measures of caregiving in different samples and culture. In five of nineteen quantitative studies, researchers did not report the reliability of measures (Camden, Livingston, & Cooper, 2011; Cohen et al., 2002; Harwood et al., 2000; Lopez et al., 2005; Rapp & Chao, 2000). Second, most researchers have not reported about validity of relevant measures used in caregiving research. For example, in one study from China, researchers did not report validity of a translated measure about perceived gains (Cheng et al., 2013). Not reporting may cause measurement errors and inconsistent research findings because of the lack of acceptable psychometric properties of measures (Tarlow et al., 2004).

Third, researchers have not defined the terms and domains of perceived gains of caregiving explicitly. Yamamoto-Mitani and team (2003) claimed that perceived gains of caregiving are multidimensional. Defining gains and specifying domains of gains would be essential to increase understanding about caregiving outcomes. Researchers have defined gains of caregiving as uplifts of caregiving (Martin Pinquart & Sörensen, 2003b), meaning of caregiving (Hunt, 2003), or positive aspects of caregiving (Tarlow et al., 2004). Unclear definitions of gains may lead to not fully explain the relationships among perceived gains and other caregiving outcomes such as depression, burdens, and caregiver health ( Pinquart & Sörensen, 2004; Tarlow et al., 2004).

Fourth, some researchers have not used a conceptual model or theory to guide their studies about caregiving experiences in perceived gains and burdens of caregivers. In twelve of nineteen quantitative studies, researchers had not used a conceptual model or theory to guide studies (Liew et al., 2012; Lopez et al., 2005; Quinn et al., 2012). Because of complexity of caregiving, researchers could apply a conceptual model or theory to describe theoretical and operational definitions of concepts and propositions among concepts about caregiving.

Researchers could also describe relationships among these caregiving concepts guided by a conceptual model or theory. Clearly operational definitions would guide researchers to choose appropriate measures. Researchers could use a conceptual framework or theory to discuss about research findings. Theory-guided studies of caregiving could increase researchers understanding about caregiving experiences and the relationships among caregiving variables.

Fifth, most studies about perceived gains have been conducted in Western Countries. In a thorough review of 25 studies about perceived gains of caregiving, I found that 21 studies were conducted in Western countries. Because cultural norms and religious beliefs may influence perceived gains of caregiving, cultural norms and religious beliefs of Western countries are different from Eastern countries. Increasing studies from Eastern countries would enhance our understanding of the impact of cultural norms and religious beliefs on perceived gains of caregiving.

# **Self-Determination Theory (SDT)**

According to a literature review about caregiving, caregivers' motivations (Quinn, Clare, McGuinnes, & Woods, 2012), perceived competence of caregivers (Liew, et al., 2010; Semiatin, & Connor, 2012), and caregiver-care recipient relationships (Fauth et al., 2012; Quinn et al., 2012) may influence perceived gains and burdens and caregiver health. These variables correspond with SDT concepts of type of motivations, perceived competence, and relatedness. I proposed to use self-determination theory (SDT) to guide this study. I describe concepts and propositions of SDT and then discuss why SDT is adequate to guide a caregiving study.

SDT explains that human motivations and psychological needs are inner resources of people toward positive tendencies for growth and personal well-being (Deci & Ryan, 2000). Psychological needs based on SDT include three components: competence, autonomy, and relatedness (Deci & Ryan, 2008). Competence refers to a person's ability to carry out activities with confidence (Vansteenkiste & Sheldon, 2006). Autonomy refers to an individual's feeling of

success, respect, and a sense of choice and volition in his/her behaviors (Vansteenkiste & Sheldon, 2006). Relatedness refers to establishing relationships with other people increased a sense of communion and belonging with others (Vansteenkiste & Sheldon, 2006). Researchers have found that the satisfaction of these three psychological needs is associated with people's growth and increased health outcomes (Custers, Westerhof, Kuin, & Riksen-Walraven, 2010; Ryan & Deci, 2000).

According to SDT, motivations are important for people to engage in activities.

Motivations stimulate people to initiate and maintain behaviors toward desired outcomes (Ryan & Deci, 2000). There are two types of motivations: autonomous motivations and controlled motivations (Ryan & Deci, 2000). Autonomous motivations refer to willing behaviors, feelings of enjoyment, and having available choices. Autonomous motivations include identified, integrated, and intrinsic motivations (Ryan & Deci, 2000). Controlled motivations refer to external and internal factors that can influence people to act such as reward, punishment, feelings of guilty, or avoidance of shame (Dici & Ryan & Deci, 2008). Controlled motivations include external and introjected motivations (Markland, Ryan, Tobin, & Rollnick, 2005; Ryan & Deci, 2000).

Numerous studies have demonstrated that autonomous motivations promote more persistent behaviors, a positive affect, increased performance, and psychological well-being (Deci & Ryan, 2008; Kim et al., 2008; Weinstein, DeHaan, & Ryan, 2010).

SDT is applicable to guide a study of perceived gains of caregiving and caregiver health. There are two reasons for using SDT to guide this study. First, according to SDT, type of motivations encourages people to act their behaviors toward desired outcomes (Ryan & Deci, 2000). According to a prominent researcher in caregiving (Kramer, 1997), "motivations for providing care may also be central to the daily and more global life goals of the caregivers" (p. 230). To increase our understanding of the caregiving experience, researchers could apply SDT to guide their studies of increasingly examining the motivations of caregivers. Because other variables may influence perceived gains and caregiver health such as relatedness and

perceived competence of caregivers (Cheng et al., 2012; Cohen et al., 2002; Fauth et al., 2012; Kim et al., 2008; Liew et al., 2010; Quinn et al., 2012; Semiatin & O'Connor, 2012), researchers could also use SDT to describe these variables that may relate to caregiving outcomes.

Researchers could use SDT to explain gains of caregiving by examining motivations that include two types of motivations (i.e., autonomous motivations and controlled motivations) and the satisfaction with psychological needs (i.e., competence, autonomy, relatedness). Based on studies that were not guided by SDT, I found that motivation, perceived competence of caregivers, and caregiver-care recipient relationships may influence perceived gains, perceived burdens, and caregiver health (Fauth et al., 2012; Kim et al., 2008; Liew et al., 2010; Quinn et al., 2012; Semiatin & O'Connor, 2012). Comparing SDT variables and variables of caregiving literature without guided by SDT, I found three variables were similar including motivations, competence, and relatedness.

Second, SDT has been applied in several fields across countries (Chirkov et al., 2003; Lynch et al., 2009; Ng et al., 2012). Researchers have used SDT to guide studies about well-being and cultural differences across countries in South Korea, China, Russia, Turkey, and the US (Chirkov et al., 2003; Lynch et al., 2009). Researchers have also applied SDT to guide studies in various fields including education, the workplace, and health care settings (Deci & Ryan, 2000; Gagne, 2003; Kim et al., 2008). In caregiving context, researchers have applied SDT to guide their studies and selected measures (Kim et al., 2008; Weinstein et al., 2010). For example, Kim and colleagues (2008, 2013) have applied SDT to guide two studies about caregiving experiences of caregivers with cancer survivors in the US. Thus, I concluded that SDT can be used for guiding caregiving studies in Eastern countries.

Kim, Carver, Deci, and Kasser, (2008) conducted a cross-sectional descriptive study to examine the impact of the relationship quality and caregiving motivations on psychological well-being, comparing husband (n = 154) and wife (n=160) caregivers of cancer. They used SDT to define concepts about type of motivations as reasons for providing care of caregivers and

relationships between these variables and psychological well-being. For example, caregivers who need to avoid disapproval from other people in society would be proposed to provide care with external motivations. Another hypothesis was that caregivers would provide care because of love and respect for care recipients and they have acknowledged the meaning of caregiving associated with purpose of life. These caregivers would provide care with integrated motivations that may promote their physical and psychological health. Because of these types of motivations, Kim and colleagues worked with Deci who developed SDT (2008), to create a measure to assess type of motivations as reasons for providing care. Their findings indicated that husband caregivers with autonomous motivations were negatively associated with depression while wife caregivers with autonomous

Kim, Carver, and Cannady (2013) conducted a study to examine the influence of autonomous motivations on well-being and quality of life in mental and physical health. They defined well-being as spirituality such as peace and faith. They conducted the study with 369 family caregivers of cancer survivors. They used SDT to guide the study to explain type of motivations as reasons for providing care. They measured caregiving motivations of family caregivers two years after care recipients were diagnosed (time one). They measured the well-being of caregivers five years after care recipient were diagnosed; this was at time two. They found that spirituality was a mediator between caregiving motivations and the quality of life of caregivers. Autonomous motivations of caregivers at time one were positive correlated to mental health at time two, whereas external motivations of caregivers at time one were negative associated with mental health at time two. Based on SDT, they concluded that autonomous motivations of caregivers of cancer survivors could significantly influence the mental health of caregivers.

Applying SDT to caregiving context, type of motivations and satisfaction with three psychological needs of caregivers are important for caregivers to engage in the caregiving role

and provide care. Caregivers who have autonomous motivations to provide care may be likely to involve in the caregiving role and report perceived gains of caregiving. In addition, the satisfaction with competence and autonomy is necessary for caregivers to have confidence to carry out caregiving activities and a sense of volition to provide care. The satisfaction with relatedness would provide support for caregivers to feel a connection with others—especially their family members to provide care. If caregivers have perceived autonomous motivations to provide care and are satisfied relationships with care recipients and abilities to be able to provide care, caregivers may report high in perceived gains and low in perceived burdens. These caregivers may also report better health outcomes of caregivers including physical, mental, and emotional health. In contrast, if caregivers do not satisfy with three basic needs and have controlled motivations to provide care because of avoiding feeling of guilt caregivers may be likely to report low in perceived gains, high in perceive burdens, and poor health outcomes. These caregivers may not want to continue to provide care.

Caregiving conditions such as extended family or family income as social environments can support caregivers for providing care. The caregiving conditions may result in the satisfaction of caregivers' needs and motivations for providing care. This may promote caregivers to perceive gains rather than burdens and maintain their health. In contrast, if caregivers do not have adequate support about caregiving conditions they may perceive burdens rather than gains and a poor health. Thus, caregiving conditions may influence caregiving outcomes. For Thai caregivers, caregiving conditions may come from their family members. For example, Thai caregivers who provide care because of cultural norms about obligations and beliefs in gratitude system, and, if they receive good supports from their family members, they may have increased perceived gains, decreased burdens, and a good health. If Thai caregivers who provide care with inadequate support from their family members they may likely enhance perceived burdens of caregiving and a poor health. I concluded that based on SDT, with support of caregiving conditions in their families could fulfill psychological needs of

caregivers to provide care. This would promote perceived gains of caregiving and health of caregivers.

I integrated concepts that may influence caregiving outcomes; these were perceived gains and burdens and caregiver health, from literature on SDT and caregiving literature. They were three key concepts: motivations, perceived competence, and caregiver-care recipient relationships. The corresponding concepts of literature on SDT included type of motivations: autonomous motivations and controlled motivations, as well as satisfaction with psychological needs: autonomy, competence, and relatedness. The concepts based on caregiving literature were: perceived informal social support, cultural norms, and religious beliefs. However, cultural norms and religious beliefs are complicated and specific issues (Dilworth-Anderson et al., 2005). In this study, I did not directly measure cultural norms and religious beliefs because of the lack of measure used (Cohen & Lee, 2006; McCleary & Blain, 2012). Yet, I chose to control for cultural norms and religious beliefs by only studying Thai caregivers.

Because of the gaps from prior literature about the lack of documentation about psychometric measures to assess caregiving outcomes, I proposed to begin with evaluating psychometric properties of measures. These measures were used to assess caregiving variables of this study. After integrating concepts that may influence caregiving outcomes this would guide variables of this study. I concluded variables of this study: (a) two types of motivations, autonomous motivations and controlled motivations, (b) satisfaction with three psychological needs, autonomy, competence, and relatedness, (c) two caregiving experiences, perceived gains and burdens, (d) perceived informal social support, and (e) caregiver health. For the information about variables that may influence caregiving outcomes from caregiving literature, see the section of literature review about caregiving variables.

## **Selected Measures of This Study**

To fill the gap about lack of document of psychometric properties of measures, I proposed to evaluate selected measures as primary purposes of this study. I planned to study caregivers in Thailand, but only a few measures about perceived gains of caregiving have been used in Thailand. Evaluating selected measures for reliability and validity would be essential to decrease measurement error, especially for the first use of such measures with Thai people.

I proposed to use six measures to assess variables that may correlate with caregiving outcomes such as perceived gains and burdens and caregiver health. Two measures were developed based on SDT: the Reason for Providing Care Questionnaire (Kim et al., 2008) and the Basic Needs Satisfaction Scale in the General (Gagne, 2003). The other four measures researchers developed based on literature: the Gain in Alzheimer Care Questionnaire (Yap et al., 2010), the Multidimensional Scale of Perceived Social Support Questionnaire (Zimet, Dahlem, Zimet, & Farley, 1988), the Short Form of the Zarit Burden Questionnaire (Bedard et al., 2001), and the SF-36 (Thai version) (Leurmarnkul & Meetam, 2000). To increase understanding about selected measures in this study, I compare among relevant measure used and provide the rationale for each measure separately.

#### Type of Motivations

I proposed to use the Reason for Providing Care Questionnaire (RPC) because this measure was developed based on SDT. The RPC was valid and reliable with caregivers of cancer survivors in the U.S. (Kim et al., 2008). Researchers have found that type of motivations of caregivers, especially autonomous motivations were positive correlated with perceived gains and caregiver health and negative correlated with burdens (Lyonette & Yardley, 2003; Ng et al., 2012; Quinn et al., 2010). SDT researchers have developed a measure of assessing reasons for providing care based on concepts about type of motivations (Kim et al., 2008). Based on SDT, type of motivations includes: autonomous motivations and controlled motivations.

Controlled motivations include introjected motivations and external motivations (Ryan & Deci, 2000). The RPC was tested with caregivers of cancer survivors in the U.S. for construct validity using factor analysis and for internal consistency reliability (Kim et al., 2008). Cronbach's alphas were .88 for autonomous motivations, .86 for introjected motivation, and .64 for external motivation (Kim et al., 2008). Although researchers have never used the RPC with people in Thailand, the RPC was developed based on the SDT and used with caregivers in the U.S. Thus, I concluded that the RPC could be applicable to use in this study.

## Satisfaction with Psychological Needs

I proposed to use the Basic Needs Satisfaction Scales in General (BNSG) because this measure was developed based on SDT and had good psychometrics properties with participants in Western countries. Researchers have found that perceived competence and caregiver-care recipient relationships had positive relationships with perceived gains and caregiver health. These variables had a negative relationship with perceived burdens (Fauth et al., 2012; Liew et al., 2010; Quinn et al., 2010; Semiatin & O'Connor, 2012). SDT researchers found that satisfaction with psychological needs: autonomy, competence, and relatedness had positive relationships with personal growth and better physical and mental health (Johnston & Finney, 2010; Ng et al., 2012; Sheldon & Niemiec, 2006).

Researchers have used the BNSG to assess satisfaction with three basic psychological needs: autonomy, competence, and relatedness. The BNSG has been used with various groups such as employees at workplace, students at school, and older adult residents in nursing home in the U.S. (Johnston & Finney, 2010; Sheldon & Niemiec, 2006). Researchers have modified the BNSG in specific context such as in workplace or in relationship (Johnston & Finney, 2010). Researchers have used the BNSG to assess satisfaction and frustration of the psychological needs across four countries: Belgium, China, USA, and Peru (Chen et al., 2015). Johnston and Finney (2010) examined construct validity of the BNSG by using confirmatory factor analysis.

They found that the BNSG had three factors when reducing items from 21 to 16. Reliability of the BNSG was supported by prior studies. The Cronbach 's alphas of the BNSG from prior studies were .69-.77 for autonomy, .71-.77 for competence, and .83-86 for relatedness ( Di Domenico & Fournier, 2014; Gagne, 2003). Although researchers have never used the BNSG with people in Thailand, the BNSG was developed based on the SDT and used in Western and Eastern countries. Thus, I concluded that the BNSG could be applicable to use in this study.

## Perceived Gains of Caregiving

I proposed to use the Gain in Alzheimer Care Questionnaire (GAIN) after comparing among three measures: the reward questionnaire, the positive aspects of caregiving, and the gain questionnaire. Researchers have defined gains of caregiving in different ways such as rewards or positive aspects of caregiving (Hunt, 2003; Tarlow et al., 2004). Thai researchers have used questionnaires about the rewards of caregiving (Rattanasuk, Nantachaipan, Sucamvang, & Moongtui, 2013; Ritteeveerakul, 2005). These questionnaires were used to measure caregivers' thoughts and feelings in positive consequences when providing care. The reward questionnaires include 5 subscales: meaning, learning, financial, spiritual, and being there (Rattanasuk et al., 2013; Ritteeveerakul, 2005). For example, a question of the reward questionnaires is "Does caring for him/her help you feel good about yourself?" The reward items were dichotomous with using "yes" or "no" answers.

Researchers who have defined gains as the positive aspects of caregiving have often used the Positive Aspects of Caregiving (PAC) scale. Researchers have used the PAC in Western and Eastern countries (Cheng et al., 2013; Hodge & FeiSun, 2012; Roff et al., 2004; Tang, 2011). Tarlow et al. (2004) developed the PAC based on two components with caregivers of PWD in the U.S.: self affirmation and outlook of life. The PAC had good construct validity by using exploratory factor analysis and internal consistency reliability with the Cronbach's alpha

.89 (Tarlow et al., 2004). Most caregivers who participated in the study of Tarlow were spousal and older caregivers with a mean age of 62 years old.

Chinese researchers have done the translation and back-translation of the PAC from English to Chinese language (Lou, Lau, & Cheung, 2015). The Cronbach's alpha of the PAC with Chinese caregivers was .89. The PAC in Chinese language was valid and reliable. Chinese caregivers in a prior study had similar caregivers' characteristics with the Tarlow's study.

Japanese researchers developed the Positive Appraisal of Care (PAC) with Japanese caregivers of older adults (Yamamoto-Mitani et al., 2003). The PAC in Japan included four subscales: (a) relationship satisfaction, (b) role confidence, (c) consequential gain, and (d) normative fulfillment. The PAC in Japan was valid and reliable with Japanese caregivers of older adults aged 65 and older (Yamamoto-Mitani et al., 2001).

Researchers in Singapore developed the Gain in Alzheimer Care Questionnaire (GAIN) (Yap et al., 2010). They developed the GAIN from their qualitative study using the grounded theory approach with 12 caregivers of PWD in Singapore. This measure was used to assess gains from caregiving in three domains: personal gains (e.g., patience, strength), gains in the relationship (e.g., closer to the PWD and family members), and high level gains (e.g., spiritual growth, altruism). Researchers selected items based on their previous study and an expert panel evaluation. The panel included a geriatrician, social worker, and nurse specializing in dementia. The items were confirmed by using a focus group of 15 caregivers. Researchers found 10 items of the GAIN. Finally, researchers tested the GAIN with 238 caregivers of PWD for construct validity using exploratory factor analysis and Pearson correlations. With using exploratory factor analysis, they found that the GAIN had a one-dimensional factor. They found that the GAIN had convergent validity when comparing with the PAC (Tarow et al., 2004). The GAIN had discriminant validity when comparing with 22-item of the Zarit Burden Interview. The Cronbach's alpha of the GAIN was .89 (Yap et al., 2010). The GAIN was reliable and valid in

Singapore (Liew et al., 2010; Yap et al., 2010). The majority of the caregiver group in these prior studies was children caregivers with a mean age of 50 years old.

After comparing measures about the reward questionnaire, the positive aspects of caregiving, and the gain questionnaire, I found that questions of the GAIN may be likely sensitive with Asian people more than others. The reward questionnaire did not focus on the relationship and personal growth of caregivers as perceived gains of caregivers. This measure may not be appropriate to assess perceived gains as I defined in this study. The PAC in Japan, researchers developed this measures with Japanese caregivers of older adults and two subscales of the PAC: role confidence and the relationship satisfaction were similar to the concept of satisfaction with competence and relatedness based on SDT. In this study, I defined the positive aspects of caregiving or perceived gains as outcome variables. I proposed satisfaction with competence and relatedness as explanatory variables that may influence outcome variable.

I proposed to use the GAIN to measure perceived gains of caregiving. The caregivers' characteristics in Singapore were similar to typical caregivers' characteristics in Thailand (Limpawattana et al., 2013; Ritteeveerakul, 2005). The GAIN was a one-dimensional measure and had acceptable for psychometric properties (Yap et al., 2010). The GAIN was developed in Singapore with psychometric acceptibility and a sensitive measure to assess perceived gains of Thai caregivers of PWD. I concluded that the GAIN could be applicable to use with Thai caregivers of PWD.

### Perceived Burdens of Caregiving

To evaluate perceived burdens of caregivers, I proposed to use the Short Form of the Zarit Burden Questionnaire (Short ZBI). Thai researchers have used the Caregiver Burden Inventory (CBI) (Muangpaisan et al., 2010) and the Thai version of 22-item Zarit Burden Inventory (ZBI) (Limpawatta et al., 2013). The CBI includes 24 items with 5 subscales. Thai

researchers did not report validity and reliability of the CBI with Thai people (Muangpaisan et al., 2010).

For the 22-item ZBI, Toonsiri, Sunsern, and Lawang, (2011) completed the translation and back-translation of the full version of the 22-item ZBI from English to Thai language. They then invited an expert panel to evaluate the content validity and tested it for construct validity using exploratory factor analysis with 501 Thai caregivers with chronic diseases. They found that the internal consistency reliability of the ZBI was .92. The 22 –item ZBI included 4 different subscales. However, Bédard et al. (2001) suggested the Short ZBI with one-dimension. The Short ZBI includes 12 selected items from the full version of the 22-item ZBI. The correlations between the Short ZBI and the full version of the ZBI with caregivers of PWD at baseline were .96. The internal consistency reliability of the Short ZBI was .88 (Bedard et al., 2001). In sum, the full version of the ZBI was valid and reliable with Thai caregivers (Limpawatta et al., 2013; Toonsiri et al., 2011).

The Short ZBI items were from the full ZBI items. The full ZBI scale was valid and reliable with Thai caregivers (Toonsiri et al., 2011). The Short ZBI has been confirmed for construct validity as one-dimensional scale by using confirmatory factor analysis ((Ballesteros et al., 2012). Although researchers have never used the Short ZBI in Thailand, this measure was valid and reliable in Western countries (Ballesteros et al., 2012; Bédard et al., 2001). Thus, I proposed to use the Short ZBI because the full ZBI has been translated by a Thai expert panel and all item of the Short ZBI were from the full ZBI. I concluded that a Thai expert panel to evaluate content validity of the Short ZBI would not be needed.

# Perceived Informal Social Support

Researchers can define informal social support in three ways: (a) the structure of support by asking the number of persons in the network, (b) the perception of available support, and (c) support which ones have received in actuality (Smerglia et al., 2007). Researchers have

found that perceived informal social support especially from family members had positive relationships with perceived gains and caregiver health and a negative relationship with burdens (Koerner et al., 2009; Harwood et al., 2000). Because of the relationships of perceived informal social support and caregiving outcomes of prior studies, I focused on assessing perceived informal social support of caregivers (Koerner et al., 2009; Harwood et al., 2000). Two measures have used widely to assess perceived informal social support: the Interpersonal support (ISEL) and the Multidimensional Scale of Perceived Social Support Questionnaire (MSPSS) (Van Durme et al., 2012; Smerglia et al., 2007).

The ISEL includes 48 dichotomous items with 4 subscales (Brookings & Bolton, 1988). Participants respond by using 2 answers "probably true" or "probably false" (Brookings & Bolton, 1988). Cohen and Wills (1985) developed the ISEL to assess perceived informal social support of four domains: (a) tangible material aid, (b) someone to discuss about problems, (c) selfesteem support from others, (d) others providing belonging support (Brookings & Bolton, 1988; Kaufman et al., 2010). The KR-20 of the ISEL was .61-.86 for four subscales. This measure was valid with a four-factor model by using confirmatory factor analysis (Brookings & Bolton, 1988). The ISEL has been never used with Thai people. Because the ISEL has 48-dichotomous questions with 4 separate subscales, this measure may increase burdens of participants' responses and decrease power of analysis. Thus, I did not propose to use the ISEL.

I proposed to use the MSPSS to assess perceived informal social support. It is a short measure with good psychometric properties with Thai people (Wongpakaran & Wongpakaran, 2012). Zimet, Dahlem, Zimet, and Farley, (1988) developed the MSPSS to assess the perceived social support from three different sources: family, friends, and significant others. Wongpakaran, Wongpakaran, and Ruktrakul, (2011) translated the MSPSS into the Thai language and evaluated its psychometric properties. They found the test-retest reliability over a four-week period was = .84. They conducted factor analysis to assess the construct validity with Thai

medical students and psychiatric patients. They found that the MSPSS in Thai version had fit in a model for the construct validity of measure.

Wongpakaran and Wongpakaran (2012) later revised the MSPSS in Thai language for internal consistency reliability and construct validity after recruiting a sample of 486 medical students. The internal consistency reliability was .92 for the whole scale, .91 for friend subscale, .88 for family subscale, and .92 for significant other subscale. Using factor analysis, they found a model was fit for the construct validity of measure. The MSPSS was valid and reliable (Wongpakaran and Wongpakaran, 2012). Although researchers have never used the MSPSS with caregivers of PWD the MSPSS was used to assess perceived informal social support with psychometric acceptability with Thai people (Wongpakaran & Wongpakaran, 2012). The MSPSS has not been tested for content validity using a Thai expert panel.

### Caregiver Health

To measure physical and psycho-emotional health of caregivers, I compared measures that Thai researchers have used to assess health status. Thai researchers have used the SF-36 (version Thai) (Lawang, Horey, & Blackford, 2015; Ritteeveerakul, 2005) and the Medical Outcomes Short Form Instrument (SF8) (Yiengprugsawan et al., 2012) for assessing caregiver health. Rsearchers have not reported validity and reliability of the SF8 with Thai caregivers (Yiengprugsawan et al., 2012),

Thai researchers have also used the 15-item short version of Thai Mental Health Indicator (TMHI) to measure mental health of caregivers. The TMHI was developed by the Department of Mental Health, the Ministry of Public Health in Thailand with valid and reliable with Thai people (Mongkol et al., 2007). The TMHI is only used to assess mental health. I planned to assess physical, mental, and emotional health of caregivers. If I used the TMHI in this study this measure may increase participant burdens as compared to what alternatives.

Ware and Sherbourne (1992) developed the SF-36 in the medical outcomes study to

assess eight health concepts: physical functioning, social functioning, report health transition, general health, bodily pain, role-physical, vitality, and mental health. Leurmarnkul and Meetam, (2000) translated the SF-36 to the Thai language and tested it for content validity, construct validity, and reliability. After that, Leurmarnkul and Meetam, (2005) revised the SF-36 Thai language for construct validity and internal consistency reliability. The internal consistency reliability of the revised SF-36 were .72 to .86 for 8 subscales (Leurmarnkul & Meetam, 2005). In Thailand, researchers have used the SF-36 to assess health status in different samples: persons with chronic low back pain (Roopsawang, Aree-Ue, & Putwatana, 2009) and persons with cardiovascular diseases (Krittayaphong et al., 2000). I proposed to use 5 subscales, rather than 8 subscales, of the SF-36 (Thai version) to assess physical and psycho-emotional health of caregivers because of being sensitive measures, supporting power of analysis, and reducing participant burdens. Five subscales of the SF-36 consist of general health, bodily pain, role-emotional, vitality, and mental health.

In summary, because selected measures have been tested differently for validity and reliability, I proposed to evaluate psychometric properties of six measures. First, I evaluated four measures for content validity due to no report about content validity using a Thai expert panel:

a) the Reason for Providing Care Questionnaire (RPC), b) the Basic Needs Satisfaction Scale in General (BNSG), c) the Gain in Alzheimer Care Questionnaire (GAIN), and d) the Multidimensional Scale of Perceived Social Support Questionnaire (MSPSS). Second, I assessed construct validity of the GAIN because of differences in culture, religious affiliation, and language. Third, I evaluated six measures for internal consistency reliability because reliability could change in different samples and conditions (Henson, 2001).

I categorized variables of this study into two sets for clarity: a) a set of explanatory variables and b) a set of outcome variables. The set of explanatory variables included; type of motivations, autonomous motivations and controlled motivations; satisfaction with psychological needs, autonomy, competence, and relatedness; perceived informal social support. The set of

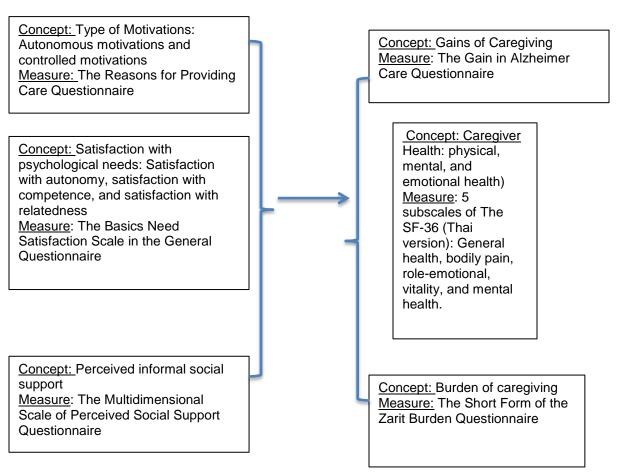
outcome variables included; caregiving experiences, perceived gains and burdens; 5 dimensions of caregiver health: general health, bodily pain, role-emotional, vitality, and mental health. These variables of caregiver health referred to physical, mental, and emotional health of caregivers. The set of explanatory variables may influence the set of caregiving outcomes. For concepts and measure used based on the variable categorization, see Figure 2.2.

Figure 2.2

Variables of Caregiving and Concepts and Measure Used Based on literature Review and SDT

A Set of Explanatory Variables

A Set of Outcome Variables of Caregiving



#### The Definition of Perceived Gains

To fill the second gap about research on perceived gains of caregiving, researchers have used differences in operational definitions of positive consequences of caregiving. Some studies used "positive aspects of caregiving" (Tarlow et al., 2004) and some studies used "gain" (Kramer, 1997). Because of various definitions of positive consequences of caregiving, I used "perceived gains of caregiving" as positive consequences of caregiving. I defined perceived gains of caregiving as caregivers' perceptions about the positive outcomes of the caregiving experience including personal growth, gains in the relationship, and spiritual growth (Koerner et al., 2009; Liew et al., 2010).

### **Literature Review about Caregiving Variables**

I found 25 relevant qualitative and quantitative studies about influences on perceived gains and burdens and caregiver health from the year 2000 to 2014. I reviewed those studies. Most studies (17 studies) used cross-sectional descriptive design. Three studies were qualitative studies. Two studies were longitudinal studies. Two studies were meta-analysis studies and one study was a systemic review study. From reviewing literature, I found eight variables. They were: a) motivations, b) caregiver-care recipient relationships, c) perceived competence, d) perceived informal social support, e) cultural norms, f) religious beliefs, g) caregivers' characteristics, and h) care recipients' characteristics. I explain each variable below.

#### **Motivations**

Motivations of caregivers refer to the expressions and meaning that direct hand-on caregivers to provide care (Dilworth-Anderson et al., 2005; Romero-Moreno et al., 2011).

Researchers have found that the motivations of caregivers were correlated to perceived gains of caregiving (Quinn et al., 2012; Romero-Moreno, Márquez-González, Losada, & López, 2011).

Several variables such as cultural norms, religious beliefs, and the quality of relationships

between the caregiver and care recipient may influence the motivations of caregivers to provide care (Dilworth-Anderson et al., 2005; Quinn, Clare, & Woods, 2010; Romero-Moreno et al., 2011). For example, informal caregivers may provide care for care recipients because of the perception of duty or obligation according to cultural norms (Dilworth-Anderson et al., 2005; Quinn et al., 2010).

Motivations consist of two types: intrinsic and extrinsic motivations. To measure the motivations of caregivers, Lyonette and Yardley (2003) categorized motivations into two types. First, intrinsic motivations refer to the perceptions of caregivers from a personal desire. Second, extrinsic motivations refer to external pressures influencing caregivers to providing care. Researchers have found that intrinsic motivations were significantly correlated to perceived gains of caregivers of PWD (Lyonette & Yardley, 2003; Quinn et al., 2010). The intrinsic motivations as reasons for providing care may lead caregivers to involve in the caregiving role and to have perceived gains of caregiving (Quinn et al., 2010). Although the type of motivations may influence perceived gains of caregiving, in general we have had a few studies to examine the type of motivations with caregivers of PWD.

