

EFFECTIVENESS OF ADULT DAY CARE PROGRAMS ON HEALTH  
OUTCOMES OF THAI FAMILY CAREGIVERS OF PERSONS WITH DEMENTIA

BY

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EFFECTIVENESS OF ADULT DAY CARE PROGRAMS ON HEALTH  
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## Abstract

Adult day care (ADC) is recognized as a supportive intervention for persons with dementia (PWD) and family caregivers during the day time. The primary aim of this study was to evaluate the effect of the Thai ADC programs for PWD on caregiver outcomes (burden, depression, health status, social support, and quality of life) between baseline and after using ADC for one and three months. The second aim of the study was to explore the caregivers' experiences of how ADC has helped the PWD and family caregivers and how their life has changed. An exploratory prospective study with a single group repeated-measures design and two main open-ended questions was employed.

Sixteen caregivers were recruited from two ADC sites including Somdet Chaophaya Institute of Psychiatry and Chiangmai Neurological Hospital. Caregiver outcomes were measured with the Zarit Burden Interview (ZBI), the Center for Epidemiologic Studies-Depression Scale (CES-D), the Short form 12-item health survey (SF-12v2), the Sarason's Social Support Questionnaire (SSQ-6), and the WHO QOL-BREF-THAI. The General Personal Data Survey and the Caregiver Evaluation of ADC (CEADC) were included. Each participant was interviewed for approximately 45-60 minutes after using ADC for 3 months.

The results of the repeated measures ANOVA showed that only mean physical component scores (PCS) of the SF-12v2 and mean physical domain scores on the WHO QOL-BREF-THAI were significantly higher than baseline after using ADC for one and three months. Interviews with sixteen participants were audio-recorded, transcribed verbatim in Thai, and back-translated. Seven main categories that emerged from content analysis of the interview data included: "Requiring medical care for persons with dementia", "Challenges for

family caregivers”, “Seeking help, access to ADC”, “Expectations for ADC”, “Perception of benefits and effects of ADC”, and “ADC in the future.”

ADC improved caregiver-reported health after using ADC. This study verified the use of Smith’s Model of Caregiving Effectiveness in dementia care including efficient use of ADC as an external resource for caregivers. The findings of this study should be interpreted with caution due to the limitations of the study.

**Key Words:** adult day care, dementia, caregiver, burden, depression, health status, social support, quality of life

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## **Chapter One**

### **Introduction**

The global population of the elderly is increasing in many countries around the world (U.S. Census Bureau, 2005). In 2006, the population aged 60 years old and above in Thailand was approximately 6.5 million or 11% of the total population (Foundation of Thai Gerontology Research and Development Institute (TGRI), 2007). Thailand's national primary health care policy promotes the concept of self-care and the community-centered system (Vithayachockitikhun, 2006). Moreover, traditional Thai culture is steeped in filial piety and moral obligation. Caring for aging parents is looked upon as a source of pride representing gratefulness for parents rather than a burden (Gadudom, 2004). Families are the primary source for old age care and support. Due to health care policy and family cultures, family caregivers are assumed to be the backbone of long-term care providing an essential source of care.

Dementia is a major cause of cognitive impairment in older adults (Gavrilova, Ferri, Mikhaylova<sup>1</sup>, Sokolova, Banerjee, & Prince, 2008). Although the prevalence of dementia varies between developed countries and developing countries, the prevalence of dementia tends to increase in all countries with age (Kalaria, Moestre, Arizaga, Friedland, Galasko, Hall, Luchsinger, Oqunniyi, Perry, Potoknik, Prince, Stewart, Wimo, Zhang, Antuono, 2008). The prevalence of dementia in the United States was approximately 14% among individuals aged 70 and older and strongly correlated with older age and fewer years of education (Plassman, Langa, Fisher, Heeringa, Weir, Ofstedal, Burke, Hurd, Potter, Rodgers, Steffens, Willis, & Wallace, 2007). A previous study in Thailand found that the prevalence of dementia was 1.8% and strongly correlated with older age, female gender, and lower education (Phanthumchinda, Jitapunkul, Sitthiamorn, Bannag, & Ebrahim,

1991). In 2001, the mean age adjusted prevalence estimate for dementia among people aged 60 years and older living in Thailand was 3.4% (Kalaria et al., 2008). The number of Thai persons with dementia is predicted to increase 100% by the year 2020 and 325% by 2040 whereas in North America dementia will increase 49% and 172% for the same time period (Access Economics, 2006).

Persons diagnosed with dementia (PWD) often present with mild to severe short and long-term memory loss, thinking and judgment deficits, altered sleep patterns, incontinence, wandering, apathy, agitation, mood disturbances, personality changes, and other problematic behaviors (Papastavrou, Kalokerinou, Papacostas, Tsangari, & Sourtzi, 2007). These problems require care from family, friends, and other social services. Family members unavoidably become primary caregivers who assume responsibility for taking care of relatives or friends with disabilities at home. Previous studies in western countries have reported that family caregivers of PWD suffer from physical health decline, psychological morbidity, and poor quality of life (Connell, Janevic, & Gallant, 2001; Clyburn, Stones, & Hadjistavropoulos, 2000). Common mental health problems include higher levels of perceived burden, depression, stress, anxiety, grief and loss, guilt and shame, hostility, lower self-esteem, frustration, weariness, and loneliness (Razani, Kakos, Orieta-Barbarbalace, Wong, Casas, Lu, Alessi, & Josephson, 2007; Smith, Murray, Banerjee, Foley, Cook, Lamping, Prince, Harwood, Levin, & Man, 2005; Bond, Clark, & Davies, 2003; Gallant & Connell, 1997).

Adult day care (ADC) is currently recognized as an important supportive intervention for dementia patients and family caregivers in the day time. Adult day care programs complement community-based services such as respite care, educational programs, and other psychological supportive programs for family caregivers to relieve

stress and increase their knowledge and coping capability in dealing with behavioral problems of PWD. The services include providing necessary information and arranging appropriate care plans in order to promote the best care for patients. Adult day care services in Thailand have been administered on behalf of general hospitals to provide special care for particular populations such as persons with mental health problems, and persons with dementia. There are only two public hospitals providing adult day care programs for PWD in Thailand. Both of them are located in urban areas and serve a limited number of PWD. Adult day programs for PWD in Thailand are usually administered by professional nurses in hospital-based day programs that emphasize cognitive training, medical treatments, therapeutic activities, health monitoring, socialization, medical care, and rehabilitation specific to functional and cognitive impairments (TGRI, 2007). Patients using ADC services receive special interventions for improving their cognitive functioning and psychological well-being. Similarly, caregivers of PWD who attend day care are expected to experience reduced stress, to relax for a while, to get mental support, and to get essential information to provide the best care for a loved one. Therefore, ADC should reduce caregiver burden and depression and enhance quality of life for family caregivers.

Studies that evaluate the effectiveness of ADC are necessary as a basis for determining best practices and to shape health care policy. Determining the level of effectiveness is an essential process that will provide both formative and summative evaluation for stakeholders to know whether the ADC program is beneficial and why (McDavid, & Hawthorn, 2006). The findings will reflect the level of success of the organizations in improving health outcomes and the gap needed to achieve desired organizational goals. Most studies reporting evidence of positive effects of ADC programs have been conducted in North America (Mason, Weatherly, Spilsbury, Arksey, Golder,

Adamson, Drummond, & Glendinning, 2007). ADC has been conceptualized as a respite care model with potential benefits in the improvement of client function, caregiver adaptation, delayed institutionalization, and cost-effectiveness (Gaugler, & Zarit, 2001; Zarit, Gaugler, & Jarrott, 1999). Effects were generally small and no reliable evidence was found that respite day care can delay entry to residential care (Mason et al., 2007) whereas most studies reported high levels of caregiver satisfaction.

The effect of ADC services in Thailand may differ from western countries because of variations in their administrative systems. Most western developed countries provide specific health services and intervention programs for patients and their caregivers in order to decrease mortality rate, reduce caregiver burden, and improve quality of life for the PWD and their family. Choices are nursing home care, respite care, assisted living, and day care services. Conversely, there are rarely nursing homes, day care services, and special clinics for PWD in many eastern developing countries, such as Thailand, India, and Russia (Graff, Vernooij-Dassen, Thijssen, Dekker, Hoefnagels, & OldeRikkert, 2007). Variations in service delivery at programmatic and individual levels also exist. For example, ADC programs in the United States have provided various therapeutic programs for both PWD and their caregivers, while ADC programs in Thailand focuses on cognitive rehabilitation and social therapeutics for only the PWD. The PWD may also choose to attend only some of the programs offered based on their preference. Lastly, filial piety and moral obligation in taking care of aging parents may affect caregiver outcomes. In fact, outcomes of ADC programs can be measured as both patient (PWD) outcomes and caregiver outcomes. Since the effects of ADC services for PWD in Thailand on family caregivers have not been evaluated, this study is needed to assess the impact of the current ADC based on family caregiver's perspectives. Therefore, the main purpose of this study is

to evaluate the effectiveness of adult day programs for PWD on caregiver outcomes especially in increasing quality of life, reducing burden, decreasing depression, and improving general health status and social support.

Caregivers' quality of life is the family caregiver's experiences in caring for the PWD at home. Some studies rely on caregiver burden and depression as the key indicators of caregiver's quality of life (Belle, Burgio, Burns, Coon, Czaja, Gallagher-Thompson, Gitlin, Klinger, Koepke, Lee, Martindale-Adams, Nichols, Schulz, Stahl, Stevens, Winter, & Zhang, 2006). However, quality of life is a multidimensional concept that has been defined and applied in a variety of ways (Brod, Steward, Sands, & Walton, 1999). Moreover, quality of life of family caregivers of PWD may differ among countries because quality of life depends on individual perceptions, cultural values, and environmental events. Numerous studies have also reported the differences in the perception of psychological well-being (Losada, Shurgot, Knight, Marquez, Montorio, Izal, & Ruiz, 2006; Shurgot & Knight, 2005; Covinsky, Newcomer, Fox, Wood, Sands, Dane, & Yaffe, 2003) and social well-being (Shurgot & Knight, 2005) of dementia family caregivers across ethnic groups. These findings may be due to the fact that cultural differences affect an individual's ways of thinking, filial obligations, coping styles, and the concept of independence (Losada et al., 2006).

Determining the effects of services on individuals is a complex process that includes many variables. Even though there are numerous studies identifying factors that influence select caregiver outcomes, the findings are not consistent. Previous studies in western countries have reported that family caregivers of PWD are at an increased risk for psychological distress including burden and depression (Papastavrou et al., 2007; Razani et al., 2007; Shua-Haim, Haim, Shi, Kuo, & Smith, 2001). Nevertheless, levels of

psychological distress vary due to ethnic background (Roth, Ackerman, Okonkwo, & Burgio, 2008; Losada et al., 2006; Convinsky et al., 2003; Adams, Aranda, Kemp, Takagi, 2002), gender and family income (Campbell, Wright, Oyebo, Job, Crome, Bentham, Jones, & Lendon, 2008; Huang, Musil, Zauszniewski, & Wykle, 2006; Convinsky et al., 2003), caregiver-patient relationship (Coen, O'Boyle, Coakley, & Lawlor, 2002), level of social support (Huang et al., 2008; Hayslip, Han, & Anderson, 2008), and severity of dementia (Huang et al. 2008). The levels of burden and depression also depend on physical health problems of both the PWD and their caregiver (Schulz, & Sherwood, 2008; Gavrilova et al., 2008; Gallant, & Connell, 1997) and caregivers' perception of overload or a lack of social support (Hayslip, Han, & Anderson, 2008; Huang et al. 2008; Kim, Knight, & Longmire, 2007). A previous study also found that higher caregiver burden was related to lower level of caregiver quality of life, more physical and cognitive impairment, more behavior problems, less adequate informal social support, less time for self, and more financial constraints (Coen, Boyle, Coakley, & Lawlor, 2002). Behavior problems have been found to be the strongest source of psychological distress for dementia caregivers (Pinquart, & Sorensen, 2003).

Understanding individual experiences in real situations, their expectations and unmet needs will bring about significant information for process improvement and the development of best practices by providers. It is too difficult to measure overall aspects of quality of life with some quantitative instruments. Therefore, two main open-ended questions were added to provide qualitative information to supplement the quantitative study data. This approach will provide pragmatic comprehensive evidence useful for providing insights in overall aspects of quality of life, unmet needs and expectation in ADC and other health care services for PWD.

### **Statement of the Problem**

Since most PWD are cared for at home, many more of those caregivers will face the unique challenges posed by the dementia of their family members. Thai family caregivers who take care of the elderly with cognitive impairment experience more burden than those who take care of the elderly with physiological problems but no cognitive impairment (Gadudom, 2004). Due to changes in family structures and increasing prevalence of nuclear families, adoption of modern lifestyles by younger persons, social pressure, and financial problems, both women and men increasingly work outside the home. Family caregivers of PWD suffer with depression, physical health decline, less adequate social support, less time for self, and poor quality of life (Coen, Boyle, Coakley, & Lawlor, 2002; Thomas, Lalloue, Preux, Hazif-Thomas, Pariel, Inscale, Belmin, & Clement, 2006). Therefore, more families rely on supportive services from communities for care of family members with dementia to maintain them at home.

ADC for PWD should be an effective service that helps families to reduce burden and depression, and improve health, social support and their quality of life. ADC programs in western countries have proven effective in reducing caregiver burden and depression and enhancing quality of life of both clients and family caregivers (Zarit, Stephens, Townsend, & Greene, 1998). The effect of ADC services in Thailand is unknown and may differ from western countries. Only two public health care institutions in Thailand have offered day care services for PWD and there are no studies evaluating their effectiveness from the perspective of Thai family caregivers.

### **Purpose of the Study**

This was an exploratory prospective study with a single group repeated-measures design and additional qualitative questions. The primary aim of this study was to evaluate the effect of the current ADC programs for PWD in Thailand on caregiver outcomes (burden, depression, health status, social support, and quality of life). The second aim of the study was to explore the caregivers' experiences of how ADC has helped the clients and family caregivers and how their life has changed.

### **Theoretical Framework**

This study is guided by the conceptual framework of Smith's Model of Caregiving Effectiveness (Smith, 1994), a midrange theory. Smith's model of caregiving effectiveness posits that caregiving effectiveness is the outcome of efficient use of resources and is influenced by caregiving context and adaptation context variables (Smith, Pace, Kochinda, Kleinbeck, Koehler, & Popkess-Vawter, 2002). The conceptual framework (Figure 1) is used to guide the study and the evaluation of ADC programs on caregiver outcomes of Thai family caregivers of PWD.

For the proposed study, a caregiver is defined as the family member who is the primary caregiver responsible for a PWD. The caregiving effectiveness outcome is defined as positive consequences of effective use of resources (in the original model) or effective use of ADC in this study that result in optimal caregivers' quality of life. Adaptive context variables are defined as transitional outcomes of the effective use of ADC services that include caregiver health status (general health and depression), family adaptation (social support), and reaction to caregiving (caregiver burden). Caregiving context variables include ADC use (frequency of service use and research site) and caregiver characteristics.



ADC is recognized by stakeholders as a therapeutic intervention for PWD at the ADC center in the day time (Smith, 2008). The effective use of adult day services will reduce caregiver burden, decrease caregiver depression, improve caregiver general health status, increase caregiver social support, and enhance caregiver quality of life. Caregiver social support is defined as the caregivers' perception of available social support and caregiver satisfaction with these support and adult day service programs. Caregiver characteristics (gender, family income, caregiver-patient relationship, and severity of dementia) influence caregiver health status (caregiver general health and caregiver depression), family adaptation (caregiver social support), and reactions to caregiving (caregiver burden), and may influence frequency of ADC use (Smith et al., 2002).

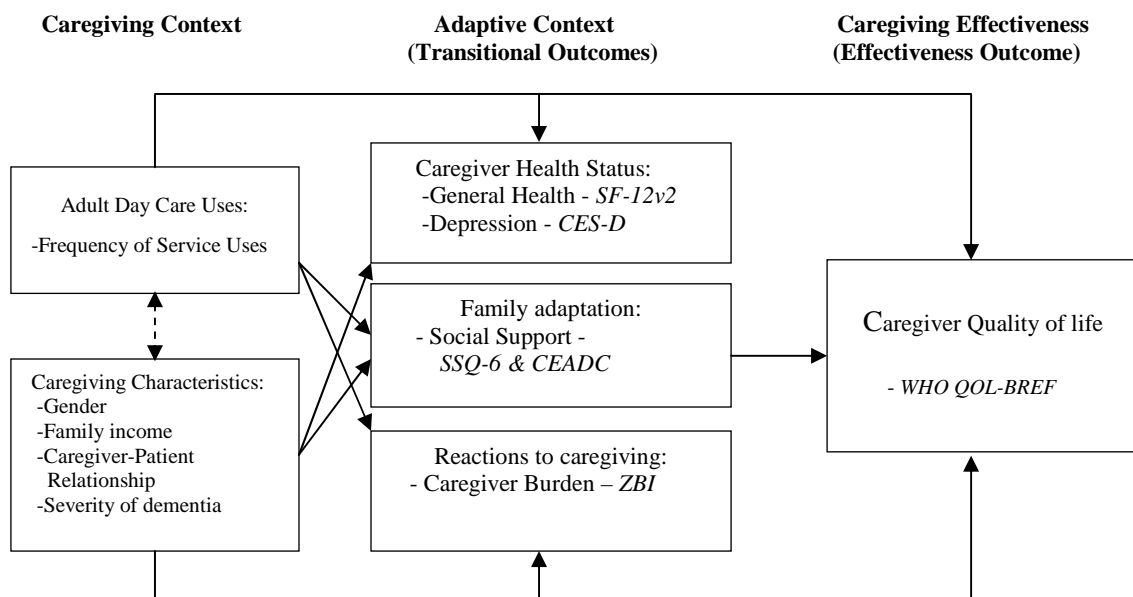


Figure 1. Model of Caregiving Effectiveness. Adapted from “Caregiving Effectiveness: Evolution of a Nursing Model for Home Care” by C.E. Smith, K. Pace, C. Kochinda, S.V.M. Kleinbeck, J. Koehler, & S. Popkess-Vawter, 2002, *Advances in Nursing Science*, 25, p.52.

- ↔ Proposed reciprocal relationships between concepts,
- ↔ Inconsistent relationship between concepts

The key concepts in this study are caregiver outcomes that include caregiver burden, caregiver depression, caregiver general health status, caregiver social support, and caregiver quality of life. Caregiver burden will be measured by the Zarit Burden Interview (ZBI) Thai version. Caregiver depression will be measured by the Epidemiologic Studies Depression Scale (CES-D) Thai version. Caregiver general health status will be measured by the Short form 12-item health survey (SF-12v2) Thai version. Caregiver social support is measured by the Sarason's Social Support Questionnaire (SSQ-6) Thai version and the Caregiver Evaluation of Adult Day Care (CEADC). Caregiver quality of life will be measured by the WHO QOL-BREF-THAI.

### **Research Questions**

The purpose of this study is to answer the following research questions:

1. Do caregivers of PWD who attended ADC have lower burden, lower depression, better health, higher social support, and higher quality of life after one month and three months compared to baseline?
2. How does ADC affect the caregiver's life?

### **Definitions of Terms**

The following terms are defined for this study:

Caregiver is defined as the person who is the primary caregiver or the person who is most involved in assisting the PWD with activities of daily living such as feeding, toileting, bathing, dressing, transferring, ambulating and taking medication at home.

Caregiver burden is defined as the extent to which caregivers of PWD perceive that their physical health, emotional health, social life, and financial status suffer as a result of

caring. Caregiver burden can be conceptualized as either subjective burden or objective burden. Subjective burden is the perceived hardship and strain of caregiving that manifests itself in attitudes and or emotional responses to the caregiving role. Objective burden is the hardship and strain of caregiving that is measurable in terms of the time involved in the physical care of the care recipient, the changes that occur in other roles due to caregiving, and the disruption that the caregiving responsibilities cause the caregiver, their family, and their household (Hoenig & Hamilton, 1966). Caregiver burden in this study will be measured by the Zarit Burden Interview -Thai version (ZBI).

Caregiver depression is defined as a syndrome of emotional disorders or symptoms of affected mood and behavioral manifestations (Shua-Haim, Haim, Shi, Kuo, & Smith, 2001) of caregivers of PWD. Depressive symptoms include a state of sadness, inadequacy in response to stress that consists of feelings of helplessness, or decreased self-esteem and mastery of care (Beck, 1973). Caregiver depression results from a complex interplay of mediated factors that includes characteristics of clients and caregivers and cultural factors such as ethnicity (Covinsky et al., 2003). Caregiver depression will be measured by the Thai version of Epidemiologic Studies-Depression Scale (CES-D) in this study.

Caregiver general health status is defined in terms of the perception of caregivers about their physical and mental health. This study will use the new version of the Medical Outcome Study Short form 12 item health survey (SF-12v2) Thai version that is a practical, reliable, and valid generic measure for measuring functional health and well being (QualityMetric, 2009).

Caregiver social support is defined as the caregivers' perception of available social support and caregiver satisfaction with available social support and adult day service programs. The caregivers' perception of available social support and caregiver satisfaction

with available social support will be assessed by Sarason's Social Support Questionnaire (SSQ-6; Sarason, Sarason, Shearin, & Pierce, 1987) translated in Thai language and caregiver satisfaction with adult day service programs is measured by Caregiver Evaluation of Adult Day Care (CEADC) in Thai language.

Caregiver quality of life is defined as the perception and interpretation of the caregiver regarding his/her life toward holistic well-being, his/her goals, expectations, standards, and concerns. Caregivers perceive their positions regarding physical and psychological health, social relationships, and environment which directly and formally incorporate the culture and value systems in which he/she lives. This study will apply WHO QOL-BREF-THAI for measuring caregiver quality of life because the instrument is a national standardized questionnaire which is useful to assess changes of quality of life scores over time.

Gender refers to the biological differences whether the caregiver is male or female.

Family income is defined as total monetary earnings per month for the whole family of the caregiver. Family income includes two categories: less than 30,000 baht (approximately \$1,000) and 30,000 baht or higher.

Caregiver-patient relationship refers to the family and social role relationship between caregiver and the PWD. For this study, caregiver-patient relationship will be divided into spouse, children, and others.

Severity of dementia is defined as the level of cognitive impairment and functional disability of PWD. Cognitive impairment will be assessed by Mini-Mental State Examination (MMSE). Functional disability will be reported by the caregiver on the Bristol Activities of Daily Living Scale (BADLS).

Frequency of service use is defined as the average number of hours per week of ADC service use. Frequency of service use will be reported in two categories: 16 hours per week or less and more than sixteen hours per week.

### **Assumptions**

The following assumptions are held for this study and used in data interpretation. These assumptions are adapted from theoretical assumptions of the Smith's Model of Caregiving Effectiveness (Smith, Pace, Kochinda, Kleinbeck, Koehler, & Popkess-Vawter, 2002).

1. Caregiving effectiveness (effectiveness outcomes) results from efficient use of adult day services and is influenced by caregiving context and adaptation context variables.
2. Caregiver characteristics (gender, family income, caregiver-patient relationship, and severity of dementia) influence adaptation context variables, but may influence frequency of ADC use or may not.
3. Caregiver burden, caregiver depression, caregiver general health status, and caregiver social support are transitional outcomes of ADC use.
4. Effectiveness of adult day services use is the positive consequences of using adult day services and caring for the PWD at home that result in transitional and optimal caregiver quality of life (effectiveness outcomes).
5. It is assumed that ADC programs that have been administered at both research sites are similar in objectives, procedures, costs, qualification and a number of health care providers across time.

### **Significance of the Study for Nursing**

ADC is an alternative health service in the continuum of long-term care designed to meet the needs of minimally impaired adults through an individualized plan of care and to help families maintain loved ones in their home. ADC programs have existed in various forms in western countries. Generally, ADC programs can be divided into two models that are social-based day programs and hospital-based day programs. Social-based day programs emphasize social activities and respite care at elderly care centers in comparison to hospital-based day programs that emphasize medical treatments and rehabilitation specific for the older people with some health problems such as dementia.

In the United States, social adult day programs are managed by social workers and nurses while hospital-based day programs are managed by nurses. Until now there are only two public institutions that have provided ADC services for PWD in Thailand and both are hospital-based day programs. Nurses play an important role in providing direct nursing care, general management, and collaboration with multidisciplinary team in providing therapeutic programs, personnel training, facility management, and other supporting services in dementia care services. Most program activities and direct patient care (such as assistance with activities of daily living (ADLs), health assessment, medication management, and an individualized plan of care) of ADC services have been administered and facilitated by nurses. Nurses also monitor, intervene, and respond to needs of family caregivers of PWD who are at risk for negative health outcomes

Since nurses are responsible to provide effective care and best practices in order to provide better outcomes, outcome assessment and evaluation are essential parts of the nursing process, in nursing practice and nursing administration. Evaluation of adult day services for PWD will identify the level of success of current adult day services within the

long-term care system. In fact, outcomes of ADC programs can be measured by both patient outcomes and caregiver outcomes. The effects of ADC for PWD in Thailand on family caregiver's outcomes have not yet been evaluated. Thus research is needed to assess the impact of the current ADC programs in Thailand. The main purpose of this study is to evaluate the effects of adult day programs for PWD on selected caregiver outcomes. Such information will be beneficial for improving quality performance, accreditation of current health care services, and changing policy by documenting ADC effects in providing sufficient supportive interventions and increasing social resources for PWD and their families.

Geriatric clinical nurse specialists, nurse practitioners and clinical nurse leaders function in an advanced role in nursing at clinical settings and communities. As a profession, nurses should actively participate in the development of body of knowledge based on evidence, empirical testing and the utilization of evidence-based practice to improve health outcomes. Due to the complex science and socio-economical changes, nurses need to collaborate with patients, family caregivers, multidisciplinary providers, and other social resources in the community to improve the health care systems and to maximize quality of life not only for clients but also for their caregivers.

## **Chapter Two**

### **Literature Review**

This chapter provides a review of literature. The review includes the experiences of family caregivers of older adults with dementia, long-term care and ADC in the United States, and long-term care and ADC in Thailand.

#### **Experiences of Family Caregivers of Persons with Dementia**

Dementia is a major cause of cognitive impairment in older adults (Gavrilova et al., 2008). PWDs often present with mild to severe short and long-term memory loss, thinking and judgment deficits, altered sleep patterns, incontinence, wandering, apathy, agitation, mood disturbances, personality changes, and other problematic behaviors. Family members unavoidably become primary caregivers who assume more responsibility for taking care of relatives with disabilities at home.

An abundance of literature on family caregivers of PWD primarily focuses on the experience of stress, burden, depression, grief and loss, and psychological distress. However, a few studies have examined the consequences of caring for PWD at home from a more holistic perspective. This chapter will review the previous studies on the experiences of family caregivers particularly as a consequence of caring a PWD and the effect of caregiving on their quality of life.

#### **Concept of Quality of Life**

Quality of life has been recognized as a pivotal health outcome of health care services for PWD and their caregivers. However, quality of life is a multidimensional



concept that has been defined and applied in a variety of ways (Brod, Steward, Sands, & Walton, 1999).

The World Health Organization (1997) defines quality of life as the individual's perception of their physical health, psychological health, level of independence, social relationships, personal beliefs, and relationship with environmental events. This perception depends on the context of culture and value systems in the individual lives and in relation to his/her goals, expectations, standards and concerns. This concept goes beyond the presence or absence of illness (Thomas et al, 2006) and represents a global conceptualization for the general population.

Tang, Aaronson, & Forbes (2004) argued that quality of life could be conceptualized in two ways: global quality of life and health-related quality of life. Global quality of life is defined as an individual's subjective well-being or life satisfaction on the main domains of physical, psychological, social, and existential well-being. On the other hand, health-related quality of life is a more focused concept related to the impact of illness or specific medical interventions on a person's physical, psychological, and social functioning. Pain, energy, independence, environment, and spirituality have all also been included in health-related quality of life (Smith et al., 2005).

Brod and her colleague (1999) stated that quality of life should consist of both subjective and objective domains especially in PWD because subjective states can be difficult to measure in dementia patients but can be inferred through knowledge of things about person, external circumstances, observable behaviors or more objective domains. The subjective domains consist of sense of well-being, aesthetics, and overall quality of life that can be measured directly from a self-reported questionnaire such as Dementia Quality of Life Instrument (DQoL; Brod, Stewart, Sands, & Walton, 1999). The objective

domains consist of physical functioning, daily activities, mobility, discretionary activities, social interaction, interaction capacity, and bodily well-being that can be measured by available proxy measures. They argue that the conceptualization of quality of life in dementia should be disease specific so that it can infer the impact of dementia related to cognitive, behavioral, and social changes accompanying disease progression. However, DQoI based on a disease specific conceptualization has been applied for assessing quality of life in PWD, but not for caregivers.

Thomas and colleague (2006) stated that caregivers' quality of life is related to patients' quality of life. Caregivers of PWDs may be exposed to their own health problems, depression, and burden. Quality of life in caregivers of PWD is the perception of caregivers related to the difficulties in dealing with dementia patients at home. It consists of four main domains that include difficulties generated by the patient, relationship with the environment, psychological perception of the situation, and perception of a possible distress that can be measured using the caregiver's quality of life scale.

Quality of life as defined by WHO has been widely used in numerous caregiver studies around the world; though, it was not specifically designed for caregivers of PWD. These studies found that quality of life of family caregivers of PWD may differ among countries because the level of quality of life depends on individual perception, their cultural values, and environmental factors. Numerous studies have also reported differences in the perception of psychological well-being (Losada et al., 2006; Shurgot & Knight, 2005; Covinsky et al., 2003) and social well-being (Shurgot & Knight, 2005) of family caregivers of PWD across ethnic groups. This may be due to the fact that cultural differences affect individual's ways of thinking, familism norms or filial obligations, coping styles, and the concept of independence (Losada et al., 2006). For example, White

caregivers listed children as primary emotional helpers more often than African Americans whereas African Americans listed friends as main emotional helpers more often than White persons (Shurgot, & Knight, 2005).

Health care services and other social supports also differ among countries. Most western developed countries provide specific health services and intervention programs for patients and their caregivers to reduce caregiver burden and increase their quality of life. Choices are nursing home care, respite care, assisted living, and day care services. Conversely, there are rarely nursing homes, day care services, and special clinics for older adults with Alzheimer's and related dementia in many developing eastern countries, such as Thailand, India, and Russia (Graff, Vernooij-Dassen, Thijssen, Dekker, Hoefnagels, & OldeRikkert, 2007).

The conceptualization of quality of life varies based on the operational definition and specific purposes of the researchers. For example, Bond and colleague (2003) evaluated quality of life of dementia caregivers in terms of health status, psychological well being and activity participation. Belle and colleagues (2006) examined quality of life of dementia caregivers with respect to caregiver burden, self-care, social support, and PWD problem behaviors. In addition, Perren, Schmid, & Wettstein (2006) assessed caregivers' subjective well-being by interviewing caregivers regarding emotional well-being and life satisfaction.

Therefore, caregivers' quality of life has usually measured well-being by using a self-reported questionnaire or interviewing caregivers that represents positive and negative consequences of caring a PWD. Another outcome which is commonly used to evaluate the impact of caring for PWD and the effectiveness of interventions for the PWD and their caregiver is "caregiver burden."

### **Differentiation between Caregiver Quality of Life and Caregiver Burden**

A common consequence in studies of caregivers' quality of life has been to assess their experiences in relation to caregiver burden. The conceptual definition of caregiver burden and caregiver quality of life is different in that caregiver burden represents caregiver strain and negative consequences of care whereas quality of life represents positive and negative global well-being or health outcomes. The term caregiver burden is widely used to refer to a multidimensional negative response of stress and coping to physical, psychological, emotional, social, and financial stressors of caregivers (Kasuya, Polgar-Bailey, & Takeuchi, 2000). Burden occurs when caregivers perceive the pressure or strain due to caring for a person with dementia and when caregiver's coping responses and supports are inadequate. In fact, some studies argued that caring for PWD may bring about pride, mastery, or positive affections in caring for the loved one as well as negative consequences at the same time.

Some studies included caregiver burden and depression as key indicators of caregiver's quality of life (Belle et al., 2006). Many studies found that caregiver quality of life was affected by caregiver burden, caregiver health, and psychosocial support (Iecovich, 2008, Hsu, 2006, Glozman, 2004, Spurlock, 2005). A previous study also supported that higher caregiver burden was related to lower levels of caregiver quality of life, more physical and cognitive impairment, more behavior problems, less adequate informal social support, less time for self, and more financial constraints (Coen, Boyle, Coakley, & Lawlor, 2002). Behavior problems of PWD have been found to be the strongest source of psychological distress for the dementia caregivers (Pinquart, & Sorensen, 2003).

Gavrilova and colleague (2008) evaluated an education program for family caregivers. They found that caregiver burden was significantly decreased after the intervention but that caregiver quality of life was not significantly increased. Caregiver burden seemed to be a more sensitive outcome measure than quality of life. These findings may depend on the effect of the intervention and the instrument applied. The intervention may be more tractable to assist caregivers in coping with stressors than reducing psychological morbidity. Otherwise, the measures of quality of life may be too broad to capture some deficits.

George and Gwyther (1986) studied the impact of caregiving upon family caregivers of demented adults. They argued that caregiver burden focuses on the characteristics of the caregiving situation and the resources available to the caregiver, rather than the conditions of the PWD. They integrated caregiver burden as a dimension of well-being in order to overcome other confounding stressors and outcomes which might not directly relate to caregiving responsibilities but that are affected by the presumed stressor and its outcomes. The information was provided about the dimension-specific prevalence of caregiver burden and general picture of relative well-being. In addition, the information was comparable with relevant comparisons groups and useful to establish population norms. However, this well-being measure was not sensitive to illness duration within all the dimensions of well being.

Therefore, caregiver burden is a useful indicator to identify caregivers' coping problems and levels of needs to help support their adaptation and achieve their well-being. However, caregiver quality of life is useful to provide a whole picture of overall well-being in both positive and negative consequences and more holistic perspective than caregiver burden.

## **Quality of Life of Caregivers of Persons with Dementia**

According to the health care literature, quality of life is widely used to reflect the experiences of caregivers of PWD. Quality of life of caregivers of PWD will be reviewed as well as physical health, mental health, social support, and characteristics of caregivers.

### **Physical health.**

Caregivers of PWD reported greater levels of physical burden or physical disability than caregivers of persons with diabetes and caregivers of cognitively intact frail elderly (Gavrilova et al., 2008). Moreover, caregivers of a family member with PWD are more likely to experience fair to poor health, to have high levels of stress hormones, reduced immune function, slow wound healing, newly diagnosed hypertension, and coronary heart disease (Alzheimer's Association, 2008).

Factors linked to the caregiver's physical health include the care recipient's behavior problems, physical and cognitive impairment, and functional disabilities, the caregiver's age, gender, psychological distress, self-care, and duration and amount of care provided. Caregivers who provide assistance with basic activities of daily living (ADLs) may neglect their own health by eating non-healthy food and failing to sleep adequately (Schulz, & Sherwood, 2008). Some caregivers reported over eating, abuse of prescribed medications and alcohol, increased smoking, and restless sleep (Gallant, & Connell, 1997). Therefore, caring for PWD is an independent risk factor for morbidity and mortality.

### **Mental health.**

Many studies report that family caregivers experience increased burden and are at risk for psychological morbidity. Common mental health problems include higher levels of

burden, depression, stress, anxiety, grief and loss, guilt and shame, hostility, lower self-esteem, frustration, weariness, and loneliness (Razani et al., 2007; Smith, et.al., 2005; Bond, Clark, & Davies, 2003; Gallant & Connell, 1997). Several studies supported that caregivers of PWD who were highly burdened also exhibited depressive symptoms (Papastavrou et al., 2007). In addition, caregivers who institutionalized their relative reported that they experienced depressive symptoms and anxiety as high as in-home caregivers (Schulz, Belle et al., 2004). A qualitative study reported that some caregivers had positive feelings such as contentment and happiness with their care of PWD (Smith et al., 2005).

The level of burden and depression vary based on many influencing factors such as health problems of both recipients and caregivers and perception of overload or a lack of social support (Hayslop, Han, & Anderson, 2008; Son, Erno, Shea, Femia, Zarit, & Stephens, 2007; Kim, Knight, & Longmire, 2007) A study of Alzheimer caregivers found that patient's depression status, functional level, and hallucination status were predictors of caregiver depression (Shua-Haim, Haim, Shi, & Kuo, 2001). More severe patient symptoms and longer duration of disease were associated with greater patient and caregiver depression due to the greater impact on caregiver schedules and reduced caregiver social functioning (Kurtz, Kurtz, Given, & Given, 2004; Glozman, 2004). Consistently, caregivers of patients who required assistance with two or more ADLs, spent more time for care, and cared for patients with behavioral disorders, particularly angry or aggressive behavior, were also more depressed (Covinsky et al., 2003). Conversely, some studies found that the amount and duration of care given did not predict caregivers' satisfaction (Perren, Schmid, & Wettsten, 2006). Matsumoto and colleague (2007)

suggested that caregiver burden and depression were associated with some symptoms of dementia but did not always depend on the frequency and severity of these symptoms.

Apathy, aggressive or threatening behaviors, dangerous behaviors, attachment behaviors, and depressive symptoms were the major memory and behavior problems of dementia care recipients that were related to caregiver burden and depression. Memory problems and communication problems were related to caregiver burden, but not to depression (Papastavrou et al., 2007). Functional disability in the PWD may lead to anxiety and hostility in the caregiver more than depression (Razani et al., 2007).

### **Social support.**

Social support has been used as a relevant determinant of coping capability and caregivers' well-being, such as burden and depressive symptoms (Perren, Schmid, & Wettstein, 2006). Caregivers who perceive high care-loads, inadequate self-capacity to function in daily life, and a lack of support tend to have reduced satisfaction and increased burden and depression compared to those with adequate social support (Hayslop, Han, & Anderson, 2008; Simonetti, & Ferreira, 2008).

Moreover, perceived social support and social support satisfaction have been found to mediate caregiver burden and depression (Iecovich, 2008; Hsu, 2006; Glozman, 2004; Spurlock, 2005). Several reviews and meta-analysis have shown that intervention strategies such as caregiver support groups, psycho-educational, and psychotherapeutic intervention have been successfully implemented to support PWD caregivers (Perren, Schmid, & Wettsten, 2006; Eters, Goodall, & Harrison, 2008; Brodaty, Green, & Koschera, 2003).



The relationship between a patient and his/her caregiver is also a critical factor influencing caregiver quality of life. Spouses who integrated the role of caregiver positively within the relationship with their spouse perceived greater well-being (Lewis, Hepburnm, Narayan, & Kirk, 2005). Relationships between patient and caregivers may influence the perception of social support, affections to care, and the satisfaction of caregiving. Glozman (2004) also supported that caregivers' quality of life could be affected by family relationship, coping strategies, and length of marriage.

The concept of relational deprivation has been used to examine quality of the relationship between a caregiver and a care recipient through the dementia process (Adams, McClendon, & Smyth, 2008). A study found that poorer quality relationship was directly related to caregiver depression and role capacity (Lawrence, Tennstedt & Assman (1998). Caregivers also felt loss and grief including loss of social interaction, loss of control over life events, and loss of well-being (Loos, & Bowd, 1997). A recent study provided evidence that family members often felt the loss of reciprocity of the relationship such as affection, care, transportation support, household tasks, and financial responsibilities during disease progresses from early stage to an advanced stage (Razani et al., 2007).

### **Characteristics of caregivers.**

Caregiver quality of life also been related to certain personal characteristics of caregivers such as gender, age, education, income, family position, and ethnicity of the caregiver (Glozman, 2004; Covinsky et.al., 2003; Connell et al., 2001). Women caregivers experienced greater loss of intimate exchange and role overload than men. Moreover, women caregivers tended to have higher burden and higher depression than men especially in suffering from relational deprivation burden and lack of social support (Papastavrou et

al., 2007; Gallicchio, Siddiqi, Langenberg, & Baumgarden, 2002; Thomson, Lewis, Murphy, Hale, Blackwell, Acton, Clough, Patrick, & Bonner, 2004). Several studies found that caregivers with PWD had financial problems (Coen, Boyle, Coakley, & Lawlor, 2002) and tended to have low quality of life particularly in older caregivers with less education (Glozman, 2004).

Ethnic identity was a factor influencing differences of coping style and cultural values. Cultural values shape one's perceptions of familial responsibilities (Etters, & Harrison, 2008) especially in Asian cultures (Kim, Shin, Jeong, Gormley, & Yoon, 2002) and African cultures (McCallum, Longmire, & Knight, 2007) that possess a greater sense of responsibility to care for elderly family member (Kim et al., 2002).

Spouses were more susceptible to personal and interpersonal losses than other relatives were (Adams, McClendon, & Smyth, 2008). A study in Ireland found that daughters had higher burden than other kinship groups (Coen, O'Boyle, Coakley, & Lawlor, 2002). However, some studies found no significant differences in caregiver burden between spouses and adult children (Chumblor, Grimm, Cody, & Beck, 2003). That may be due to cultural factors that shape individual's perceptions of familial responsibilities and thus also influence the perception of caregiver burden (Etters, Goodall, & Harrison, 2008). A previous study found that ethnicity was not directly related to familism after controlling for education (Kim, Knight, & Longmire, 2007). Therefore, education might be a moderator in the relationship between familism and caregiver outcomes.

The effectiveness of an intervention program may differ among different ethnic groups. Belle and her colleague (2006) studied the effectiveness of an intervention program (the Resources Enhancing Alzheimer's Caregiver Health II: REACH II) and found different improvement of quality of life among different ethnic or racial caregiver

groups. They found no overall clinically significant effects for African-American caregivers, but showed significant improvement of quality of life in Hispanic or Latino and White or Caucasian caregivers. Other previous studies also supported that African-American caregivers were less likely to experience burden and depression (Janevic, & Connell, 2001) and poorer physical health than White caregivers because of their use of avoidant coping strategies (Kim, Knight, & Longmire, 2007; Covinsky et al., 2003). In contrast, African-American caregivers who perceived positive support from others tended to have lesser burden since perceived positive support partly mediated the relationship between ethnicity and burden (Shurgot, & Knight, 2005).

In summary, quality of life is a global and national health indicator. Family caregivers are the main source of care for PWD. Caring for a family member with PWD results in negative outcomes (such as burden, anxiety, and depression) that influence but are not the same as quality of life. Therefore it is important to address quality of life as a distinct outcome for caregivers of PWD.

The conceptualizations of quality of life vary based on the operational definition and specific purposes of the researchers. Health status and functional ability have been studied as a determinant of quality of life as well as caregiver burden and other psychological distress. Social support has been used as a predictor of coping capability and caregiving outcomes. Spiritual well-being is less commonly measured in quantitative studies of caregiving for PWD.

Many studies reported that caregivers of PWD experienced a decrease in several aspects of well-being especially in psychological well-being. Burden and depression become major mental health problems for caregivers and have been the most frequently studied consequences of caregiving. Moreover, quality of life was affected by other factors

including increased problematic behaviors of a PWD, severity of dementia, duration of care, caregivers' health problems, inadequate psychosocial support, financial constraints, relationship to patient, and other personal characteristics of caregivers. The study of caregiver quality of life promotes understanding of the impact of caring for PWD and supports the design of appropriate interventions to enhance overall quality of life for PWD and their families.

### **Long-Term Care and ADC in the United States**

Long-term care is a variety of services that includes medical and non-medical care to people who have a chronic illness or disability. Nurses play an important role in providing and managing care and facilities in the long-term care system within a multidisciplinary health care team in both community-based and institutional facilities. The long-term care delivery system in the United States and Thailand are different in the development process, health care policies, kinds of facilities, and service provision. Long-term care for the elderly in the United States and Thailand were reviewed in order to understand and compare the development, service delivery, and long-term care policies in both countries. Long-term care in the United States provides an example of long-term care systems in the western countries and serves as a model for a comparison with the long-term care system in Thailand, a developing country in Southeast Asia.

### **Long-Term Care in the United States**

Long-term care has improved slowly and sporadically over the past 100 years. Before the 20<sup>th</sup> century, most of the long-term care homes were not established for profit or business enterprises. Many long-term homes were sponsored by ethnic community or

religious organizations, and public service organizations, such as almshouses, poor houses, poor farms, and county infirmaries to provide food and shelter for the elderly, orphans, and people who were poor, lonely, frail, mentally deteriorated or chronically ill.

Efforts to improved custodial care and undesired conditions in the almshouses by nurses started at the beginning of the 20<sup>th</sup> century. The growth in the number of long-term institutions increased empirically based on increases in the aged population, public policy and public budget. As a result of the Social Security Act 1935, many public institutions for the aged transformed into private institutions. There were several names for these private institutions, their names, provided services, and qualified residents were not yet clearly defined although the number of nursing homes increased dramatically, the quality of nursing home widely varied. Services provided in some long-term care institutions were entirely unprofessional and obviously unwholesome. No public legislation and self-regulation controlled quality of private nursing homes until the middle of the 20<sup>th</sup> century (Katz, Kane, & Mezey, 1999).

Due to business competition, government regulation, and professional self-regulation, the long-term care system transformed into the long-term care industry. Long-term care administrators required skills, experience, and administrative ability to guide over-all operations, coordinate several functions, delegate responsibility, act as the liaison between the board and staff, train staff to provide care, and solve social and financial problems of homes (Kaplan, 1959). Administrators were necessary to collaborate with the variety of special groups such as physicians, hospitals, patients and their families, health departments, fire inspectors, insurance groups, labor unions, volunteer, and other community resources. Most institutions for the elderly set out to provide holistically individual care, appetizing food, pleasant living arrangements, competent medical care,

social interaction, and home environment. Government regulation of and reimbursement for long-term care services with the enactment of Medicare and Medicaid in 1966 resulted in improved standards of care and accessibility for older adult (Vladeck, 1999).

The aged population continues to increase and have a greater prevalence of chronic illnesses requiring more health services including long-term care, both community-based and institutional services. According to the Census Bureau, the number of person aged 65 or older is estimated to be 86.7 million by 2050 (U.S. Census Bureau, 2005). In 1999, approximately 1.6 million older people were cared for in nursing homes and the number is projected to increase to 3 million by 2020 (Administration on Aging, 1999). Long-term care institutions were encouraged to be private enterprises but most still need financial support from government funding.

