# **CHAPTER 1**

# Introduction

### **Background and Significance of the Research Problem**

The structure of the Thai population has changed, especially the elderly population which has increased in number owing to social and economic development. Birth control has resulted in a decrease in the birth rate, and an advancement in medicine has decreased the death rate of the elderly population. In 2007, people aged 60 and over comprised 10.70% of the population of Thailand (National Statistical Office, 2008). This figure increased to 11.47% and 14.73% in 2009 and 2013 respectively (Mahidol Population Gazette, 2009, 2013). It is estimated that by 2030, the proportion of elderly people in Thailand will increase to 25.12% (College of Population Studies, Chulalongkorn University, 2008). Elderly people experience changes and degeneration of their overall body function. They also experience changes in their living environment, lifestyle living and health behaviors. All of these factors cause illnesses which are frequently chronic. Degenerative changes both physically and mentally, lead to increased limitations. Impairments of the musculoskeletal system, circulatory system, and nervous system lead to inability to perform activities of daily living (Jithapunkul, 2001; Assantachai, 2009). In some cases, chronic illnesses and disability limit their performance of daily tasks (Jithapunkul, 2001). Common chronic illnesses in the elderly population include hypertension (31.7%), diabetes mellitus (13.3%), heart disease (7.0%), hemiplegia or hemiparesis (2.5%), cerebrovascular disease (1.6%), and cancer (0.5%) (National Statistical Office, 2008). Furthermore, one in four of elderly persons has a disability and one in five has a disability lasting longer than 6 months (Bureau of Health Promotion, Department of Health, Ministry of Public Health, 2010). Psychologically, elderly people are at risk of having depression, isolation and feeling of decreased self-value (Assantachai, 2009). However, elderly people will have to face physical deterioration in accordance with age, and still be faced with health problems leading to a need for care from caregivers in their families (Yodpetch, 2006). Dependency is a state in which a person loses their autonomy due to physical or psychological impairments causing them to be unable to care for themselves in everyday living and needing help from others. Elderly people often have some dependency and need assistance in basic tasks such as activities of daily living, basic living needs, financial support as well as love, affection and security in order to be able to function adequately (O'Shea, 2002; Jithapunkul, 2001; Boonthamcharoen, 2009).

There can be dependency in many aspects such as physical, psychological, economical and health dependency. Physical dependency, commonly found in older persons, stems from impairment in bodily functions which prevent performance of basic activities of daily living such as bathing, dressing, feeding, mobility, toileting and control of bowel and bladder (Jithapunkul, 2001). According to the National Statistical Office's 2007 Disability Survey, it demonstrated that 15 per cent of the elderly population in Thailand suffered from physical disability, with female elderly at a higher proportion (female 16.6 per cent and male 13.1 per cent). In 2010, there were 499,837 dependent elders. This number is estimated to increase to 741,766 in 2020 and 1,103,754 in 2030 (Jithapunkul & Kespichayawattana, 2001). The deterioration correlatively increases with age (age 70 and over accounting for 43.7 per cent, age 70 -74 accounting for 22.7 per cent, and age 60 - 64 accounting for 14.6 per cent). Nearly one-fourth of the disabled elderly reported having difficulty to look after themselves, furthermore Prasartkul (2012) states that the number of Thai dependent elders who have disability which cannot help themselves increased to 294,200 in 2010 and is estimated to increase to 739,600 in 2015. It can be seen that elders will have more disability than other aged leading to physical dependency. Furthermore, psychological and social dependency is due to psychological impairment as well as problems with social interaction. Elderly people with illnesses experience anxiety, stress, pressure and frustration that they pose burdens on their family (Anaeksook & Sangkachat, 2005).

The family plays an important role in caregiving for the family members to be able to live with quality and take care of its members both in wellness and illness. Despite these daunting challenges, family members have traditionally taken on the role of caregiving. Nevertheless, due to current changes in the environment, economy, society and culture, modern households are reducing in size and family members are faced with an increased burden in caregiving for dependent elders. Consequently, these changes have contributed to an increasingly complex role of caregiving by family caregivers (Yodpetch, 2006). The family members are most often the primary caregivers of the dependent elders; they must care for them and support them to make them feel loved and secure (Boonthamcharoen, 2009; Yodpetch, 2010). Among the family caregivers, some take the role of the primary caregiver and others take the role of the secondary caregiver. The primary caregiver assists the elderly in activities of daily living and physical activities, and they must spend most of their time in caregiving for the dependent person. The secondary caregiver offers occasional help and can be a family member or a member of a social organization which offers support to the primary caregiver. The primary caregiver offers constant care for the elderly in activities of daily living as well as emotional, psychological and healthcare support, bathing, feed, dressing, mobility and toileting. The primary caregiver also supports the elderly socially including shopping, preparation of meals, making phone calls and purchasing goods, psychological and emotional support, financial support and taking the elderly to religious ceremonies. Healthcare support is also an important part of caregiving. This includes preparation of medications, coordination with healthcare personals and caregiving for the overall safety and well-being of the elderly (Schumacher, Beck, & Marren, 2006; Lertrat, 2008).