#### Caregiver-Care Recipient Relationships

The caregiver-care recipient relationship may influence perceived gains of caregiving and health outcomes of caregivers. Researchers have described that the quality of the relationship between the caregiver and care recipient both before and during caregiving may lead to motivations of caregivers in providing care (Carbonneau, Caron, & Desrosiers, 2010; Quinn et al., 2010). Researchers have found that the quality of the caregiver-care recipient relationship before caregiving has positively correlated to perceived gains of caregiving (Koerner et al., 2009). The quality of emotional relationships between caregivers and care recipients previous and current providing care has been positively correlated with perceived gains of caregiving (López, López-Arrieta, & Crespo, 2005). From a longitudinal study,

researchers have found that a poor quality of the caregiver-care recipient relationship could predict poor physical and psychological health of caregivers over time (Fauth et al., 2012). Researchers have found that a higher quality of the caregiver-care recipient relationship before and during caregiving had positive relationships with intrinsic motivation and perceived gains of caregiving (Lyonette & Yardley, 2003; Quinn et al., 2012). If caregivers are satisfied relationships with care recipients, this may motivate caregivers to provide care and perceive more gains of caregiving than caregivers with unsatisfied relationships. This may result from a sense of fulfillment in the caregiving role (Quinn et al., 2010).

### Perceived Competence

Based on SDT, perceived competence refers to people's perceptions of their abilities to carry out activities with confidence and competence (Ryan, et al., 2008; Vansteenkiste & Sheldon, 2006). Self-efficacy is the degree to which caregivers believe in their own abilities to perform specific activities regarding a desired effect (Bandura, 1994). Therefore, perceived competence is a similar concept to self-efficacy as discussed by Bandura (Vansteenkiste & Sheldon, 2006). According to one qualitative study, caregivers who were able to perform and master caregiving tasks expressed gains of caregiving (Netto et al., 2009; Peacock et al., 2009). In quantitative research, researchers have found that perceived competence has a positive association with perceived gains of caregiving (Liew et al., 2010; Semiatin & O'Connor, 2012). If caregivers perceive competence when providing care, they may likely to report more perceived gains of caregiving than caregivers without competence. This may result from feelings of accomplishment and satisfaction to providing care (Netto et al., 2009; Peacock et al., 2009). Au et al. (2009) have found that perceived competence of caregivers had a negative relationship with depression and a positive relationship with better physical health of caregivers.

## Perceived Informal Social Support

One major variable has correlated to perceived gains of caregiving is informal social support. Informal social support refers to "assistance provided by family members or friends based upon feelings of affection or personal obligation toward the recipients of the assistance" (Kaufman, Kosberg, Leeper, & Tang, 2010, p. 252). Researchers have found that informal social support has been positively associated with perceived gains of caregiving (Harwood et al., 2000; Koerner et al., 2009; Lee & Bronstein, 2010). Researchers have found that informal social support from spouses/partners has had strong positive correlation with perceived gains of caregiving than informal social support from other family members (Koerner et al., 2009; Lee & Bronstein, 2010). In contrast, Hodge and Sun, (2012) and Parveen and Morrison, (2012) have reported that social support was not correlated with perceived gains of caregiving. But they did not specify the type of social support. They measured the quantity and satisfaction of social support. To conclude, researchers need to clarify conceptual and operational definitions of social support because the concept of social support is broad. This would guide researchers to choose an appropriate measure to assess social support in their studies.

#### Cultural norms

Culture is a multi-dimensional concept, including shared symbols, beliefs, and customs that shape people's behaviors (Dilworth-Anderson et al., 2005). Cultural norms about family obligation and reciprocity provided a reason for family members to engage in the caregiving role (McCleary & Blain, 2013). Tang (2011) studied cultural norms and perceived gains among 113 Chinese -American caregivers of dependently older relatives by using a cross-sectional descriptive study. Cultural norms in Tang study refer to caregivers' concern about caregiving for older adults in filial obligations, family values, and intergenerational relationships. She found that caregivers who had more intact cultural norms showed moderate positive association with perceived gains than caregivers who had less intact cultural norms. The findings were

inconsistent to a cross-sectional descriptive study of Lee and Bronstein (2010). They examined relationships between culture factors as level of acculturation, the number of years lived in the U.S., and familism and perceived gains. They found that cultural factors were not significant associated with perceived gains of Korean-American caregivers of PWD. These findings were not significant because of different explanations about cultural factors between children and spousal caregivers.

In another study, Parveen and Morrison (2012) examined changes among familism, illness perceptions, caregiving tasks, coping, and social support related to gains of 123 caregivers of persons with chronic disease by using a longitudinal study over 9 months.

Familism referred to loyalty, reciprocity, and solidarity among family members. They indicated that caregivers' gains were not significantly changed over time. However, familism of caregivers significantly decreased over time and was positively related to gain at time 2 and time 3 of the study (i.e., researchers collected data at three time points: baseline as time 1, 3 months after baseline as time 2, and 9 months after baseline as time 3).

### Religious Beliefs

Religion is the one of several factors that people use as an internal resource to handle with problems and it is often related to the culture and spirituality. Spirituality is relatively based on religion that is associated with the culture of people in society (Hodge & FeiSun, 2012). Ferrell and Baird (2012) mentioned, "spirituality extends beyond religion and encompasses a broad range of existential concerns" (p. 257). Religious beliefs in caregiving studies often referred to frequent prayer, importance of religion, and attendance at religious services (Haley et al., 2004; Roff et al., 2004).

Because of the lack of studies about caregiving and religious beliefs of caregivers, researchers have examined religious beliefs and caregiving outcomes of caregiving comparing between African-American and Caucasian caregivers. Roff et al. (2004) examined differences in

perceive gains of caregiving between 275 African American caregivers and 343 Caucasian caregivers by using a cross-sectional descriptive design. They assumed that believing and practicing religious activities of caregivers might correlate to perceive gains of caregiving differently in African American and Caucasian caregivers. African American caregivers would have more perceived gains than Caucasian caregivers because of higher religiosity and lower levels of anxiety and depression. They found that African American caregivers reported higher scores of perceived gains and religious beliefs, and lower scores of anxiety and feelings of bother from behavioral problems of care recipients than Caucasian caregivers. Researchers have found that African American caregivers demonstrated greater well-being and dedication to their religious practices, lower anxiety, and more benign appraisals of stress and perceived gains of caregiving than Caucasian caregivers (Haley et al., 2004). Researchers have found that although Latina caregivers were significantly younger in average age, lower SES, poor overall health, and provided more hours of care than Caucasian caregivers, they reported higher positive experiences, less stress, and used more religious beliefs than Caucasian caregivers (Coon et al., 2004). Religious beliefs may be caregiving antecedents of caregivers.

### Caregivers' Characteristics and Caregiving Factors

Caregivers' characteristics, especially age and race, may influence perceived gains and burdens and caregiver health. Additionally, health status and caregiving factors such as the length of providing care may influence perceived gains and burdens and caregiver health.

Researchers have found that caregivers who were older and experienced a longer time of providing care had a positive relationship with gains of caregiving (Liew et al., 2010; Tang, 2011; Yamamoto - Mitani et al., 2003). Caregivers who provided care with a long period of time may have learned to cope with caregiving problems (Liew et al., 2010). In contrast, the caregivers who could not continue to provide care for another may have their own health

problems that they are not able to function in the caregiving role. Researchers have found that burdens of caregiving were negative correlated to well-being and health status of caregivers (Spillman et al., 2014). Tang (2011) has found that caregivers who have reported better physical health have also had higher levels of gains from caregiving than caregivers with worse physical health.

One of other factors, race, may influence caregiving outcomes. Researchers have compared health outcomes of caregivers (i.e., physical and mental health, anxiety, religious beliefs, and perceived gains) by race (Haley et al., 2004; Hilgeman et al., 2007; Roff et al., 2004). The findings showed that caregivers who had different races might have different caregiving outcomes. However, other factors about caregivers' characteristics such as sex, education, and income, although research findings of the relationships between these characteristics and gains of caregiving have been inconsistent (Hodge & Sun, 2012; Liew et al., 2010) there were a few studies. To control other factors such as caregivers' characteristics that may influence caregiving outcomes researchers may consider these factors as potential covariates.

### Care Recipients' Clinical Problems

The characteristics of care recipients such as a dependence level, a stage of dementia, and a level of cognitive impairment may influence perceived gains and burdens and caregiver health. Researchers have found that the dependence level of care recipients was positive correlated with perceived gains of caregiving (Yamamoto - Mitani et al., 2003). The activity of daily living (ADL) scores had positive relationship with mental health of caregivers (Au et al., 2010). In contrast, a few studies using a cross-sectional design have shown that ADL and instrumental activities of daily livening (IADL) scores of needs of care recipients were not associated with perceived gains (Hodge & Sun, 2012; López et al., 2005; Rapp & Chao, 2000).

In addition, Liew et al. (2010) have found that stages of dementia of care recipients had a positive relationship with perceived gains of caregivers. In contrast, Pinquart and Sörensen, (2003b; 2004) found that the relationships between the level of physical and cognitive impairments of care recipients and caregiving outcomes such as perceived gains and burdens were inconsistent. Further research on caregiving outcomes should consider these variables as potential covariates that might influence perceived gains and burden and caregiver health.

The findings from literature have indicated that motivations, perceived competence, caregiver-care recipient relationships, perceived informal social support, cultural norms, and religious beliefs may influence perceived gains and burdens and caregiver health. Other variables including, caregivers' characteristics, caregiving factors, and care recipients' clinical problems, may be potential covariates when explaining caregiving outcomes. However, researchers have not fully described the relationships among these variables. Examining relationships among caregiving variables would help increase understanding about caregiving experiences.

Researchers have demonstrated that cultural norms and religious beliefs may influence perceived gains and burdens of caregiving and caregiver health (Haley et al., 2004; Parveen & Morrison, 2012; Roff et al., 2004; Tang, 2011). Caregivers may explain their caregiving experiences regarding their cultural norms and religious beliefs differently between Western countries and Eastern countries (Cohen & Lee, 2006; McCleary & Blain, 2013; Wang, 2012). I did not assess influences of cultural norms and religious beliefs in caregiving outcomes of Thai caregivers of PWD. The part of my reasoning is that the number of measures about cultural norms and religious beliefs are limited (Cohen & Lee, 2006; McCleary & Blain, 2013). Cultural norms and religious beliefs about caregiving are complicated and different based on groups of people (Dilworth-Anderson et al., 2005; Dilworth & Gibson, 2002). Instead of measuring cultural norms and religious beliefs, I chose to control for these factors by studying only caregivers in Thailand.

# Significance of Studying with Thai Caregivers

Researchers have never studied perceived gains and burdens of caregiving and caregiver health among Thai caregivers of PWD. This study follows the WHO's direction of studying in a specific context about caregiving outcomes based on cultural norms and religious beliefs. Researchers have not fully understood what explanatory variables such as type of motivations and perceived competence may explain perceived gains and burdens and caregiver health. Most prior research in Thailand has focused on perceived burdens more than perceived gains (Limpanichkul & Magilvy, 2003; Limpawattana et al., 2013). Thus, by studying experiences of Thai caregivers, I could contribute caregiving information about caregiving outcomes, such as perceived gains and burdens and caregiver health, and the relationships of caregiving explanatory and outcome variables.

Informal social support is a main resource for caregivers in Thailand. Formal support may be insufficient for Thai caregivers of PWD because of no respite care or a few long-term care facilities for PWD such as adult day care and or nursing home (Srithamrongsawat, Bundhamcharoen, Sasat, & Amnatsatsue, 2009; Srithamrongsawat, Bundhamcharoen, Sasat, Odton, & Ratkjaroenkhajorn, 2009). Family members who do not provide direct hands-on care or help caregivers provide care will often give support indirectly to caregivers such as financial support and emotional support (Limpawattana et al., 2013). This is because of cultural norms about family obligations and religious beliefs in the gratitude system of Thai people (Ritteveerakul, 2005). No researchers have studied whether informal social support may influence perceived gains and burdens of caregiving and caregiver health. Thus, by studying informal social support while also studying experiences of Thai caregivers, I could contribute information about informal social support and caregiving outcomes such as perceived gains or burdens of Thai caregivers.

## **Summary**

Based on literature on SDT and literature on caregiving, demonstrated variables that may influence experiences of caregiving and caregiver health. Other variables including, caregivers' characteristics, caregiving factors, and care recipients' clinical problems may need to be considered as potential covariates that may influence caregiving outcomes. From literature review, I found the gaps about the lack of documentation about psychometric properties of measures, unclear definition of gains in caregiving, the lack of applying a conceptual framework or theory to guide caregiving studies, and the lack of studies in Eastern countries. From literature review, I found the strengths that researchers have identified variables related to perceived gains and burdens and caregiver health. However, no researchers have studied influences of these variables together on caregiving outcomes. Also, the relationships among these variables and the relationships among outcome variables have not been examined. A better understanding about those relationships would be helpful for health professionals to increase understanding about caregiving experiences and outcomes

The primary purposes of this study were to evaluate the psychometric properties of selected measures. This was because of the lack of documentation about psychometric measures with Thai caregivers of PWD. The secondary purposes were to examine the relationships of explanatory variables such as motivations and caregiver-care recipient relationships and outcome variables such as perceive gains and burdens of caregiving of caregivers of persons with dementia in Thailand.

The specific aims of this study were:

1. To evaluate the content validity of four measures: (a) the Reason for Providing Care Questionnaire, (b) the Basic Needs Satisfaction Scale in General, (c) the Gain in Alzheimer Care Questionnaire, and (d) the Multidimensional Scale of Perceived Social Support Questionnaire.

- 2. To assess the internal consistency reliability of six measures: (a) the Reason for Providing Care Questionnaire, (b) the Basic Needs Satisfaction Scale in General, (c) the Gain in Alzheimer Care Questionnaire, (d) the Multidimensional Scale of Perceived Social Support Questionnaire, (e) the Short Form of the Zarit Burden Questionnaire, and (f) 5 subscales: general health, bodily pain, role-emotional, vitality, mental health of the SF-36 (Thai version).
- 3. To investigate the construct validity of the measure of the Gain in Alzheimer Care Questionnaire.
- 4. To describe informal caregivers' characteristics, caregiving factors, care recipients' characteristics, as well as the degree of; motivations, autonomous, and controlled; satisfaction of psychological needs, autonomy, competence, and relatedness; perceived informal social support; perceptions of caregiving, gains and burdens; health in 5 dimensions: general health, bodily pain, role-emotional, vitality, and mental health of Thai caregivers of PWD at home.

### 5. To examine relationships as follows:

5a. the relationships between a set of explanatory variables (autonomous motivations, controlled motivations, satisfaction with autonomy, satisfaction with competence, satisfaction with relatedness, and perceived informal social support) and a set of outcome variables (perceived gains of caregiving, perceived burdens of caregiving, and 5 dimensions of health: general health, bodily pain, role-emotional, vitality, and mental health).

5b. the relationships among the explanatory variables (autonomous motivations, controlled motivations, satisfaction with autonomy, satisfaction with competence, satisfaction with relatedness, and perceived informal social support)

5c. the relationships among the outcome variables (perceive gains of caregiving, perceived burdens of caregiving, and 5 variables of caregiver health: general health, bodily pain, role-emotional, vitality, and mental health).

### Innovation

I proposed to evaluate psychometric properties of selected measures with caregivers of PWD in Thailand. Assessing the psychometric properties of the proposed measures is important. This would help develop appropriate measures based on theoretical and operational definitions of variables. If the measures were acceptable for psychometric properties then this could decrease any measurement bias. Researchers and clinicians could use these measures in the future.

This was the first time of applying SDT to guide explanatory variables including type of motivations and satisfaction with three psychological needs in caregiving context of caregivers of PWD. I applied SDT to describe propositions between explanatory and outcome variables of caregiving. Using SDT would be meaningful to explain concepts and propositions among caregiving variables. I defined concepts carefully. Because caregiving is complex, providing definitions of caregiving variables would be helpful to increase understanding caregiving experiences.

Because I studied the relationships between a set of explanatory variables and a set of outcome variables, the relationships among explanatory variables, and the relationships among outcome variables, I could clarify a breadth of relationships among caregiving variables. This would be helpful for researchers to increase understanding about caregiving experiences of informal caregivers. As caregiving by informal caregivers is often long-term, understanding about caregiving experiences could help health professionals to improve long-term care in the future. Additionally, the findings could help researchers conduct a further longitudinal study to increase our understanding of how caregiving experiences influence caregiving outcomes. This study would support in the next step for researchers to develop an intervention to improve caregiving outcomes such as caregiver health.

#### **CHAPTER 3**

#### **METHODS**

### Introduction

This study included five specific aims. The first specific aim was to evaluate content validity of the measures by Thai experts. The second specific aim was to evaluate internal consistency reliability of measures by caregivers' responses. The third specific aim was to evaluate construct validity of measures by caregivers' responses. The fourth specific aim was to describe caregivers' characteristics, caregiving factors, care recipients' characteristics, and degree of variables. The fifth specific aim was to examine the relationships between a set of explanatory variables and a set of outcome variables of caregiving, the relationships among explanatory variables, and the relationships among outcome variables. In this chapter, I describe the study design, setting, measures, participant protection, sample, procedure, and data analysis.

### Study Design

I used a cross-sectional and correlational descriptive design.

# **Settings**

In Thailand, general and specialized hospitals typically provide care for persons with dementia (PWD). These hospitals have sufficient resources and specialists to provide care for PWD and their caregivers. Thus, research assistants and I recruited caregivers of PWD at outpatient clinics of four of those hospitals in Thailand. I describe the information of four hospitals about the name, province, type, area, name of the clinic, and how often PWD and their caregivers come to visit the outpatient clinics (see Table 3.1).

Table 3.1

Descriptions of Study Sites in Thailand

Site	Name	Province	Type	Area	Clinic	Time of Clinic
1	Prasat Neurological Institute	Bangkok	Specialized hospital	Urban	Dementia	monthly
2	Nakhon Ratchasima Rajanagarindi Psychiatric Hospital	Nakhon Ratchasima ra	Specialized hospital	Suburban	Psychiatry	five days a week
3	Maharat Nakhon Ratchasima Hospital	Nakhon Ratchasima	General hospital	Suburban	Dementia Neuro-med	weekly dical biweekly
4*	Pakchong Nana Hospital	Nakhon Ratchasima	Community hospital	Suburban	Psychiatry	five days a week

<sup>\*</sup> This hospital has affiliated with the Maharat Nakhon Ratchasima Hospital. They refer PWD to the Maharat Nakhon Ratchasima Hospital.

#### **Measures**

This study included six sets of measures. I used two measures guided by self-determination theory (SDT): the Reason for Providing Care Questionnaire (RPC) to assess type of motivations and the Basic Needs Satisfaction Scale in General (BNSG) to evaluate satisfaction with three psychological needs. I used two measures to reflect the experiences of caregiving; these were the Gain in Alzheimer Care Questionnaire (GAIN) to assess perceived gains of caregiving and the Short Form of the Zarit Burden Questionnaire (Short ZBI) to assess perceived burden of caregiving. I used the Multidimensional Scale of Perceived Social Support Questionnaire (MPSS) to examine perceived informal social support of caregivers. Finally, I used 5 subscales of the SF-36 (Thai version) to assess caregiver health. The five subscales were: general health, bodily pain, role emotional, vitality, and mental health (see Table 3.2).

Three sets of these six measures were not available in Thai language when I planned this study. They were: type of motivations and satisfaction with psychological needs, based on SDT. The other was used to assess perceived gains of caregiving. To use these measures with Thai people, I did translation and back-translation of these measures, as described below.

#### Translation and Back-Translation of Three Measures

The translation and back-translation process needs to be rigorous to decrease measurement errors. Sousa and Rojjanasrirat (2011) reviewed 47 studies focusing on translation of measures. Then they provided recommendations for using a seven- step guideline of translation. Their guideline is useful for cross-cultural research. I applied the guidelines of Sousa and Rojjanasrirat (2011) to do the translation and back-translation of three sets of measures.

The purpose of the translation and back-translation processes was to meet equivalence in semantics, concepts, and content between the original measures in the English language and the target measure in the Thai language. Additionally, cultural and language factors was important to consider. Because both the RPC and the BNSG as original measures were developed in Western country, Western culture and language were relevant to the measures. Although the GAIN was developed with caregivers in Singapore, these caregivers may have differences in cultural beliefs and language than caregivers in Thailand. Thus, the translation and back-translation processes were important to control measurement errors in the cross-cultural study.

One of the important criteria of translation was a translator. The translator should have well-qualified and distinct backgrounds (Sousa & Rojjanasrirat, 2011). The translator needed to work individually and as a team. Different backgrounds and experiences of translators would be helpful to improve the quality of translation and back-translation. Based on the guideline of Sousa and Rojjanasrirat (2011), I invited six translators. Five translators were native Thai

speakers. They were bilingual in Thai and English language. Five Thai translators were: a) one PhD student in nursing, who was not the PI, had experiences of working with caregivers, b) one Pharm D pharmacist who had experiences of working with caregivers, c) three teachers who had a master's degree in linguistics and taught English at different universities in Thailand. The other translator was a native English speaker who worked as a secretary. This translator did not know Thai language. Based on the guideline five steps were completed in the following:

- 1. One PhD student in nursing, one Pharm D pharmacist, and one teacher did the initial translation of a set of original measures from English language into the Thai language independently. This resulted in three sets of measures in Thai version. Then, comparisons between sets of measures in Thai version and the set of original measures were done for wording, sentence structure, and meaning consistency. Any ambiguities and discrepancies were discussed and resolved among the translators. This process resulted in a set of measures in Thai, which I called, version 1.
- 2. Two translators who were bilingual did blind back-translation of the set of measures in Thai version 1 to English language. The two translators were blind to the set of original measures. They did the back-translations separately. This process produced a set of measures in English which I called versions 1 and 2.
- 3. A native English speaker compared among the set of measures in English versions 1 and 2, and the set of original measures. They evaluated similarity in words, sentence structures, meanings, and the relevance. Any discrepancies or ambiguities were discussed with the two translators in step 2 by the PI. This process produced a set of measures in English, called version 3.
- 4. Five Thai translators did a translation of the set of measures in English version 3 into Thai language. This process resulted in a set of measures in Thai version 2. The translation team checked the set of measures in Thai version 2 for words, sentence structures, and meanings for clarity regarding Thai language and culture. The translation team and the PI

discussed and reconciled discrepancies or ambiguities to reach the consensus of the final translated version. If discrepancies on the items could not been resolved, the whole processes of translation and back-translation were repeated. We had to do this for six items. This process provided a set of measures in Thai, called version 3.

5. In the pilot testing, I provided the set of measures in Thai version 3 to five Thai caregivers of persons with dementia. They answered the set of questionnaires and were asked to circle some words that were not clear to them. They circled a few words in 5 questions. I revised a set of questionnaires based on caregivers' suggestions for clarity and using lay language. This process resulted in a set of measures in Thai, called version 4,

Because of the study aims, six sets of measures were used in this study. Four sets of measures were provided for Thai experts to assess content validity. Six sets of measures were provided for Thai caregivers to assess internal consistency reliability, construct validity, and the relationships among variables. I describe each set of measures below.

#### Measures for Thai experts

One set of measures was provided to Thai experts to assess content validity. This set included four measures: (a) the Reason for Providing Care Questionnaire (RPC), (b) the Basic Needs Satisfaction Scale in General (BNSG), (c) the Gain in Alzheimer Care Questionnaire (GAIN), and d) the Multidimensional Scale of Perceived Social Support Questionnaire (MSPSS). The first three measures had been newly translated for this study. The other measure was the MSPSS. This measure has been already translated and used with Thai people (Wongpakaran and Wongpakaran, 2012). Yet, researchers had never evaluated for content validity by a Thai expert panel.

The experts were asked to rate each item of the questionnaires for relevance using a four-point scale from 1 "not important" to 4 "extremely important." The experts also rated each item of the questionnaires for clarity using a four-point scale from 1 "not clear" to 4 "extremely

clear." For each overall scale, the experts rated the scale for comprehensiveness using a four-point scale from 1 "not comprehensive" to 4 "extremely comprehensive." In addition, the experts rated each overall scale for cultural relevance using a four-point scale from 1 "not cultural relevance" to 4 "extremely cultural relevance." If an expert rated the scale for comprehensiveness or the scale for cultural relevance with less than a "3," the expert was asked to circle unclear words to improve the quality of the measures for using in the cross-cultural study. Finally, the experts were asked to share their additional comments of each scale to improve the measure.

### Measures for caregivers

Six measures were provided to caregivers. One measure, perceived gains, was used to assess for construct validity. All measures were used to assess for internal consistency reliability and the relationships among variables: (a) the Reasons for Providing Care Questionnaire to measure type of motivations, b) the Basic Needs Satisfaction Scale in General to measure of satisfaction with three psychological needs, (c) the Multidimensional Scale of Perceived Social Support Questionnaire to measure perceived informal social support, (d) the Gain in Alzheimer Care Questionnaire to measure perceived gains, (e) the Short Form of the Zarit Burden Questionnaire to measure of perceived burdens, and (f) the 5 subscales of the SF-36 (Thai version) to measures of caregiver health.

Based on each concept below, I describe the information on each measure, including the number of items, an example of question, rating scales, scoring, and interpretation. I summarize the information of all measures (see Table 3.2).

## Type of Motivations

Based on self-determination theory (SDT), the type of motivations of caregivers to provide care was measured using the Reason for Providing Care Questionnaire (RPC) (Kim et al., 2008). The RPC is a 9-item self-report questionnaire. This questionnaire had originally been developed based on SDT to assess four types of motivations including integrated motivations (2 items), identified motivations (2 items), introjected motivations (2 items), and external motivations (3 items) (Kim et al., 2008). For example, a question was "It was important to me personally to do so." Participants were asked to rate the degree to which they agree or disagree with each statement about the reasons for providing care. Responses were rated on a seven-point scale from 1 "strongly disagree" to 7 "strongly agree." Based on SDT and high correlations between subscales the items of the integrated motivations and the items of identified motivations, Kim et al. (2008) combined these two types of motivations as autonomous motivations. The items of introjected motivations and the items of external motivations were combined as controlled motivations. Thus, the resulting RPC included two subscales. An average score of each subscale was computed. The highest score was 5. Higher scores on the subscales indicated a higher level of each type of motivation.

#### Satisfaction with Psychological Needs

Based on SDT, satisfaction with psychological needs was measured using the Basic Needs Satisfaction Scale in General (BNSG) (Gagne, 2003; Johnston & Finney, 2010). The BNSG is a 21-item, self-report questionnaire. This questionnaire was developed to evaluate satisfaction with components of psychological needs: autonomy (7 items), competence (6 items), and relatedness (8 items). For example, a question was "I feel like I am free to decide for myself how to live my life." Participants were asked to rate how true each item is for them. Responses were rated on a seven-point scale ranging from 1 "not at all true" to 7 "very true." three items of each subscale were negatively worded questions. These nine items BNSG were

recoded before computing a total score. An average score of each subscale was computed. The highest score was 7. Higher scores of each subscale indicated a higher level of satisfaction of each component of psychological needs.

### Perceived Informal Social Support

Perceived informal social support was measured using the Multidimensional Scale of Perceived Social Support Questionnaire (MSPSS) (Wongpakaran & Wongpakaran, 2012). The MPSS is a 12-item self-report questionnaire. This questionnaire was developed by Zimet, Dahlem, Zimet, & Farley (1988) to assess perceived support from family, friends, and significant others. For example, a question was "My family really tries to help me." Participants were asked to rate the degree to which they agreed or disagreed with each statement. Responses were rated on a seven-point scale from 1 "strongly disagree" to 7 "strongly agree." An average score of the scale was computed. The highest score was 7. Higher scores indicated higher levels of perceived informal social support.

#### Perceived Gains of Caregiving

Perceived gains of caregiving were measured using the Gain in Alzheimer Care Questionnaire (GAIN) (Yap et al., 2010). The GAIN is a 10-item, self-report questionnaire. This questionnaire was developed to assess perceived gains of caregiving including personal gains, gains in relationships, and higher level gains. For example, a question was "Given me deeper insights into the meaning of life and my life's perspective." Participants were asked to rate the degree to which they agreed or disagreed with each statement. Responses were rated on a five-point scale from 1 "disagree a lot" to 5 "agree a lot." An average score of the scale was computed. The highest score was 5. Higher scores indicated higher levels of perceived gains of caregiving.

## Perceived Burden of Caregiving

Burden of caregiving was measured using the Short Form of the Zarit Burden

Questionnaire (ZBI). The ZBI is a 12-item self-report questionnaire. This questionnaire is the short form of the 22-item ZBI to assess unidimensional burden of caregiving. For example, a question was, "Do you feel your relative is dependent on you?" Participants were asked to rate how they feel for each statement. Responses were rated on a five-point scale from 0 "never" to 4 "nearly always." An average score of the scale was computed. The highest score was 5.

Higher scores indicated higher levels of burden of caregiving.

### Caregiver Health

Caregiver health was measured using selected subscales of the SF-36 (Thai version). The SF-36 is a self-report questionnaire. This questionnaire was developed by Ware and Sherbourne (1992) to describe health status in the Medical Outcomes Study. I selected to use five of nine subscales of the SF-36 with caregivers. They were: bodily pain (2 items), general health (5 items), vitality (4 items), role-emotional (3 items), and mental health (5 items).

In addition, I used one item about reported health. This question was, "Compared to one year ago, how would you rate your health in general now?" This used to describe typical health of caregivers. This item was not added with other items based on the based on the guideline of developers (Ware & Sherbourne, 1992).

Three subscales were not used in this study: physical functioning, role-physical, and social functioning. Those three subscales may not be sensitive to assess health of caregivers when providing care. I proposed to use 5 subscales that could refer to caregiver health in the caregiving role. Using 5 subscales would help maintain power of analysis and decrease participant burden. The measure 5 subscales and one item about reported health transition added to 20 items. For most items, participants were asked to rate on a five-point scale from 1 to 5. Only the subscale of bodily pain, participants were asked to rate on a six-point scale from 1

to 6. For scoring, I used the guideline of Ware and Sherbourne (1992). Some items were recoded because they had been worded in reverse. The formula of transformation was used to compute raw scores to 0-100 scores. The highest score of each subscale was 100. Higher scores of each subscale indicated better health.

## Demographic Data and Caregiving Factors

I developed a set of questions about caregivers' characteristics, caregiving factors, and care recipients' characteristics. The questions about caregivers' characteristics were such as age, sex, religious affiliation, and education. The questions about caregiving factors were such as the length of providing care, hours of providing, and having someone help to provide care. The questions about care recipients' characteristics were such as age, sex, religious affiliation, and diagnosis.

**Table 3.2**Summarizing Measures by Concept, Name, Initial Language, Number of Subscales, and Type of Rating scale

Concept	Name of	Initial language	Number of subscales	Rating scale
	measure	before testing	(total items)	
Type of motivations: a)autonomous motivations, and b) controlled motivations	The Reason for Providing Care Questionnaire	9	2 subscales (9 items)	A 7-point scale from 1 "strongly disagree" to 7 "strongly agree"
Satisfaction with psychological needs: competence, autonomy, and relatedness	The Basic Need Satisfaction Sca in General	3 -	3 subscales (21 items)	A 7-point scale from 1 "strongly disagree" to 7 "strongly agree"
Perceived informal social support	The Multidimen Scale of Percei Social Support Questionnaire		1 scale (12 items)	A 7-point scale from 1 "strongly disagree" to 7 "strongly agree"
Perceived gains of caregiving	The Gain in Alzheimer Care Questionnaire	English	1 scale (10 items)	A 5-point scale from 1 "disagree a lot" to 5 "agree a lot"
Perceived burden of caregiving	The Short Form the Zarit Burde Questionnaire		1 scale (12 items)	A 5-point scale from 0 "never" to 4 "nearly always"
Caregiver health	5 subscales of The SF-36 (Thai version) : general health mental health, vitality, bodily p and role-emoti One item of he report transitio	h, pain, on. ealth	5 subscales (20 items)	A 5-point scale from 1 "poor" to 5"excellent"

# **Participant Protection**

Typically, each hospital in Thailand has own IRB. The PI needs to submit IRB documents based on the guideline of each hospital. IRBs meet monthly. Some IRB may ask the PI to present and answer the questions in the IRB meeting. After IRB meeting IRB staff will provide the results to the PI to revise documents. Then, the PI needs to submit the revised documents. The IRB may ask the PI to revise documents more than one time. Each IRB approval in Thailand will take about 2-4 months.

