



ปัจจัยที่มีอิทธิพลต่อภาระการดูแลในญาติผู้ดูแลผู้ป่วยโรคหลอดเลือดสมอง
FACTORS INFLUENCING BURDEN AMONG STROKE FAMILY
CAREGIVERS

SUNEERAT BOONSIN

Burapha University

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FACTORS INFLUENCING BURDEN AMONG STROKE FAMILY
CAREGIVERS



SUNEERAT BOONSIN

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THE REQUIREMENTS FOR DOCTOR OF PHILOSOPHY
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Family caregivers play important roles in helping stroke survivors in all aspects of their lives. New caregivers report difficulty adjusting to new roles, duties, and responsibilities. The purpose of this study was to test a causal model of burden among family caregivers who were taking care of stroke survivors during the first six months after stroke. A convenience sample was used to recruit 200 family caregivers of stroke survivors in Saraburi and Phra Nakhon Si Ayutthaya hospitals. Research instruments were a demographic survey of stroke caregivers and patients, the Zarit Burden Interview, the Health Perception Scale for Thai adults, the Barthel Index, the General Perceived Self-efficacy Scale, the revised Multidimensional Scale of Perceived Social Support, and the World Health Organization Quality of Life-BREF. AMOS software was used to test the Structural Equation Model [SEM].

The findings showed that caregivers reported mild burden ($M = 29.89$, $SD = 12.50$). The model of caregiver burden showed that functional status of patient, hours of caregiving, duration of caregiving, and self-efficacy had direct effects on caregiver burden. Moreover, functional status of patient had an indirect effect on caregiver burden through hours of care and self-efficacy. Duration of caregiving had an indirect effect on caregiver burden through self-efficacy. The total variance explained was 39% ($R^2 = .39$). Additionally, a model of caregivers' Quality of Life [QOL] revealed that caregiver burden and self-efficacy had direct effects on caregivers' QOL. Self-efficacy had an indirect effect on caregivers' QOL through caregiver burden. The model explained 37% ($R^2 = .37$) of the variance in caregivers' QOL.

The findings suggest that nurses can reduce stroke family caregiver burden by assessing stroke survivors' functional status prior to discharge and by ongoing assessment and enhancement of caregiver self-efficacy.

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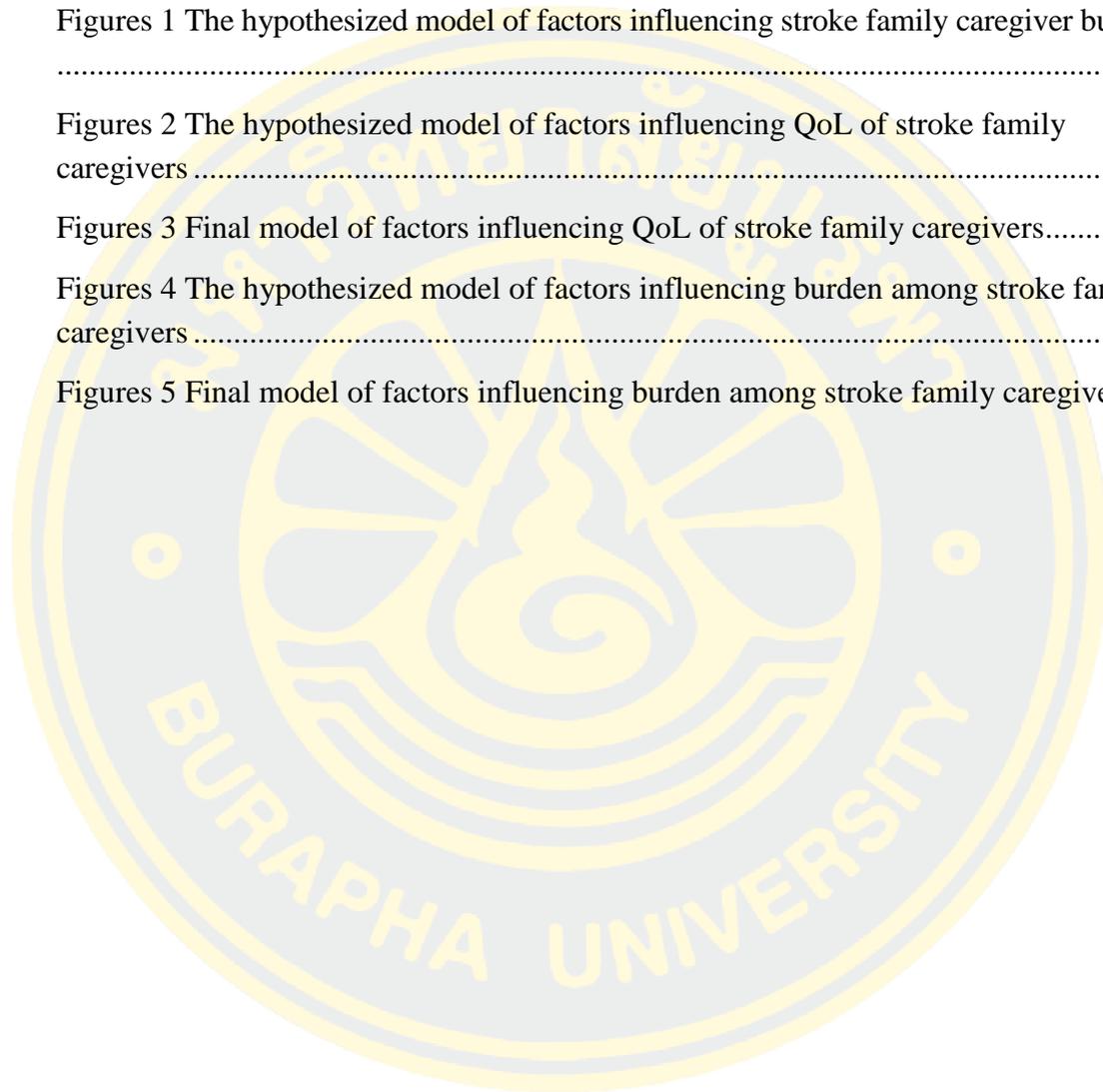
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CHAPTER 1