Home-based care and community-based care are the most common care arrangements for older Americans. People prefer care at home and use community services rather than staying in a nursing home (Rantz, Marek, & Zwycart-Stauffacher, 2000). About 70 to 80% of noninstitutionalized older people receive care from friends and family (U.S. Census Bureau, 2005). Medicare-either alone or with private insurance- and Medicaid are the main financing support for the older and the disabled populations. Medicare is sponsored by the federal government to provide health care to older people. For long-term care, Medicare has generally paid only for medically necessary skilled nursing facility or home health care, not for custodial care or supporting daily activities. Some Medicare Advantage Plans (formerly Medicare plus Choice) may offer limited skilled nursing facility and home care (skilled care) coverage if the care is medically necessary. Medicaid is funded by federal and state governments to provide health care to poor or uninsured people. Another source of government funding is military health care plans, including

Comprehensive Health and Medical Plan for Uniformed Services (CHAMPUS) and Civilian Health and Medical Program of the Department of Veterans Affairs (CHAMPVA). Medicaid benefits were shaped by Medicare's omissions and the Medicaid program covered medical costs of nursing home care and home care services when medical bills exceeded a state-determined percentage of monthly income. There are enormous differences in state policies for nursing home care and some conflicts between the federal and state government.

### **ADC in the United States**

ADC is considered a comprehensive community-based program intended to assist physically and mentally impaired adults and support caregivers in caring their relatives at home. A variety of adult day programs are offered through local hospitals and day care centers for promoting a continuum of care from post-acute hospitalization toward long-term care services. There is a diversity of clients using adult day programs such as adults with Alzheimer's disease and other dementias, depression, Down syndrome, stroke, chronic diseases, and frail older adults. The growth of ADC in the United States occurred during two periods of time, of the end of the 20<sup>th</sup> century and at the beginning of the 21<sup>th</sup> century.

ADC services began in the United States in the late 1960s. The first adult day programs were developed in the form of day hospitalization at Cherry hospital in Goldsboro, North Carolina under the pioneering direction of Lionel Cousin (Lamden, Tynan, & Warnke, 1994). The primary purpose of day care programs was to prepare patients for discharge by teaching and promoting independent living skills. The 1970s adult day services emerged in various forms in order to provide elder care assistance at the centers without the need for institutionalization. Early expansion of ADC was due to the

efforts of a grass roots movement that pushed for recognition and funding (Lamden, Tynan, & Warnke, 1994). The advent of title XIX and XX reimbursement during the 1960s allowed small numbers of low-income elderly to access the services. A major force shaping the future adult day services was the development of national standards in 1984 by the National Institute on Adult Day Care (NIAD). The NIAD, a constituent unit of the National Council on the Aging, also set forth guidelines for practitioners as an impetus toward professionalism. Between 1980 and 1990, the number of ADC centers rapidly grew from 1,200 to 3,000 (the National Institute on ADC (NIAD), 1991) and changed from a small unlicensed non-profit organization for profit organizations, with a small provider network.

In 1991, there was increasing interest and support for developing community-based, long-term care options throughout the United States. ADC centers offered a variety of health, social, recreational, and related services such as routine daily care, medical care, group activities, assistance with finances and social security and legal benefits. National regulations were established by the National Institute on Adult Daycare, local and state agencies on aging such as the National Council on Aging and the National Adult Day Services Association (NADSA).

The NIAD (1991) defined ADC as “community-based program designed to meet the needs of functionally impaired adults through an individualized plan of care during part of a day but less than 24-hour care.” (Fettig & Riegel, 1998, p. 189). An individual plan of care is developed under the interdisciplinary assessment of nurses, social workers, staff, and participant's preference. Day care programs have been offered through three alternative levels of care. In level one, the client needs some socialization, supervision, supportive services, and minimal assistance with activities of daily living (ADLs). In level two, the



client needs a health assessment, oversight or monitoring by a nurse, therapy services at a functional maintenance level, and moderate assistance with one to three ADLs. Finally, at level three, the client needs maximum assistance with ADLs and his or her medical condition is unstable and requires monitoring intervention by a nurse (Brunk, 1996 cited in Fettig & Riegel, 1998). These options provided an opportunity not only for customers to choose the kind of services and service providers that they need but also for nurses to become nurse entrepreneurs.

Adult day services can be divided into three models based on service delivery: the medical model, the social model, and the combined model. The medical model centers on providing skilled assessment, treatment, and rehabilitation goals. The social model focuses on socialization and preventive services. The combined model has elements of both a social and medical model depending on individual client needs (van Beveren & Hetherington, 1998; Dabelko & Zimmerman, 2008).

Day care programs before year 2000 were based on the social model of care rather than a medical model of care. Most of these day programs focused on providing daily activities assistance, promoting social support system, and respite to families or caregivers in providing care for the older adults with minimal health problems. Activities provided include cognitive stimulation, physical exercise, reminiscence, and socialization. ADC clients usually attended day care 2-3 days each week for about 5 hours a day. A survey study of the Oklahoma State Health Department (1997) and Travis with his colleague (2001) reported that Oklahoma centers offered adult care programs using a social model of care. Most Oklahoma centers were open 7:00 am until 5:00 pm, Monday through Friday. The number of patients depended on the size of the centers because the license regulations required a minimum of 40 square feet of activities space for each patient and patients with

special needs required more additional space. All centers were required to have a director, an activity director, and nursing assistants at the settings and readiness to access health care coordinators, social workers, case manager, and dietitians for meeting client's needs. Most patients of Oklahoma day care centers are female (81%) and most lived with family members (87%). Most of them had occasional problems with incontinence (86%) or significant cognitive impairments (78%) that necessitated professional health services on-site whereas all centers had a part-time or full-time registered nurse or licensed practical nurses for providing nursing care.

Moreover, the major reimbursement for the Oklahoma centers came from the department of Human Services (40%), and private funds (30%). Other sources of funding were United Way scholarship funds, private donations, Veterans administration, mental health services, and local scholarship funds. Due to small centers with limited budgets and limited staff, it was difficult to offer full service day programs for clients with diverse health and social needs. Although the number of clients who need the third level of care (18%) were less than clients of the first (41%) and the second level of care (41%), approximately a half of clients were discharged to nursing home care. The findings suggested that the social model of day care had a limitation in providing long-term care for the elderly who had active health problems and required advanced medical interventions.

As the elderly population increased over time, a need for community-based, long-term care options appeared to be high, however, the growth of ADC centers did not dramatically increase as much as assisted living and home health care services did. The licensure requirements appeared to be an important milestone for the ADC business because it created access to federal and state fund and reimbursement. Before 1995, one half of the United States provided Medicaid waivers under Title III of the Older American

Act, but these funds were limited and unreliable. ADC programs were not reimbursed under Medicare. Most ADC programs relied upon fee-for-service payment and philanthropic funding to pay their overhead costs (Fettig, & Riegel, 1998). The fee for adult day programs is an out of pocket expense. Families who received financial support from foundations often received monies for elders to attend only once a week whereas elders who qualified for the state Medicaid program were eligible for the Family Care Program that provides funds for elders to attend between two and five times per week (Bull & McShane, 2008). Most ADC centers faced economical problems, human resources deficits, and difficulty in providing clearly differentiated programs of care to groups with special needs. The majority of customers tended to have notable cognitive impairment or physical functioning problems that required more intense medical care from professional health care providers. These obstacles challenged the growth of adult day services.

ADC is currently recognized as a community-based program intervention or therapeutic day programs for adults who need assistance with activities of daily living to support their abilities to continue to live at home and to reduce caregivers' burden, stress, and depression in taking care of the elderly. A wide array of services are usually provided including activities of daily living, therapeutic activities, social interaction, comprehensive health assessment and monitoring, nursing services, medication management, rehabilitation, personal care, meals, and transportation. Respite is an important part of adult day services which are widely provided through a center-based day program so that caregivers can take a break or do anything they desired outside the home. Generally, respite services can be delivered in three different ways: center-based day program, in-home or domiciliary respite, and institutional respite or vacation respite. These different

types of respite suit different caregiver and family needs at different points in time (Gottlieb, & Johnson, 2000).

Today there are more than 4,000 ADC services and centers in the United States which usually operate during business hours during the week day. The number of adult day centers has not increased dramatically that may be from the problem of reimbursement. Medicaid, not Medicare, became a primary funding source for the adult day programs. The administration of ADC in the 21st century still faces the financial problem of hiring qualified professionals.

The National Council on the Aging and the National Adult Day Services Association (NADSA) is currently developing a certification program for adult day center administrators and directors. However, adult day programs are different across centers depending on settings, their philosophy of care, service delivery, and funding sources. Quality and standards of care vary from state to state. The medical adult day programs or day hospitals are generally provided through a department in hospitals whereas most of the social programs are offered in community-based centers. The philosophy of medical adult day programs focuses on providing an individual care plan, personal care, rehabilitation and health maintenance after an acute care hospital. On the other hand, the philosophy of social adult day programs emphasizes multipurpose services, social interaction and therapeutic recreation for chronically functioning disabilities. The services of the medical program are arranged so that they qualify for Medicaid including employing therapists as consultants under Medicaid and licensing regulations. In contrast, the social adult day programs were largely funded through the Social Act and the Older Americans Act.

The effectiveness of ADC programs have been demonstrated mostly in North America (Mason et al., 2007). Benefits include the improvement of client functioning,

caregiver adaptation, delayed institutionalization, and cost-effectiveness (Gaugler, & Zarit, 2001; Zarit, Gaugler, & Jarrott, 1999). Effectiveness evidence suggests that the consequences of respite care upon caregivers and care recipients were generally small and no reliable evidence was found that respite care can delay entry to residential care (Mason et al., 2007). However, many studies reported high levels of caregiver satisfaction with ADC services. Even though adult day services provided care through medical or social day care programs, the medical and social models of adult day programs did not significantly decrease depression, anger, role overload, and worry over the three-month period (Leitsch, Zarit, Townsend, & Greene, 2001). In fact, a caregiver whose elder relative attended the medical adult day programs experienced greater financial burden because the medical programs cost more than the social programs. This might be because clients of the medical programs have more severe health problems, and need specific medical services for a longer period of time (Leitsch, Zarit, Townsend, & Greene, 2001).

Moreover, most studies employed quasi-experimental designs that may result in unreliable evidence. The need for experimental study design with better controlled studies in particular elderly population has been recommended (Mason et al., 2007; Zarit, Gaugler, & Jarrott, 1999).

Many adults day programs are designed and developed in order to maximize their cost-effectiveness and to enhance better clients' or family caregivers' outcomes. There are many studies on the impact of services and interventions designed for adult day programs. The benefits of adult day services can be organized into three outcome areas: improved caregiver adaptation, improved client functioning, and delayed nursing home placement (Gaugler & Zarit, 2001). The findings have not been consistently documented.

Reever, Mathieu, & Dennis, & Gitlin (2004) proposed a model of adult day services with care management for primary family caregivers and compared the outcomes with 2-group quasi-experimental design. The specific goals of the model were to work collaboratively with family caregivers, assist family caregivers to identify areas of difficulty with caregiving, develop a care plan to minimize these difficulties, and implement the care plan using counseling, education, referral, and regular supportive follow up. This model provided clinically significant benefits for families by reducing burden, increasing confidence in managing problems, and enhancing caregivers' well being compared with a control group that did not use day care services. Caregivers also reported that providing comprehensive and systemic care management was very valuable for them in providing necessary support, education, and feedback about basic home management techniques. However, the model of this study focused on the role of a social worker, not a professional nurse.

Zarit, Stephens, Townsend, & Greene (1998) studied the impact of day care services on clients with dementia and family caregivers. The caregivers reported less overload and depression after three months of adult day program use than caregivers who did not use ADC. They also reported that clients with dementia experienced decreased confusion and agitation as well as improved mood, life satisfaction, engagement in activities, and well being. The effect of adult day services on improving clients' functioning is rarely found from previous studies. Some studies did not find the improvement in family caregivers well being or depression (Warren, Kerr, Smith, & Godkin, 2003; Baumgarten, Lebel, Laprise, LeClerc, & Quinn, 2002).

ADC also helped caregivers become more comfortable with caregiving responsibilities due to having more free time to get something done. However, some

studies showed high dropout rates in the first few months of use due to their distress (Leitsch, Zarit, Townsend, & Greene, 2001). Many caregivers use day care services for only a brief period of time. Day programs seem to serve as an earlier step to other long-term options and nursing home placement (Gottlieb, & Johnson, 2000).

Berry, Zarit, & Rabatin (1991) reported that caregivers spend more of their free time in preparing relatives to leave the house, collaborating in day care activities such as training, education, and support initiatives and transportation. The first month of ADC use is a critical time period that family caregivers experienced stresses.

Bull & McShane (2008) examined reasons of high drop-out rates during the first months of ADC services. The findings showed that transportation problems and lack of success in matching adult day programs with elders' interests and abilities were factors that led families to stop using the services. Caregivers who care for elders attending adult day services at least three times a week adjusted and coped with stresses more rapidly. This finding is congruent with the study of Warren, Kerr, Smith, & Godkin (2003) in that time conflicts and transportation problems brought about dissatisfaction of using day care services.

### **Issues & Future Directions**

Day care centers have faced several issues in administration and providing services to meet individual and community needs.

1. Day care centers are faced with financial and human resource challenges. Education and staff training is necessary for staff to maintain and improve health outcomes. There is a need for collaborating with community and other social networks for reducing cost, gaining more funding resources and achieving social interaction activities

for the clients. The Family Caregiver Alliance and American Respite Care Association and health care professionals might advocate increased funding for adult day programs so that accessibility might be extended beyond the Medicaid population (Bull & McShane, 2008). Moreover, working with a marketing expert might help day centers learn how to tailor their marketing messages to the specific needs of clients and caregivers.

2. Many day care centers provide programs which are somewhat general for very diverse groups of customers. There is heterogeneity among day care programs, clients, and funding sources. There is a need for an effective day care program that fits a specific population to improve better outcomes for both clients and family caregivers. Providing day care programs for a specific population should be better but it is higher cost to hire special health care providers.

3. The heterogeneity of day care programs, participants, and funding sources creates challenges in defining and measuring health outcomes of adult day services. Additional outcome research requires development of valid and reliable measures to identify the effectiveness and to explore the meaning of desired outcomes, such as quality of life and service satisfaction, from participant's perspectives.

4. Nurses and social workers play an importance role in managing social ADC programs. The medical adult day service programs should be more appropriate for impaired or frail elderly regardless of the cost. This provides a better chance for nurses to develop a significant role in designing day care programs to meet specific clients' needs especially medical treatment and advanced care while minimizing the medical cost.

5. Improving functioning and psychosocial well being of clients and family caregivers has becomes an essential part of the ADC mission through a variety of day care services including creating a therapeutic environment, social and recreation activities, and



respite. However, promoting interpersonal relationships especially in peer group and patient-family relationships, and spiritual well-being could also be integrated into the ADC goals.

6. The quality of adult day programs need to be monitored and evaluated by clients, family caregivers, and staff for the improvement of process and outcomes of services being provided. Due to caregivers reported problems of time conflict and transportation, these problems would be solved if adult day services were opened a full-day and arranged transportation services.

7. For providing a continuum of care, a holistic approach, and individualized care approach, creating partnerships and social network with other community services providers would provide more benefit for centers, clients, and caregivers including financial and spiritual support.

In summary, ADC program serve as a choice of post-hospitalization and long-term care options when family members need community services to support them in caring for their elderly family members in their home. Adult day services will be a vital part of the long-term care continuum which is generally considered cost effective when compared with the cost of institutional care.

Day care centers are faced with the problems of financial funding and obtaining adequate human resources. The growth of day care services also requires government and community support. Creating community partnerships and other social networks are needed to provide continuum of care, minimize service costs, and gain supports.

To provide the best practice, it is necessary for health providers to recognize the importance of collaborating with interdisciplinary services, listening to client and caregiver voices, providing well-designed facilities, and promoting a holistic approach, especially in

improving the functioning and psychosocial well-being of clients and family caregivers. Day care programs in each setting need to be monitored and evaluated for process and program improvement. An individual care plan of care should be planned and evaluated by the client, caregivers, and responsible staff members to ensure the quality of care delivery and the improvement of the quality of life for both clients and caregivers. A well-designed facility is vital in providing and supporting ADC activities including building a homelike and safe environment which allows for the performance of activities of daily living, the stimulation of sensory and motor functioning, and the promotion of social interaction.

Evidence-based research is also needed to investigate the advantages and drawbacks of current ADC programs and develop new programs which meet the needs of clients and their family. The advantages include decreasing health care costs, minimizing out-of-pocket expense, saving caregivers time, reducing the risks and frequency of hospitalization, and solving problems of care at home.

### **Long-Term Care and ADC in Thailand**

According to the aging trends of the global population, the number of the elderly as a percentage of the population of Thailand has been increasing faster than in many developed countries. In addition, this trend will continue in the next two decades (Sokolovsky, 1997; U.S. Census Bureau, 2001). In 2006, the population aged 60 and above in Thailand was approximately 6.5 million or 11% of total population. The median age of the Thai population was 33 years old (Foundation of Thai Gerontology Research and Development Institute (TGRI), 2007). This information reflects that Thailand is becoming

an aging country; recently the Thai government recognized the necessity to develop social welfare policies and health care systems to readily cope with the aging population.

### **Long-Term Care in Thailand**

The Foundation of Thai Gerontology Research and Development Institute (TGRI) began to provide an annual report on the elderly situation as designated and supported by the National Commission on the Elderly. Generally, Thai elderly are defined as those 60 years old and above. This annual report stated that most of the elderly (56%) were female and lived with extended family. Eighty-six percent of elderly males lived with their spouse whereas 65% of female elders lived with a spouse. However, the proportion of older persons living alone increased from 6.3% in 2002 to 7.9% in 2006. Approximately half of these elderly had chronic diseases such as cardiovascular diseases, endocrine disorders, muscle, tendon and bone diseases, gastrointestinal diseases, and respiratory diseases. Moreover, the elderly frequently have chronic diseases as they become older, especially for the elderly aged 70-74. In 2006, more than half of the elderly (51.4%) died with non-communicable diseases and 25.4% died with old age diseases. The elderly were the highest group (12.7%) admitted in medical care institutions. Therefore, it could be summarized that most elderly dwell with family since only 7.8% of total elderly lived alone.

In Thailand, the health care for older adults is paid for by the health security card, civil servants' medical benefits, private health insurance, social security/compensation fund, and other health welfare provided by employers and other organizations. Basically, the government issues the health security card free of charge for all Thai people aged 60 and above (TGRI, 2007).

Families have played a significant role in taking care of the elderly. Due to changes of family structure from extended to nuclear, cultural lifestyle of younger generation, social pressure and financial problems, both men and women have to work outside their home. Families tend to require more supporting services from communities to take care of their older relatives and relieve their burden. Nowadays, nursing homes and day care centers become more significant in providing support for older persons. However, such kind of these services were limited and found in the private sector (TGRI, 2007). The health security card does not cover these long-term care services provided by the private sector. The Thai national policy promotes community-based social care network from all participating sectors (public, private, and municipalities) and Home-Based Long Term Care in giving care of the elderly in their community. The future long-term care, pension policy, and the expansion of the coverage of the old-age allowance universal for all elderly become as philosophical and complicated issues (Suwanrada, 2009).

The concept of “Active Ageing” recommended by the World Health Organization (WHO) has been introduced and adopted in the welfare plans including long-term care for the elderly. Active ageing is the process of optimizing opportunities for health, participation, and security in order to enhance quality of life as people age (Thanakwang, 2006). To achieve “active aging” for the elderly will require contributions from the public and other societal sectors.

Typically in Thailand, long-term care is offered by government organizations, non-profit organizations, private entities, and family caregivers. The government organizations provide care in the forms of homes for the aged, elderly clinics, home health care, ADC or respite care, and hospice care. In 2008, a total of twenty homes for the aged were operated by the Ministry of Social Development and Human Security. The elderly

who are unable to live with family or have no family can apply to be a resident of this service. This service provides living space, food, clothing, medication, physical therapy, occupational therapy, religious worships, recreation, and other social services. Moreover, the services of some homes for the aged may provide assisted living so that private-pay residents will have a choice to live in a private or shared room including meals and housekeeping services. Generally, homes for the aged in Thailand are managed by social workers. Nurses can provide physical screening and first aid for ill residents. However, the older adults with more serious illnesses or who need more advanced medical care will be sent to the hospital.

Moreover, non-profit organizations may offer care free of charge, but it could be in a form of charity by temples. On the other hand, the private sector does not provide free care since it is mainly for-profit. This includes private hospitals or other private entities providing individualized care at the institutions or sending a provider to care for clients at home. Therefore, the family caregiver is a major mechanism of elderly care in Thailand.

In fact, the welfare system in the Thai society is still not fully accessible for older persons. The mechanisms that drove policy implementation did not work well in driving policy implementation for the Thai elderly due to the weakness of political component. Therefore, the elderly require both health promotion and medical care services. Moreover, long-term care is also limited and does not meet the standards of quality care (Sritanyarat, 2004).

The institutional care for the elderly such as hospitals and homes for the aged are insufficient in the number of spaces and funding. Hospitals provide the medical treatment and individualized care serving both physical and mental problems whereas homes for the aged or residential homes provide the lower level of care and focus on general personal

care such as supporting daily and recreational activities. Therefore, it is necessary for a group of older residents requiring higher level assistance or nursing skills to access nursing homes and special services. Currently, the residents of homes for the aged tend to require a higher level of care due to health problems. However, in 2006 there were only 18 private nursing homes for the elderly and mostly licensed by various government agencies. Of those, only eight were registered with the Medical Registration Division as medical care institutions for the chronically diseased. Moreover, two of the eighteen homes were registered with the Ministry of Commerce and the Ministry of Labor respectively, whereas the others were not registered with any organization. Simply, there are still no rules clearly prescribing registration of nursing homes (TGRI, 2007).

The community-based providers play a more significant role in providing necessary services and supporting systems for caregivers to cope with any level of stress, handle effective caregiving, maintain the functioning role, and fulfill life satisfaction as much as possible. Basically, temples and community groups are major mechanisms of community-based providers in supporting long-term care since temples are centers of religious and social activities in the community for Thai culture. Moreover, temples are generally appropriate places for older persons to maintain their spiritual needs through religious morality and gain mental support from monks, neighbors, friends, and other people. In addition, some temples provide alternative medicine, traditional Thai massage, education, and other services for society. Moreover, several groups or associations such as elderly clubs were established through the promotion by the government or the private sector to encourage community members in providing assistance and social activities for older people. Therefore, temples and community groups are a key component of community-based providers in supporting long-term care. Nowadays, the government

encourages temples and community groups to integrate into the development of the well-being of people in the community including the elderly (TGRI, 2007).

There are numerous research studies regarding the impact of residential care and supporting services for the elderly and caregivers and most are published in the Thai language. Several studies provide interesting suggestions for improving residential homes as well as encouraging and supporting family caregivers in taking care of older relatives effectively at home. Panitchob (2001) studied quality of life among residents at home for the aged and private homes. This study showed that residents of private homes had a better level of quality of life than those living in home for the aged. The most significant reason was that the services of homes for the aged responded only to the physical needs and not for mental; moreover, other reasons were the individual different characteristics such as age, sex, education level, economic status, health status, and relationship with others (Panitchob, 2001; Jongsatitman & Sintunava, 2000; Sumonwong, 1993). The common problems with homes for the aged residents were health problems, problems of the relationship with other members, and loneliness (Sumonwong, 1993).

Some researchers studied problems and needs of homes for the aged residents and suggested that nurses could play an important role in providing medical and individualized care for the ill or disabled residents who need medium and high levels of care such as persons with dementia and stroke. Hishinuma and colleagues (2005) mentioned that the coordinating model and the network model of nursing practice were suitable for the care of elderly people in Kenya, Ghana, Sri Lanka, Thailand, Korea, and Finland. Also, they suggested that people-centered care was the most important factor of primary health care and nursing practice.

Since 2002, the Thailand Research Fund under the Health Research Network by Thai National Health Foundation has continuously supported research on the elderly. In 2006, the elderly organizations made the joint conclusion of guidelines on operation of tasks on the elderly. The priority of the task was to make the family and the community institutions as the foundation of providing services for the elderly. Based on such conclusion, it leads to the study of the suitable community-based model for development of life quality of the elderly (TGRI, 2007). According to the limitation of institutional care, the development of ADC is a wise alternative to encourage the community to provide elderly care and other supporting services for engaging in “active ageing” throughout the community and country.

### **ADC in Thailand**

Day care programs are usually operated by hospitals and some by local elderly care centers in order to provide social interaction and supportive services including daily activities assistance for the elderly groups. In 2007, adult day services were found in some public and private hospitals which may be called adult hospital day care. This program works like an intervention for patients in the transitional period from hospital to community after the patients passed through acute or critical illness and for patients with chronic illness such as dementia, stroke, and disabled elderly. Generally, both social and hospital day care programs are designed as a combination of hospital, school and social groups under a multidisciplinary team significantly promoting social interaction of patients. Therefore, day care services should really be a solution in supporting the elderly at home and reducing caregiver's burden as well.



There are only two public institutions that provide ADC services for PWD in Thailand. These are Somdet Chaophaya Institute of Psychiatry (Bangkok) and Chiangmai Neurological hospital, (Chiangmai) in Thailand. Both of them are general psychiatric hospitals that are governed by the Ministry of Public Health. The administration of ADC programs is based on a model of day hospital that aims to provide additional medical care, therapeutic interventions and cognitive rehabilitation for PWD who currently achieve medical care at their neuro-geriatric outpatient clinic. In 2010, each site provides day care for only 7 to 10 persons per day and most current patients are repeated users, with few new admissions to ADC services. The average admission rate for new patients is one patient per month. Most activities are ministered by skilled nurses and social workers with the collaboration of multidisciplinary health care professions.

ADC is well known by the name “Memory Clinic” that offers holistic care, therapeutic interventions for the improvement of cognitive impairment and the delay of advanced problematic symptoms. The program activities for PWD include the practice of self-care in daily activities, memory stimulation, speech therapy, and social activities, aroma therapy, creation groups, recreation, and other group activities. In addition, the clinic aims to educate family caregivers about disease and how to care their PWD at home and reduce caregiver burden. They provide group education and emotional support for family caregiver of PWD who enroll in the day care clinic. Day and respite care is another support service provided during the day time (8 am-4 pm) except for the weekend and national holidays.

Only the PWD with stage I or stage II of dementia will be recommended by his or her physician to enroll in the memory clinic. In addition, their family needs to provide consent for their PWD to attend the memory clinic and get an approval that they have no

financial problem and negligent issue. Prior to admission, nurses will inform PWD and their family about disease and progression of PWD, purposes and procedures of the memory clinic, costs, and others.

Individuals with dementia have been classified as having Alzheimer's disease, fronto-temporal dementia, vascular dementia, and other diagnoses. Alzheimer's disease is the most common etiology of dementia. Main clinical features of dementia are cognitive impairment and psycho-behavioral disorders. The cognitive function declines from an individual baseline, caused by neither delirium nor mental illness (DSM IV, American Psychiatric Association, 2000). The diagnosis is based on clinical assessment and interviews of informants and family members. After a physical examination, cognitive function has usually been evaluated using the Mini-Mental State Examination (MMSE). The Neuropsychiatric Inventory (NPI) and laboratory examination have also been examined. The NPI measures frequency and severity of ten behavioral and psychological disturbances occurring in dementia patients: delusions, hallucinations, dysphoria, anxiety, agitation/aggression, euphoria, disinhibition, irritability/lability, apathy, and aberrant motor activity (Cummings, Mega, Gray, Rosenberg-Thompson, Carusi, and Gornbein, 1994; Fletcher, 2009). A laboratory evaluation includes a complete blood cell count, blood chemistry and determination of thyroid-stimulating hormone. In addition, functional ability and behavioral symptoms related to dementia are usually assessed.

Basically, severity of dementia can be divided into three stages based on DSM IV criteria. These are 1) early stage or mild dementia, 2) moderate stage of dementia, and 3) severe dementia or late-to-end stage (Wayne, & Segal, 2009).

1) Early stage or mild dementia is illustrated with frequent recent memory loss, particularly of recent conversations and events, repeated questions, and difficulty in

writing and in using familiar objects. Depression and apathy can occur. Drastic personality changes may accompany functional decline. The early stage is characterized by the need for reminders in daily life activities as well as difficulties with sequencing which impacts the ability to drive. The duration of this stage is approximately 2-4 years.

2) Moderate stage of dementia is characterized by pervasive and persistent memory loss, rambling speech, faulty reasoning, confusion about current events, time, and place in familiar settings, sleep disturbances, and mood and behavioral symptoms. Nearly 80% of patients exhibit emotional and behavioral problems which are aggravated by stress and change. Slowness, rigidity, tremors, and gait problems impact mobility and coordination. At this stage there is a need for structure, reminders, and assistance with activities of daily living. The duration of this stage is approximately 2-10 years.

3) Severe dementia or late-to-end stage is illustrated with confusion about past and present and loss of recognition of familiar people and places. Generally, they are incapacitated with severe to total loss of verbal skills and the inability to care for themselves. Falling and immobility are likely as well as difficulties with swallowing, incontinence, and illness. Extreme problems are moodiness and behavioral issues in addition to hallucinations and delirium. At this stage patients need total support and care and often die from infections or pneumonia. The duration of this stage is approximately 1-3 years.

Severity of dementia usually results in cognitive impairment and functional disabilities. Furthermore, previous studies showed that burden and depression of caregivers of PWD was associated with cognitive impairment and daily functional disabilities (Razani et al., 2007, Shua-Haim, Haim, Shi, Kuo, & Smith, 2001). This study examined confounding effect of severity of dementia through cognitive impairment and daily

functional activities. The cognitive impairment was assessed by the MMSE and the daily functional activities was assessed by the Bristol Activities of Daily Living Scale (BADLS).

The MMSE (Folstein, Folstein, & McHugh, 1975) is recognized as a standard tool to measure memory and cognitive ability. It is commonly used to assess cognition change over time (Fletcher, 2009). The scores range from 0 to 30. According to the ADC sites, the MMSE score between 16 and 24 is determined as the Stage I or mild dementia. The MMSE score lower than 16 is the Stage II or moderate dementia. The duration of progressive symptoms differs from person to person. The annual rate of decline on the MMSE in PWD is 3.3 points annually (Fletcher, 2009). Another measure, the BADLS (Buck, Ashworth, Wilcock, & Siegfried, 1996) is commonly used to assess functional ability both basic and instrumental daily living activities. The scale consists of 20 items and was designed to be brief and sensitive to change over time. This measure can be reported by the caregivers of PWD. The BADLS scores ranges from 0 to 42. A minimum possible score of 0 means totally independent and a maximum score of 60 means totally dependent. The scores are highly correlated with the MMSE (Buck, Ashworth, Wilcock, & Siegfried, 1996).

### **Issues and Future Directions**

1. ADC could be an effective choice especially when family members require community services to enhance care at home for their elderly members. Basically, ADC would be suitable for Thai culture because of the belief of most Thai people in filial piety. Therefore, taking care of the elder parents is a very significant responsibility for a family.

2. There is a need for research to provide and distribute information to policy makers and providers in order to improve social welfare policies and to develop long-term care programs to enhancing the well-being of Thai elderly and their family caregivers.

3. Even though the government recognizes the importance of social welfare reform for the elderly, insufficient funding is a critical barrier to the revolution of long-term care in Thailand. Therefore, the collaboration among public, private, municipalities in the national level and international networks would support funding, sharing information, and other resources to improve social welfare system for the elderly in Thailand.

Thai health care system for the elderly is abstruse and complex. Although Thai elderly are offered free security cards, ADC costs are not reimbursed. Given the expected increase in the elderly population, the extension of both quantity and quality of services and support for the aged should be carefully considered by the public and private sectors in order to satisfy social needs and improve well-being of the Thai elderly. Nurses are able to extend their roles to provide specialized nursing care with many kinds of long-term care for the specific elderly groups such as adult day programs in hospitals and home care in other residential settings. Moreover, it would be useful to develop a continuum of long-term-care system for the elderly with the collaboration between institutional and community-based care to support families for taking care of older relatives at home.

### **Summary**

The reviewed literature supports the statement of the problems and purposes of the proposed study. Family caregivers suffer with physical health decline, psychological morbidity, and poor quality of life. ADC programs are viewed as an alternative of nonpharmacologic approach for PWD and an essential supportive service for family

caregivers with PWD. ADC for PWD would be an effective alternative support service that would help families to improve their quality of life. Effectiveness studies of ADC are necessary as a basis for best practices and to shape policy. The effectiveness of ADC services in Thailand on family caregiver perspectives would be useful for nurse administrators and policy makers to improve current adult day programs and achieved better outcomes.

## **Chapter Three**

### **Method**

This chapter details the research design, sample and settings, instruments, procedures, and data analyses. The time frame of the study is also presented.

### **Research Design**

An exploratory prospective study with a single group repeated-measures design and additional qualitative questions was used to test the proposed research questions. The caregiver outcomes (burden, depression, health status, social support, and quality of life) were measured using questionnaires and surveys and compared between baseline and one and three months after starting ADC services. Repeated measures analysis of variance (ANOVA) was employed to examine the significance of the treatment effects across time and the differences in patterns of change. Univariate analysis of variance is based on the assumption of normality, homogeneity of variance and homogeneity of covariance (sphericity) between repeated assessments. The effect of caregiver characteristics (gender, family income, caregiver-patient relationship, frequency of service use, and severity of dementia) were examined on baseline data with independent t-tests in order to examine equality of these possible confounding variables on all dependent variables. If significant differences were found, the repeated measures analysis of covariance (ANCOVA) was employed.

Caregiver participants were also interviewed after completing 3 months of ADC use. The interviews lasted 45 to 60 minutes and included two open-ended questions and additional probes. The interviews were audio-taped and transcribed into Thai language. Qualitative data from the caregivers of the PWD provided rich details about their quality of

life and their experience with ADC services that was not captured by the quantitative measures. Observations, field notes, official documents, and related materials were also integrated into the data analysis.

### **Advantages of the Repeated-Measures Design**

Repeated-measures analysis is an important tool and widely used to evaluate the effects of the performance of health care interventions. Repeated-measures designs are also called within-subjects designs (Maxwell & Delaney, 2004). The repeated-measures design is especially well suited for studying the developmental outcomes or other changes that take place over time (Gravetter & Wallnau, 2007). The repeated-measures design uses multiple measurements of the same individual or experimental unit at different time points. The repeated assessments might be measured under different experimental conditions (Sullivan, 2008). In repeated-measures analysis, each subject is considered as a block in order to reduce within group variability due to individual differences and minimize error (within group) variance. The variability among subjects due to individual differences is completely removed from the error term (Stevens, 2007; Maxwell & Delaney, 2004). Since subjects serve as their own control, within-subjects variation is reduced compared to between-subject comparisons. Therefore, the correlation among responses results in a more precise and powerful statistical analysis than between-subjected designs or independent-measure design (Sullivan, 2008; Stevens, 2007).

In addition, the repeated-measures design requires fewer subjects to achieve statistical power than between-subjected designs (Stevens, 2007; Maxwell & Delaney, 2004; Nimon & Wasiams, 2009). Three or four time points in repeated measures are appropriate to optimize power of the study (Vickers, 2003). The repeated-measures design



was selected in this study due to a limited available sample of PWD in ADC. For this study caregiver outcomes were measured at three time points, at baseline, 1 month and 3 months after using adult day services in order to identify the short-term effects of the use of ADC services on established caregiver outcomes across time.

### **Disadvantages of the Repeated-Measures Design**

Three major disadvantages of repeated measures are incidental effects, the inability to assure the same intervention, and the possible violation of the assumptions for statistical analysis. The incidental effects occur because participants change as they are repeatedly tested. For example, participants are able to improve scores due to their own practice or their scores may deteriorate due to tiredness or boredom in responding to repeated measures. The boredom may also result in dropping out of the study. Maintaining good relationships with PWD and caregiver participants may prevent drop out (Leonard, Lester, & Rotheram-Borus, 2003). Researchers should assess practice effect, and minimize or balance it as much as possible during data collection (PsychoMetrics, 2009). In this study the investigator and research assistants kept in touch with all participants either by phone or in meetings at the ADC every two weeks during the study.

The other disadvantage of repeated measures is that each participant may not experience the same intervention effects because participants might selectively attend different amounts of ADC activities. For example, one PWD may attend 5 days per week while another may only attend once a week. It is important to consider individual subject profiles over time. Therefore, the effect of the ADC setting, frequency of adult day service use and severity of the disease were examined as potential covariates.

In addition, the underlying assumptions for ANOVA (such as normality and sphericity) were examined in order to select an appropriate statistical analysis (either univariate analysis or multivariate analysis). However, data were not completely independent due to measurements on the same subjects. This issue was a limitation of the study.

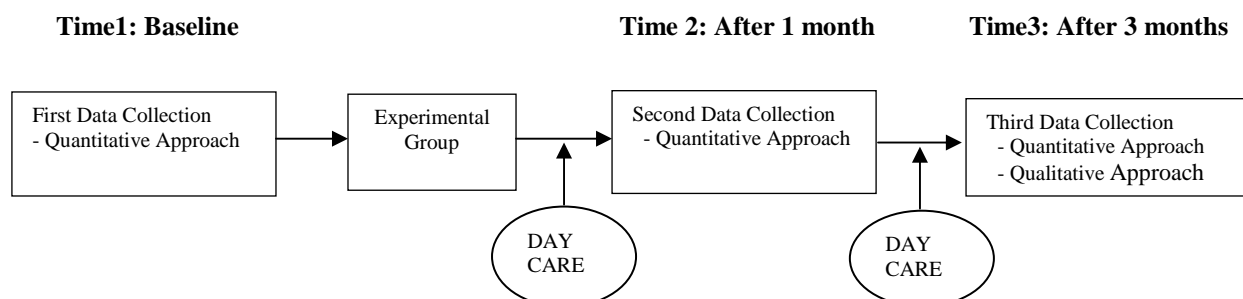
This study was an exploratory study with a limited sample size because of the limited number of ADC services available in Thailand. A small sample size can result in low statistical power that can lead to unstable and/or invalid inferences (Hollenbeck, DeRue, & Mannor, 2006). Moreover, the small size of the sample leads to the drawing of inferences that are not robust and sensitive to sampling error (Hollenbeck, DeRue, & Mannor, 2006).

Only two institutions provided ADC services for PWD in Thailand during the study. Each site provided ADC for only 7 to 10 persons per day and most of the current patients were repeated users, with few new admissions to ADC services. The average admission rate for new patients was one patient per month. Therefore, all new participants were invited to participate in the study in order to obtain an adequate sample and reduce selection bias.

Hollenbeck, DeRue, & Mannor (2006) concluded that a small sample size might be completely acceptable in exploratory studies so that researchers can search for insights that can later be replicated with other techniques using larger samples. A previous study used a one-group repeated measures design with baseline, 8 weeks, 16 weeks, and 36-week follow-up telephone interviews conducted with 22 initial recruited subjects. Even though only 16 subjects completed the entire intervention, the results showed significant differences in caregiver outcomes (Bormannen, Warren, Regalbuto, Glaser, Kelly, Schnack

& Hinton, 2009). Related studies with small sample sizes were found in qualitative studies in India (Shaji, Smitha, Lal, & Prince, 2003) that used open-ended interviews with 17 caregivers of people with Alzheimer’s disease. Another study was conducted in South Carolina that applied in-depth telephone interviews with 21 directors of ADC for PWD (Kelsey, & Laditka, 2005). In addition, there are several studies of psychosocial interventions for caregivers with PWD that used a small sample size (Cooke, McNally, Mulligan, Harrison, & Newman, 2001). All the studies provided valuable information to promote best practices and further studies for PWD and their family caregivers.

Since the sample size was limited, qualitative data was used to supplement the quantitative measures used in the proposed study. Qualitative data can contribute substantively to assess meaningful change in caregiver outcomes and to understand the effectiveness of ADC services by providing more information about intervention utility and significance as seen through eyes of the participants (Sandelowski, 1996; Fogg & Gross, 2000; Hollenbeck, DeRue, & Mannor, 2006). Qualitative interview questions were useful to explore the impact of ADC services over time and to validate the quantitative data. This combined approach efficiently answered the research questions with a relatively small sample.



*Figure 2.* Timeline and data collection.

### Sample and Setting

The goal of the study was to enroll a convenience sample of approximately 15-20 caregivers of PWD using ADC services in either Somdet Chaophaya Institute of Psychiatry (in Bangkok) or Chiangmai Neurological hospital (in Chiangmai province), Thailand. Both of these research sites are part of outpatient geriatric clinics of general hospitals in Thailand that provide inpatient and outpatient services.

Inclusion criteria for caregiver participants was 1) being at least 18 years old at the time of enrollment; 2) being a family caregiver of PWD with stage I or stage II (mild to moderate) dementia diagnosed by a physician, 3) providing at least 4 hours of supervision or direct care per day; 4) enrolling their PWD in ADC services at least one day per week; 5) providing informed consent for participation; and 6) using a dementia clinic at a research site. Exclusion criteria include 1) being a hired caregiver; and 2) being a family caregiver of PWD who had previously used ADC services.

Cohen (1992) recommended that a sample size of 26 subjects was sufficient for ANOVA to achieve a minimum acceptable power (0.80) and large effect size (0.40) at alpha level of 0.05. However, Cohen's effect sizes are based on the between-subjects design with an underlying the assumption that measurements are uncorrelated.

Barcikowski and Robey (1985) estimated the number of subjects necessary to achieve 80% power in the preparation of a single group exploratory repeated measure analysis based on a modification of a FORTRAN program. The estimates are based on the assumption of "compound symmetry" in that autocorrelation parameter ( $\rho$ ) among repeated measures was constant. They recommended that the effect sizes of repeated measures design should be larger than one of Cohen's effect size for an ANOVA with K independent levels. The effect size based on either the univariate analysis ( $f_u$ ) or the multivariate analysis ( $f_M$ ) was

equal to the effect size divided by the square root of one minus autocorrelation ( $f/\sqrt{1-\rho}$ ). They recommend that the Cohen's effect size estimating the autocorrelation parameter ( $\rho$ ) of .50 because in most cases the effect sizes based on an autocorrelation of .50 will slightly underestimate the actual effect size. A sample size necessary to achieve large, medium, and small effect size are 14, 34, and 198 respectively for measurements at three points of time. For this study, a sample size of 14 was required to detect a large effect size ( $f/\sqrt{1-\rho} = 0.40/\sqrt{1-0.5} = 0.56$ ) and to achieve 80% power at an alpha level of 0.05. For this study, the sample size of 16 would be large enough to provide a normal distribution with a visual plot and large enough to achieve acceptable statistical power for a large effect size at an alpha level of .05.

### **Instrumentation**

According to the research questions, independent variables included the use of ADC services for one month and three months. The study outcomes or dependent variables included caregiver burden, caregiver depression, caregiver health status, caregiver social support, and caregiver quality of life. See Table 1. The outcomes of interest also included experiences, perceptions, and feelings of family caregivers for PWD regarding their quality of life during the use of ADC services. Both quantitative and qualitative data were used to address the research questions.

### **Quantitative Data**

Outcomes were measured with five instruments with established reliability and validity and two surveys. (see Table 1) All of instruments had been translated into Thai language. The five instruments that were completed by caregiver participants included the

Zarit Burden Interview (ZBI), the Epidemiologic Studies-Depression Scale (CES-D), the Short form 12-item health survey (SF-12v2), the Sarason's Social Support Questionnaire (SSQ-6), and the WHO QOL-BREF. Two additional surveys, the General Personal Data Survey and the Caregiver Evaluation of Adult Day Care (CEADC), were completed. Estimation of time required for caregivers to complete all measures was approximately 45-60 minutes.

1. The Zarit Burden Interview (ZBI) was selected because it is the most commonly used measure of burden among family caregivers for demented older adults. (see Appendix E and F). The ZBI was designed by Professor Steven Zarit and colleagues (Zarit, Reever, & Bach-Peterson, 1980) to measure caregiver burden for relatives of PWD who were cared for in a home setting. The ZBI is a 22-item self-reported questionnaire, using a 5-point Likert-type scale, measuring the degree to which caregivers perceive their responsibilities as having an adverse effect on their physical health, emotional well being, social life, finances, and interpersonal relations. The range of possible ZBI scores is 0–88, with higher totals reflecting greater burden. The cut off points are: less than 20 non burden or little burden; 21–40 'mild to moderate' burden; 41–60 'moderate to severe' burden and more than 61 severe burden. Cronbach's alpha coefficient for use of this scale by dementia caregivers is high (alpha = .86-.95) (McCallum, Longmire, & Knight, 2007; Kim, Knight, & Longmire, 2007; Papastavrou et al., 2007). Factor analysis identified four factors including personal strain, role strain, relational deprivation and the management of care (Papastavrou et al., 2007). The ZBI has been translated into many languages including the Thai language. Cronbach's alpha for the Thai version of ZBI in 22 caregivers of PWD was 0.89 (Pankong, 2004) and .92 in 610 caregivers of elderly relatives (Gadudom, 2004).

2. The Center for Epidemiologic Studies-Depression Scale (CES-D; Radloff, 1977) was primarily designed to measure self-reported symptoms associated with depression experienced in the past week. (see Appendix G and H). The measure is useful in the initial screening of symptoms related to depression or psychological distress in the general population across age groups in many western and Asian countries (Leitsch, Zarit, Townsend, & Greene, 2001; Mackinnon, McCallum, Andrews, & Anderson, 1998). The CES-D has been widely used in dementia caregiving research (Roth, Ackerman, Okonkwo, & Burgio, 2008). Therefore, it was appropriate to use the CES-D for measuring the presence of depressive symptoms in this study because the family caregivers for Thai elderly were spouses and younger relatives who did not have psychiatric disorders (Choowattanapakorn, 1999).

The CES-D is a 20-item self-reported scale that measures the major components of depressive symptomatology, including depressive mood, feelings of guilt and worthlessness, psychomotor retardation, loss of appetite, and sleep disturbance. Each item ranges from 0-3 (four-point scale), corresponding to the frequency of each statement within the last week. The possible scores can range between 0 and 60, with a higher score indicating the presence of more depressive symptomatology. A score of 16 is considered to reflect the need for further assessment and evaluation for depression (Radloff & Teri, 1986; Nabkasorn, Miyai, Sootmongkol, 2005). Cronbach's alpha coefficient for caregivers of PWD was high (alpha = .77-.88) (McCallum, Longmire, & Knight, 2007; Kim, Knight, & Longmire, 2007; Mitrani, Vaughan, McCabe, & Feaster, 2008; Mitrani, Lewis, Feaster, Czaja, Eisdorfer, Schulz, & Szapocznik, 2006). Previous factor analysis studies in dementia caregivers have consistently identified four underlying constructs, including

depressed affect, well-being, interpersonal problems, and somatic symptoms (Roth, Ackerman, Okonkwo, & Burgio, 2008; O'Rourke, 2005).