The effects of caregiving for the elderly can have both positive and negative effects on the family caregiver. The positive effects include the feeling of happiness and satisfaction that the caregiver is able to care for another person, especially if the elderly is their mother or father. The negative effects include fatigue of having to care for the elderly and move them around the house. Some caregivers do not get enough rest which can negatively affect their health. These negative effects may in turn cause the relationship in the family to worsen and cause conflict among members of the family (Pattaravanich & Poomsaitong, 2009). This conflict may lead to abuse or negligence of the elderly causing the elderly to feel powerless and depleted of self-worth (Lertrat, 2008). Despite their love and concern, family caregivers are undoubtedly faced with serious problems in caregiving for dependent elders, including health problems and declining physical function compounded by psychological and social changes (Yodpetch, 2004; 2006). Moreover, confronting the problems of family caregivers

becomes a complicated process of either solving or supporting decisions regarding caregiving. The complications associated with family caregiving result in escalating family expenses with impacts on family lives as family capacity for caregiving diminishes (Yodpetch, 2004; 2006). Eventually, family caregivers discover themselves unable to devote more time to caregiving for dependent elders in line with Thai cultural and social roles. Therefore, caregiving capability further declines, especially in terms of essential knowledge and skills for caregiving assistance (Yodpetch, 2006). The findings of Yodpetch (2004, 2006) in studies on the care of dependent elders discovered family caregivers to have deficient caregiving knowledge and skills with no effort in procuring equipment and problems with proper caregiving management.

Caregivers of elders or persons with chronic diseases will have reduced caregiving capacity due to care burdens, the illnesses of care recipients and poor relationships during care. Snyder (2000) studied the impacts of caregiving in terms of burdens and satisfaction in the care of dependent elders in a qualitative study by interviewing caregivers from ten families. According to the findings, as many as four families were found to have conflicts between caregivers and the elderly, poor intrafamilial relationships, failures to speak to one another every day and no intimacy or closeness with one another. Furthermore, elders felt themselves to be a burden. Families with good, quality relationships help caregivers and elders participate in jointly setting goals until caregivers and elders are able to help or perform various activities. Families with this problem have increased care burdens consequently resulting in reduced selfcare ability. This finding concurred with the study of Kim, Chang, Rose & Kim (2012) who studied the predictors of caregiver capacity in terms of various aspects toward assessing function and burdens in providing care for dementia patients. According to the findings, personal factors and the illness influenced the care burden at 16%. Hence, caregivers' capacity for providing care also diminished. Moreover, caregivers who were not ready to provide care in terms of finance or care-related expenses have lower capacity to provide care for elders (Bambara, Owsley, Wadley, Martin, Porter, & Dreer, 2009).

Caregivers with poor caregiving capacity or ability will provide care with poor quality. Quality of care includes structure, process and outcomes (Donabedian, 2003), meaning capabilities with maximum benefit for the situation which can occur effectively. Quality of care for dependent elders is a result of the care provided by caregivers. Caregivers who are unable to provide care for dependent elders will have negative outcomes resulting in impacts on care and poor quality of care. In addition, promoting good family capacity has been found to have a positive effect on quality of care (Mok, Chan, Chan & Yeung, 2002: Shyu, Kuo, Chen & Chen, 2010). According to the study of Zahid & Ohaeri (2010) on correlations among caregiver burden and quality in one hundred and twenty-one psychiatric patients in Middle Eastern countries, most caregivers (73.5%) were found to be confronted with high to highest care burdens, despite playing roles indicating normal caregiving capacity. Hence, caregivers were found to have reduced care ability and quality of life. This finding concurred with the study of Smith, Williamson, Miller & Schulz (2011) who studied the correlations between stress, depression and care quality in three hundred and ten caregivers. According to the findings, stress stemming from acceptance of care burdens in terms of physical condition, activities patients were unable to perform and caregivers' necessity to assist and perform activities on behalf of patients such as daily activities, including the management of changing behaviors, caused caregivers to have higher level of stress leading to greater risk for depression and decreased quality of care.