I submitted IRB documents to three IRB hospitals in Thailand. These were the Prasat Neurological Institute, Nakhon Ratchasima Rajanagarindra Psychiatric Hospital, and Maharat Nakhon Ratchasima Hospital. I did not need to submit IRB documents for the Pakchong Nana Hospital because they are affiliated with the IRB of the Maharat Nakhon Ratchasima Hospital. Thus, before collecting data at the Pakchong Nana Hospital, I must have the IRB approval letter from the Maharat Nakhon Ratchasima. The IRB documents included IRB forms, research proposal, consent form, study information sheet, questionnaires, curriculum vitae of the principle investigator, and curriculum vitae of each research assistant. After I got IRB approvals from three hospitals in Thailand I submitted IRB documents to Health Science IRB of UW-Madison.

The Health Science IRB of UW-Madison provided exemption for this study. Research assistants were qualified about HIPAA from IRBs in Thailand. The research assistants included two nurses, one psychologist, and one senior undergraduate student. Three research assistants did not work at study sites. Only one research assistant worked in one study site, but she did not work where the team recruited caregivers of PWD. These factors lessened any potential risk of coercion from the research team to caregivers.

After getting the IRB approval in Thailand, I sent a letter to ask for permission from the director of the hospital to collect data. During waiting for getting permission, I provided the study information and discussed with the research assistants about the protocols to recruit eligible participants and collect data. We worked as a team. After getting permission, the team came to

meet a head nurse at the outpatient clinic to inform and discuss about the study. The team scheduled time to come for recruitment and data collection.

To maintain confidentiality, we assigned a code number to questionnaires before we provided to participants. After caregivers completely answered questionnaires, the team separated written consent forms from questionnaires. I could not trace the participants' identity. For confidentiality of data, the team entered data by using a code number. Then, I kept the data in the computer with password protection at the School of Nursing. I analyze data in an aggregated manner and presented data as a group.

## Sample

In this study, I proposed to have two convenience samples that were recruited as follows:

- 1. Sample 1 was five native Thai people. They were invited to join the study as experts. They were invited to rate the questionnaires for content validity. Polit and Beck (2006) have recommended that five experts' ratings would be sufficient to assess content validity of measures. These experts were specialized in geriatric nursing, mental health, and psychiatric illness. They were knowledgeable about persons with dementia and caregivers. Experts included three PhD nursing instructors, one psychologist with a master's degree, and one psychiatric nurse with a master's degree.
- 2. Sample 2 was 150 Thai informal caregivers who provided direct hands-on care for PWD. The team recruited those caregivers to answer a set of questionnaires to assess psychometric properties of measures and to describe the relationships among variables.

Before recruiting the sample 2, I estimated the sample size to have sufficient power of analysis. For health science studies, Green (1991) recommended a formula to estimate a sample size of assessing the multiple relationships with a power.80 and an alpha = .05. The formula is  $N \ge 104 + m$  (number of parameter) (Green, 1991). Because one of the study aims

was to examine relationships among variables, I used the formula to estimate the sample size. Based on caregiving literature, researchers may need to consider possible covariates such as hour of providing care, age of caregivers, or length of providing care (Liew et al., 2010; Yamamoto - Mitani et al., 2003). I estimated to have 3 possible covariates and this study had 13 parameters. The total of parameters of this study was 16. The desired sample size was: N ≥ 104+16 = 120. Therefore, the sample size of this study was 120 or higher.

Based on a previous study about caregivers of persons with dementia in Thailand, about 60% of caregivers who came with patients to clinic provided direct hands-on care (Muangpaisan et al., 2010). About 80% of those caregivers provided the consent and participated in the study as potential participants (Muangpaisan et al., 2010). Additionally, some participants may not answer the questionnaires completely. To obtain 120 participants with completed data, the team aimed to recruit 150 caregivers.

Each hospital, a head nurse provided the estimate numbers of caregivers who came to visit the clinic appointment of patients per month. Caregivers may come with PWD for clinical appointments. As well as, caregivers may come alone to receive patient medicine. From four hospitals, the estimate number of caregivers of PWD who visit the outpatient clinics is 120-160 persons per month. To recruit 150 caregivers, I estimated to collect data about 4- 5 months.

# Inclusion Criteria of Sample 2

Inclusion criteria were that informal caregivers who were providing direct hands-on care for persons with dementia at home. They provide at least one activity for activities of daily living (ADL) and at least two activities of instrumental activities of daily living (IADL) (Ciro, 2014). They provided care for persons with dementia at least three months after patients' diagnosis for Alzheimer's disease or dementia. They aged 18 years and over. Finally, they were able to speak Thai.

### Exclusion Criteria of Sample 2

The team excluded informal caregivers of the study if they were not able to comprehend the study information. If caregivers were not able to tell about the study information in their own words, the team concluded that caregivers might have limited understanding and communication of the study. If they did not understand the study, then we decided not to include them in this study because they may not be able to understand information of the study and answer questionnaires correctly.

Researchers have used teach-back and teach-to-goal techniques to assess comprehension of participants (Kripalani et al., 2008; Sudore & Schillinger, 2009). The teach-back technique was a method designed to ask participants to repeat given information in their own words (Baker, Wolf, Feinglass, & Thompson, 2008). The teach-to-goal technique was "a method of targeted education that repeats material until understanding is achieved" (Kripalani et al., p. 6). This method was used after using the teach-back technique if participants could not repeat back the information. Researchers have used both techniques to assess participants' ability to communicate and understand about research information in the informed consent (Kripalani et al., 2008; Sudore & Schillinger, 2009). The participants needed to use the short-term and long-term recall (Kripalani, Bengtzen, Henderson, & Jacobson, 2008), memory, and language communication to confirm their understanding (Baker et al., 2008).

# Sampling method for sample 2

To recruit all potential participants, I used two sampling methods as follows.

1. Using a direct method, the team recruited caregivers at the outpatient clinics. Some caregivers came with PWD for clinic appointments. Some caregiver came alone to receive patient medicine. The clinic staff invited caregivers who were waiting to meet a doctor to join this study. Caregivers who were interested in this study came to meet the research team. Then, the team recruited caregivers to join this study.

2. Using an indirect method, the team planned to recruit caregivers by phone. Some attendees were persons who came with PWD at outpatient clinics, but they were not caregivers. The team spoke with attendees to ask their willingness to take an information sheet of the study to caregivers of PWD. After caregivers got the study information they would call us if they were interested in participating in the study. Then, the team would call the caregivers back to recruit them to the study.

### **Procedures**

Recruitment and data collection with sample 1

I recruited sample1: five native Thai experts. I invited and asked experts to provide consent by e-mail. If they replied to my e-mail, this meant they provided consent. After all experts consented, I sent a set of questionnaires to them via e-mail. I asked the experts to rate items in a set of questionnaires for assessing content validity. After the experts completed questionnaires they sent them to a research assistant. The research assistant coded to each set of responses by using a given number. Then the research assistant sent only a set of questionnaires to the PI without experts' name and e-mail address. These methods were to keep confidentiality of data.

Screening for inclusion and exclusion criteria of sample 2

This was the plan of screening for sample 2. The team screened potential participants with a screening form. The potential participants met inclusion criteria and then the team did informed consent. The team used the teach-back technique and the teach-to- goal technique to assess comprehension of participants. The team told potential participants about the study's (a) purposes, (b) procedures, (c) possible risks, and (d) possible benefits. The team asked potential participants to repeat back each of these four types of the information in their own words. If

potential participants could do so, the team concluded that they were able to comprehend: (a) informed consent and (b) accurate information in this study.

If potential participants could not repeat all four details of the study, the team used the teach-to-goal technique to restate the study information and asked for their understanding within a few minutes (Kripalani et al., 2008). If potential participants could do so, the team concluded that they were able to comprehend the study information to participate. If caregivers could not repeat relevant study information, the team thanked for their interest and told that they were not good matches for this study.

## Consenting of Sample 2

If the potential participants could comprehend the study information, the team provided the consent form. Then, the team asked potential participants for their consent either by words or in writing. We accepted verbal consent because potential participants understood the study and agreed to participate. Based on Thai culture potential participants might feel uncomfortable to sign the consent form because it seemed a formal way for them. Also, we accepted written consent because potential participants understood the study and agreed to sign the consent to participate.

# Collecting data with sample 2

After eligible participants provided consent, the team explained a set of questionnaires (e.g., instructions to answer questionnaires, estimated time to complete questionnaires) and provided it. Participants could fill out the questionnaires by themselves. After completing the questionnaires on site the team provided 300 baht (about \$9) as compensation for the participants' time and to help support the cost of transportation.

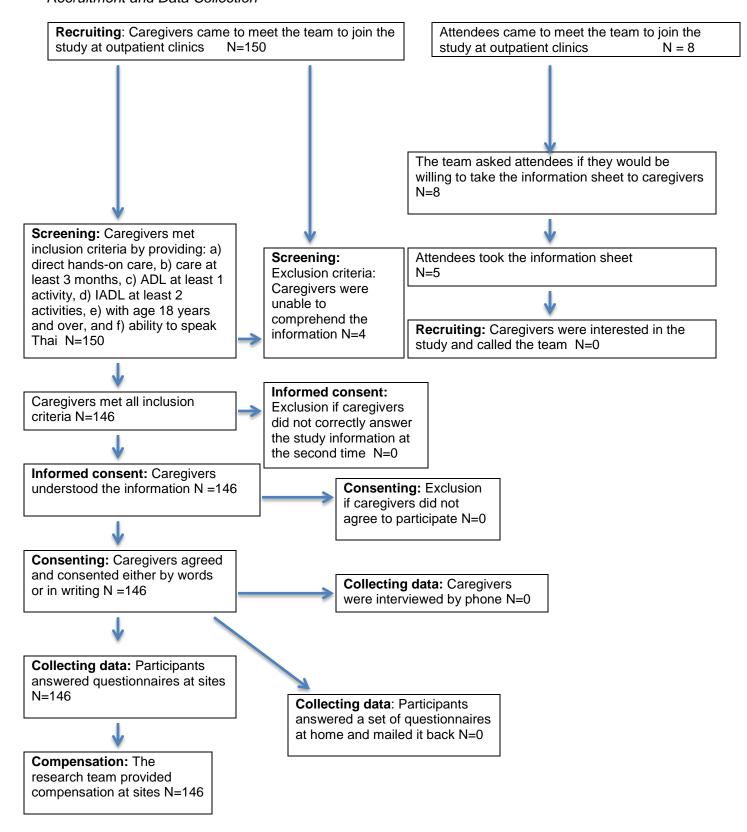
At study sites, based on participant preferences the team provided alternative ways for caregivers to answer questionnaires. Some participants might have time limitation at outpatient

clinics. Some participants might want to closely take care patients. The alternative ways for participants' preferences included: a) choosing to be interviewed by the team, b) completing a set of questionnaires at home, or c) wanting to have an interview by phone. For filling out the questionnaires at home, the team provided a set of questionnaires and an enclosed envelope to mail questionnaires back. For interviewing by phone, the team called to interview the participants using the same questionnaires as at the sites. After getting the questionnaires back by mail or finishing the interview by phone then the team mailed compensation.

When caregivers were interested in this study, they called the team. A team member screened caregivers for inclusion criteria. If caregivers met inclusion criteria and were able to comprehend the study information the team did informed consent. After caregivers provided the verbal consent the team told participants about two options to answer the questionnaires: a) to fill out a set of the questionnaires at home and mail it back or b) to be interviewed by phone. Then, the team followed the protocols of each method as same as at study sites (see Flow chart 3.1).

Figure 3.1

Recruitment and Data Collection



Recruitment and data collection were done in this study

After getting IRB approval in Thailand and UW-Madison, the team followed the protocols to recruit and collect data with sample 1 and sample 2. For sample 1, I recruited five Thai experts and collected data as the plan. For sample 2, after inviting caregivers by the staff clinic caregivers who were interested in the study came to meet the team. The team recruited 150 caregivers at study sites by using the direct methods because mostly caregivers came with PWD at clinic appointment. In each month, I estimated the number of caregivers who were not want to join this study at clinics by comparing with the actual number of caregivers who came for clinic appointments. About 5 caregivers in each month did not want to join the study. The team collected data for 4 months; therefore, the number of caregivers who did not want to join the study was 20. About 12% of caregivers did not want to join this study. A few attendees came at clinics and took the information sheet to caregivers. The team did not get any call from caregivers who were interested in the study. Two of 150 caregivers did not meet the criteria of providing care at least 3 months. Another two caregivers did not have any relationship with care recipients. Caregivers hired those people to provide care for care recipients when the caregivers worked.

One hundred and forty six potential participants met inclusion criteria. The team only used the teach-back technique to assess comprehension of potential participants. A few potential participants asked a question about the study for clarity. One hundred and fourteen (78%) potential participants provided the written consent to join the study. Only thirty-two (22%) potential participants provided the verbal consent. The team explained instructions about how to answer questionnaires and that completing questionnaires would likely take about 20-30 minutes. Thirty-six (25%) participants filled out the questionnaires by themselves. Most people who chose to do a written questionnaire had education at college level or higher. One hundred and ten (75%) preferred to be interviewed by using the questionnaires (see Figure 3.2). Participants who preferred to be interviewed were more likely to be older people than others.

During interviewing, a few participants were crying about their feeling on caregiving. The team did not get any participants who had a risk of severe psychological disturbances. The team observed that all participants felt relief after talking. All participants competed questionnaires at sites. After completing questionnaires, the team provided 300 baht (about \$9) as compensation for the participants' time and transportation. After providing the compensation a few participants did not want to keep it. They returned it back to the team. A few participants donated the compensation to the hospital. The team recruited and collected data for 4 months, from November 2014 to March 2015 (see Figure 3.3). Finally, 146 of 150 caregivers completed questionnaires; this was 97% of eligible caregivers who fully completed questionnaires.

Figure 3.2

Providing Consent and Answering Questionnaires of Sample 2

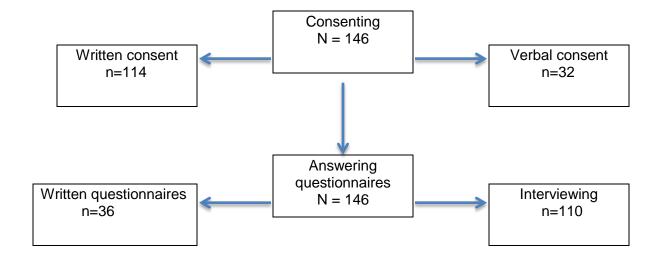
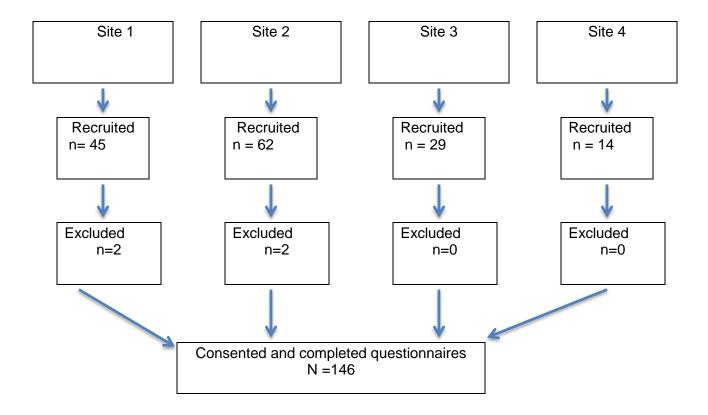


Figure 3.3

Comparing among Sites about Recruitment of sample 2



## **Data Analysis**

Sample 1: I entered and cleaned data. Then, I check the data for errors and missing. The data of experts' rating were no missing data. Then, I computed for content validity index scores using an excel spread sheet.

Sample 2: as using a double-entry method one research assistant entered data twice into two excel files. She entered data of sample 2 for two weeks. I compared both sets of data for discrepancies and errors. I corrected and the research assistant corrected all discrepancies and errors. I saved the corrected file of data to SPSS version 21. I used SPSS to analyze the data of sample 2 for the pattern of missing data. I used NCSS version 10 to test the data of sample 2 for normality and computed these data for transformation, and variance.

After cleaning data I check the data for missing. The data of caregivers' responses were

missing data 2.7% of the cases. From 146 caregivers' responses, five participants did not complete of an entire questionnaire. Three participants did not answer the questionnaire about reasons for providing care. One participant did not answer the questionnaire about perceived gains of caregiving. One participant did not answer the questionnaire about perceived informal social support. Meyers, Gamst, and Guarino (2006) suggested that if missing data constituted less than 5% of the cases, researchers could ignore those cases. If there was more than 75% missing data in a case, then this case was deleted. To deal with missing data, I handled with those cases with few missing data by entering the code number 999. I deleted those 5 cases with completely missing data of the entire questionnaire. In addition, I tested for the pattern of missing data by using Little's Missing Completely at Random (MCAR) in SPSS program (Little, 1988). The results showed that all missing data of this study were MCAR.

#### Possible Covariates

Based on literature, caregivers' characteristics, clinical problems of caregivers, and caregiving factors may influence perceived gains and burdens and caregiver health.

Researchers may consider caregivers' characteristics such as age, race, sex, education, and income as potential covariates (Liew, et al., 2010). For clinical problems of caregivers, researchers may ask caregivers about having any health problems to consider as a potential covariate (Tang, 2011). For caregiving factors, researchers may consider such as hours of providing care, the length of providing care, dependent levels, stages of dementia, the number activities of ADL, and the number activities of IADL as potential covariates (Liew et al., 2010; Spillman et al., 2014; Yamamoto - Mitani et al., 2003). I concluded that researchers might consider twelve factors about caregivers' characteristics, clinical problems of caregivers, and caregiving factors as potential covariates of caregiving studies. Additionally, three factors in this study could refer to demands of caregiving. Caregivers needed to provide care for care

recipients each day. They were: the number activities of IADL, the number activities of ADL, and hour of providing.

The team collected demographic data of caregivers' characteristics, clinical problems of caregivers, caregiving factors, and care recipients' characteristics. Caregivers' characteristics included age, sex, religious affiliation, education, marital status, and income. Clinical problems of caregivers were asked by using a dichotomous question about having any health problems. Caregiving factors included the length of providing care, hours of providing care, relationship with care recipients, living arrangement, working outside home, the number activities of ADL, the number activities of IADL, hours of someone help, providing care for others, and having experiences of providing care. Care recipients' characteristics included age, sex, religious affiliation, marital status, diagnosis, having other health problems, and paying for care recipients' treatment.

In this study, I had 8 potential covariates. I considered potential covariates based on literature of caregiving, the assumption of variables about continuous data, and the data collection of this study. When comparing potential covariates from literature and this study, I did not have data about levels of dependence and stages of dementia of care recipients. This was because of collecting data with caregivers. In addition, I did not ask caregivers about race because of focusing on only Thai caregivers. Although researchers have not mentioned about hours of someone to help provide care as a potential covariate, this variable may relate to hours of providing care. If caregivers have someone to help provide care they may provide care only a few hours. They may have less perceived burdens than caregivers with a long hour or those providing care with no one to help. Because hours of someone to help provide care may relate to hours of providing care, this variable may influence caregiving outcomes. Thus, hours of someone to help provide care were considered as a potential covariate.

Additionally, I planned to use Pearson 's product moment correlation coefficients to analyze bivariate relationships between potential covariates and study variables. After

considering factors that may influence caregiving outcomes of this study, I concluded 8 potential covariates because of prior literature and statistics used. Eight potential covariates included: age of caregivers, education of caregivers, income of caregivers, hours of providing care, the length of providing care, hours of someone help provide care, the number activities of ADL, and the number activities of IADL.

Huitema (1980) proposed the number of covariates in a study by using a formula. The number of covariates may use up to N - (J+1) covariates, where N is the total number of subjects and J is the number of groups. In this study, the total number of subjects was 146 and the number of groups was 1; the number of covariates may use up to 146 - (1+1) = 145. Huitema (1980) also suggested to limit the number of covariates using this ratio:

Covariate Ratio (CR) = 
$$\frac{C + (J - 1)}{N}$$

The C is the number of covariates, J is the arms of the study, and N is the total number of subjects. The CR should be < .10. This study had 8 potential covariates. The arm of the study was 1 and the total number of subjects was 146. Therefore, the CR of this study was 0.05.

# Data analysis for aim 1

To meet aim 1 for content validity, I computed the data of the experts' ratings in the excel files for the content validity index (CVI) and the scale-level content validity index (S-CVI). For each item, I computed the CVI for relevance and clarity. The CVI of each item was computed by using the number of experts who rate an item (either 3 or 4) divided by the total number of experts (Polit, Beck, & Owen, 2007). If the CVI of an item was .80 or higher (Polit et al., 2007) then the item was accepted for clarity and relevance. Additionally, I computed the CVI of each scale for comprehensiveness and cultural relevance. If the CVI of a scale was .80 or higher (Polit et al., 2007), then the scale was accepted for comprehensiveness and cultural relevance.

For each scale, I computed the average of the S-CVI. The S-CVI was computed by summing the I-CVI of each item divided by the number of items (Polit & Beck, 2006). To be acceptable, the S-CVI was .80 or higher (Polit et al., 2007). If a measure met the proposed criteria of the CVI and the average of the S-CVI, then I concluded that the measure was valid for the content. Finally, I counted the number of experts who circled unclear words in items. I summarized the main points from experts' comments on each measure for qualitative data.

#### Data analysis for aim 2

To meet aim 2 for internal consistency reliability, the data from the 146 caregivers were analyzed for the Cronbach's alpha coefficient. The Cronbach's alpha coefficient was analyzed for each measure. Three measures consisted of a single scale. These were: the Gain in Alzheimer Care Questionnaire, the Multidimensional Scale of Perceived Social Support Questionnaire, and the Short Form of the Zarit Burden Questionnaire. The Cronbach's alpha coefficient was analyzed of a composite score for each subscale. Three measures had subscales. First, the Reason for Providing Care Questionnaires had two subscales: autonomous motivations and controlled motivations. Second, the Basic Needs Satisfaction Scale in General Questionnaire had three subscales: satisfaction with autonomy, satisfaction with competence, and satisfaction with relatedness. Third, the 5 subscales of SF-36 (Thai version) were analyzed for the Cronbach's alphas for each subscale of general health, bodily pain, role emotional, vitality, and mental health. If the Cronbach's alpha coefficient for a measure was .70 or higher then I concluded that the measure was acceptable for internal consistency reliability following the rule of thumb about good and excellent Cronbach's alphas of Georg and Mallery (2003) (as cited in Gliem & Gliem, 2003).

### Data analysis for aim 3

To meet aim 3 for construct validity of the Gain in Alzheimer Care Questionnaire (GAIN), two types of this construct validity were evaluated: convergent and discriminant validity. I used the Pearson's Product-Moment Correlations to analyze data of caregivers' responses.

For convergent validity, the Basic Needs Satisfaction Scale in General (BNSG) was used to compare the GAIN. Because the GAIN and to the BNSG had a similar attribution to assess personal gains and gains in the relationship (Johnston & Finney, 2010; Yap et al., 2010). I hypothesized that the GAIN would have a moderate positive relationship with the BNSG at p < 0.05. I analyzed bivariate correlations between scores of the GAIN and scores of the BNSG. If the findings met the hypothesis, I concluded that I had the evidence for convergent validity of the GAIN (Polit & Beck, 2008).

For discriminant validity, the Short Form of the Zarit Burden Questionnaire (Short ZBI) was used to compare with the GAIN. The Short ZBI was used to assess the burden of caregiving whereas the GAIN was used to assess perceived gains of caregiving. Thus, the two measures had a different attribution to assess perceptions of caregivers. I hypothesized that the GAIN had a small negative relationship with the Short ZBI at p < .05. If the findings met hypothesis, I concluded that I had the evidence for discriminant validity of the GAIN when comparing with the Short ZBI (Polit & Beck, 2008).

Campbell and Fiske (1959) suggested one of several methods to assess discriminant validity of measures. Researchers can compare two scales that have different concepts to compute for discriminant validity by using correlations and reliability. If two scales are not highly correlated then researchers can conclude that the scale has discriminant validity. If two scales have positive high correlation to each other researchers can conclude that two scales have similar concepts. Both measures are likely to measure the same concept. They proposed the equation:

Disattenuated 
$$r_{xy} = \frac{r_{xy}}{\sqrt{r_{xx} \cdot r_{yy}}} < 0.85$$

The  $r_{xy}$  is correlation between x and y. The  $r_{xx}$  is the reliability of x and  $r_{yy}$  is the reliability of y. If results are less than .85 we can conclude that two scales have discriminant validity. Because of Campbell and Fiske's equation, they use a correlation and reliability of measures to compute discriminant validity. In this study, I computed for correlations and reliability of measures. Thus, I could use Campbell and Fiske's method to confirm discriminant validity of the GAIN in this study.

I would conclude that the GAIN had construct validity, if the GAIN had both convergent and discriminant validity.

# Data analysis for aim 4

To meet aim 4 of describing caregivers' characteristics, caregiving factors, care recipients' characteristics, and degree of explanatory and outcome variables, this analysis was for descriptive statistics: frequencies, percentages, mean, standard deviation, minimum scores, and maximum scores. These data were utilized to describe caregivers' characteristics, caregiving factors, care recipients' characteristics, type of motivations, degree of perceived informal social support, degree of satisfaction with psychological needs, degree of perceived gains of caregiving, degree of perceived burden of caregiving, and degree of caregiver health.

### Data analysis for aim 5

To meet aim 5 about examining the relationships among multiple variables, I had three specific aims: 5a) to examine the relationships between a set of explanatory variables and a set of outcome variables, 5b) to examine the relationships among explanatory variables, and 5c) to examine relationships among outcome variables.

### Bivariate analyses

To meet aim 5a to 5c, two methods of analyses were used. The Pearson's Product-Moment Correlations were used to analyze data of potential covariates, explanatory, and outcome variables for bivariate correlations. The Pearson product-moment correlation coefficient (r) for two variables at p < .05 was computed. I considered the value and direction of r at p < .05 (Polit & Beck, 2008) for interpreting the correlation of two variables. Because of conducting bivariate analyses several times with different pairs of variables, I adjusted the p-value.

## P-value Adjustment

Using multiple statistical tests across many bivariate and multivariate analyses can give a chance of false positives (Bender & Lange, 2001; Silicon Genetics, 2003). Researchers have proposed several methods for corrections with multiple testing, such as Bonferroni or the false discovery rate (FDR) of Benjamini and Hochberg (1995) (Feise, 2002; Silicon Genetics, 2003). For bivariate relationships, I analyzed several pairs of variables from 21 variables: 8 covariates, 6 explanatory variables, and 7 outcome variables. This would provide a total of 210 tests. To control the errors among the probability of false positive, the FDR (Benjamini and Hockberg, 1995) was used to adjust p-value of bivariate relationships of this study.

The FDR adjustments were calculated as follows:

- 1) The raw p-values of each correlation were ranked from the largest to the smallest.
- 2) The largest raw p-value remains as it was.
- 3) The second largest raw p-value was multiplied by the total number of correlations divided by its rank. If less than 0.05, it was significant. Corrected raw p-value = raw p-value\*(n/n-1) < 0.05, if so, correlation was significant.

4) The third p-value was multiplied as in step 3: Corrected p-value = p-value\*(n/n-2) < 0.05, if so, correlation was significant and computing as the same way in the following p-value (see Table 3.3).

**Table 3.3**An Example of the Calculation by Using the False Discovery Rate (FDR) Adjustments with k = 64 Correlations and with Error Rate = 0.05

Correlation	Unadjusted p-value (from largest to smallest)	Rank	Correction correlation	Is significant after correction?
1	0.10	64	No correction	0.1>0.05 = No
2	0.06	63	64/63*0.06 = 0.0610	0.0610 > 0.05 = No
3	0.04	62	64/62*0.04 = 0.0413	0.0413 < 0.05 = Yes
	·			
64	0.001	1	64/1*0.001 = 0.064	0.064 > 0.05 = No

As one can see from the example, the correction becomes more stringent as the p-value decreases; the error rate is a proportion of the number of correlations. After using bivariate analyses, I adjusted p-value for accuracy.

From bivariate analyses with p-value adjustment, I found two covariates that had significant relationships with caregiving outcome. Two covariates were: the age of caregivers and the number activities of ADL.

## Multivariate analyses

The composite indicator structural equation model (CISE)

Based on aim 5, examining relationships among multiple variables, I proposed to use the CISE. The CISE is a method to adjust measurement errors by using Cronbach's alphas of composite scores (McDonald, Dickinson, & Seifert, 2005). The error variance of each parameter

is computed by using the formula: (1 – Cronbach's alpha)\* variance (Baumgartner & Homburg, 1996 cited in Petrescu, 2013; Laimek, 2014). Researchers need to specify the fixed measurement error variances of each parameter using CISE. Before using the CISE researchers may need to consider four issues: reliable measures, sufficient sample sizes, composite scales with normal distributions, and multicollinearity. If one issue does not meet acceptable points this may influence biased parameter estimates (McDonald et al., 2005). Because measurement errors may influence parameter biases and standard errors, controlling for measurement errors would be important (McDonald et al., 2005). I had 13 parameters and 2 covariates. With this many parameters, measurement errors may be an issue of this study. I concluded that using the CISE for multivariate analyses would be appropriate.

# Normality

Based on assumptions of the CISE, I checked the data for normality. With histograms of each variable, I found that 6 scores had normal distributions: satisfaction with autonomy, satisfaction with competence, satisfaction with relatedness, body pain, vitality, and mental health. The other 7 variables were not normal distributions because of extreme values, two frequent values in one set of data, and skewness. These variables were: autonomous motivations, controlled motivations, perceived gains of caregiving, perceived burden of caregiving, perceived informal social support, general health, and role emotional. To use the CISE for multivariate analyses, I used the Box Cox transformation procedure to modify 7 variables that were not normally distributed (NCSS Statistical Software, 2015). The Box Cox transformation procedure is used to equalize variances for both positive and negative skewness to distribute normally (Osborne, 2010). But, this procedure did not provide transformed scores for analysis. I computed transformation scores of each variable by using the formula:  $Y = (X + \delta)^{\Lambda}$  Using the Box Cox transformation procedure provided the value of X (Lambda) and X0 (Shift); X1 was an original score.

In this study, I had 6 original scores with normal distribution and 7 transformed scores with normal distributions. Considering of using appropriate scores for multivariate analyses of the CISE was important. I developed three sets of scores in order to test as appropriate scores using CISE. I made three sets of scores: (a) a set of original scores of all variables, (b) a set of combined scores between original scores and transformed scores with normal distributions, and set of transformed scores of all variables. By comparing among three sets of scores, I found that a set of original scores did not support an assumption about using normality for the CISE. Most scores were not normal distributions. For a set of combined scores, although 6 original scores had normal distributions, their distributions may not be perfectly normal. When using 6 original scores with transformed scores, the original scores may interfere relationships of other scores. For a set of all transformed scores, by using the Box Cox transformation procedure may alter original scores slightly to be more normal distributions. All 13 scores had been transformed by using the same method for normal distribution. This supported the assumptions of the CISE. Because I had 13 scores of variables I gave an example of the results of the transformed scores about perceived burdens of caregiving by using the Box Cox transformation procure. I gave an example of the results of one variable as plots and the histogram (see Figure 3.4).

#### Multicollinearity

One of important assumption of using the CISE was that there is no meaningful multicollinearity among the variables. Multicollinearity refers to two or more variables that are strongly correlated with each other (Meyer et al., 2006). To check multicollinearity of all scores, analyzed my data for the Variance Inflation Factor (VIF), a measure of correlations among variables (Meyer et al., 2006). If VIF is not more than 10, this indicates the acceptable point about multicollinearity in the model (Meyers et al., 2006). In this study, the VIF of variables were 1.12 to 2.4.