The Epidemiologic Studies-Depression Scale (CES-D) had been translated into Thai language in order to assess depressive symptoms in diverse Thai populations. The CES-D was translated into Thai with back translation and has shown acceptable internal consistency in studies in Thailand with Cronbach's alpha ranging from .80 to .89 (Ross, 2005).

3. The WHO QOL-BREF-THAI is a standardized national questionnaire, a short version of a set of quality of life indicators (WHO QOL-100) developed by an expert group from different countries and the World Health Organization (WHO). See Appendix I and J. The questionnaire consists of 26 items on a 5-point Likert-Type scale, and scores can range from 26-130. A score of 26-60 indicates low quality of life, a score of 61-95 indicates moderate quality of life, and a score of 96-130 indicates high quality of life.

The WHO QOL-BREF-THAI assesses self-reported subjective and objective QOL in four main domains: physical health; psychological well being; social relationships; and environment. Physical health includes item 3, 4, 10, 15, 16, 17, and 18. Psychological well being includes item 5, 6, 7, 11, 19, and 26. Social relationships include item 20, 21, and 22. Environment includes item 8, 9, 12, 13, 14, 23, 24, and 25. The WHO QOL-BREF-THAI has reported reliability and content validity in various groups of Thai population. Internal consistency with Cronbach's alpha coefficients has been reported at 0.84 (Department of Mental Health, Thai Ministry of Public Health, 2008.; Mahatnirankul, 1997). A study in Thai population confirmed that this Thai version has construct validity equivalent to the original language scale (Sakthong, Schommer, Gross, Sakulbumrungsil, & Prasithsirikul, 2007). This study applied the WHO QOL-BREF-THAI for measuring



caregiver quality of life because the instrument is a standardized questionnaire. For this study, Cronbach's alpha coefficient of the WHO QOL-BREF-THAI-Thai version was .94 at three points of time which indicates a high level of internal consistency.

4. The Short Form 12 item health survey (SF-12v2) is a practical, reliable, and valid generic measure for measuring functional health and well being (QualityMetric, 2009). (see Appendix K and L). The SF-12v2 is the improved version of the SF-12v1 that was a previous short-form of the Medical Outcome Study Short form 36-item health survey (SF-36). The SF-12v2 was improved in five ways: brevity and simplicity, layout, compatibility with regard to translation, and cultural relevance and expanded and uniform response categories (Ware, Kosinski, Keller, 1996). This version includes 12 items, shorter and simplified instructions and questionnaire items, more consistent layout and format, and the provision for estimating the eight domains of health (SF Community, 2009). These domains include physical functioning (PF, 2 items), role limitations due to physical health problems (RP, 2 items), bodily pain (BP, 1 item), general health perception (GH, 1 item), vitality (energy/fatigue) (VT, 1 item), social functioning (SF, 1 item), role limitations due to emotional problems (RE, 2 items) and mental health (psychological distress and psychological well being) (MH, 2 items) (see Appendix K).

The SF-12v2 was used to calculate two component scores, the physical component scale (PCS) and the mental component score (MCS). Both component scores were computed by the QualityMetric Health Outcomes Scoring Software (Ware, Kosinski, Turner-Bowker, & Gandek, 2002). According to the software syntax, the physical component scale includes item SF1 (GH), SF2a (PF), SF2b (PF), SF3a (RP), SF3b (RP), and SF5 (BP) (see Appendix K). The mental component scale includes item SF4a (RE), SF4b (RE), SF6a (MH), SF6b (VT), SF6c (MH), and SF7 (SF). Higher scores represent

better health status. Interpretation of the SF-12v2 required norm-based scoring algorithms that resulted in scale and summary scores being standardized with a mean of 50 and a standard deviation of 10. The procedures for scoring the SF-12v2 were reported in the survey's manual (Ware et al., 2002).

It was reported in the survey's manual that the SF-12v2 had strong internal consistency, reliability, and validity. The reliability coefficients of the eight survey scales ranged from .72 to .87, including physical functioning=.78, role physical=.86, general health=.75, vitality=.74, social functioning=.75, role limitation due to emotional problems=.74 and mental health=.87. The reliability of the physical component summary was .89 and the emotional component summary was .86 (Ware et al., 2002).

Even though the SF-12v2 Thai version was available, there was no published evidence of its psychometric properties in Thai population. Some previous study showed that the SF-12 Thai version yielded sound psychometric properties in Thai people in many populations such as persons with HIV/AIDS (Chariyalertsak, Kawichai, Ruangyuttikarn, Wu, Thapinta, Kemerer, & Malitz, 2004), hip fractures (Suriyawongpaisal, Chariyalertsak, & Wanvarie, 2003), and pregnant women (Sricamsuk, 2006). Therefore, the SF-12v2 is more appropriate for measuring the physical and mental health of participants who are older adults who may be uncomfortable in answering a long questionnaire.

5. The Sarason's Social Support Questionnaire (SSQ-6; Sarason et al., 1987) is a 6-item questionnaire that assesses the amount of perceived social support (SSQ-N) and a 6-item questionnaire that assesses satisfaction with available social support (SSQ-S). (see Appendix M and N). The size of the social network is calculated as the total number of persons listed by the patient as support contacts. Satisfaction with support was assessed using a scale from 1 (not satisfied) to 6 (highly satisfied). Internal Consistency of SSQ-6 is

very high for dementia caregivers (Clay, Roth, Wadley, & Haley, 2008) and Thai adults with mild traumatic brain injury (Petchprapai, 2007). In Petchprapai (2007), the Cronbach's alpha of the SSQ-N was .92 and the SSQ-S was .94. This demonstrates that the Thai version is equivalent to the English version and was used in this study.

6. The General Personal Data Survey was designed by the researcher (see Appendix C and D) in order to assess baseline personal information of caregivers and PWD that was used for screening qualified participants of the study. This questionnaire was composed of two parts. The first part consisted of 10 items that asked demographic information about the PWD (illness duration, frequency of ADC use, and severity of dementia). The second part consisted of 36 items that asked demographic information about the caregiver participant (numbers of family members, relationship to the care recipient, the quality of the relationship, duration of care, satisfaction with their care, family support, ADC use, and other social supports).

Severity of dementia was assessed by using the Mini-Mental State Examination (MMSE) and the Bristol Activities of Daily Living scale (BADLS). The MMSE was administered by the research investigator. The MMSE (Folstein, Folstein, & McHugh, 1975) is recognized as a standard tool to measure memory and cognitive ability in clinical practice. The scores range from 0 to 30. A MMSE score between 16 and 24 is determined to be stage I or mild dementia. The MMSE score lower than 16 is stage II or moderate dementia. Internal consistency of the MMSE in a mixed sample of elderly hospitalized patients was .96 (Foreman, 1987). This study applied MMSE-Thai 2002 that was established high internal consistency in Thai population (Kuha et al., 2008). A cut-off score of MMSE-Thai 2002 for persons who had education higher than primary school level

is 22, for persons who had education in primary school level is 17, and for persons who are illiterate is 14.

The BADLS (Buck, Ashworth, Wilcock, & Siegfried, 1996) is commonly used to assess functional ability both basic and instrumental daily living activities in PWD. This measure was a supplement to determine the levels of severity of dementia. It was reported by caregivers. The BADL measure consists of 20 items and possible scores ranges from 0 to 42. A minimum possible score of 0 means totally independent and a maximum score of 60 means totally dependent. Validity and good test-retest reliability were reported in many studies (Burns, Lawlor, & Craig, 2002; Sikkes, Klerk, Pijnenburg, Scheltens, & Uitdehaag, 2008).

7. The Caregiver Evaluation of Adult Day Care (CEADC) is an evaluation of ADC service program that is composed of three parts. The researcher adapted the first and second part from measures of Jarrott and her colleagues (Jarrott et al., 1999) who developed these measures to assess caregiver satisfaction with adult day service programs in New Jersey. The first part consists of 12 items with a five-point Likert scale that measure caregiver satisfaction with adult day service use. The second part consists of 17 items with a five-point Likert scale that measure benefits and drawbacks of adult day service use (see Appendix O and P). The third part consists of two open-ended questions and additional probes (see Appendix O) that were added to obtain additional qualitative data for this study. The first and second parts were used for the second phase of data collection. The entire CEADC was used for only the third phase or for participants who used ADC services for three months or more.

Content validity of the CEADC was examined by three Thai experts. Two were clinical nurses working in the ADC programs. Another was a professor working in the

field of adult and elderly nursing. Items with a content validity index (CVI) of .66 or less were revised or deleted. Finally, two items with a CVI of .66 were revised and two items were added due to the recommendations of the experts to fit with ADC programs for both research sites in Thailand to address the respect for human rights, spiritual and religious beliefs, and to assess for improvement in depression, apathy, agitation or aggressive behaviors, cognition, behaviors, and activities of daily living. As a result, the 25 original items were revised into the 27 item CEADC with 12 items in the first part and 17 items in the second part. A total of 12 items of the first part and 17 items of the second part were retained with a CVI of 1.00.

Table 1  
*Quantitative Variables, Instruments and Surveys, Operational Definition, Reliability, and Validity*

Quantitative Variables	Instruments/Surveys	Operational Definition	Type	Validity/Reliability
Caregiver Burden	ZBI (Zarit, Reever, & Bach-Peterson, 1980)	Perception of suffering with physical health, emotional health, social life, and financial status.	22-item Likert	Construct validity .86-.95 <sup>a</sup> .89 <sup>b</sup>
Caregiver Depression	CES-D (Radloff, 1977)	Symptoms of affected mood and behavioral manifestations including depressive mood, feeling of guilt and worthlessness, psychomotor retardation, loss of appetite, and sleep disturbance.	20-item Likert	Construct validity .77-.88 <sup>a</sup> .80-.89 <sup>b</sup>
Caregiver Health	SF-12v2	Perception about their general health especially physical and mental health.	12-item Likert	Construct validity Test-retest= .89 <sup>a</sup> &.86 <sup>a</sup>
Caregiver Social Support	SSQ-6 (Sarason et al. 1987)	Perception of available social support and caregiver satisfaction with available social support and adult day service programs.	6-item questionnaire	Construct validity .92-.94 <sup>b</sup>
	CEADC (modified version)	Satisfaction with adult day care services.	PartI-10-item PartII-15-item PartIII-2 open-ended questions	
Caregiver Quality of Life	WHO QOL-BREF	Perception of physical health, psychological well-being, social relationships, and environment.	26-item Likert	Construct validity 0.84 <sup>b</sup>
Caregiver Characteristics & Frequency of Service Use	General Personal Data Survey	General information of PWD and caregivers includes gender, family income, frequency of ADC use, severity of dementia, caregiver-patient relationship, quality of relationship, duration of care, satisfaction with their care, family support, and other social supports.	PartI-10 items, PartII-36 items	

<sup>a</sup> Cronbach's alpha of original version with dementia caregivers

<sup>b</sup> Cronbach's alpha of Thai version with dementia caregivers or Thai population

No research documenting the sensitivity of the outcome measures to capture the changes occurring over time was found. A previous study with a single group repeated-measures design in 10 Thai caregivers of PWD found that the ZBI was sensitive enough to capture significant differences in caregiver burden between baseline and one-month after the intervention (Pankong, 2004). Another study tested an intervention for family caregivers of PWD at 3 time points (pre-intervention or the first week, post-intervention (week 8), and the 16-week follow-up) and showed that the ZBI and the CES-D captured significant changes in caregiver burden and depression between the first week and the sixteenth week ( $n = 16$ , Bormann et al., 2009). A similar study found that the CES-D was sensitive to significant differences in caregiver depression between baseline and three months of ADC use ( $n=400$ , Gaugler, Zarit, Townsend, Stephens, & Greene, 2003). Dias and colleagues showed that the ZBI measure was sensitive enough to capture significant differences in caregiver burden between baseline and at 6 months ( $n=80$ , Dias, Dewey, D'Sousa, Dhume, Motghare, Shaji, Menon, Prince, & Potel, 2008).

Caregiving characteristics are background factors that might affect the caregiving experience that may act as confounding variables or covariates. These variables include gender, family income, caregiver-patient relationship, and severity of dementia. Frequency of service use and research site were also examined for a covariate effect on the study outcomes. Caregiving characteristics were collected with the General Personal Data Survey.

### **Qualitative Data**

Qualitative data were collected from interviews, observations, field notes, documents, and other related materials. The research investigator who collected data served as the “instrument” through which data were collected (Rew, Bechtel, & Sapp,

1993). Caregiver participants who used the ADC services at least 3 months were interviewed for approximately 45-60 minutes. A semi-structured interview with two open-ended questions was used to guide the interviews. The interviews were conducted by a researcher who was trained for collecting data with qualitative techniques. Two open-ended questions were “What are your experiences with ADC?” and “Has your life changed in any way since your relative started attending ADC?” Questions to gain further understanding or clarification might include “How do you feel about it?”, “How does your family feel about it?”, “What are your positive experiences?”, and “What are your negative experiences?” Follow-up probes were used to encourage participants to explain more fully or to clarify meanings of participants’ responses.

The interviews were audio-taped, transcribed in Thai, and analyzed to establish categories in Thai. All emerged categories and quotes were translated from Thai to English before blind back-translation by an outside bilingual translator. An expert panel committee which included native and bilingual speakers verified the findings of both versions in order to ensure equivalence of meaning for both versions (Chen, & Boore, 2009). Observations and field notes were written in a personal notebook at each visit to the ADC sites or in meetings with participants. Documents and other related materials, for example, brochures of ADC programs, schedules of ADC services, pictures, and any available official reports were also collected for data analyses.

### **Procedures**

A single group repeated-measures design was employed to answer the proposed research questions to determine whether family caregivers of PWD who used ADC experience lower burden, lower depression, better health, and higher quality of life after



one and three months compared to baseline. This study evaluated adult day services as an intervention compared over three months.

A clinical nurse at each research site was invited to be a research assistant to help screen and encourage eligible caregivers of PWD to enroll and participate in the study. The research assistants were a clinical nurse manager of the long-term care unit and a clinical registered nurse of ADC. Both research assistants were trained about human subject protection and the Health Insurance Portability Accountability Act of 1996 (HIPAA) online training, research protocol, procedures, questionnaires, and informed consent sheets. They asked permission from eligible participants to allow a contact with the research investigator for a research invitation and a formal research informed consent. The research investigator contacted caregiver participants to provide questionnaires and make an appointment for the next questionnaires and an interview. The research investigator also met caregiver participants during the study periodically to talk about their relative and their daily problems.

### **Ethical Considerations**

The research proposal was submitted to both ADC settings and to the Institutional Review Board (IRB) from the Kansas University Medical Center (KUMC) for approval. Both research assistants completed KUMC Human Subject Committee and Conflict of Interest forms including KUMC human subjects protections and HIPAA online training. Letters were sent to both ADC settings to ask permission for collecting data with dementia patients and their caregivers. After receiving permission and approval of this research proposal, meetings among the research investigator and the ADC personnel were held to assure that research procedures were conducted in the same manner at both sites.

Eligible caregivers at both ADC sites were contacted and invited to participate in the study. The researcher explained the purpose, benefits and risks of the study including the participants' right to withdraw at any time. Only family caregivers who were willing to participate in the study and who provided their signature on a written consent form were eligible. The written informed consent that was obtained from the caregiver participants included verbal assent for the PWD. (See Appendix B)

### **Data Collection Procedures**

After caregiver participants provided their signature on the consent form, they were interviewed with the General Personal Data Survey at either the ADC settings or the caregiver's home. They were also asked to complete the questionnaires which included the ZBI, the CES-D, the WHO QOL-BREF, the SF-12v2 health survey, and the Sarason's Social Support Questionnaire (SSQ-6) before or within one week after admission to the ADC. For the second phase (one month later) participants were contacted and asked to independently complete the same set of questionnaires. For the third phase participants were again asked to complete the same questionnaires and the CEADC. A separate interview between each caregiver and the research investigator was also conducted in order to ask two open-ended questions and additional probes. Each participant consented to the audio-recorded interview. Each interview lasted approximately 45-60 minutes and was conducted at the ADC site, caregiver's home, or an alternatively agreed upon confidential place. Each participant was encouraged to respond to questions until the point of data saturation or no new information. The interviewer summarized the main information and asked participants to verify their comments at the end of the interview.

During the study, the research investigator and two research assistants kept in touch and followed up with each participant through phone or in-person at the ADC site every two weeks. The meetings among the research investigator and the ADC administrators were conducted every month in order to identify and discuss any existing research issues.

## **Data Analyses**

### **Quantitative Data Analyses**

Questionnaire responses including key sample characteristics were coded and entered into the Statistical Program for Social Sciences (SPSS) software program version 19.0. The independent variable was ADC use. The quantitative outcomes included scores on the measures of caregiver burden, caregiver depression, caregiver health status, caregiver social support, and caregiver quality of life. Repeated measure ANOVA was used to compare differences in the outcomes over time. Student's t-test (independent t-test) was employed to examine covariate effects of the key characteristics (gender, family income, caregiver-patient relationship, frequency of service use, and severity of dementia) that could act as covariates (Campbell et al., 2009; Coen, O'Boyle, Coakley, & Lawlor, 2002; Huang et al., 2008). The research sites were also examined for a covariate effect. The Student's t-test is commonly used to examine equality of means as well as covariate imbalances of two groups (Zhao, Hill, & Palesch, 2012).

Prior to analysis, quantitative data collected at each time (baseline and after 1 month and 3 months) was explored to identify missing data and outliers and to evaluate the normal distribution of each studied variables. The amount and the patterns of missing data were considered. Systematic missing data or missing not at random was critically judged

with the appropriate solution identified in order to strengthen the validity of the findings. Content validity and reliability were assessed on the measured.

Descriptive statistics and frequency distributions were used to describe the characteristics of the sample and the study variables. Preliminary analyses were conducted to examine the underlying assumptions of the Student's t-tests, the repeated measures ANOVA and multivariate analysis such as normality, linearity, homogeneity of variance-covariance matrices, independence of observations, and reliability of measurement through histograms, boxplots, Kolmogorov-Smirnov tests, Shapiro-Wilk test, residuals analysis, Box's M test, Bartlett's test, and Cronbach alphas. Since the effects of caregiver characteristics (gender, family income, caregiver-patient relationship, and the severity of dementia) and frequency of service use might also affect caregiver outcomes, Student's t-tests (independent sample t-tests) were conducted to determine whether these factors were significant covariates and to examine homogeneity across the ADC settings. If significant differences between the two ADC settings were found on the outcome variables, settings were considered as another possible covariate factor. Content validity and reliability were assessed on the measures.

Repeated measures ANOVA was used to test whether there were significant differences between baseline and after using ADC services at one and three months. A decrease, increase or no change in caregiver outcomes were possible. When statistical significance was obtained in the repeated measures ANOVA, Bonferroni's post-hoc test was used to identify which of the group mean differ from each other. The Bonferroni's test is a powerful procedure with a small number of contrasts (Park, Cho, & Chi, 2009).

Another advantage of the Bonferroni method is that it reduces the probability of a Type I error by its limits on alpha inflation (McHugh, 2011).

If covariate factors were identified, they will be controlled in the analysis.

MANOVA is an alternative method to examine the differences across time when the assumption of sphericity necessary for ANOVA is not met (Overall & Atlas, 1999; Maxwell, & Delaney, 2004). However, the MANOVA is less powerful than repeated measures ANOVA when the sample size is smaller than number of levels of the repeated measures factor plus ten ( $n < k + 10$ ) (Moulton, 2010). When the sphericity violation is not large (epsilon ( $\epsilon$ ) > .7), an adjustment to the numerator and denominator degrees of freedom with the Greenhouse-Geisser or Huynh-Feldt estimates should be used for the correction (Moulton, 2010). The Huynh-Feldt correction should be applied when epsilon is larger than .75 and the Greenhouse-Geisser should be applied when epsilon is less than .75 (Girden, 1992).

These analyses provided answers for the first research question: whether family caregivers of PWD who used ADC for one and three months experienced reductions in burden and depression, better health, and higher quality of life than before using ADC services. An alpha level of 0.05 was established as the criteria for significance for all statistical tests.

### **Qualitative Analysis**

Two questions with additional probes were used to explore caregivers' experiences with ADC and how their life changed since their PWD started attending the ADC. These interviews were conducted after 3 months of ADC use. These qualitative data also provided an evaluation of the effectiveness of the ADC services from the perspective of program users. Qualitative data in summative evaluations typically add depth, detail, and nuance to quantitative finding, rendering insights through examining individualized

outcomes and issues of quality or effectiveness. Summative evaluations serve the purpose of rendering an overall judgment about the effectiveness of the program that could support a decision for continuing ADC services. This information may or may not be generalized to other situations (Patton, 2002).

Qualitative data analysis was initiated at the beginning of data collection. Observations and field notes were recorded to provide insight and other needed information over time. The final analysis or content analysis was conducted after all data collection was completed. All interviews were transcribed verbatim in Thai (without correction of grammar). Following transcription, the content was checked for accuracy.

Inductive content analysis was used to analyze the interview transcripts and other qualitative data, using the process described by Elo and Kyngas (2007). The analysis process is a systemic and objective means of describing and quantifying phenomena (Elo and Kyngas, 2007; Sandelowski, 1995) and generally used to refer to any qualitative data reduction and sense-making effort that takes a volume of qualitative material and attempts to identify core consistencies and meanings (Patton, 2002). The core meanings were categories and patterns describing the study phenomena. Basically, inductive content analysis aims to organize fragmented qualitative data into a larger and more meaningful phenomenon and it is used when there is not enough former knowledge about the phenomena. The inductive content analysis includes open coding, creating categories, and abstraction (Elo & Kyngas, 2007).

All interview transcripts, field notes, and documents were initially read thoroughly several times to get a sense of the whole. Transcripts were searched for recurring words and sorted into categories by open coding. The units of analysis, which were specified as word, phrase, sentence, part of a clause and part of a sentence, were written down in the

margins in order to capture all answers to the two main open-ended questions and to describe all aspects of the content. The units of meaning were collected from the margins and transferred on to coding sheets.

Categories, sub-categories and patterns were organized, labeled, and revised on the coding sheet and included feelings, expectations, outcomes, changes of life, difficulties, strengths, weaknesses and recommendations. Comments were organized into similar categories. Similarities and differences were explored and compared. Similar units of meaning or patterns were grouped together. Smaller categories were collapsed into broader higher order categories. Sub-categories with similar events and incidents were grouped together as main categories. Each category was named according to its content. Themes were not identified at this time. The emerged main categories and sub-categories were compared and linked together in order to figure out possible associations or causal relationships in the findings.

Abstraction means formulating description through generating categories. The aim of this abstraction was to form descriptive categories which offer considerable depth and breadth of understanding about the phenomena of interest and the relationships to other categories.

The processes of inductive content analysis were interrelated and fully iterative. All transcripts were again read line by line and coded systematically. These codes were then compared, integrated, and refined to develop the main categories and sub-categories of this study. The interpretation moved back and forth between part and the whole of the data. Data saturation was reached when codes and categories in the data become repetitive and redundant, and no new information was obtained by further data collection (Polit, Beck, & Hungler, 2001; Polit, & Beck, 2008).

Interviews, field notes, and observations data were transcribed verbatim in Thai. The data analysis process was done by hand in the Thai language. Data was discussed and debated with research assistants and experts experienced in qualitative research to enhance trustworthiness and methodological rigor. The Thai main categories, sub-categories, and quotes were translated into English by a researcher. These main categories, sub-categories, and quotes in English version were validated with a Thai bilingual specialist and a native speaker. The Thai bilingual specialist was a Thai qualitative expert who well understood both languages and who reviewed interview transcripts, the findings, and the translation from Thai language to English in order to validate the content. The back-translation of all descriptions and quotes by an outside bilingual speaker who was familiar with the area was conducted. An expert panel committee which composed of bilingual speakers and native speaker compared and validated the findings between English version and Thai version in order to reach final agreement on the translation. The translation, blind back-translation, and the involvement of the expert panel were recommended in this study in order to ensure equivalence of meaning of the findings across languages, achieve comparability of grammatical forms, make participants' words understandable, and increase trustworthiness and rigour of the study (Chen & Boore, 2009).

### **Time Frame**

The study took place from January 2010 through May 2011. The research investigator began to collect data after getting an approval and permission from both research sites and IRB, KUMC in May 2010. Data collection was continued until at least 16 caregivers completed the study.



## **Chapter Four**

### **Results**

This chapter presents the study results including descriptive data and data analyses. The descriptive data includes demographic characteristics of caregivers, demographic characteristics of PWD receiving care, description of the settings, and description of transitional and effectiveness outcomes. Quantitative caregiver outcomes from surveys and qualitative analysis of caregiver interviews were completed. Both quantitative and qualitative findings from data analyses are reported.

#### **Descriptive data**

##### **Demographic Characteristics of Caregivers**

Eighteen family caregivers were enrolled in the study. Two of them dropped out during the study because they discontinued the use of ADC services. One of them was too agitated to participate in ADC activities and the other moved their residence far away from the ADC setting. Ultimately, only sixteen family caregivers continued to use ADC services and completed the study. Data analysis included those 16 caregivers who completed the study.

Most family caregivers were female ( $n=9$ , 56.3%). The age of participants was from 39-71 years and the mean age was 53.56. The ages can be broken into five groups: below 40 ( $n=1$ , 6.3%), 41-50 ( $n=7$ , 43.7%), 51-60 ( $n=3$ , 18.8%), 61-70 ( $n=4$ , 25%), and older than 71 ( $n=1$ , 6.3%). Most participants ( $n=7$ , 43.7%) were between 41 and 50 and the remaining are detailed in table 2.

Most participants were married ( $n=7$ , 43.7%) while others were single ( $n=4$ , 25%), divorced ( $n=4$ , 25%) or widowed ( $n=1$ , 6.3%). Most of them held a Bachelor's

degree ( $n=7$ , 43.7%). Five participants (31.3%) had less education than a Bachelor's degree, and four participants (25%) had higher than a Bachelor's degree. Most of them ( $n=8$ , 50.2%) earned an average family income lower than 30,000 baht (as equivalent as \$1,000) a month while the remainder ( $n=7$ , 43.7%) earned higher than 30,000 baht. The average family income for a Thai in Bangkok and Metropolitan Region is approximately 33,000 baht (\$1,100) per month (National Statistical Office Thailand, 2011). One participant did not provide this information. Most participants were either a son or a daughter of their care recipient ( $n=11$ , 68.8%). Five participants (25%) were the care recipients' spouse and one (6.3%) was a sister. All participants reported that they provided both supervision and direct care at least 4 hours per day. Eight of them (50%) reported that they provided both supervision and direct care 24 hours per day. The demographic characteristics of caregivers and caregiving characteristics are summarized in Table 2 and Table 3.

Table 2

*Demographic Data of Family Caregiver Participants. (N=16)*

Characteristics		Number (n)	Percent (%)
Gender	Female	9	56.3
	Male	7	43.7
Age	≤ 40	1	6.3
	41-50	7	43.7
	51-60	3	18.8
	61-70	4	25.0
	≥ 71	1	6.3

Table 2

*Demographic Data of Family Caregiver Participants. (N=16) (continued)*

Characteristics		<i>n</i>	Percent (%)
Marital status	Married	7	43.7
	Single	4	25.0
	Divorced	4	25.0
	Widowed	1	6.3
Education	Below Bachelor's degree	5	31.3
	Bachelor's degree	7	43.7
	Higher than Bachelor's degree	4	25.0
Family income (Missing =1)	Lower than 30,000 baht	8	50.2
	30,000 baht or higher	7	43.7
Caregiver relationship	Children	11	68.8
	Spouse	4	25.0
	Others (sister)	1	6.3
Hours per day of daily care	4- 8 hours	4	25.0
	9-16 hours	4	25.0
	17-24 hours	8	50.0

Most participants ( $n=7$ , 43.8%) rated their monthly family income as adequate or 5 on a scale ranging from 0 (I can't make ends meet) to 10 (I always have money left over). According to table 3, mean adequacy of monthly family income of this sample group was 6.03 where as standard variation was 2.52. Seven participants (43.7%) rated the

level of attachment in their relationship with their PWD. On a rating scale of 0 (not attached) to 10 (very attached), mean attachment was 8.38 ( $SD= 1.89$ ).

Table 3

*Mean and Standard Variation of Age, Adequacy of Family Income and Quality of Attachment (N=16)*

Characteristics	<i>M</i>	<i>SD</i>
Age	53.56	10.21
Adequacy of family income (range 0-10)	6.03	2.52
Quality of attachment (range 0-10)	8.38	1.89

### **Demographic Characteristics of PWD Receiving Care**

Most of the PWD were female ( $n=12, 75\%$ ). The age of participants ranged from 52-87 years and mean of age was 73.81. PWD age can be grouped into four distinct groups: less than 60 ( $n=1, 6.3\%$ ), 61-70 ( $n=5, 31.3\%$ ), 71-80 ( $n=5, 31.3\%$ ), and greater than 81 years ( $n=5, 31.3\%$ ). Five participants ( $31.3\%$ ) were between 61-70, 71-80, and 81-90, and only one was in range between 51 and 60.

Most PWD were widowed ( $n=8, 50\%$ ), but others were married ( $n=7, 43.7\%$ ), or divorced ( $n=1, 6.3\%$ ). Most had less than a Bachelor's degree ( $n=13, 81.3\%$ ). Two of them ( $12.5\%$ ) had a Bachelor's degree and only one ( $6.3\%$ ) had education higher than a Bachelor's degree. Most PWD ( $n=9, 56.3\%$ ) were in the second stage of disease (moderate dementia) as classified by the researcher with the MMSE and the BADLS. Others were in the first (mild) stage of disease ( $n=7, 43.7\%$ ). Most PWD in the study ( $n=9, 56.3\%$ ) used ADC services at Chiangmai Neurological hospital and others used ADC services at

Somdet Chaophaya Institute of Psychiatry, Bangkok in Thailand ( $n=7$ , 43.7%). Seven PWD (43.7%) used ADC services one day per week. Five PWD (31.3%) used ADC services 4-5 days per week, and four PWD (25%) used ADC services 2-3 days per week. Mean frequency of ADC use was 2.63 days per week. The demographic data of the PWD are summarized in Table 4 and Table 5.

Table 4

*Demographic data of PWD*

Characteristics		<i>n</i>	Percent (%)
Gender	Female	12	75.0
	Male	4	25.0
Age	≤ 60	1	6.3
	61-70	5	31.3
	71-80	5	31.3
	≥ 81	5	31.3
Marital Status	Married	7	43.7
	Divorced	1	6.3
	Widowed	8	50.0
Education	Less than Bachelor's degree	13	81.3
	Bachelor's degree	2	12.5
	Higher than Bachelor's degree	1	6.3

Table 4

*Demographic Data of PWD (continued)*

Characteristics		<i>n</i>	Percent (%)
Stage of Disease	Stage I	7	43.7
	Stage II	9	56.3
Research site	Bangkok	7	43.7
	Chiangmai	9	56.3
Frequency of service use at baseline	1 day per week	7	43.7
	> 1 day per week	9	56.3

Table 5

*Mean and Standard Variation of Age and Frequency of ADC Use (N=16)*

Characteristics	<i>M</i>	<i>SD</i>
Age	73.81	9.74
Frequency of ADC use (days per week)	2.63	1.78

**Description of the Settings**

ADC services are recognized as a specialized intervention for PWD and their family caregivers in the day time. The Somdet Chaophaya Institute of Psychiatry provides ADC services focusing on structured therapeutic activities for the PWD 3 days per week. Caregivers received systematic assessment and individual counseling as needed. Seminars for caregivers were arranged periodically. The Chiangmai Neurological Hospital provides ADC services 5 days per week, but only one day per week provides structured therapeutic activities and a support group for family caregivers. These therapeutic services were

provided by occupational therapists, psychologists, nutritionists, and nurses. During the remainder of the week ADC staff generally assist PWD in activities of daily living and personal care. The PWD at both research sites continue to receive medical care and meet with their physician as usual. Neither ADC site provided transportation. One PWD at the Somdet Chaophaya Institute of Psychiatry was transported to ADC by a staff member of the Somdet Chaophaya Institute of Psychiatry.

Staff at the Somdet Chaophaya Institute of Psychiatry ADC included two registered nurses and a nurse aid, whereas the Chiangmai Neurological Hospital staff was composed of one registered nurse and two nurse aids. Approximately 3-6 PWD attended at both ADC sites each day. Both research sites were different in settings and surroundings. The Somdet Chaophaya Institute of Psychiatry is located in a compact room at ground-level in the outpatient neurological department. The Chiangmai Neurological Hospital is located in a hall room on the second floor with an elevator provided for convenience. Each ADC site has a large table with chairs for group activities. There are benches and couches provided for caregivers in an adjoining room that is visible to the patient area. The ADC staff of both research sites had their lunch at the same table as the PWD to make the environment more home-like and foster a sense of family. The ADC in Chiangmai Neurological Hospital provides amenities such as a small aquarium, a television, and a refrigerator. In addition children and cats are allowed to visit the area. The ADC in Somdet Chaophaya Institute of Psychiatry provides a television and a refrigerator but pets are not allowed to come in the area. See Table 6 for examples of typical activities at each ADC.

Table 6

*Examples of Daily Activities in ADCs*

Somdet Chaophaya Institute of Psychiatry	Chiangmai Neurological Hospital
09.00 am Orientation	08.00 am Table Games
09.15 am Buddhist Prayer	09.00 am Orientation & Participant Introduction
09.30 am Brain Stimulation Activities (word puzzles/ card games/guess the place etc.)	09.15 am Exercise
10.30 am Break	09.30 am Brain Stimulation Activities (neurobic- exercises/card games/guess the word etc.)
10.45 am Group activities (games, drawing, creation)	10.45 am Snack Break & Table Discussion Group
12.00 Lunch	12.00 Lunch
01.00 pm Recreation/Creation/Exercises/Cooking	01.00 pm Recreation/Creation/Exercise/Cooking
03.00 pm Break & Table Discussion Group	03.00 pm Snack Break & Games
04.00 pm Closed	03.30 pm Shower
	04.00 pm Closed

**Description of Transitional and Effectiveness Outcomes**

Data were collected from the caregivers of PWD at three periods of time: within one week of enrollment in ADC (baseline), and one and three months after starting ADC services. Quantitative outcomes compared caregiver burden, caregiver depression, caregiver general health status, caregiver social support, and caregiver quality of life. The caregiver outcomes were measured with five instruments and two surveys. All of them have been translated into Thai language. The five instruments included the Zarit Burden Interview (ZBI), the Epidemiologic Studies-Depression Scale (CES-D), the Short form 12-item health survey (SF-12v2), the Sarason's Social Support Questionnaire (SSQ-6), and the WHO QOL-BREF-THAI. The two surveys included the General Personal Data Survey and the Caregiver Evaluation of Adult Day Care (CEADC).



Caregiver burden was measured by the Zarit Burden Interview (ZBI). The means of the ZBI scores at baseline, 1 month, and 3 months were 37.19 ( $SD=17.57$ ), 36.31 ( $SD=17.96$ ), and 33.06 ( $SD=14.63$ ) with a range from 16-74, 11-75, and 10-60 respectively. At the baseline two caregivers (12.5%) received ZBI scores greater than 60 (indicating severe burden), four caregivers (25%) received ZBI scores from 41 to 60 (indicating moderate-severe burden), six caregivers (37.6%) received ZBI scores from 21 to 40 (indicating mild-moderate burden), and four caregivers (25%) received ZBI scores from 0 to 20 (indicating no burden). After using ADC for a month two caregivers (12.5%) received ZBI scores greater than 60, and each five caregivers (31.3%) received ZBI scores from 21 to 40 and 41 to 60. After the use of ADC for 3 months four caregivers (25%) received ZBI scores from 41 to 60, eight caregivers (50%) received ZBI scores from 21 to 40, three caregivers have no burden, and none have severe burden.

Possible scores of each item on the ZBI scale ranges from 0 (never or no burden) to 4 (nearly always or highest burden). Mean scores for specific items on the ZBI scale ranged from .69 to 2.25 and only two items ranged from 2.69 to 3.19. The former one, “Do you feel your relative is dependent on you?” Participants perceived that their dementia relative was dependent on them quite frequently ( $M_1=3.19$ ,  $SD=.98$ ;  $M_2=3.06$ ,  $SD=1.34$ ;  $M_3=2.75$ ,  $SD=1.13$ ). This was congruent with another item, “Do you feel that your relative seems to expect you to take care of him/her as if you were the only one he/she could depend on?” Participants perceived that their relative expected them to take care of him/her rather frequently ( $M_1=2.69$ ,  $SD=2.69$ ;  $M_2=2.69$ ,  $SD=1.45$ ;  $M_3=2.31$ ,  $SD=1.49$ ). Overall, participants perceived their burden in caring for their dementia relative in the moderate level ( $M_1=2.06$ ,  $SD=1.29$ ;  $M_2=2.69$ ,  $SD=1.45$ ;  $M_3=2.00$ ,  $SD=1.26$ ).

The mean of some items fluctuated. For example, one item of the ZBI, “Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?” The mean item scores increased from baseline ( $M_1 = 2.06$ ,  $SD = 1.24$ ) after one month ( $M_2 = 2.25$ ,  $SD = .96$ ) and decreased at the third month ( $M_3 = 1.63$ ,  $SD = 1.24$ ) at ADC use. For this study, Cronbach’s alpha coefficient of the ZBI-Thai version ranged from .93 to .94 which indicated a high level of internal consistency.

Caregiver depression was measured by the Epidemiologic Studies Depression Scale (CES-D). Scores on four items including item 4, 8, 12, and 16 were reversed before computing the caregiver depression scores per scoring instructions. The means of the CES-D scores at baseline, 1 month, and 3 months were 18.56 ( $SD = 12.54$ ), 17.96 ( $SD = 10.42$ ), and 16.38 ( $SD = 10.42$ ) with a range from 5-44, 3-36, and 3-40 respectively. At baseline nine caregivers (56.3%) received CES-D scores 16 or above considered to reflect the need for further assessment and evaluation for depression. Eight of all caregivers (50%) received CES-D scores 16 or above at the first month and seven caregivers (43.8%) received CES-D scores 16 or above at the third month.

Possible scores on each item on the CES-D scale ranged from 0 (never or no depression) to 4 (most or highest depression). Mean scores for specific items on the CES-D scale ranged from .25 to 1.69 after four positive items were reversed. Scores of some items suggested that caregivers recovered from depression after using ADC services. For example, one caregiver reported their depressive emotion through an item “I felt depressed.” The mean score of this item decreased after 3 months ( $M_3 = .63$ ,  $SD = .72$ ) when compared with baseline ( $M_1 = 1.0$ ,  $SD = .97$ ). On the other hand, caregivers reported their happiness through an item “I was happy”. The mean scores of this item were higher after

the use of ADC for one and three months ( $M_1=1.69, SD=.79; M_2=1.88, SD=.62, M_3=2.06, SD=.93$ ).

Moreover, caregivers reported that they felt better about themselves through an item “I felt I was just as good as other people.” The mean scores of this item were higher after the use of ADC for one and three months ( $M_1=1.31, SD=1.14; M_2=1.88, SD=.96, M_3=2.06, SD=.93$ ). Some caregivers reported that the use of the ADC showed the goodness of caregivers who took care of their parent or loved one. The mean scores of an item “I had trouble keeping my mind on what I was doing” decreased across time ( $M_1=1.5, SD=1.15; M_2=1.18, SD=.91, M_3=.94, SD=.85$ ). For this study, Cronbach’s alpha coefficient of the CES-D-Thai version ranged from .92 to .93 which indicated a high level of internal consistency.

Caregiver quality of life was measured by the WHO QOL-BREF-THAI. Scores of three items including item 3, 4, and 26 were reversed per scoring instructions before computing the caregiver quality of life scores. Means of physical domain at baseline, 1 month, and 3 month were 11.96 ( $SD= 1.71$ ), 12.78 ( $SD= 1.71$ ), and 13.29 ( $SD= 1.81$ ) with a range from 8-14, 9-16, and 10-17 respectively. Means of psychological well being domain at baseline, 1 month, and 3 month were 12.67 ( $SD= 2.48$ ), 13.50 ( $SD= 1.89$ ), and 13.42 ( $SD= 2.15$ ) with a range from 8-17, 11-17, and 11-17 respectively. Means of social relationships domain at baseline, 1 month, and 3 month were 6.67 ( $SD= 3.67$ ), 14.00 ( $SD= 2.83$ ), and 13.92 ( $SD= 3.3$ ) with a range from 7-17, 9-20, and 8-20 respectively. The mean of environment domain at baseline, 1 month, and 3 month were 12.59 ( $SD= 2.75$ ), 13.16 ( $SD= 2.51$ ), and 13.69 ( $SD= 2.31$ ) with a range from 9-20, 9-18, and 11-19 respectively.

Means of the WHO QOL-BREF-THAI scores at baseline, 1 month, and 3 months were 86.93 ( $SD=15.24$ ), 89.25 ( $SD=14.70$ ), and 89.88 ( $SD=15.88$ ) with a range from 62-

120, 70-120, and 71-122 respectively. At baseline, most caregivers ( $n=11$ , 68.8%) reported a moderate level of quality of life and others received a high level quality of life.

When comparing the means of each item across time, the WHO QOL-BREF-THAI scores were not very different. Possible scores of each item on the WHO QOL-BREF-THAI scale ranges from 1 (very dissatisfied) to 5 (very satisfied). Mean scores for specific items on the WHO QOL-BREF-THAI ranged between moderate and high (from 2.88 to 4.13). For example, the mean scores of an item “How much do you enjoy life?” increased at one month and dropped at three months ( $M_1=3.31$ ,  $SD=.79$ ;  $M_2=3.56$ ,  $SD=.89$ ,  $M_3=3.38$ ,  $SD=1.02$ ). Similarly, the mean scores of an item “How would you rate your quality of life?” increased at three months ( $M_1=3.38$ ,  $SD=.72$ ;  $M_2=3.31$ ,  $SD=.71$ ,  $M_3=3.56$ ,  $SD=.81$ ). These findings suggest that caregivers who used ADC services had moderate and high overall quality of life.

Most participants reported moderate satisfaction with their health. For example, the mean scores of an item “How satisfied are you with your health?” decreased slightly after one and three months when compared with baseline ( $M_1=3.31$ ,  $SD=.87$ ;  $M_2=3.19$ ,  $SD=.91$ ,  $M_3=3.13$ ,  $SD=.96$ ). Moreover, the mean scores of an item “How often do you have negative feelings such as blue mood, despair, anxiety, depression?” also supported that most caregivers reported stable depressive emotions at one and three months compared with baseline ( $M_1=3.81$ ,  $SD=.83$ ;  $M_2=3.75$ ,  $SD=.77$ ,  $M_3=3.88$ ,  $SD=.81$ ). However, most participants indicated that they had little need for medical treatment through an item “How much do you need any medical treatment to function in your daily life?” ( $M_1=4.13$ ,  $SD=.96$ ;  $M_2=4.06$ ,  $SD=.85$ ,  $M_3=3.94$ ,  $SD=1.12$ ).

Some items suggested that caregivers experienced better quality of life after the use of ADC services. For example, most participants reported that they had improved

concentration through an item “How well are you able to concentrate?” The mean score of this item at one and three months increased when compared with baseline ( $M_1 = 3.13$ ,  $SD = .81$ ;  $M_2 = 3.44$ ,  $SD = .73$ ,  $M_3 = 3.38$ ,  $SD = .89$ ). Moreover, most participants reported that they were moderately satisfied with their capacity for work through an item “How satisfied are you with your capacity for work?” The mean scores were increased at one and three months when compared with baseline ( $M_1 = 3.00$ ,  $SD = .82$ ;  $M_2 = 3.19$ ,  $SD = .98$ ,  $M_3 = 3.25$ ,  $SD = 1.13$ ). Furthermore, most caregivers reported that they were moderately satisfied with their sleep through an item “How satisfied are you with your sleep?” The mean scores of this item at one and three months were increased when compared with baseline ( $M_1 = 3.19$ ,  $SD = .98$ ;  $M_2 = 3.38$ ,  $SD = 1.26$ ,  $M_3 = 3.31$ ,  $SD = 1.08$ ). In addition, most caregivers reported that they were moderately satisfied with their leisure activities through an item “To what extent do you have the opportunity for leisure activities?” The mean scores of this item were fluctuated ( $M_1 = 3.19$ ,  $SD = .75$ ;  $M_2 = 2.88$ ,  $SD = .81$ ,  $M_3 = 3.00$ ,  $SD = .8$ ). Caregivers reported moderate satisfaction with their work, sleep, and relaxation during the study.

Most participants responded that they were more satisfied with social support over time. The mean scores of an item “How satisfied are you with the support you get from your friends?” increased at one and three months when compared with baseline ( $M_1 = 3.00$ ,  $SD = .89$ ;  $M_2 = 3.31$ ,  $SD = 1.14$ ,  $M_3 = 3.44$ ,  $SD = 1.03$ ). Therefore, there was a trend for increased social support for caregivers after using ADC services. For this study, Cronbach’s alpha coefficient of the WHO QOL-BREF-THAI-Thai version was .94 at three points of time which indicated a high level of internal consistency.

Caregiver general health status was measured by the Short form 12-item health survey (SF-12v2). The scores were computed into the norm-based physical component score (PCS) and the mental component score (MCS). The means of the PCS scores at

baseline, 1 month, and 3 months were 40.78 ( $SD=9.99$ ), 46.95, ( $SD=6.60$ ), and 47.98 ( $SD=10.01$ ) with a range from 10.24-54.63, 37.40-56.61 and 24.32-60.38 respectively. The means of the MCS scores at baseline, 1 month, and 3 months were 44.73 ( $SD=10.21$ ), 45.50 ( $SD= 6.60$ ), and 47.58 ( $SD=10.77$ ) with a range from 19.61-60.27, 19.61-63.10, and 25.34-68.22 respectively. For SF-12v2 (Thai version) in this study, Cronbach's alpha coefficient of the PCS ranged from .73 to .77 and of the MCS ranged from .79-.89.