INTRODUCTION

Statements and significance of the problems

Stroke is a chronic health problem that results in disability and an increased mortality rate. The World Health Organization estimates there were more than 15 million stroke patients worldwide and that the prevalence of stroke will double by 2020 (Thai Stroke Society, 2017). In Thailand, the Thai Stroke Society (2017) projects that there will be 150,000 new cases diagnosed each year. The effects of surviving a stroke include hemiparesis, language and speech disorders, memory loss, sensory impairment, difficulty swallowing, dizziness, fatigue, and other physical, mental, and emotional deficits (Fizsimmons & Lazzaro, 2012). Even when neurological symptoms and vital signs come stable, stroke patients frequently experience some functional impairment (Winstein et al., 2016). Two studies of Asian families have shown that following hospitalization (Kim, Hwang, Oh, & Kang, 2013; Somotun, Osungbade, Akinyemi, Obembe, & Adeniji, 2017) stroke patients may be cared for by their families at home or by other caregivers who are close to the family, though most survivors of stroke did not fully recover and had permanent limitations.

Stroke patients may be rehabilitated at home. Coccia and Provinciali (2017) stated that in the acute phase, or in the first three months after the initial cerebrovascular accident [CVA], stroke patients could experience dysphagia, malnutrition, and dehydration. Half of all stroke patients during this phase may not be able to walk and require gait assistance or training. Saha et al. (2018) reported that most stroke survivors were significantly disabled one month after the stroke had occurred. In the sub-acute phase, lasting from 10 weeks to six months post-CVA, dementia (Winstein et al., 2016) and depression (Karube et al., 2016) were common outcomes. Stroke survivors had difficulty with the ability to move and with personal care, including performing activities of daily living [ADL] because their upper and/or lower limbs were spastic and stiff. In the chronic phase, lasting more than six months post-CVA, many survivors remain disabled and needed help with ADLs (Karube et al., 2016).

The caregiver is a key person to help stroke survivors in all aspects of their lives. There are two types of caregivers, formal and informal. Both formal and informal caregivers have the responsibility for taking care of the physical, emotional, and financial support of those who have a stroke, who were unable to take care of themselves because of their disabilities (National Alliance for Caregiving, 2010). Informal caregivers are usually family members who take care of close relatives without payment, whereas formal caregivers refer to those who are trained and paid for their services (Reinhard, Given, Petlick, & Bemis, 2008). In Thailand, it is a social norm for families to take care of their close relatives who have a stroke rather than hire external caregivers.

Family caregivers are usually unprepared to assume the role of caregiver because strokes occur suddenly and often without warning. Therefore, many families experience difficulty in adjusting to their new roles, duties, and responsibilities (Limpawattana, Intarasattakul, Chindaprasirt, & Tiamkao, 2015). Giving care to stroke survivors is highly demanding, such as giving hygiene care, administering medications, monitoring health and illness, planning social services, and managing finances (Asiret & Kapucu, 2013; Lai, 2012; Lutz, Young, Cox, Martz, & Creasy, 2011). Several studies indicate that family caregivers of stroke survivors are overwhelmed, exhausted, isolated from social networks, lack self-care; experience anxiety, stress, depression; and participate less in social activities (Andrew, Kilkenny, Naylor, Purvis, & Cadilhac, 2015; Asiret & Kapucu, 2013; Chuluunbaatar, Chou, & Pu, 2016; Dong et al., 2017; Rodriguez, 2017; Zhang & Lee, 2017). For families, the impact of informal caregiving can lead to caregiver burden and a lower quality of life [QoL].

Caregiver burden is experienced when family caregivers respond to stressful tasks and assume a major change in role (Zarit & Zarit, 2015). It is the most important negative outcome of taking care of stroke survivors. Caregiver burden can take the form of objective burden and subjective burden (George & Gwyther, 1986; Montgomery, Gonyea, & Hooyman, 1985). Objective burden refers to the tasks of giving care, the time family caregivers devote to assisting stroke survivors, and the changes in leisure, work, and social involvement. Subjective burden also refers to the feelings or emotions that family caregivers experience in dealing with objective

stressors (Sales, 2003). In this study, the researcher focused on subjective burden. Family caregivers might perceive the burden differently, depending on the stroke survivor's condition, the caregivers themselves, and the context of care.

Several studies had reported on the burden that caregivers experienced with stroke survivors. Limpawattana et al. (2015) found that 45.5% of Thai stroke caregivers reported mild to severe burden. Kunyodying, Pothiban, and Khampolsiri (2015) found that 40% of older caregivers of stroke survivors perceived high levels of burden, 36.67% reported mild subjective burden. Jaracz, Grabowska-Fudala, Gorna, and Kozubski (2014) also found that 47% of caregivers of stroke survivors experienced a moderate or severe burden six months after the patient's hospitalization. Gbiri, Olawale, and Isaac (2015) stated that 79.2% of informal caregivers of stroke survivor reported mild subjective burden.

Furthermore, stroke has a great impact on the quality of life of patients and their family caregivers. Not only the patients but also their caregivers need professional attention and support in order to maintain their QoL (Opara & Jaracz, 2010). The burden of giving care can impact the QoL of family caregivers. Researchers have reported that family caregivers rate their quality of life moderate to fairly well (Akosile, Okoye, Nwankwo, Akosile, & Mbada, 2011; Caro, Costa, & Da Cruz, 2018; Chuluunbaatar et al., 2016). Family caregivers have to support stroke survivors during the time of illness; thus, the negative outcome affects their quality of life. Several studies have found a negative relationship between family caregiver burden and QoL of stroke caregivers (Kumar, Kaur, & Reddemma, 2016; Ogunlana, Dada, Oyewo, Odole, & Ogunsan, 2014; Tsai, Wu, Hung, Chou, & Su, 2016). Their results cover four domains of QoL: physical, psychological, social, and environment and one study showed that the psychological domain was the most affected (Rawat, Sharma, & Goel, 2017). Most of literature reviews examined effect of family caregiver burden on their QoL. However, it remains question QoL of caregivers might impact to caregiver burden.