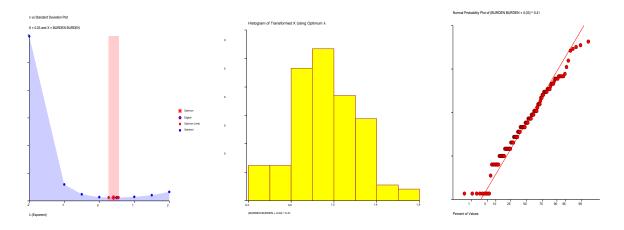
#### Measurement errors

For using CISE, I computed for the error variance of each score. Before computing the error variance of each score, I computed the data for the Cronbach's alphas (α) and the variances of scores. The Cronbach's alphas for measures were 0.26 to 0.93. The variances of scores were 0.10 to 20.83. Then, I computed the error variance of each score following the formula: (1 – Cronbach's alpha)\* variance. The error variances of each score were 0.01 to 1.56.

I had four measures without acceptable points for Cronbach's alpha. Using these Cronbach's alpha to compute error variances of variables may interfere relationships of other variables in a model using CISE. To test influences of error variances on relationships among variables, I compared the results about relationships among variables between using CISE for controlling error variances and path analysis. I found that those results were similar. I conclude that error variances of measures with unacceptable points of Cronbach's alphas may slightly interfere relationships among variables of this study. Thus, I used CISE for multivariate analyses of this study for aims 5a to 5c: 5a) the relationships between explanatory variables and outcome variables, 5b) the relationships among explanatory variables, and 5c) the relationships among outcome variables. With using CISE provided two models. Model 1 was without covariates and model 2 was with covariates.

Figure 3.4

An Example of The Box Cox Plot, Histogram, and Normal P-P Plot of Perceived Burdens of Caregiving by Using the Box Cox Transformation Procedure



# Summary

This study used a cross-sectional and correlational descriptive design to examine content validity by experts' ratings, internal consistency reliability by caregivers' responses, construct validity by caregivers' responses, and relationships among variables of caregiving by caregivers' responses. I recruited and collected data with five Thai experts. For caregiver participants, the team recruited those caregivers at outpatient clinics of 4 hospitals in Thailand. One hundred and forty-six potential participants consented and answered questionnaires at outpatient clinics. I estimated that another 20 caregivers did not show interest in this study. This meant about 88% of those attending clinics were interested. For data collection methods, the team provided four choices for participants to answers questionnaires without coercion. Most participants preferred to answer questionnaires by an interview. Finally, I got 146 participants who completed questionnaires. Then, the team entered data twice. I cleaned and tested data for missing patterns.

For data analysis, I chose to use excel to compute data from experts' ratings for the CVI of each item for clarity and relevance. I also computed for the CVI of each scale for

comprehensiveness and cultural relevance. The average of the S-CVI was computed for each scale. The number of experts who circled unclear words was counted. All comments from experts were summarized for each measure as qualitative data.

For data from caregivers' responses, I chose to use descriptive statistics to identify such as frequency, percentage, mean, or standard deviation of caregivers' characteristics, caregiving factors, care recipients' characteristics, and degree of study variables. To examine the relationships among variables, I chose to use Pearson product-moment correlation to assess bivariate correlations between covariates and study variables. I also used CISE for multivariate analyses with controlling measurement errors to produce two models based on study aims.

#### **CHAPTER 4**

#### RESULTS

In this chapter, I present results including descriptive data of caregivers of persons with dementia (PWD), caregiving factors, care recipients, and explanatory and outcome variables. Then, I describe the results regarding the study aims of assessing content validity of measures by experts, internal consistency reliability of measures by caregivers, construct validity of the GAIN by caregivers, and relationships among variables by caregivers.

# **Descriptive Data for Samples**

The study had two samples. Sample 1 consisted of five native Thai experts in geriatric nursing, mental health, and psychiatric illness for the purpose of assessing content validity. For a qualitative description of the sample, see chapter 3 under the section of sample 1.

Sample 2 consisted of 146 Thai caregivers of PWD. The majority of caregiver participants were female (82%) and married (64%). Caregivers had a mean age of 51.1 years (SD = 11.9). Most caregivers were Buddhist (95%) and education at bachelor degree and higher (41%). Caregiver monthly incomes were 10,001-20,000 baht (25%) and 5,00-10,000 baht (19%). For details of caregivers' characteristics on demographic data, see Table 4.1.

I describe caregivers' characteristics on social factors, health problems, and caregiving situation. The major group of caregivers was daughters (57%). A mean of the length of caregivers providing care was 4.59 years (SD = 3.55). Caregivers provided care with a mean of 14.83 hours per day (SD = 8.19). Seventy-two percent of caregivers had someone to help provide care. Most caregivers lived with care recipient (85%) and had a health problem (51%). For information of caregivers' characteristics, see Table 4.2. By using the single item of reported health, most caregivers had good health (53%). Using the single item of reported health compared to one year ago, most caregivers had their health the same as one year ago (68%).

Table 4.1

Caregivers' Characteristics on Demographic Data

Characteristic	<i>n</i> =146	%	М	SD Min- Max
Age (years old)			51.1	11.89 25-82
21-30	5	3.4		
31-40	21	13.4		
41-50	50	34.3		
51-60	39	26.7		
61-70	22	15.0		
71 and over	9	6.2		
Sex				
Male	26	17.8		
Female	120	82.2		
Religious Affiliation				
Buddhism	139	95.2		
Christian	3	2.1		
Islam	4	2.7		
Education level				
Less than high school	40	27.6		
High school	23	15.8		
Associated degree	22	15.1		
Bachelor degree	47	32.2		
More than bachelor degree	13	8.9		
Marital status				
Single	42	28.7		
Married	94	64.4		
Divorced	5	3.4		
Other	4	2.7		
Missing	1	0.7		
Monthly Income				
Less than 5,000 baht	24	16.4		
5,000-10,000 baht	27	18.5		
10,001-20,000 baht	36	24.7		
20,001-30,000 baht	18	13.7		
More than 30,000 baht	34	23.3		
Missing	5	3.4		

Note \$1 = 32.5 baht; Min = observed minimum number; Max = observed maximum number. For comparing incomes, the average incomes of Thai people in 2014 were 13581 baht or \$418 per month reporting by the National Statistical Office Thailand (<a href="https://www.tradingeconomics.com">www.tradingeconomics.com</a>).

**Table 4.2**Describing Caregivers' Characteristics on Social Factors, Health Problems, and Caregiving Situation

Characteristic	<i>n</i> =146	%	М	SD	Min-Max
Length of providing care (years)			4.59	3.55	0.03-20.00
Hours of providing care per day			14.83	8.19	2.00-24.00
Relationship with CR			14.00	0.13	2.00-24.00
Daughter	83	56.8			
Son	18	12.3			
Wife	23	15.8			
Husband	23 5	3.4			
Others	17	11.7			
Living arrangement	404	04.0			
Always Living with CR	124	84.9			
Living with CR some days	14	9.6			
Not living with CR	8	5.5			
Having a health problem					
Yes	69	47.3			
No	75	51.4			
Missing	2	1.4			
Working outside home					
Yes	100	68.5			
No	43	29.5			
Missing	3	2.1			
Caregiver provides ADL per day					
1-2 activities	59	40.4			
3-4 activities	29	19.8			
5-6 activities	58	39.7			
Caregiver provides IADL per day					
1-2 activities	2	1.4			
3-4 activities	11	7.5			
5-6 activities	26	17.8			
7-8 activities	107	73.3			
Caregiver has someone to help pr		. 0.0			
No	41	28.1			
Yes	105	71.9			
If Yes,	100	7 1.0			
Hour of help by someone	92	87.6	6.29	7.09	1-24
Missing	13	12.4	0.29	1.03	1-24
Caregiver provides care for other provides care for ot	43	29.5			
No	103	70.5			
Caregiver had experiences before	. •				
Yes	11	7.5			
No	135	92.5			

*Note*. CR = care recipient; ADL = activities of daily living; IADL = instrumental activities of daily living; Min = observed minimum number; Max = observed maximum number.

# Descriptive data of care recipients

Care recipients had a mean age of 76.18 (SD = 9.14). The majority of care recipients were female (58%), married (72%), and Buddhist (95%). Most care recipients had been diagnosed with Alzheimer's disease (74%) and other types of dementias (26%) by physicians. Care recipients often had other health problems (66%). Mostly, government paid for care recipients' treatment (49%). The details of care recipients' characteristics on demographic data, clinical problem, and payment for care recipients' treatment, are in Table 4.3.

Table 4.3

Care Recipients' Characteristics on Demographic Factors, Clinical Problems, and Payment for Care Recipients' treatment

Characteristic	n =146	%	М	SD	Min-Max
Age of CR (years old)			76.18	9.14	36-92
31-50	1	0.7			
51-60	10	6.8			
61-70	19	13.0			
71-80	66	45.3			
81-90	26	31.5			
90 and over	4	2.8			
Sex					
Male	61	41.8			
Female	85	58.2			
Religious Affiliation					
Buddhism	139	95.2			
Christian	3	2.1			
Islam	4	2.7			
Marital status					
Single	8	5.5			
Married	105	71.9			
Widowed	32	21.9			
Separated	1	0.7			
Diagnosis					
Alzheimer's disease	108	74.0			
Dementia with Parkinson	8	5.5			
Vascular Dementia	19	13.0			
Dementia	11	7.5			
Having other health Problems					
Yes	96	65.8			
No	50	34.2			
Paying for care recipients' treatme					
Caregiver	39	26.7			
Government	71	48.7			
Universal coverage	12	8.2			
Social security	2	1.4			
Other	22	15.1			

Note. Min = observed minimum number; Max = observed maximum number

# **Descriptive data of variables**

For explanatory variables, caregivers had higher mean scores on autonomous motivations (M = 6.72, SD = 0.53) than scores on controlled motivations (M = 5.62, SD = 1.37). They had moderately high scores of satisfaction with autonomy, competence, and relatedness (Ms = 5.25-5.61, SDs = 0.81-0.88). Caregivers had a high score of perceived informal social support (M = 5.95, SD = 1.17).

For outcome variables, caregivers had higher mean scores on perceived gains of caregiving (M = 3.7, SD = 0.45) than scores on perceived burden of caregiving (M = 0.93, SD = 0.73). For health subscales, caregivers had the highest score on role-emotional (75.23) and the lowest score of general health (58.44). For descriptive data of explanatory and outcome variables of caregiving, see Table 4.4.

Table 4.4

Descriptive Data of Proposed Explanatory and Outcome Variables about Caregiving

Variables	n	Mean	SD	Min-Max
Explanatory variables				_
Type of motivations for providing	care			
Autonomous motivations	144	6.72	0.53	4.25-7.00
Controlled motivations	144	5.62	1.37	1.00-7.00
Satisfaction of psychological nee	ds			
Autonomy	144	5.43	0.88	2.00-7.00
Competence	144	5.25	0.86	3.33-7.00
Relatedness	144	5.61	0.82	3.50-7.00
Perceived Informal social suppor	t 145	5.95	1.17	2.08-7.00
Outcome variables				
Perceived gains of caregiving	145	3.70	0.45	1.90-4.00
Perceived burden of caregiving	146	0.93	0.73	0.00-3.42
Caregiver health				
General health	146	58.44	22.05	10.00 - 92.00
Bodily pain	146	62.05	17.81	0.00 - 90.00
Role-emotional	146	75.23	22.49	0.00-100.00
Vitality	146	65.20	17.48	12.50-100.00
Mental health	146	70.82	16.33	20.00-100.00

Note. Min= observed minimum score; Max = observed maximum score

Aim 1: To evaluate the content validity of four measures including a) the Reasons for Providing Care Questionnaire (RPC), b) the Basic Needs Satisfaction Scale in General Questionnaires (BNSG), c) the Gain in Alzheimer Care Questionnaire (GAIN), and d) the Multidimensional Scale of Perceived Social Support Questionnaire (MSPSS).

Based on experts' ratings, I present the content validity index, CVI, for items on each scale regarding clarity and relevance. For computing CVI, see the section of data analysis in Chapter 3. Then, I present the CVI for scales on comprehensiveness and cultural relevance. Finally, I present the number of experts who indicated revisions were needed. The results are presented by measure.

The Reasons for Providing Care Questionnaire (RPC)

The CVI scores for the nine items of the RPC were 0.60-1.00 for clarity and 0.80-1.00 for relevance. For the CVI of each item, and for the number of experts indicating revisions were needed, see Table 4.5. The CVI scores for this scale were 0.80 for comprehensiveness and 1.00 for cultural relevance.

Table 4.5

Experts' Ratings on Each Item for Clarity and Relevance and the Number of Experts Indicating Revisions Needed on the Reason for Providing Care Questionnaire

Item	Clai	rity	Relevance	Relevance		
	Number of expe	erts	Number of experts		indicating revision	
	Rating scale as	3 or 4 CVI	Rating scale as 3 or 4	CVI	of an item	
Autor	nomous motivation	ns (4 items)			_	
1	4/5	0.80	5/5	1.00	3	
4	4/5	0.80	5/5	1.00	1	
5	5/5	1.00	5/5	1.00	3	
8	3/5	0.60	4/5	0.80	2	
Contr	olled motivations	s (5 items)				
2	5/5	1.00	5/5	1.00	2	
3	4/5	0.80	5/5	1.00	1	
6	4/5	0.80	5/5	1.00	2	
7	4/5	0.80	5/5	1.00	1	
9	5/5	1.00	5/5	1.00	2	

*Note.* CVI = content validity index

The Basic Needs Satisfaction Questionnaire in General (BNSG)

The CVI scores of items in the BNSG for clarity were: 0.80- 1.00 in the satisfaction with autonomy scale, 0.80 -1.00 for satisfaction with competence scale, and 0.80-1.00 for satisfaction with relatedness scale. The CVI scores of items in the BNSG for relevance were: 0.80- 1.00 in satisfaction with autonomy, 0.80 -1.00 in satisfaction with competence, and 0.80- 1.00 in satisfaction with relatedness. For details of the CVI of each item and for the number of experts indicating for revision needed, see Table 4.6. The CVI scores of this scale were 0.80 for comprehensiveness and 0.80 for cultural relevance.

Table 4.6

Experts' Rating on Each Item for Clarity and Relevance and the Number of Experts Indicating Revisions Needed of the Basic Needs Satisfaction Questionnaire in General

Revisions Needed of the Basic Needs Satisfaction Questionnaire in General							
Item	Clarity		Relevance		Number of experts		
	Number of experts		Number of experts		indicating revision		
	Rating scale as 3 or 4	CVI	Rating scale as 3 or 4	CVI	of an item		
Satist	faction with Autonomy						
1	5/5	1.00	5/5	1.00	1		
4	5/5	1.00	5/5	1.00	0		
8	5/5	1.00	5/5	1.00	2		
11	5/5	1.00	5/5	1.00	1		
14	4/5	0.80	4/5	0.80	2		
17	4/5	0.80	4/5	1.00	2		
20	4/5	0.80	4/5	0.80	2		
Satisf	faction with Competend	ce (6 item	ns)				
3	4/5	0.80	5/5	1.00	3		
5	4/5	0.80	5/5	1.00	1		
10	5/5	1.00	5/5	1.00	1		
13	4/5	0.80	5/5	1.00	0		
15	5/5	1.00	5/5	1.00	1		
19	4/5	0.80	4/5	0.80	2		
Satist	faction with Relatednes	ss (8 item	ıs)				
2	4/5	0.80	5/5	1.00	1		
6	4/5	0.80	5/5	1.00	2		
7	5/5	1.00	5/5	1.00	0		
9	5/5	1.00	4/5	0.80	2		
12	4/5	0.80	5/5	1.00	3		
16	4/5	0.80	5/5	1.00	1		
18	4/5	0.80	5/5	1.00	2		
21	4/5	0.80	5/5	1.00	1		

*Note.* CVI = content validity index

The Gain in Alzheimer Care Questionnaire (GAIN)

The CVI scores of items in the GAIN scale were 0.80-1.00 for clarity and 0.80-1.00 for relevance. For details of the CVI of each item and for the number of experts indicating revisions needed, see Table 4.7. The CVI scores of this scale were 0.80 for comprehensiveness and 0.80 for cultural relevance.

**Table 4.7**Experts' Rating on Each Item for Clarity and Relevance and the Number of Experts Indicating Revisions Needed of the Gain in Alzheimer Care Questionnaire

Item	Clarity		Releva	Relevance		
	Number of experts		Number of expe	erts	indicating revision	
	Rating scale as 3 or 4	CVI	Rating scale as	3 or 4 CVI	of an item	
1	5/5	1.00	5/5	1.00	2	
2	5/5	1.00	5/5	1.00	2	
3	4/5	0.80	4/5	0.80	0	
4	5/5	1.00	5/5	1.00	2	
5	4/5	0.80	4/5	0.80	0	
6	5/5	1.00	5/5	1.00	0	
7	4/5	0.80	5/5	1.00	2	
8	4/5	0.80	4/5	0.80	2	
9	4/5	0.80	4/5	0.80	1	
10	4/5	0.80	4/5	0.80	0	

*Note.* CVI = content validity index

The Multidimensional Scale of Perceived Social Support Questionnaire (MSPSS)

The CVI scores of items in the MSPSS were 0.80-1.00 for clarity and 0.80-1.00 for relevance. For details of the CVI of each item and the number of experts indicating for revision needed, see Table 4.8. The CVI scores of this scale were 1.00 for comprehensiveness and 1.00 for cultural relevance.

Table 4.8

Experts' Rating on Each Item for Clarity and Relevance and the Number of Experts Indicating Revisions Needed of the Multidimensional Scale of Perceived Social Support Questionnaire

Item	Clarity	Clarity		Relevance		
	Number of experts		Number of experts		indicating revision	
	Rating scale as 3 or 4	CVI	Rating scale as 3 or 4	CVI	of an item	
1	4/5	0.80	5/5	1.00	2	
2	4/5	0.80	4/5	0.80	2	
3	4/5	0.80	4/5	0.80	2	
4	5/5	1.00	5/5	1.00	2	
5	4/5	0.80	4/5	0.80	2	
6	4/5	0.80	4/5	0.80	1	
7	4/5	0.80	4/5	0.80	1	
8	5/5	1.00	5/5	1.00	0	
9	4/5	0.80	4/5	0.80	3	
10	4/5	0.80	4/5	0.80	1	
11	5/5	1.00	5/5	1.00	0	
12	5/5	1.00	5/5	1.00	0	
Mata	CV/I contant validity	:				

*Note.* CVI = content validity index

From experts' ratings on items, I computed the average the content validity index of the scale (S-CVI). I present the average of the S-CVI and the number of experts providing additional comments. The averages of the S-CVI of two subscales in the RPC were: the autonomous motivations were 0.80 for clarity and 0.95 for relevance, and the controlled motivations were 0.88 for clarity and 1.00 for relevance. The average of the S-CVI of three subscales in the BNSG were: the satisfaction with autonomy was 0.91 for clarity and 0.94 for relevance, the satisfaction with competence was 0.87 for clarity and 0.97 for relevance, and the satisfaction with relatedness was 0.85 for clarity and 0.98 for relevance. The average of the S-CVI of the GAIN was 0.88 for clarity and 0.90 for relevance. The average of the S-CVI of the MSPSS was 0.87 for clarity and 0.88 for relevance. For the average of the S-CVI across measures and the number of experts providing additional comments, see Table 4.9.

Table 4.9

The Average Content Validity Index by Scale (S-CVI) and Number of Experts Providing Additional Comments

Scale		S-CVI	Number of experts providing additional
	Clarity	Relevance	comments
RPC			3
Autonomous Motivations	0.80	0.95	
Controlled Motivations	0.88	1.00	
BNSG			4
Satisfaction with Autonomy	0.91	0.94	
Satisfaction with Competence	0.87	0.97	
Satisfaction with Relatedness	0.85	0.98	
GAIN	0.88	0.90	3
MSPSS	0.87	0.88	2

Note. RPC = Reason for Providing Care Questionnaire; BNSG = Basic Needs Satisfaction Questionnaire in General; GAIN = Gain in Alzheimer Care Questionnaire; MSPSS = Multidimensional Scale of Perceived Social Support Questionnaire

Summarizing Experts' Additional Comments for Revisions by Measure

The RPC: For a 9-item measure, three experts provided additional comments for revising questionnaires. One expert suggested that researchers needed to revise some words such as item 1 "personally", and item 4 "love and/or respect" by using formal Thai language for clarity, rather than more informal words. The other expert provided suggestions in general that the RPC has some limitations to assess the caregiving context regarding religious beliefs and cultural norms of Thai people, such as the law of Karma and Bunkhun.

The BNSG: For a 21-item measure, four experts provided additional comments to revise questionnaire for clarity. One expert suggested about deleting some items that had similar meaning such as the question number 1 and number 8 to decrease the number of questions. Two experts suggested that researchers should revise some words for clarity by using formal Thai language to increase clarity. One expert suggested that items 3,13,15, and 19 might not be suitable with Thai culture especially about expressing caregivers' abilities. For example, the question of item 3 is, "Often, I do not feel very competent."

**The GAIN**: For a 10-item measure, three experts provided additional comments for revising the questionnaire. Two experts suggested that item 1, 2, and 4 had two main points, rather than only one. Separating that question to two questions according with each main point would increase clarity. One expert mentioned that some words were difficult to understand.

Researchers needed to revise a few items by using lay language.

**The MSPSS**: For a 12-item measure, two experts provided additional comments for revising some items to increase clarity such as "someone special" and "really tried to help me".

Additionally, while caregivers answered a set of questionnaires the team asked caregivers to circle some words or sentences that were not clear for them. I found that five participants circled some words and sentences. Four participants circled words in the item 3, 6, and 9 in the BNSG. One participant circled words in the item 1, 2, 5, 10 of the MSPSS. Thus, 5 of 146 commented on clarity in 7 of items across all measures.

Aim 2: To assess the internal consistency reliability of six measures including a) the RPC, b) the BNSG, c) the MSPSS, d) the GAIN, e) the Short Form of the Zarit Burden Questionnaire (Short ZBI), and f) the 5 subscales of health (General Health, Body Pain, Role Emotional, Vitality, Mental Health).

From caregivers' responses, I computed Cronbach's alpha of each measure. For the two RPC subscales, the Cronbach's alpha of the autonomous motivations was 0.26. The Cronbach's alpha of the controlled motivations was 0.70. For the three BNSG subscales, the Cronbach's alpha for satisfaction with autonomy was 0.63; for satisfaction with competence, it was 0.38; for satisfaction with relatedness, it was 0.68. The Cronbach's alpha of the MSPSS was 0.89. The Cronbach's alpha of the GAIN was 0.88. The Cronbach's alpha of the Short ZBI was 0.89. For 5 health subscales were 0.57 to 0.93. For details of the Cronbach's alpha of each health subscale, see Table 4.10.

For three subscales, the Cronbach's alphas were less than .60. They were: autonomous

motivation subscale, satisfaction with competence subscale, and vitality subscale. To explore whether or not I could improve these Cronbach's alphas, I deleted an item that had the most poorly correlated with other items in subscales. I found that after deleting one item on autonomous motivation subscale. The Cronbach's alpha changed from .26 to .27. For the satisfaction with competence, after deleting one item in this subscale the Cronbach's alpha changed from .38 to.41. For the vitality subscale, after deleting one item in this subscale the Cronbach's alpha changed from .57 to .53. Thus, the Cronbach's alphas of three subscales did not increase in a meaningful way. If I were to use revised subscales, then I could not compare my findings from these subscales to those from prior studies. I concluded that I should use the original subscales rather than revised ones.

**Table 4.10**Caregivers' Responses on Six Measures about Caregiving to Assess Cronbach's Alpha ( $\alpha$ ) for Internal Consistency Reliability and Reducing an Item in Three Subscales with  $\alpha$  < 0.60

Measure	Numbers	Initial α	Reducing	Subsequent α
	of items		an item	
Newly Translated Scales				_
Reasons for Caregiving (RPC)				
<b>Autonomous Motivations</b>	4	0.26	3	0.27
Controlled Motivations	5	0.70		
Needs Satisfaction (BNSG)				
Autonomy	7	0.63		
Competence	6	0.38	5	0.41
Relatedness	8	0.68		
GAIN	10	0.88		
Previously Translated in Thai Langua	ge			
Burden (Short ZBI)*	10	0.89		
Informal Social Support (MSPSS)	12	0.89		
5 Subscales of the SF-36 (Thai versio	n)			
General Health	<sup>^</sup> 5	0.81		
Bodily Pain	2	0.75		
Role Emotional	3	0.93		
Vitality	4	0.57	3	0.53
Mental Health	5	0.65		
	· ·	2.00		

Note. α = Cronbach's alpha, RPC = Reason for Providing Care Questionnaire; BNSG = Basic Needs Satisfaction Questionnaire in the General; GAIN = Gain in Alzheimer Care Questionnaire; MSPSS = Multidimensional Scale of Perceived Social Support Questionnaire; Short ZBI = Short Form of the Zarit Burden Questionnaire.\* The Short ZBI is from the full-scale of ZBI.

# Aim 3: To investigate the construct validity of the GAIN

For convergent validity, I assessed whether or not the three subscales of the BNSG had moderate positive relationships with the GAIN. I observed that the GAIN scale had moderate positive relationships with autonomy (r = .33, p < .01) and relatedness subscales (r = .39, p < .01). The GAIN had a small positive relationship with competence (r = .19, p < .05) (see Table 4.11).

For discriminant validity, I examined whether or not the GAIN scale had a negative relationship with the Short ZBI. I observed that the GAIN had a moderate negative relationship with the Short ZBI (r = -.28, p < .01) (see Table 4.11).

Additionally, for discriminant validity, I examine whether or not the Short ZBI had negative relationships with the three subscales of the BNSG. I observed that the Short ZBI had moderate negative relationships with satisfaction with autonomy (r = -.43, p < .01) and satisfaction with relatedness (r = -.34, p < .01) subscales but not with satisfaction with competence subscale (r = .16, p > .05) (see Table 4.11).

I also computed discriminant validity of the GAIN compared with the Short ZBI based on the equation of Campbell and Fiske (1959). The  $r_{xy}$  of the GAIN and the Short ZBI was -.28. The  $r_{xx}$  of the reliability of the GAIN was .88. The  $r_{xy}$  of the reliability of the Short ZBI was .89. Based on my calculations :

(Disattenuated 
$$r_{xy} = \frac{r_{xy}}{\sqrt{r_{xx} \cdot r_{yy}}} < 0.85$$
)

When comparing the GAIN and Short ZBI then the disattenuated  $r_{xy}$  was -.32. By comparing the GAIN with the BNSG and Short ZBI, I concluded that the GAIN were acceptable for convergent and discriminant validity.

Table 4.11

Correlations between the Gain in Alzheimer Care Questionnaire (GAIN) and the Three Subscales of the Basic Needs Satisfaction Questionnaire in General (BNSG), the Short ZBI to Assess for Convergent Validity and Discriminant Validity by Using Pearson-Product Moment Correlations

	GAIN		BNSG		Short ZBI
		Autonomy	Competence	Relatedness	
GAIN BNSG	-	.33**	.19*	.39**	
Autonomy Competence	.33** .19*	- .41**	_		
Relatedness	.39**	.57**	.40**	-	
Short ZBI	28**	43**	16	34**	-

Note. BNSG = Basic Needs Satisfaction Questionnaire in the General; GAIN = Gain in Alzheimer Care Questionnaire; Short ZBI = Short Form of the Zarit Burden Questionnaire.

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

Aim 5: To examine relationships among caregiving variables as below:

Aim 5a: the relationships between explanatory variables and outcome variables.

Aim 5b: the relationships among explanatory variables

Aim 5c: the relationships among outcome variables

## **Bivariate Analyses**

For bivariate analyses, I identified which relationships among potential covariates, explanatory, and outcome variables were significant. These were based on having a p-value below at p < .05 using an adjustment with the False Discovery Rate (FDR). I reported r values of bivariate relationships (see Table 4.12 for bivariate correlations and Table 4.13 with p-value adjustment). I present the results of relationships between covariates and caregiving outcomes. Then I present the results based on study aims.

The relationships between covariates and caregiving outcomes

I examine whether or not covariates had significant relationships with caregiving outcomes in order to control these covariates. The age of caregivers had a small positive relationship with perceived gains of caregiving scale (r = .23). The number activities of ADL had a moderate positive relationship with perceived burdens of caregiving scale (r = .29). In contrast, the number activities of ADL had small to moderate negative relationships with 4 subscales of caregiver health: general health (r = -.22), role-emotional (r = -.26), vitality (r = -.29), and mental health (r = -.26). For bivariate correlations between covariates and outcome variables, see Table 4.12 and Table 4.13). Only 2 covariates, the age of caregivers and the number activities of ADL, had significant relationships with caregiving outcomes. Therefore, I added the age of caregivers and the number activities of ADL as covariates into multivariate analyses. For more information of bivariate correlations between covariates and study variables, see Table 4.12). For more information of using the False Discovery Rate (FDR) to adjust p-value, see Table 4.13).

The relationships between explanatory variables and outcome variables

I examined whether or not satisfaction with psychological needs: autonomy, competence, and relatedness had significant relationships with caregiving outcomes, because these variables have had positive relationship with such perceived gains and physical and mental health of participants in other SDT research. Consistent with SDT, I found that the satisfaction with autonomy had moderate positive relationships with perceived gains of caregiving scale (r = .33) and 4 subscales of caregiver health: bodily pain (r = .28), role-emotional, (r = .21), vitality (r = .28), and mental health (r = .39). Additionally, the satisfaction with autonomy subscale had a moderate negative relationship with perceived burden of caregiving scale (r = .43). Consistent with SDT, the satisfaction with competence had small to moderate positive relationships with 3 subscales of caregiver health: role emotional (r = .23),

vitality (r=. 22), and mental health (r=. 41). Consistent with SDT, the satisfaction with relatedness had moderate positive relationships with perceived gains of caregiving (r=.39), and 2 subscales of caregiver health: role-emotional (r=.28) and mental health (r=.32). Additionally, the satisfaction with relatedness had small positive relationships with the perceived informal social support (r=.24). The satisfaction with relatedness had a moderate negative relationship with perceived burdens of caregiving (r=-.34).

I examined whether or not the RPC subscales had significant relationships with perceived gains and caregiver health based on SDT. Consistent with SDT, I found that the controlled motivations had a small positive relationship with perceived gains of caregiving (r =. 24), but I did not observed any meaningful correlations between controlled motivations and health subscales. I also did not find the relationships of the autonomous motivations and caregiving outcomes.

I examined whether or not perceived informal social support had significant relationships with caregiving outcomes based on prior literature. I found that the perceived informal social support had moderate positive relationships with perceived gains (r =. 26) and the bodily pain subscale of caregiver health (r =. 27). The perceived informal social support had a moderate negative relationship with perceived burdens of caregiving (r =-.32)

The relationships among explanatory variables

I looked at the inter-correlations among the satisfaction with psychological need subscales, of the BNSG, based on SDT. Not surprisingly, I found that the satisfaction with autonomy subscale had small to moderate positive relationships with the satisfaction with competence subscale (r = .41) and the satisfaction with relatedness subscale (r = .57). The satisfaction with competence subscale had moderate positive relationships with the satisfaction with relatedness (r = .40)

I examined the correlations between the autonomous motivation subscale and controlled motivations subscale, of the RPC, based on SDT. Not surprisingly, I found that the autonomous motivations had a significant moderate relationship with the controlled motivation subscale (r = .40).

## The relationships among outcome variables

I examined relationships among perceived gains, perceived burdens, and 5 subscales of caregiver health. I did these because, base on prior literature, perceived gains have had positive relationships with caregiver health and a negative relationship with perceived burdens. Not surprisingly, I found that the perceived gains of caregiving scale had small to moderate positive relationships with 3 subscales of caregiver health: role-emotional (r = .25), vitality (r = .27), and mental health (r = .24). The perceived gains of caregiving scale had a negative moderate relationship with the perceived burdens of caregiving (r = -.28).

I examined the relationships between perceived burdens and 5 subscales of caregiver health. I did these because perceived burdens have had negative relationships with caregiver health based on prior literature. Not surprisingly, I found that the perceived burdens of caregiving had moderate negative relationships with 5 subscales of caregiver health (r = -.32 to -.45).

I examined the inter-correlations among 5 subscales of caregiver health. I did these because 5 subscales have had positive relationships with each other based on literature. Not surprisingly, I found that the 5 subscales of caregiver health had moderate to strong relationships with each other (r = .25 - .70).