Caregiver social support was measured by the Sarason's Social Support Questionnaire (SSQ-6). The scores of SSQ-N were from the summary of the number of available social support and divided by 6. The scores of SSQ-S were from the summary of the satisfaction with the available social support and divided by 6. The means of the SSQ-N scores at baseline, 1 month, and 3 months were 2.78 ( $SD=1.95$ ), 3.18 ( $SD= 2.14$ ), and 3.26 ( $SD= 2.15$ ) with a range from 0-6.17, 0-8.33, and 0.5-8 respectively. The means of the SSQ-S scores at baseline, 1 month, and 3 months were 5.21 ( $SD= 0.55$ ), 5.19 ( $SD= 0.50$ ), and 5.19 ( $SD= 0.53$ ) with a range from 4.17-6, 4.5-6, and 4.5-6 respectively.

Possible social support for each item ranged from 0-9. When comparing the means of SSQ-S across time, the mean scores of SSQ-S were not very different ( $M_1= 31.25$ ,  $SD=3.32$ ,  $M_2= 31.13$ ,  $SD=3.00$ ,  $M_3= 31.13$ ,  $SD=3.18$ ) and ranged from 25-36, 27-36, and 27-36 respectively. Each item ranged from 3 (a little satisfied) to 6 (very satisfied). Cronbach's alpha coefficient of the SSQ-N ranged from .95-.98 while the SSQ-S ranged from .81 to .92.

The evaluation of ADC was measured by the Caregiver Evaluation of Adult Day Care (CEADC) only after three months of attending ADC. Scores on the CEADC were divided into caregiver satisfaction with adult day care (CEADC Part I) and the benefit of adult day care (CEADC Part II). Scores of item 14, 15, and 16 of the CEADC Part II which

measured the drawbacks of adult day service use were reversed. The mean of the 12 item CEADC Part I ranged from 2.38 to 3.25 ( $SD=.60-1.15$ ) with a range from 0 to 4. The mean of the 17 item CEADC Part II ranged from 0.63 to 3.00 ( $SD=.62-1.45$ ) with a range from 0 to 4.

Caregivers were mostly satisfied with the use of the ADC services. Scores on individual items ranged from 1.88 to 3.63 and averaged 2.76 out of a maximum 4 points. The mean scores of each item of the CEADC Part I and Part II were summarized in Table 6 and Table 7. All study outcomes were summarized in Table 8. For this study, Cronbach's alpha coefficient of the CEADC Part I and Part II was .89 and .85 respectively.

Table 7

*Mean, Standard Variation, and Range of Each Item on the CEADC Part I (N=16)*

Items	<i>M</i>	<i>SD</i>	<i>Range</i>
<i>CEADC Part I</i>			
1. Skill of staff caring for patients with dementia	2.88	.62	1-4
2. Staff's ability to handle problematic behaviors of my Recipient	2.38	.81	1-3
3. Providing information needed for caring my recipient	2.81	.83	1-4
4. Friendliness and concern of staff	2.94	.68	1-4
5. Program activities	2.63	.89	0-4
6. Program meals	2.69	.60	2-4
7. Numbers of hours per day	2.63	.72	1-4
8. Numbers of day per week	2.56	.89	1-4
9. Location of day care	3.00	.73	2-4
10. Cost of day care	2.44	1.15	0-4
11. Respect for Human Rights	3.25	.68	2-4
12. Concern with spiritual and religious beliefs	2.88	.72	2-4

Table 8

*Mean, Standard Variation, and Range of Each Item of the CEADC Part II (N=16)*

Items	<i>M</i>	<i>SD</i>	<i>Range</i>
<u><i>CEADC Part II</i></u>			
1. My recipient is less agitated after attending ADC.	1.88	1.09	0-4
2. My recipient is less symptoms of apathy or depression after attending ADC.	2.31	1.08	0-4
3. My recipient is easier to handle after attending ADC.	2.56	1.09	1-4
4. My recipient sleeps better at night after attending ADC.	2.85	.86	1-4
5. My recipient benefits from being around others at ADC.	3.00	1.03	1-4
6. My recipient looks forward to going to ADC.	2.06	1.06	0-4
7. I look forward to time when my relative is at ADC.	2.38	1.45	0-4
8. I think ADC helps my relative function better mentally.	3.00	1.10	0-4
9. I think ADC helps my relative function better in activities of daily living.	2.88	1.09	1-4
10. I have time to relax when my relative is at ADC.	2.81	1.04	1-4
11. I have time to do chores when my relative is at ADC.	2.81	.91	1-4
12. I can do thing for myself when my relative is at ADC.	2.44	1.15	0-4
13. I have more time for my family while my relative is at ADC	2.38	1.26	0-4
14. Difficult to get my relative ready to go to ADC	.63	1.09	0-4
15. My recipient unwilling to go to ADC	1.13	1.4	0-4
16. My recipient is upset with me after attending at ADC	.38	.62	0-2
17. I worry about my relative when she is at ADC	.63	1.02	0-3



Table 9

*Mean and Standard Variation of the Study Outcomes at Three Periods of Time (N=16)*

Variables	Time 1 (baseline)			Time 2 (1 month)			Time 3 (3 months)		
	M	SD	Range	M	SD	Range	M	SD	Range
Caregiver burden (ZBI)	37.19	17.57	16-74	36.31	17.96	11-75	33.06	14.63	10-60
Caregiver depression (CES-D)	18.56	12.54	5-44	17.00	10.42	3-36	16.38	10.42	3-40
Caregiver quality of life (WHO QOL-BREF)	86.93	15.24	62-120	89.25	14.70	70-120	89.88	15.88	71-122
Caregiver health status									
- Physical component (PCS)	40.78	9.99	10.24-54.63	46.95	6.60	37.40-56.61	47.98	10.01	24.32-60.38
- Mental component (MCS)	44.73	10.21	19.61-60.27	45.50	6.60	19.61-60.27	47.58	10.77	25.34-68.22
Caregiver social support									
- Number of social support (SSQ-N)	2.78	1.95	0-6.17	3.18	2.14	0-8.33	3.26	2.15	1-48
- Satisfaction with social support(SSQ-S)	5.21	0.55	4.17-6	5.19	0.50	4.5-6	5.19	0.53	27-36
Evaluation of adult day care (CEADC)									
- Satisfaction with adult day care (Part I)	-	-	-	-	-	-	33.06	6.30	19-43
- Benefit of adult day care (Part II)	-	-	-	-	-	-	46.50	10.18	28-64

## **Data Analyses**

To answer the established research questions, data analyses included both quantitative and qualitative analysis components. Quantitative analysis was used to test for differences in caregiver outcomes at three points of time: baseline, after 1 and 3 months of ADC use. Qualitative analysis was employed to ascertain caregiver quality of life and changes due to the use of ADC services that could not be derived directly from the quantitative questionnaire.

### **Quantitative Analyses and Findings**

#### **Preliminary analyses.**

Prior to analysis, quantitative data from each period of data collection (baseline, after 1 month and after 3 months) were explored to identify missing data and outliers and to evaluate the normal distribution of each studied variables. Only some caregiver characteristics and some items of the General Personal Data Survey were missing. One of the caregivers chose not to provide information about their family income. Some participants could not answer some items of the General Personal Data Survey that related to their satisfaction with their experiences in ADC services due to being asked this on the first day of the use of ADC.

All of the dependent variables were normally distributed and linear at baseline as reflected in histograms, boxplots, normal probability plots, Kolmogorov-Smirnov tests and the Shapiro-Wilk test. Skewness of the SSQ-S scores was .07 that approximates normality. Skewness of the ZBI scores, the CES-D scores, the WHO QOL-BREF-THAI scores, and the SSQ-N scores were moderately skewed (.61, .66, .63, and .55 respectively). Skewness of the PCS scores (= -1.43) and MCS scores (= -1.21) were skewed left. Kurtosis ranged -

.62 to 3.9. However, the result of Kolmogorov-Smirnov test indicated that this set of data was normally distributed.

The results of histograms, boxplots, and normal probability plots showed graphically that the data collected at 1 month was normally distributed. Skewness of the ZBI scores was .12, approximately normal. The CES-D scores, the WHO QOL-BREF-THAI scores, the PCS scores, the MCS scores, and the SSQ-N scores, and the SSQ-S scores were moderately skewed (.51, .93, .28, .26, .84, and .52 respectively) and kurtosis ranged -.82 to .82. However, the result of Kolmogorov-Smirnov test and Shapiro-Wilk test indicated that this set of data reflected a normal distribution.

The results of histograms, boxplots, normal probability plots showed visually that the data set of the data collected at 3 months was normally distributed. The ZBI scores, the CES-D scores, the WHO QOL-BREF-THAI scores, the PCS scores, the MCS scores, the SSQ-N scores, and the SSQ-S scores were moderately skewed (.54, .74, 1.01, -.75, .08, .62, and .47 respectively) and kurtosis ranged -1.05 to .47. Despite the skewness of these scores, the result of Kolmogorov-Smirnov test and Shapiro-Wilk test indicated that this set of data were normally distributed.

In summary, the results showed that data from each of the three periods of time were normally distributed as reflected in histograms, boxplots, normal probability plots, Kolmogorov-Smirnov test and the Shapiro-Wilk test. The Shapiro-Wilk test, an appropriate alternative method to test normality for a group less than 50 cases, also found data on gender, family income, caregiver-patient relationship, frequency of service use, severity of dementia, and research sites were normally distributed.

**Initial assessment for possibility of covariates.**

A large number of covariates may reduce the statistical efficiency of procedures, however, particularly with small sample sizes, adding effective covariates can markedly improve the sensitivity of the statistical tests (Tabachnick & Fidell, 1996). The selected variables included were gender, family income, caregiver-patient relationship, frequency of service use, severity of dementia, and research sites. Based on the literature the following factors were examined for possible covariate effects on the dependent variables (Montgomery & Williams, 2001).

Due to the small sample size, these variables were treated as dichotomous variables with normal distributions. The Student's t-test (independent t-test) was employed to examine equality of these possible confounding variables on the study outcomes. The results of t-tests are equivalent to the results of ANOVA in examining group difference in normally distributed outcomes and the results of a linear regression with a single indicator variable (Lunt, 2012).

A significant difference between dichotomous group means is evidence of a relationship between the possible confounding variable and intervention effect. The apparent relationship is not due to the chance and the possible covariate needs to be controlled (Simkiss, Edmond, & Waterston, 2012). However, equivalent effects of potential covariate subgroup means indicate that the factor does not confound the analysis (and statistical adjustments are not indicated) (Watt & Berg, 2002). See Table 10.

Gender was divided into male and female. Family income was divided into average family income and lower (30,000 baht per month and lower) and higher than average family income (30,000 baht per month or higher). Caregiver-patient relationship was divided into children and others (spouse and sister). Frequency of service use was

divided into one day per week and more than one day per week. One day per week was equivalent to approximately four to ten hours per day. Since the hours per day or week in ADC varied among participants and services provided by research sites, it is more appropriate to classify attendance at ADC by days per week rather than hours per week. Severity of dementia was classified into stage I and stage II. Research sites were divided into Bangkok and Chiangmai.

Means of the ZBI scores, the CES-D scores, the WHO QOL-BREF-THAI scores, the PCS scores, the MCS scores, the SSQ-N scores, and the SSQ-S scores at the baseline were compared between females and males. The results showed that there were no significant differences on the ZBI scores ( $t=1.30$ ,  $df=14$ ,  $p >.05$ ), CES-D scores ( $t=.38$ ,  $df=14$ ,  $p >.05$ ), the WHO QOL-BREF-THAI scores ( $t=.73$ ,  $df=14$ ,  $p >.05$ ), the PCS scores ( $t=-.09$ ,  $df=14$ ,  $p >.05$ ), the MCS scores ( $t=.53$ ,  $df=14$ ,  $p >.05$ ), the SSQ-N scores ( $t=.12$ ,  $df=14$ ,  $p >.05$ ), and the SSQ-S scores ( $t=.79$ ,  $df=14$ ,  $p >.05$ ) based on gender.

Family income was divided into two groups to determine if outcome scores varied by participants of higher versus lower family incomes. Family income was divided into greater than or less than 30,000 baht, the average household family income in Bangkok (National Statistical Office Thailand, 2011). There were no significant differences on the ZBI scores ( $t=.92$ ,  $df=13$ ,  $p >.05$ ), CES-D scores ( $t=.75$ ,  $df=13$ ,  $p >.05$ ), the WHO QOL-BREF-THAI scores ( $t=-.79$ ,  $df=13$ ,  $p >.05$ ), the PCS scores ( $t=.87$ ,  $df=13$ ,  $p >.05$ ), the MCS scores ( $t=.$ ,  $df=13$ ,  $p >.05$ ), the SSQ-N scores ( $t=-.52$ ,  $df=13$ ,  $p >.05$ ), and the SSQ-S scores ( $t=.96$ ,  $df=13$ ,  $p >.05$ ) based on family income.

Also, caregiver-patient relationship was entered to examine whether outcome scores varied based on relationship status. The results showed that there were no statistically significant differences on the ZBI scores ( $t=-.21$ ,  $df=14$ ,  $p >.05$ ), CES-D

scores ( $t=-.81$ ,  $df=14$ ,  $p >.05$ ), the WHO QOL-BREF-THAI scores ( $t=.64$ ,  $df=14$ ,  $p >.05$ ), the PCS scores ( $t=.26$ ,  $df=14$ ,  $p >.05$ ), the MCS scores ( $t=1.0$ ,  $df=14$ ,  $p >.05$ ), the SSQ-N scores ( $t=.94$ ,  $df=14$ ,  $p >.05$ ), and the SSQ-S scores ( $t=.36$ ,  $df=14$ ,  $p >.05$ ) based on caregiver-patient relationship.

In addition, frequency of service use was examined to determine any effects of this variable. The results showed that there were no significant differences on the ZBI scores ( $t=-.29$ ,  $df=14$ ,  $p >.05$ ), CES-D scores ( $t=-.20$ ,  $df=14$ ,  $p >.05$ ), the WHO QOL-BREF-THAI scores ( $t=1.14$ ,  $df=14$ ,  $p >.05$ ), the PCS scores ( $t=.88$ ,  $df=14$ ,  $p >.05$ ), the MCS scores ( $t=.21$ ,  $df=14$ ,  $p >.05$ ), the SSQ-N scores ( $t=.02$ ,  $df=14$ ,  $p >.05$ ), and the SSQ-S scores ( $t=.90$ ,  $df=14$ ,  $p >.05$ ) related to frequency of service use.

Severity of dementia was examined to determine if outcome scores varied by participants classified as stage I or II. There were no statistical significant differences on the ZBI scores ( $t=.25$ ,  $df=14$ ,  $p >.05$ ), the CES-D scores ( $t=1.02$ ,  $df=14$ ,  $p >.05$ ), the WHO QOL-BREF-THAI scores ( $t=.28$ ,  $df=14$ ,  $p >.05$ ), the PCS scores ( $t=-.03$ ,  $df=14$ ,  $p >.05$ ), the MCS scores ( $t=.27$ ,  $df=14$ ,  $p <.05$ ), the SSQ-N scores ( $t=.17$ ,  $df=14$ ,  $p >.05$ ), and the SSQ-S scores ( $t=-.69$ ,  $df=14$ ,  $p >.05$ ) based on severity of dementia.

Research site data was compared to determine whether site influenced outcome scores. The results showed that there were no significant differences on the ZBI scores ( $t=.16$ ,  $df=14$ ,  $p >.05$ ), CES-D scores ( $t=.38$ ,  $df=14$ ,  $p >.05$ ), the WHO QOL-BREF-THAI scores ( $t=1.27$ ,  $df=14$ ,  $p >.05$ ), the PCS scores ( $t=.49$ ,  $df=14$ ,  $p >.05$ ), the MCS scores ( $t=.27$ ,

Table 10

*T-Test for Equality of Mean Dependent Variables on Potential Covariates*

Dependent Variables	Gender		Family Income		Caregiver-Patient Relationship		Frequency of Service Use		Severity of Dementia		Research Sites	
	t	P	t	P	t	P	t	P	t	P	t	P
Caregiver burden (ZBI)	1.30	.22	.92	.37	.21	.84	.29	.78	.25	.80	.16	.93
Caregiver depression (CES-D)	.38	.71	.75	.47	.81	.43	.20	.85	1.02	.32	.38	.82
Caregiver quality of life (WHO QOL-BREF-THAI)	.73	.48	.79	.44	.64	.54	1.14	.27	.28	.79	1.27	.43
Caregiver health status												
- Physical component (PCS)	.09	.93	.87	.40	.26	.80	.88	.40	.27	.79	.49	.63
- Mental component (MCS)	.53	.61	.38	.71	1.0	.33	.21	.84	1.14	.27	.27	.80
Caregiver social support												
- Number of social support (SSQ-N)	.12	.91	.52	.36	.94	.37	.02	.98	.17	.87	.71	.47
- Satisfaction with social support (SSQ-S)	.79	.44	.96	.32	.36	.73	.90	.38	.69	.50	1.74	.09

$df=9.94, p >.05$ ), the SSQ-N scores ( $t=1.14, df=13.62, p >.05$ ), and the SSQ-S scores ( $t=-1.74, df=14, p >.05$ ) based on research site.

In summary, at baseline the findings showed that gender, family income, caregiver-patient relationship, frequency of service use, and research site were equivalent between groups. Therefore, these variables were not analyzed as covariates for this study. Moreover, MANOVA was not applied in this study because no evidence of potential confounding variables that should be added as independent variables in the MANOVA.

### **Results of Repeated Measures ANOVA Testing.**

Quantitative analysis was used to answer the first research question: “Do caregivers of PWD who attended ADC have lower burden, lower depression, better health, higher social support, and higher quality of life after one month and three months compared to baseline?”

The repeated measures ANOVA was employed to examine the effect of ADC use on the dependent variables across three points of time. The Bonferroni's post-hoc test was employed to determine a pair of differences. Underlying assumptions of the repeated measures ANOVA such as normality, linearity, homogeneity of variance, and sphericity (or compound symmetry) were met as examined through histograms, boxplots, Q-Q plots, Kolmogorov-Smirnov test, Shapiro-Wilk test, and Mauchly's sphericity test. A significant level ( $p \leq .5$ ) of the Mauchly's sphericity test indicates that the sphericity assumption of the repeated measures ANOVA is not violated. That is, the variances of the differences between treatment levels are equal and the repeated measures analysis is robust (Park, Cho, & Ki, 2009). However, an adjustment to the degree of freedom can be used for the minimal sphericity violation ( $\epsilon > .7$ ) in small samples ( $n < k + 10$ ) (Moulton, 2010). The repeated



measures ANOVA approach possesses greater power than the MANOVA approach when sample size is small and the sphericity violation is not large (Moulton, 2010).

**Caregiver burden.** The ZBI scores were compared at three time points by using repeated measures ANOVA. Mauchly's sphericity test indicated that the assumption of sphericity was not violated ( $\chi^2(2) = 4.51, p > .05$ ). The results of the repeated measures ANOVA showed that there were no significant difference in the ZBI scores ( $F(2,30)=1.5, p > .05$ ) across the three time periods.

**Caregiver depression.** The CES-D scores were compared at three time points by using repeated measures ANOVA. Mauchly's sphericity test indicated that the assumption of sphericity was not violated ( $\chi^2(2) = 2.79, p > .05$ ). The results of the repeated measures ANOVA showed that there were no statistically significant differences in the CES-D scores ( $F(2,30)=1.93, p > .05$ ) across the three time periods.

**Caregiver quality of life.** Each domain of the WHO QOL-BREF-THAI scores was compared at three time points by using repeated measures ANOVA. The physical health domain scores were compared. Mauchly's sphericity test indicated that the assumption of sphericity was not violated ( $\chi^2(2) = .21, p > .05$ ). The results of the repeated measures ANOVA showed that there were significant difference in the physical domain of the WHO QOL-BREF-THAI scores ( $F(2, 30)=4.86, p < .05$ ) across the three time periods. The Bonferroni post-hoc test was used to perform pairwise comparisons and to identify mean difference across time. Mean differences in the physical health domain scores between baseline and one month ( $p < .05$ ) and three month ( $p < .05$ ) were significant.

The psychological well being domain scores of the WHO QOL-BREF-THAI scores were compared at three time points by using repeated measures ANOVA. Mauchly's sphericity test indicated that the assumption of sphericity was not violated ( $\chi^2(2) = 4.16$ ,  $p > .05$ ). The results of the repeated measures ANOVA showed that there were no statistically significant differences in the psychological domain ( $F(2,30)=1.38$ ,  $p > .05$ ) across the three time periods.

The social relationship domain of the WHO QOL-BREF-THAI scores was examined in at three time points by using repeated measures ANOVA. Mauchly's sphericity test indicated that the assumption of sphericity was not violated ( $\chi^2(2) = 2.56$ ,  $p > .05$ ). The results of the repeated measures ANOVA showed that there were no statistically significant differences in the social relationship domain ( $F(2,30)=2.88$ ,  $p > .05$ ) across the three time periods.

The environment domain of the WHO QOL-BREF-THAI scores was examined in at three time points by using repeated measures ANOVA. Mauchly's sphericity test indicated that the assumption of sphericity was not violated ( $\chi^2(2) = 4.27$ ,  $p > .05$ ). The results of the repeated measures ANOVA showed that there were no statistically significant differences in the psychological domain ( $F(2,30) = 1.70$ ,  $p > .05$ ) across the three time periods.

The total WHO QOL-BREF-THAI scores were compared at three time points by using repeated measures ANOVA. Mauchly's sphericity test indicated that the assumption of sphericity was not valid ( $\chi^2(2) = 7.41$ ,  $p < .05$ ). The Geisser-Greenhouse epsilon was suggested to use for a correctional adjustment when the violation is minimal ( $.9 > \epsilon^{\wedge} > .7$ ) (Moulton, 2010). For this analysis, the epsilon was .71. The Greenhouse-Geisser correction was used because of the minimal sphericity violation. When using repeated measures of

ANOVA with a Greenhouse-Geisser correction, there were no significant difference in the WHO QOL-BREF-THAI scores ( $F(1.42, 21.26) = .98, p > .05$ ) across the three time periods.

**Caregiver health status.** The PCS scores were compared at three time points by using repeated measures ANOVA. Mauchly's sphericity test indicated that the assumption of sphericity was not violated ( $\chi^2(2) = .03, p > .05$ ). The results of the repeated measures ANOVA showed that the mean scores for the PCS scores were significantly different ( $F(2,30) = 9.70, p < .001$ ) across three time periods. The Bonferroni post-hoc test was used to perform pairwise comparisons and to identify mean difference across time. Mean differences in the PCS scores between baseline and 1 month ( $p < .001$ ) and 3 months ( $p < .001$ ) were significant difference.

The MCS scores were compared at three time periods by using repeated measures ANOVA. Mauchly's sphericity test indicated that the assumption of sphericity had not been violated ( $\chi^2(2) = 3.49, p > .05$ ). The results of the repeated measures ANOVA showed that there were no statistically significant differences in the MCS scores ( $F(2,30) = 1.36, p > .05$ ) across time.

**Caregiver social support.** The SSQ-N scores and the SSQ-S scores were compared at three time periods by using repeated measures ANOVA. Mauchly's sphericity test indicated that the assumption of sphericity had not been violated ( $\chi^2(2) = .95, p > .05$ ) and ( $\chi^2(2) = 3.93, p > .05$ ) respectively. The results of repeated measures ANOVA showed that the mean SSQ-N scores ( $F(2,30) = .03, p > .05$ ) and the SSQ-S scores ( $F(2,30) = 0.03, p > .05$ ) were not different across time respectively. Results of the repeated measures ANOVA were summarized in Table 11.

### Summary of Repeated Measures ANOVA Results.

To answer the first research question “Do caregivers of PWD who attended ADC have lower burden, lower depression, better health, higher social support, and higher quality of life after one month and three months compared to baseline?” Only the mean on the PCS scores (on the SF-12) and the mean physical domain scores (on the WHOQOL-BREF-THAI) were significantly higher than baseline after using ADC at one and three months. Therefore, caregivers of PWD who attended ADC reported improved physical health after using the ADC at one month and three months compared to baseline. According to quantitative analysis, caregiver’s quality of life did not significantly differ over time. Qualitative analysis would provide more information to answer the second research question.

Table 11

#### *Results of Repeated Measures ANOVA for Caregiver Outcomes Across Time*

Sources of variation	SS	df	MS	F	p
<b>Caregiver Burden</b>					
Time	151.17	2	75.58	1.50	.24
Error	1511.50	30	50.38		
<b>Caregiver Depression</b>					
Time	113.17	2	56.58	1.93	.16
Error	880.17	30	29.34		
<b>Caregiver Quality of Life (Overall)</b>					
Time	80.17	1.42	56.56	.98	.37
Error	1222.50	21.26			

\* Significant at  $p \leq .05$

Table 11

*Results of Repeated Measures ANOVA for Caregiver Outcomes Across Time (continued)*

Sources of variation	<i>SS</i>	<i>df</i>	<i>MS</i>	<i>F</i>	<i>p</i>
Physical Health Domain of Caregiver Quality of Life					
Time	10.38	2	5.19	4.86	.02*
Error	32.07	30	1.07		
Mental Health Domain of Caregiver Quality of Life					
Time	5.56	2	2.78	1.38	.27
Error	60.52	30	2.02		
Social Relationship Domain of Caregiver Quality of Life					
Time	40.67	2	20.33	2.88	.07
Error	211.78	30	7.06		
Environment Domain of Caregiver Quality of Life					
Time	4.95	2	2.47	1.70	.20
Error	43.55	30	1.45		
Physical Health of Caregiver Health Status					
Time	485.75	2	242.88	9.70	.001*
Error	751.01	30	25.03		
Mental Health of Caregiver Health Status					
Time	69.65	2	34.83	1.36	.27
Error	769.84	30	25.66		

\* Significant at  $p \leq .05$

Table 11

*Results of Repeated Measures ANOVA for Caregiver Outcomes Across Time (continued)*

Sources of variation	<i>SS</i>	<i>df</i>	<i>MS</i>	<i>F</i>	<i>p</i>
Number of Available Social Support					
Time	68.63	2	34.31	2.57	.09
Error	400.04	30	13.34		
Caregiver Satisfaction of Available Social Support					
Time	.17	2	.08	.03	.97
Error	85.83	30	2.86		

\* Significant at  $p \leq .05$

### **Qualitative Analysis and Findings**

All sixteen caregiver participants were interviewed at a convenient place after using ADC at least 3 months. A semi-structured interview with two open-ended questions and additional probes were employed. Responses from the semi-structured interview focused on answering two main open-ended questions, “What are your experiences with ADC?” and “Has your life changed in any way since your relative started attending ADC?” The research investigator who conducted the interviews has a nursing background and interview experience. All interviews were audio-recorded and transcribed in Thai language. Transcription, observations, field notes, documents and other related materials were used in the content analysis.

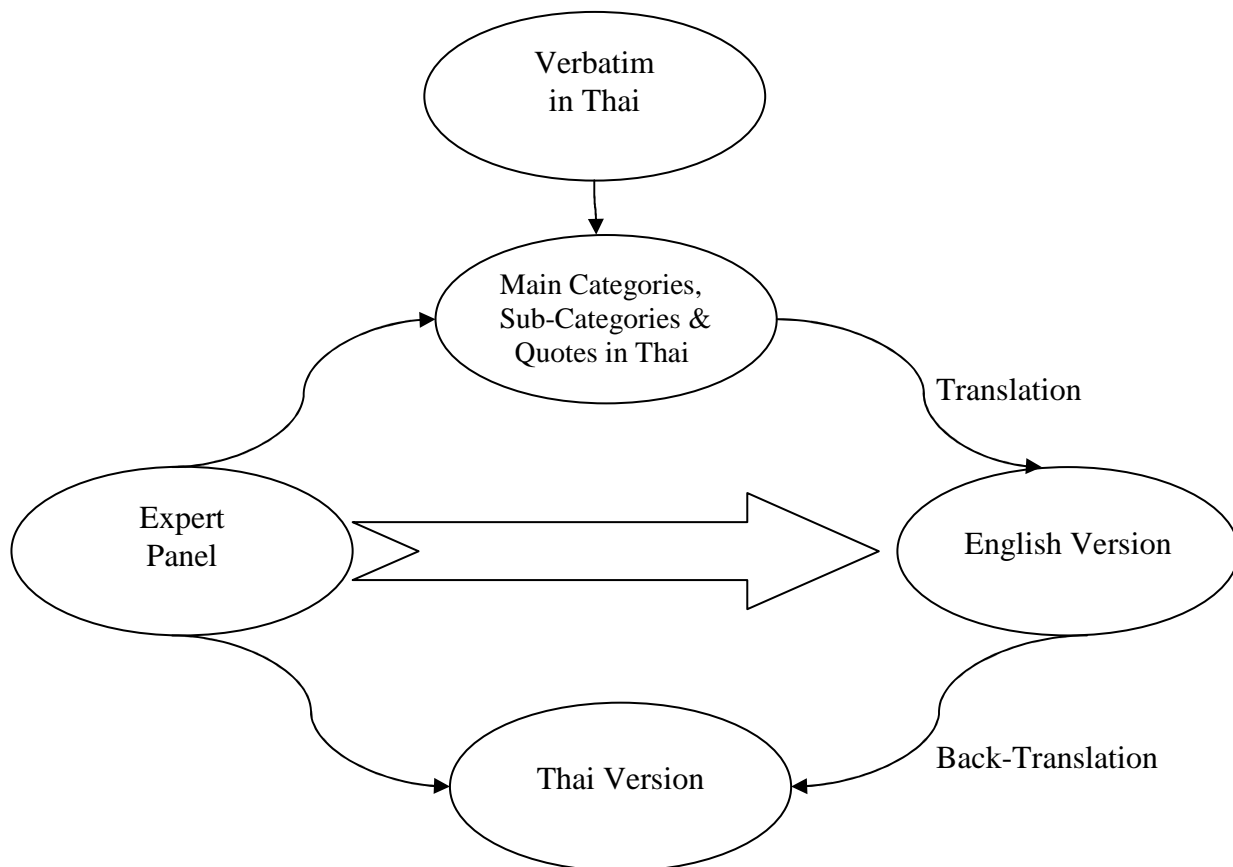
Inductive content analysis was used to analyze the interview transcripts. The aim was to gain insight on experiences of family caregivers who used ADC services and to attain comprehensive and meaningful description for the ADC program evaluation on

caregiver perspective. All transcripts were read and hand coded in Thai. The main goal of the content analysis was to obtain a set of categories that provided comprehensive and meaningful description for the ADC program evaluation on caregiver perspective. The frequency of statements in each category was also used to observe the differences among caregivers.

The combined translation technique included the blind back-translation method and an expert panel to obtain equivalent meaning of the Thai and English language and validate the qualitative findings (Chen & Boore, 2009). See Figure 3. The initial main categories, sub-categories and quotes were validated and translated to English by the research investigator. The translation was then validated for meaning and accuracy by a Thai bilingual specialist and by a native speaker. Next, the English version was back-translated to Thai by another Thai bilingual health care professional.

The English version and both Thai versions were compared to determine translation differences in vocabulary, idioms, grammar and syntax (Sechrest & Fey, 1972). All differences in translation, approximately thirty percent of the sample, were discussed by the experts who were involved in the translation until the final consensus was reached.

Seven main categories and eight sub-categories emerged from data. Seven main categories were: “Requiring medical care for persons with dementia”, “Challenges for family caregivers”, “Seeking help, access to adult day care”, “Expectations for adult day care”, “Perception of benefits and effects of adult day care”, and “Adult day care in the future.” See Table 12. Further analysis into themes was not completed at this time.



*Figure 3.* Translation and back translation to qualitative findings



Table 12

*Main Categories and Sub-Categories*

Main Categories and Sub-Categories	
Main Category 1	Requiring medical care for persons with dementia
Main Category 2	Challenges for family caregivers <ul style="list-style-type: none"> <li>Sub-category 2.1 Negative psychological effects</li> <li>Sub-category 2.2 Social isolation</li> <li>Sub-category 2.3 Financial hardship</li> <li>Sub-category 2.4 Physical health effects</li> <li>Sub-category 2.5 Family dynamics</li> </ul>
Main Category 3	Seeking help
Main Category 4	Access to adult day care
Main Category 5	Expectations for adult day care
Main Category 6	Perception of benefits and effects of adult day care <ul style="list-style-type: none"> <li>Sub-category 6.1 Benefit of adult day care</li> <li>Sub-category 6.2 Effects of adult day care</li> </ul>
Main Category 7	Adult day care in the future.

**Main category 1: Requiring medical care for persons with dementia.**

Caregivers witnessed uncommon behaviors and personality changes in their relative with dementia. Most caregivers reported that their relative with dementia had difficulty remembering things, thinking clearly, communicating with others, and taking care of themselves. In addition, dementia relatives sometimes had mood swings and even changed personality and behavior. Even though the progression of dementia varied from

person to person, symptoms of dementia developed gradually and typically became worse over a number of years. Family caregivers sought medical care for their dementia relative when they recognized the recurrence of uncommon personality and behavioral problems.

A retired caregiver brought her younger sister with moderate (stage II) dementia to the ADC. She stated her experience regarding uncommon behaviors of her sister as the following:

*“She got up and turned the light on at 2 am or 3 am...turned the water tap on... turned on all the lights...have bowel movement without wiping herself...Have a BM in her pants and not in the toilet. She did not flush toilet after urinating... I am not sure if she is incontinent or not ...I don’t understand yet...”*

Most caregiver participants reported that they felt worried that their relative might get lost and experienced trouble or undesired events due to cognitive deterioration and a self-care deficit. Some caregivers were concerned over the impact of the relative’s condition worsening on their own lives in the future.

*One husband commented on his wife that “I was very worried. She went out and bought a lot of food. She got on a bus and got lost for two days.”*

*A wife of a PWD stated that “Recently, he walked slower and often tripped over. I am so afraid that he might fall down. He’s old... If he falls down he may die.”*

Caregivers recognized the ADC as part of specialized medical care for the PWD. They believed that medication could help maintain the PWD’s remaining cognitive capabilities and activities of daily living and slow down the dementia process.

*A husband of a PWD stated that “I am concerned that the medication may not help much. It just slows down the dementia process”*

*A daughter of a PWD stated that “It would save money to take care of my mother at home. It was not really true. To hire somebody, I had to pay for her living cost and her care. Bringing her here (ADC) is the best option for me to do. It was more expensive, but my mom got a treatment, got medical care, and got better, so I am willing to pay.”*

### **Main category 2: Challenges for family caregivers.**

Family member played a significant role in taking care of their dementia relative at home. Caregivers tried to provide holistic and continuing care when their relative stayed at home. The symptoms of the PWD were described as forgetfulness, repeated speech, difficulty in communication, poor personal hygiene, unusual bathing and dressing, sleep disturbance, immobility and behavioral disturbance. Caring for a dementia relative posed many challenges for families and caregivers.

The challenges of taking care of a relative with dementia might be either positive or negative depending on several factors such as the amount of family and social support, severity of stress, daily life styles, economic status, and the attitude about life and actualization. The effects of being a family caregiver were generally negative with high rates of workload, negative psychological effects, social isolation, financial hardship, and physical ill-health. These effects increased as the caregivers confronted progressive symptoms of dementia while balancing the demands of caregiving with their other responsibilities. Caregivers coped with stress and responded to increased demands for care

in their own way. However, some caregivers were able to deal with the increased care demand and still have a normal life.

Challenges for family caregivers comprised 6 sub-categories: work load, negative psychological effects, social isolation, financial hardship, physical health effects, and family dynamics.

***Sub-Category 2. 1: Negative psychological effects.***

Caregivers reported negative psychological effects, such as stress and anxiety ( $n=13$ ), worry ( $n=9$ ), distress ( $n=4$ ), irritation ( $n=4$ ), tiredness ( $n=4$ ), depression or sadness ( $n=3$ ), and guilt ( $n=1$ ). Caregivers coped with the stress and responded to the increased demands for care in several ways.

Some caregivers reported that their stress level increased due to their having to make life changes in order to provide care for their relative. Additionally, they were frustrated due to their caregiving responsibilities.

*A son of a PWD stated that “It affects my emotion a lot because it takes all my personal time away. I am not able to get away or spend quality time with my family...no way...because I have to take my mom wherever we (he and his family) go...At the same time I have to take care of my family. After losing my dad, my mom got ill and had no one to take care of her. So she moved in with us. Once she moved in, we could not do things that we wanted to do... We could not make any comments because she is my mom...”*

A daughter of a PWD reported that she felt distressed, frustrated, and guilty because her daughter and husband whose mother was sick moved from another country so

that she could provide care for her mother. She was the only child and had to be solely responsible to take care of her mother.

*“My daughter missed her opportunity to study abroad. I don’t want her to miss her opportunity...I don’t know what to do. I am worried about my mom and don’t know what to do. Somebody has to sacrifice. My husband and daughter have made a sacrifice. I don’t know what else to do. I felt frustrated. I also have another problem. My mother-in-law is also ill (in another country) and is being cared for by my husband. I don’t know what to do. My husband is the only one who can care for his mother and stay with her. He came here to be with me...I don’t know what else to do.”*

Many caregivers admitted that they were overwhelmed in providing total care for their relative with dementia. Some of them expressed that they were also depressed as a result of the caregiving role and unpleasant behaviors of the PWD. A sister of PWD stated:

*“At the beginning, I and my younger sister took turns to take care of her. Now my sister is very stressed and depressed. Me too.”*

Some caregivers accepted that they felt irritated sometimes due to problems of memory loss in their relative with dementia. The PWD often asked them the same questions, walked around the home at night, or misplaced some belongings.

*A son of a PWD stated that “at the beginning...It’s quite difficult to understand...I was irritated with his behavior changes and forgetfulness. He keeps asking me the same questions over and over.”*

*A wife of a PWD stated that “I got frustrated with him sometimes...I can’t find my things... Oh! (Somebody) took my things again.”*

Caregivers experienced exhaustion with their caregiving role and an increased workload beyond their usual responsibility. Caregiving typically involved a significant expenditure of time, energy, and money. The increased workload became difficult to deal with when dementia symptoms worsened especially when caregivers lacked supporting persons to share care responsibilities at home. Below is an example by a son of a PWD:

*“When I could not find somebody to help take care of my mom at home...I became more exhausted, anxious, stressed... because I’m swamped by the workload”*

#### ***Sub-Category 2.2: Social isolation.***

Another negative effect of being a family caregiver was social isolation. Five caregivers reported that they had family separation or had other conflicts in the family. Two caregivers reported that it was necessary for them to take an early retirement because there was no one else that could take care of their relative. Afterwards they felt trapped in the caregiving role with social isolation, a lack of personal time, relaxation and freedom to do their usual activities.

*A daughter of a PWD stated that “I am so stressed. My husband and I argued until I told him to stay at his old house; you please come back once a week on Friday. I am tired, so overwhelmed and can’t take care of everybody.”*

*Another daughter of a PWD stated that “I took an early retirement from my work because my father had no one else who could take care of him...that made a big*

*impact on me, loss of social interaction, no friend contact some kind like this...no social activities like others and I'm not be able to do my favorite things."*

***Sub-Category 2.3: Financial hardship.***

Caregivers were faced with increased expenses regarding PWD's costs of treatment and medication. Two caregivers ( $n=2$ , 12.50%) complained that they had some financial hardship because the medication and other out-of-pocket fees for ADC services were at high cost.

*A husband of a PWD stated that "I have some financial difficulty. I am not eligible for reimbursement. Eventually, my expenses had increased more and more."*

***Sub-Category 2.4: Physical health effects.***

Caregivers experienced not only negative psychological, social, and financial effects, but also physical distress as a result of their caregiving responsibilities. Two caregivers reported that they became ill. One of them had a cerebrovascular disease while another experienced significant weight loss along with stress and depression.

*An older caregiver who was a sister of a PWD stated that "That time was so bad. I have to adapt myself to her. So bad! That time I was so exhausted and lost a lot of weight."*

***Sub-Category 2.5: Family dynamics.***

Although most of the psychological effects brought about difficulties in coping, caregivers were willing to take care of their relative as best as they could. Nine of sixteen

caregivers reported that they did not feel burdened nor had too many difficulties in providing care for their relatives with dementia. They indicated that caring for their relative with dementia did not cause hardships in their lives, but became a positive experience in caregiving for their loved one. Caregiving was a part of the relationship and regarded as an obligation for spouse, parent, and sibling. Children caregivers reported that caregiving for their parent was a good opportunity for them to give back.

*A husband of a PWD stated that “I am determined to give the best care as possible to her. The sickness is a natural part of life. I don’t feel disappointed or sad because my health conditions declined also. Sickness is common for everybody. Everybody could get sick from different causes.”*

*Another husband of a PWD stated that “We suffered many difficulties together in the past. She had done many good things. This is the end of her life. I do not want to bother her. It is not a burden. I am willing to care for her. ”*

Caregivers reported that they learned how to take care of their relatives by seeking helpful information from several sources such as books, the internet, local experts and other resources. The following is an expression by one daughter:

*“I learned about the symptoms at each stage of Alzheimer’s ... What are the side effects? I had to take care of her. I understood and accepted...accepted the reality. At the beginning, I had to learn about her illness. How could I take care of her? After approximately 3 weeks, I knew a lot more and was more confident. It became my routine.”*



Caregivers provided care differently depending on the self-care deficit of their dementia relative, their family's capacity to provide care, the social support they received, and other resources available to them. Common care activities included monitoring, bathing, toileting, dressing, preparing foods, going outdoors, and other personal care. It was important for caregivers to understand the symptoms and behavioral changes of their relative and learn how to deal with those changes. Moreover, some caregivers suggested that they needed to manage their time as well as take care of themselves to reduce their stress, feelings of burden, and other negative psychological effects.

*A daughter of a PWD stated that "We have many family members, uncle, younger and older brother. So it does not affect us much. We each help one another."*

A son of a PWD reported that it took some time for him and his family to accept what happened with his mother. Finally, his family members accepted the diagnosis and planned to share the caregiving responsibilities. The following is one such report:

*"I am stressed out. My family members are also stressed. Our house is so quiet. They accept the situation now. We take her to wherever she would like to go in order to make her happy. We take turns caring for her. I take care of her from morning until 5 pm. My sister will take care of her in the evening and throughout the night."*

### **Main category 3: Seeking help.**

Due to memory loss and behavioral changes, the PWD generally had some functional disabilities and required assistance from family members. Caregivers also reported that they needed help so that they could continue to provide care for their

dementia relative in addition to their ordinary family role and maintain their own health and well-being. Such help included knowledge and information, mental support, financial and tangible support, respite care, security and welfare for the elderly, and other resources. Family was one of the essential sources of care and support. Family members sought and shared support duties with one another as well as with hired help who also assisted with care in the home. Moreover, they also sought support from dedicated organizations providing medical services and ADC services for the PWD. The ADC services were an alternative for family caregivers.

*A son of a PWD stated that “All three of us help each other; my youngest brother takes a big responsibility in paying for the treatment expenses. The other younger brother looks after our father during the day. I take care of him in general and at night time.”*

A common complaint among family caregivers was that providing care was so time-consuming it afforded them little time to rest. They reported that they had to manage their time, take time away from work, adapt their habitual activities and seek care support in order to provide sufficient care around the clock and be able to work or do something else.

*A sister of a PWD stated that “I had no personal time. I am hiring someone to help take care of her and now I feel relieved.”*

All caregivers in this study were the primary persons who provided care for their relative with dementia at home. Most of them had relatives who shared caregiving responsibilities, such as taking turns for part of a day or week, assisting in direct care,

taking to hospital, and providing financial and mental support. Some caregivers reported that their younger children were good care assistants in staying close to, playing games and talking with the relative with dementia.

*A daughter of a PWD stated that “My mother’s memory improved. My relatives said that it might be due to my daughter because she usually plays with my mom. I let her take care of my mom too. I call her ‘nurse kitty’. When I went back home and did laundry, I asked her to take care of my mom. She sat down on my mom’s lap and not let my mom walk around. They play something together.”*

*A husband of a PWD stated that “If I have to go somewhere for a long time. I have to plan in advance to find someone to take care of her while I am not at home. Sometimes I ask my sister or my daughter (to be with us) when she is not in school.”*

Caregivers not only received support from family members, they also hired others who were not relatives so as to help them in care activities and house-keeping. Nine caregivers reported that they hired non-relative caregivers to take care of the PWD at home. Others reported that it was difficult to find a caregiver. Some of the participants reported that they were not satisfied with hiring someone to take care of their dementia relative at home. When family caregivers faced difficulties in caregiving, they asked for help from family, friends, neighbors, and many possible social resources, such as hospital and ADC services. They also found that the ADC service provided an alternative support for caregiving of the PWD during the day. So that they were able to go to work, perform chores, and do other things.

*A daughter of a PWD stated that “My housemate has helped me take care of my mom for the past seven years. I usually take care of her, when I get home from work..”*

*A son of a PWD stated that “I hired somebody to take care of my mother when my father got sick, but my mom was not satisfied with her. Sometimes my mom forgot where she moved her belongings. My mom accused her of stealing. We changed housemaids several times.”*

Some caregivers did not want to hire a non-relative informal caregiver at home and needed the ADC services. A daughter of a PWD reported her experience of seeking care support for her mother and provided reasons why she did not hire informal caregivers.

*She stated that “At that time we felt stressed that nobody was able to take care of our mother because everyone had to work....We looked through many places and around our neighborhood to find anyone we would trust. We went to one of the homes for the elderly but there was no day care service. A staff member there suggested that I come here. After we became aware of the day care services here, everyone was okay. To hire somebody to take care of my mom at home, it made me worry. First, how much we can trust them, second, high expenses for each one. Also, she will live in my house and I do not know her...makes me more worried than bringing my mother to ADC, right? Something may be stolen, I don't know”*

**Main category 4: Access to adult day care.**

Variations in access to ADC services have been explained in terms of the utilization of available services and barriers to service utilization. The ADC services were provided for caregivers who met the admission criteria and were able to afford the transportation costs as well as the cost of ADC services. Caregivers who lived in urban areas were more likely to use ADC services than those in more remote areas. The majority of caregivers brought their relative to the ADC setting by themselves. Most caregivers reported that they had no difficulty with patient preparation and transportation. Only one dementia participant was picked up on a motorcycle that was serviced from the ADC. Many caregivers reported they enrolled in several caregiver programs at the ADC such as a nutrition group and periodic conferences for dementia caregivers. Some caregivers reported that they were usually contacted by the staff of the ADC by telephone in order to consult on problems of care.