Caregivers with good ability to care for elders or chronic disease patients can be seen to create good care quality. Dependent elders or elders with chronic illnesses requiring care will receive care from individuals, families and communities together with support in terms of basic needs involving environmental, physical, health and psychological aspects with meeting respect and economic needs (Phillips & et al., 1990a; 1990b). Caregivers who are unable to provide good care will have a negative impact on the quality of care. Therefore family caregivers need to be strengthened their caregiving ability by promoting capacity building in caregiving for dependent elders (Yodpetch, 2004; 2006) by improving knowledge and training caregiving with family nurses or community nurses (Lertrat, 2008).

The concept of family empowerment, proposed by Hulme in 1999, encourages the family to be able to face the challenge of caregiving for the elderly with chronic illnesses. It is composed of four phases including the professional-dominated phase in which the family is dependent on healthcare professionals, the participatory phase where the family shares decision making with healthcare professionals, the challenging

phase in which the responsibility is mostly transferred to the family and the collaborative phase in which all members of the family contribute to care. This concept helps the family collaborate with the healthcare professionals and take great responsibility of patient care. It also improves the family's knowledge and skill which would improve patient care (Wuest & Stem, 1991). Family caregiver capacity building can be applied to help develop people, family members, and healthcare professionals including children, adults, the elderly and the caregiver and improve the relationships in the family, increase awareness of their own ability, have self-worth, improved skills and knowledge which translates to better patient care (Li, Melnyk, McCann, Chatcheydang, Koulouglioti, Nichilas, et al., 2003; Sahar, Courtney & Edwards, 2003; Shyu, Kuo, Chen & Chen, 2010).

The care ability for the dependent elderly reflects the acceptance of the role of caregiving by the caregiver through a process of learning, understanding and giving appropriate care such as hygiene, feeding, dressing, mobility and toileting. Family caregiving also involves social aspects such as shopping, preparation of meals, telephoning, use of money, aid in participation in religious ceremonies, healthcare and coordination with a healthcare professional (Lertart, 2008; Mok, Chan, Chan & Yeung, 2002; Li., et al., 2003; Sahar, Courtney & Edwards, 2003; Chaoniyom, Suwannapong, Howteerakul & Pacheun, 2005). Moreover, capacity building affects the quality of care for the elderly. The quality of care can be structure, process or result. In terms of process, quality of care means quality of activities of care covering the environment, physical, psychological, economical aspects as well as respect towards the elderly person themselves (Phillips & et al., 1990a; 1990b). Family capacity building has been found to improve care for the dependent elderly (Mok, Chan, Chan & Yeung, 2002: Shyu, Kuo, Chen & Chen, 2010). If the caregiver lacks the knowledge and understanding of the process of care for the elderly and if they cannot access supporting resources, it could adversely affect the quality of care (Kelly, Buckwalter, & Maas, 1999). The family should be encouraged to improve their knowledge and skills of caregiving with emphasis on the needs of the caregiver, the role in the family of other family members and the available resources (Given, Sherwood & Given, 2008). For the caregiving to be adequate, the caregiver must be evaluated for their knowledge by healthcare professionals in various aspects including wellness of caregiving, caregiving of mastery, self-efficacy, competency and preparedness all of which would lead to the ability of care even in complex situations (Schumacher, Stewart, Archbold, Dodd & Dibble, 2000). Caregiving for dependent elders depends on assistance from other persons and management training for the caregiver enhances the knowledge and understanding, and training for a particular skills in caregiving with family caregivers, and creating cooperation with all sectors within community organizations (Foundation of Thai Gerontology Research and development, 2009).