# **Multivariate Analyses**

With using the CISE to examine relationships among variables, two models were produced. In model 1, I examined the relationships without covariates based on study aims (see

Figure 4.1). In model 2, I examined the relationships with two covariates including the age of caregivers and the number activities of ADL based on study aims (see Figure 4.2). I describe each model separately based on study aims. I identify significant relationships among study variables based on having a p value below .05 and report  $\beta$  values as unstandardized estimation of using CISE.

## Model 1

The relationships between explanatory and outcome variables

I examined whether or not the satisfaction of psychological needs had significant relationships with caregiving outcomes because, based on other SDT research, these variables have had positive relationship with such perceived gains and physical and mental health of participants. Consistent with SDT, I found that the satisfaction with autonomy subscale had positive relationships with perceived gains scale ( $\beta$  = 0.19) and mental health subscale ( $\beta$  = 0.20). Additionally, the satisfaction with autonomy had a negative relationship with perceived burdens of caregiving ( $\beta$  = -0.02). For every one unit increase of satisfaction with autonomy scores, perceived gain scores were increased 0.19. For every one unit increase of satisfaction with autonomy scores, mental health scores increased 0.20. For every one unit increase of satisfaction with autonomy scores, perceived burden scores decreased 0.02.

The satisfaction with competence subscale had positive relationships with 4 of 5 subscales of caregiver health, consistent with SDT. The betas were as follows: general health ( $\beta$  = 0.50), bodily pain ( $\beta$  = 0.74), vitality ( $\beta$  = 0.61), and mental health ( $\beta$  = 0.61). I did not observe a significant relationship of the other subscale of health and satisfaction with competence subscale. In addition, the satisfaction with relatedness subscale had a positive relationship with role-emotional subscale of caregiver health ( $\beta$  = 0.28), but not with other 4 of 5 health measures.

I examined the relationships between perceived informal social support and caregiving

outcomes based on prior caregiving literature. I found that the perceived informal social support had positive relationships with 2 subscales of caregiver health: general health ( $\beta$  = 0.03) and bodily pain ( $\beta$  = 0.07). For the relationships between explanatory and outcome variables, see Table 4.14).

## The relationships among explanatory variables

I examined the inter-relationships among the satisfaction with psychological need subscales. As expected from SDT, I found that the satisfaction with autonomy subscale had positive relationships with the satisfaction with competence subscale ( $\beta$  = 0.93) and the satisfaction with relatedness subscale ( $\beta$  = 6.37). The satisfaction with competence subscale had a positive relationship with the satisfaction with relatedness subscale ( $\beta$  =1.29).

I examined the relationships between the autonomous motivation subscale and the controlled motivation subscale as guided by SDT. I found that the autonomous motivation subscale had positive relationships with the controlled motivation subscale ( $\beta$  = 6.34) and the satisfaction with relatedness subscale ( $\beta$  = 2.93).

I examined the relationships among perceived informal social support, the satisfaction with psychological need scales, and the type of motivation scales, based on prior caregiving literature and SDT. I found that the perceived informal social support had a positive relationship with the controlled motivation subscale ( $\beta$  = 9.90) and a negative relationship with the satisfaction with competence subscale ( $\beta$  =-1.05). Additionally, the perceived informal social support had positive relationships with the satisfaction with relatedness subscale ( $\beta$  = 8.01) and the autonomous motivation subscale ( $\beta$  = 8.71). For the relationships among explanatory variables, see Table 4.15.

The relationships among outcome variables

I examined the relationships among perceived gains, perceived burdens, and 5 subscales of caregiver health. I found that the perceived gains scale had a positive relationship with the vitality subscale of caregiver health ( $\beta$  = 0.81). Additionally, the perceived burden scale had negative relationships with 5 subscales of caregiver health ( $\beta$  = -0.11 to -0.54). I did not observe the significant relationship of perceived gains with perceived burdens.

I examined the inter-relationships among 5 subscales of caregiver health. As expected from literature, I found that the 5 subscales of caregiver health had positive relationships with each other ( $\beta$  = 0.51 to 3.02). For relationships among outcome variables, see Table 4.17.

## Model 2

I added two covariates: the age of caregivers and the number activities of ADL in this model because these variables had significant relationships with caregiving outcomes in this study. Additionally, hour of providing care as a demand of caregiving, I added this factor in model 2. I did not observe significant relationships of hour of providing with caregiving outcomes. For model 2, I only had two covariates. I present the results of relationships among covariates, explanatory, and outcome variables. Then, I presented the results based on study aims. Finally I compared the results between model 1 and model 2.

The relationships among covariates, explanatory, and outcome variables

I examined the relationships between the age of caregiver and explanatory variables. I found that the age of caregivers had positive relationships with the satisfaction with autonomy subscale ( $\beta$  = 0.05), the satisfaction with relatedness subscale ( $\beta$  = 0.05), and the autonomous motivation subscale ( $\beta$  = 0.07). In contrast, the age of caregivers had a negative relationship with the satisfaction with competence subscale ( $\beta$  = -0.03). For relationships between the age of caregivers and explanatory variables, see Table 4.18.

I examined the relationship between the age of caregivers and outcome variables. I found that the age of caregivers had positive relationships with the perceived burden scale  $(\beta = 0.01)$  and the perceived gain scale  $(\beta = 0.06)$ . In contrast, the age of caregivers had a negative relationship with the bodily pain subscale of caregivers  $(\beta = -0.03)$ . For relationships between the age of caregivers and outcome variables, see Table 4.19.

I examined the relationships among the number activities of ADL and outcome variables. I found that the number activities of ADL had negative relationships with 5 subscales of caregiver health ( $\beta$  = -0.10 to -0.56). For the relationships between covariates and explanatory variables and the relationships between covariates and outcome variables, see Table 4.19.

The relationships among explanatory variables

Because limitation of parameters in model 2, I could not analyze relationships among explanatory variables that I did in model 1. I decided to examine only relationships among variables guided by SDT. These consisted of relationships among satisfaction with three psychological needs and the relationship between autonomous and controlled motivations.

For inter-relationships among the satisfaction with psychological need subscales based on SDT, I found that the satisfaction with psychological need scales had positive relationships to each other ( $\beta$  = 1.13 to 5.94).

For the relationships between autonomous and controlled motivation subscales based on SDT, I found that the autonomous motivation scale had no significant relationship with the controlled motivation scale. For the relationships among explanatory variables, see Table 4.16.

The relationships among outcome variables

I examined the relationships among perceived gains, perceived burdens, and 5 subscales of caregiver health, based on prior caregiving literature. I found that the perceived gains scale had a positive relationship with the vitality subscale of caregiver health ( $\beta = 0.70$ ),

but not with 4 of 5 subscales of caregiver health. Additionally, the perceived burden scale had negative relationships with 4 subscales of caregiver health: general health, role-emotional, vitality, mental health ( $\beta$  = -0.09 to -0.45), but not with the other subscale. I did not observe a significant relationship between perceived gains and burdens.

I examined the inter-relationships among 5 subscales of caregiver health. As expected from literature, I found that the 5 subscales of caregiver health had positive relationships with each other ( $\beta$  = 0.31 to 2.53). For relationships among outcome variables, see Table 4.17.

# Comparing Model 1 and Model 2

Comparing between model 1 and model 2, overall, many of the relationships between the explanatory and outcome variables in model 1 were similar to those relationships in model 2. The differences were that the satisfaction with autonomy subscale had a significant relationship with the perceived gain scale in model 1 but it did not have in model 2. Also, I found the satisfaction with autonomy subscale had a positive relationship with bodily pain in model 2 but it did not have in model 1. In addition, the satisfaction with competence subscale had a positive relationship with the bodily pain subscale in model 1, but it did not have in model 2. The perceived informal social support had a positive relationship with the general health subscale in model 1, but it did not have in model 2. Thus, I observed a pattern of relationships between explanatory and outcome variables in model 2. Overall, I found that this pattern had reduced betas when comparing with model 1. For the relationships between explanatory and outcome variables, see Table 4.14.

For the relationships among explanatory variables, focusing on relationships among satisfaction with three psychological needs subscales and the relationship between autonomous and controlled motivation subscales based on SDT, After comparing between model 1 and model 2, the relationships among satisfaction with psychological need scale in model 1 were similar to those relationships in model 2. However, the autonomous motivation subscale had a

significant positive relationship with the controlled motivation subscale in model 1, but it did not have in model 2. Thus, I observed a pattern of relationships among satisfaction with three psychological needs in model 2. Overall, I found that this pattern had increased betas when comparing with model 1. For the relationships among explanatory variables, see Table 4.15 and Table 4.16.

For the relationships among outcome variables, after comparing between model 1 and model 2, overall, many of the relationships among outcome variables in model 1 were similar to those relationships in model 2. The differences were that, in model 2, the bodily pain subscale had not significant relationships with the role-emotional subscale, the vitality subscale, and the perceive burden scale. Thus, I observed a pattern of relationships among outcome variables in model 2. Overall, I found that this pattern had reduced betas when comparing with model 1. For the relationships among outcome variables, see Table 4.17.

Additionally, I explored whether or not the relationships among study variables changed when I substituted revised measures with better Cronbach's alphas. I did this because the error variances of CISE depending on Cronbach's alphas. When I substituted revised measures of the RPC, autonomous motivation subscale, and the BNSG, satisfaction with competence subscale, I observed that the unstandardized estimations of relationships among study variables did not changed. The findings were similar and therefore robust.

**Table 4.12**Bivariate Correlations among Potential Covariates on Caregivers' Characteristics, Potential Covariates on Caregiving Factors, Explanatory Variables, and Outcome Variables

Variables	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21
Potential Covariates on Caregivers'																					
characteristics																					
1. Age of CG	1																				
2. Education of CG	22**	1																			
3. Income of CG	07	.53**	1																		
Potential Covariates on																					
Caregiving factors																					
4. Length of providing care	.07	11	06	1																	
5. Hour of providing care	.44**	24**	17	.09	1																
6. Hour of someone help	06	.12	.15	02	11	1															
providing care				.02		•															
7. ADL	.10	03	06	.24**	.20*	.01	1														
8. IADL	.20*	22**	03	.14	.19*	.19*	.03	1													
Explanatory variables																					
9. Autonomy	.14	.06	03	06	.09	06	06	.08	1												
10. Competence	02	.11	.23**	.08	.01	.09	01	01	.41**	1											
11. Relatedness	.19*	14	01	.05	.20*	.01	02	11	.57**	.40**	1										
12. Autonomous	.13	17*	06	.01	.08	03	10	.11	.07	.15	.18*	1									
Motivations			.00	.01	.00	.00			.07												
13. Controlled Motivations	.06	23**	09	.06	.03	.09	.05	.14	16*	18*	.05	.40**	1								
14. Perceived informal	.00	04	.00	07	.00	.18*	05	.16	.12	.03	.24**	.25**	.24**	1							
social support		.01		.01	.00					.00		.20		•							
Outcomes variables																					
15. Perceived gains	.23**	15	03	.09	.07	.13	15	.13	.33**	.19*	.39**	.24**	.10	.26*	1						
16. Perceived burden	.11	.05	.01	.08	.08	03	.29**	00	43**	16	34**	07	00	32**	28**	1					
17. General health	13	.13	.16	13	19*	.15	22**	04	.21*	.19*	.11	01	01	.19*	.09	45**	1				
18. Bodily pain	14	.14	00	.02	.01	.02	20**	.07	.28**	.06	.17*	.01	05	.27**	.13	32**	.48**	1			
19. Role emotional	04	03	.10	13	05	.10	26**	04	.21**	.23**	.28**	.02	.04	.05	.25**	50**	.42**	.27**	1		
20. Vitality	04	01	00	.02	05	.11	29**	11	.28**	.22**	.20*	.12	13	.09	.27**	39**	.45**	.25**	.38**	1	
21. Mental health	.06	02	04	06	05	.01	26**	10	.39**	.41**	.32**	.16	09	.02	.24**	40**	.39**	.26**	.43**	.70**	1
																					•

Note. CG = Caregiver, CR = care recipient; ADL = activities of daily living; IADL = instrumental activities of daily living p < .05, \*p < 0.01

**Table 4.13**P-value Adjustment by Using the False Discovery Rate (FDR) of Bivariate Correlations among Potential Covariates on Caregivers' Characteristics, Potential Covariates on Caregiving Factors, Explanatory Variables, and Outcome Variables

	1 <.00	1																		
51 <	•	1																		1
51 <	•	1																		
51 <	•	1																		
51 <	<.00	1																		
60	.36	.68	1																	
00	.02	.13	.50	1																
66	.34	.18	.95	.38	1															
2	.85	.70	.02	.07	.98	1														
)6	.03	.86	.23	.08	.07	.03	1													
21	.68	.86	.66	.49	.68	.68	.57	1												
)1	.38	.03	.53	.97	.49	.97	.98	<.00	1											
	.24	.97	.74	.06	.99	.96		<.00	<.00	1										
24	.12	.67	.99	.53	.85	.41	.65	.63	.18	.08	1									
	.02	.48	.70	.85	.48	.74	.23	.13	.10	.74	<.00	1								
9	.78	.99	.63	1.00	.09	.71	.15	.35	.85	.02	.02	.02	1							
	.17	.85	.49	.63	.26	.19	.26	<.00	.07	<.00	.02		.01	1						
88	.74	.97	.52		.84	<.00		<.00	.15	<.00	.63	.99	<.00	<.00	1					
24	.25	.17	.24	.08	.19	.03	.82	.05	.08	.40	.99	.99	.08	.51	<.00	1				
22	.24	.99	.93	.97	.96	.05	.61	.01	.69	.12	.99	.75	.01	.26	<.00	<.00	1			
'8	.86	.44	.24	.74	.44	.01	.83	.04	.02	.01	.99	.83	.75	.02	<.00	<.00	.01	1		ĺ
	.99	.99	.96	.71	.40	<.00	.39	.01	.03	.06	.28	.27	.47	.01	<.00	<.00	.01	<.00	1	ĺ
	.92	.83	.70	.74	.97	.01	.41	<.00	<.00	<.00	.15	.47	.92	.02	<.00	<.00	.01	<.00	<.00	1
000 66 12 10 10 10 10 10 10 10 10 10 10 10 10 10		.02 .34 .85 .03 .68 .38 .24 .12 .02 .78	0 .02 .13 .34 .18 .85 .70 .03 .86 .68 .86 .38 .03 .24 .97 .12 .67 .02 .48 .78 .99 .78 .99 .78 .99 .79 .25 .17 .24 .99 .86 .44 .99 .99	.02	.02	.02       .13       .50       1         .34       .18       .95       .38       1         .85       .70       .02       .07       .98         .03       .86       .23       .08       .07         .68       .86       .66       .49       .68         .38       .03       .53       .97       .49         .24       .97       .74       .06       .99         .12       .67       .99       .53       .85         .02       .48       .70       .85       .48         .78       .99       .63       1.00       .09         .4       .97       .52       .54       .84         .25       .17       .24       .08       .19         .99       .93       .97       .96         .86       .44       .24       .74       .44         .99       .99       .96       .71       .40	.02       .13       .50       1         .34       .18       .95       .38       1         .85       .70       .02       .07       .98       1         .03       .86       .23       .08       .07       .03         .68       .86       .66       .49       .68       .68         .38       .03       .53       .97       .49       .97         .24       .97       .74       .06       .99       .96         .12       .67       .99       .53       .85       .41         .02       .48       .70       .85       .48       .74         .78       .99       .63       1.00       .09       .71         .4       .74       .97       .52       .54       .84       <.00	0       .02       .13       .50       1         .34       .18       .95       .38       1         .85       .70       .02       .07       .98       1         .03       .86       .23       .08       .07       .03       1         .68       .86       .66       .49       .68       .68       .57         .38       .03       .53       .97       .49       .97       .98         .24       .97       .74       .06       .99       .96       .36         .12       .67       .99       .53       .85       .41       .65         .02       .48       .70       .85       .48       .74       .23         .78       .99       .63       1.00       .09       .71       .15         .17       .85       .49       .63       .26       .19       .26         .74       .97       .52       .54       .84       <.00	0       .02       .13       .50       1         1       .34       .18       .95       .38       1         2       .85       .70       .02       .07       .98       1         1       .03       .86       .23       .08       .07       .03       1         1       .68       .86       .66       .49       .68       .68       .57       1         2       .38       .03       .53       .97       .49       .97       .98       <.00	0       .02       .13       .50       1         .34       .18       .95       .38       1         .85       .70       .02       .07       .98       1         .03       .86       .23       .08       .07       .03       1         .68       .86       .66       .49       .68       .68       .57       1         .38       .03       .53       .97       .49       .97       .98       <.00	0       .02       .13       .50       1 </td <td>0       .02       .13       .50       1         1       .34       .18       .95       .38       1         2       .85       .70       .02       .07       .98       1         1       .03       .86       .23       .08       .07       .03       1         1       .68       .86       .66       .49       .68       .68       .57       1         1       .38       .03       .53       .97       .49       .97       .98       &lt;.00</td> 1         1       .24       .97       .74       .06       .99       .96       .36       <.00	0       .02       .13       .50       1         1       .34       .18       .95       .38       1         2       .85       .70       .02       .07       .98       1         1       .03       .86       .23       .08       .07       .03       1         1       .68       .86       .66       .49       .68       .68       .57       1         1       .38       .03       .53       .97       .49       .97       .98       <.00	0       .02       .13       .50       1 </td <td>0       .02       .13       .50       1       .38       1   <td>0</td><td>0</td><td>0 .02</td><td>0</td><td>0 .02</td><td>0 .02</td></td>	0       .02       .13       .50       1       .38       1 <td>0</td> <td>0</td> <td>0 .02</td> <td>0</td> <td>0 .02</td> <td>0 .02</td>	0	0	0 .02	0	0 .02	0 .02

Note. CG = Caregiver, ADL = activities of daily living, IADL = instrumental activities of daily living

**Table 4.14**Relationships between Explanatory and Outcome Variables in Model 1: Without Covariates and in Model 2: With Covariates

	Model 1: W	ithout covariate	S		Model 2	2: With covariate	S	
	Unstandardized Estimates (SE)	Unstandardized 95% CI		andardized Estimates	Unstandardize Estimates (SE	ed Unstandardized E) 95% CI		dardized timates
Autonomy → Gain	0.19(0.08)	[0.02, 0.35]	0.03*	0.22	0.17(0.09)	[0.00, 0.34]	0.05	0.20
$Competence \to Gain$	0.51(0.30)	[-0.07, 1.09]	0.09	0.19	0.36(0.40)	[-0.32, 1.04]	0.30	0.14
$Relatedness \to Gain$	0.10(0.08)	[-0.06, 0.26]	0.22	0.13	0.09(0.08)	[-0.06, 0.25]	0.23	0.13
Auto Motivations $\rightarrow$ Gain	0.07(0.06)	[-0.05, 0.18]	0.24	0.10	0.06(0.05)	[-0.05, 0.16]	0.31	0.09
Cont Motivations $\rightarrow$ Gain	0.11(0.07)	[-0.02, 0.24]	0.10	0.16	0.08(0.05)	[-0.01, 0.18]	0.07	0.17
Informal Support→ Gain	0.05(0.03)	[-0.02, 0.11]	0.14	0.13	0.08(0.05)	[-0.01, 0.11]	0.12	0.13
$Autonomy \to Burden$	-0.02(0.01)	[-0.04, -0.01]	0.01*	-0.25	-0.03(0.01)	[-0.05, -0.01]	<0.00**	-0.32
$Competence \to Burden$	-0.04(0.03)	[-0.10, 0.02]	0.21	-0.14	0.03(0.04)	[-0.04, 0.10]	0.42	0.10
$Relatedness \to Burden$	-0.00(0.01)	[-0.02, 0.01]	0.68	-0.05	-0.01(0.01)	[-0.03, 0.01]	0.19	-0.13
Auto Motivations $\rightarrow$ Burden	0.01(0.01)	[-0.00, 0.02]	0.14	0.13	0.01(0.01)	[-0.00, 0.02]	0.17	0.11
Cont Motivations $\rightarrow$ Burden	-0.01(0.01)	[-0.02, 0.01]	0.28	-0.10	-0.01(0.01)	[-0.02, 0.00]	0.12	-0.14
Informal Support →Burden	0.01(0.00)	[-0.02, -0.00]	<0.00**	-0.27	-0.01(0.00)	[-0.02, -0.00]	<0.00**	-0.24
${\sf Autonomy} \to {\sf General\ Health}$	0.04(0.03)	[-0.03, 0.10]	0.25	0.12	0.05(0.03)	[-0.01, 0.11]	0.11	0.17
Competence→ General Health	0.50(0.11)	[0.28, 0.72]	<0.00**	0.55	0.32(0.13)	[0.07, 0.57]	0.01*	0.35
$Relatedness \to General\;Health$	-0.05(0.03)	[-0.11, 0.01]	0.14	-0.18	-0.03(0.03)	[-0.08, 0.03]	0.33	-0.11
Auto Motivations → General Health	-0.03(0.02)	[-0.07, 0.01]	0.18	-0.13	-0.03(0.02)	[-0.07, 0.01]	0.17	-0.12
Cont Motivations → General Health	0.03(0.03)	[-0.02, 0.08]	0.29	0.11	0.03(0.02)	[-0.01, 0.06]	0.14	0.14
Informal Support → General Health	0.03(0.01)	[0.00, 0.05]	0.02*	0.22	0.02(0.01)	[-0.00, 0.04]	0.07	0.16
$Autonomy \to Bodily \; Pain$	0.09(0.05)	[-0.02, 0.19]	0.10	0.18	0.15(0.05)	[0.04, 0.25]	0.01*	0.29
$Competence \to Bodily \ Pain$	0.74(0.19)	[0.37, 1.12]	<0.00**	0.49	0.31(0.21)	[-0.10, 0.72]	0.14	0.20
$Relatedness \to Bodily \ Pain$	-0.08(0.05)	[-0.18, 0.03]	0.15	-0.17	-0.04(0.05)	[-0.13, 0.05]	0.39	-0.10
Auto Motivations →Bodily Pain	-0.05(0.04)	[-0.12, 0.02]	0.18	-0.13	-0.05(0.03)	[-0.12, 0.01]	0.10	-0.14
Cont Motivations → Bodily Pain	0.01(0.04)	[-0.07, 0.10]	0.76	0.03	0.07(0.03)	[0.01, 0.13]	0.01*	0.23

Note. Autonomy = satisfaction with autonomy; Competence = satisfaction with competence; Relatedness = satisfaction with relatedness; Auto Motivations = autonomous motivations; Cont Motivations = controlled motivations; SE= unstandardized error; CI = confident interval; p = p-value of unstandardized estimates; \*\* p < .01; \*p < .05

**Table 4.14** (Cont'd)

Relationships between Explanatory and Outcome Variables in Model 1: Without Covariates and in Model 2: With Covariates

	Model 1: W	thout Covariate	S		Мо	del 2: With Cov	ariates	
	Unstandardized Estimates (SE)	Unstandardized 95% CI	-	andardized Estimates	Unstandardize Estimates (SE	ed Unstandardized E) 95% CI		dardized imates
Informal Support → Bodily Pain	0.07(0.02)	[0.03, 0.11]	<0.00**	0.32	0.05(0.02)	[0.01, 0.08]	0.01*	0.23
$Autonomy \to Role\text{-}Emotional$	0.20(0.14)	[-0.08,0.48]	0.16	0.14	0.17(0.15)	[-0.13, 0.46]	0.27	0.12
$Competence \to Role\text{-}Emotional$	0.03(0.50)	[-0.96, 1.02]	0.95	0.01	-0.30(0.59)	[-1.46, 0.87]	0.62	-0.07
$Relatedness \to Role\text{-}Emotional$	0.28(0.14)	[0.01, 0.55]	<0.05*	0.23	0.34(0.13)	[0.08, 0.60]	0.01*	0.28
Auto Motivations $\rightarrow$ Role-Emotional	-0.09(0.10)	[-0.28, 0.11]	0.40	-0.08	-0.04(0.09)	[-0.23, 0.14]	0.64	-0.04
Cont Motivations $\rightarrow$ Role-Emotional	0.15(0.13)	[-0.07, 0.37]	0.18	0.13	-0.02(0.08)	[-0.18, 0.13]	0.78	-0.03
Informal Support $\rightarrow$ Role-Emotional	-0.02(0.06)	[-0.13, 0.09]	0.73	-0.03	-0.01(0.05)	[-0.11, 0.10]	0.92	-0.01
$Autonomy \to Vitality$	0.06(0.05)	[-0.03, 0.16]	0.20*	0.16	0.07(0.05)	[-0.03, 0.17]	0.16	0.18
$Competence \to Vitality$	0.61(0.18)	[0.26, 0.95]	<0.00**	0.50	0.58(0.20)	[0.18, 0.98]	<0.00**	0.48
$Relatedness \to Vitality$	-0.02(0.05)	[-0.11, 0.07]	0.69	-0.05	-0.01(0.05)	[-0.10, 0.08]	0.82	-0.03
Auto Motivations $\rightarrow$ Vitality	0.03(0.03)	[-0.04, 0.10]	0.35	0.11	0.01(0.03)	[-0.05, 0.07]	0.69	0.04
Cont Motivations $\rightarrow$ Vitality	-0.04(0.04)	[-0.12, 0.03]	0.26	-0.14	-0.01(0.03)	[-0.06, 0.05]	0.79	-0.03
Informal Support→ Vitality	0.02(0.02)	[-0.01, 0.06]	0.20	0.15	0.01(0.02)	[-0.02, 0.05]	0.51	0.07
Autonomy → Mental Health	0.20(0.06)	[0.07, 0.31]	<0.00**	0.35	0.15(0.06)	[0.03, 0.27]	0.02*	0.27
$Competence \to Mental\;Health$	0.61(0.22)	[0.18, 1.03]	0.01*	0.37	0.77(0.25)	[0.27, 1.26]	<0.00**	0.46
Relatedness → Mental Health	0.02(0.06)	[-0.09, 0.14]	0.70	0.05	0.03(0.06)	[-0.09, 0.14]	0.66	0.05
Auto Motivations $\rightarrow$ Mental Health	0.08(0.04)	[-0.00, 0.16]	0.07	0.19	0.07(0.04)	[-0.01, 0.14]	0.08	0.16
Cont Motivations $\rightarrow$ Mental Health	-0.00(0.05)	[-0.10, 0.09]	0.94	-0.01	-0.05(0.03)	[-0.11, 0.02]	0.17	-0.14
Informal Support $\rightarrow$ Mental Health	-0.01(0.02)	[-0.06, 0.03]	0.58	-0.06	-0.01(0.02)	[-0.06, 0.03]	0.53	0.06

Note. Autonomy = satisfaction with autonomy; Competence = satisfaction with competence; Relatedness = satisfaction with relatedness; Auto Motivations = autonomous motivations; Cont Motivations = controlled motivations; SE= unstandardized error; CI = confident interval; p = p-value of unstandardized estimates; \*\* p < .01; \*p < .05

 Table 4.15

 Relationships among Explanatory Variables in Model 1: Without Covariates

	Unstandardized Estimates	SE	Unstandardized 95% CI	р	Standardized Estimates
Autonomy → Competence	0.93	0.33	[0.27, 1.58]	<0.00**	0.29
$Autonomy \to Relatedness$	6.37	1.09	[4.23, 8.50]	<0.00**	0.56
$Competence \to Relatedness$	1.29	0.39	[0.53, 2.05]	<0.00**	0.35
Auto Motivations → Autonomy	1.36	1.10	[-0.80, 3.51]	0.22	0.11
Auto Motivations → Competence	-0.23	0.43	[-1.06, 0.61]	0.60	-0.05
Auto Motivations→ Relatedness	2.93	1.28	[0.42, 5.44]	0.02*	0.20
Auto Motivations→Cont Motivations	6.34	1.44	[3.51, 9.16]	<0.00**	0.40
Cont Motivations → Autonomy	-1.32	1.04	[-3.35, 0.72]	0.20	-0.11
Cont Motivation $\rightarrow$ Competence	-1.05	0.41	[-1.86, -0.25]	0.01*	-0.27
Cont Motivations → Relatedness	1.31	1.19	[-1.02, 3.64]	0.27	0.09
Cont Motivations $\rightarrow$ Informal Support	9.90	2.56	[4.88, 14.93]	<0.00**	0.34
Informal Support →Autonomy	3.44	1.99	[-0.45, 7.33]	0.08	0.15
Informal Support → Competence	-0.84	0.77	[-2.35, 0.67]	0.28	-0.11
Informal Support→ Relatedness	8.01	2.36	[3.39, 12.63]	<0.00**	0.30
Informal Support $\rightarrow$ Auto Motivations	8.71	2.68	[3.45, 13.97]	<0.00**	0.28

Note. Autonomy = satisfaction with autonomy; Competence = satisfaction with competence; Relatedness = satisfaction with relatedness; Auto Motivations = autonomous motivations; Cont Motivations = controlled motivations, SE= unstandardized error, CI = Confident interval, p = p-value of unstandardized estimates, \*\* p < .01, \*p < .05

 Table 4.16

 Relationships among Explanatory Variables in Model 2: With Covariates

	Unstandardized Estimates	SE	Unstandardized 95% CI	р	Standardized Estimates
Autonomy → Competence	1.13	0.32	[0.49, 1.74]	<0.00**	0.37
$Autonomy \to Relatedness$	5.94	1.04	[3.90, 7.98]	<0.00**	0.54
Competence→ Relatedness	1.48	0.37	[0.74, 2.21]	<0.00**	0.43
Auto Motivations $\rightarrow$ Control motivations	3.45	1.78	[-0.04, 6.93]	0.05	0.17

*Note.* Autonomy = satisfaction with autonomy; Competence = satisfaction with competence; Relatedness = satisfaction with relatedness; Auto Motivations = autonomous motivations; Cont Motivations = controlled motivations, SE= unstandardized error, CI = Confident interval, p = p-value of unstandardized estimates, \*\* p < .01, \*p < .05

Table 4.17

Relationships among Outcome Variables in Model 1: Without Covariates and in Model 2: With Covariates

	Without Co	variates (Model	1)			With Covariate	es (Mode	el 2)
	Unstandardized Estimates (SE)	Unstandardized 95% CI	D	andardized Estimates	Unstandardize Estimates (SE)	d Unstandardized 95% CI	р	Standardized Estimates
General Health → Bodily Pain	0.51(0.14)	[0.23, 0.79]	<0.00**	0.49	0.43(0.12)	[0.19, 0.66]	<0.00**	0.45
$Role\text{-Emotional} \to General \; Health$	1.63(0.37)	[0.90, 2.36]	<0.00**	0.50	1.43(0.34)	[0.77, 2.09]	<0.00**	0.46
$Role\text{-}Emotional\toBodily\;Pain$	1.41(0.60)	[0.23, 2.59]	0.02*	0.26	0.98(0.53)	[-0.06, 2.02]	0.06	0.20
Vitality → General Health	0.52(0.13)	[0.26, 0.78]	<0.00**	0.66	0.44(0.12)	[0.21, 0.67]	<0.00**	0.62
Vitality →Bodily Pain	0.43(0.21)	[0.02, 0.84]	0.04*	0.32	0.31(0.18)	[-0.05, 0.67]	0.09	0.28
Vitality→Role-Emotional	2.29(0.57)	[1.17, 3.42]	<0.00**	0.55	1.71(0.52)	[0.69, 2.73]	<0.00**	0.46
Mental Health →General Health	0.47(0.16)	[0.17, 0.78]	<0.00**	0.46	0.42(0.14)	[0.14, 0.70]	<0.00**	0.46
Mental Health→ Bodily Pain	0.35(0.26)	[-0.15, 0.86]	0.17	0.21	0.33(0.23)	[-0.12, 0.78]	0.14	0.23
$\text{Mental Health} \rightarrow \text{Role-Emotional}$	3.02(0.72)	[1.62, 4.42]	<0.00**	0.56	2.53(0.66)	[1.23, 3.83]	<0.00**	0.54
$\text{Mental Health} \rightarrow \text{Vitality}$	1.64(0.28)	[1.10, 2.17]	<0.00**	1.25	1.42(0.26)	[0.92, 1.92]	<0.00**	1.31
Gain → General Health	0.07(0.20)	[-0.33, 0.47]	0.74	0.04	0.09(0.19)	[-0.28, 0.45]	0.64	0.05
Gain →Bodily Pain	0.07(0.35)	[-0.62, 0.75]	0.85	0.02	0.09(0.31)	[-0.52, 0.69]	0.78	0.03
$Gain \to Role\text{-}Emotional$	1.54(0.94)	[-0.30, 3.37]	0.10	0.16	1.56(0.88)	[-0.16, 3.28]	0.08	0.17
Gain→ Vitality	0.81(0.33)	[0.17, 1.45]	0.01*	0.35	0.70(0.30)	[0.11, 1.30]	0.02*	0.34
Gain → Mental Health	0.30(0.40)	[-0.48, 1.07]	0.46	0.10	0.17(0.37)	[-0.55, 0.90]	0.64	0.07
Burden→ General Health	-0.11(0.02)	[-0.15, -0.06]	<0.00**	-0.52	-0.09(0.02)	[-0.13, -0.05]	<0.00**	-0.47
Burden → Bodily Pain	-0.08(0.04)	[-0.16, -0.00]	0.04*	-0.23	-0.03(0.03)	[-0.09, 0.04]	0.38	-0.10
Burden→ Role-Emotional	-0.54(0.11)	[-0.76, -0.33]	<0.00**	-0.50	-0.45(0.10)	[-0.64, -0.25]	<0.00**	-0.47
Burden $\rightarrow$ Vitality	-0.15(0.04)	[-0.22, -0.08]	<0.00**	-0.57	-0.11(0.03)	[-0.17, -0.05]	<0.00**	-0.51
Burden → Mental Health	-0.15(0.05)	[-0.24, -0.07]	<0.00**	-0.46	-0.14(0.04)	[-0.22, -0.06]	<0.00**	-0.49
Burden → Gain	-0.09(0.06)	[-0.20, 0.03]	0.15	-0.14	-0.09(0.05)	[-0.20, 0.01]	0.09	-0.17