Several factors are known to be related to stroke caregiver burden and QoL of caregivers. These include the caregiver's age, their health, daily hours of care, duration of caregiving, functional status of the stroke survivor, duration of the stroke, self-efficacy, and social support (Gbiri et al., 2015; Han et al., 2017; Jaracz et al.,

2014; Kruithof et al., 2016; Tosun & Temel, 2017; Vincent-Onabajo, Ali, & Hamzat, 2013). Factors that relate to the tasks of giving care were the chronicity of the stroke patient condition, and the survivor's progressive impairment. Other factors are the characteristics of the caregiver and the environmental context that might lead to stress and affect an individuals' well-being (Pearlin, Mullan, Semple, & Skaff, 1990). These factors influence the direct and/or indirect effects of caregiver burden, as well as the interactions that occur among them.

Functional status of stroke survivors has been found to influence caregiver burden directly and indirectly (Kamel, Bond, & Froelicher, 2012). Gorgulu, Polat, Kahraman, Ozen, and Arslan (2016) showed that 41.3% of stroke survivors were dependent on others for assistance and 23.8% of them were severely dependent. Stroke survivors relied on family caregivers, and their demand for help depended on functional status (Hilton, Mudzi, Ntsiea, & Olorunju, 2013). Assistance with activities of daily living included bathing, feeding, dressing, getting on and off the toilet, positioning, and moving from bed to wheel chair (National Alliance for Caregiving, 2010). Ogunlana et al. (2014) found caregivers experienced high levels of strain when providing care to stroke survivors who had lower functional status. Family caregivers experienced lower burden when caring for stroke survivors who had good functional status (Asiret & Kapucu, 2013). Functional status of the stroke survivor was the key determinant of caregiver burden (Badaru, Ogwumike, Adeniyi, & Nelson, 2017). The more dependency that stroke survivors experienced, the more difficult it was for caregivers to perform care (Pearlin et al., 1990). The levels of dependency and difficulty in providing care required time and effort from caregivers, leading to caregiver burden (Greenwood, Mackenzie, Cloud, & Wilson, 2008; Kamel et al., 2012; McCullagh, Brigstocke, Donaldson, & Kalra, 2005). Moreover, stroke survivors who had more disability was found to be influenced on the QoL of caregivers (Badaru et al., 2017; Ogunlana et al., 2014).

The duration of stroke affects the family's caregiver burden. At the early stage of stroke, family caregivers may experience high levels of burden (Gbiri et al., 2015) because of the sudden, unexpected change in roles. They experience stressful conditions, leading to burden. However, after a long duration following a stroke,

caregiver burden may decrease because the functional status of the patient improves with adaptation.

The age of caregivers of stroke survivors is also related to burden (Han et al., 2017). Younger caregivers may experience an increase in caregiver burden (Bhattacharjee, Vairale, Gawali, & Dalal, 2012). However, Jaracz et al. (2014) and Kruithof et al. (2016) reported that the age of most family caregivers was about 60 years old and they had developed their own chronic diseases. Older family caregivers have more difficulty maintaining their health than those who are younger because older caregivers often experience their own physical and functional health decline (Han et al., 2017; Watanabe et al., 2015). In other words, health often gets worse with age.

Family caregivers' health status can be affected because of caregiver burden. They often face physical, social, and psychological problems as they give care to a family member. Several studies have reported that family caregivers suffer from hypertension (48.9%), disc herniation (38.3%), difficulty sleeping and headaches (33.3%) (Asiret & Kapucu, 2013; Pesantes, Brandt, Ipince, Miranda, & Diez-Canseco, 2017), and weakness and emotional distress (Rodriguez, 2017). Chou (2000) and Jaracz et al. (2014) found that caregivers in existing poor health had an even higher burden than those in good health. Asiret and Kapucu (2013) showed that nearly half of family caregivers (47.8%) claimed their health problems were associated with their caregiving duties. Hanh, Jullamate, and Piphatvanitcha (2017) found that caregiver's general health perception was negatively related to caregiver burden. Furthermore, giving care to assist stroke survivors continuously may lead to health problems, such as exhaustion and fatigue. Family caregivers who face exhaustion and fatigue will experience increased levels of burden (Asiret & Kapucu, 2013).

The number of hours in providing care to stroke survivors has been associated with family caregivers' burden. Bhattacharjee et al. (2012) and Gbiri et al. (2015) found that long caregiving hours each day increased the level of burden that family caregivers experience over time. Many studies have reported that the time required to take care of stroke survivors was between 8-15 hours each day. For example, Yu, Hu, Efird, and McCoy (2013) found that over half of the caregivers (52.1%) spent more than eight hours a day taking care of the stroke survivors. Asiret

and Kapucu (2013) found that caregivers provided 13.5 hour each day. In addition, Rawat et al. (2017) found that more half (56.67%) of stroke caregivers expressed severe burden while providing continuous care to stroke survivors. The number of hours of caregiving for stroke survivors was a determinant of caregiver burden because of the decrease in leisure time and reduced social activities (Hanh et al., 2017; Kamel et al., 2012).