The previous studies concluded that problems of caregiving often result from limitation of time, economic resources, and that members of the family often have sandwich roles of caregiving in that they have to care for the elderly, and also their children. This leads to a diminished quality of care, and relationship problems (Lertrat, 2008; Chamrasrittirong & Choolert, 2009). The problem is tending to get worse. With the capacity building to care from the family caregiver reduced, family members lack knowledge and skills to care for the elderly (Kelly, Buckwalter, & Maas, 1999). This often leads to the family placing the burden of care on the healthcare system. The family caregivers are still the most important part of care for the elderly (Yodpetch, 2010). The family caregiver capacity building programs to aid the family in caregiving for the elderly by empowerment that we propose consist of giving knowledge to the family about elderly dependency and skills needed for care which will be delivered by a nurse in the form of learning activities and teaching. It emphasizes on the interaction between the elderly and the family caregivers which would facilitate participation of patient care, increase knowledge, the ability to care for the elderly and the ability to make decisions. This process consists of 4 steps. The professional-dominated phase is the first phase in which the community nurse or family nurse interacts with the family, suggesting and guiding adequate care for the dependent elderly. The next step is the participatory phase where the family begins to take part in the care. The challenging phase follows when most of the responsibilities are passed on to the family. The collaborative phase is when the family feels confident about their ability to deliver appropriate care. According to a review of literature, there has not been any householdbased empowerment program for family caregivers who provide care for dependent elders. Therefore this study is designed to evaluate the effect of family caregiver capacity building program within an empowerment concept on skills of the caregiver and quality of care for the dependent elders. This program will be beneficial to the elderly, family caregivers and their families so that they can deliver appropriate and adequate care. Healthcare professionals will also benefit since they can use the information to better plan strategies of care and will ultimately increase the knowledge of nursing care for the elderly and help facilitate care for the dependent elders.

#### **Research Objectives**

The purpose of this research project was to examine the effects of the family caregiver capacity building program. The specific objectives were:

1. To compare care ability between family caregivers receiving the family caregiver capacity building program and those who do not receive the program.

2. To compare quality of care between family caregivers receiving the family caregiver capacity building program and those who do not receive the program.

3. To compare care ability of family caregivers between before and after receiving the family caregiver capacity building program.

4. To compare quality of care of family caregivers between before and after receiving the family caregiver capacity building program.

## **Research Hypotheses**

MAI UNIV 1. The family caregivers who receive the family caregiver capacity building program will have better care ability than those who do not receive the program.

2. The family caregivers who receive the family caregiver capacity building program will have better quality of care than those who do not receive the program.

3. Care ability of the family caregivers after receiving the family caregiver capacity building program is better than before receiving the program.

4. Quality of care of the family caregivers after receiving the family caregiver capacity building program is better than before receiving the program.

## Scope of the Study

The randomized control trial pretest-posttest control group design is aimed to investigate the effectiveness of the family caregiver capacity building program on care ability and quality of care of dependent elders covering both urban and rural areas in Bang Pa-In district, Phra Nakhnon Si Ayutthaya province from November 2013 to May 2014.

## **Definition of Terms**

Family caregiver capacity building program refers to the activities designed to enhance capacity of family caregivers of the dependent elders in order to improve care ability and quality of care. The program was developed by the investigator based on the family empowerment model of capacity building of Hulme (1999) including four phases: 1) Professional-dominated phase: activities include individual and group education to build trust by creating rapport with the families and establish a direct relationship with the family caregivers, helping the family to determine and set priority, provide accurate and complete information, and supporting setting goals. It aims to improve knowledge regarding family caregiving for the dependent elders of family caregivers. Those activities were applied for 2 weeks, 2) Participatory phase: activities include group and individual demonstration of family caregiving skills including dayto-day activities, illness-related care, care management and invisible care. It was applied for 2 weeks, 3) Challenging phase: strategies include peer support group, reinforcing the family's ability to identify choices in health care to expand its sort of alternate possibilities, and discuss with the family caregivers in which works in the system and building skills in negotiating with health professionals by using role play. Those strategies were applied for one week, and 4) Collaborative phase: strategies include acknowledging family caregivers for good care provided to the dependent elders by home and telephone visit. Strategies were applied for one week.

**Care ability** refers to the capacity of caregivers to provide care for dependent elders consisting of the ability to provide physical, psychological, social and environmental care. It was measured by the Caregiver's Care Ability Scale modified from the Ability of Care for Older Persons with Alzheimer Scale developed by Pukdeeporm (2005).

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Quality of care refers the extent to which care activities provided to dependent elders improve desired outcomes including environmental, physical, medical management, psychological, human rights and financial aspects. It was measured by the QUALCARE scale developed by Phillips et al. (1990a, 1990b).

**Dependent elders** are persons aged 60 years and over who require regular assistance in performing basic activities of daily living that is essential for staying alive such as eating, dressing, bathing, toileting, movement in the house and activities outside the house are included in this measurement. The score of each activity will be assigned due to the level of ability to perform of the respondent physical dependency. It was measured by the Dependency Screening Tool for Village Health Volunteers developed by Pothiban, Vathisunthorn and Panuthai (2010).

**Family caregiver** is a spouse, adult, children, or other relatives who has a personal relationship with, and provides a wide range of unpaid assistance for the dependent elders without pay or financial compensation.



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