Note. SE= unstandardized error; CI = confident interval; p = p-value of unstandardized estimates; \*\* p < .01; \*p < .05

**Table 4.18**Relationships between Covariates and Explanatory Variables in Model 2

	Unstandardized Estimates	SE	Unstandardized 95% CI	р	Standardized Estimates
Age of Caregiver → Autonomy	0.05	0.02	[0.01, 0.09]	0.01*	0.21
ADL Activities → Autonomy	-0.06	0.13	[-0.32, 0.19]	0.63	-0.04
Age of Caregiver $\rightarrow$ Competence	-0.03	0.01	[-0.04, -0.09]	<0.00**	-0.30
ADL Activities → Competence	-0.04	0.05	[-0.14, 0.06]	0.43	-0.08
Age of Caregiver → Relatedness	0.05	0.02	[0.01, 0.10]	0.02*	0.19
ADL Activities → Relatedness	-0.05	0.15	[-0.35, 0.24]	0.72	-0.03
Age of Caregiver $\rightarrow$ Auto Motivations	0.07	0.03	[0.02, 0.12]	0.01*	0.21
ADL Activities $\rightarrow$ Auto Motivations	-0.16	0.17	[-0.50, 0.18]	0.36	-0.08
Age of Caregiver $\rightarrow$ Cont Motivations	-0.07	0.04	[-0.14, 0.00]	0.06	-0.16
ADL Activities $\rightarrow$ Cont Motivations	-0.13	0.22	[-0.56, 0.30]	0.55	-0.05
Age of Caregiver $\rightarrow$ Informal Support	0.06	0.05	[-0.04, 0.15]	0.25	0.10
ADL Activities → Informal Support	-0.13	0.31	[-0.74, 0.48]	0.68	-0.04

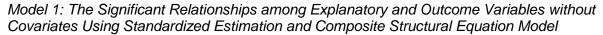
Note. Autonomy = satisfaction with autonomy; Competence = satisfaction with competence; Relatedness = satisfaction with relatedness;, ADL activities = number of ADL activities per day providing by caregivers; SE= unstandardized error,; CI = confident interval; p = p-value of standardized estimates; \*\* p < .01; \*p < .05

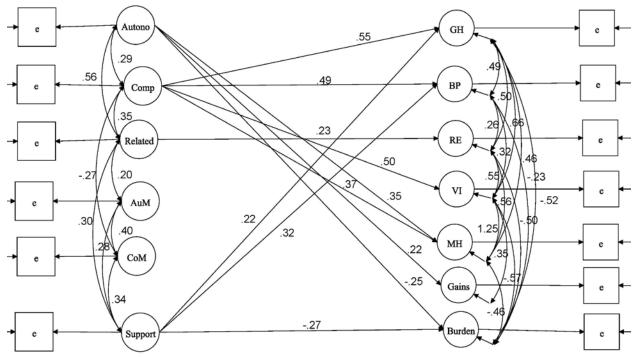
**Table 4.19**Relationships between Covariates and Outcome Variables in Model 2

	Unstandardized Estimates	SE	Unstandardized 95% CI	р	Standardized Estimates
Age of Caregiver → Gain	0.06	0.02	[0.02, 0.09]	0.01*	0.26
ADL Activities $\rightarrow$ Gain	-0.19	0.10	[-0.39, 0.02]	0.07	-0.14
Age of Caregiver $\rightarrow$ Burden	0.01	0.00	[0.00, 0.01]	0.02*	0.21
ADL Activities $\rightarrow$ Burden	0.04	0.01	[0.02, 0.06]	<0.00**	0.28
Age of Caregiver $\rightarrow$ General Health	-0.01	0.01	[-0.02, 0.01]	0.30	-0.10
ADL Activities $\rightarrow$ General Health	-0.10	0.04	[-0.17, -0.02]	0.01*	-0.21
Age of Caregiver $ ightarrow$ Bodily Pain	-0.03	0.01	[-0.05, -0.00]	0.03*	-0.21
ADL Activities $\rightarrow$ Bodily Pain	-0.16	0.06	[-0.29, -0.04]	0.01*	-0.21
Age of Caregiver $\rightarrow$ Role-Emotional	-0.02	0.03	[-0.09, 0.04]	0.50	-0.06
ADL Activities $\rightarrow$ Role-Emotional	-0.56	0.18	[-0.90, -0.21]	<0.00**	-0.25
Age of Caregiver $\rightarrow$ Vitality	-0.00	0.01	[-0.03, 0.02]	0.86	-0.02
ADL Activities $\rightarrow$ Vitality	-0.22	0.06	[-0.34, -0.10]	<0.00**	-0.35
Age of Caregiver $\rightarrow$ Mental Health	0.02	0.01	[-0.01, 0.04]	0.28	0.11
ADL Activities $\rightarrow$ Mental Health	-0.23	0.08	[-0.38, -0.08]	<0.00**	-0.27

*Note.* ADL activities = number of ADL activities per day providing by caregivers; SE= unstandardized error; CI = confident interval; p = p-value of standardized estimates; \*\* p < .01; \*p < .05

# Figure 4.1

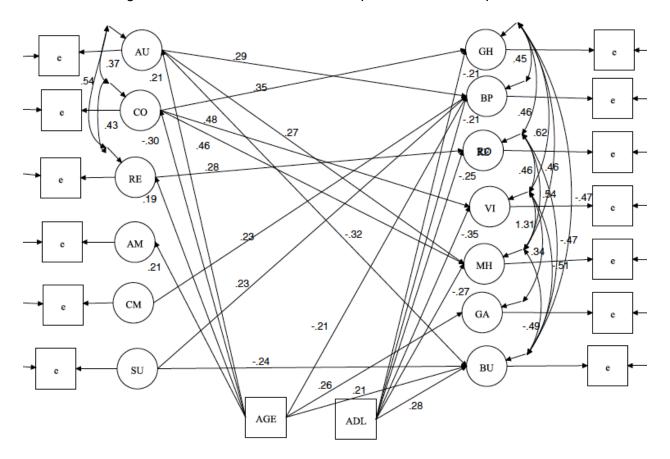




Note. Autono = satisfaction with autonomy; Comp = satisfaction with competence; Related = satisfaction with relatedness; AuM = autonomous motivations; CoM = controlled motivations; Support = perceived informal social support; GH = general health; BP = bodily pain; RE= role emotional; VI = vitality; MH = mental health; Gains = perceived gains of caregiving; Burden = perceived burden of caregiving; e = error variances of measures.

# Figure 4.2

Model 2: The Significant Relationships among Explanatory variables, Outcome Variables, and Covariates Using Standardized Estimation and Composite Structural Equation Model.



Note. AU = satisfaction with autonomy; CO = satisfaction with competence; RE = satisfaction with relatedness; AM = autonomous motivations; CM = controlled motivations; SU = perceived informal social support; GH = general health; BP = bodily pain; RO= role emotional; VI = vitality; MH = mental health; GA = perceived gains of caregiving; BU = perceived burden of caregiving; e = error variances of measures.

# **Summary**

The majority of caregivers were daughters with a mean age of 51. A mean of the length providing care was 5 years. Caregivers provided a mean of 15 hour of care a day for care recipients who were on average 76 years old. Caregivers had high satisfaction with their psychological needs, motivations, perceived gains of caregiving, perceived informal social support, and health outcomes. Most caregivers had a low mean score on perceived burden of caregiving.

For assessing content validity of four measures by experts' ratings, the CVI scores of most questions were high. This met the acceptable point (i.e. 0.80 and higher) for clarity and relevance. Only one item of the RPC, the CVI was 0.60 for clarity. The CVI scores of each measure for comprehensiveness and cultural relevance were high and acceptable. The average scores of the S-CVI were high (0.84-0.91) for clarity and (0.88-0.98) for relevance. Experts provided a few comments for revisions on each measure. Additionally, a few caregivers circled a few words that were not clear during answering the questionnaires.

For internal consistency reliability of six measures, Cronbach's alphas of thirteen composite scales varied from 0.26 -0.93.I looked to see whether these scales were 0.70 and higher to be acceptable for internal consistency reliability. The Cronbach's alphas of 9 composite scales were acceptable. The Cronbach' alphas of 4 composite scales were not acceptable.

For construct validity of the GAIN, the GAIN had significant positive relationships with three subscales of the BNSG and a significant negative relationship with the Short ZBI as expected. Also, the GAIN had a low correlation with the Short ZBI for discriminant validity. I concluded that the GAIN had construct validity.

Comparing two models about relationships between explanatory and outcome variables by using multivariate analyses, based on SDT, I found that the satisfaction with autonomy subscale had a significantly positive relationship with mental health subscale and a significantly negative relationship with perceived burden scale. Consistent with SDT, the satisfaction with competence subscale had significantly positive relationships with 3 subscales of health: general health, vitality, and mental health.

Comparing two models about relationships among satisfaction with three psychological needs by using multivariate analyses, as expected from SDT, I found that the satisfaction with autonomy subscale had significantly positive relationships with the satisfaction with competence subscale and the satisfaction with relatedness subscale.

Comparing two models about the relationships among outcome variables by using multivariate analyses, I found that the perceived informal social support had a significantly positive relationship with the bodily pain subscale and a significantly negative relationship with perceived burden scale. The perceived burden scale had significantly negative relationships with 4 subscales of caregiver health: general health, role-emotional, vitality, and mental health. Not surprisingly, the 5 subscales of health had significant positive relationships with each other.

#### **CHAPTER 5**

#### DISCUSSION

In this chapter, I discuss findings of descriptive data on sampling procedures, characteristics of caregivers of persons with dementia (PWD), and care recipients. Then, I discuss the findings according to two aims: the primary aims of assessing psychometric properties of measures and the secondary aims of examining relationships among explanatory and outcome variables of caregiving. Finally, I discuss the limitations and implications of this study.

# **Sampling Procedures**

One of the strengths of the study was good response rate of 97% (Shadish, Cook, & Campbell, 2002). To obtain a power.80 and an alpha = .05 for assessing relationships among multiple variables, 120 caregivers were needed based on 13 parameters of this study to compute in the formula of Green, (1991). I got 146 caregivers 'responses. This supported the sufficient power for assessing relationships among multiple variables. I got excellent response rate because I proposed to offer choices for participants to answer questionnaires. Providing choices for participants, thorough protocols and training research assistants were essential to decrease errors from data collection by using different methods.

Getting sufficient sample size of this study because of two reasons. First, I had sufficient study sites. I added three study sites from the original plan because of a problem of one study site. Second, I worked with the key persons and research assistants as a team. Based on Thai culture, I met and discussed with key persons of study sites for building relationships and confidence. Discussion with the key persons was helpful to have an actual plan for data collection. I used the actual plan to work with research assistants. We worked as a team. To build on trust and friendship with research assistants, we made contacts regularly in several

ways by phone, in-person, or by e-mail. We discussed about study protocols and data collection twice a week.

## Caregivers of persons with dementia (PWD)

Although the mean age of Thai caregivers was less than the mean age of American caregivers of PWD (Mohamed et al., 2010; Spillman et al., 2014), the mean age of Thai caregivers was consistent with the mean age of the caregivers of prior studies in Thailand and Singapore (Liew et al., 2010; Limpawattana et al., 2013; Yap et al., 2010). Other characteristics of caregivers, such as sex, relationship with care recipients, marital status, and religious affiliation were consistent with prior studies in Thailand ((Limpawattana et al., 2013; Ritteeveerakul, 2005). The similarities between my sample and others in Thai research on caregivers make me conclude that the major group of Thai caregivers of PWD was in middle age. They also were married and daughter caregivers.

The major group of caregivers in Thailand was daughters, which were inconsistent with a prior U.S study in which the major group of caregivers was spouses (Spillman et al., 2014). The mean of hours providing care of caregivers in this study (M = 14.83, SD = 8.19) was two more hours per day than a prior study of caregivers of PWD (M = 12.78, SD = 7.61) in Thailand (Ritteeveerakul, 2005). Based on caregivers' reports the differences of hours of providing care may relate to care recipients' needs for assistance such as ADL or IADL (Ciro, 2014).

Overall, this study obtained diversity of caregivers regarding socioeconomic status and caregiving experiences. For example, 28% of caregivers in the study had education less than high school and 32% of caregivers had education more than bachelor's degree. Because I collected data with caregivers who had different socioeconomic status in four different Thai sites, this could increase generalizability of this study in Thailand.

#### **Care recipients**

Female care recipients were the major group of care recipients in this study and prior studies (Mohamed et al., 2010; Ritteeveerakul, 2005). The mean age of care recipients in this study was 76.18 (SD = 9.14) and similar to prior studies in Thailand and the U.S. (Mohamed et al., 2010; Ritteeveerakul, 2005). The major group of care recipients in this study had Alzheimer's disease rather than other dementias. This observation was consistent with a prior study of PWD in Thailand (Ritteeveerakul, 2005).

# **Primary aims**

To address my primary aim, all six measures were evaluated for internal consistency reliability and four of six measures were assessed for content validity. Because three of six measures were single scales and the three others had subscales, for subscales I discuss each subscale first and then summarize the whole measure for clarity. In this section, I comment here on the similarities or differences in descriptive data about the measures used in this study and these measures were used in prior studies. Then, I discuss the validity, reliability, and my conclusions about psychometric properties of measures.

## The Reason for Providing Care Questionnaire (RPC)

#### Autonomous motivations

The mean and standard deviation of autonomous motivation subscale in this study (M = 6.72, SD = 0.53) were similar to the mean and standard deviation of this scale (M = 6.77, SD = 0.76) in a prior U.S. study (Kim et al., 2008).

Experts provided quantitative data for content validity index and qualitative data on revisions. For quantitative data, all experts agreed on the autonomous motivation subscale: a) most items were clear and relevant and b) a set of questions was substantially comprehensive and culturally relevant. For qualitative data, one expert suggested that the autonomous

subscale might limit to ask about cultural norms and religious beliefs of Thai caregivers. Three experts suggested about item revisions for clarity in item 1 and item 5.

For example, the question of item 1 is, "it was important to me personally to do so." The word "personally" may not be applicable to use with Thai people. Thai people are likely to focus on collectivism more than individualism. Collectivism refers to the priority focused on other people's as a group' needs, norms, and goals (Chirkov, Ryan, Kim, & Kaplan, 2003). The meaning of the item may induce uncomfortable feelings of caregivers by focusing only on themselves. Thai people are likely to provide care because of cultural norms about family obligation and religious beliefs about the gratitude system (Sethabouppha & Kane, 2005; Wongsawang et al., 2013). Especially, cultural norms about family obligation, family members expect daughters to provide care. Daughter caregivers may provide care regarding family expectations. They may focus on family more than themselves.

Because this is the first time using the autonomous motivation subscale in Thailand, I also evaluated this subscale for reliability. The autonomous motivation subscale did not have acceptable reliability (alpha = .26). This was inconsistent with the reliability of the autonomous motivation scale in a prior U.S. study where the Cronbach 's alpha was .88 (Kim et al., 2008).

#### Controlled motivation

The mean score of controlled motivation subscale that included introjected and external motivations of caregivers in this study (M=5.62, SD=1.37) was higher than the mean score of introjected (M=4.11) and external motivations (M=2.79) of caregivers in a prior U.S study (Kim et al., 2008). The standard deviation of controlled motivation subscale of caregivers in this study was lower than standard deviation of introjected (SD=2.41) and external motivations (SD=1.85) of caregivers in a prior U.S. study (Kim et al., 2008).

Experts provided quantitative data for content validity index and qualitative data on revisions. For quantitative data, experts agreed on the controlled motivation subscale: a) most

items were clear and relevant and b) a set of questions was substantially comprehensive and culturally relevant. For qualitative data, a few experts suggested about revisions some words for clarity.

Because this is the first time of using the controlled motivation subscale in Thailand, I also evaluated this subscale for reliability. The controlled motivation subscale of the RPC of this study had acceptable for reliability (alpha = .70). This was consistent with the reliability of the introjected motivations (alpha = .86), but inconsistent with the reliability of external motivations (alpha = .64) in a prior U.S. study (Kim et al., 2008).

## Summary

From literature, I found only two studies of Kim et al. that the researchers used the RPC in the U.S. with caregivers of cancer survivors (2008, 2013). The RPC is relatively new to use with caregivers. When comparing the mean score and the standard deviation of the RPC autonomous motivation subscale of the RPC between this study and a prior study with caregivers in the U.S. (Kim et al., 2008) these scores were consistent. But, the mean score and standard deviation of controlled motivation subscale of this study were inconsistent to a prior U.S. study (Kim et al., 2008). The similarity may result from recruiting caregiver samples. The major group of caregivers in prior studies (M = 56.50, SD = 10.62) had similar mean age of this study (M = 51.1, SD = 11.89) as middle aged (Kim et al., 2008, 2013). For differences on controlled motivation subscale may result from a prior study only focusing on spousal caregivers. The major group of caregivers in this study was daughter caregivers. Spousal caregivers and daughter caregivers may explain their motivations differently.

The RPC is used to assess type of motivations based on SDT. For content validity, all experts had acceptable the content validity indices for both subscales of the RPC. And a few experts asked for a few item revisions especially in the autonomous motivation subscale. For internal consistency reliability, the autonomous motivation subscale did not have acceptable.

Measures cannot be acceptable for validity if these measures do not have acceptable reliability (Tavakol & Dennick, 2011). Because of inconsistent findings about psychometric properties of two subscales, I concluded that the RPC were questionable for content validity and internal consistency reliability of this study. Revisions of a few items are needed for clarity and cultural relevance especially in the autonomous motivation subscale. Then, researchers would need to assess a revised or new measure for reliability before using in the future.

## The Basic Needs Satisfaction Scale in General (BNSG)

Building on prior literature, research, and SDT, this study advanced understanding about the psychometric properties of a satisfaction with psychological needs scale, based on SDT, in Thailand.

#### Satisfaction with Autonomy

The mean score of satisfaction with autonomy subscale of this study (M = 5.43) was higher than the mean score of this subscale in a prior study in the U.S. (M = 4.80) (Domenico & Fournier, 2014). However, the standard deviation of the satisfaction with autonomy subscale of this study (SD = .88) was lower than that in a prior study in the U.S (SD = 1.01) Domenico & Fournier, 2014).

Experts provided quantitative data for content validity index and qualitative data on revisions. For quantitative data, experts agreed on the satisfaction with autonomy subscale: a) most items were clear and relevant and b) a set of questions was substantially comprehensive and culturally relevant. For qualitative data, a few experts suggested about revisions some words for clarity.

The satisfaction with autonomy subscale did not have acceptable reliability (alpha =.63). This was lower than the reliability of the satisfaction with autonomy subscale of a previous study in the U.S. (alpha =.77). (Domenico & Fournier, 2014). The satisfaction with autonomy subscale

included 7 items. I explored by deleting one item which had the most poorly correlations with other items. The Cronbach's alpha increased to meet acceptable points (Johnston & Finney, 2010). However, I decided to use the original scores for a meaningful way of comparing findings with prior studies.

#### Satisfaction with Competence

The mean score of the satisfaction with competence subscale of the BNSG of this study (M = 5.25) was higher than the mean score of this subscale in a prior US study (M = 4.88) (Domenico & Fournier, 2014). The standard deviation for the satisfaction with competence subscale in this study (SD = 0.86) was lower than the standard deviation for this subscale in a prior US study (SD = 1.11) (Domenico & Fournier, 2014).

Experts provided quantitative data for content validity index and qualitative data on revisions. For quantitative data, experts agreed on the satisfaction with competence subscale:

a) most items were clear and relevant and b) a set of questions was substantially comprehensive and culturally relevant.

For qualitative data, caregivers and four experts suggested item revisions for clarity. One expert suggested that cultural norms about Thai caregiving might influence participants' expressions about caregivers' abilities. For example, the question is "Often, I do not feel very competent." This item does not ask specifically about one kind of competence. Participants may feel unsure about hoe to answer that item because the wording is too general and because of . cultural norms about Thai caregiving (Limpanichkul & Magilvy, 2004). Based on cultural norms, Thai people may not be likely to express their competence directly or externally. Thai people may be likely to accept if other people tell that they are competence rather than they tell others about their competence by themselves.

The satisfaction with competence subscale did not have acceptable reliability (alpha = .38). This was inconsistent with findings from a previous study in the U.S. (alpha = .77)

(Domenico & Fournier, 2014). After exploring to delete one item which had the most poor correlations with others, Cronbach's alpha did not increase in a meaningful way in this study. To improve Cronbach's alpha of the satisfaction with competence subscale, revising a few items for clarity may support consistency of Thai participants' responses.

#### Satisfaction with Relatedness

The mean score of the satisfaction with relatedness subscale of the BNSG of this study (M = 5.61) was slightly higher than that in a prior study in the U.S. (M = 5.08) (Domenico & Fournier, 2014). In contrast, the standard deviation of the satisfaction with relatedness subscale in this study (SD = 0.82) was slightly lower than the standard deviation of the scale in a prior study in the U.S (SD = .99) (Domenico & Fournier, 2014).

Experts provided quantitative data for content validity index and qualitative data on revisions. For quantitative data, experts agreed on the satisfaction with relatedness subscale: a) most items were clear and relevant and b) a set of questions was substantially comprehensive and culturally relevant. For qualitative data, a few experts and caregivers suggested about a few item revisions to increase clarity.

The satisfaction with relatedness subscale of the BNSG of this study had acceptable reliability (alpha = .68), but not high. This was lower than the findings of the satisfaction with relatedness scale for reliability in a previous U.S. study (alpha = .83) (Domenico & Fournier, 2014).

#### Summary

Building on past research and theory relevant to caregiving, I documented the validity and reliability of an SDT measure, the BNSG scale, in a Thai sample of caregivers. When comparing the mean score and the standard deviation of satisfaction with three needs subscales of the BNSG between this study and a prior study with samples in the U.S.

(Domenico & Fournier, 2014), these scores were inconsistent. The differences may result from different of participants' characteristics such as the mean age and race. The participants of a prior study were American people, they were aged 18-76 years old (Median age = 30, SD = 11.95) and researchers did not ask participants whether or not they were in the caregiving role. In this study, I recruited Thais who were a mean age of 51.1 (SD = 11.89) and the age of caregivers was from 25 -82 years old.

Because of inconsistent findings about psychometric properties across three subscales of the BNSG, I conclude that the BNSG may not be acceptable for content validity and internal consistency reliability. Revisions of a few items are needed for clarity and cultural relevance. Then, researchers can reassess a revised measure for content validity and reliability before using in the future.

SDT scholars made the BNSG measure. The BNSG is used to assess satisfaction with three psychological needs in general. Because caregiving is a specific context researchers may need to consider a measure of satisfaction with psychological needs in a specific context such as caregiving. For example, people can perceived that they are competent in one context but not another. Scales to consider using in the future would be the BNSG in relationships (La Guardia et al., 2000) or the Balanced Measure of Psychological Needs Scale (BMPN) (Sheldon & Hilpert, 2012).

## The Gain in Alzheimer Care Questionnaire (GAIN)

Because this is the first time of using the GAIN in Thailand The overall mean score of the GAIN in this study (M = 3.70) was higher than the overall mean score of this scale in prior studies of caregivers of PWD in Singapore (M = 3.00-3.05) (Liew et al., 2010; Yap et al., 2010). The standard deviation of the GAIN of this study (SD = 0.45) was lower than the standard deviation of this scale in prior studies of caregivers of PWD in Singapore (SD = 6.5-6.6) (Liew et al., 2010; Yap et al., 2010). The differences may result from Thai caregivers were likely to report

perceived gains of caregiving based on cultural norms and religious beliefs (Limpanichkul & Magilvy, 2004; Ritteeveerakul, 2005).

I generated support for content validity of the GAIN by using an expert panel. For quantitative data, all experts agreed on the GAIN: a) most items were clear and relevant and b) a set of questions was substantially comprehensive and culturally relevant. For qualitative data by experts' comments, a few experts suggested about a few item revisions for clarity.

The GAIN of this study was acceptable for construct validity in convergent validity and discriminant validity. This was consistent with the GAIN for construct validity in a prior study (Yap et al., 2010).

Because this is the first time of using the GAIN in Thailand, I also evaluated this scale for reliability. The GAIN of this study had acceptable reliability. This was consistent with the findings of the GAIN for reliability of a previous study in the Singapore (Liew et al., 2010; Yap et al., 2010).

I concluded that the GAIN was valid and reliable to assess perceived gains of caregiving in Thai samples.

#### The Multidimensional Scale of Perceived Social Support Questionnaire (MSPSS)

The overall mean score and standard deviation of the MSPSS in this study (M = 5.95, SD = 1.17) were slightly higher than these scores of the MPSS in a prior study in Thailand (M = 5.80, SD = 0.84) (Wongpakaran & Wongpakaran, 2012). The differences may result from different participants' characteristics. Participants in the prior study were medical students and younger adults. They might be likely to report perceived informal support less than caregivers due to different needs.

One of the strengths of this study is that I generated support for content validity of the MSPSS. For qualitative data by experts' ratings, they agreed on the MSPSS: a) most items were clear and relevant and b) a set of questions was substantially comprehensive and

culturally relevant. For qualitative data, a few caregivers and experts suggested about word revisions on "significant others" for clarity.

I demonstrated that the MSPSS had acceptable reliability (alpha = .89). This finding was consistent with a previous Thai study (alpha = .91) (Wongpakaran & Wongpakaran, 2012).

In summary, the MSPSS had acceptable for content validity and internal consistency reliability. Minor revisions are needed to increase clarity in one team that was similar to the suggestion of a prior Thai study (Wongpakaran & Wongpakaran, 2012). I concluded that the MPSS was valid and reliable to assess perceived informal social support. Because the MSPSS was developed to assess different sources of informal support (Zimet et al., 1988), in the future study, I would need to distinguish these sources rather than focusing on the whole concept of informal social support.

# The Short Form of the Zarit Burden Questionnaire (Short ZBI)

The mean score and standard deviation of the Short ZBI (M = 0.93, SD = 0.73) was lower than these scores in a prior study in Canada (M = 1.72, SD = 1.30) (Bedard et al., 2001). The differences may result from differences of caregivers' characteristics such as the mean age and the relationship with care recipients. The mean age of caregivers of PWD in a prior study was 61.01 (SD = 13.85) (Bedard et al., 2001) and the mean age of caregivers of PWD in this study was 51.1 (SD = 11.89). The major group of caregivers of PWD in a prior study was spousal caregivers (Bedard et al., 2001); this differed from this study because daughters were major. Compared to the full-scale of the ZBI in a prior study in Thailand, Thai caregivers reported no burden (52%) and mild burden (44%) (Limpawattana et al., 2013).

One of the strengths of the study is that I generated support for the reliability of the Short ZBI in Thailand. The finding of the Short ZBI of this study for reliability was consistent with the finding of this scale for reliability of a previous study in Canada (Bedard et al., 2001). This study built on previous research (Toonsiri et al., 2011) because I evaluated the reliability of the Short

ZBI in the first time. From prior studies about caregiving in Thailand, Thai caregivers were likely to report low perceived burdens of caregiving because of reluctant sharing their problems with other people (Muangpaisa et al., 2010; Limpawattana et al., 2013). Overall, Thai caregivers in prior studies may likely report low perceived burdens. I concluded that the Short ZBI was reliable to assess one-dimension perceived burdens of caregiving.

# The Five Subscales of the SF-36 (Thai version)

The mean scores of health on general health, bodily pain, vitality, and mental health of this study were higher than the findings in a prior study with caregivers in Thailand (Lawang, Horey, & Blackford, 2015). The standard deviations of health on general health, bodily pain, vitality, and mental health of the SF-36 were lower than the findings in a prior study with caregivers in Thailand (Lawang et al., 2015). However, the mean score and the standard deviation of health on role-emotional subscale of the SF-36 of this study was lower in the mean score and higher in the standard deviation of this subscale than in a prior study with caregivers in Thailand (Lawang et al., 2015). This meant that caregivers of PWD in this study were more likely to report a better health in physical and mental health except for the emotional interference than a prior study of caregivers in Thailand. The differences may result from differences in care recipients' diagnosis, care recipients' needs, educational level, or employment status (Lawang et al., 2015). The care recipients in a prior study were persons with acquired physical disability, but the care recipients in this study were persons with dementia. When comparing the mean scores and standard deviations of health on 5 health subscales between this study with adult caregivers and a prior study with Thai adults, the findings of these subscales of this study were lower than the findings of these subscales of a prior study with Thai adults (Vathesatogkit et al., 2012). Because a prior study was conducted with Thai adults who had current employment and did not work in the caregiving role, this suggested that caregivers in this study were likely to report poor health status than non-caregivers in Thailand.

The 4 subscales of caregiver health on general health, bodily pain, role-emotional, and mental health were acceptable for reliability. The vitality subscale was not acceptable for reliability. This was inconsistent with the findings of the vitality subscale of caregivers of a previous study in Thailand (Lawang, Horey, & Blackford, 2015). In a prior study, researchers have found the vitality subscale had acceptable for internal consistency reliability this subscale had the lowest of Cronbach's alpha among 5 subscales of health of the SF-36 (Lim, Seubsman, & Sleigh, 2008). In addition, the vitality subscale had high correlation with the mental health subscale of the SF-36. This may be because Buddhist people believe that a good mental health is fundamental of vitality (Lim, Seubsman, & Sleigh, 2008). In addition, some items of vitality and mental health may influence respondents' confusion due to be placed in the same section (Leurmarnkul & Meetam, 2005). Also, the total items of the vitality subscale of the SF-36 are 4 items. Because the total items were likely small this may reduce Cronbach's alpha of the vitality subscale had questionable in this study. In concluded that the 4 subscales of caregiver health: general health, bodily pain, role-emotional, and mental health were reliable in this study.

## Secondary aims

In this section, I begin with a discussion of the findings from bivariate analyses among covariates, explanatory variables, and outcome variables to increase a better understanding about relationships about bivariate correlations of all variables. Then, I discuss relationships among multiple variables of interests comparing between model 1 without covariates and model 2 with covariates regarding three specific aims.

# **Bivariate Analyses**

One of the main covariates of this study was age of caregivers. This factor had a significantly positive relationship with perceived gains of caregiving. The finding of this study

was consistent to prior studies (Liew et al., 2010; Ritteeveerakul, 2005; Peacock et al., 2010; Tang, 2011). The consistency may be explained by the fact that caregivers are getting older and are likely to have provided care longer than younger caregivers, with a long time of providing care may increase an opportunity for caregivers to be closer with care recipients. Conversely, caregivers who provide care with a long period of time may report perceived burdens because of doing several things for care recipients or not having time for themselves (Spillman et al., 2014). Caregivers may need to balance those perceptions in the caregiving role. However, caregivers who get older may feel competent to provide care for care recipients due to increase caregiving experiences. These factors may lead caregivers to likely report perceived gains of caregiving in personal growth and gains in relationships with care recipients (Liew et al., 2010; Peacock et al., 2010).