The duration of caregiving has been associated with caregiver burden. Most studies have reported that the majority of caregivers had been giving care to the stroke survivor from one to five years (Asiret & Kapucu, 2013; Tosun & Temel, 2017). The duration or length of time giving care was found to be related to caregiver burden (Asiret & Kapucu, 2013; Chang, Chiou, & Chen, 2010). Caregiver burden increased with longer care duration (Tosun & Temel, 2017). However, the level of burden of giving care to stroke survivors was found to be low in the one- to five-year period and highest after five years, if the stroke survivors were still needing care because of their disabilities (Asiret & Kapucu, 2013; Tosun & Temel, 2017). The burden increased for caregivers over time because of the difficulty in moving survivor's large muscles and developing health problems (Tosun & Temel, 2017; Unuigbo, Lee, Vaughn, Kaufman, & Gallo, 2017).

Self-efficacy of family caregivers has been associated with caregiver burden. Family caregivers often have to provide unanticipated care for stroke survivors without nursing knowledge and preparation. Hence, the situation leads to stress and burden. Several studies have reported that perception of strong self-efficacy among caregivers could promote coping with the negative consequences of caregiving (Kruithof et al., 2016). Family caregivers with high self-efficacy set higher goals for themselves, devote more energy, and persist longer than those with lower self-efficacy, thus they experience a lower burden (Kruithof et al., 2016). Caregivers with high self-efficacy tend to be able to deal more readily with caregiving stress and tasks (Hu, Dolansky, Hu, Zhang, & Qu, 2016). Moreover, greater perceived self-efficacy has been associated with a better QoL for caregivers (Warapornmongkholkul, Howteerakul, Suwannapong, & Soparattanapaisarn, 2018).

Social support also has a strong association with caregiver burden. It has been shown to be a major source of assistance to help caregivers cope with the

challenges they face. Social support is a significant factor assisting caregivers to maintain good physical and mental health while caring for a family member (Adzovie, 2016). In one study, family caregivers of stroke survivors reported a moderate level of social support from families, friends, and significant others throughout a six-month period (Hanh et al., 2017). Rodriguez (2017) found that high social support might be the strongest factor in protecting caregivers against burden. Conversely, low social support has been shown to increase the burden of family caregivers of stroke survivors (Olai, Borgquist, & Svärdsudd, 2015; Tosun & Temel, 2017). Burden might be decreased when family caregivers share the responsibilities of caregiving with others or when caregivers receive support from families, friends and significant others. Moreover, better social support may be attributed to an increase in self-efficacy of family caregivers to provide care for stroke survivors and lead to a decreased level of caregiver burden.

According to Roland and Chappell (2017), caregiver burden is considered a negative outcome of caregiving. The burden of giving care by families of stroke survivors is influenced by the interaction of caregiver characteristics, stressors, and social support. The caregiver's older age, poor health, long duration of time in caregiving, and long hours of care were characteristics that had a direct effect on high caregiver burden. Stroke family caregivers who were older had higher caregiver burden and lower QoL because older family caregivers had more physical health problems than younger family caregivers (Watanabe et al., 2015).

Primary stressors that have a direct effect on high caregiver burden include the low functional health status of stroke survivors and a short duration of stroke. Hence when stroke survivors have a low functional health status, family caregivers spend more time in taking care of them with an increased effort in assisting them, leading to higher caregiver burden. Thus, family caregivers perceive that they not only have a higher burden but also have a lower QoL (Ogunlana et al., 2014). Higher self-efficacy has a direct effect on lowering caregiver burden. Good social support has a direct moderate effect on caregiver burden and indirectly provides a buffer from negative effects of caregiver's health and self-efficacy. Moreover, stroke family caregivers who experience a high burden of care also perceive a low QoL (Ogunlana et al., 2014).

In summary, several factors directly and indirectly influence caregiver burden and QoL of caregivers. Caregiver's age directly affects caregiver burden and indirectly affects burden through caregivers' health. Functional health status of stroke patient directly affects caregiver burden and also indirectly affects caregiver burden through the hours of care. When the hours of care lengthen, the burden increases (Asiret & Kapucu, 2013). Self-efficacy of family caregivers directly affects caregiver burden and QoL of caregivers. Social support directly affects caregiver burden and QoL of caregivers and also social support indirectly affects caregiver burden and QoL of caregivers through self-efficacy of caregivers. Moreover, caregiver burden directly affects QoL of caregivers. As stated above, it should be done by examining the complex relationships among these variables.

There are several limitations of the previous studies, such as duration of care following a stroke, methodology, and cultural context. First, most studies on caregiver burden investigated providing care for long periods of time, such as two months to five years after post-CVA. According to Coccia and Provinciali (2017), the more highly stressful time of family caregiver usually occurs six months after a stroke or between the acute and sub-acute phases. During this time, stroke survivors face problems associated with functional status and psychological impairment. Consequently, family caregivers need to adapt to new changing roles. Few studies, however, have focused on the burden of stroke family caregivers during the acute or sub-acute stroke phase. Second, most research studies have focused on relationships between influencing factors and burden separately at the simplest level but few studies have evaluated simultaneously the relationships between influencing factors and burden in a more complicated model.

Finally, most published studies had been conducted in Western countries where the responsibilities for chronic illness shifts to nursing homes or similar facilities. However, Thai culture had collectivism as a social norm. Taking care of a person with a chronic illness, such as a stroke, is the responsibility of the family and care shifts to the home or home ward. Therefore, family caregivers assume an important role in caring for stroke survivors. People in differences cultures may have different perceptions of burden. Although the results of several studies in Thailand

have described, explained, and predicted family caregiver burden, some of these studies focused on burden among older family caregivers.

Therefore, the purpose of this study was to test a causal model of burden of family caregivers who were taking care of stroke survivors during the first six months after a stroke. It is anticipated that the findings from this study will contribute to a greater understanding of the complexity of care required of stroke caregivers and lead to developing appropriate interventions to decrease the burden of care and enhance their QoL.

Research objectives

The objectives of this study were:

1. To describe the level of burden among family caregiver of stroke patients
2. To examine the causal model of caregiver's age, caregiver's health, functional status of patient, duration of stroke, hour of caregiving, duration of caregiving, self-efficacy, and social support on caregiver burden and quality of life.