*A spouse of a PWD who lived near an ADC stated that "I took her to the hospital. I dropped her off in the morning and I come to pick her up and take her back home in the evening. I do not need to worry about her. The transportation was not a problem"*

Seven caregivers preferred to wait for their relative at the ADC and then take him/her back home. Some caregivers reported that they participated in the ADC activities and felt relaxed while waiting for their dementia relatives. Four caregivers who did not wait for their relatives reported that they did not know much about the activities provided for the PWD.

*A son of a PWD stated that “ I stayed with him (at the ADC) three day a week,... take some books to read,... watch the activities that they do... sometime I take a nap at a bench, or go outside to find some food to eat , and then we go back home together by taxi.”*

However, some caregivers experienced particular barriers to ADC service utilization due to the long distance from their home, traffic congestion in the city, and the high cost of ADC services. Four caregivers reported that they had some difficulties with transportation. Two of them reported that their house was located so far from the hospital that it resulted in high transportation cost. One caregiver stated that he had to carefully manage his time in order to be able to pick his mother up at the hospital during periods of high traffic congestion.

*A son of a PWD stated that “I have to manage my time in terms of transportation when I go to work somewhere. I am afraid that I won’t be able to pick her up in time. If I take my mother to participate in a group activity for only two hours, I’ll wait for her. It is not worth driving her here and then having to come back and pick her up again in 2 hours!. Traffic is heavy and I might not be able to come back in time. I am tired of the traffic. Driving in a heavy traffic is exhausting.”*

The costs of ADC services were out of pocket for most caregivers who did not receive reimbursements from the government. Only two caregivers were reimbursed in full for the ADC service fees and only one received partial reimbursement. Eleven caregivers received financial support for ADC services from other family members. Only two caregivers reported that they had some difficulty in paying for the use of ADC services.

*A daughter of a PWD stated that “People complained that it was expensive. These day care bills were not eligible for reimbursement, but I am not concerned about that. I am interested in that as long as the service is worth the money I pay. I will continue to use the ADC service”*

### **Main category 5: Expectation of adult day care.**

Caregiver expectations for the activities and the setting of the ADC have been reported. Caregivers explained that their primary expectation of the benefit of ADC services was for the improvement of brain functions and the rehabilitation of their dementia relative and not to benefit themselves. Caregivers reported their expectations for their relatives with dementia to receive benefits of the ADC services as following: to activate cognitive functions ( $n=9$ ), to get social interaction ( $n=9$ ), to be happy or satisfied ( $n=3$ ), and to get health rehabilitation ( $n=2$ ) during the use of ADC. They also expected to receive knowledge and necessary information regarding caregiving for the PWD via brochures, caregiver group meetings, and one-on-one counseling for themselves.

*A husband of a PWD stated that “I want her to get brain stimulation. If she stays at home, she watches television all day without using her brain much. Perhaps... (ADC) may help perform her daily activities, remember the children...perhaps not get worse than this.”*

*A daughter of a PWD stated that “Activities should be appropriate to patient symptoms. If they are forgetful, we need to use a certain approach or some tactics to stimulate and exercise the brain, use theories or some tactics. If they act absent-mindedly, we should encourage them to paint or play with color as the*

*activities that they do now, but increase more activities. Don't let them sit too long because we expect that patients who go to ADC will be able to relax and participate in many activities. The activities should be changed often to keep the patients alert."*

Some caregivers felt that some activities, such as watching television without movement for a long time, using old games, and activities repeatedly, might not activate cognitive and physical functions. On the other hand, their relative might be bored, sorrowful, and not want to go to the ADC. Many caregivers expected that the ADC environment and surroundings should be safe, comfortable, stimulating, and home-like. Some caregivers reported that they felt uncomfortable with the long-term care unit because it left them feeling sorrowful. They were afraid that their relative might feel similarly when they were involved in some activities at the long-term care unit.

*A daughter of PWD stated that "I expect adult day care to be homelike and natural as much as possible so that we feel trust and comfortable to let my relative stay there. It should be located in a new building, a large hall, and let family visitors see inside like a nursery"*

*A wife of a PWD stated that "The environment and surroundings should not make him feel depressed or sad."*

**Main category 6: Perception of benefits and effects of adult day care.**



Caregiver participants were asked to evaluate the benefits and effects of the ADC on their life and their relative's behaviors. In addition, they were asked to discuss their satisfactions with the ADC services and to provide comments.

“Perception of benefits and effects of adult day care” comprised 2 sub-categories: “Benefits of adult day care” and “Effects of adult day care”.

***Sub-Category 1: Benefits of adult day care.***

All caregivers reported that the ADC provided benefits for them and their dementia relative by providing several activities for the PWD and their caregivers during day time hours. The benefits for caregivers were that they had more time to do other things such as working and relaxing. They also received mental support, knowledge and beneficial information, and suggestions for care. Nine caregivers stated that their life improved because they were able to consult a staff of the ADC regarding the sickness of their relative and how to provide better care. The ADC also helped them to connect with a physician and other specialists for appropriate care. This was an example by a caregiver male:

*“The benefits of the ADC, first, to help patient for health rehabilitation, day care should provide physical therapist to help patient in physical rehabilitation. Second, to help family or caregivers have more time to work and do other activities. Third, to provide knowledge, consultation and suggestions when caregivers have problems of caring for the patients, and fourth, to arrange beneficial activities for patients with dementia and their family.”*

*Sub-Category 2: Effects of adult day care.*

ADC affected family caregivers and their dementia relatives' feelings and sometimes produced desired outcomes and undesired outcomes. The satisfaction of caregivers and their dementia relatives was viewed as the strengths of the ADC. Additionally, the dissatisfaction of caregivers was viewed as the weaknesses of the ADC. The dissatisfaction of PWD was in doubt because the caregivers were unsure whether it was due to the forgetfulness of their relative.

The majority of caregivers were satisfied with the ADC services provided. Particularly, the strengths of the ADC were the service-minded and creative thinking of the staff, group activities for the PWD and caregivers, the provision of holistic care, access and location of the ADC services, and a clean and home-like environment. In addition, the collaboration of the multidisciplinary team, the use of a report notebook and telephone contact for communication between caregivers and staff all contributed to the satisfaction with the ADC in providing continuing care.

*A daughter of a PWD stated that "After I took my mom to day care, I do not feel worried about her. If something happened, we could talk via phone. We have usually communicated via phone at anytime we want to. The day care daily report is very helpful as a way to communicate with ADC staff. It described what they (ADC staff) did with my mom regarding meals, medications, changing clothes and diapers. I used to have a question, Why they used a lot of diapers? But once we talk, I understand it. She (a staff) was very nice and creative."*

*A son of a PWD appreciated staff of the ADC. "I am impressed with the staff and how they care for and teach patients. They are so patient. They kept asking questions to patients repeatedly."*

Caregivers were satisfied with several activities provided for the PWD such as games, brain exercises, physical exercises, creative activities, recreation, cooking, praying and meditation, out-door activities, physical therapy, and so on. These activities provided opportunities for their relative to stimulate brain functions ( $n=9$ ), be away from home ( $n=7$ ), get social interaction ( $n=5$ ), receive recreation and relaxation ( $n=3$ ), and exercise muscles and body ( $n=3$ ).

Caregivers reported that their relatives' memory improved ( $n=6$ ) and had increased happiness ( $n=6$ ), alertness ( $n=4$ ), and more restful sleep ( $n=2$ ) while decreasing depression ( $n=1$ ), and the frequency of getting lost ( $n=1$ ). Many caregivers said that they experienced the most satisfaction when they saw that their relative was happy and enjoying activities as opposed to being at home and doing nothing.

*A son of a PWD stated that "He enjoyed activities with nurses and friends (other participants) when he was at ADC. That time he was happy which is different from when he was at home."*

*A daughter of a PWD stated about her mother that "She is very happy. She said today that she cooked dessert. She told me she was happy. She likes it. Activities may include cooking, handcraft, games, and so on. I cannot do that. I have many things to do at home. These activities exercise brain and other skills. It enhances her mood."*

*A son of a PWD stated that “From my observation, my mother is satisfied with ADC, and not reluctant to go. She is better...I can tell...(she) has better responses and her memory is better. This might be due to the medication or to the group activities.”*

The satisfaction of the PWD was reported with respect to their desire to go to ADC. Most caregivers stated that their relative was eager to go to the ADC. However, they unexpectedly changed their mind sometimes due to their mood fluctuations and limited attention spans.

*A daughter of a PWD stated that “He was happy, enjoyed it. Only that day he did not want to come here, but the first time he said would like to come. May be he did not have a good mood that day. Today I told him ahead of time. He was eager to dress up and wait for me to come here. He wanted to come here.”*

Only two caregivers stated that their relative disliked going to ADC. One of them felt separated from her husband and another one did not accept her sickness because other patients were worse than her.

*A husband of a PWD stated that “After I dropped her off at ADC that day...she did not want to go back (to ADC) again. When I asked her to go to ADC, she shook her head. She did not want to be at the ADC because we have always been together.”*

Three caregivers stated that the symptoms of their relative were stable after using ADC services for 3 months. In contrast, three caregivers said that their relative got worse

while using ADC services. Following are undesired outcomes that were reported. One of caregivers stated that some activities of the ADC reinforced existing memories of the PWD and gave their relative the false impression that he/she was not experiencing confusion or forgetfulness.

*A husband of a PWD stated that “It (ADC) helps a little bit, but not much. Not much activity each day. Sometimes, they had an exercise activity, but it was not so long... She was not excited to go (to ADC), but she dressed up and wait to be ready to come here.”*

*A daughter of a PWD stated that “She seemed to get worse, and could not help herself. She just sat down for hours...or walking back and forth. She sometime washed dishes then left the faucet on.”*

Twelve caregivers did not experience any negative impacts with the use of the ADC services. They reported that the preparation of the PWD and transportation did not disturb them. They accepted that they adapted their life patterns or shared caregiving responsibilities with other family members in order to be able to send their relative to the ADC setting. However, some caregivers ( $n=4$ ) reported that they had some difficulties in transportation or financial problems ( $n=2$ ) due to the cost of ADC. The physical and psychological problems during the study were not explained as the direct effects of the ADC utilization, but they might cause more difficulties for access to the ADC services.

**Main category 7: Adult day care in the future.**

ADC should provide a standard of care and beneficial services for the PWD and caregivers. All caregivers stated that the ADC services should be continued in order to provide benefits for the elderly with dementia and their caregivers. They provided several recommendations for the ADC in the future that were summarized as follows:

1. Activities for the PWD should aim to stimulate their brain functions and other reserve skills and to increase attention span, alertness, and happiness. The proposed activities were a variety of brain exercises, physical therapy, outdoor activities, and muscle massage. Additionally, activities should have enough group members participating in order to stimulate alertness and increase enjoyment of the PWD.

*A spouse of a PWD suggested that “I want more activities. I want her to exercise brain functions in a variety of activities. I would like adult day care to continue to provide this program. It can improve the brain functions.”*

A daughter of a PWD recommended that the ADC services should include outdoor activities and spiritual activities. Since Buddhism is an essential part of Thai culture and monks play an important role in providing a spiritual need for Buddhist people, she suggested that the ADC should integrate spiritual needs and out-door activities into the ADC services.

*“If patients are able to walk, and safety is not an issue...bringing them to a temple to discuss spiritual things with a monk would be nice!. Going to the temple could be a way to change their routine and environment.”*

2. ADC should provide respite care and other supporting services for caregivers consistently. The ADC services should be available as many days as possible so that caregivers can use an ADC whenever they need. The ADC services for caregivers should include caregiver group meetings, beneficial brochures, consultation, and counseling. The supporting groups for caregivers were helpful because caregivers can learn and share experiences with one another. Some caregivers would like brochures that provide necessary information about dementia care, nutrition, and supporting resources.

*A spouse of a PWD complained that “Day care was cancelled too many times. This month was available only a few days. I think three days per week was not enough. Day care should be available every day.”*

3. ADC should provide services as a whole system. Physical therapy and home health care should be integrated into the ADC services. Transportation service should be provided. Community volunteers may be involved in some activities of the ADC.

*A daughter of a PWD stated that “I want to see adult day care provide a whole service, including a variety of activities, and more staff to provide care thoroughly.”*

*Another daughter of a PWD stated that “I recommend that rehabilitation and physical therapy for the elderly should be a part of ADC. I don’t think that patients should have to pay extra for that.”*

4. ADC should approach a therapeutic milieu that helps clients feel comfortable, increase their well-being, and facilitate patient rehabilitation. The setting should be located separately from long-term care and other clinical units.

*A daughter of a PWD stated that “(ADC) should be arranged like home or look like staying with family, should be located at the ground level with green space.”*

5. Staff should include psychiatrists, nutritionists, nurses and physical therapists. Nurses should be specialists with training in nursing, psychology, nutrition and physical therapy. The number of staff should be adequate to provide effective care. Moreover, staff members should be dedicated to care for the elderly and need to learn about each PWD. New staff should be oriented, trained, and monitored effectively.

*A husband of a PWD stated that “The more the number of PWD continues to increase in our country, the more necessary adult day care is. Psychiatrist, nutritionists, nurses and physical therapists are important. Sure, nurses not only know how to care, but they also need to learn from psychiatrist, nutritionists, and physical therapists.”*

*A daughter of a PWD stated that “Staff should be trained and should not change often because patients are dementia. The same staff will be familiar with each patient’s habits. It is important to have a staff to know her job well, passionate, pay attention to provide care, and inform the family as appropriate.”*



*Another daughter of a PWD stated that “Staff orientation is important. It is necessary to start explaining, then (staff member’s name) must be patient to teach new staffs as we need them to be and she has to monitor them.”*

6. ADC should receive more financial support from the government and their services should be promoted to the public. The dementia clients should be eligible for partial or total reimbursement for the ADC services.

*A son of a PWD stated that “Sometimes I feel that a lot of improvement can be done to the ADC. (ADC) does not work because people do not know what services in the ADC, and second, budget ... It is very important. If not enough financial support, even if staff gets the best training, they cannot do much.”*

7. Evaluation of ADC services should be done by assessing the outcomes of caregivers and the PWD in order to receive important information beneficial to improve ADC services.

*A daughter of PWD stated that “I would like to recommend that adult day care should evaluate outcomes, not only output that showed your current programs and personnel. Outcomes will be useful to improve the current services. It is important to monitor outcomes from users of your services or stakeholders.”*

### **Methodological Rigor**

The trustworthiness of the qualitative analysis was evaluated based on Lincoln and Guba’s (1985) criteria for credibility, confirmability, dependability, and transferability. Credibility is defined as the confidence in the truth of the findings that will be increased

with prolong engagement, persistent observation and triangulation (Lincoln, & Guba, 1985). Confirmability is defined as a degree of consistency of the raw data, analysis notes, data reconstruction and synthesis product, process notes, personal notes, and preliminary developmental information that can be confirmed by the triangulation, a reflexive journal, the audit trail and the audit process (Lincoln, & Guba, 1985). Dependability is defined as the possibility of the replication of the findings that can be examined with the audit process (Lincoln, & Guba, 1985). Transferability is a degree of neutrality or applicability of the findings in other context that might be shown with the description necessary to enable someone interested in making a transfer to reach a conclusion about (Lincoln, & Guba, 1985).

Methodological rigor was maintained by the use of an audit trail and peer-debriefing. An audit trail was the process of maintaining records and documenting analytic decision making in memos throughout the analytic process. The persistent observations and field notes at the research sites were supported creditability and trustworthiness of the study. An external expert was also audited the documents and the findings. During the data coding and analysis, triangulation of investigators provided verification.

Peer-debriefing was conducted by meeting with two research assistants and a qualitative expert during the study. The study procedures and the interpretation of findings were discussed to ensure the accuracy of data interpretation focused on participants' perspectives and the real context. The research assistants were nurses who worked at the ADC and were able to clarify participant's statements because they knew the PWD, caregiver, and their situation. The expert also helped to promote reflexivity and verify the categories, quotes, and descriptions that emerged from data. The audit trail and peer-debriefing lead to clear and comprehensive identification of the qualitative findings by

providing credibility and confirmability to the qualitative analysis (Lincoln & Guba, 1985). The interviewer restated and summarized narratives and their meaning during and at the end of each interview so that informants were able to clarify the meaning of their narratives and provide feedback during the interview. However, “member checking” (Lincoln & Guba, 1985) was not completed after data were analyzed into categories and is a limitation of the study.

Data collection lasted for a year and all family caregivers entering ADC services in the year of study were eligible for the study. The sample is representative of the Thai population who used ADC during the study; consequently, the findings meet standards for dependability and transferability. The blind back-translation and the use of an expert panel eliminates any concern for epistemological and cultural issues and achieves necessary rigour for a qualitative research study conducted in different language (Chen & Boore, 2009). The agreement of the expert panel also establishes credibility of the study (Graneheim & Lundman, 2004). Therefore, the findings meet standards for credibility, confirmability, dependability and transferability.

## **Chapter Five**

### **Discussion and Recommendations**

This chapter presents a summary of the findings, followed by discussion of the findings as they relate to the literature. In addition, conclusions, recommendations for future research, recommendations for ADC policy, implications for practice, and limitations are addressed.

### **Summary of the Findings**

ADC plays an important role in providing a variety of supportive services for PWD and their family caregivers. Only two public hospitals, Somdet Chaophaya Institute of Psychiatry, Bangkok and Chiangmai Neurological Hospital, in Northern Thailand provide ADC services for PWD in Thailand. Effective ADC services should reduce caregiver burden and depression, and improve their health, social support and quality of life. This study was conducted to evaluate the effectiveness of the ADC services on these caregiver outcomes as well as caregiving effectiveness based on the conceptual framework of Smith's Model of Caregiving Effectiveness (Smith, 1994).

The primary aim of this study was to evaluate the effect of current ADC programs for PWD in Thailand on caregiver outcomes (burden, depression, health status, social support, and quality of life). The second aim of the study was to explore the caregivers' experiences of how ADC affected PWD and family caregivers and how their lives were changed by ADC. The following research questions were identified to accomplish the purposes of this study.

1. Do caregivers of PWD who attended ADC report reduced burden and depression, and better health, higher social support, and higher quality of life one month and three months after starting ADC compared to baseline?

2. How does ADC affect caregiver's life?

An exploratory prospective study with a single group repeated-measures design and additional two open-ended questions was employed to address the two research questions. All family caregivers of PWD who started ADC services at each research site were eligible and were invited to participate in the study. Eighteen family caregivers were enrolled in the study, but only sixteen family caregivers completed the study. One of them dropped out because their relative was too agitated to participate in ADC activities and another one moved their residence far away from the ADC setting.

Caregiver outcomes including burden, depression, general health status, social support, and quality of life were measured with five instruments and two surveys. The five instruments included the Zarit Burden Interview (ZBI), the Epidemiologic Studies-Depression Scale (CES-D), the Short form 12-item health survey (SF-12v2), the Sarason's Social Support Questionnaire (SSQ-6), and the WHO QOL-BREF-THAI. Surveys included the General Personal Data Survey and the Caregiver Evaluation of ADC (CEADC). All of them had been previously translated into Thai language.

The caregiver outcomes were compared between baseline and one month and three months after initiating the use of ADC services. The quantitative data were analyzed descriptively and with repeated measures ANOVA. The results of the repeated measures ANOVA showed that mean physical component scores (PCS) of the SF-12v2 were significantly higher than baseline after one and three months of ADC use. Similarly, mean physical domain scores on the WHO QOL-BREF-THAI were significantly higher than

baseline after one and three months of ADC use. These findings suggest that caregivers of PWD who attended ADC at least one day per week reported improved physical health after the use of ADC services for one month and three months. There were no statistically significant changes in the ZBI scores (burden), CES-D scores (depression), the total WHO QOL-BREF-THAI scores (quality of life), the MCS component scores (mental health) on the SF-12v2, the SSQ-N scores (number of social support) and the SSQ-S scores (satisfaction with social support) on the SSQ-6 across time.

In addition, a semi-structured interview with two main open-ended questions and additional probes, was conducted after participants completed 3 months of the use of ADC services. Two open-ended questions were “What are your experiences with ADC?” and “Has your life changed in any way since your relative started attending ADC?” Additional probes were used to explore caregivers’ experiences including feelings, thoughts, expectations, perceived outcomes, and any changes in their life related to ADC service utilization. Each interview lasted approximately 45-60 minutes. All interviews were conducted in a private place and audio-recorded and transcribed verbatim in Thai.

Interviews were analyzed using inductive content analysis, described by Elo and Kyngas (2007). Recoding was first transcribed verbatim, hand coded, and analyzed in Thai by the research investigator. Seven main categories and eight sub-categories emerged from data. All findings in Thai version were translated into English version by the research investigator and validated in meaning and accuracy with a Thai bilingual specialist and a native speaker. All findings in the English version was back-translated into Thai by another Thai bilingual person in the related health care area. The original Thai version and back-translated version were compared. All problematic equivalences, approximately thirty percent of a set of the findings, were discussed for a consensus by an expert panel

including research investigator, a native speaker and two bilingual persons. The seven main categories were: “Requiring medical care for persons with dementia”, “Challenges for family caregivers”, “Seeking help, access to ADC”, “Expectations for ADC”, “Perception of benefits and effects of ADC”, and “ADC in the future.”

The “Challenges for family caregivers” included 6 additional sub-categories: “Negative psychological effects”, “social isolation”, “financial hardship”, “physical health effects”, and “family dynamics”. The “Perception of benefits and effects of ADC” included 2 sub-categories: “Benefits of ADC” and “Effects of ADC.” Those descriptions and quotations explore the caregivers’ experiences of how ADC has helped the clients and family caregivers and how their life has changed while they used the ADC services. The qualitative findings provide comprehensive and meaningful description for the ADC program evaluation from the caregiver perspective.

### **Discussion of the Findings**

ADC in both Somdet Chaophaya Institute of Psychiatry and Chiangmai Neurological Hospital were similar in providing services based on the medical model by multidisciplinary professionals. Most of these ADC services focused on health assessment, neurological and psychiatric treatment, cognitive stimulation, physical rehabilitation, and recreation for PWD. Some ADC services were established for caregivers of PWDs such as education group, individual counseling, and caregiver support group. The main purposes of ADC services were to control and delay progressive symptoms of dementia, to educate caregivers about disease, dementia care, and self-care, and to reduce caregiver stress and burden. Program activities differed in the two sites (see Table 6 in chapter 4). The ADC programs at Somdet Chaophaya Institute of Psychiatry were designed to provide daily

concentrated programming to reduce behavioral and psychological symptoms of PWD compared with Chiangmai Neurological Hospital site that focused on providing general nursing care with therapeutic activities only one day per week.

This study examined the effect of research sites as well as caregiver characteristics. There were no significant differences among these variables. One of the initial study assumptions was that both research sites were administered with similar objectives, procedures, costs, qualification and number of health care providers across time. Preliminary analysis showed both research sites were equivalent on caregiver measures at baseline. The results of repeated measures ANOVA showed that the only statistically significant change was in mean PCS scores (on the SF-12v2) and mean physical domain scores (on the WHO QOL-BREF-THAI) that increased after one and three months of ADC use indicating improved physical health. There were no statistically significant differences on the ZBI scores, CES-D scores, the total WHO QOL-BREF-THAI scores, the MCS scores, the SSQ-N scores, and the SSQ-S scores across time. Caregivers of PWD who attended ADC at least one day per week reported better physical health after using ADC for one month and three months.

There are more varied therapeutic and recreational programs provided at ADC in the United States compared to Thailand. American ADCs provide music therapy, reminiscence, cognitive and behavioral interventions, case management, and care management support (Reever, Mathieu, Dennis, & Gitlin, 2004; Jarrott, Zarit, Berg, & Johansson, 1998 ). These therapeutic programs could reduce caregiver stress, depression, and anger after 3 months, compared with control group not using ADC (Zarit, Stephens, Townsend, & Greence, 1998).



The care management support, through which caregivers received additional training, counseling, and follow-up, also benefited caregivers in improved caregiver self-efficacy, increased self-confidence, and enhanced well-being (Gitlin, Reeve, Dennis, Mathieu, & Hauck, 2006). Moreover, the common purpose in the use of ADC for Thai caregivers was for PWD to receive medical treatment, cognitive training, recreation, and social interaction activities. A few caregivers used ADC as a respite care. The differences of ADC services and the common purposes of the use of ADC might influence the differences of caregiver outcomes between countries.

### **Caregiver Health Status**

#### **Caregiver physical health.**

Caregiver physical health was measured by PCS scores, a part of SF-12v2 and physical domain of WHO QOL-BREF-THAI in this study. Caregiver reported physical health did differ at one and three months compared with baseline, suggesting that ADC service utilization was effective in improving caregiver physical health. The mean PCS score of 40.78 ( $SD=9.99$ ) and the physical domain (of WHO QOL-BREF-THAI) of 11.96 were low at baseline. Scores for the PCS and MCS are normed to the US population ( $M=50, SD=10$ ). These findings are congruent with previous studies (Fortinsky, Kercher, & Burant, 2002; Gottlieb & Johnson, 1995). Fortinsky, Kercher, and Burant (2002) that reported that caregivers who are better able to use community support services and manage patients' symptoms have fewer physical health symptoms. Similarly, Gottlieb and Johnson (1995) reported that caregivers who used an ADC program for an average of one-and-a-half days a week for five months reported significant reduction in physical manifestation of psychological distress such as aches, pain, and discomfort.

All caregiver participants in this study reported that taking care of PWD consumed their personal time. Half of the participants reported that they took care of the PWD around the clock. Increased caregiving responsibilities can induce role overload with loss of personal time to take care of themselves. Caregivers who provide extensive assistance, such as activities of daily living (ADLs) might neglect their own health and fail to get adequate sleep (Schulz & Sherwood, 2008).

Caregivers typically report exhaustion, fatigue, symptoms related to stress, physical burden or physical disability (Gavrilova et al., 2008; Aneshensel et al., 1995). In this study, most caregiver participants reported poor physical health at baseline. The poor physical health may be due to secondary stress, depression, burden, workload, tension, sleeplessness, and inadequate relaxation. According to the qualitative data, caregiver physical health in this study was also linked to the severity of cognitive and functional disabilities of the PWD, the caregiver's age, the caregiver's psychological distress, financial problems, and a shortage of caregiving support. However, caregivers who reported illnesses stated that they also received medical care for these conditions during the study. Most of them also reported that they received advice from ADC staff regarding how to take care of themselves. This may have contributed to improvement in their physical health.

The improvement in caregiver physical health might be due to reduced tension and stress. Other researchers have found that utilization of institutional respite care assists family caregivers and PWD to increase total sleep time per night (Lee et al., 2007). Many participants in this study reported that the PWD slept easier and longer at night after ADC was initiated. The ADC personnel attempted to stimulate the PWD with a variety of activities during the day time so that the PWD and caregivers would sleep better at night.

During the use of ADC, approximately half of the caregivers reported an increased ability to relax while their relative attended at ADC. This included reading a book, newspaper, or magazines, taking a nap, visiting their friends, and going shopping etc. The ADC also provided face-to-face and telephone consulting, education, and support groups for caregivers. Those activities may alter caregivers' feelings of stress, worry, overload, and physical tension and allow caregivers to recharge their energy. On the other hand, some caregivers went to work, or went back home to do house-keeping and other role obligations after leaving their relative at the ADC site. Most caregivers reported that they were less tired and stressed when the PWD attended ADC.

This study found the benefit of ADC in improving physical health, but not in improving mental health. Hypothesized improvements in caregiver burden, depression, quality of life and social support were not supported in this study. This may be due to the low statistical power of the study, measurement limitations, limited duration or dosage of ADC use, types of interventions provided at ADC, and cultural factors. The small sample size resulted in low statistical power. Some questionnaires might not sensitive to detect changes over time. Approximately half of participants used ADC only one day per week and most participants did not regularly attend supportive services provided for caregivers. In addition, interventions and supportive services for PWD and caregivers were different among settings. Moreover, Thai culture is rooted in filial piety or parent repayment that would bring about a sense of obligation, conflicts, and hardships of life (Choowattanapakorn, 1999). These factors could have affected the results in this study. These findings should be interpreted with caution due to the small sample, limitations of non randomization design and the measurement tools, the heterogeneous sample, and

variability in caregiver participation in supportive activities provided for caregivers at ADC.

### **Caregiver mental health.**

Caregiver mental health was measured by MCS scores, a part of SF-12v2 in this study. Caregiver mental health did not significantly differ across time compared with baseline. The mean MCS score of 44.73 ( $SD=10.21$ ) were low at baseline compared to normal population. The mental health scores tended to increase indicating improved mental health across three points of time, but no significant difference was found. This finding is contrary to previous studies (Zarit, Stephens, Townsend, & Greene, 1998; Gaugler, Zarit, Townsend, Stephens, & Greene, 2003) that found significant effects in reducing caregivers' emotional and psychological effect after using ADC services.

Zarit and colleague (1998) used a quasi-experiment with a control group design. A sample of 121 caregivers in the treatment group who used ADC services at least two times per week compared with 203 caregivers in the control group at a period of 3 months and 12 months. Caregivers who used ADC experienced significantly lower feelings of role over load (for example, fatigue and exhaustion), worry/strain, depression, and anger at the 3 months, but no effect was found on worry/strain and anger at the 12 months. This study also showed no effect on role capacity (that caregivers felt constrained with obligation in the caregiving role), in contrast to findings in prior research that found that ADC can be effective in providing caregivers with emotional and psychological relief in perceptions of their caregiving responsibility and obligation.

The findings of this study are in contrast with the study of Zarit and colleagues possibly due to the small sample size, the different types of therapeutic interventions

provided in ADC, and differences in cultural values between people living in western countries and Thailand. The Zarit study used a quasi-experiment with a control group design. A sample of 121 caregivers in the treatment group compared with 203 caregivers in the control group had more power than this study. In addition, ADCs in Zarit's New Jersey study were based on a social model of care that may provide more effective services than ADCs in Thailand that are based on the medical model. Moreover, Thai people expect that adult children are responsible for care of their elder parents. This cultural value may result in feelings of added stress and burden when not fulfilling obligations of the caregiving role (Choowattanapakorn, 1999).

Gaugler and colleagues (2003) reported that caregivers ( $n=153$ ) of PWD experienced reductions in memory problems and caregivers experienced reduced role overload after use of ADC for 3 months. The ADC might provide effective therapeutic activities that reduced disorientation for PWD and decreased caregiving hours. ADC services might have offered respite sufficient to reduce feelings of exhaustion and fatigue for caregivers. However, this study failed to support benefits of ADC use in reducing role capacity, worry and strain, and depression. Caregivers might experience difficulties and added worry in preparing the PWD to attend ADC.

There are several reasons that the use of ADC services may not have had effects on caregiver mental health in this study. The possible reasons are severity of disease, inadequate supporting services, lack of awareness of available services, small sample size, and short duration of ADC utilization.

First of all, dementia is a persistent, progressive, irreversible disorder and PWD may have developed more severe symptoms over time despite receiving ADC services. The level of cognitive and functional disability of PWD adds to caregiver suffering,

irritation, and difficulties in coping over time (Zarit, 2008). Descriptive data in this study revealed that nine caregivers experienced improved mental health, but others did not perceive better emotional and psychological health. Most caregivers reported they had negative psychological effects, such as stress and anxiety, worry, distress, irritation, tiredness, depression or sadness, and guilt.

Secondly, ADC interventions and supporting services may not have been provided in sufficient amounts for caregivers to reduce potential psychological distress. In addition, ADC activities may help to reduce some stress, but not relieve all caregiver stress. For example, the ADC staff might advise caregivers to deal with current behavior problems of the PWD, but caregivers still felt stressed and worried about their life in the future. One caregiver reported feelings of disappointment and hopelessness with no cure for dementia. The ADC might not provide sufficient supporting services for caregivers specific to moderate their emotional and psychological distress. This explanation was congruent with the study of Schacke and Zank (2006) that reported that the use of ADC was effective in alleviating some aspects of caregiver stress by significantly reducing role conflicts between caregiving and job requirements, caregiving and family needs, and recreational constrictions.

Thirdly, caregivers who experienced psychological distress might not be aware of available ADC services such as caregiver support groups and seminars. Most caregivers had work or other obligations during day time and it was hard for them to participate in supportive services provided for caregivers by the ADC.

Lastly, the sample size and duration of ADC utilization may not have been adequate to make statistically significant changes in mental health. The sample size of this study was small when compared with previous studies. Therefore, the findings in this study

did not show any effects of ADC use on mental health. These reasons may explain why ADC use had less than significant effects on the caregiver mental health.

### **Caregiver Burden**

Caregiver burden did not significantly differ across time compared with baseline in this study. The findings are similar with previous studies (Smith, 2008; Girlin et al., 2006; Gaugler et al., 2003). Smith (2008) compared caregiver burden in 8 caregivers at baseline and after use of ADC for 3 months. The results showed a mean burden score decrease that was not statistically significant due to insufficient power. The findings from focus groups in Smith's study revealed that caregivers got tremendous relief during the hours of ADC services, but little relief upon returning home.

Girlin and colleague (2006) compared the effectiveness of the usual ADC and an innovative intervention (ADS Plus) that added systematic care management for caregivers. They found that caregivers in the ADS Plus reported decreased burden but this was not statistically significant after using the ADC services for 3 months. That might be due to the fact that caregivers in the ADS Plus attended the program more days than caregivers in the usual ADC that would result in more expenses and financial burden. In contrast, Mossello and colleague (2008) compared caregiver burden between Italian caregivers who used ADC ( $n=30$ ) and caregivers who used usual home care ( $n=30$ ). The findings showed that caregiver burden was significantly reduced after using ADC for 2 months, but no effect was found on caregiver stress, anxiety, and depression. The reason might be that ADC provided effective therapeutic interventions such as counseling for family caregivers (2 -6 days weekly) and the caregiver burden interview measure is likely to be more sensitive to

detect variability of change over time. Meanwhile, caregiver depression reflected gradually adaptation.

Caregiver burden in this study was measured by the Zarit Burden Interview -Thai version (ZBI; Zarit, Reever, & Bach-Peterson, 1980) and additional qualitative questions. Even though there were no significant differences on caregiver burden across time, means of caregiver burden scores decreased after using ADC for 1 month and 3 months. Most caregiver participants ( $n=12$ , 75%) in this study reported moderate burden (ZBI score greater than 20) and two of them (12.5%) reported severe burden (ZBI score greater than 60) while four caregiver participants (25%) report no burden (ZBI score less than 20) at baseline. The mean burden score for this sample at baseline was 37.19 ( $SD=17.57$ ) and a range of 16-74 that was in 'mild to moderate' *range* and similar to means of burden scores in previous studies in the United States and other countries (Yeager, Hyer, Hobbs, Coyne, 2010 ( $M= 36.9$ ,  $SD= 16.2$ ); Sussman & Regehr, 2009 ( $M=35$ ,  $SD=14.1$ ), Gitlin et al., 2006 ( $M=36.6$ ,  $SD=10.3$ ); Arai, Zarit, Sugiura, Washio, 2002 ( $M=34.1$ ,  $SD=14.2$ )). This was in agreement with other reports that caregiving PWD brought about burden (Papastavrou et al., 2007), but it did not support that women were more burdened than men. However, when comparing with the study of the 10/66 Dementia Research Group (2004), mean burden score of this study was higher than Indian caregivers, Chinese ( $M=26.7$ ,  $SD=15.2$ ) and South East Asian caregivers ( $M=25.9$ ,  $SD=18.2$ ) because causes of dementia in a sample of PWDs were heterogeneous. In addition, mean burden score of this study was lower than caregivers of PWD who had psychosis or advanced symptoms in previous studies (Yeager, Hyer, Hobbs, Coyne, 2010 ( $M=47.9$ ,  $SD=12.9$ ); Papastavrou et al., 2007 ( $M=50.29$ ,  $SD=17.35$ )) because a few of PWDs of this study had psychosis or advanced symptoms of dementia.



After using ADC services for one month, one caregiver's reported burden changed from "moderate-severe" level to "mild-moderate" level. After the use of ADC for 3 months seven caregivers (43.8%) reported improved burden and no caregivers reported severe burden. Four burdened caregivers (25%) reported little changes compared to baseline. Two caregivers who reported increased burden reported that they were more worried because their PWD got worse. However, more than half of participants reported during the interview (after using ADC 3 months) reported that they did not feel burdened nor had too many difficulties in providing care for their PWD. In contrast, they indicated that caring for their relative with dementia is a positive experience in caregiving and repayment for their loved one. Filial piety is rooted in the Thai society. Caregiving older parents is valued as a way of "merit making" that may reduce feelings of a burden (Choowattanapakorn, 1999). Therefore, some Thai caregivers may not see caregiving for PWD as much a burden as persons of other cultures.

However, most caregivers still reported feeling moderately burdened before and during the use of ADC. Approximately half of the total caregivers reported reduced burden during the use of ADC. The common causes of caregiver burden in this study were related to the hardship to taking care of the PWD due to cognitive impairment, the disability of daily activities, limitation of family support, inadequate time for relaxation, role conflicts, physical strain, financial hardship, and undesired changes in their normal life that resulted from caregiving responsibilities. The use of ADC helped them provide care during the daytime so that they could get some relaxation and could work or do other things as needed. Caregivers could also receive other supports to improve coping with PWD and be able to deal with some financial issues. In addition, the ADC provide a variety of

therapeutic activities for PWD that might improve cognition, emotion, and behavior problems of PWD.

The mean of some items showed that participants adapted themselves in order to access the ADC services. A mean score of some items increased from baseline after using ADC for one month and decreased from baseline after using ADC for three months. It might be that the caregivers needed time to adapt or change their daily activities or functional roles upon initiating ADC services in the first month, but felt comfortable by the third month. Moreover, most caregivers stayed with their PWD at ADC during the first month to familiarize them with ADC and staff, frequently participating in ADC activities. It may be that after the PWD felt familiar with the ADC activities and the ADC staff, caregivers might go to work, visit some friends, go shopping or do other obligations. So caregivers benefits from ADC respite may have been delayed.

The findings of this study are similar to a previous study in the Netherlands (Meiland et al., 2001) that reported that caregivers who used ADC facilities experienced more burden due to disruptions in daily schedule activities. Meilands and colleagues (2001) employed a cross-sectional designed and collected data with questionnaire interviews in 93 family caregivers who were enrolled in the waiting list project for a nursing home in Amsterdam. They found that caregivers who used ADC experienced more burden due to disruptions in daily schedule activities. However, participants in the study of Meilands and colleagues (2001) might not have used the ADC services long enough to reduce their burden.

The qualitative data revealed that caregivers found that caring for PWD who used ADC services was an added responsibility that might result in physical, psychological, emotional, social, and financial stressors. Before the use of ADC services, most caregivers

reported that they had negative experiences caring for their relative such as stress, depression, social isolation, financial hardship, physical ill-health, irritation, tiredness, and other psychological effects. These negative experiences became burdensome when caregivers perceived pressure or strain and when their coping responses and supports were inadequate.

Some caregivers reported that the difficulty of transporting the PWD and the cost of ADC were hardships. Seven caregivers reported that they used ADC only when therapeutic interventions were offered. This may not have been enough to reduce their level of burden. Most caregivers reported that ADC relieved some of their burden by providing respite care and mental support, providing care advice, giving knowledge and necessary information, arranging caregiver support groups, and coordinating care with physicians, physical therapists, nutritionists, and other social support resources. Some caregivers might experience a reduced level of burden during the use of ADC. The use of ADC service helped them in providing care of their relative in the daytime so that they could get some relaxation. Although caregivers were relieved of care responsibilities when their relative attended ADC, they still had to take care of PWD at home, especially if they had no other caregiver helping them at home.

Moreover, many caregivers of this study returned to work or do other obligations after leaving a PWD at the ADC. Some caregivers reported that they had some financial difficulties due to dementia medication and ADC costs. Although the ADC had scheduled several educational classes for caregivers, some classes were cancelled due to poor attendance. Many caregivers did not attend caregiver support groups and then they did not gain benefits from this service. Therefore, some caregivers might not experience a reduced

level of burden due to advanced symptoms of PWD, inadequate family support, role overload, excessive financial costs and inadequate use of the ADC.

### **Caregiver Depression**

Caregiver depression did not differ significantly across time compared with baseline. The findings are similar with several studies (Zank & Schacke, 2002; Gottlieb & Johnson, 1995) that found that ADC use did not offer benefits for caregiver depression. In contrast, some previous studies found positive effect of ADC use on caregiver depression after the use of ADC for 3 months (Zarit, Stephens, Townsend, & Greene, 1998; Gaugler et al., 2003; Gitlin et al., 2006).

Caregiver depression was measured by the Thai version of Epidemiologic Studies-Depression Scale (CES-D) and additional two qualitative questions. Even though there were no significant differences on caregiver depression across time, means of CES-D scores decreased (indicating reduced depressive symptoms) after using ADC at 1 month and 3 months. Nine caregivers (56.3%) scored 16 or greater on the CES-D that considered to need further assessment and evaluation for depression (Radloff & Teri, 1986; Nabkasorn et al., 2005). Three caregivers (18.8%) reported improved depression after using ADC for 1 month. Five caregivers (31.3%) reported improved depression after using ADC for 3 months. One caregiver (6.3%) reported increased depression after using ADC for 3 months because their relative got worse.

The mean depression score for this sample at baseline was 18.56 ( $SD=12.54$ ) and a range of 5-44 that was close to means of depression scores in previous studies in Greek caregivers (Papastavrou et al., 2007 ( $M=18.68$ ,  $SD=7.27$ )) and American caregivers (Longmire & Knight, 2010 ( $M=17.74$ ,  $SD=9.64$ ); Majerovitz, 2007 ( $M=16.77$ ,  $SD=12.56$ )).

This was in agreement with other reports that caregivers of PWD received lower mean levels of depression (Longmire & Knight, 2010). However, the mean depression score in this sample was higher than previous studies in North America (Gitlin et al., 2006) ( $M=9.33$ ,  $SD=6.6$ ) and Japan (Sugihara, Sugisawa, Nakatani, & Hougham, 2004) ( $M = 11.92$ ,  $SD= 0.29$ ) that may be due to many factors.

Caregivers who reported that they understood the nature of dementia symptoms and learned to adapt themselves to the PWD reported lower depression. Most of these caregivers also reported that they had adequate social support. Therefore, caregivers with coping skills and social support may be less depressed.

Although more than a half of the caregivers ( $n=8$ , 50%) reported that they experienced depressive symptoms, seven depressed caregivers reported lower CES-D scores across time. Only two of these caregivers scores improved to a normal level and both of these caregivers used ADC services 3 days or more per week during the study. Therefore, the dose of the ADC use might affect caregiver depression. Moreover, this might be due to the fact that the ADC did not provide enough assessment and intervention for caregiver depression. Additionally, caregivers who had to work could not participate in any activities for caregivers with PWD provided by the ADC settings.

### **Caregiver Quality of Life.**

The mean scores on the physical domain of the WHO QOL-BREF-THAI were significantly higher than baseline, whereas overall quality of life was not found to significantly differ after one and three months of ADC use. These results were similar to a previous work (Zank & Schacke , 2002). Zank & Schacke (2002) evaluated the effects of geriatric day care units on caregiver's subjective well-being (measured by life satisfaction,

perceived social support, self-esteem, and depression) and burden in caregivers of PWD and of caregivers of older adults with normal cognition that found no effects of ADC on either caregiver well-being or burden after using ADC for 6 and 9 months. They suggested that the reasons for the lack of significant findings were the small sample size ( $n=42$ ), instruments that were insensitive to changes, and late baseline measurement (after using of ADC for 10 days). If caregivers reported low levels of burden at baseline, long-term effects of ADC use may be underestimated. Moreover, some caregivers in the treatment group were caregivers of persons without dementia that could have less strain (Zarit, Stephens, Townsend, & Greene, & Femia, 2003).

The benefit of ADC use in improving caregiver well-being was found in a few studies with inconsistent effects across time (Zarit, Stephens, Townsend, & Greene, 1998; Gitlin et al., 2006). Several studies showed significant amounts of stress reduction for family caregivers who used ADC on a regular and sustained basis (Zarit, Stephens, Townsend, & Greene, 2003). It may be because ADC in these studies may have provided effective therapeutic activities that helped reduce more severe disorientation and/or repetitious questioning on the part of PWD. In addition, the ADC may have offered respite care and assisted in activities of daily living sufficient to improve psychological well being such as caregiver depression. However, these studies did not show significant benefits on some aspects of well-being consistently in both short-term and long-term effects. The study of Zarit and colleague (Zarit, Stephens, Townsend, & Greene, 1998) showed no effect in reducing role captivity that was the extent to which caregivers feel trapped and constrained in the caregiving role after using ADC for 3 and 12 months, and no effect in reducing worry/strain and anger after using ADC for 12 months. Whereas the study of Gitlin and colleague (Gitlin et al., 2006) showed no effect in reducing burden after use of

ADC Plus for 3 and 12 months, and no effect in enhancing perceived well-being after use of ADC Plus for 12 months.

Caregiver quality of life in this study was measured by the WHO QOL-BREF-THAI and additional qualitative questions. Even though the finding showed that there were no significant differences on total caregiver quality of life across time, means of total caregiver quality of life increased after using ADC at one month and three months. The mean total quality of life score for this sample at baseline was 86.93 ( $SD=15.24$ ) and a range of 62-120 that was higher than Chinese caregivers (Wang & Chien, 2011)( $M=68.2$ ,  $SD=13$ ), Australian caregivers (O'Connor & McCabe, 2011)( $M=65.69$ ,  $SD=14.05$ ), and Brazilian caregivers (Amendola, Oliveira, & Alvarenga, 2010)( $M=54.6$ ,  $SD=21.4$ ), but was lower than some study (Novelliab, Nitrinia, & Caramelliac, 2010). This was contrast with the meta-analysis of Pinquart and Sorensen (2003) stated that caregivers of PWD had low quality of life. Most caregivers reported moderate to high level of quality of life at baseline because most caregivers in this study had good education and average family income. Four participants reported a high level of quality of life over time and had little change. An intervention is unlikely to influence dependent outcomes if baseline scores are relatively low or high (ceiling and floor effects)(Cooke, McNally, Mulligan, Harrison, & Newman, 2001). During interviews, most caregivers also reported that the use of ADC services did not have much of an effect on their life in general. Absolutely, those caregivers were able to cope with the additional stress and burden and still maintain a high level of quality of life.

However, most caregivers did not always cope with the extra stressors effectively. The ADC should enlarge social support for caregivers with the PWD. Although most participants experienced moderate satisfaction with their life such as physical and

psychological health, social relationships, financial status, and other environment, the use of ADC might not contribute directly to all of their needs in order to significantly improve their quality of life. Low doses of ADC use and a small sample size might be additional issues contributing to non-significant outcome. In addition, ADC may have been limited to make a big impact to respond all factors contribute to caregiver quality of life.