The other covariate of this study was the number activities of ADL. This factor had significant relationships with perceived burdens of caregiving and caregiver health. The findings of this study were consistent to the prior study (Au et al., 2010; Spillman et al., 2014).

Caregivers who provide care with many activities of ADL may be likely to report perceived burdens of caregiving because feelings of many activities to do or being exhausted from providing care (Spillman et al., 2014). Care recipients with moderate and advance stages of dementia may need several activities of ADL with routine and continuous care from caregivers (Ciro, 2014; Huang et al., 2015; Shim, Barroso, & Davis, 2012). These caregivers who assisted care recipients with many ADL may perceive burden of caregiving and subsequently experience poor health in physical, mental, and emotional (Pinquart & Sörensen, 2003a; Ritteeveerakul, 2005). However, I did not ask about the stages of dementia of care recipients in this study. Researchers should consider stages of dementia that may be another potential covariate of caregiving studies.

One of the strengths of this study was assessing both positive and negative experiences of caregivers in Thailand. Caregivers can have perceived gains and burdens of caregiving when

providing care (Shim et al., 2012). From bivariate analyses, perceived gains had a moderate negative relationship with perceived burdens and positive relationships with psycho-emotional health of caregivers. In contrast, perceived burdens had moderate negative relationships with physical and psycho-emotional health of caregivers. This could support that perceived burdens and perceived gains are different concepts. It does not mean that perceived gains and burdens are opposite side from each other (Carbonneau et al., 2010). If caregivers do have perceived gains they might have or not have perceived burdens. Thus, I would suggest that researchers should study on positive and negative consequences of caregiving to increase a better understanding about caregiving experiences.

### **Multivariate Analyses**

From multivariate analyses, two models were produced: the model 1 without covariates and the model 2 with covariates: the age of caregivers and number activities of ADL. Comparing findings from two models regarding specific aims about examining relationships. I focus more on model 2 than model 1 because model 2 demonstrated realistic caregiving experiences.

5a) Relationships between explanatory and outcome variables
Satisfaction with autonomy and caregiving outcomes

One of the strength of the study was that I found support for relationships between the satisfaction with autonomy that is volition of caregivers and caregiving outcomes. This was the first time to assess relationships among the satisfaction of psychological needs, such as, autonomy with perceived gains of caregiving, perceived burdens of caregiving, and physical and mental health of caregivers of PWD in Thailand. Thus, I found partial support between the satisfaction with autonomy and caregiving outcomes as expected. If caregivers have satisfied with their feelings of volition to provide care they may likely engage in the caregiving role.

When comparing two models, the findings were slightly different between the satisfaction

with autonomy and caregiving outcomes. When adding covariates, the satisfaction with autonomy were not significantly positive relationship with perceived gains (p =.05). Yet, satisfaction with autonomy had positive relationships with the age of caregivers and caregiver health such as mental health and a negative relationship with perceived burdens. Thai caregivers who voluntarily provide direct hands-on care may face unexpected symptoms for PWD about caregiving. Caregivers who have satisfaction with autonomy may stay in the caregiving role because they volition to do so. Caregivers who satisfied with their autonomy of providing care they may be likely to report less negative consequences of caregiving such as depression or perceived burdens and better physical and mental health than caregivers who did not satisfy with autonomy (Ng et al., 2012).

Satisfaction with competence and caregiver health

When comparing two models positive relationships of satisfaction about competence with physical health and mental health of caregivers were similar. Interpreting these relationships were needed to be cautious due to unacceptable reliability of the measure.

The findings were consistent to a prior study guided by SDT (Ng et al., 2012). These findings of were partially consistent to a prior study about a positive relationship between caregivers' competence and physical health, yet a negative relationship depression (Au et al., 2010). The findings showed that 93% of caregivers did not have experiences to provide care and this may be important to promote satisfaction with competence of caregivers. Conversely, if caregivers have not satisfied with their competences of providing care they may seek for helps or stop providing care. Thus, if caregivers satisfied that they are competent to provide care and deal with caregiving situations, they may report a good physical and mental health.

Satisfaction with relatedness and emotional interference

When comparing two models, the finding of positive relationships between satisfaction with relatedness and emotional interference of caregivers was consistent to a prior study (Fauth

et al., 2012). In Thai caregivers, satisfaction with relatedness had a positive relationship with a better emotional health. Buddhist people may believe that they should provide care for care recipients in the present because of law of Karma, that is, caregiving is a one way to express gratefulness for their care recipients (Sethabouppha & Kane, 2005). Particularly, daughter caregivers provide care for their parents because their parents give merit to raise and care for them when they are children (Limpanichkul & Magilvy, 2004). Caregiving involves reciprocal actions and can be consistent with caregivers' beliefs about Bunkhun that is a reason for caregivers to provide care as a good thing for their parents (Limpanichkul & Magilvy, 2004). Based on SDT, if caregivers fulfill their satisfaction with relationships between them and other people they may be likely to have a better health (Deci & Ryan, 2000).

Informal social support and caregiving outcomes

When comparing two models, a positive relationship of perceived informal social support with bodily pain and a negative relationship with perceived burden of caregiving were partially consistent to a prior study (Harwood et al., 2000). The study of Harwood et al. (2000) revealed the relationship between informal social support and perceived burdens but they did not find the relationship between informal social support and physical health of caregivers. These findings were inconsistent to a prior study of caregivers of PWD in the U.S. (Kaufman et al., 2010). The differences may result from different caregivers' needs in informal social support, different defining informal social support, and different measures used (Smerglia et al., 2007). Informal social support is defined in different ways such as structure of informal social support or perceived informal social support (Smerglia et al., 2007). In this study, I defined informal social support as perceptions of recipients about sources of support. For the findings of this study, this may explain that caregivers may perceive helpful to receive informal social support from family members, friends, or significant others. Especially, receiving informal social support from family members to help caregivers provide care sometimes. These caregivers might perceive little burden of caregiving and a good physical health. This may support caregivers to likely report

little burden of caregiving and a good physical health than others without someone to help.

Type of motivations and caregiving outcomes

When comparing two models, a positive relationship between controlled motivations and bodily pain of caregivers, and a not significant relationship between autonomous motivations and caregiving outcomes were inconsistent with a prior study (Ng et al., 2012; Kim et al., 2008). The differences may come from how caregivers explain their reasons for providing care regarding cultural norms and religious beliefs (Limpanichkul & Magilvy, 2004; Sethabouppha & Kane, 2005). Thai daughter may be expected from others to provide care for their parents based on cultural norms and religious beliefs. To fulfill in the caregiving role of daughter caregivers may avoid their feeling guilty or ashamed. Cultural norms and religious beliefs may influence other family member to help provide care and any support for caregivers. With the feelings of fulfillment family's expectations and getting any support from family caregivers may overcome personal motivations of caregivers to provide care. Caregivers who provide care may fulfill their obligation with support from their family. This may lead caregivers to likely report a good physical health of caregivers. Thus, cultural norms and religious beliefs about caregiving may overcome Thai individual motives to provide care.

### 5b) Relationships among explanatory variables

When comparing two models the findings of what type of relationships of motivations, satisfaction with psychological needs, and what else of this study supported SDT. Cultural norms and religious beliefs about caregiving may influence the satisfaction with autonomy, relatedness, and competence of Thai caregivers, daughter caregivers may be satisfied in fulfilling their expected relationships as caregivers to care recipients. The caregiving role may help support caregivers to satisfy with their abilities and autonomy of providing care. I concluded that Thai caregivers may be likely to view caregiving as family obligations that everybody in

families may engage in the caregiving role to provide care for their love one.

### 5c) Relationships among outcome variables

When comparing two models about relationships among 5 subscales of caregiver health: general health, bodily pain, role-emotional, vitality, and mental health of this study were consistent to the findings of these relationships in a prior study (Lim, Seubsman, & Sleigh, 2008). However, the vitality and mental health subscales were high correlated. This may be because Buddhist people believe that a good mental health is fundamental of vitality (Lim, Seubsman, & Sleigh, 2008).

The findings of negative relationships between perceived burdens and caregiver health were consistent to prior studies (Knight & Losada, 2011; Pinquart & Sörensen, 2003a, 2003b; Schulz & Martire, 2004). The findings of negative relationships between the number activities of ADL and physical, mental and emotional health of caregivers were partially consistent with a prior study (Au et al., 2010). This prior study only demonstrated a negative relationship between ADL scores and mental health of caregivers. The finding of a positive relationship between the number activities of ADL and perceived burdens of caregiving was consistent with a prior study (Spillman et al., 2014). In this study, I did not find a significant relationship between perceived gains and burdens. This may result from low variability and ceiling effect of perceived gain scores. The perceived burden scores had low variability and floor effect. I conclude that perceived burdens of caregiving may be a measure to describe physical, mental, and emotional health of caregivers. The number activities of ADL may be as a covariate to explain physical and psycho-emotional health of caregivers and perceived burdens of caregiving.

### Limitations

One of the limitations of the study is that I assessed of psychometric properties of measures with the same sample in which I examined relationships among explanatory and

outcome variables. This may lead to inflated relationships among variables of interests.

Another limitation is a use of the convenience sampling to recruit participants. This could result in a sampling bias. Because I collected data at hospital sites with caregivers who came for clinical appointments of care recipients, these caregivers may likely be concerned about providing care for recipients and their health. I did not collect data with caregivers in community sites. Caregivers who did not come to clinics and caregivers who were in communities for providing care may respond to caregiving questionnaires differently because of site differences. Additionally, I focused on caregivers who provided direct hands-on care. This may limit other caregivers who provide other caregiving for care recipients such as monitoring or supporting care. The sampling bias of this study may limit accuracy of data and generalizability.

Another limitation is this study using self-report questionnaires and methods to answer questionnaires of participants. Asking their experiences about caregiving for the past four weeks by using self-report questionnaires, participants might forget their thoughts and feelings.

Participants could respond by written questions or interview based on their preferences. Most participants in this study responded by interviewing rather than written questionnaires. An interviewer could have influenced respondents. Responding in person could have influenced social desirability. These may reduce response accuracy.

Finally, the use of a cross-sectional design of the study, I could not explain a causal relationship between explanatory on outcome variables of caregiving.

### **Implications**

I recommend researchers and clinicians to use four measures. They were: the measure of assessing perceived gains, the measure of assessing perceived burdens, the measure of assess perceived informal social support, and the measure of assessing caregiver health.

Because these measures were valid and reliable researchers and clinicians could use them in

their studies about caregiving in the future.

This study helped researchers increase understanding caregiving experiences about relationships among caregiving outcomes. Caregivers reported high scores in perceived gains and low scores with perceived burdens. Perceived burdens had a significant negative relationship with perceived gains in bivariate correlations. Perceived burdens had significant negative relationships with caregiver health. With low in perceived burdens, this did not mean that caregivers did not have any health problems of providing care. Using a self-report questionnaire may not be meaningful. Other qualitative methods to assess perceived burdens may need to consider such as a focus group. This may help researchers increase understanding about perceived burdens. Using a focus group would also support sharing about perceived burdens among caregivers.

The findings of this study about relationships among caregiving outcomes may be meaningful for health educators to develop an intervention for caregivers. Health educators may support caregivers to share their caregiving experiences in positive and negative consequences by using a group counseling. A group counseling for caregivers would be a resource for caregivers to learn and understand caregiving by sharing their experiences. Health educators could also teach caregivers how to deal with caregiving problems and strengthen perceived gains of caregivers. This would help support caregivers to maintain in the caregiving role with reducing burdens and having better health.

SDT was helpful to guide concepts, propositions, and measure used about caregiving in this study. I applied SDT to describe concepts about type of motivations, satisfaction with psychological needs, and relationships among these concepts toward caregiving outcomes. I also used two measures guided by SDT. I applied SDT to explain the findings about relationships among study variables to increase understanding about caregiving experiences of Thai caregivers. Because some subscales of two measures based on SDT did not have psychometric acceptability in this study, SDT may use to guide other measures about

satisfaction with psychological needs in specific contexts such as the measure of satisfaction with psychological needs in relationship. I concluded that using a conceptual model or theory such as SDT is helpful for researchers to define concepts, to describe propositions, to guide measure used, and to discuss findings of studies in the future.

The findings of the study could increase understanding about caregiving experiences in Thailand. For example, perceived informal social support may influence caregiving outcomes such as perceived burdens and gains. This may stimulate researchers to increase studying about informal social support of caregivers in Thailand. The findings showed that perceive gains had a negative relationship with perceived burdens using bivariate correlations. These supported that perceived gains and burdens are different concepts (Carbonneau et al., 2010). Both concepts may relate to each other. In this study, I examined perceived gains and burdens of as the same time. Perceived gains may be likely to correlate with mental health of caregivers. Perceived burdens may correlate with physical, mental, and emotional health of caregivers. Additionally, cultural norms and religious beliefs may influence perceptions of caregivers about gains and burdens. In sum, although the findings of this study may not directly guide to improve a caregiving policy, researchers could increase understanding about caregiving experiences of Thai caregivers of PWD. Thus, researchers may examine antecedent and outcome variables of caregiving regarding cultural norms and religious beliefs of caregivers. In particular, researchers should examine caregiving outcomes in both perceived burdens and gains of caregiving.

This study suggests future research as following:

Researchers could evaluate construct validity and internal consistency reliability of a revised measure of satisfaction with psychological needs or a new measure of satisfaction with psychological needs in a specific context by using confirmatory factor analysis.

Researchers could examine caregiving processes with using a longitudinal design to

increase understanding about antecedents such as satisfaction with psychological needs or perceived informal social support and consequences such as perceived gains and burdens for explanations about causality.

Researchers could examine perceived gains and burdens of caregiving by using a focus group and extend to examine influences of cultural norms and religious beliefs on perceptions of caregiving. Researchers would collect data with caregivers in community settings. This would help researchers increase understanding perceptions of caregiving and generalizability.

Researchers would examine differences on satisfaction with psychological needs and caregiving outcomes by comparing between caregivers who provide direct hands-on care and caregivers who provide other caregiving such as monitoring or organizing care in community settings.

Based on SDT, researchers would investigate whether satisfaction with psychological needs mediate relationships between characteristics of caregivers such as age of caregivers and caregiver health.

Based on SDT, autonomy support from import other may facilitate satisfaction with psychological needs of people to manage their health behaviors (Williams et al., 2006). This may correlate with physical and mental health of people (Ng et al., 2012). Applying SDT to caregiving contexts, researchers may examine whether satisfaction with psychological needs mediate relationships between autonomy support and caregiver health.

### Conclusion

Assessing psychometric properties of measures are important to confirm that these measures are valid and reliable. The findings of this study provided in depth examination of psychometric properties of selected measures in a new context; in Thailand regarding caregiving. My findings suggest that researchers can use the following measures, with good

psychometric properties in the future. The study was the first time to apply the SDT to guide propositions among concepts in a study of Thai caregivers. Based on SDT, satisfaction with autonomy, competence, and relatedness would be important for caregivers to maintain in providing care. Researchers may extend to examine the satisfaction with autonomy of caregivers and caregiving outcomes. The main limitation of this study was that I accessed content validity, construct validity, and internal consistency reliability of the measures and examined the relationships among variables within the same sample. This may lead to findings biases because of inflated relationships among variables. Future study to replicate the findings of this study with caregivers in community sites would increase generalizability. Future study with a better design would be needed to control sampling bias and increase generalizability.

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Appendices

## Appendix A: Approval Letters

University of Wisconsin-Madison

### IRB Review Determination for Exemption or Not Human Subjects Research

Health Sciences IRB • Health Sciences Minimal Risk IRB

Project/Protocol Number: 2014-1264

Project Lead/Principal Investigator: Diane Lauver

Project/Protocol Title: Assessing Measures and Caregiving Experiences of Thai Caregivers of

Persons with Dementia

Staff Reviewer & Contact Information: Sherry Holcomb; ssholcomb@medicine.wisc.edu

Date Exemption Granted: 11/14/14

The IRB has reviewed the study indicated above for exemption and its determination is indicated below. Please review this determination and any additional guidance provided by the IRB. If you have any questions regarding this determination, please contact the staff reviewer listed above. For additional details regarding the submitted exemption application, you must log in to your ARROW account at <a href="https://www.arrow.wisc.edu">www.arrow.wisc.edu</a>.

☐ IRB review is not required because, in accordance with federal regulations, your project does not: ☐ constitute research as defined under 45 CFR 46.102(d) ☐ involve human subjects as defined under 45 CFR 46.102(f)
Additional Information:
Please note: If this application falls under VA purview, no activities should begin until VA R&D approval is received.
∑ Your study qualifies for exemption under category: 45 CFR 46.101(b)(2). Although your study is exempt from federal regulations, UW Human Research Protection Program policy requires that all human subjects research be conducted in accordance with the highest ethical standards/Belmont Report. Please contact the staff reviewer listed above if you plan to make a significant change to your research that affects the exempt status of your study (see examples below).
Additional Information: Please note that the Thai versions of all scripts, information sheets, consent forms, and the survey must be submitted to the staff reviewer above when they are available.
Please note: If this application falls under VA purview, no activities should begin until VA R&D approval is received.
<ul> <li>☐ Your study involves the use and/or disclosure of PHI and therefore, HIPAA regulations apply. The following are approved by the IRB:</li> <li>☐ HIPAA Authorization Form</li> <li>☐ Application for Waiver of Authorization</li> <li>☐ Other:</li> </ul>
Additional Information:

Examples of changes that could affect the exempt status of a study:

45 CFR 46.101(b)(1): Changes to the setting in which the educational activity is being conducted could affect the exempt status. In addition, changes to the purpose for which an educational activity is being conducted (e.g., conducting an activity specifically for research purposes rather than a standard class requirement) could also affect the exempt status under category 1.

45 CFR 46.101(b)(2): Changes to the identifiability of survey or interview results could affect the exempt status under category 2, as well as changes to the survey or interview tools to add collection of sensitive or stigmatizing information.

University of Wisconsin-Madison

### IRB Review Determination for Exemption or Not Human Subjects Research

Health Sciences IRB . Health Sciences Minimal Risk IRB

Project/Protocol Number: 2015-0260

Project Lead/Principal Investigator: Diane Lauver

Project/Protocol Title: Assessing Measures and Caregiving Experiences of Thai Caregivers of

Persons with Dementia Phase 2

Staff Reviewer & Contact Information: Sherry Holcomb; ssholcomb@medicine.wisc.edu

Date Exemption Granted: 4/20/15

The IRB has reviewed the study indicated above for exemption and its determination is indicated below. Please review this determination and any additional guidance provided by the IRB. If you have any questions regarding this determination, please contact the staff reviewer listed above. For additional details regarding the submitted exemption application, you must log in to your ARROW account at <a href="https://www.arrow.wisc.edu">www.arrow.wisc.edu</a>.

☐ IRB review is not required because, in accordance with federal regulations, your project does not: ☐ constitute research as defined under 45 CFR 46.102(d) ☐ involve human subjects as defined under 45 CFR 46.102(f)
Additional Information:
Please note: If this application falls under VA purview, no activities should begin until VA R&D approval is received.
Your study qualifies for exemption under category: 45 CFR 46.101(b)(2). Although your study is exempt from federal regulations, UW Human Research Protection Program policy requires that all human subjects research be conducted in accordance with the highest ethical standards/Belmont Report. Please contact the staff reviewer listed above if you plan to make a significant change to your research that affects the exempt status of your study (see examples below).
Additional Information: Study activities may begin at Nakhon Ratchasima Rajanagarindra Psychiatric Hospital and Fort Suranari Hospital only. Study activities at Maharat Nakhon Ratchasima Hospital may not begin until IRB approval for that site is submitted to the IRB staff reviewer.
Please note: If this application falls under VA purview, no activities should begin until VA R&D approval is received.
☐ Your study involves the use and/or disclosure of PHI and therefore, HIPAA regulations apply. The following are approved by the IRB: ☐ HIPAA Authorization Form ☐ Application for Waiver of Authorization ☐ Other:
Additional Information:

### Examples of changes that could affect the exempt status of a study:

45 CFR 46.101(b)(1): Changes to the setting in which the educational activity is being conducted could affect the exempt status. In addition, changes to the purpose for which an educational activity is being conducted (e.g., conducting an activity specifically for research purposes rather than a standard class requirement) could also affect the exempt status under category 1.

45 CFR 46.101(b)(2): Changes to the identifiability of survey or interview results could affect the exempt status under category 2, as well as changes to the survey or interview tools to add collection of sensitive or stigmatizing information.

ที่ สิจิ ๐๓๑๐ (๑๒๕๐๐)/๑๐๔๘

สำนักงานคณะกรรมการวิจัยสถาบันประสาทวิทยา ศูนย์วิจัยสถาบันประสาทวิทยา สถาบันประสาทวิทยา เลชที่ ๓๑๒ ถนนราชวิถี แชวงทุ่งพญาไท เขตราชเทวี กรุงเทพฯ

**๑**๑๙ กันยายน ๒๕๕๗

เรื่อง อนุมัติให้ดำเนินการวิจัยได้

เรียน พ.ต.หญิงปิยอร วจนะทินภัทร

ตามที่ท่านซึ่งเป็น หัวหน้าโครงการวิจัยตามรายละเอียดข้างท้าย ได้เสนอโครงการวิจัยดังกล่าวต่อคณะกรรมการวิจัย สถาบันประสาทวิทยา

เลขที่โครงการ ๕๗๐๔๗

ชื่อโครงการวิจัย การประเมินเครื่องมือของการให้การดูแล และความสัมพันธ์ระหว่างตัวแปรต่าง ๆ ของผู้ดูแล คนไทยที่ให้การดูแลบุคคลที่มีภาวะสมองเสื่อม

ในการนี้ คณะกรรมการวิจัยสถาบันประสาทวิทยา ซึ่งเป็นคณะกรรมการวิจัยสถาบัน (Institutional Review Board : IRB) ที่มีการดำเนินงานตามแนวทางการวิจัยสถาบันประสาทวิทยา ซึ่งเป็นคณะกรรมการวิจัยสถาบัน (Institutional Review Board : IRB) ที่มีการดำเนินงานตามแนวทางการวิจัยทั้งกลินิกที่ดี (ICH GCP) ได้พิจารณา และมีมติอนุมัติให้ดำเนินการโครงการวิจัยดังกล่าว ในสถาบันประสาทวิทยาได้ โดยผู้วิจัยจะต้องมีหน้าที่และความรับผิดชอบภายหลังได้รับการอนุมัติ คือ ต้องปฏิบัติตามพระราชบัญญัติ สุขภาพแห่งชาติ พ.ศ. ๒๕๕๐ มาตรา ๗ "ข้อมูลสุขภาพของบุคคล เป็นความลับส่วนบุคคล ผู้ใดจะนำไปเปิดเผยในประการที่น่าจะทำให้ บุคคลนั้นเสียหายไม่ได้ เว้นแต่การเปิดเผยนั้นเป็นไปตามความประสงค์ของบุคคลนั้นโดยตรง" โดยเคร่งครัดและจะต้องรายงาน ความก้าวหน้าของโครงการวิจัยเมื่อมีการร้องขอและ/หรือเมื่อเกิดเหตุการณ์ต่อไปนี้ ทุกครั้ง ได้แก่

- ๑. ควรพิจารณาดำเนินการให้นักวิจัยและผู้ช่วยนักวิจัยทุกคน ผ่านการอบรมทางด้านจริยธรรมการวิจัยในคน
- เมื่อโครงการวิจัยยุติลง ซึ่งอาจจะเป็นการดำเนินการวิจัยเสร็จสิ้นสมบูรณ์ หรืออาจจะไม่สามารถดำเนินการวิจัย ต่อไปได้ พร้อมทั้งแจ้งสาเหตุของการยุติโครงการวิจัยให้ทราบด้วย
- ๓. เมื่อมีการเปลี่ยนแปลงในโครงการวิจัยต้องระบุให้ชัดเจนว่า มีการเปลี่ยนแปลงอะไร อย่างไร พร้อมเหตุผลที่ต้องเปลี่ยนแปลง
- ๔. เมื่อมีการเปลี่ยนแปลงหัวหน้าโครงการวิจัยพรือเพิ่มเติมคณะผู้วิจัย ต้องส่งประวัติของคนที่เปลี่ยนแปลงพร้อมเหตุผล ให้คณะกรรมการ ๆ ทราบด้วย
- ๕. เมื่อมีอาการไม่พึงประสงค์เกิดขึ้นในโครงการวิจัย ขอให้ผู้วิจัยวิเคราะห์สถานการณ์การเกิดอาการ ไม่พึงประสงค์ ที่ relate, possible/likely, probably related, fatal กับโครงการวิจัยที่ท่านรับผิดชอบอย่างไร รวมทั้งขอทราบ มาตรการในการดูแลป้องกันอาสาสมัครในประเทศไทยด้วย
- ๖. จัดส่งรายงานการศึกษาวิจัย จำนวน ๒ ขุด ให้แก่สำนักงานคณะกรรมการวิจัยสถาบันประสาทวิทยา เมื่อสิ้นสุดการดำเนินงาน
- ๗. หากการวิจัยเกินเวลากว่า ๑ ปี จะต้องรายงานความก้าวหน้าของโครงการวิจัย พร้อมดำเนินการขอต่ออายุการรับรอง ก่อนหมดอายุอย่างน้อย ๓๐ วัน

จึงเรียนมาเพื่อโปรดทราบ

ขอแสดงความนับถือ

(นายสุชาติ หาญไชยพิบูลย์กุล)

ประธานคณะกรรมการวิจัยสถาบันประสาทวิทยา

สำนักงานคณะกรรมการวิจัยสถาบันประสาทวิทยา ศูนย์วิจัยสถาบันประสาทวิทยา

# analle of

	แบบเสนอเค้าโครง 🗖 งานวิจัย 🗖 การศึกษาอิสระ 🌉 วิทยานิพนธ์ เพื่อมาศึกษาในโรงพยาบาลจิตเวชนครราชสีมาราชนครินทร์
	วันที่30 เคือนธันวาคมพ.ศ2557
เรียน ผู้อำนวย	ยการโรงพยาบาลจิตเวชนครราชสีมาราชนครินทร์
เมคิสัน กลุ่มงาน	ข้าพเจ้าพ.ต.หญิง ปียอร วจนะทินภัทรตำแหน่ง นักศึกษาปริญญาเอก มหาวิทยาลัยวิสคอนสิน- /หน่วยงาน
ชื่อเรื่อง ภาษาไม ภาวะสมองเสื่อม	มีความประสงค์ของเสนอเค้าโครง 🔲 งานวิจัย 🔲 การศึกษาอิสระ 🌉 วิทยานิพนธ์ กย การประเมินเครื่องมือ และประสบการณ์ของการให้การดูแลในผู้ดูแลคนไทยที่ให้การดูแลบุคคลที่มื J( Assessing Measures and Caregiving Experiences of Thai Caregivers of Persons with Dementia) โครงมาพร้อมนี้จำนวน ๑ ชุด เพื่อมาศึกษาในโรงพยาบาลจิตเวชนครราชสีมาราชนครินทร์
į.	จึงเรียนมาเพื่อโปรคพิจารณาอนุมัติต่อไปด้วย จะเป็นพระกุณยิ่ง
	ลงชื่อ พ.ต.หญิง ปียอฮ สานะทินส์การ ผู้เสนอเค้าโครง
	(ปียอร วจนะทินภัทร)
คณะกรรมการวิ	จัยโรงพยาบาลจิตเวชนครราชสีมาราชนครินทร์  [ โห็นควรอนุมัติ
	🗖 ความเห็นอื่น
	ลงชื่อ ครั้งครั้ง พืชบาง ประธานคณะกรรมการวิจัย ( วันที่ 2b ) มหา / 78  อนุมัติ
	<ul> <li>ไม่อนุมัติ เนื่องจาก</li></ul>
	ลงชื่อ



# บันทึกข้อความ

ส่วนราชการ ศูนย์แพทยศาสตรศึกษาชั้นคลินิก โรงพยาบาลมหาราชนครราชสีมา โทร.๕๒๒๒-๓ ที่ นม ๐๐๓๒.๑๒๔/ ๙๎๏ ๓ วันที่ ๓๐ เมษายน ๒๕๕๘

เรื่อง ขอแจ้งผลการพิจารณาโครงการ

เรียน พ.ต.ปิยอร วจนะทินภัทร

ตามที่ท่านได้ส่งเอกสารซี้แจงข้อสอบถามจากคณะกรรมการพิจารณาจริยธรรมการวิจัย ในคน ของ โครงการวิจัยเรื่อง "การประเมินเครื่องมือและประสบการณ์ของการให้การดูแลในผู้ดูแลคนไทยที่ให้การดูแลบุคคลที่มี ภาวะสมองเสื่อม" ดังรายละเอียดในบันทึกข้อความที่ นม ๐๐๓๒.๑๑๘/๓๒ ลงวันที่ ๒๖ มีนาคม ๒๕๕๘ นั้น

ทางคณะกรรมการพิจารณาจริยธรรมการวิจัยในคนโรงพยาบาลมหาราชนครราชสีมา ได้พิจารณาครั้งที่ ๔/๒๕๕๘ เมื่อวันที่ ๒๓ เมษายน ๒๕๕๘ แล้วมีมติรับทราบ และอนุมัติให้ดำเนินการวิจัยได้ จึงเรียนมาเพื่อทราบ

April 3mm

(นายนิพัทธ์ สีมาขจร) ประธานคณะกรรมการพิจารณาจริยธรรมการวิจัยในคน

### Appendix B: Questionnaires

Please answer each question on these pages. And, we would like you to tell us if some words are not clear. As you go through our directions and questions, **please circle** any words or phrases that you think are not clear to you.

### Thoughts and Feelings about Your Life

Please read each of the following items carefully. We would like you to think about how it relates to your life. Then, you circle one number that best matches what you think. Please be honest. There are no "right" or "wrong" answer.

### 1. I feel like I am free to decide for myself how to live my life

1 Not at all true 2. I really like th	2 A little bit true ne people I inte	3 Mildly true eract with	4 Somewhat true	5 Moderate true	6 Mostly true	7 Very true
1 Not at all true 3. Often, I do	2 A little bit true not feel very	3 Mildly true competer	4 Somewhat true	5 Moderate true	6 Mostly true	7 Very true
1 Not at all true 4. I feel pressi	2 A little bit true ured in my life	3 Mildly true	4 Somewhat true	5 Moderate true	6 Mostly true	7 Very true
1 Not at all true 5. People I kn	2 A little bit true ow tell me I a	3 Mildly true m good a	4 Somewhat true at what I do	5 Moderate true	6 Mostly true	7 Very true
1 Not at all true 6. I get along	2 A little bit true with people I	3 Mildly true come into	4 Somewhat true contact with	5 Moderate true	6 Mostly true	7 Very true
1 Not at all true	2 A little bit true	3 Mildly true	4 Somewhat true	5 Moderate true	6 Mostly true	7 Very true
7. I pretty muc	ch keep to my	self and	don't have a lo	t of social cor	ntacts	
1 Not at all true	2 A little bit true	3 Mildly true	4 Somewhat true	5 Moderate true	6 Mostly true	7 Very true

<sup>1
\*\*</sup> Were there any words or phrases above that were not clear for you? If so, then please circle them
Questionnaires about caregiving v.7, 10/3/

# 8. I generally feel free to express my ideas and opinions

1 Not at all true 9. I consider th	2 A little bit true ne people I re	3 Mildly true egularly in	4 Somewhat true teract with to I	5 Moderate true be my friends	6 Mostly true	7 Very true
1 Not at all true 10. I have bee	2 A little bit true n able to lear	3 Mildly true rn interes	4 Somewhat true ting new skills	5 Moderate true recently	6 Mostly true	7 Very true
1 Not at all true 11. In my daily	2 A little bit true life, I freque	3 Mildly true ntly have	true	5 Moderate true m told	6 Mostly true	Very true
1 Not at all true 12. People in I	2 A little bit true my life care a	3 Mildly true bout me	4 Somewhat true	5 Moderate true	6 Mostly true	7 Very true
1 Not at all true 13. Most days	2 A little bit true I feel a sens	3 Mildly true e of acco	true	5 Moderate true om what I do	6 Mostly true	7 Very true
1 Not at all true 14. People I in	2 A little bit true teract with or	3 Mildly true n a daily b	4 Somewhat true pasis tend to ta	5 Moderate true ake my feeling	6 Mostly true gs into consid	7 Very true deration
1 Not at all true 15. In my life I	2 A little bit true do not get m	3 Mildly true uch of a	true	5 Moderate true w how capable	6 Mostly true e I am	7 Very true
1 Not at all true	2 A little bit true	3 Mildly true	4 Somewhat true	5 Moderate true	6 Mostly true	7 Very true

### 16. There are not many people that I am close to

1	2	3	4	5	6	7
Not at all	A little bit	Mildly	Somewhat	Moderate	Mostly	Very
true	true	true	true	true	true	true
17. I feel like I	can pretty m	uch be m	yself in my dai	ly situations		
1	2	3	4	5	6	7
Not at all	A little bit	Mildly		Moderate	Mostly	Very
true	true	true	true	true	true	true
18. The people	e I interact wi	ith regula	rly do not seen	n to like me m	uch	
1	2	3	4	5	6	7
Not at all	A little bit	Mildly		Moderate	Mostly	Very
true	true	true	true	true	true	true
19. I often do	not feel very	capable				
1	2	3	4	5	6	7
Not at all	A little bit	Mildly	Somewhat	Moderate	Mostly	Very
true	true	true	true	true	true	true
20. There is no	ot much char	nce for me	e to decide for	myself how to	do things ii	n my daily life.
1	2	3	4	5	6	7
Not at all	A little bit	-	Somewhat	Moderate	Mostly	Very
true	true	true	true	true	true	true
21. People are	e generally pr	etty frien	dly towards me	9.		
1	2	3	4	5	6	7
Not at all	A little bit	Mildly	Somewhat	Moderate	Mostly	Very
true	true	true	true	true	true	true

### Reasons for Providing Care

There are a variety of reasons why you provided care to this person through his/her experience with dementia. Please read each of the following items carefully. Then, you circle one number that best matches what you think. Please be honest.