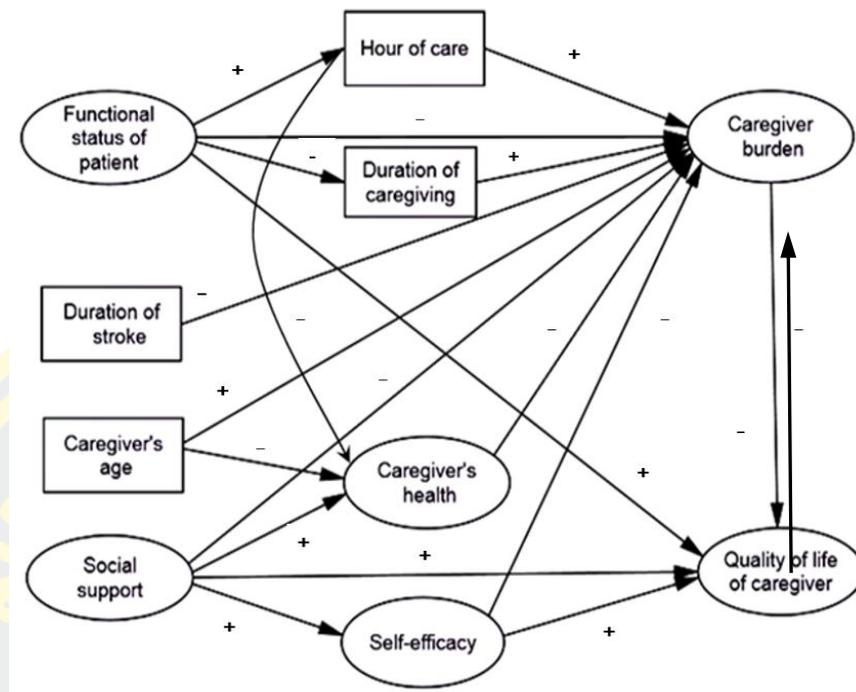
Research hypotheses

1. Family caregiver's age, family caregiver's health status, functional status of patient, duration of stroke, hour of caregiving, duration of caregiving, self-efficacy, and social support had direct effect on family caregiver burden.
2. Functional status of patient, family caregiver burden, self-efficacy, and social support had direct effect on QoL of caregiver.
3. Functional status of patient had indirect effect on family caregiver burden through hour of care, duration of caregiving.
4. Caregiver's age had indirect effect on family caregiver burden through caregiver's health status.
5. Social support had indirect effect on family caregiver burden through caregiver's health status and self-efficacy.
6. Hour of caregiving had indirect effect on caregiver burden through family caregiver's health status.

Conceptual framework

The conceptual framework that guide this study is the Modified Stress Process Model (Roland & Chappell, 2017) because many components of the caregiving environment are related to caregivers' experiences of burden. There are four core components in their model including characteristics of the caregiver, primary stressors and secondary stressors, moderator, and outcomes. Caregiver burden as an outcome of caregiving is affected by the interaction of these components. According to their model, outcomes are influenced directly by caregiver characteristics, primary and secondary stressors. Moreover, outcomes are indirectly influenced by moderator. However, moderator has directly moderate caregiver burden, as well as indirectly provide a buffer from the negative effects of stressors.

In this study, it was hypothesized that burden would be influenced by factors related to caregivers and stroke survivors. Burden was potentially influenced by key characteristic of the caregiver including caregiver's age, caregiver's health status, hour of caregiving, and duration of care giving. These factors were expected to be directly affecting the level of burden (Asiret & Kapucu, 2013; Jaracz et al., 2014; Jeong, Jeong, Kim, & Kim, 2015; Kruithof et al., 2016). As specified by the Modified Stress Process Model, primary stressors for caregivers were the functional status of stroke patient and duration of stroke. Stroke patients often had limited functional status. Thus, stroke patients needed more hours for providing care. Family caregivers spent more time took care with a longer duration of care until the functional status of stroke patients improve. This led to an increase in caregiver burden (Gorgulu et al., 2016; Jaracz et al., 2014; Kamel et al., 2012; Ogunlana et al., 2014). Moderator were self-efficacy and social support. Self-efficacy referred to caregivers' confidence in their ability to carry out self-care activities which directly affect the caregiver burden. Self-efficacy might be decreased when family caregivers encountered the stressors, thereby increasing their level of caregiver burden. Social support had directly lower the level of burden. Moreover, caregiver's age, functional status of patient, caregiver burden, and social support were directly affect quality of life. In summary, burden among family caregiver of stroke patients as shown in Figure 1.



Figures 1 The hypothesized model of factors influencing stroke family caregiver burden

Scope of the study

This study tested model of burden among family caregiver of stroke patients. The settings were at Out Patient Department in Saraburi hospital and Phra Nakhon Si Ayutthaya hospital. Data were collected from 200 stroke family caregivers. The period of collecting data were from January to June, 2019.

Definition of terms

Stroke family caregiver referred to family caregiver providing direct care for feeding, bathing, grooming, dressing, bowels, bladder, toileting, transfers, mobility, and stair to stroke survivors most of the time.

Caregiver burden referred to stroke family caregiver perceive related to impact of care giving process for stroke patients in four domains: personal strain, privacy conflict, guilt, and uncertain attitude. It was measured by Zarit, Reever, and

Bach-Peterson (1980) and translated into a Thai version by Toonsiri, Sunsern, and Lawang (2011).

Quality of life referred to stroke family caregivers perceive of satisfaction in all four aspects of their life, including physical, mental, social, and environment. The quality of life was measured by the World Health Organization Quality of Life [BREF] developed by World Health Organization [WHO] (2004), and translated into a WHOQOL- BREF-THAI Version by Department of Health, Ministry of Public Health, Thailand

Functional status of patient referred to ability of stroke patients to perform activities of daily living such as feeding, bathing, grooming, dressing, bowels, bladder, toileting, transfers, mobility, and stair. It was measured by Barthel Index [BI] developed by Mahoney and Barthel (1965) and translated into Thai by Department of Health, Ministry of Public Health, Thailand.