### **Caregiver Social Support.**

Caregiver social support did not significantly differ after using ADC compared with baseline. These results were similar with a previous study (Zank & Schacke, 2002) in that perceived social support scores of the treatment group were higher than the control group but this finding was not significant. This might be due to a small sample size ( $n=42$ ), instrument insensitivity to statistical change, and late measurement for baseline data (after the use of ADC for 10 days). Caregivers already experienced high levels of social support at the beginning of ADC use with little change after using ADC for one and three months.

Caregiver social support was measured by the Sarason's Social Support Questionnaire (SSQ-6; Sarason et al., 1987) in order to assess the amount of perceived social support (SSQ-N) and satisfaction with available social support (SSQ-S). Mean SSQ-N score in this sample at baseline was 2.78 ( $SD=1.95$ ) and a range of 0-6.17 that was lower than the study of Majerovitz (2007,  $M=3.61$ ,  $SD=1.88$ ); Chien & Lee, 2010). Mean SSQ-S score in this sample at baseline was 5.2 ( $SD=0.55$ ) and a range of 4.17-6 that was very high and similar to Chien and Lee's study (2010)( $M=5.3$ ,  $SD=1.8$ ) in China and Majerovitz's study (2007)( $M=4.92$ ,  $SD=1.13$ ) in North America. Most of caregiver participants ( $n=11$ , 68.8%) reported that they had more social support after one and three months than baseline. Some participants reported that they had nobody to support them at



baseline and after using ADC for some items. This revealed that some caregivers experienced a lack of social support when they needed help, when they were under pressure or tense, when they were feeling down-in-the-dumps, when they were very upset, and a lack of persons who accepted them totally and could really count on to care about them. Some of them included staff of the ADC in their list of supports. They reported that staff of the ADC provided mental support for them that they usually called a familiar staff in order to consult when they felt suffered and could not deal with their PWD. The ADC provided education class, caregiver meetings, and individual counseling for caregivers of PWD. However, there were no significant differences on the amount of perceived social support reported across time.

Therefore, there were no significant differences on caregiver reported social support across time. This might be due to the small sample size and to low variability of scores. Most participants did not list staff of the ADC as supports. Some participants reported the maximum number of available social supports at baseline. However, other caregivers had no social supports and might be dissatisfied with their available social supports. The ADC service might not appropriately assess and address caregiver social support needs. The SSQ-6 may not have been sensitive enough to assess the amount of perceived social support (SSQ-N) and satisfaction with available social support. Although some participants included staff of ADC, these additional supports may not have been adequate for significant outcome on the SSQ-6.

### **Evaluation of the ADC**

The ADC services were evaluated by the Caregiver Evaluation of Adult Day Care (CEADC) after using ADC for 3 months. The CEADC is composed of three parts

including CEADC Part I, CEADC Part II, and two additional questions. The CEADC Part I assessed caregiver satisfaction with ADC, and the CEADC Part II measured benefits and drawbacks of ADC.

Caregivers in this study were mostly satisfied with the respect for human rights, spiritual and religious beliefs, skills and friendliness of staff, provision of necessary information, program activities, program meal, time of services, and location of the ADC. They were moderately satisfied with staff's ability to handle problematic behaviors of the PWD and cost of ADC services. Scores on individual items averaged 2.76 out of a maximum 4 points.

Caregivers in this study reported that their relative benefited from being around others, improving mental function, improved function in activities of daily living, and slept better at night. Caregivers also reported that their relative was rarely upset with them, and sometimes showed less symptoms of apathy or depression after attending ADC. They were rarely worried when their relative was at the ADC and did not experience difficulties in getting their relative ready to go to the ADC. According to the benefits of ADC for themselves, caregivers reported that they had more time to do chores or other things and were more easily able to handle their relative as a result of ADC. This finding was congruent with the interview.

### **Conclusions**

This study supported the premise that the use of ADC services in Thailand improved the physical health of caregivers of the PWD. However, it also found no significant effects on reducing caregiver burden, depression and mental health. In addition, there were no significant improvements in quality of life or social support. This finding is

congruent with previous studies suggesting that ADC has limited benefits for some domains of caregiver well-being (Zarit, Femia, Haley, & Stephens, 2004; Zank & Schacke, 2002).

Quality of life is a multidimensional concept and influenced on numerous factors. The insignificant positive effects in this study may be due to small sample size, different of the ADC interventions, heterogeneity of caregivers and PWD, including the relationship of the caregiver to the PWD, low frequency use of the ADC services, insensitive and self-reported measures, and cultural differences.

This study was conducted over a year with eighteen caregivers admitted in both ADC sites; however, only sixteen caregivers remained in ADC at least 3 months. There were relatively small changes in caregiver burden, depression, quality of life, psychological health, and social support. Again, the results might not be significant due to the small sample size (Sugihara, Sugisawa, Nakatani, & Hougham, 2004).

Approximately fifty six percent used ADC services at Chiangmai Neurological hospital (Chiangmai) while the rest used ADC services at Somdet Chaophaya Institute of Psychiatry (Bangkok) in Thailand. Both sites were part of hospital-based ADC programs. Interventions provided by ADCs in Thailand are different from western countries and may affect the differences in outcomes.

ADCs in the United States are based on a social service model that offers social support for persons with chronic disabilities or diseases, in contrast, ADCs in Thailand are day hospitals that focus on medical care and rehabilitation for persons with or without dementia. ADC programs in the United States have provided various types of services and interventions for both PWD and their caregivers such as in- home respite care and institutional day care. Moreover, several studies demonstrated the effectiveness of ADC in

the United States (Mason et al., 2007) with potential benefits in the improvement of client functioning, caregiver stress reduction, delayed institutionalization, and cost-effectiveness (Gaugler & Zarit, 2001; Zarit, Gaugler, & Jarrott, 1999). Conversely, no studies have been conducted to evaluate the effectiveness of ADC in Thailand. ADCs in Thailand focus on cognitive stimulation, physical rehabilitation, and recreational activities for PWD. In one of the Thai ADC settings, therapeutic activities were only provided one day each week with remaining days including primarily custodial care. Nurses play an important role in providing medical and personal care for PWD in Thai ADCs including facilitating a variety of therapeutic interventions for PWD involving multidisciplinary collaboration. Differences in therapeutic interventions between countries may influence the variability of PWD and caregiver outcomes.

Moreover, participants in this study might be different from American caregivers using ADCs. Caregivers in this study were likely to be typical Thai caregivers of PWD who were city dwelling, were well educated, and had average to above average family income. However, participants in this study may not be representative of the Thai population of caregivers of PWD who may be less likely to be referred to and to accept ADC services. Approximately half of participants stayed at ADC whereas American caregivers did not stay with the PWD at ADC. The common purpose for attending ADC in Thai caregivers was focused on therapeutic interventions for PWD rather than the caregiver themselves and this might be different from American caregivers. These differences may have affected caregiver responses on the scales used for outcomes.

ADC services included a variety of supportive activities for caregivers of the PWD such as group education and seminars as well as caregiver support groups. Many caregivers in the study did not use these services regularly and some caregivers never used

these services. However, caregivers reported that ADC staff advised them in taking care of themselves and this may explain why significant improvements in caregiver physical health were reported. The intention of the ADC staff was to provide necessary information and emotional support regarding the caregivers' needs. Most caregivers contacted ADC staff in person, but some caregivers preferred to contact the ADC staff over the phone. The primary emphasis of the ADC services; however, was the PWD rather than their caregivers. Caregivers may also choose to attend only some of the programs offered based on their preference. The different types of service use, the duration of use as well as the different ADC services may have contributed to heterogeneous outcomes. In addition, caregivers and PWD of this study were heterogeneous in respect to caregiving context, their relationship to PWD, and individual differences.

The findings of this study are congruent with some previous studies (Fortinsky et al., 2002; Gottlieb & Johnson, 1995) but contrast with others. One reason might be the dose of ADC use, and types of services. Gottlieb and Johnson (1995) reported that PWD needed to attend ADC at least one-and-a-half days a week for five months to realize positive effects while Zarit and colleague (2002) recommended the use of the ADC 2 days per week for at least 3 months. The mean of frequency of the ADC utilization in this study was two and a half days per week for 3 months and is congruent with these previous studies.

Although the frequency of ADC use in this study averaged 2.63 days per week, approximately half of the participants ( $n=7$ , 43.7%) used ADC services only one day per week. Caregivers may experience improved outcomes if they participate in any available support services. Some caregivers used ADC as a respite so that they could return to work or do other things during the daytime. Therefore, they may not have experienced relaxation

and may not have participated in caregiver support services. The interview data revealed that some caregivers experienced increased stress due to the time required for transportation to the ADC site. That may have added to their perception of burden, depression, and lack of social support and reduced their quality of life.

Several studies also showed little or no effect of ADC use with many explanations for a lack of positive findings (Zarit, Stephens, Townsend, & Greene, and Femia, 2003). ADC use altered subjective caregiver stress in some domain, but not all domains (Zarit, Stephens, Townsend, & Greene, 1998). A lack of sensitivity in outcome measures may be another reason and changes in caregiver well-being may be different depending on the type of outcome measures. The use of many self-reported questionnaires in this study may burden participants and affect their attention to responses. Questionnaire length was limited to one hour to avoid this. However, self-reported measures are subject to bias and may be influenced by the informant's mood state or perceptions (Burns, Lawlor, & Craig, 2002). Moreover, general well-being measures such as burden, depression, and quality of life may be inadequate to detect variability of change in caregivers and less sensitive than caregiver-specific outcomes such as role overload. Consequently, the outcomes are more likely to be stable (Sugihara, Sugisawa, Nakatani, & Hougham, 2004). It has also been suggested that the ZBI, which is widely used to assess caregiver burden, may be insensitive to change (Cooke, McNally, Mulligan, Harrison, & Newman, 2001).

Another reason for the lack of significant findings may be differences in cultural differences or traditional norms of behavior in western countries and Asian countries. In Asian societies, family members are expected to provide care for the older parents and older family members due to filial piety, family intimacy, reciprocal interdependence, and

national laws. The filial piety and family intimacy are the key variables that support the Thai familial elder system of care. Based on a value of filial piety, adult children are expected to take responsibilities for caring for their older parents. Caregivers who had a strong sense of filial piety may have experienced either beneficial or harmful effects. Reciprocal filial piety is positive as it facilitates care and mutual attachment because of love and a wish to repay sacrifices; on the other hand, authoritarian filial piety facilitates a sense of obligation and encourages obedience and compliance (Laidlaw, Wang, Coclho, & Power, 2010; Kuang-Hei, 2003). Filial piety might be associated with burden, depression, insufficient social support, and reduced quality of life in Thai caregivers. A study in an Arab-Israeli sample found that filial piety was a positive predictor for caregiver burden and filial piety was not directly related to depressive symptoms, but rather worked indirectly through caregiving burden (Rabia and Howard, 2011).

The findings of this study suggested limited benefits of ADC for caregivers of the PWD. ADC services are not as numerous and their benefits are not promoted to the general public in Thailand as they are in western countries. Quality of life of family caregivers of PWD may differ among countries because quality of life depends on individual perceptions, cultural values, and environmental factors. The variation in program administration, service delivery and users' preference may also affect in differences in outcomes among countries. Participants in this study who were likely to have educated and high family income reported that they wanted the ADC services and would like to see an expansion of services in the future. This study demonstrated a need for the Thai government to recognize the importance of such services. It is important for ongoing research to evaluate ADC in order to shape health care policy regarding long-term

care and to develop the best practices of therapeutic interventions in order to optimize the benefits for the elderly with dementia and their caregivers.

### **Recommendations for Future Research**

ADC for PWD is a care alternative for Thai people. Future research needs to include program evaluation of ADC services as a basis for growth and development of ADC in Thailand. Future ADC evaluation research should be longitudinal with a larger sample in order to examine long-term effects because length of attendance at ADC could influence caregiver outcomes changing over time. It may take longer than 3 months to reduce negative caregiver outcomes. As this study suggests future research should use mixed methods. Triangular techniques are useful to evaluate several aspects of program provided. Future studies should include staff and customer perspectives including expectations, unmet needs, strengths, weaknesses and recommendations that would be helpful for the process and outcome improvement. Future studies should also evaluate the cost effectiveness of the program provided in order to guide the program management. In addition, the use of objective outcome measurements may increase sensitivity to change resulting from ADC use. Future research should incorporate additional objective measures (such as blood pressure and serum cortisol levels). More distal caregiver outcomes (such as morbidity and mortality) should be also examined.

For research focused on Thai ADC, different cost outcome measures are indicated. In the United States, cost is indirectly assessed by measures of institutionalization. For example, interventions such as ADC can delay costly nursing home placement. Because nursing home care is not widely available in Thailand, cost measures may instead need to include estimates of time families spend providing care, any



costs for hiring help, and whether caregivers leave or reduce employment (and income) to provide care.

Future research is also needed to design a set of effective therapeutic interventions specifically tailored for use in Thai ADC programs with PWD and their caregivers. Outcome research is needed to examine statistically and clinically significant benefits for PWD and families. The interventions or activities should be sensitive to meet PWD and caregivers' needs in order to enhance better outcomes.

Future research should evaluate the effectiveness of ADC on PWD as well as the caregivers, to provide a comprehensive view of the effectiveness of ADC on both users. In addition, the ongoing research may develop an ADC model that provides services as a whole system including screening, interventions, and home health care for PWD and their family. A modern model of ADC is needed to support and monitor caregiver well-being through use of technology and sophisticated communication systems (Schulz & Martire, 2004). This should be focused on health promotion starting in the early stages of dementia and continue through palliative care.

### **Recommendations for ADC Policy**

Numerous studies support ADC as a therapeutic day program for adults who need assistance with activities of daily living, enabling them to continue to live at home and also supporting caregivers by providing care assistance and support in the daytime (Reever et al., 2004; Gitlin et al., 2006) This study found that ADC is perceived as a respite service by Thai caregivers, although some participants waited at ADC while their PWD received ADC services. The use of ADC improved self-reported physical health of family caregivers of PWD. Several studies (Zarit, Stephens, Townsend, & Greene, 1998)

have also shown that ADC services can reduce psychological distress of caregivers, but this was not confirmed in this study. Since the percentage of elderly people and those with dementia is growing, the need for effective and widespread ADC services is becoming increasingly important.

Only two public hospitals provide ADC services for PWD in Thailand. Both hospitals are located in urban areas and serve a limited number of PWD. Most Thai people are unaware of ADC services due to a lack of promotion and publicity. In order for more PWD and their caregivers to benefit from ADC services, there needs to be an increase in public awareness through the media and official government policy. Caregivers in this study expressed wishes for continued and expanded ADC services. They wanted their relatives to live with them at home until the end of their lives. These study findings have important policy implication for the Thai government as well as the private sector. There is a strong need to recognize the importance of health promotion for caregiver well-being as well as for the Thai elderly in early dementia detection and rehabilitation. Financial support for research and ADC services should provide a variety of effective therapeutic interventions and supporting activities to enhance better outcomes for PWD and family caregivers. An important benefit of increased ADC availability and usage would be more people being screened and an increase in the likelihood of early detection and rehabilitation of brain functions. Caregivers could benefit by reducing physical distress and other negative effects due to taking care of the PWD. ADC services may help caregivers increase their capability to take care of their PWD at home and also help the PWD fulfill their desire to stay at home at the end of their life.

Increasing numbers of family members are required to provide primary home-based care for their PWD. ADC services could be applied through home and

complementary community-based services such as respite care, mental support services, physical activity programs, and educational programs for family caregivers to relieve stress and increase their coping capability in the caregiving role. Community volunteers may be involved in some activities of ADC. To increase the effectiveness of the ADC services, they need to be supported by health care policy and their benefits made known to all stakeholders. This study explored the expectation, unmet needs, strengths, weaknesses, and recommendation for the future ADC services in Thailand from the user's perspective. The information is useful for guiding health care policy for long-term care and welfare of the aged in Thailand.

The increase in the number of PWD means a growing burden of care for the elderly care will be placed upon family caregivers. Young people today experience several conflicts with the obligation to care for their parents that result in increased problems of parental abandonment in Thai society. These conflicts rise from economic problems, health problems, social problems, family relationship problems and limitation of community support resources (Rachiwong, 2002). Caregivers may become physically ill and experience psychological distress such as depression, stress, and worry that may lead to a risk of a breakdown. This study proposed that ADC services, as a social service assistance program, would be beneficial to provide physical care, emotional support, wider social networks and increased access to community support services for caregivers who are assuming enormous responsibilities that is both satisfying and rewarding. However, the findings of this study did not support the benefits in improving caregiver burden, depression, mental health, (overall) quality of life, and social support.

ADC is a creative strategy to support health and well-being of the elderly as well as family caregivers based on the concept of "Active Ageing" as well as "Family Caregiver

Wellness.” Program and policymakers play an important role in creating and promoting various supportive services that are uniquely suited to the needs of PWD and family caregivers including affordable ADCs. These services will support the strengths of caregivers who are the mainstay of caregiving for the growing number of the elderly in Thailand.

### **Implications for Practice**

The findings of this study suggested responses from caregivers who were users and evaluators of ADCs that would be useful for providers to understand users’ expectations and their experiences for process improvement and the development of best practices. To provide a standard of care and effective services for PWD and their caregivers, it is important that the ADC staff should be specialists in order to provide effective care and manage interventions or support activities that meet the needs of users. The demands and negative impacts of dementia caregiving are generally higher than non-dementia caregivers such as greater burden, strain, and depression (Ory, Hoffman, Yee, Tennstedt, & Schulz, 1999). Moreover, caregivers have high expectations regarding the expertise of professionals in providing education, advice, and support regarding dementia, as well as cooperating between professionals (de Jong & Boersma, 2009)

Nurses play an important role in the coordination and management of ADCs and providing care for the PWD and their caregivers. Nursing staff require several practical skills such as communication skills, interpersonal skills, clinical competencies, creative thinking, and counseling skills. Communication skills and interpersonal skills are essential to promote successful collaboration among nurses and a multidisciplinary team to organize therapeutic interventions for PWD and caregivers.

Nurses and caregivers are in partnership to provide continuing care for PWD. Nurses and caregivers need to develop communication skills in order to understand PWD who have had communication difficulties. Nurses may use several means of communication with caregivers to support, monitor, advise, and follow-up such as face-to-face conversation, paper reports, and available technologies (such as telephone contacts) that would increase the effectiveness of communication. The consequences not only bring about beneficial information for program evaluation, but also increase access to services and foster the effectiveness of ADC services.

The relationships between nurses and PWD and their caregivers are an important aspect of ADC (de Jong & Boersma, 2009). The relationship should be based on professional and therapeutic approaches. The therapeutic relationship demands a wide range of communication strategies and interpersonal skills such as listening, questioning, encouraging ventilation, reflecting on content and clarifying, and using humor (Scanlon, 2006). Effective nurse-client relationships allow nurses to understand the holistic needs of PWD and caregivers including their physical, emotional, social, financial, and spiritual needs while enabling them to respond to their needs safely, specifically, and ethically.

Dementia care requires special competencies. The ADC staff need to be professionally trained in order to understand and be able to deal with behavioral problems of PWD and to provide the right services for their caregivers. A full professional assessment is required. An individual care plan should be created with purposes of a PWD and their caregiver (Aminzadeh, Dalziel, Wilson, Papahariss-Wright, 2005). Nursing process is an essential part of the nursing care plan and leads nurses to assess, monitor, and evaluate desired outcomes continually and systematically. Nursing care and therapeutic approaches need to be directed at improving outcomes. Therapeutic approaches with PWD

include reality orientation, validation therapy, progressively lowered stress threshold, and resolution therapy (Williams & Tappen, 1999).

Williams, Kelly, and Tappen (2005) identified dementia-specific competencies and developed a training curriculum for health care providers including hospice and ADC personnel. These competencies included: demonstrating a working knowledge of dementia; recognizing, preventing, and managing distress behaviors of PWD; understanding special needs of family caregivers; promoting independent activities in daily living; promoting an optimal environment; recognizing and incorporating ethical issues that arise in dementia care, and advanced competencies. Moreover, creative thinking is essential in decision making for problem solving, care management, and therapeutic innovations. Furthermore, patience, empathy, compassion, tact and a sense of humor are vital personal qualities required for ADC personnel.

Nurses also need to be concerned with caregiver health and well-being. The caregiver assessment is also helpful to understand caregiver's health, needs, and expectations. The assessment of physical and psychological distress of caregivers should be included so that caregiver burden and depression can be detected and assisted in time. In addition, reducing the impact of physical disability could ameliorate caregiver stress (Bruce, Paley, Nichols, Robert, Underwood, & Schaper, 2005). This study identified that ADC staff advised Thai caregivers in self-care strategies and this may explain improvements in caregiver-reported health. Thus, these best practices should be continued in Thai ADC programs. To be most effective, ADC services for caregivers should combine psychosocial counseling, behavioral-skills training, education, environmental modification, and support groups with higher frequency and duration (Schulz & Martire, 2004). Counseling skills are helpful to provide effective individual and group counseling

including family counseling. The ADC services should include health assessment and outcome evaluation systematically and periodically. The findings of outcome evaluation will provide important information for process and outcome improvement.

Nurses can support family caregiving by providing effective services for caregivers and promoting efficient use of resources available to them. It is necessary for caregivers to learn about the illness, symptoms, medication, treatments, complications, and how to relate to health care professionals so that they can be confident with a sense of mastery to provide effective caregiving (Piamjariyakul, Williams, Prapakorn, Khuhaprema, Kanka, Jermson, Kim, Park, Rojjanasrirat, & Williams, 2010; Aminzadeh, Dalziel, Wilson, Papahariss-Wright, 2005). Caregivers who reported a sense of mastery tended to experience less burden and depressive symptoms (Rabia and Howard, 2011).

Therapeutic interventions and innovations should provide more variety and benefits sensitive to caregiver's needs and cultural values. Wang and Chien (2011) reported the effectiveness of a family-led mutual support program, which integrated educational, supportive and opening communication, and sharing components congruent with Chinese-oriented culture, in reducing caregiver burden and increase quality of life. Most Thai people are Buddhists who believe in a chain of rebirth. They believe that human beings are reborn depending on individual merit-making such as ministering to parents, the practice of meditation, and performing religious activities. Being virtuous will result in prosperity and happiness in current and future lives. ADC services for Thai people should include religious activities and traditional Thai customs also.

Family caregivers may experience emotional and physical pain along with feelings of powerlessness (Che, Yeh, and Wu, 2006). Nursing interventions should include empowering family caregivers to upgrade their abilities in care management for PWD and

themselves so that caregivers can handle the difficulties and mobilize available resources necessary to satisfy their needs and overcome problems.

Although a variety of interventions are available for PWD and dementia caregivers, additional interventions need to be developed, best practices should be identified, and cost effectiveness evaluated. Professionally trained providers are keys to enable excellent care services. Process and outcome evaluation should be established systematically to ensure quality of care and client (both PWD and family caregivers) satisfaction. Transportation should also be considered.

### **Verifying Smith's Model of Caregiving Effectiveness**

This study verified the application of Smith's Model of Caregiving Effectiveness for dementia caregivers including efficient use of ADC as an external resource that can promote adaptive coping to meet caregiving demands and enhance caregiver effectiveness. This study validated that variables in the caregiving context influence the adaptive context variables and thus lead to caregiving effectiveness (Smith, 1994a, p.30). Although Smith's model was initially designed to apply to family caregivers of technologically dependent adults residing at home, this theory can be generalized to caregivers of PWD as well and to specifically to the population of dementia caregivers in Thailand. ADC is a small part of a larger umbrella of home and community based services required to keep people with disabilities in the community (Smith, 2008).

Caregivers need effective adaptation in order to respond to increased care demands while enhancing their own well-being. Families can be guided to cope by obtaining the needed social support (Smith et al., 1998). Nurses play an important role in providing care management and a variety of supporting services sensitive to assist family



coping. Quality of life for both patients and caregivers are important outcomes of nursing care (Smith, 1994).

Smith's model of caregiving effectiveness posits that caregiving effectiveness is the outcome of efficient use of resources and is influenced by caregiving context and adaptation context variables (Smith, Pace, Kochinda, Kleinbeck, Koehler, & Popkess-Vawter, 2002). The adaptive context variables (caregiver burden, caregiver depression, and caregiver social support) are important mediators that lead to caregiving effectiveness (caregiver quality of life). Adaptation in family caregiving is mediated by social and family support as well as caregiving characteristics. The lack of family support and ineffective use of social resources would influence caregiver coping and result in caregiver reactions (caregiver burden and depression) (Smith, 1994). The caregivers' perceptions about their family financial ability are related to worry, strain, and fatigue (Smith et al., 1997).

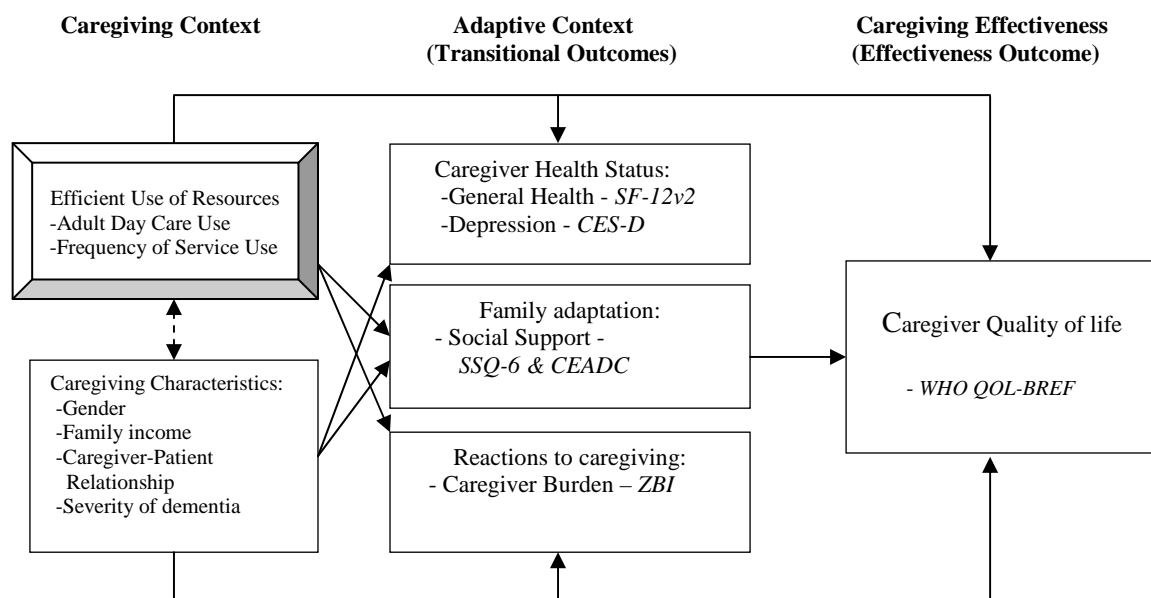


Figure 4. Model of Caregiving Effectiveness. Adapted from “Caregiving Effectiveness: Evolution of a Nursing Model for Home Care” by C.E. Smith, K. Pace, C. Kochinda, S.V.M. Kleinbeck, J. Koehler, & S. Popkess-Vawter, 2002, *Advances in Nursing Science*, 25, p.52.

↔ Proposed reciprocal relationships between concepts,

←----> Inconsistent relationship between concepts

Smith's Model of Caregiving Effectiveness is useful to explain the experiences of family caregivers who take care of the PWD at home. The findings of this study showed that ADC service use was effective for caregiver physical health status, but it was not effective enough for other components of adaptive context and the caregiving effectiveness outcome. Physical health is only a part of the adaptive context. To achieve caregiving effectiveness or caregiver's quality of life, it is necessary to reduce caregiver's burden and caregiver's depression, and increase caregiver's social support.

Even though, caregivers in this study used the ADC services, service use alone may not be enough to reduce caregiver's burden and depression. Other resources in their community may be needed to provide adequate support. The lack of service awareness and inadequate availability of resources can be a barrier to caregiver effectiveness. Caregivers who are aware of available resources tend to use services and technologies more often. For example, they may seek help by using a telephone or counseling hot line to support them. They may also search for knowledge and information on the internet and through other information resources to increase their capability and self-esteem to provide care.

This study used both quantitative and qualitative components. This triangular approach provided valuable insights about the experiences of family caregivers during using ADC services. This study provides foundational information and guidance for practitioners to improve the standard of care and create specialized interventions significant for ADC service users. The findings reflect the needs of Thai people and calls for policy makers and the private sectors to provide assistance for family caregivers in their efforts to care for impaired family members. ADC providers should understand caregiver's needs and the effects of the services have on caregivers in order to design a set of innovative interventions that benefit them and increase their quality of life. This evaluation

research also provides valuable information for service organizations and policy makers to make judgment about the program significance and inform decisions about future long-term care programming.

### **Limitations**

There are several limitations in this study that included small sample size, research design, the use of numerous questionnaires with repeated measures, limitations of self-reported measures, the low frequency use of the ADC services, the different of the ADC interventions, and the heterogeneity of caregivers and PWD.

The major limitation of this study is the small sample size, The small sample size contributes to low statistical power of the study and probability of detecting an effect (Land & Zheng, 2010). The study took place in a specific and limited time frame and with limited admissions of new patients in the ADC sites.

The second limitation is due to quasi-experimental design without randomization and a control group. Randomization was not feasible and would present ethical issues due to limiting the use of needed services to participants assigned to a control group was used. Therefore, a convenient sample and quasi-experimental design were selected for this study. The convenient sample and lack of randomization limit generalization of the study findings to other population but provide preliminary information about ADC benefits to family caregivers in Thailand. Since almost users of both ADC sites participated in the study, the sample is likely representative for the Thai population who could afford ADC. Most caregivers had educated and had an average to higher than average family income. In addition, they had been in urban area and were able to access ADC by public transportation or their own vehicles. This sample is not representative of all Thai populations.

The third limitation is related to the use of many questionnaires with repeated measures. Participants were asked to complete at least five questionnaires at three time points and may have become bored or burdened in responding to repeated measures. Participants responses to the interview questions may also have been influenced by social desirability or the Hawthorne effect. In addition, self-reported outcomes such as physical health, are less objective than actual physical measures and a demand effect for pleasing the investigator may have biased participant responses (Bager, Stabile, & Deri, 2004).

Participants also selectively attended different amounts and types of ADC activities. Thus participants received different doses of the ADC intervention. The admission criteria might result in a typical sample who were able to afford ADC. In these sites physicians identified PWD who qualify for ADC services, taking into account factors such as severity of disease, financial support, and preference of family members.

Next, both ADC sites are located in different parts of Thailand. This might bring about the differences in caregiving contexts and result in a heterogeneous sample. These two programs differ in some aspects, but are mostly similar in objectives and procedures. Both ADC centers are located in urban areas and are convenient to transportation. This study examined the differences among groups on gender, family income, caregiver-patient relationship, frequency of service use, severity of dementia, and research site. There were no statistical effects of these potential covariate factors. However, the results of t-test may be different in a larger sample. The ANOVA and regression analysis is more appropriate in the larger sample.

The strength of the study is its study design which combined two main open-ended questions with repeated measures design. The quantitative and qualitative approaches brought about rich information to understand several aspects of quality of life

for the PWD and their caregivers. Qualitative data contributed substantively to assessing meaningful changes in caregiver outcomes and to understanding the effectiveness of ADC services from the caregiver's perspective.

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**Appendix A**  
**Research Informed Consent**

**EFFECTIVENESS OF ADULT DAY CARE PROGRAMS ON HEALTH  
OUTCOMES OF THAI FAMILY CAREGIVERS OF PERSONS WITH  
DEMENTIA**

**Researchers:**

1. Kristine Nordlie Williams, RN, PhD, APRN, BC, Associate Professor (Faculty, School of Nursing, KUMC)
2. Sandra Bergquist-Beringer, BSN, Ph.D, Associate Professor (Faculty, School of Nursing, KUMC)
3. Elaine Williams Domian, RNCS, MSN, PhD, Clinical Assistant Professor (Faculty, School

- of Nursing, KUMC)
4. Wilaiporn Rojjanasrirat, RN, PhD, Research Assistant Professor (Faculty, School of Nursing, KUMC)
  5. Tracey A. LaPierre, BA, MS, MA, PhD, Assistant Professor (Faculty, Department of Sociology and the Gerontology Center, KU)
  6. Premruetai Rattanaivilai, RN, MS (PhD student, School of Nursing, KUMC)

**Responsible Organization and Address:** School of Nursing, University of Kansas Medical Center, 3901 Rainbow Boulevard, Kansas City, KS 66160, United States

You are being invited to join a research study because you are a caregiver of person with dementia using adult day care services at Somdet Chaophaya Institute of Psychiatry, Bangkok or Chiangmai Neurological Hospital, Chiang Mai in Thailand. Also, as the caregiver who is making decisions on behalf of a person with dementia, you are being asked to approve his or her participation in this research study. The main purpose of research is to create new knowledge for the benefit of future patients and society in general. Research studies may or may not benefit the people who participate.

Research is voluntary, and you may change your mind at any time. You do not have to participate in this research study. There will be no penalty to you if you decide not to participate, or if you start the study and decide to stop early. Either way, you can still get medical care and services at Somdet Chaophaya Institute of Psychiatry or Chiangmai Neurological Hospital as usual.

This consent form explains what you have to do if you are in the study. It also describes the possible risks and benefits. Please read the form carefully. You can ask as many questions as you need to, before you decide to participate in this study or anytime during the study. The researchers will tell you if they receive any new information that might cause you to change your mind about participating.

This research study will take place at Somdet Chaophaya Institute of Psychiatry and Chiangmai Neurological Hospital in Thailand. This study is being conducted through the University of Kansas Medical Center with Kristine Williams, PhD as the primary investigator and Premruetai Rattanaivilai as the student investigator. About 20 participants will be in the study.

## **BACKGROUND**

Many persons with dementia are cared for at home. However, some persons with dementia attend an adult day care. We believe that adult care may reduce stress for families caring for persons with dementia but there have been no studies evaluating the effectiveness of these adult day services for person with dementia from the perspective of Thai family caregivers.

## **PURPOSE**



By doing this study, the primary aim of this study is to evaluate the effect of the current adult day care programs for persons with dementia (PWD) in Thailand on caregiver outcomes (burden, depression, health status, social support, and quality of life). The second aim of the study is to explore the caregivers' experiences of how adult day care has helped the clients and family caregivers and how the life has changed.

### **PROCEDURES**

If you are eligible and decide to participate in this study, your participation will involve answering questionnaires, surveys, and open-ended questions after the use of the adult day care services within first week, at one month, and three months in a participant's home or other convenient places. During the first session, you will complete five questionnaires and a survey. During the second session, you will complete five questionnaires and two surveys. Finally, at three months, you will complete five questionnaires and two surveys. Additionally, an interview with two open-ended questions will be asked on the following day. Each session will take approximately an hour to complete the questionnaires and surveys. The questionnaires, surveys and an interview will ask you about your life and experiences with adult day care services. The interview will take approximately an hour and will be audio taped. The audio tapes will be transcribed, analyzed, and kept in a locked cabinet that is accessible only by the researchers. With your permission we will access the medical charts of the patient for whom are making decisions and record health information such as physician diagnosis and severity of disease.

### **RISKS**

You may feel uncomfortable answering some of the questions in the surveys, questionnaires, and interview. If at any point you feel uncomfortable you may skip a question or stop participating all together without penalty. If necessary, support and referral to a counselor will be offered as needed. Since the study will involve data from medical records, the risk of a breach of confidentiality is possible. However, extra efforts will be made to keep patients' personal information confidential.

**BENEFITS**

There are no direct benefits to you and your recipient in joining the study. It is hoped that the information obtained will help the investigators learn more about the overall aspects of caregivers' quality of life, experiences and expectations in the use of adult day care. It is hoped that this information will be useful to improve adult day care programs and other supportive services for caregivers and persons with dementia.

**ALTERNATIVES**

Participation in this study is voluntary. Deciding not to participate will have no effect on the care or services you receive at adult day care settings.

**COSTS/PAYMENTS**

There are no costs in joining the study; neither your recipient nor you will receive payment to join the study.

**INSTITUTIONAL DISCLAIMER STATEMENT**

If you think you have been harmed as a result of participating in research at the University of Kansas Medical Center (KUMC), you should contact the Director, Human Research Protection Program, Mail Stop #1032, University of Kansas Medical Center, 3901 Rainbow Blvd., Kansas City, KS 66160. Under certain conditions, Kansas state law or the Kansas Tort Claims Act may allow for payment to persons who are injured in research at KUMC.

**CONFIDENTIALITY AND PRIVACY AUTHORIZATION**

Efforts will be made to keep you and your recipient's personal information confidential. The researchers will only use and share information that is needed for the study. Your health information that will be collected such as name, address, phone, date of birth, or other identifiers will be used at KUMC by Premruetai Rattanaivilai and members of the research team, the KUMC Human Subjects Committee and other committees and offices that review and monitor research studies. If the results of this study are published or presented in public, information that identifies you and your recipient will be removed. Since identifiers will be removed, your name and your recipient's health information will not be re-disclosed by outside persons or groups and will not lose its federal privacy protection. Absolute confidentiality cannot be guaranteed because persons outside the study team may need to look at the study records. Study records might also be reviewed by government officials who oversee research, if a regulatory review takes place.

Your health information is protected by an American federal privacy law called HIPAA. By signing this consent form, you are giving permission for Somdet Chaophaya Institute of Psychiatry, Prasat Chiang Mai hospital, and KUMC to use and share your and the recipient's health information. If you decide not to sign the form, you and your recipient cannot be in the study.

Your permission to use and share your and the recipient's health information remains in effect until the study is complete and the results are analyzed. After that time, researchers will remove personal information from study records. However, the de-identified data can be used for secondary analyses.

### **QUESTIONS**

Before you sign this form, Dr. Kristine Nordlie Williams or Premruetai Rattanavilai or other members of the study team should answer all your questions. You can talk to the researchers if you have any more questions, suggestions, concerns or complaints after signing this form. If you have any questions regarding this study, you should immediately contact Dr. Kristine Nordlie Williams at 001-913-588-1624 (United States), [kwilliams1@kumc.edu](mailto:kwilliams1@kumc.edu) or Premruetai Rattanavilai at 2503-2620 (Thailand), [prattanavilai@kumc.edu](mailto:prattanavilai@kumc.edu). If you have any questions about your rights as a research subject, or if you want to talk with someone who is not involved in the study, you may call the Human Subjects Committee at 001-913-588-1240. You may also write to Human Subjects Committee, Mail Stop #1032, University of Kansas Medical Center, 3901 Rainbow Blvd, Kansas City, KS 66160.

### **SUBJECT RIGHTS AND WITHDRAWAL FROM THE STUDY**

You may stop being in the study at any time. Your decision to stop will not prevent your recipient from getting treatment or services at Somdet Chaophaya Institute of Psychiatry and Chiangmai Neurological Hospital. The entire study may be discontinued for any reason without your consent by the investigator conducting the study.

You have the right to cancel your permission for researchers to use your recipient's and your health information. If you want to cancel your permission, please write to Dr. Kristine Nordlie Williams. The mailing address is Dr. Kristine Nordlie Williams, University of Kansas Medical Center, Mailstop 4043, 3901 Rainbow Boulevard, Kansas City, KS 66160, United States. Or you may write to Premruetai Rattanavilai, School of Nursing, Sukhothai Thammathirat Open University, Pakkred, Nonthaburi 11120 Thailand. If you cancel permission to use your recipient's and your health information, you will be withdrawn from the study. The research team will stop collecting any additional information about you.

\_\_\_\_\_  
Print Name of Investigator Providing Informed Consent

\_\_\_\_\_  
Signature of Investigator Providing Informed Consent

\_\_\_\_\_  
Date

**CONSENT**

On behalf of myself and the person for whom I am making decisions, I freely and voluntarily consent to participate in this research study. I acknowledge that I can withdraw or stop this consent anytime with no effect on the care or services I and my recipient have received.

Dr. Kristine Nordlie Williams or the research team has given me information about this research study. She has explained what will be done and how long it will take. She explained any inconvenience, discomfort or risks that may be experienced during this study. I acknowledge that I am being asked to participate in this study for myself and on behalf of my recipient with dementia. By signing this form, I have read the information and had my questions answered. The researchers are willing to answer any questions anytime throughout the study. They will keep my personal information confidential. I will receive a signed copy of the consent form to keep for my records.

\_\_\_\_\_  
Print Name of Caregiver Participant

\_\_\_\_\_  
Signature of Caregiver Participant

\_\_\_\_\_  
Date

\_\_\_\_\_  
Print Name of Investigator

\_\_\_\_\_  
Signature of Investigator

**RESIDENT ASSENT**

Dr. Kristine Williams and Premruetai Rattanavilai of the University of Kansas Medical Center are conducting a research study at Somdet Chaophaya Institute of Psychiatry and Chiangmai Neurological Hospital. I understand that I am being asked to join in this research project and my health information including my functional and cognitive abilities will be used in the study. I agree to let Dr. Williams' research team assess any of my capabilities and review my medical record for information as needed for this study. Researchers will keep my personal information confidential. The study has been explained to me and I agree to participate in the study. I understand that I don't have to be in this study. I don't have to be in the study even if my caregiver says it is O.K. for me to do it. I have had the chance to ask any questions that I have. I understand that I can stop being in the study at any time and it won't affect the care I get from my doctor. I also agree to let my caregiver provide his/her signature instead of me in this consent form in order to present my verbal assent to participate in the study.