## I provide care to a patient because.....

1. It was important to me personally to do so

1 Strongly disagree	2 Moderate disagree	3 Slightly disagree	4 Neutral	5 Slightly agree	6 Moderate agree	7 Strongly agree	
2. My family and friends expected me to do so							

1	2	3	4	5	6	7
Strongly	Moderate	Slightly	Neutral	Slightly	Moderate	Strongly
disagree	disagree	disagree		agree	agree	agree

3

Were there any words or phrases above that were not clear for you? If so, then please circle them Questionnaires about caregiving v.7, 10/3/

# 3. I would feel like a bad person if I did not provide care for him/her

1 Strongli disagre 4. I lov	-	3 Slightly disagree t him/her	4 Neutral	5 Slightly agree	6 Moderate agree	7 Strongly agree
1 Strongl disagre 5. It w	•	3 Slightly disagree leeply valued	4 Neutral doing	5 Slightly agree	6 Moderate agree	7 Strongly agree
1 Strongl disagre 6. I wo	•	3 Slightly disagree r ashamed of			agree	7 Strongly agree n/her.
1 Strongl disagre 7. I w <b>as</b> a	•	3 Slightly disagree wouldn't like	4 Neutral me if I did	5 Slightly agree not provide ca	agree	7 Strongly agree er
1 Strongl disagre 8. It w	,	3 Slightly disagree nt and meanir		5 Slightly agree to do so	6 Moderate agree	7 Strongly agree
1 Strongl disagre 9. I dia	•	3 Slightly disagree se; I had to do	4 Neutral	5 Slightly agree	6 Moderate agree	7 Strongly agree
1 Strongl disagre	•	3 Slightly disagree	4 Neutral	5 Slightly agree	6 Moderate agree	7 Strongly agree

<sup>\*\*</sup> Were there any words or phrases above that were not clear for you? If so, then please circle them Questionnaires about caregiving v.7, 10/3/

#### Caregiving Experiences - Part 1 These questions are about your thoughts and feelings in caregiving experiences. Please read each question. Then, you circle the best number to describe how you feel. Please be honest. 1. Do you feel that because of the time you spend with your relative that you don't have enough time for yourself? 0 1 2 3 Never Sometimes Quite frequently Rarely Nearly always

2. Do you feel stressed between caring for your relative and trying to meet other

	responsibilities for	your family or wo	rk?		
	0 Never	1 Rarely	2 Sometimes	3 Quite frequently	4 Nearly always
3.	Do you feel your re	elative is depende	ent on you?		
	0	1	2	3	4
	Never			Quite frequently	Nearly always
1.	Do you feel straine	ed when you are a	around your rel	ative?	
	0	1	2	3	4
	Never	Rarely	Sometimes	Quite frequently	Nearly always
5.	Do you feel your h	nealth has suffered	d because of yo	our responsibility with	your relative?
	0	1	2	3	4
				Quite frequently	
3.	Do you feel that yo	ou don't have as n	nuch privacy as	s you would like beca	use of your relative?
	0	1	2	3	4
	Never	Rarely	Sometimes	Quite frequently	Nearly always
7.	Do you feel that yo	our social life has	suffered becau	se you are caring for	your relative?
	0	1	2	3	4
	Never	Rarely	Sometimes	Quite frequently	Nearly always
2	Do you feel that yo	u will be unable to	take care of v	our relative much lon	ger?

0 3 1 Never Rarely Sometimes Quite frequently

Sometimes Quite frequently Never Rarely Nearly always 9. Do you feel you have lost control of your life since your relative's illness?

<sup>\*\*</sup> Were there any words or phrases above that were not clear for you? If so, then please circle them Questionnaires about caregiving v.7, 10/3/

10. Do you wish you could leave the care of your relative to someone else?											
0		1	2		3	4	ı				
Neve		Rarely	_		Quite frequentl	v Nearly	always				
		certain about				, itouin	amays				
0	)	1	2		3	4	1				
Neve	er	Rarely	Some	etimes	Quite frequently	y Nearly	always				
12. Ove	erall, how bu	ırdened do yo	u feel in cari	ng for you	r relative?						
0	)	1	2		3	4	1				
Neve	er	Rarely	Some	etimes	Quite frequently	y Nearly	always				
Т е F *	Help From Others These questions are about your thoughts and feelings of help from others. Please read each statement carefully. Then, you circle the best number to describe how you feel. Please be honest. *Some special or a special person means significant others who are important to help caregivers										
1. *Soı	meone spec	ial is within re	ach when I n	need help.							
	1	2	3	4	5	6	7				
	Strongly	Moderate	Slightly	Neutral	Slightly	Moderate	Strongly				
0 *0	disagree	disagree	disagree	والموام والمواد	agree	agree	agree				
2. "501	neone spec	iai is able to s	nare my ove	rwneimin	g happiness an	a griet.					
	1	2	3	4	5	6	7				
	Strongly	Moderate	Slightly	Neutral	Slightly	Moderate	Strongly				
2 14.4	disagree	disagree	disagree		agree	agree	agree				
3. IVIY I	amily really	tries to help n	ne.								
	1	2	3	4	5	6	7				
	Strongly	Moderate	Slightly	Neutral	Slightly	Moderate	Strongly				
4 1 1 1 2 2	disagree	disagree	disagree	6	agree	agree	agree				
4. I na	ve received	inspiration an	a morai supp	ort from r	ny family when	i needed it.					
	1	2	3	4	5	6	7				
	Strongly	Moderate	Slightly	Neutral	Slightly	Moderate	Strongly				
<b>5</b> 11	disagree	disagree	disagree		agree	agree	agree				
b. I na	ve "a specia	l person who	is the true so	ource of m	iy morale.						
	1	2	3	4	5	6	7				
	Strongly	Moderate	Slightly	Neutral	Slightly	Moderate	Strongly				
	disagree	disagree	disagree		agree	agree	agree				
								6			

<sup>\*\*</sup> Were there any words or phrases above that were not clear for you? If so, then please circle them Questionnaires about caregiving v.7, 10/3/

6. My friend has really tried to help me.

7. I ca	_	2 Moderate disagree n my friend w	3 Slightly disagree hen failures h	4 Neutral appen.	5 Slightly agree	6 Moderate agree	7 Strongly agree
8. I ca	1 Strongly disagree n tell my pro	2 Moderate disagree blems to my	3 Slightly disagree family.	4 Neutral	5 Slightly agree	6 Moderate agree	7 Strongly agree
9. I ha		2 Moderate disagree vho can shar	3 Slightly disagree e my overwhe		5 Slightly agree biness and gri	6 Moderate agree ef.	7 Strongly agree
10.	1 Strongly disagree There is *a s	2 Moderate disagree pecial persor	3 Slightly disagree n in my life wh	4 Neutral no cares ab	5 Slightly agree out my feeling	6 Moderate agree gs.	7 Strongly agree
11.	1 Strongly disagree My family is	2 Moderate disagree willing to help	3 Slightly disagree o me make de	4 Neutral cisions.	5 Slightly agree	6 Moderate agree	7 Strongly agree
12. l ar	1 Strongly disagree n able to tel	2 Moderate disagree	3 Slightly disagree s to my friend	4 Neutral	5 Slightly agree	6 Moderate agree	7 Strongly agree
, <u> </u>	1 Strongly disagree	2 Moderate disagree	3 Slightly disagree	4 Neutral	<b>5</b> Slightly agree	6 Moderate agree	7 Strongly agree

### Caregiving Experiences –Part 2

These questions are about your thoughts and feelings in caregiving experiences. Please read each statement carefully. Then, you circle one number to describe how much you agree or disagree with each statement. Please be honest.

### Providing care to my relative is......

1. Helped to increase my patience and be a more understanding person

0	1	2	3	4
Disagree	Disagree	Neither agree	Agree	Agree
a lot	a little	nor disagree	a little	a lot
2. Made me	a stronger and	more resilient person		
0	4	•	2	4
0	Diagrama	2	3	4
Disagree	Disagree	Neither agree	Agree	Agree
a lot	a little	nor disagree	a little	a lot
3.Increased	my sell-awaren	ess, making me more	aware or mysen	
0	1	2	3	4
Disagree	Disagree	Neither agree	Agree	Agree
a lot	a little	nor disagree	a little	a lot
4. Increased	my knowledge	and skills in dementia	a care and more	
0	1	2	3	4
Disagree	Disagree	Neither agree	Agree	Agree
a lot	a little	nor disagree	a little	a lot
<ol><li>Helped me</li></ol>	e grow closer to	my relative with dem	entia	
0	1	2	3	4
Disagree	Disagree	Neither agree	Agree	Agree
a lot	a little	nor disagree	a little	a lot
6.Helped to I	bond my family	closer		
0	1	2	3	4
Disagree	Disagree	Neither agree	Agree	Agree
a lot		nor disagree	a little	a lot
		ite to older persons ar		
0	1	2	3	4
Disagree	Disagree	Neither agree	Agree	Agree
a lot	a little	nor disagree	a little	a lot

<sup>\*\*</sup> Were there any words or phrases above that were not clear for you? If so, then please circle them

Questionnaires about caregiving v.7, 10/3/

8. Given me	deeper insights in	ito the meaning of I	ife and my view o	of life in the future.					
0	1	2	3	4					
Disagree	Disagree	Neither agree	Agree	Agree					
a lot	a little	nor disagree	a little	a lot					
<ol><li>Helped me material world</li></ol>			od and being al	ble to look beyond the					
0	1	2	3	4					
Disagree	Disagree	Neither agree	Agree	Agree					
a lot	a little	nor disagree	a little	a lot					
10. Sparked				wanting more to help					
		e going through sim							
0	1	2	3	4					
Disagree	Disagree	Neither agree	Agree	Agree					
a lot	a little	nor disagree	a little	a lot					
These questic carefully. The Please be ho 1. In general,	Your Health in Body and Mind These questions ask for your views about your health. Please read each statement carefully. Then, you circle one number to describe how you feel and how well you are. Please be honest.  1. In general, would you say your health is: (Please circle one number that best describes your answer)								
1 Excellent	2 Very good	3 Good	4 Fair	5 Poor					
Excellent	very good	Good	raii	POOI					
	2. <u>Compared to one year ago</u> , how would you rate your health in general <u>now</u> ? Please circle one number that best describes your answer								
<ul><li>2 = Somewh</li><li>3 = About th</li><li>4 = Somewh</li></ul>	etter now than one nat better now that he same as one w nat worse now that orse now than on	an one week ago veek ago an one week ago							

3. During the past four weeks, think of how much of the time have you had any of the following problems with your work or other regular daily activities. Then think of how much of the time this was the <u>result of any emotional problems</u> (such as feeling depressed or anxious)? Please circle one number on each line

	All of the	Most of the	Some of the	A little of the	None of the
	time	time	time	time	time
a. Cut down on the amount of time you	1	2	2	4	5
spent on work or other activities	<b>'</b>		٥	4	3
b. Accomplished less than you would like	1	2	3	4	5
c. Did work or other activities less carefully	1	2	3	4	5
than usual					

4. How much bodily pain have you had during the past four weeks? Please	circle	one
number that best describes your answer		

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

5. During the <u>past four weeks</u>, how much did pain interfere with your normal work? Include both work outside the home and houseworkPlease circle one number that best describes your answer

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

6. These questions are about how you feel and how things have been with you <u>during</u> the past four 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 four weeks....

	All of the time	Most of the	Some of the	A little of the time	None of the
		time	time		time
a. Did you feel full of life?	1	2	3	4	5
b. Have you been very nervous?	1	2	3	4	5
c. Have you felt so down in the dumps	1	2	3	4	5
that nothing could cheer you up?					
d. Have you felt calm and peaceful?	1	2	3	4	5
e. Did you have a lot of energy?	1	2	3	4	5
f. Have you felt downhearted and depressed?	1	2	3	4	5

10

Were there any words or phrases above that were not clear for you? If so, then please circle them

Questionnaires about caregiving v.7, 10/3/

	All of the time	Most of the time	Some of the time	A little of the time	None of the time
g. Did you feel worn out?	1	2	3	4	5
h. Have you been happy?	1	2	3	4	5
i. Did you feel tired?	1	2	3	4	5

# 7. How TRUE or FALSE is <u>each</u> of the following statements for you? Please circle one number on each line

	Definitely		Don't	Mostly	Definitely
	true	true	know	false	false
a. I seem to get sick a little easier than	1	2	3	4	5
other people					
b. I am as healthy as anybody I know	1	2	3	4	5
c. I expect my health to get worse	1	2	3	4	5
d. My health is excellent	1	2	3	4	5

### My Background

We would like to know a little more about the lives of those who I have gotten information from, so I would like to learn about your life. Please check ✓ in the □ or specify the answer that is true for you.

I am a	☐ Male ☐ Female
How would you best describe yourself, if you had to choose	☐ Single ☐ Married ☐ Widowed ☐ Divorced
one of these words?	☐ Separated
What is your religion background?	□ Buddhism □ Christian □ Islam
	☐ Other (please specify your religion)
How many years of school have you completed?	□ Fourth Grade □ Sixth Grade
	☐ High school ☐ Associated degree (1-3 years after high
	school) $\square$ Bachelor's $\square$ Master's
	☐ Other (please specify)
Are you working for pay now?	□ No □ Yes
	If "yes" please mark in one box:
	□ Full-time job □ Part-time job
What is your income a month?	☐ less than 5,000 baht ☐ 5,001-10,000 baht
1	
	□ 10,001-20,000 baht □ 20,001-25,000 baht

<sup>\*</sup> Were there any words or phrases above that were not clear for you? If so, then please circle them Questionnaires about caregiving v.7, 10/3/

Is your income enough to meet	□ No □ Yes
your usual needs?	
Please estimate, how many	Laura a dan
hours a day do you provide	hours a day
direct care for the person with	
dementia at home?	
Have you already had	□ No □ Yes
experienced to take care the	
person with health problems at	
home?	
Does anybody help you take	□ No □ Yes
care the person with dementia at	If "yes" how many hours a day of that person to help you
home?	take care the person with dementia at home?hours a day
Are you living with the persons	□ Not at all □ Sometimes □ Always
with dementia?	If "sometimes" please tell us how often are you living with the person with dementia? days per week
Do you have any on going health	□ No □ Yes
problems that health care	If "yes" what is your health problems? (please specify)
providers have told you?	
During helping the person with	□ No □ Yes
dementia at home, do you have	If "yes" how many hours a day that you have to take care
to take care other persons?	that person? (please specify)
Have you joined in groups about	□ No □ Yes
caregiving?	If "yes" what kind of groups that you have joined? (please specify)
	specify)
What is the main source of current income to pay for	☐ Pension's the person with dementia
treatment of the person with	☐ Pension' s the caregiver
dementia?	□Family member of the caregiver
	☐ Relatives' the person with dementia
	☐Your saving
	☐ Other source (please specify)

<sup>\*\*</sup> Were there any words or phrases above that were not clear for you? If so, then please circle them Questionnaires about caregiving v.7, 10/3/

### **Background of Persons with Dementia**

We would like to know a little more about the lives of persons with dementia. Please check  $\checkmark$  in the  $\square$  or specify the answer that is true for those persons.

How old is the person with dementia now?	years old
The person with dementia is a	□ Male □ Female
How would you best describe the person with dementia, if you had to choose one of	☐ Single ☐ Married ☐ Widowed ☐ Divorced ☐ Separated
these words?	
What is the religion background of the person with dementia?	☐ Buddhism ☐ Christian ☐ Islam ☐ Other (please specify the religion)
5 1 1 1 1	
Do you know what stage of dementia the person has?	<ul> <li>No ☐ Yes</li> <li>If "yes" please choose one stage of dementia that health care providers have told you?</li> <li>☐ Mild ☐ Moderate ☐ Sever</li> </ul>
Does the person with dementia have any ongoing health problems that health care providers have told you?	☐ No ☐ Yes  If "yes" what are health problems of the person with dementia? (please specify)

Thank you for your time and for your thoughts! We appreciate your input!

Appendix C: Consent form, Information Sheet, and Scripts



# UNIVERSITY OF WISCONSIN-MADISON Consent to Join in a Study

This consent information sheet was made to tell you about the study. We would like to ask if you would be willing to join the study or not. If you want to join the study you would say "yes" to join the study or sign this sheet. After you agree by words or signing to participate, we will ask you some questions about your thoughts and feelings in caregiving, such as reasons/ motives to provide care, your health in body and mind, your background, and patient background.

Title of the Study: Caregiving Experiences

The researcher: Piyaorn Wajanatinapart, PhD candidate, MSN, RN

University of Wisconsin Madison, School of Nursing

The research assistant: Warakorn Juttakul and Kamonat Soysungnern

Research advisor: Diane Lauver. PhD RN

University of Wisconsin Madison, School of Nursing

**Invitation:** You are invited to the study because you:

- Are providing direct hand-on care for persons with dementia at home at least 3 months.
  - Age over 18 years old
  - Are able to speak Thai language

<u>What are the purposes of the study?</u> The main purpose of this study is to assess the quality of caregiving measures. We would also like to learn more about caregiving experiences.

The researcher will include 150 caregivers.

If Join, what will this mean to me? If you decide to join, then you will be asked to answer questions about your thoughts and feelings in caregiving, your health in body and mind, your background, and patient background. You may fill out the questions at the outpatient unit. If you do not have enough time to do so you may fill out the questions at home or answer questions by phone. We will ask for your contact

information to send questionnaires or call you. It might take you 30-45 minutes to complete questionnaires. By phone, this depends on how much we talk.

### Are there any risks?

- One risk is that you might feel uncomfortable to answer questions about caregiving.
- Another risk of taking part in this study is that your information could become known to someone who is not involved in this study.

<u>Are there any benefits?</u> We cannot promise direct benefits to you, although some questions may help you to understand better your caregiving experience. You may feel good in knowing that you helped a nurse researcher on a study about caregiving.

<u>Will I be paid for being in this study?</u> After finishing the interview by phone or getting your questions back by mail, we will mail 300 baht (\$10) for your thoughts and your time.

### How will you keep what I share as private?

- We are careful to protect what you share with us
- We will give each person who joins the study a code number. We will write code numbers on questions instead of names. All responses will be anonymous. (Anonymous means that no one could link names with comments.)
- The information you share will be kept in locked offices and on computers that cannot be used without special passwords.
- Our written reports will include peoples' comments in a combined form. For example, we would average responses. That way, no one could know who said what.

The information that we get from you during this study will be used by the researcher. Information we get may also be shared with research advisors at the UW-Madison.

### If I decide to join the study, can I change my mind?

Your decision to join in this study is your choice. It is up to you whether or not you join the study. This will not affect any benefits of yours. You may choose not to join. If you do decide to join, you may choose to stop being in this study at any time. You can skip any questions that you do not feel comfortable answering. You will not be lost any benefits that you had prior to the study.

#### Who should I contact if I have questions?

You may ask questions about the study at any time. You can call the:

• The research assistants: Warakorn Juttakul Phone: 080-335-8233 or Komonat Soysungnern Phone: 082-144-2208

You can ask questions about your rights as a participant in research. You can call the:

- Review Board of Nakhon Ratchasima Rajanagarindra Psychiatric Hospital, 86 Changpuak Rd, Tambon Nai Mueang, Amphoe Mueang, Nakhon Ratchasima, 30000, Thailand, Tel: 044-342-666
- Review Board of Maharat Nakhon Ratchasima Hospital, 49 Elephant Rd, Amphoe Mueang, Nakhon Ratchasima, 30000, Thailand. Tel: 044-235-000 Please take the time as you need to choose whether or not to join this study

### Agreement to join in this study

If I prefer not to sign this consent or give consent over the phone, I may give my consent verbally.

If I prefer to sign this consent I have read and understood this consent. It describes the study purposes, procedures, risks, and benefits. I have had a chance to ask questions about the study and I have received answers to my questions. I agree to join this study.

Name of Participant (please print):			
Signature of Participant	Date		
Signature of person getting the consent and authorization	 Date		

You can get a copy of this form to keep

#### A Screening Form for Research Assistants to Screen Volunteers 1. What was your age at your last birthday? (Write in Age; we do not want birth date.) (Criteria: Over 18 years old) 2a. Does the care recipient have a diagnosis of dementia by physician? (Check which applies) Yes. Go to 2b No If "no", then research assistants will tell volunteers that they do not match for this study. Research assistants will thank for their interest and time. 2b. What is your understanding of its name? \_Alzheimer' s disease Other kinds of dementia (e.g., Parkinson's dementia or Vascular dementia) (please 3. How long have you been helping the care recipient? \_\_\_\_\_years \_\_\_ months (Write in the number for years and months) (Criteria at least three months) 4. Please describe your relationship with the care recipient, such as: (Check which applies) (Criteria one answer) Daughter \_\_\_\_\_ Daughter-In-law \_\_\_\_\_Son-in-law Niece Nephew Relative Friend Partner Other (please specify) 5. Please describe what kind of things that you might do with or for the care recipient most days? (Check which applies for ADL and IADL) Activities of Daily living (ADL) (Criteria at least one activity) Bathing: Yes No Dressing: Yes No Yes Moving: \_\_\_\_\_ Toileting: \_\_\_\_\_Yes No No Controlling Urinary Bladder: \_\_\_\_\_Yes \_\_\_\_\_No Feeding: \_\_\_\_Yes Instrumental Activities of Daily living (IADL) (Criteria at least two activities) Using telephone: \_\_\_\_\_ Yes Shopping: Yes \_\_\_\_ No Housekeeping: Yes Preparing Food: \_\_\_\_\_Yes No \_\_\_\_Yes Laundry: \_\_\_\_\_Yes \_\_\_\_ No Using transportation: Managing Finances: Taking Medications: Yes No Yes • If volunteers do not do at least two of these activities/ things of ADL and at least two of these activities/things of IADL for the care recipients, then research assistants will tell volunteers that they do not match for this study. However, research assistants will ask those volunteers for their willingness to take an information sheet and consent form about this study to someone who is a direct caregiver for the care recipient who they came with today. If volunteers want to do so, then research assistants will provide both information sheets of the study. If volunteers meet all of the five criteria: a) age over 18 years old. b) providing care for care recipients with any kind of dementia or Alzheimer's disease, as diagnosed by physician. c) providing care for at least three months, d) having relationships with care recipients, and e) providing direct, hands-on care at least two activities of ADL <u>and</u> 2 of IADL, for a total of 4 activities, please check "Yes". If volunteers do not meet one criterion above, then please check "No" and tell them that they do not match for this study. Then research assistants will thank for their interest and time.

**Conclusion**: volunteers who meet all five criteria are eligible for the study Yes

Research Assistants' initials\_\_\_\_\_



# An Information Sheet about a Caregiving Study

## A Study about Caregiving

**Why?** Nurses want to learn more about experiences of people who are care for persons with dementia at home. Yet, they do not have good measures to do so. We want to have your opinions on these questions to improve measures of caregiving and to study caregiving in the future.

## Who are we looking for? People who are:

- Providing care for a person with dementia
  - o at home
  - o for at least 3 months and
  - doing direct hand-on care for that person such as dressing or preparing food
- Over 18 years of age
- To be able to speak Thai language

What would this involve? If you decide to join this study, then we would ask you a set of questions. You could answer these in writing or interview by phone.

These questions would ask:

- Thoughts and feelings about
  - o reasons/motives to provide care
  - your life in general about contacting with others, doing things by yourself, and making a decision about your life.
  - what help you might get from others
  - gains and burdens of caregiving experience
- · About your health in body and mind
- Your background such as age and education
- Patient background such as age, medical condition

### Where would I do this?

If you want to do this by phone, then we will call you to ask our questions

If you want to do this in writing at home, then we will mail a set of questions to you

## How long would this take me?

It might take 30-45 minutes for answering questions. We will do this only once.

## Are there any risks to me?

- Some questions may cause you to feel uncomfortable. But we have worded these questions with care to try to avoid this. You may refuse to answer any question that makes you feel uncomfortable.
- Someone other than the research team might see your answers. Yet, we are careful to protect what you share with us.

## Are there any benefits to me?

We cannot promise direct benefits to you, although some questions may help you to understand better your caregiving experience. You may feel good in knowing that you helped a nurse researcher on a study about caregiving.

**What else?** After finishing the interview by phone or getting your questions back by mail, we will mail 300 baht for your thoughts and your time.

# If you would like to join in this study, or if you have questions, then please contact:

- Warakorn Juttakul, a psychologist with the research team, Tel: 080-335-8233
- When you call, tell Warakorn that you are in the interested in the study

Thank you for your interest!

# A Phone Script of Caregiving Study

	Script	Evaluation (check one)
Introductions	My name is I am a research assistant of the caregiving study. Thank you for calling us and for your interest in our study. We would like to learn more about your caregiving experiences. We call you for the purpose to see if you would be a good match for this study. If you match and agree to join we will ask questions such as your thoughts and feelings. During answering questions you can stop or skip any at any time without losing any benefits that you have before. Answering questions will take about 30-45 minutes if written or if phone. After you finish to answer questions we will ask you about your address for mailing 300 baht (10\$) for your thoughts and time. After we do so we will destroy your address, no one can link your name to your responses. The information you share will be kept in locked offices with using a code number. We are careful to protect what you share with us.	
Screening	To do so, we want to see if you are a good match for our study. We will ask some questions about your caregiving experiences. This will take about 5 minutes of your time.	Eligibility to join:YESNO
	The research assistant uses a screening form. This form includes questions such as length of time caregiving and for whom with what diagnosis.	
	<ul> <li>If the caregiver is eligible: "You are a good match for our study".</li> <li>If the caregivers is not eligible: "Thank you for your interest and your time, but you are not a good match for our study."</li> </ul>	
Informed Consent	The research assistant uses a script of assessing volunteer comprehension as a guide. This should help volunteers understand about information of the study. Therefore, volunteers can give a truly informed consent.	Repeat 4 main points of the study information
	If the caregiver cannot repeat all four types of the study information, we will describe our study information again.	correctly:YES
	<ul> <li>If the caregiver can repeat all four types of the study information correctly with this second chance, then we will ask the caregiver, "do you have two forms about our study?"</li> </ul>	
	<ul> <li>If caregivers say, "yes" we will say "Please look at the form named "Consent to Join in a Study?"</li> </ul>	
	We will say: "This form was made to tell you about the study. We would like to ask if you would be willing to join the study or not. If you want to join the study you would say "yes" to join the study. After saying that you would agree, then you would answer some questions about your thoughts and feelings in caregiving, such as reasons/motives to provide care, your health in body and mind, your background, and patient background. We would not link your answers with your name or the name of the person you are caring for.	
	"You can read details of the study in this form. You can stop to join in this study at any time without any penalty. If you have any questions about the study, you can ask questions at any time. We will give time as much as you need to make a decision whether or not you want to join in this study."	
	We will ask: "Can I call you back to ask about your consent? When would be a good date and time for you?"	

A alsimar for	"I are the constitute study. We would like to leave more shout your	Dravidina
Asking for consent	"I am from the caregiving study. We would like to learn more about your caregiving experiences. From the last time, we asked some questions about caregiving with you. You are a good match for our study. Today, we call you for the purpose to ask you about your consent. Would you like to join in this study? If the caregiver says "no", we will say thank you for caregiver time."	Providing Consent:YESNo
Data Correction	If the caregiver says "yes" to joining the study, then we will provide two options for	Answering
Data Correction	the caregiver to answer our questions.	questions:
	If the caregiver wants to answer a set of questions <b>at home</b> , we will say, "We will send a set of questions and an envelope with stamp to you. These questions	At home
	include 10 pages. There are no "right" or "wrong" answers. If you find any words or phrases that you think are not clear, please circle them. You might take 30-45 minute to complete the questions. Would you please share your address with us?	By phone
	"If you have any questions while answering a set of questions of the study, you can call us at any time. After you complete to answer a set of questions, please mail it back to us. After we get a set of questions back we will mail 300 baht (\$10) to you for your thoughts and time".	
	If caregivers want to answer a set of questions by phone:	
	"It would take you about 30-45 minutes, depending on how much we talk."	
	"Do you want to answer a set of questions now or later?"	
	If the caregiver wants to <b>answer questions later</b> : "When do you think it would be a good date and time for you?" "We would like to call you for asking questions about caregiving "We will ask those questions only once.	
	The research assistant uses a set of questionnaires.	
	• If the caregiver wants to <b>answer questions now</b> , we will say, "You will answer a set of questions. If you think any words or phrases that we ask you are not clear please tell us about that. To answer questions, there are no "right" or "wrong" answer. If you have any questions please feel free to ask and stop at any time. Are you ready?"	
	We will start with questions about "Thoughts and feeling about your life" and so on.	
	After completely answering a set of questions by phone:	
	"We would like to mail 300 baht (\$10) for your thoughts and time. Would you please share your address with us?"	
	"Thank you for your valuable time and thoughts of answering questions about caregiving."	

# A script to assess volunteers' ability to repeat study information by using an interview

This is a study about caregiving. I will tell you about four types of the study information. After that I will ask you to repeat that information.

<u>Study purposes:</u> We have two study proposes. First, this study is to assess the quality of caregiving measures. Second, this study is to learn more about caregiving experiences.

<u>Procedures of the study</u>: If you decide to join, then

- You will be asked to answer questions about your experiences in caregiving, your health in body and mind, your background, and patient's background.
- You may fill out the questions at the outpatient unit.
- If you do not have time at the outpatient unit you may answer a set of questions either at home or by phone.
- If you get an information sheet of the study and call us to join you may answer a set of questions either at home or by phone.
- To answer questions, it might take 30-45 minutes to complete.

### Possible risks of the study:

- One risk is that you might feel uncomfortable to answer questions about caregiving
- Another risk is that someone, other than the research team, would see your answers.

<u>Possible benefits of the study:</u> We cannot promise there are direct benefits to you. By joining the study you could recognize about your caregiving experiences that you may feel good.

### Could you please tell me back about the study information?

To help volunteers recall, the research assistant can ask: "Can you tell me what are purposes of the study? Can you tell me what are procedures of the study? Can you tell me what are possible risks of the study? Can you tell me what are possible benefits of the study?

At the first time, is a volunteer able to join the study?
yes (a volunteer correctly answers in all four types of the study information)no
If you check no you need to tell the study information again and then ask the volunteer
to repeat the study information.
At the second time, is a volunteer able to join in the study?
yes (a volunteer correctly answers in all four types of the study information)
no
If you check no you will thank for his/her interest and tell she/he does not match for this
study.
Interviewer