Duration of stroke referred to the number of months or year of the patient had suffered stroke. It was measured by self-report duration of stroke in month or year.

Caregiver's age referred to age of caregiver. It was measured by self-report age in year.

Caregiver health status referred to stroke family caregivers perceive of their health status in the current, future and understanding of health. It was measured by Health perception scale for Thai adults [HPS-T] developed by Brook et al. (1979) and translated into Thai by Rojpaisarnkit (2001). It was included current health, health outlook, health concern, resistance or susceptibility to illness, health threat, and sickness orientation.

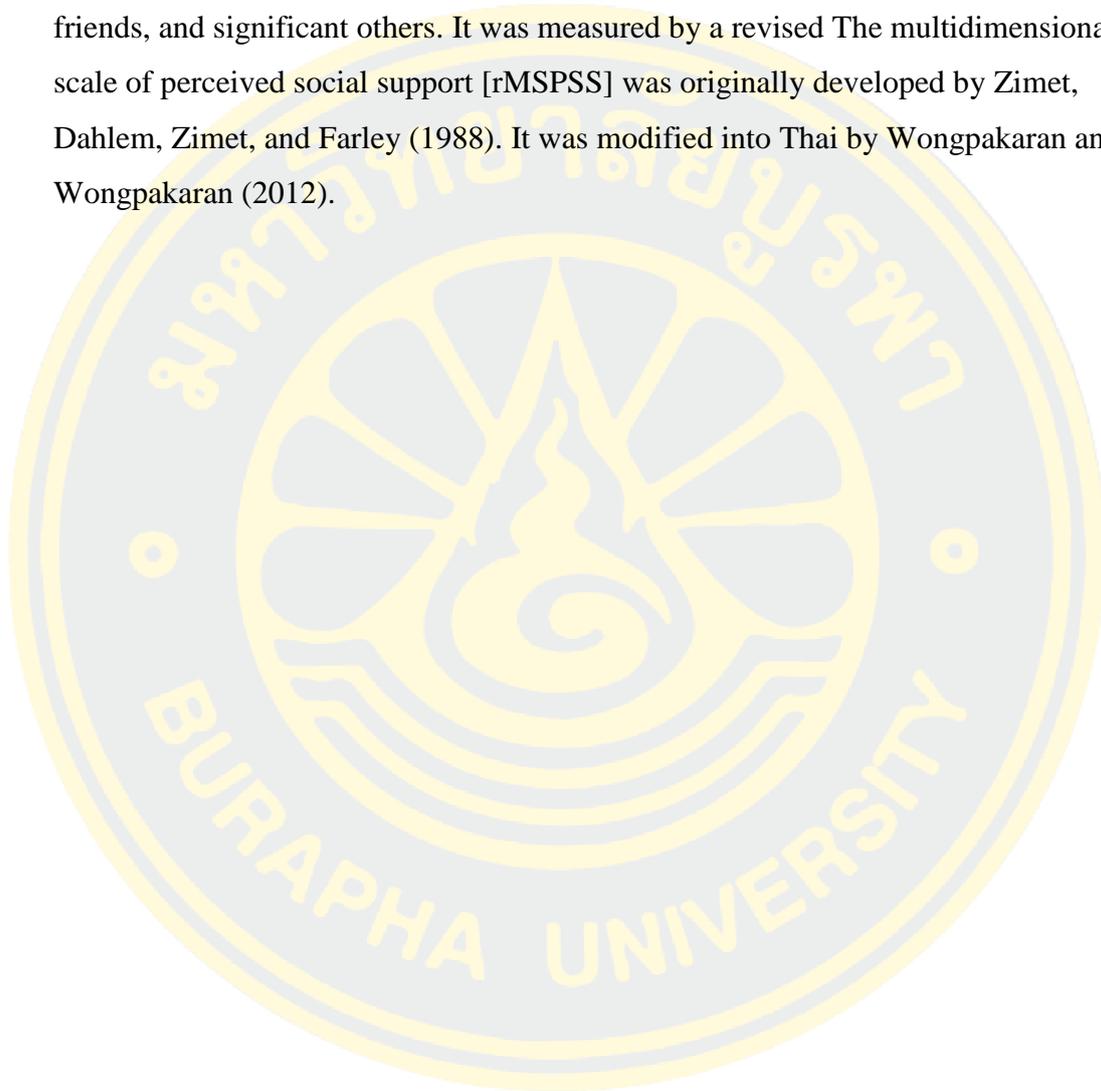
Hour of care referred to the number of hours per day for caring stroke survivors. It was measured by self-report hour of caregiving per day in hours.

Duration of caregiving referred to the year of the family caregivers had been caregiver for stroke survivors. It was measured by self-report duration of being caregiver in month.

Self-efficacy referred to family caregivers perceive related to confidence in their ability to manage problems successfully. It was measured by General Perceived

Self-efficacy Scale [GSES] developed by Schwarzer and Jerusalem (1995) and it was translated into a Thai version by Sukmak, Sirisoonthon, and Meena (2002).

Social support referred to family caregivers perceive related to social network or relationship provided by others that support related to family members, friends, and significant others. It was measured by a revised The multidimensional scale of perceived social support [rMSPSS] was originally developed by Zimet, Dahlem, Zimet, and Farley (1988). It was modified into Thai by Wongpakaran and Wongpakaran (2012).



CHAPTER 2

LITERATURE REVIEWS

This chapter describes a review of related literature. The first part is stroke and stroke survivors. The second part describes family caregiver and family caregiver' responsibilities. The third part presents impacts of stroke on family caregivers, family caregivers' burden, and theory guide for the model of stroke family caregiver burden. The fourth part discusses about factors affecting burden of stroke family caregivers.