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Print Name of Patient

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Date

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Print Name of Caregiver Participant

---

Signature of Caregiver Participant

---

Print Name of Investigator

---

Signature of Investigator

**Appendix B**  
**Research Informed Consent - Thai**

### เอกสารคำชี้แจงผู้เข้าร่วมโครงการวิจัย

**ชื่อโครงการวิจัย :** ประสิทธิภาพของโปรแกรมการดูแลผู้ที่มีภาวะสมองเสื่อมที่จัดบริการในรูปแบบโรงพยาบาลกลางวันที่มีต่อญาติผู้ดูแลในประเทศไทย

**รายชื่อผู้ร่วมวิจัย :**

1. Kristine Nordlie Williams, RN, PhD, APRN, BC, Associate Professor (Faculty, School of Nursing, KUMC)
2. Sandra Bergquist-Beringer, BSN, Ph.D, Associate Professor (Faculty, School of Nursing, KUMC)
3. Elaine Williams Domian, RNCS, MSN, PhD, Clinical Assistant Professor (Faculty, School of Nursing, KUMC)
4. Wilaiporn Rojjanasrirat, RN, PhD, Research Assistant Professor (Faculty, School of Nursing, KUMC)
5. Tracey A. LaPierre, BA, MS, MA, PhD, Assistant Professor (Faculty, Department of Sociology and the Gerontology Center, KU)
6. เปรมฤทัย น้อยหมื่นไวย, RN, MS (PhD student, School of Nursing, KUMC)

**หน่วยงานที่รับผิดชอบงานวิจัยและที่อยู่ :** School of Nursing, University of Kansas Medical Center, 3901 Rainbow Boulevard, Kansas City, KS 66160, United States

**การศึกษาวิจัยนี้เกี่ยวกับเรื่องอะไร**

ท่านได้รับเชิญให้เข้าร่วมการวิจัยในครั้งนี้ เนื่องจากท่านเป็นญาติผู้ดูแลผู้ที่มีภาวะสมองเสื่อมที่เข้ารับบริการ ในรูปแบบโรงพยาบาลกลางวันแก่ผู้ที่มีภาวะสมองเสื่อม หรือคลินิกความจำ ณ สถาบันจิตเวชศาสตร์สมเด็จเจ้าพระยา หรือโรงพยาบาลประสาทเชียงใหม่ในระหว่างปี 2553 การวิจัยครั้งนี้มีวัตถุประสงค์เพื่อศึกษาประสิทธิภาพของ การจัดกิจกรรมในรูปแบบโรงพยาบาลกลางวันในประเทศไทยที่มีต่อญาติผู้ดูแลผู้ที่มีภาวะสมองเสื่อม ถึงแม้ว่า ผู้เข้าร่วมการวิจัยอาจจะไม่ได้รับประโยชน์จากการเข้าร่วมวิจัยครั้งนี้โดยตรง ความรู้ที่ได้รับจะเป็นประโยชน์อย่างยิ่ง สำหรับการจัดการบริการทางสังคมแก่ผู้ที่มีภาวะสมองเสื่อมของประเทศไทยในอนาคต

การเข้าร่วมการวิจัยครั้งนี้เป็นไปด้วยความสมัครใจ ท่านอาจจะไม่เข้าร่วมในการวิจัยครั้งนี้เมื่อไรก็ได้ โดยที่การตัดสินใจของท่าน จะไม่มีผลต่อการบริการที่ท่านจะได้รับจากสถาบันจิตเวชศาสตร์สมเด็จเจ้าพระยา หรือโรงพยาบาลประสาทเชียงใหม่แต่อย่างใด

แบบยินยอมเพื่อเข้าร่วมในงานวิจัยฉบับนี้อธิบายเกี่ยวกับกิจกรรมของผู้เข้าร่วมในการวิจัย ประโยชน์และความเสี่ยงที่อาจเกิดขึ้น ขอความกรุณาท่านได้อ่านรายละเอียดดังกล่าวอย่างละเอียด และสอบถามข้อสงสัยต่างๆ ที่ท่านมีทั้งหมด ก่อนที่ท่านลงลายมือชื่อในเอกสารฉบับนี้หรือท่านอาจจะสอบถามข้อสงสัยต่างๆ ในเวลาใดก็ได้ระหว่างการดำเนินการวิจัย

สถานที่ดำเนินการวิจัยครั้งนี้คือ สถาบันจิตเวชศาสตร์สมเด็จเจ้าพระยา และ โรงพยาบาลประสาทเชียงใหม่ ทั้งนี้คุณเปรมฤทัย น้อยหมื่นไวย หนึ่งในคณะผู้วิจัยจะเป็นผู้ประสานงานและดำเนินการ เก็บรวบรวม

ข้อมูลจากญาติ ผู้ดูแลผู้มีภาวะสมองเสื่อมที่เข้ารับบริการในรูปแบบโรงพยาบาลกลางวันหรือคลินิกความจำ รวมจำนวน 20 ท่าน

### ความเป็นมา

ผู้มีปัญหาสมองเสื่อมส่วนใหญ่มักได้รับการดูแลที่บ้าน จากการศึกษาในต่างประเทศพบว่า ญาติ ผู้ดูแล ผู้มีภาวะสมองเสื่อมมักมีความเหนื่อยล้าและภาวะซึมเศร้าเพิ่มขึ้น สุขภาพร่างกายแย่งลง ขาดการช่วยเหลือที่เพียงพอ จากสังคม ขาดเวลาในการเอาใจใส่ตัวเอง และมีคุณภาพชีวิต (ชีวิตความเป็นอยู่) ที่ลดลง การให้บริการในรูปแบบ โรงพยาบาลกลางวันแก่ผู้มีภาวะสมองเสื่อม หรือที่เรียกว่าคลินิกความจำนี้ เป็นการบริการหนึ่งที่สามารถช่วยเหลือ ครอบครัวและญาติผู้ดูแลในการลดความเหนื่อยล้าและภาวะซึมเศร้า ส่งเสริมการมีสุขภาพร่างกายที่ดีขึ้น เพิ่มระดับ ของการบริการทางสังคม และส่งเสริมคุณภาพชีวิตโดยรวม อย่างไรก็ตามในขณะนี้ยังไม่มีการศึกษาใดในประเทศไทย ที่ศึกษาประสิทธิภาพของการบริการในรูปแบบดังกล่าว

### ศึกษาเรื่องนี้เพื่ออะไร (วัตถุประสงค์ของการวิจัย)

การวิจัยครั้งนี้มีวัตถุประสงค์สองข้อ วัตถุประสงค์แรกเพื่อประเมินผลของการจัดกิจกรรมในรูปแบบโรงพยาบาลกลางวันแก่ผู้มีภาวะสมองเสื่อมในประเทศไทย ที่มีต่อความเหนื่อยล้า ภาวะซึมเศร้า ภาวะสุขภาพ แรงสนับสนุนทางสังคม และคุณภาพชีวิตของญาติผู้ดูแล วัตถุประสงค์ที่สองของการวิจัยเพื่อรับทราบ ประสพการณ์ ของญาติผู้ดูแลว่าการจัดกิจกรรมในรูปแบบโรงพยาบาลกลางวันสามารถช่วยผู้ป่วยและญาติผู้ดูแลได้อย่างไรและทำให้ชีวิตภายหลังเข้ารับบริการมีการเปลี่ยนแปลงอย่างไร

### ท่านจะได้ประโยชน์อะไรจากการศึกษาวิจัยนี้ (ผลประโยชน์)

ท่านและญาติของท่านจะไม่ได้รับประโยชน์โดยตรงจากการเข้าร่วมงานวิจัยครั้งนี้ แต่ข้อมูลที่ท่านให้ จะเป็น ประโยชน์ต่อพยาบาล ทีมสุขภาพและผู้ที่เกี่ยวข้องที่จะเข้าใจคุณภาพชีวิตหรือสภาพชีวิตความเป็นอยู่ของญาติผู้ดูแลผู้มีภาวะสมองเสื่อม รวมทั้งประสพการณ์และความคาดหวังในการเข้ารับบริการ โรงพยาบาล กลางวันแก่ผู้มี ภาวะสมองเสื่อม ข้อมูลดังกล่าวจะเป็นประโยชน์ต่อการปรับปรุงการจัดกิจกรรม ของโรงพยาบาล กลางวันและการจัด บริการทางสังคมอื่นๆ แก่ผู้มีภาวะสมองเสื่อมและญาติผู้ดูแล

### ท่านจะต้องปฏิบัติตัวอย่างไร (ขั้นตอนการวิจัย)

ถ้าท่านตัดสินใจเข้าร่วมในการวิจัยครั้งนี้ ท่านจะถูกขอให้เซ็นชื่อในแบบยินยอมเพื่อเข้าร่วมในงานวิจัย และ ได้รับเชิญให้ตอบแบบสอบถามและแบบสำรวจต่างๆ รวม 3 ช่วงเวลา คือ ภายหลังจากญาติของท่านเข้าใช้ บริการใน โรงพยาบาลกลางวันหรือคลินิกความจำภายในสัปดาห์แรก หนึ่งเดือนและสามเดือนที่บ้านหรือที่ สะดวกอื่นตามที่ นัดหมาย นอกจากนี้ในครั้งสุดท้ายเมื่อญาติของท่านเข้าใช้บริการใน โรงพยาบาลกลางวัน หรือ คลินิกความจำอย่างน้อย สามเดือน ท่านจะถูกขอสัมภาษณ์อีกประมาณ 1 ชั่วโมง เพื่อรับทราบข้อมูลชีวิตและ ประสพการณ์ของท่านที่เกี่ยวข้อง กับการใช้บริการในโรงพยาบาลกลางวันหรือคลินิกความจำ การสัมภาษณ์ของ



ท่านจะถูกบันทึกเทป และถูกถอดเป็น ข้อความ เพื่อนำไปใช้ในการวิเคราะห์ข้อมูล ซึ่งเทปบันทึกเสียงและเอกสารต่าง ๆ ที่บันทึกข้อมูลของท่านจะถูกเก็บรักษา ในสถานที่ที่มิดชิดที่ผู้วิจัยสามารถเข้าถึงได้เท่านั้น

### ค่าใช้จ่าย/ค่าตอบแทน

การเข้าร่วมในการวิจัยครั้งนี้ท่านและญาติของท่านไม่ต้องเสียค่าใช้จ่ายใดๆ เพิ่มเติม และไม่มีค่าตอบแทนใด ๆ แก่ท่านและญาติของท่าน

### ความเสี่ยง

การวิจัยครั้งนี้ไม่ได้มีความเสี่ยงต่อผู้เข้าร่วมวิจัยแต่อย่างใด อย่างไรก็ตามหากท่านมีความรู้สึกไม่สบายใจใด ๆ ในระหว่างที่ท่านตอบแบบสอบถามและถูกสัมภาษณ์ ผู้วิจัยยินดีที่จะให้ความช่วยเหลือ ประคับประคองทางอารมณ์ รวมทั้งการส่งท่านเข้าพบนักแนะแนวหากท่านต้องการ

### ทางเลือก

การเข้าร่วมการวิจัยครั้งนี้เป็นไปด้วยความสมัครใจ ท่านและญาติของท่านสามารถปฏิเสธที่จะเข้าร่วมงานวิจัย โดยการตัดสินใจดังกล่าวจะไม่ก่อให้เกิดผลกระทบใดๆ ต่อการใช้บริการที่โรงพยาบาลแห่งนี้

### สิทธิผู้ป่วยและการถอนตัว

ท่านสามารถถอนตัวจากงานวิจัยนี้ได้ทุกเมื่อไม่ว่าด้วยเหตุผลใดก็ตามโดยไม่ขึ้นอยู่กับความยินยอมของผู้วิจัย และจะไม่มีผลกระทบต่อการใช้บริการที่ท่านและญาติของท่านจะได้รับ โดยกรุณาแจ้งคุณเปรมฤทัย น้อยหมั่นไวย สาขาวิชาพยาบาลศาสตร์ มหาวิทยาลัยสุโขทัยธรรมาธิราช ปากเกร็ด นนทบุรี 11120 หรือเขียนหนังสือถึง ดร.คริสทีน นอร์ดลี วิลเลียม (Dr. Kristine Nordlie Williams) ได้ตามที่อยู่ ดังนี้ University of Kansas Medical Center, Mailstop 4043, 3901 Rainbow Boulevard, Kansas City, KS 66160, United States ซึ่งผู้วิจัยจะหยุดการรวบรวมข้อมูลเกี่ยวกับท่านถ้าท่านถอนตัวจากงานวิจัย

### การพบข้อมูลใหม่

หากมีการเปลี่ยนแปลงใดๆ เกิดขึ้นกับขั้นตอนการวิจัย ท่านจะได้รับทราบการแจ้งข้อมูลต่างๆ เพื่อที่ท่านจะสามารถเลือกได้ว่าจะยังคงร่วมในการวิจัยต่อไปหรือไม่ ซึ่งผู้วิจัยอาจขอให้ท่านลงลายมือชื่อในแบบยินยอมเพื่อเข้าร่วมในงานวิจัยฉบับใหม่

### การปกปิดข้อมูล / การคุ้มครองข้อมูลส่วนตัวผู้ป่วย

ผู้วิจัยจะปฏิบัติตามกฎหมายคุ้มครองข้อมูลส่วนตัวของผู้ป่วยอย่างเคร่งครัด ข้อมูลของท่านและญาติของท่านจะถูกเก็บเป็นความลับ โดยข้อมูลดังกล่าวจะถูกนำมาใช้สำหรับการวิจัยเท่านั้น ข้อมูลส่วนตัวของท่าน ได้แก่ ชื่อ ที่อยู่ เบอร์โทรศัพท์ วันเดือนปีเกิดและข้อมูลสุขภาพอื่นๆ อาจถูกศึกษาหรือใช้โดย คณะผู้วิจัย คณะกรรมการการ คุ้มครองสิทธิของผู้ป่วยของมหาวิทยาลัยแคนซัสและผู้เกี่ยวข้องในงานวิจัยนี้

ข้อมูลส่วนตัวของท่านและญาติของท่านจะถูกบันทึกก่อนที่ผลงานวิจัยจะถูกนำไปเผยแพร่ ดังนั้นข้อมูลส่วนตัวและข้อมูลสุขภาพของท่าน และญาติ ของท่านจะไม่ถูกเปิดเผยไปยังบุคคลภายนอก อย่างไรก็ตาม ข้อมูลดังกล่าวอาจได้รับการตรวจสอบจากบุคคลนอก คณะผู้วิจัย ได้แก่ เจ้าหน้าที่รัฐที่มีหน้าที่ควบคุมกำกับ การวิจัย

การลงชื่อของท่านเป็นการแสดงการตกลงยินยอมเข้าร่วมงานวิจัย และอนุญาตให้สถาบันจิตเวชศาสตร์ สมเด็จพระเจ้าพระยา โรงพยาบาลประสาทเชียงใหม่ และมหาวิทยาลัยแคนซัส ร่วมใช้ข้อมูลสุขภาพของท่านเพื่อเป็น ประโยชน์ในงานวิจัย ข้อมูลส่วนตัวของท่านจะได้รับการคุ้มครองตามกฎหมายคุ้มครอง ข้อมูลส่วนตัวของผู้ป่วย ของประเทศสหรัฐอเมริกาที่เรียกว่า HIPPA ท่านและญาติของท่านจะไม่สามารถ เข้าร่วมงานวิจัยได้หากท่านไม่ลง ลายมือชื่อในแบบยินยอมฉบับนี้ การยินยอมให้ใช้ข้อมูลสุขภาพของท่าน และญาติของท่านจะสิ้นสุดลง และข้อมูล ส่วนตัวของท่านและญาติของท่านจะถูกบันทึกเมื่อข้อมูลได้รับการ วิเคราะห์แล้วและการวิจัยสิ้นสุดลง อย่างไรก็ตาม ข้อมูลที่ถูกบันทึกข้อมูลส่วนตัวของท่านอาจถูกนำมาใช้ในการ วิเคราะห์ในการวิจัยครั้งต่อไปได้

#### คำถาม

ถ้าท่านและญาติผู้มีภาวะสมองเสื่อมมีคำถามใดๆ เกี่ยวกับงานวิจัยครั้งนี้ ขอให้ท่านติดต่อ ดร.คริสทีน นอร์คลี วิลเลียม ที่หมายเลขโทรศัพท์ 001-913-588-1624 (ประเทศสหรัฐอเมริกา) หรือ คุณเปรมฤทัย น้อยหมั่นไวย ที่หมายเลขโทรศัพท์ 02-504-8036 (ประเทศไทย) หากท่านมีคำถามเกี่ยวกับสิทธิของผู้ป่วย ท่านสามารถติดต่อ คณะกรรมการคุ้มครองสิทธิของผู้ป่วยมหาวิทยาลัยแคนซัสที่หมายเลขโทรศัพท์ 001-913-588-1240 (ประเทศสหรัฐอเมริกา) หรือที่อยู่ดังนี้ Human Research Protection Program, Mail Stop #1032, University of Kansas Medical Center, 3901 Rainbow Blvd., Kansas City, KS 66160 , United States

#### คำชี้แจง

หากท่านคิดว่าตัวท่านและญาติของท่าน ได้รับความเสียหายใดๆ อันเนื่องจากมาจากงานวิจัยครั้งนี้ ขอให้ท่านติดต่อ คณะกรรมการคุ้มครองสิทธิของผู้ป่วยมหาวิทยาลัยแคนซัสได้ ตามที่อยู่ดังนี้ Human Research Protection Program, Mail Stop #1032, University of Kansas Medical Center, 3901 Rainbow Blvd., Kansas City, KS 66160, United States เพื่อขอรับค่าชดเชยตามที่กฎหมายระบุไว้

ชื่อ-สกุลของผู้วิจัยผู้ให้ข้อมูลเพื่อขอความยินยอม      ลายเซ็นผู้วิจัยผู้ให้ข้อมูลเพื่อขอความยินยอม

วันที่

### แบบยินยอมเพื่อเข้าร่วมในงานวิจัย

ข้าพเจ้าขอให้ความยินยอมของตนเองที่จะเข้าร่วมในงานวิจัยเรื่อง ประสิทธิภาพของโปรแกรมการดูแลผู้มี ปัญหาสมองเสื่อมที่จัดบริการในรูปแบบ โรงพยาบาลกลางวันที่มีต่อญาติผู้ดูแลในประเทศไทย ข้าพเจ้ายินยอมเข้าร่วมการวิจัยด้วยความสมัครใจ และสามารถถอนตัวเมื่อใดก็ได้โดยจะไม่มีผลกระทบต่อ การบริการที่ข้าพเจ้าและญาติของข้าพเจ้าได้รับ

ดร.คริสทีน นอร์คลี วิลเลียม มหาวิทยาลัยแคนซัส หรือคณะผู้วิจัยได้อธิบายเกี่ยวกับ โครงการการ วิจัยขั้นตอนการวิจัย ประโยชน์และความเสี่ยงที่เกี่ยวข้องกับการวิจัยครั้งนี้เป็นอย่างดีแล้ว การลงนามใน แบบยินยอมฉบับนี้ท่านได้รับทราบเกี่ยวกับการวิจัยครั้งนี้เป็นอย่างดีและเต็มใจที่จะเข้าร่วมการวิจัย ท่านได้ มีโอกาสสอบถามเกี่ยวกับข้อสงสัยต่างๆ ก่อนลงนามในเอกสารนี้ ผู้วิจัยมีความยินดีที่จะให้คำตอบต่อทุก คำถามที่ข้าพเจ้าอาจมีได้ตลอดระยะเวลาการเข้าร่วมการวิจัยครั้งนี้ ผู้วิจัยรับรองว่าจะเก็บข้อมูลเฉพาะที่ เกี่ยวกับตัวข้าพเจ้าเป็นความลับและจะเปิดเผยได้เฉพาะ ในรูปที่เป็นสรุปผลการวิจัย ผู้วิจัยมีความยินดีช่วยเหลือเต็มที่หากเกิดมีอันตรายจากการวิจัยดังกล่าว ผู้วิจัยได้มอบเอกสารพร้อมลายเซ็นให้ข้าพเจ้าเก็บไว้ด้วย 1 ฉบับ

ในกรณีที่เกิดข้อข้องใจหรือปัญหาที่ข้าพเจ้าต้องการปรึกษากับผู้วิจัย ข้าพเจ้าสามารถติดต่อกับผู้วิจัย คือดร.คริสทีน นอร์คลี วิลเลียม ที่หมายเลขโทรศัพท์ 1-913-588-1624 (ประเทศสหรัฐอเมริกา) หรือ คุณ เปรมฤทัย น้อยหมื่นไวย ที่หมายเลขโทรศัพท์ 02-504-8036

ชื่อ-สกุลผู้เข้าร่วมการวิจัย

ลายเซ็นผู้เข้าร่วมการวิจัย

วันที่

ชื่อ-สกุลของผู้วิจัยผู้ขอลายเซ็นผู้เข้าร่วมการวิจัย ลายเซ็นผู้วิจัยผู้ขอลายเซ็นผู้เข้าร่วมการวิจัย

ชื่อ-สกุลพยาน

ลายเซ็นพยาน

### การยินยอมของผู้ป่วย

ดร.คริสทีน นอร์คัล วิลเลียม และคุณเปรมฤทัย น้อยหมื่นไวย จากมหาวิทยาลัยแคนซัสกำลังดำเนินการศึกษาวิจัย ณ สถาบันจิตเวชศาสตร์สมเด็จพระยา และโรงพยาบาลประสาทเชียงใหม่ ข้าพเจ้าเข้าใจว่าข้าพเจ้าได้รับเชิญให้เข้าร่วมในงานวิจัย และข้อมูลสุขภาพของข้าพเจ้าซึ่งรวมถึงความสามารถต่าง ๆ และพฤติกรรมของข้าพเจ้าจะถูกนำมาศึกษาในครั้งนี้

ข้าพเจ้ายินยอมให้ ดร.คริสทีน นอร์คัล วิลเลียมและคณะผู้วิจัยประเมินสมรรถภาพของข้าพเจ้า และใช้ข้อมูลสุขภาพของข้าพเจ้าจากบันทึกทางการแพทย์ได้ตามความจำเป็น ข้าพเจ้าได้รับการอธิบายเกี่ยวกับการวิจัยเป็นอย่างดีและตกลงยินยอมเข้าร่วมงานวิจัย ผู้วิจัยรับรองว่าจะเก็บข้อมูลเฉพาะที่เกี่ยวข้องกับตัวข้าพเจ้าเป็นความลับและจะเปิดเผยได้เฉพาะ ในรูปที่เป็นสรุปผลการวิจัย ข้าพเจ้าเข้าใจว่าข้าพเจ้าสามารถปฏิเสธการเข้าร่วมงานวิจัยได้แม้ว่าญาติผู้ดูแลของข้าพเจ้าจะตกลงยินดีก็ตาม ข้าพเจ้ามีโอกาสดูถามข้อคำถามต่างๆ ที่มี ข้าพเจ้าเข้าใจว่าข้าพเจ้าสามารถหยุดเข้าร่วมการวิจัยได้ทุกเมื่อ ซึ่งจะไม่มีผลกระทบต่อการรักษาจากแพทย์ที่ข้าพเจ้าได้รับอยู่ ข้าพเจ้ายินยอมให้ญาติผู้ดูแลของข้าพเจ้าลงลายมือชื่อของเขาแทนการเซ็นชื่อของข้าพเจ้าในแบบยินยอมเพื่อเข้าร่วมในงานวิจัยฉบับนี้ เพื่อแสดงการกล่าวยินยอมของข้าพเจ้าเพื่อเข้าร่วมในงานวิจัยนี้

ชื่อ-สกุลผู้ป่วย

วันที่

ชื่อ-สกุลของญาติผู้ดูแลผู้เข้าร่วมการวิจัย

ลายเซ็นญาติผู้ดูแลผู้เข้าร่วมการวิจัย

ชื่อ-สกุลของผู้วิจัยขอลายเซ็นผู้เข้าร่วมการวิจัย

ลายเซ็นผู้วิจัยขอลายเซ็นผู้เข้าร่วมการวิจัย

ชื่อ-สกุลพยาน

ลายเซ็นพยาน

**Appendix C**  
**General Personal Data Survey**





12. How long do you start taking care of your dementia recipient.....year.....month

13. How many hours per day do you usually spend time for providing daily care of your dementia recipient (supervision and direct care).....

14. Could you rate your satisfaction for yourself in providing care for your dementia recipient from 0 extremely dissatisfied to 10 extremely satisfied? (Please identify the number).....

0 \_\_\_\_\_ 10  
Extremely Dissatisfied Extremely Satisfied

15. Do you have other persons who share responsibility in caring your dementia relative at home?

- 1. Yes    2. No

16. If question 15 you answer yes. Number of family numbers who help you taking care of your recipient.....

Could you explain more, who and how?

.....  
.....

17. Could you rate your satisfaction of your perceived family support as a whole from 0 extremely dissatisfied to 10 extremely satisfied? (Please identify the number).....

0 \_\_\_\_\_ 10  
Extremely Dissatisfied Extremely Satisfied

18. Have you ever used adult day care services at here before?

- 1. Yes    2. No

19. How many hours per week do you plan to use adult day services .....

20. How do you know about adult day care services?

- 1. Adult day care centers
- 2. Family
- 3. Friend
- 4. Newspaper
- 5. Brochure
- 6. Internet
- 7. Others.....

21. Do you current use adult day care services?

- 1. Yes    2. No

If you answer No in question 21 Let go question 34

22. How many **hours per week** do you usually use adult day care services?.....hours







**Appendix D**  
**General Personal Data Survey - Thai**

## แบบสำรวจข้อมูลส่วนบุคคลทั่วไป

**คำชี้แจง** กรุณาให้ข้อมูลเกี่ยวกับตัวท่านและผู้ที่ท่านให้การดูแล ข้อมูลดังกล่าวนี้จะไม่นำไปเผยแพร่ที่ใด นอกจากคณะผู้วิจัย คุณอาจจะไม่ตอบคำถามบางข้อถ้าคุณไม่ทราบหรือไม่ต้องการที่จะตอบ ขอขอบคุณคุณอย่างสูงที่กรุณาให้ความร่วมมือในการวิจัยครั้งนี้ ข้อมูลของคุณจะนำไปใช้ประโยชน์ในการวิจัยเท่านั้น

### ส่วนที่ 1 ข้อมูลผู้ป่วย

1. อายุ .....ปี (เต็มปี เศษของปีตัดทิ้ง)
2. เพศ :                    1. ชาย                    2. หญิง
3. สถานภาพสมรส :
  1. โสด
  2. แต่งงาน
  3. หม้าย
  4. หย่าร้าง
  5. อื่นๆ (ระบุ).....
4. ระดับการศึกษา :
  1. ต่ำกว่าปริญญาตรี
  2. ปริญญาตรี
  3. ปริญญาโทหรือสูงกว่า
5. ค่าใช้จ่ายสำหรับการดำรงชีวิตประจำวันมาจาก
  1. เงินเก็บสะสมของผู้ป่วย
  2. รายได้ของครอบครัว
  3. อื่นๆ (ระบุ) .....
6. ค่าใช้จ่ายสำหรับการใช้บริการที่ ADULT DAY CARE มาจาก
  1. เงินเก็บสะสมของผู้ป่วย
  2. รายได้ของครอบครัว
  3. อื่นๆ (ระบุ) .....
7. ค่าใช้จ่ายจาก ADULT DAY CARE สามารถเบิกจากส่วนราชการได้หรือไม่
  1. ได้ทั้งหมด            2. ได้บางส่วน            3. เบิกไม่ได้
8. ความถี่ของการเข้ารับบริการ ADULT DAY CARE (เฉลี่ยต่อสัปดาห์) .....

9. ความรุนแรงของภาวะสมองเสื่อม :

1. ทราน (ระบุ) .....

2. ไม่ทราน

10. ระยะเวลาของความเจ็บป่วย (นับจากครั้งแรกที่ทราบการวินิจฉัยจากแพทย์).....ปี.....เดือน

## ส่วนที่ 2 ข้อมูลญาติผู้ดูแล

1. อายุ .....ปี (เต็มปี เศษของปีตัดทิ้ง)

2. เพศ :

1. ชาย                      2. หญิง

3. สถานภาพสมรส :

1. โสด                      2. แต่งงาน                      3. หม้าย                      4. หย่าร้าง

5. อื่นๆ (ระบุ).....

4. ระดับการศึกษา :

1. ต่ำกว่าปริญญาตรี                      2. ปริญญาตรี                      3. ปริญญาโทหรือสูงกว่า

5. รายได้ของครอบครัวต่อเดือน (เฉลี่ยจากช่วง 3 เดือนที่ผ่านมา) .....

1. น้อยกว่า 10,000 บาท

2. 10,000 – 29,999 บาท

3. 30,000 – 49,999 บาท

4. 50,000 หรือมากกว่า

6. จำนวนสมาชิกในครอบครัว.....คน

7. คุณคิดว่ารายได้ครอบครัวของคุณมีความเพียงพอในระดับใด? กรุณากำหนดค่าตัวเลขจาก 0-10

ถ้า 0 หมายถึง your adequacy of monthly family income from 0 “รายได้ไม่พอใช้ในแต่ละเดือน” และ 10

“ฉันมีเงินพอใช้และมีเงินเหลือในแต่ละเดือน”

0 \_\_\_\_\_ 10

รายได้ไม่พอใช้ในแต่ละเดือน

ฉันมีเงินพอใช้และมีเงินเหลือในแต่ละเดือน

8. คุณได้รับเงินค่าจ้างในการดูแลหรือไม่?

1. ได้

2. ไม่ได้





29. การเพิ่มพูนความรู้สึกมั่นคงแก่คุณในการเป็นผู้ให้การดูแลผู้ป่วยที่มีภาวะสมองเสื่อม.....

30. การบรรเทาความรู้สึกเหน็ดเหนื่อยจากการเป็นผู้ให้การดูแล.....

31. ความพึงพอใจโดยรวมต่อการบริการที่ได้รับจาก ADULT DAY CARE .....

32. คุณมีความยุ่งยากในการเตรียมผู้ป่วยและการรับส่งผู้ป่วยไปยัง ADULT DAY CARE หรือไม่

1. มี (ระบุ).....

2. ไม่มี

33. คุณรับส่งผู้ป่วยจากบ้านไปยัง ADULT DAY CARE โดย.....

34. คุณมีความยุ่งยากในการเตรียมผู้ป่วยและการรับส่งผู้ป่วยไปยัง ADULT DAY CARE ในระดับใด กรุณา  
กำหนดค่าตัวเลขจาก 0-10 ถ้า 0 หมายถึง “ยุ่งยากมากที่สุด” และ 10 “สะดวกมากที่สุด”

0 \_\_\_\_\_ 10

ยุ่งยากมากที่สุด

สะดวกมากที่สุด

35. คุณได้รับการบริการทางสังคมจากองค์กรหรือมูลนิธิใดๆ ที่ช่วยเหลือบทบาทของผู้ดูแลบ้างหรือไม่?

1. ได้รับ

2. ไม่ได้ได้รับการบริการทางสังคมอื่นๆ

ในข้อที่ 35 ถ้าคุณตอบข้อ 1 กรุณาอธิบายว่าหน่วยงานใดและอย่างไร

.....  
.....

36. คุณมีความพึงพอใจในการบริการทางสังคมจากข้อที่ 35 ในระดับใด กรุณา กำหนดค่าตัวเลขจาก 0-10

ถ้า 0 หมายถึง “ไม่พึงพอใจมากที่สุด” และ 10 “พึงพอใจมากที่สุด”

0 \_\_\_\_\_ 10

ไม่พึงพอใจมากที่สุด

พึงพอใจมากที่สุด



**Appendix E**  
**Zarit Burden Interview**

### Zarit Burden Interview (ZBI)

Indicate how often you experience the feelings listed by circling the number in the box that best corresponds to the frequency of these feelings.

	Never	Rarely	Sometimes	Quite Frequently	Nearly Always
1. Do you feel that your relative asks for more help than he/she needs?	0	1	2	3	4
2. 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	4
3. Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?	0	1	2	3	4
4. Do you feel embarrassed over your relative's behavior?	0	1	2	3	4
5. Do you feel angry when you are around your relative?	0	1	2	3	4
6. Do you feel that your relative currently affects your relationships with other family members or friends in a negative way?	0	1	2	3	4
7. Are you afraid what the future holds for your relative?	0	1	2	3	4
8. Do you feel your relative is dependent on you?	0	1	2	3	4
9. Do you feel strained when you are around your relative?	0	1	2	3	4
10. Do you feel your health has suffered because of your involvement with your relative?	0	1	2	3	4
11. Do you feel that you don't have as much privacy as you would like because of your relative?	0	1	2	3	4
12. Do you feel that your social life has suffered because you are caring for your relative?	0	1	2	3	4
13. Do you feel uncomfortable about having friends over because of your relative?	0	1	2	3	4
14. Do you feel that your relative seems to expect you to take care of him/her as if you were the only one he/she could depend on?	0	1	2	3	4
15. Do you feel that you don't have enough money to take care of your relative in addition to the rest of your expenses?	0	1	2	3	4
16. Do you feel that you will be unable to take care of your relative much longer?	0	1	2	3	4

	Never	Rarely	Sometimes	Quite Frequently	Nearly Always
17. Do you feel you have lost control of your life since your relative's illness?	0	1	2	3	4
18. Do you wish you could leave the care of your relative to someone else?	0	1	2	3	4
19. Do you feel uncertain about what to do about your relative?	0	1	2	3	4
20. Do you feel you should be doing more for your relative?	0	1	2	3	4
21. Do you feel you could do a better job in caring for your relative?	0	1	2	3	4
22. Overall, how burdened do you feel in caring for your relative?	0	1	2	3	4

Source: MAPI Research Trust

**Appendix F**

**Zarit Burden Interview (ZBI) - Thai**

### แบบวัดความเหนื่อยล้า

**คำชี้แจง** ด้านล่างนี้คือรายการข้อความที่สะท้อนให้เห็นว่าบางครั้งคนเรารู้สึกอย่างไรเมื่อต้องดูแลผู้อื่น หลังจากอ่านแต่ละข้อความแล้ว ให้ระบุว่าคุณรู้สึกเช่นนั้นบ่อยเพียงใด ทั้งนี้ไม่มีคำตอบใดที่ถูกต้องหรือผิด

1. คุณรู้สึกหรือไม่ว่า ญาติของคุณขอความช่วยเหลือจากคุณมากเกินไปจนเกินกว่าความจำเป็นของเขา/เธอ

0. ไม่เคยเลย	1. นาน ๆ ครั้ง	2. บางครั้ง	3. ค่อนข้างบ่อย	4. แทบทุกครั้ง
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2. คุณรู้สึกหรือไม่ว่า การที่คุณใช้เวลาไปกับญาติของคุณทำให้คุณมีเวลาไม่พอสำหรับตัวเอง

0. ไม่เคยเลย	1. นาน ๆ ครั้ง	2. บางครั้ง	3. ค่อนข้างบ่อย	4. แทบทุกครั้ง
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3. คุณรู้สึกเครียดกับการที่ต้องดูแลญาติและยังต้องรับผิดชอบหน้าที่อื่น เช่น เรื่องครอบครัวหรือการทำงานของ คุณหรือไม่

0. ไม่เคยเลย	1. นาน ๆ ครั้ง	2. บางครั้ง	3. ค่อนข้างบ่อย	4. แทบทุกครั้ง
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4. คุณรู้สึกลำบากใจกับพฤติกรรมที่ญาติของคุณแสดงต่อคนอื่นหรือไม่

0. ไม่เคยเลย	1. นาน ๆ ครั้ง	2. บางครั้ง	3. ค่อนข้างบ่อย	4. แทบทุกครั้ง
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5. คุณรู้สึกโกรธเวลาที่คุณอยู่กับญาติของคุณหรือไม่

0. ไม่เคยเลย	1. นาน ๆ ครั้ง	2. บางครั้ง	3. ค่อนข้างบ่อย	4. แทบทุกครั้ง
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6. คุณรู้สึกหรือไม่ว่า ทุกวันนี้ญาติของคุณส่งผลกระทบในทางลบต่อความสัมพันธ์ของคุณกับสมาชิก คนอื่นๆ ในครอบครัวหรือเพื่อนฝูง

0. ไม่เคยเลย	1. นาน ๆ ครั้ง	2. บางครั้ง	3. ค่อนข้างบ่อย	4. แทบทุกครั้ง
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7. คุณรู้สึกกังวลว่าจะเกิดอะไรขึ้นในอนาคตกับญาติของคุณหรือไม่

0. ไม่เคยเลย	1. นาน ๆ ครั้ง	2. บางครั้ง	3. ค่อนข้างบ่อย	4. แทบทุกครั้ง
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8. คุณรู้สึกว่าญาติของคุณต้องพึ่งพาอาศัยคุณหรือไม่

0. ไม่เคยเลย	1. นาน ๆ ครั้ง	2. บางครั้ง	3. ค่อนข้างบ่อย	4. แทบทุกครั้ง
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9. คุณรู้สึกเครียดเวลาที่อยู่กับญาติของคุณหรือไม่

0. ไม่เคยเลย	1. นาน ๆ ครั้ง	2. บางครั้ง	3. ค่อนข้างบ่อย	4. แทบทุกครั้ง
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10. คุณรู้สึกว่าสุขภาพของคุณแย่ลงเพราะคุณต้องคอยดูแลญาติหรือไม่

0. ไม่เคยเลย	1. นาน ๆ ครั้ง	2. บางครั้ง	3. ค่อนข้างบ่อย	4. แทบทุกครั้ง
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11. คุณรู้สึกหรือไม่ว่า คุณไม่มีเวลาส่วนตัวที่จะทำกิจกรรมต่าง ๆ ของคุณ ได้มากพออย่างที่คุณต้องการ  
เพราะต้องคอยดูแลญาติของคุณ

0. ไม่เคยเลย	1. นาน ๆ ครั้ง	2. บางครั้ง	3. ค่อนข้างบ่อย	4. แทบทุกครั้ง
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12. คุณรู้สึกหรือไม่ว่า การใช้ชีวิตในสังคมของคุณประสบปัญหาเพราะคุณต้องคอยดูแลญาติของคุณ

0. ไม่เคยเลย	1. นาน ๆ ครั้ง	2. บางครั้ง	3. ค่อนข้างบ่อย	4. แทบทุกครั้ง
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13. คุณรู้สึกลำบากใจที่จะชวนเพื่อน ๆ มาที่บ้านเพราะญาติของคุณหรือไม่

0. ไม่เคยเลย	1. นาน ๆ ครั้ง	2. บางครั้ง	3. ค่อนข้างบ่อย	4. แทบทุกครั้ง
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14. คุณรู้สึกหรือไม่ว่า ญาติของคุณดูเหมือนจะคาดหวังให้คุณดูแลเขา/เธอ ราวกับว่าคุณเป็นคนเดียวเท่านั้นที่  
เขา/เธอสามารถพึ่งพาอาศัยได้

0. ไม่เคยเลย	1. นาน ๆ ครั้ง	2. บางครั้ง	3. ค่อนข้างบ่อย	4. แทบทุกครั้ง
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15. คุณรู้สึกหรือไม่ว่า คุณมีเงินไม่พอที่จะดูแลญาติของคุณ นอกเหนือจากค่าใช้จ่ายต่าง ๆ ที่คุณต้องใช้

0. ไม่เคยเลย	1. นาน ๆ ครั้ง	2. บางครั้ง	3. ค่อนข้างบ่อย	4. แทบทุกครั้ง
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16. คุณรู้สึกหรือไม่ว่า คุณอาจจะไม่สามารถดูแลญาติของคุณได้อีกต่อไป

0. ไม่เคยเลย	1. นาน ๆ ครั้ง	2. บางครั้ง	3. ค่อนข้างบ่อย	4. แทบทุกครั้ง
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17. คุณรู้สึกหรือไม่ว่า คุณไม่สามารถควบคุมชีวิตของตัวเองได้อีกเลยตั้งแต่ญาติคุณป่วย

0. ไม่เคยเลย	1. นาน ๆ ครั้ง	2. บางครั้ง	3. ค่อนข้างบ่อย	4. แทบทุกครั้ง
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18. คุณนึกอยากผลัดภาระการดูแลญาติของคุณไปให้ใครสักคนบ้างหรือไม่

0. ไม่เคยเลย	1. นาน ๆ ครั้ง	2. บางครั้ง	3. ค่อนข้างบ่อย	4. แทบทุกครั้ง
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19. คุณรู้สึกไม่แน่ใจบ้างหรือไม่ว่า คุณจะดูแลญาติของคุณได้อย่างไร

0. ไม่เคยเลย	1. นาน ๆ ครั้ง	2. บางครั้ง	3. ค่อนข้างบ่อย	4. แทบทุกครั้ง
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20. คุณรู้สึกหรือไม่ว่า คุณควรจะทำอะไรให้ญาติของคุณได้มากกว่านี้

0. ไม่เคยเลย	1. นาน ๆ ครั้ง	2. บางครั้ง	3. ค่อนข้างบ่อย	4. แทบทุกครั้ง
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21. คุณรู้สึกหรือไม่ว่า คุณสามารถดูแลญาติของคุณได้ดีกว่านี้

0. ไม่เคยเลย	1. นาน ๆ ครั้ง	2. บางครั้ง	3. ค่อนข้างบ่อย	4. แทบทุกครั้ง
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22. โดยภาพรวมแล้ว คุณรู้สึกว่าภาระการดูแลญาติของคุณเป็นภาระที่หนักเพียงใด

0. ไม่นักเลย	1. เล็กน้อย	2. ปานกลาง	3. ค่อนข้างมาก	4. มากที่สุด
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**Appendix G**

**Center for Epidemiologic Studies Depression Scale (CES-D)**



### Center for Epidemiologic Studies Depression Scale (CES-D)

Below is a list of the ways you might have felt or behaved. Please tell me how often you have felt this way during the past week.

During the past week	Rarely or none of the time (less than 1 day)	Some or a little of the time (1-2 days)	Occasionally or a moderate amount of time (3-4 days)	Most or All of the time (5-7 days)
1. I was bothered by things that usually don't bother me.	0	1	2	3
2. I did not feel like eating; my appetite was poor.	0	1	2	3
3. I felt that I could not shake off the blues even with help from my family or friends.	0	1	2	3
4. I felt I was just as good as other people.	0	1	2	3
5. I had trouble keeping my mind on what I was doing.	0	1	2	3
6. I felt depressed.	0	1	2	3
7. I felt that everything I did was an effort.	0	1	2	3
8. I felt hopeful about the future.	0	1	2	3
9. I thought my life had been a failure.	0	1	2	3
10. I felt fearful.	0	1	2	3
11. My sleep was restless.	0	1	2	3
12. I was happy.	0	1	2	3
13. I talked less than usual.	0	1	2	3
14. I felt lonely.	0	1	2	3
15. People were unfriendly.	0	1	2	3
16. I enjoyed life.	0	1	2	3
17. I had crying spells.	0	1	2	3
18. I felt sad.	0	1	2	3
19. I felt that people dislike me.	0	1	2	3
20. I could not get "going."	0	1	2	3

Source: Center for Epidemiologic Studies, National Institute of Mental Health. The scale is in the public domain. Therefore, it may be used without copyright permission (National Institute of Mental Health, 2009).

**Appendix H**

**Center for Epidemiologic Studies Depression Scale (CES-D) - Thai**

### แบบวัดภาวะซึมเศร้า

**คำชี้แจง** ต่อไปนี้เป็นข้อความที่สะท้อนเกี่ยวกับความรู้สึกหรือพฤติกรรมที่อาจเกิดขึ้นกับคุณได้ หลังจากอ่านแต่ละข้อความแล้ว ให้ระบุว่าคุณรู้สึกหรือมีพฤติกรรมเช่นนั้นบ่อยเพียงใดในหนึ่งสัปดาห์ที่ผ่านมา คำตอบเหล่านี้เป็นเพียงการทดสอบเกี่ยวกับความรู้สึกของคุณเท่านั้น ทั้งนี้ไม่มีคำตอบใดที่ถูกหรือผิด

ระหว่างหนึ่งสัปดาห์ที่ผ่านมา	ไม่เคย (น้อยกว่า 1 วัน)	นานๆ ครั้ง (1-2 วัน)	ค่อนข้างบ่อย (3-4 วัน)	แทบตลอดเวลา (5-7 วัน)
1. ฉันรู้สึกหงุดหงิดง่าย	0	1	2	3
2. ฉันรู้สึกเบื่ออาหาร	0	1	2	3
3. ฉันรู้สึกว่าฉันไม่สามารถจัดความหม่นหมองออกจากใจได้ แม้ว่าจะมีคนในครอบครัวหรือเพื่อนคอยช่วยเหลือก็ตาม	0	1	2	3
4. ฉันรู้สึกว่าตนเองมีความดี ทดเทียมคนอื่นๆ	0	1	2	3
5. ฉันรู้สึกลำบากในการตั้งสมาธิเพื่อทำสิ่งใดสิ่งหนึ่ง	0	1	2	3
6. ฉันรู้สึกหดหู่ใจ	0	1	2	3
7. ฉันรู้สึกว่าทุกๆ สิ่งที่ทำฉันกระทำได้ต้องฝืนใจทำ	0	1	2	3
8. ฉันรู้สึกว่ามีความหวังเกี่ยวกับอนาคต	0	1	2	3
9. ฉันรู้สึกว่าชีวิตฉันมีแต่ความลึ้มเหลว	0	1	2	3

ระหว่างหนึ่งสัปดาห์ที่ผ่านมา	ไม่เคย (น้อยกว่า 1 วัน)	นานๆ ครั้ง (1-2 วัน)	ค่อนข้างบ่อย (3-4 วัน)	ตลอดเวลา (5-7 วัน)
10. ฉันรู้สึกหวาดกลัว	0	1	2	3
11. ฉันนอนไม่ค่อยหลับ	0	1	2	3
12. ฉันมีความสุข	0	1	2	3
13. ฉันไม่ค่อยอยากคุยกับใคร	0	1	2	3
14. ฉันรู้สึกอ้างว้างเดียวดาย	0	1	2	3
15. ผู้คนทั่วไปไม่มีความเป็นมิตร	0	1	2	3
16. ฉันรู้สึกว่าชีวิตนี้สนุกสนาน	0	1	2	3
17. ฉันมักร้องไห้	0	1	2	3
18. ฉันรู้สึกเศร้า	0	1	2	3
19. ผู้คนรอบข้างไม่ชอบฉัน	0	1	2	3
20. ฉันรู้สึกท้อถอยในชีวิต	0	1	2	3

**Appendix I**  
**WHOQOL-BREF**

### WHOQOL-BREF

The following questions ask how you feel about your quality of life, health, or other areas of your life. I will read out each question to you, along with the response options. **Please choose the answer that appears most appropriate.** If you are unsure about which response to give to a question, the first response you think of is often the best one.

Please keep in mind your standards, hopes, pleasures and concerns. We ask that you think about your life **in the last four weeks.**

		Very poor	Poor	Neither poor nor good	Good	Very good
1.	How would you rate your quality of life?	1	2	3	4	5

		Very dissatisfied	Dissatisfied	Neither dissatisfied or satisfied	Satisfied	Very satisfied
2.	How satisfied are you with your health?	1	2	3	4	5

The following questions ask about **how much** you have experienced certain things in the last four weeks.

		Not at all	A little	A moderate amount	Very much	An extreme amount
3.	To what extent do you feel that physical pain prevents you from doing what you need to do?	5	4	3	2	1
4.	How much do you need any medical treatment to function in your daily life?	5	4	3	2	1
5.	How much do you enjoy life?	1	2	3	4	5
6.	To what extent do you feel your life to be meaningful?	1	2	3	4	5

		Not at all	A little	A moderate amount	Very much	Extremely
7.	How well are you able to concentrate?	1	2	3	4	5
8.	How safe do you feel in your daily life?	1	2	3	4	5
9.	How healthy is your physical environment?	1	2	3	4	5

**The following questions ask about how completely you experience or were able to do certain things in the last four weeks.**

		Not at all	A little	Moderately	Mostly	Completely
10.	Do you have enough energy for everyday life?	1	2	3	4	5
11.	Are you able to accept your bodily appearance?	1	2	3	4	5
12.	Have you enough money to meet your needs?	1	2	3	4	5
13.	How available to you is the information that you need in your day-to-day life?	1	2	3	4	5
14.	To what extent do you have the opportunity for leisure activities?	1	2	3	4	5

		Very poor	Poor	Neither poor nor good	Good	Very good
15.	How well are you able to get around?	1	2	3	4	5

		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
16.	How satisfied are you with your sleep?	1	2	3	4	5
17.	How satisfied are you with your ability to perform your daily living activities?	1	2	3	4	5
18.	How satisfied are you with your capacity for work?	1	2	3	4	5

		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
19.	How satisfied are you with yourself?	1	2	3	4	5
20.	How satisfied are you with your personal relationships?	1	2	3	4	5
21.	How satisfied are you with your sex life?	1	2	3	4	5
22.	How satisfied are you with the support you get from your friends?	1	2	3	4	5
23.	How satisfied are you with the conditions of your living place?	1	2	3	4	5
24.	How satisfied are you with your access to health services?	1	2	3	4	5
25.	How satisfied are you with your transport?	1	2	3	4	5

**The following question refers to how often you have felt or experienced certain things in the last four weeks.**

		Never	Seldom	Quite often	Very often	Always
26.	How often do you have negative feelings such as blue mood, despair, anxiety, depression?	5	4	3	2	1

Source: World Health Organization 2004



**Appendix J**  
**WHOQOL-BREF-THAI**

### แบบวัดคุณภาพชีวิต (WHOQOL - BREF - THAI)

**คำชี้แจง** ข้อคำถามต่อไปนี้จะถามถึงประสบการณ์อย่างใดอย่างหนึ่งของคุณในช่วง 2 สัปดาห์ที่ผ่านมา ให้คุณสำรวจตัวคุณเองและประเมินเหตุการณ์หรือความรู้สึกของคุณ แล้วทำเครื่องหมาย ✓ ในช่องคำตอบที่เหมาะสมและเป็นจริงกับตัวคุณมากที่สุด โดยคำตอบมี 5 ตัวเลือก คือ

ไม่เลย หมายถึง คุณไม่มีความรู้สึกเช่นนั้นเลย รู้สึกไม่พอใจมาก หรือรู้สึกแย่มาก

เล็กน้อย หมายถึง คุณมีความรู้สึกเช่นนั้นนาน ๆ ครั้งรู้สึกเช่นนั้นเล็กน้อยรู้สึกไม่พอใจ หรือ รู้สึกแย่น้อย

ปานกลาง หมายถึง คุณมีความรู้สึกเช่นนั้นปานกลาง รู้สึกพอใจระดับกลาง ๆ หรือรู้สึกแยระดับกลาง ๆ

มาก หมายถึง คุณมีความรู้สึกเช่นนั้นบ่อย ๆ รู้สึกพอใจหรือรู้สึกดี

มากที่สุด หมายถึง คุณมีความรู้สึกเช่นนั้นเสมอ รู้สึกเช่นนั้นมากที่สุด หรือรู้สึกดีว่าสมบูรณ์

	ในช่วง 2 สัปดาห์ที่ผ่านมา	ไม่เลย	เล็กน้อย	ปานกลาง	มาก	มากที่สุด
1	ท่านคิดว่าท่านมีคุณภาพชีวิต (ชีวิตความเป็นอยู่) อยู่ในระดับใด					
2	คุณพอใจกับสุขภาพของคุณในตอนนี้เพียงใด					
3	การเจ็บปวดตามร่างกาย เช่น ปวดหัว ปวดท้อง ปวดตามตัว ทำให้ท่านไม่สามารถทำในสิ่งที่ต้องการอย่างน้อยเพียงใด					
4	ท่านจำเป็นต้องไปรับการรักษาพยาบาลอย่างน้อยเพียงใด เพื่อที่จะทำงานหรือมีชีวิตอยู่ไปได้ในแต่ละวัน					
5	คุณรู้สึกพึงพอใจในชีวิต (เช่น มีความสุข ความสงบ มีความหวัง) มากน้อยเพียงใด					

	ในช่วง 2 สัปดาห์ที่ผ่านมา	ไม่เคย	เล็กน้อย	ปานกลาง	มาก	มากที่สุด
6	ท่านรู้สึกว่าคุณมีความหมายมากน้อยแค่ไหน					
7	คุณมีสมาธิในการทำงานต่าง ๆ ดีเพียงใด ท่านรู้สึกว่าคุณมีความหมายมากน้อยแค่ไหน					
8	ท่านรู้สึกว่าคุณมีความมั่นคงปลอดภัยดีไหมในแต่ละวัน					
9	สภาพแวดล้อมดีต่อสุขภาพของท่านมากน้อยเพียงใด					
10	ท่านมีกำลังเพียงพอที่จะทำสิ่งต่าง ๆ ในแต่ละวันใหม่ (ทั้งเรื่องงาน หรือการดำเนินชีวิตประจำวัน)					
11	ท่านยอมรับรูปร่างหน้าตาของตัวเองได้ไหม					
12	ท่านมีเงินพอใช้จ่ายตามความจำเป็น มากน้อยเพียงใด					
13	ท่านได้รู้เรื่องราวข่าวสารที่จำเป็นในชีวิตแต่ละวัน มากน้อยเพียงใด					
14	ท่านมีโอกาสได้พักผ่อนคลายเครียดมากน้อยเพียงใด					
15	ท่านสามารถไปไหนมาไหนด้วยตนเองได้ดีเพียงใด					
16	ท่านพอใจกับการนอนหลับของท่านมากน้อยเพียงใด					

	ในช่วง 2 สัปดาห์ที่ผ่านมา	ไม่เลย	เล็กน้อย	ปานกลาง	มาก	มากที่สุด
17	ท่านรู้สึกพอใจมากน้อยแค่ไหนในสิ่งที่สามารถทำอะไรๆ ผ่านไปได้ในแต่ละวัน					
18	ท่านพอใจกับความสามารถในการทำงานได้อย่างที่เคยทำมามากน้อยเพียงใด					
19	ท่านรู้สึกพอใจในตนเองมากน้อยแค่ไหน					
20	ท่านพอใจต่อการผูกมิตรหรือเข้ากับคนอื่นอย่างที่ผ่านมาแค่ไหน					
21	ท่านพอใจในชีวิตทางเพศของท่านแค่ไหน? (ชีวิตทางเพศ หมายถึง เมื่อเกิดความรู้สึกทางเพศขึ้นแล้วท่าน มีวิธีจัดการทำให้ผ่อนคลายลงได้ รวมถึง การช่วยตัวเองหรือการมีเพศสัมพันธ์)					
22	ท่านพอใจกับการช่วยเหลือที่เคยได้รับจากเพื่อน ๆ แค่ไหน					
23	ท่านพอใจกับสภาพบ้านเรือนที่อยู่ตอนนี้มากน้อยเพียงใด					
24	ท่านพอใจที่จะสามารถไปใช้บริการสาธารณสุขได้ตามความจำเป็นเพียงใด					
25	ท่านพอใจกับการเดินทางไปไหนมาไหนของท่าน (หมายถึงการคมนาคม) มากน้อยเพียงใด					
26	ท่านมีความรู้สึกไม่ดี เช่น รู้สึกเหงา เศร้า หดหู่ สิ้นหวัง วิตกกังวล บ่อยแค่ไหน					

**Appendix K**

**SF-12v2 Health Survey Standard Version**

### SF-12v2 Health Survey Standard Version

This survey asks for your views about your health. This information will help you keep track of how you feel and how well you are able to do your usual activities. Thank you for completing this survey!