Stroke and stroke survivors

Stroke is used to describe brain injury caused by an abnormality of the blood supply to part of the brain (Caplan, 2006). Stroke occurs when nourishment and supply to the brain cells is decreased or interrupted. When a part of the brain does not receive adequate oxygen or glucose, brain cells begin to die and become unable to function normally (Caplan, 2006; Radaelli, Mancina, Ferrarese, & Beretta, 2017) in what is also known as a cerebral vascular accident [CVA] (Williams, 2010).

There are two major types of stroke, namely ischemic stroke and hemorrhagic stroke. Ischemic stroke is the most common type and occurs when a blood vessel to the brain is obstructed by a blood clot. There are two sub-classes of ischemic stroke: thrombotic, which happens when a thrombus forms in one of the arteries supplying blood to the brain. The second sub-class is embolic, which occurs when a blood clot or embolism forms in a different part of the body and is carried through the blood vessels, eventually plugging narrow brain arteries (Williams, 2010). A hemorrhagic stroke occurs when a blood vessel in the brain becomes weak and ruptures, causing blood to leak inside the skull, into the brain or into the fluid surrounding the brain (Caplan, 2006). Intracerebral hemorrhage [ICH] is a common brain injury due to hemorrhagic stroke (Silverman & Rymer, 2010). Both of these types of stroke are marked by several of symptoms, depending on the type of stroke and part of the brain affected (Caplan, 2006; UPMC, 2017).

In general, the incidence of ischemic stroke accounts for approximately 90% of stroke, whereas hemorrhagic stroke accounts for the remaining 10% (Aminoff, Greenberg, & Simon, 2015; Williams, 2010). A higher proportion of ischemic stroke in comparison to hemorrhagic stroke is found in 12 countries (13 regions) in Asia. According to a report of prevalence of stroke in northeast China by Zhang et al. (2017), 91.7% of all stroke patients have ischemic stroke and 8.3% have hemorrhagic stroke. In Thailand, ischemic stroke is the major type of stroke, while hemorrhagic stroke accounts for approximately 20% of all stroke cases (Suwanwela, 2014).

The prevalence of stroke has been estimated by World Health Organization (WHO) at more than fifteen million stroke patients worldwide with 150,000 new cases in Thailand each year (Thai Stroke Society, 2017). According to the latest WHO data published in 2017, stroke-related deaths in Thailand reached 55,319, or 11.04% of all deaths. The age adjusted death rate is 62.45 per 100,000 people (World Health Organization, 2017), and the prevalence of stroke increases with age (Zhang & Lee, 2017). Due to the aging population, the stroke rate doubles every 10 years in both males and females > 55 years of age with approximately two-thirds of all strokes occurring in persons aged ≥ 65 years) (Grotta & Lo, 2015; Radaelli et al., 2017). In Thailand, stroke is more prevalent in men than women (Areechokchai, Vjitsoonthornkul, Pongpan, & Maeakhian, 2017; Suwanwela, 2014) and the mean age of stroke onset is 65 years (Suwanwela, 2014). The highest prevalence of stroke is in Bangkok (3.34%), followed by the central (2.41%), southern (2.29%), northern (1.46%) and north-eastern regions (1.09%) (Hanchaiphiboolkul et al., 2011).

The risk factors for stroke can be divided into the following two categories (Seshadri & Wolf, 2016): 1) non-modifiable risk factors; in which it has been shown that risk factors differ between hemorrhagic and ischemic stroke. As previously mentioned, the incidence of stroke increases with age with approximately two-thirds of all strokes occurring in people older than 65 years. Age-adjusted stroke risk is somewhat higher in men than in women and African Americans > Hispanics > Caucasians; 2) modifiable risk factors include systolic or diastolic hypertension, atrial fibrillation, coronary heart disease, cardiac failure (Seshadri & Wolf, 2016), diabetes mellitus, dyslipidemia, obesity, obstructive sleep apnea syndrome and family history

of stroke (Aminoff et al., 2015). Moreover, environmental factors such as cigarette smoking, oral contraceptives, alcohol consumption, physical inactivity and diet (Seshadri & Wolf, 2016) are also modifiable risk factors.

Stroke survivors

After stroke, survivors are not able to perform usual functions (Fitzsimmons & Lazzaro, 2012). According to Nagi's disablement model, active injury is cerebral vascular and identified as a disruption to the integrity of physical mobility. Impairment or abnormality of an organ or system, such as diminished internal rotation range of motion, then occurs. Stroke patients have restrictions in performance related to social roles and normal daily activities. Finally, disability is defined as the inability of a person to fulfill his or her desired or necessary social or personal roles. Thus, stroke affects part of brain and leads to various types of dysfunction and disabilities (Aminoff et al., 2015; Caplan, 2006).

The most common consequence of stroke is motor dysfunction, which is referred to as decreased motion and movement of the limbs. After stroke, many stroke survivors are weak, stiff or unable to move a part of a limb which involved the arm, hand, leg, and foot on one side of the body. The term of one-sided weakness is referred to as hemiparesis. Motor abnormalities also frequently involve the structures of the mouth, throat and larynx muscles involved in speaking with low volume, handling food inside the mouth and difficulty swallowing. Moreover, cognitive and behavioral changes involve creating new memories, speaking, reading, writing and recalling the locations of objects and places. In addition, other dysfunctions and disabilities occur after stroke, including sensory dysfunction, abnormalities of interest in daily activities, planning, judgment and performance with difficulty expressing and interpreting emotions, visual abnormalities and urinary/ bowel dysfunctions (Aminoff et al., 2015; Caplan, 2006; Fitzsimmons & Lazzaro, 2012).

Rehabilitation can improve muscle movements after suffering a stroke and decrease the disability of stroke survivors. According to Coccia and Provinciali (2017), stroke rehabilitation is a dynamic pathway starting after symptom onset and accompanying patients in the care pathway until their return to community. There are three phases of post-stroke rehabilitation. In acute phase during the first three months, dysphagia is common following stroke and affects 13-94% of acute stroke patients.