For each of the following questions, please click the circle that best describes your answer.

---

1) In general, would you say your health is:

Excellent	Very good	Good	Fair	Poor
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

---

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

	Yes, limited a lot	Yes, limited a little	No, not limited at all
a. Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Climbing several flights of stairs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

---

3) During the past 4 weeks, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of your physical health?

	All of the time	Most of the time	Some of the time	A little of the time	None of the time
a. Accomplished less than you would like	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Were limited in the kind of work or other activities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

---

4) During the past 4 weeks, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

	All of the time	Most of the time	Some of the time	A little of the time	None of the time
a. Accomplished less than you would like	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Did work or activities less carefully than usual	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

5) During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?

Not at all	A little bit	Moderately	Quite a bit	Extremely
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

6) These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks...

	All of the time	Most of the time	Some of the time	A little of the time	None of the time
a. Have you felt calm and peaceful?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Did you have a lot of energy?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Have you felt downhearted and depressed?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

7) During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting friends, relatives, etc.)?

All of the time	Most of the time	Some of the time	A little of the time	None of the time
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Source: <http://www.mindbodymedicine.com/sf12v2.htm>

**Appendix L**

**SF-12v2™ Health Survey Standard Version - Thai**



**แบบสำรวจภาวะสุขภาพ (SF-12 VERSION 2)**

**คำชี้แจง** โปรดเลือกตัวเลือกที่แสดงถึงภาวะทางสุขภาพของคุณที่ตรงตามความรู้สึกและกิจวัตรของคุณอย่างมากที่สุดในช่วง 1 เดือนที่ผ่านมา ทั้งนี้ไม่มีคำตอบใดที่ถูกหรือผิด

1) โดยทั่วไป คุณสามารถพูดได้ว่าสุขภาพของคุณเป็นอย่างไร

ดีเยี่ยม                      ดีมาก                      ดี                      ปานกลาง                      ไม่ดี

2) เรื่องต่อไปนี้เป็นเรื่องเกี่ยวกับกิจกรรมที่คุณทำในแต่ละวัน คุณคิดว่าสุขภาพของคุณเป็นปัญหา / อุปสรรคในการทำกิจกรรมของคุณหรือไม่ ถ้าใช่ มากน้อยแค่ไหน

	เป็นปัญหา/อุปสรรค อย่างมาก	เป็นปัญหา/อุปสรรค เพียงเล็กน้อย	ไม่เป็นปัญหา/ อุปสรรค
2.1) กิจกรรมที่ใช้กำลังปานกลาง เช่น ยกโต๊ะ ทำความสะอาด ปิดกวาด เช็ดบ้าน หรือหิ้วของกลับจากตลาด			
2.2) การเดินขึ้นตึก 3-2 ชั้น หรือเดินขึ้นเนิน			

3) ในช่วง 1 เดือนที่ผ่านมา คุณเคยมีปัญหาในเรื่องต่อไปนี้กับงานของคุณหรือกิจกรรมที่ทำเป็นประจำทุกวัน เนื่องจากสุขภาพของคุณหรือไม่

	ตลอดเวลา	เกือบ ตลอดเวลา	บางครั้ง	นานๆ ครั้ง	ไม่เลย
3.1) ทำงานได้ปริมาณน้อยลงกว่าที่ ต้องการ					
3.2) ไม่สามารถทำงานได้ทุกอย่าง ตามที่ตั้งใจไว้ ต้องเลือกทำบางอย่าง เท่านั้น					

4) ในช่วง 1 เดือนที่ผ่านมา คุณเคยมีปัญหาในเรื่องต่อไปนี้กับงานของคุณ หรือกิจกรรมที่ทำเป็นประจำทุกวัน เนื่องมาจากปัญหาด้านอารมณ์ของคุณหรือไม่ เช่น ความรู้สึกซึมเศร้า หรือวิตกกังวล

	ตลอดเวลา	เกือบตลอดเวลา	บางครั้ง	นานๆ ครั้ง	ไม่เลย
4.1) ทำงานได้ปริมาณน้อยกว่าที่ต้องการ					
4.2) ทำงาน หรือทำกิจกรรมอื่นๆ โดยปราศจากความระมัดระวัง สับสน เพลิดเพลินอย่างที่เคย					

5) ในระหว่าง 1 เดือนที่ผ่านมา ปัญหาการเจ็บปวดตามร่างกายทำให้คุณไม่สามารถทำงานประจำวันได้ตามปกติ (งานในบ้านและนอกบ้าน) มากน้อยเพียงใด

ไม่เลย                      เล็กน้อย                      ปานกลาง                      ค่อนข้างมาก                      มากที่สุด

6) คำถามต่อไปนี้เกี่ยวข้องกับความรู้สึก และสิ่งต่างๆ ที่เกิดขึ้นกับคุณ กรุณาเลือกคำตอบที่ตรงกับความรู้สึกของคุณมากที่สุดเพียงข้อเดียวในช่วง 1 เดือนที่ผ่านมา คุณมีความรู้สึกต่อไปนี้ บ่อยแค่ไหน...

	ตลอดเวลา	เกือบตลอดเวลา	บางครั้ง	นานๆ ครั้ง	ไม่เลย
6.1) คุณรู้สึกใจสงบ ใจนิ่ง มีสมาธิ					
6.2) คุณรู้สึกแข็งแรง กระปรี้กระเปร่า สดชื่น					
6.3) คุณรู้สึกเศร้า หดหู่					

7) ในระหว่าง 1 เดือนที่ผ่านมา บ่อยแค่ไหนที่คุณรู้สึกว่าปัญหาทางสุขภาพหรือปัญหาทางอารมณ์เป็นอุปสรรคขัดขวางการทำกิจกรรมทางสังคมของคุณ เช่น การไปเยี่ยมเพื่อน หรือญาติสนิท เป็นต้น

ตลอดเวลา                      เกือบตลอดเวลา                      บางครั้ง                      นานๆ ครั้ง                      ไม่เลย

**Appendix M**

**Social Support Questionnaire Short Form (SSQ6)**

### Social Support Questionnaire Short Form (SSQ6)

**Direction:** The following questions ask about people in your environment who provide you with help or support. Each question has two parts. For the first part, please list all the people you know, excluding yourself, whom you can count on for help or support in the manner described. Give the person's initial and their relationship to you.

For the second part, circle how satisfied you are with the overall support you have.

If you have had no support for a question, check the words "NO ONE", but still rate your level of satisfaction. Do not list more than nine persons per question.

Please answer all questions as best as you can. All your responses will be kept confidential.

1. Whom can you really count on to be dependable when you need help?

No One 1) 4) 7)  
2) 5) 8)  
3) 6) 9)

How satisfied?

6- very satisfied	5-fairly satisfied	4-a little satisfied	3-a little Satisfied	2-fairly satisfied	1-very satisfied
-------------------	--------------------	----------------------	----------------------	--------------------	------------------

2. Whom can you really count on to help you feel more relaxed when you are under pressure or tense?

No One 1) 4) 7)  
2) 5) 8)  
3) 6) 9)

How satisfied?

6- very satisfied	5-fairly satisfied	4-a little satisfied	3-a little Satisfied	2-fairly satisfied	1-very satisfied
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3. Who accepts you totally, including both your worst and your best point?

No One 1) 4) 7)  
2) 5) 8)  
3) 6) 9)

How satisfied?

6- very satisfied	5-fairly satisfied	4-a little satisfied	3-a little Satisfied	2-fairly satisfied	1-very satisfied
-------------------	--------------------	----------------------	----------------------	--------------------	------------------

4. Whom can you really count on to care about you, regardless of what is happening to you?

No One 1) 4) 7)  
 2) 5) 8)  
 3) 6) 9)

How satisfied?

6- very satisfied	5-fairly satisfied	4-a little satisfied	3-a little Satisfied	2-fairly satisfied	1-very satisfied
-------------------	--------------------	----------------------	----------------------	--------------------	------------------

5. Whom can you really count on to help you feel better when you are feeling generally down-in-the-dumps?

No One 1) 4) 7)  
 2) 5) 8)  
 3) 6) 9)

How satisfied?

6- very satisfied	5-fairly satisfied	4-a little satisfied	3-a little Satisfied	2-fairly satisfied	1-very satisfied
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6. Whom can you count on to console you when you are very upset?

No One 1) 4) 7)  
 2) 5) 8)  
 3) 6) 9)

How satisfied?

6- very satisfied	5-fairly satisfied	4-a little satisfied	3-a little Satisfied	2-fairly satisfied	1-very satisfied
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Source: Sarason, I.G., Sarason, B.R., Shearin, E.N., Pierce, G.R. (1987). A brief measure of social support: practical and theoretical implications. *Journal of Social and Personal Relationships*, 4, 497–510.

**Appendix N**

**Social Support Questionnaire Short Form (SSQ6) -Thai**

**แบบวัดแรงสนับสนุนทางสังคม (SARASON'S SOCIAL SUPPORT QUESTIONNAIRE)**

**คำชี้แจง** ต่อไปนี้เป็นคำถามเกี่ยวกับบุคคลรอบข้างของคุณที่ให้ความช่วยเหลือคุณ แต่ละคำถามประกอบไปด้วย 2 ส่วน ส่วนที่หนึ่ง ให้คุณระบุคนที่คุณรู้จักไม่เกิน 9 คนที่สามารถช่วยเหลือคุณในเรื่องนั้นๆ ได้ ส่วนที่สอง ขอให้คุณพิจารณาว่า คุณพึงพอใจหรือไม่พึงพอใจในความช่วยเหลือที่ได้รับ จากนั้นขอให้คุณระบุระดับของความพอใจหรือไม่พอใจในแต่ละข้อว่าอยู่ในระดับ มาก ปานกลาง หรือน้อย หากคุณไม่มีผู้ที่ให้การช่วยเหลือโปรดตอบ ไม่มีเลย และระบุระดับของความพึงพอใจหรือไม่พึงพอใจ

**1. มีใครบ้างที่คุณสามารถที่จะพึ่งพาอาศัยได้เมื่อคุณต้องการความช่วยเหลือ**

- |          |    |    |    |
|----------|----|----|----|
| ไม่มีเลย | 1) | 4) | 7) |
|          | 2) | 5) | 8) |
|          | 3) | 6) | 9) |

**คุณรู้สึกพึงพอใจหรือไม่**

6- พอใจมาก	5-ค่อนข้างพอใจ	4-พอใจบ้างเล็กน้อย	3-ไม่พอใจบ้างเล็กน้อย	2-ค่อนข้างไม่พอใจ	1-ไม่พอใจอย่างมาก
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**2. มีใครบ้างที่จะทำให้คุณรู้สึกผ่อนคลายได้ในยามที่คุณรู้สึกเครียดหรือกดดัน**

- |          |    |    |    |
|----------|----|----|----|
| ไม่มีเลย | 1) | 4) | 7) |
|          | 2) | 5) | 8) |
|          | 3) | 6) | 9) |

**คุณรู้สึกพึงพอใจหรือไม่**

6- พอใจมาก	5-ค่อนข้างพอใจ	4-พอใจบ้างเล็กน้อย	3-ไม่พอใจบ้างเล็กน้อย	2-ค่อนข้างไม่พอใจ	1-ไม่พอใจอย่างมาก
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3. มีใครบ้างที่ยอมรับคุณได้ทุกอย่างที่คุณเป็น ไม่ว่าจะเป็นเรื่องดีหรือเรื่องร้าย

- ไม่มีเลข 1) 4) 7)  
2) 5) 8)  
3) 6) 9)

คุณรู้สึกพึงพอใจหรือไม่

6- พอใจมาก	5-ค่อนข้างพอใจ	4-พอใจบ้างเล็กน้อย	3-ไม่พอใจบ้างเล็กน้อย	2-ค่อนข้างไม่พอใจ	1-ไม่พอใจอย่างมาก
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4. มีใครบ้างที่เป็นห่วงเป็นใยคุณ ไม่ว่าจะอะไรจะเกิดขึ้นกับคุณก็ตาม

- ไม่มีเลข 1) 4) 7)  
2) 5) 8)  
3) 6) 9)

คุณรู้สึกพึงพอใจหรือไม่

6- พอใจมาก	5-ค่อนข้างพอใจ	4-พอใจบ้างเล็กน้อย	3-ไม่พอใจบ้างเล็กน้อย	2-ค่อนข้างไม่พอใจ	1-ไม่พอใจอย่างมาก
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5. มีใครบ้างที่จะสามารถทำให้คุณรู้สึกดีขึ้นได้ในยามที่คุณรู้สึกแย่มากๆ

- ไม่มีเลข 1) 4) 7)  
2) 5) 8)  
3) 6) 9)

คุณรู้สึกพึงพอใจหรือไม่

6- พอใจมาก	5-ค่อนข้างพอใจ	4-พอใจบ้างเล็กน้อย	3-ไม่พอใจบ้างเล็กน้อย	2-ค่อนข้างไม่พอใจ	1-ไม่พอใจอย่างมาก
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6. มีใครบ้างที่จะช่วยปลอบใจคุณ ในยามที่คุณรู้สึกผิดหวัง

- |          |    |    |    |
|----------|----|----|----|
| ไม่มีเลย | 1) | 4) | 7) |
|          | 2) | 5) | 8) |
|          | 3) | 6) | 9) |

คุณรู้สึกพึงพอใจหรือไม่

6- พอใจมาก	5-ค่อนข้างพอใจ	4-พอใจบ้างเล็กน้อย	3-ไม่พอใจบ้างเล็กน้อย	2-ค่อนข้างไม่พอใจ	1-ไม่พอใจอย่างมาก
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**Appendix O**

**Caregiver Evaluation of Adult Day Care (CEADC)**

### Caregiver Evaluation of Adult Day Care (CEADC)

Part I : Please indicate how satisfied are you with adult day service use from your current experiences.

	Quite dissatisfied	Mildly dissatisfied	Neutral	Mostly Satisfied	Very Satisfied
1. Skill of staff caring for patients with dementia					
2. Staff's ability to handle problematic behaviors of my recipient					
3. Providing information needed for caring my recipient					
4. Friendliness and concern of staff					
5. Program activities					
6. Program meals					
7. Numbers of hours per day					
8. Numbers of day per week					
9. Location of day care					
10. Cost of day care					
11. Respect for Human Rights					
12. Concern with spiritual and religious beliefs					

Part II : Please indicate the frequency with each statement from your experiences with adult day care service use.

	Never	Rarely	Sometimes	Quite Frequently	Nearly Always
1. My recipient is less agitated after attending ADC.					
2. My recipient is less symptoms of apathy or depression after attending ADC.					
3. My recipient is easier to handle after attending ADC.					
4. My recipient sleeps better at night after attending ADC.					

	Never	Rarely	Sometimes	Quite Frequently	Nearly Always
5. My recipient benefits from being around others at ADC.					
6. My recipient looks forward to going to ADC					
7. I look forward to time when my relative is at ADC					
8. I think ADC helps my relative function better mentally.					
9. I think ADC helps my relative function better in activities of daily living.					
10. I have time to relax when my relative is at ADC.					
11. I have time to do chores when my relative is at ADC.					
12. I can do thing for myself when my relative is at ADC.					
13. I have more time for my family while my relative is at ADC.					
14. Difficult to get my relative ready to go to ADC.					
15. My recipient unwilling to go to ADC.					
16. My recipient is upset with me after attending at ADC					
17. I worry about my relative when she is at ADC.					

Part III Qualitative questions for participants who have used adult day care services for three months or more.

1. What are your experiences with ADC?
  - Probe - How do you feel about it?
  - Probe - How does your family feel about it?
2. Has your life changed in any way since your relative started attending ADC?
  - Probe - What are your positive experiences?
  - Probe - What are your negative experiences?

**Appendix P**

**Caregiver Evaluation of Adult Day Care (CEADC) - Thai**

### แบบประเมินการใช้บริการโรงพยาบาลกลางวันแก่ผู้มีภาวะสมองเสื่อม

แบบสอบถามต่อไปนี้เป็นความต้องการทราบประสบการณ์ของคุณที่เกี่ยวข้องกับการใช้บริการในรูปแบบโรงพยาบาลกลางวันแก่ผู้มีภาวะสมองเสื่อม (คลินิกความจำ)

ส่วนที่ 1 : กรุณาระบุระดับความพึงพอใจของคุณจากประสบการณ์ในช่วงเดือนที่ผ่านมา

	ไม่พึงพอใจมากที่สุด	ไม่พึงพอใจเพียงเล็กน้อย	เฉยๆ	พึงพอใจอย่างมาก	พึงพอใจมากที่สุด
1. ทักษะของเจ้าหน้าที่ผู้ให้การดูแลผู้มีภาวะสมองเสื่อม					
2. ความสามารถในการเผชิญกับพฤติกรรมต่างๆ ที่เบี่ยงเบนจากปกติของผู้มีภาวะสมองเสื่อม					
3. การให้ความรู้หรือข้อมูลที่เป็นประโยชน์ต่อการให้การดูแลญาติของคุณ					
4. ความเอาใจใส่และเป็นกันเองของเจ้าหน้าที่ผู้ให้การดูแล					
5. กิจกรรมที่จัดในโปรแกรมของโรงพยาบาลกลางวัน					
6. การจัดให้บริการอาหาร					
7. ช่วงเวลาในการให้บริการในแต่ละวัน					
8. จำนวนวันในการให้บริการต่อสัปดาห์					
9. สถานที่ตั้งของโรงพยาบาลกลางวัน					
10. ค่าบริการในการเข้าใช้บริการโรงพยาบาลกลางวัน					
11. ผู้ให้บริการให้ความเคารพสิทธิของผู้ป่วย					
12. ผู้ให้บริการปฏิบัติต่อผู้มีภาวะสมองเสื่อมโดยคำนึงถึงความเชื่อทางศาสนา					

ส่วนที่ 2 : กรุณาประเมินการเปลี่ยนแปลงความบ่อยครั้งของประสบการณ์ที่เกิดขึ้นกับคุณหรือญาติของคุณ  
 ภายหลังจากใช้บริการในรูปแบบโรงพยาบาลกลางวัน (คลินิกความจำ)

	ไม่เลย	นานๆ ครั้ง	เกิด/ไม่เกิด พอๆ กัน	บ่อยครั้ง	ตลอดเวลา
1. ญาติของฉันลดความวุ่นวายลงหลังจากใช้บริการในคลินิกความจำ					
2. ญาติของฉันลดความเฉาหรือลดอาการซึมเศร้าลงหลังจากใช้บริการในโรงพยาบาลกลางวัน					
3. ฉันสามารถเผชิญกับพฤติกรรมที่เบี่ยงเบนต่างๆ ของญาติฉันได้ง่ายขึ้น					
4. ญาติที่ป่วยของฉันสามารถนอนหลับได้ดีขึ้น					
5. ญาติที่ป่วยของฉันได้รับประโยชน์จากการอยู่ร่วมกับผู้อื่นที่โรงพยาบาลกลางวัน					
6. ญาติที่ป่วยของฉันตั้งตาคอยที่จะไปโรงพยาบาลกลางวัน					
7. ฉันรอคอยเวลาที่ญาติของฉันจะใช้บริการที่โรงพยาบาลกลางวัน					
8. ฉันคิดว่าโรงพยาบาลกลางวัน ช่วยฟื้นฟูสมรรถภาพทางการจำและการรู้จักของญาติของฉัน					
9. ฉันคิดว่าโรงพยาบาลกลางวันช่วยกระตุ้นให้ญาติที่ป่วยของฉันสามารถทำกิจวัตรประจำวันของตัวเองได้ดีขึ้น					
10. ฉันรู้สึกได้มีเวลาผ่อนคลายยามเมื่อญาติของฉันอยู่ที่โรงพยาบาลกลางวัน					
11. ฉันมีเวลาได้ทำงานบ้านหรือทำงานบางสิ่งให้เสร็จสิ้นยามเมื่อญาติของฉันอยู่ที่โรงพยาบาลกลางวัน					

	ไม่เคย	นานๆ ครั้ง	เกิด/ไม่เกิด พอๆ กัน	บ่อยครั้ง	ตลอดเวลา
12. ฉันมีเวลาดูแลตัวเองยามเมื่อญาติของฉันอยู่ที่ โรงพยาบาลกลางวัน					
13. ฉันมีเวลาสำหรับครอบครัวฉันมากขึ้นยาม เมื่อญาติของฉันอยู่ที่โรงพยาบาลกลางวัน					
14. มีความยุ่งยากและลำบากในการนำญาติของ ฉันมายังโรงพยาบาลกลางวัน					
15. ญาติของฉันไม่ยินดีที่จะมาโรงพยาบาล กลางวัน					
16. ญาติของฉันอารมณ์เสียกับฉันหลังจากเข้าใช้ บริการที่โรงพยาบาลกลางวัน					
17. ฉันรู้สึกกังวลและเป็นห่วงญาติของฉันเมื่อเขา อยู่ที่โรงพยาบาลกลางวัน					



**Appendix Q**

**The Mini-Mental State Exam**

### The Mini-Mental State Exam

Name \_\_\_\_\_ Date \_\_\_\_\_

Maximum Score  
Score Achieved

Record client's answers in the spaces provided

5		Orientation Q1: What is the (year) (season) (date) (day) (month)? Q2: Where are we stay (country) (town) (street) (address number)?
3		Registration: Q3: Name 3 objects: flower, river, train 1 second to say each. Then ask the patient all 3 after you have said them. Score 1 point for each correct answer for each one correct on the first attempt. Repeat them (maximum 5 times) until he/she learns them. Count trials and record. Trials: _____
5		Attention and Calculation Q4: Serial 7's. Count backwards from 100 by subtracting 7 (93 86 79 72 65) Score 1 point for each correct answer. Stop after 5 answers. Alternatively spell "משה" forward and backward. Score 1 point for each letter in correct order. e.g. משה = 5, המשה = 3
3		Recall: Q5: Ask for the 3 objects given to remember in Q3. Score 1 point for each correct answer, irrespective of the order.
2 1 3		Language: Q6: Name a pencil and watch. Q7: Repeat the following "No ifs, ands, or buts" Q8: Follow a 3-stage command: "Take a paper in your hand, fold it in half, and put it on the floor." Score 1 point for each part correctly executed.
1		Q9: Read and obey the following: CLOSE YOUR EYES
1		Q10: Ask the person to write a sentence of his/her own choice. The sentence should contain a subject and an object and make sense. Ignore spelling errors.
1		Q11: Ask the person to copy the design. Score 1 point if all sides and angles are preserved and the intersecting sides form a quadrangle.

Total Scores \_\_\_\_\_

The measure is adapted from Folstein, M.F., Folstein, S.E., & McHugh, P.R. (1975). "MINI-MENTAL STATE." A practical method for grading the cognitive state of patients for the clinician. *Journal of Psychiatric Research*, 12, 189-198.

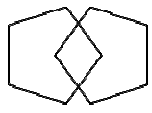
**Appendix R**

**The Mini-Mental State Exam-Thai**

## แบบทดสอบสภาพสมองเบื้องต้นฉบับภาษาไทย (MMSE-Thai 2002)

ชื่อ \_\_\_\_\_ วันที่ตรวจ \_\_\_\_\_

คะแนนสูงสุด คะแนนที่ได้

5		<b>Orientation:</b> 1. วันนี่วันที่เท่าไร วันอะไร เดือนอะไร ปีอะไร ฤดูอะไร 2. สถานที่ตรงนี้เรียกว่าอะไร และ...ชื่ออะไร ขณะนี้อยู่ชั้นที่เท่าไรของของตัวอาคาร ที่นี้อยู่ในอำเภออะไร ที่นี้จังหวัดอะไร ที่นี้ภาคอะไร
5		
3		<b>Registration:</b> 3. บอกชื่อของ 3 อย่างแล้วให้ผู้ถูกทดสอบพูดตาม ▪ ดอกไม้ ▪ แม่น้ำ ▪ รถไฟ ในกรณีที่ทำแบบทดสอบซ้ำภายใน 2 เดือน ให้ใช้คำว่า ▪ ต้นไม้ ▪ ทะเล ▪ รถยนต์
5		<b>Attention and Calculation:</b> 4. คิดเลขในใจให้เอา 100 ตั้ง ลบออกทีละ 7 ไปเรื่อยๆ ได้ผลลัพธ์เท่าไร ..... (93 86 79 72 65) ตอบถูกได้ 1 คะแนน อีกกรณีหนึ่ง สะกดคำว่า <u>มะนาว</u> ให้ฟัง แล้วให้ผู้ถูกทดสอบสะกดออกหลังจากพยัญชนะตัวหลัง ไปตัวแรก “มอม่่า-สระอะ-นอหนู-สระอา-วอแหวน” ..... (วานะม) ตอบถูกได้ 1 คะแนน
3		<b>Recall:</b> 5. เมื่อสักครู่นี้ให้จำของ 3 อย่าง จำได้ไหมมีอะไรบ้าง ▪ ดอกไม้ ▪ แม่น้ำ ▪ รถไฟ ตอบถูกได้ 1 คะแนน ในกรณีที่ทำแบบทดสอบซ้ำภายใน 2 เดือน ให้ใช้คำว่า ▪ ต้นไม้ ▪ ทะเล ▪ รถยนต์ ตอบถูกได้ 1 คะแนน
1		<b>Language:</b> 6. ขึ้นดินสอให้ผู้ถูกทดสอบดูและถามว่า “ของสิ่งนี้เรียกว่าอะไร” ขึ้นาฬิกาข้อมือให้ผู้ถูกทดสอบดูและถามว่า “ของสิ่งนี้เรียกว่าอะไร” 7. พูดข้อความแล้วให้พูดตาม โดยบอกเพียงครั้งเดียว “ใครใคร่ขายไก่ไป” 8. บอกผู้ถูกทดสอบว่าจะส่งกระดาษให้ แล้วให้รับด้วยมือขวา พับครึ่งด้วยมือ 2 ข้าง แล้ววางไว้ ที่..... (พื้น, โต๊ะ, เติง) ส่งกระดาษเปล่าขนาดประมาณ เอ-4 ไม่มีรอยพับ ให้ผู้ถูกทดสอบ ▪ รับด้วยมือขวา ▪ พับครึ่ง ▪ วางไว้ที่ (พื้น, โต๊ะ, เติง) ทำถูกได้ช่องละ 1 คะแนน 9. ให้ผู้ถูกทดสอบอ่านข้อความที่กำหนด แล้วให้ทำตามจะอ่านออกเสียงหรืออ่านในใจก็ได้ ผู้ทดสอบแสดงกระดาษที่เขียนว่า “หลับตา” ▪ หลับตาได้ ทำถูกได้ 1 คะแนน 10. ให้ผู้ถูกทดสอบเขียนข้อความอะไรก็ได้ที่อ่านแล้วรู้เรื่อง หรือมีความหมายมา 1 ประโยค
1		
1		
3		
1		
1		<b>Visuoconstruction:</b> 11. ข้อนี้เป็นคำสั่ง “ให้วาดภาพเหมือนภาพตัวอย่าง” <div style="text-align: center;">  </div>

คะแนนรวม \_\_\_\_\_

## **Appendix S**

### **The Bristol Activities of Daily Living Scale**

### The Bristol Activities of Daily Living Scale

This questionnaire is designed to reveal the everyday ability of people who have memory difficulties of one form or another. For each activity (Nos. 1-20), statements a-e refer to a different level of ability. Thinking of the last 2 weeks, please select the statement that represents your relative's/friend's ability. (If in doubt about which box to tick, choose the level of ability which represents their *average* performance over the last 2 weeks)

	Scoring
<b>1. FOOD</b>	
a. Selects and prepares food as required	0
b. Able to prepare food if ingredients set out	1
c. Can prepare food if prompted step by step	2
d. Unable to prepare food even with prompting and supervision	3
e. Not applicable	0
<b>2. EATING</b>	
a. Eats appropriately using correct cutlery	0
b. Eats appropriately if food made manageable and/or uses spoon	1
c. Uses fingers to eat food	2
d. Needs to be fed	3
e. Not applicable	0
<b>3. DRINK</b>	
a. Selects and prepares drinks as required	0
b. Can prepare drinks if ingredients left available	1
c. Can prepare drinks if prompted step by step	2
d. Unable to make a drink even with prompting and supervision	3
e. Not applicable	0
<b>4. DRINKING</b>	
a. Drinks appropriately	0
b. Drinks appropriately with aids, beaker/straw etc.	1
c. Does not drink appropriately even with aids but attempts to	2
d. Has to have drinks administered (fed)	3
e. Not applicable	0
<b>5. DRESSING</b>	
a. Selects appropriate clothing and dresses self	0
b. Puts clothes on in wrong order and/or back to front and/or dirty clothing	1
c. Unable to dress self but moves limbs to assist	2
d. Unable to assist and requires total dressing	3
e. Not applicable	0

6. HYGIENE	Scoring
a. Washes regularly and independently	0
b. Can wash self if given soap, flannel, towel, etc.	1
c. Can wash self if prompted and supervised	2
d. Unable to wash self and needs full assistance	3
e. Not applicable	0
7. TEETH	
a. Cleans own teeth/dentures regularly and independently	0
b. Cleans teeth/dentures if given appropriate items	1
c. Requires some assistance, toothpaste on brush, brush to mouth, etc.	2
d. Full assistance given	3
e. Not applicable	0
8. BATH/SHOWER	
a. Bathes regularly and independently	0
b. Needs bath to be drawn/shower turned on but washes independently	1
c. Needs supervision and prompting to wash	2
d. Totally dependent, needs full assistance	3
e. Not applicable	0
9. TOILET/COMMODOE	
a. Uses toilet appropriately when required	0
b. Needs to be taken to the toilet and given assistance	1
c. Incontinent of urine or faeces	2
d. Incontinent of urine and faeces	3
e. Not applicable	0
10. TRANSFERS	
a. Can get in/out of chair unaided	0
b. Can get into a chair but needs help to get out	1
c. Needs help getting in and out of a chair	2
d. Totally dependent on being put into and lifted from chair	3
e. Not applicable	0
11. MOBILITY	
a. Walks independently	0
b. Walks with assistance, i.e. furniture, arm for support	1
c. Uses aids to mobilize, i.e. frame, sticks etc.	2
d. Unable to walk	3
e. Not applicable	4
12. ORIENTATION--TIME	
a. Fully orientated to time/day/date etc.	0
b. Unaware of time/day etc but seems unconcerned	1
c. Repeatedly asks the time/day/date	2
d. Mixes up night and day	3
e. Not applicable	0

13. ORIENTATION--SPACE	Scoring
a. Fully orientated to surroundings	0
b. Orientated to familiar surroundings only	1
c. Gets lost in home, needs reminding where bathroom is, etc.	2
d. Does not recognize home as own and attempts to leave	3
e. Not applicable	0
14. COMMUNICATION	
a. Able to hold appropriate conversation	0
b. Shows understanding and attempts to respond verbally with gestures	1
c. Can make self understood but difficulty understanding others	2
d. Does not respond to or communicate with others	3
e. Not applicable	0
15. TELEPHONE	
a. Uses telephone appropriately, including obtaining correct number	0
b. Uses telephone if number given verbally/ visually or predialled	1
c. Answers telephone but does not make calls	2
d. Unable/unwilling to use telephone at all	3
e. Not applicable	0
16. HOUSEWORK/GARDENING	
a. Able to do housework/gardening to previous standard	0
b. Able to do housework/gardening but not to previous standard	1
c. Limited participation even with a lot of supervision	2
d. Unwilling/unable to participate in previous activities	3
e. Not applicable	0
17. SHOPPING	
a. Shops to previous standard	0
b. Only able to shop for 1 or 2 items with or without a list	1
c. Unable to shop alone, but participates when accompanied	2
d. Unable to participate in shopping even when accompanied	3
e. Not applicable	0
18. FINANCES	
a. Responsible for own finances at previous level	0
b. Unable to write cheque but can sign name and recognizes money values	1
c. Can sign name but unable to recognize money values	2
d. Unable to sign name or recognize money values	3
e. Not applicable	0
19. GAMES/HOBBIES	
a. Participates in pastimes/activities to previous standard	0
b. Participates but needs instruction/ supervision	1
c. Reluctant to join in, very slow, needs coaxing	2
d. No longer able or willing to join in	3
e. Not applicable	0



20. TRANSPORT	Scoring
a. Able to drive, cycle or use public transport independently	0
b. Unable to drive but uses public transport or bike etc	1
c. Unable to use public transport alone	2
d. Unable/unwilling to use transport even when accompanied	3
e. Not applicable	0

Thank you for taking the time to complete this questionnaire.

Resource: Buck, R.S., Ashworth, D.L., Wilcock, G.K., & Siegfried, K. (1996). Assessment of Activities of Daily Living in Dementia: Development of the Bristol Activities of Daily Living Scale. *Age and Aging*, 25, 113-120.

## **Appendix T**

### **The Bristol Activities of Daily Living Scale-Thai**

### แบบวัดความสามารถในการปฏิบัติกิจกรรมประจำวัน (The Bristol Activities of Daily Living Scale)

แบบสอบถามนี้เกี่ยวข้องกับการประเมินความสามารถในการปฏิบัติกิจกรรมในแต่ละวัน กรุณาเลือกข้อความที่บ่งถึงความสามารถโดยเฉลี่ยของญาติผู้ที่มีภาวะสมองเสื่อมที่ท่านให้การดูแลในช่วง 2 สัปดาห์ที่ผ่านมา

#### 1. การเตรียมอาหาร

- ก. เลือกและเตรียมอาหารได้เองตามที่ต้องการ
- ข. สามารถเตรียมอาหารได้ ถ้าจัดเตรียมส่วนผสมของอาหารให้
- ค. สามารถเตรียมอาหารได้ ถ้าแนะให้ทีละขั้นตอน
- ง. ไม่สามารถเตรียมอาหารเองได้แม้ได้รับการชี้แนะ
- จ. ไม่ตอบ

#### 2. การรับประทานอาหาร

- ก. รับประทานอาหารได้เองเป็นปกติและใช้อุปกรณ์ได้เหมาะสม
- ข. รับประทานอาหารได้อย่างเหมาะสมถ้าจัดเตรียมช้อนให้
- ค. ใช้นิ้วหยิบอาหารกิน
- ง. จำเป็นต้องป้อนให้
- จ. ไม่ตอบ

#### 3. การเตรียมเครื่องดื่ม

- ก. เลือกและเตรียมเครื่องดื่มได้เองตามที่ต้องการ
- ข. สามารถเตรียมเครื่องดื่มอง ถ้าจัดเตรียมให้
- ค. สามารถเตรียมเครื่องดื่ม ถ้าแนะให้ทีละขั้นตอน
- ง. ไม่สามารถเตรียมเครื่องดื่มได้เอง แม้ได้รับการชี้แนะ
- จ. ไม่ตอบ

#### 4. การดื่ม

- ก. ดื่มเครื่องดื่มได้เองตามที่ต้องการ
- ข. สามารถดื่มน้ำเองได้ ถ้าช่วยเหลือ
- ค. สามารถดื่มน้ำได้ ต้องช่วยและใช้ความพยายาม
- ง. ไม่สามารถดื่มน้ำเองได้แม้ได้รับการชี้แนะ
- จ. ไม่ตอบ

## 5. การแต่งตัว

- ก. เลือกเสื้อผ้าและแต่งตัวได้เองตามที่ต้องการ
- ข. ใส่เสื้อผ้าผิด กลับหน้ากลับหลัง หรือเสื้อผ้าปกติ
- ค. ไม่สามารถใส่เสื้อผ้าได้เอง แต่ช่วยขยับแขนขาใส่เสื้อผ้าได้
- ง. ไม่สามารถใส่เสื้อผ้าได้เอง ต้องช่วยเหลือทั้งหมด
- จ. ไม่ตอบ

## 6. ความสะอาดส่วนบุคคล

- ก. ดูแลความสะอาดของร่างกายเองได้เองตามปกติ
- ข. ดูแลความสะอาดของร่างกายได้เอง แต่ต้องช่วยเตือนหรือเตรียมอุปกรณ์ให้
- ค. ดูแลความสะอาดร่างกายเองได้แต่ต้องคอยชี้แนะทีละขั้นตอน
- ง. ไม่สามารถดูแลความสะอาดร่างกายเองได้ ต้องการความช่วยเหลือทั้งหมด
- จ. ไม่ตอบ

## 7. การแปรงฟัน

- ก. แปรงฟันได้เองตามปกติ
- ข. แปรงฟันได้เอง แต่ต้องช่วยเตรียมอุปกรณ์ให้
- ค. แปรงฟันได้แต่ต้องช่วยเตรียมอุปกรณ์และการชี้แนะหรือกำกับดูแล
- ง. ไม่สามารถแปรงฟันได้เอง ต้องการความช่วยเหลือทั้งหมด
- จ. ไม่ตอบ

## 8. การอาบน้ำ

- ก. อาบน้ำได้เองตามปกติ
- ข. อาบน้ำได้เอง แต่ต้องช่วยเปิดปิดน้ำให้
- ค. ต้องการการชี้แนะหรือกำกับดูแล
- ง. ไม่สามารถอาบน้ำเองได้ ต้องการความช่วยเหลือทั้งหมด
- จ. ไม่ตอบ

## 9. การเข้าห้องน้ำ

- ก. ใช้ห้องน้ำได้อย่างเหมาะสมตามที่ต้องการ
- ข. ต้องการความช่วยเหลือพาเข้าห้องน้ำ
- ค. ปัสสาวะหรืออุจจาระราด
- ง. ปัสสาวะและอุจจาระราด
- จ. ไม่ตอบ

## 10. การลุกขึ้นนั่ง

- ก. สามารถลุกนั่งได้เองตามปกติตามที่ต้องการ
- ข. ต้องการความช่วยเหลือขณะลุกขึ้นจากที่นั่ง
- ค. ต้องการความช่วยเหลือทั้งนั่งในเก้าอี้และการลุกขึ้นจากที่นั่ง
- ง. ไม่สามารถช่วยเหลือตัวเองได้เลย ทั้งนั่งในเก้าอี้และการลุกขึ้นจากที่นั่ง
- จ. ไม่ตอบ

## 11. การเคลื่อนย้าย

- ก. สามารถเดินไปมาได้เองตามปกติตามที่ต้องการ
- ข. เดินเองได้แต่ต้องการความช่วยเหลือประคับประคอง
- ค. ต้องการอุปกรณ์ช่วยในการเดิน เช่น ไม้เท้า
- ง. ไม่สามารถเดินเองได้
- จ. ไม่ตอบ

## 12. การรับรู้ - วันเวลา

- ก. สามารถจำวันเวลา ได้ตามปกติ
- ข. ไม่สนใจวันเวลา
- ค. ต้องบอกวันเวลา วันที่ซ้ำ ๆ
- ง. บอกวันเวลากลางวัน กลางคืนสับสน
- จ. ไม่ตอบ

## 13. การรับรู้ - สถานที่

- ก. สามารถจำสถานที่ได้ตามปกติ
- ข. จำสถานที่ที่ตนคุ้นเคยได้เท่านั้น
- ค. เดินหลงภายในบ้าน ต้องการเตือนความจำสถานที่ตั้งของห้องน้ำ
- ง. ไม่สามารถจำบ้านตนเองได้และพยายามเดินออกนอกบ้าน
- จ. ไม่ตอบ

## 14. การพูดคุย

- ก. สามารถสนทนาพูดคุยได้อย่างเหมาะสม
- ข. แสดงความเข้าใจสิ่งที่พูด พยายามตอบด้วยคำพูดและท่าทางประกอบ
- ค. สามารถเข้าใจตนเอง แต่ไม่ค่อยเข้าใจผู้อื่น
- ง. ไม่พูดคุยโต้ตอบกับผู้อื่น
- จ. ไม่ตอบ

## 15. การใช้โทรศัพท์

- ก. สามารถใช้โทรศัพท์อย่างเหมาะสม จำหมายเลขโทรศัพท์ได้
- ข. ใช้โทรศัพท์ได้ถ้าบอกหมายเลขโทรศัพท์ที่ต้องการติดต่อ
- ค. โต้ตอบโทรศัพท์ได้ แต่ไม่สามารถโทรออกได้ถูกต้อง
- ง. ไม่ต้องการพูดคุยโทรศัพท์หรือใช้โทรศัพท์ไม่เป็น
- จ. ไม่ตอบ

## 16. การทำงานบ้าน

ก.

สามารถทำงานบ้านหรือทำสวนได้ตามปกติ

- ข. สามารถทำงานบ้านหรือทำสวนได้ แต่ไม่เรียบร้อยเหมือนเช่นเคย
- ค. ทำงานบ้านได้แต่ต้องชี้แนะอย่างมาก
- ง. ไม่ต้องการทำงานบ้านหรือมีส่วนร่วมในงานที่เคยทำอยู่
- จ. ไม่ตอบ

## 17. การซื้อของ

- ก. สามารถออกไปซื้อของได้ตามปกติ
- ข. สามารถซื้อของได้ตามที่จดไว้หรือได้เพียง 1-2 อย่าง
- ค. ไปสามารถออกไปซื้อของได้ตามคำฟัง
- ง. ไม่สามารถมีส่วนร่วมในการซื้อของได้แม้ว่าไปด้วยกัน
- จ. ไม่ตอบ

## 18. การเงิน

- ก. สามารถรับผิดชอบการเงินของตนเองได้ตามปกติ
- ข. สามารถรับรู้ค่าของเงิน
- ค. ไม่สามารถรับรู้ค่าของเงิน แม้เซ็นชื่อใน cheque ได้
- ง. ไม่สามารถเซ็นชื่อใน cheque ได้ และไม่สามารถรับรู้ค่าของเงิน
- จ. ไม่ตอบ

## 19. งานอดิเรก

- ก. สามารถทำงานอดิเรกหรือเล่นเกมได้ตามปกติ
- ข. สามารถทำงานอดิเรกหรือเล่นเกมได้ถ้ามีการชี้แนะ
- ค. ลังเลที่จะมีส่วนร่วม ช้ามาก
- ง. ไม่ยินดีหรือไม่สามารถมีส่วนร่วมได้
- จ. ไม่ตอบ

## 20. การเดินทาง

- ก. สามารถขับขีรถหรือใช้รถประจำทางได้ตามปกติ
- ข. ไม่สามารถขับขีรถได้ แต่ใช้จักรยานได้และใช้รถประจำทางได้
- ค. ไม่สามารถใช้รถประจำทางได้ตามลำพัง
- ง. ไม่ยินดีหรือไม่สามารถมีส่วนร่วมได้
- จ. ไม่ตอบ

ขอขอบคุณท่านที่กรุณาตอบแบบสอบถามนี้