Dysphagia is also associated with increased risk for aspiration pneumonia, malnutrition and dehydration. Early mobilization is perceived as one of the activities of acute stroke care that is responsible for good outcomes, because it reduces bedsores, orthostatic hypotension, deep venous thrombosis, pulmonary embolism and pneumonia. Thus, early mobilization during the acute phase significantly increases the 6-month survival rate. In the acute phase, approximately 50% of patients currently do not walk and 12% require walking assistance. The ability of stroke survivors to independently undertake ADL depends on the recovery of upper limb function. Approximately 70% of stroke patients suffer discomfort involving upper extremity [UE] impairment. Improved limb dexterity is scarce at 18%, 25% and 31% at 3, 6 and 12 months after stroke, respectively (Saha et al., 2018) reported the short term outcome of stroke at nearly 63.8% cases of ICH and 50% of infarctions were significantly disabled one month post-stroke.

The sub-acute phase has been defined as from 10 weeks to six months after stroke onset (Winstein et al., 2016), and post-stroke cognitive impairment is a common consequence following stroke. Prevalence data shows that 10% of patients already have dementia at the time of the stroke, while 10% develop dementia after the first stroke and 30% develop dementia after stroke relapse. The 3-month post-stroke rates of dementia vary from 6% to more than 30%. Percentages increase when non-dementia cognitive disorders are considered: 20-90% of stroke patients exhibit mild cognitive impairment at three months post-stroke. Physical defects in stroke survivors also cause psychological changes such as aggression, impatience, stress, negativism and depression. Depression is the most common psychological disorder reported in stroke survivors and might affect physiological defects (Karube et al., 2016). Post-stroke depression [PSD] has a cumulative incidence of up to 52% within five years after a stroke with a pooled prevalence of 29% that remains stable in the first 10 years after a stroke across different study settings. Most patients who have suffered depression after stroke become depressed shortly after the acute event.

Spasticity following stroke interferes with quality of movement and contributes to functional limitations in mobility, personal hygiene, comfort and many ADLs. Stroke patients with upper or lower limb spasticity have greater waste of energy, difficulty in positioning and using orthosis and splints with a higher risk for

developing joint stiffness, pressure sores and pain. Post-stroke pain [PSP] refers to a broad range of clinical conditions responsible for post-stroke pain, not only restricted to central post-stroke pain, which affects from 10 to 50% of patients. Shoulder pain is one of the most frequent manifestations of PSP and commonly affects 25-50% of stroke patients. Several studies have been conducted to investigate the outcome of stroke in stroke survivors. After stroke with hemiparesis, 60% of patients will develop joint contracture on the affected side within the first year with wrist contractures occurring most commonly in patients who do not recover functional hand use (Malhotra, Pandyan, Rosewilliam, Roffe, & Hermens, 2011; Sackley et al., 2008). Most stroke survivors at an average of 16 months post-stroke in South-Western Nigeria reported high prevalence of disability in ambulating/ mobility, self-care and life activities (Oyewole, Ogunlana, Oritogun, & Gbiri, 2016). In Thailand, Panidchakul and Boonsin (2013) found the major symptoms at more than one year post-stroke to be hemiparesis (100%), imbalance movement (39.8%), aspirate and constipation (20.4%), respectively.

The chronic phase is referred to as a period more than six months post-stroke. Occupational therapy can improve performance and reduce the risk for functional deterioration. At this time, the clear and correct identification of the following complications are crucial: pain, spasticity, dementia and depression. Karube et al. (2016) interviewed 53 stroke out-patients from several months to several years post-stroke who were visiting the Hirosaki Stroke and Rehabilitation Hospital. They found that a number of stroke patients remain disabled or unable to return to work or recover and need assistance in the activities of daily living [ADL]. Thus, these problems affect the quality of life of stroke survivors. Panidchakul and Boonsin (2013) studied quality of life in 103 community-dwelling stroke survivors in Thailand. They found that most stroke survivors perceived their overall quality of life at a moderate level (76.7%) based on physical function (61.2%); emotional (67%) social relationship and environmental aspects (53.4%) and conditions (49.5%). (Chuluunbaatar et al., 2016) revealed the changes in QoL of 155 first-time stroke patients in the first year after stroke. The stroke patients reported that QoL in the domains of physical and environmental aspects had improved significantly after one

year; however, social relationships and psychological health had declined, but the decline was not significant.

Stroke is a life-changing event that affects not only the survivor of the stroke, but also has great impact on family members and caregivers (Massaro, 2013). From the acute phase to the sub-acute phase post-stroke, family caregivers are more likely to provide more hours of care. Providing care during the first few months after stroke is stressful, and it is important to provide appropriate information and support.

Moreover, stroke caregivers are increasingly performing tasks similar to nurses (Happ, 2017), including personal care, dressing, tube feeding, catheter care and other complex responsibilities. Stroke caregivers may require help at night in going to the toilet and washing themselves (and/or changing their bedding). Thus, family caregivers' sleep is also disrupted (Arber & Venn, 2011). For the long-term care of the stroke patients, family caregivers have to be concerned with blood pressure and lipid level in order to maintain adequate cerebral perfusion and continuously rehab to reduced mortality as well as long-term disability (Alexander, 2013). Therefore, stroke family caregivers encounter many difficult responsibilities potentially leading to caregiver burden.

Family caregivers

A family caregiver is someone who is responsible for attending to the daily needs of another person (National Alliance for Caregiving, 2010). Family caregivers are responsible for the physical, emotional, social, and often financial support of another person who is unable to care for him/herself due to illness, injury or disability. The care recipient may be a family member, life partner or friend.

There are two types of caregivers. "Family caregivers" are sometimes described as "informal," a term professionals use to describe those who care for family members or friends in the home, typically without pay, such as spouses, adult children, siblings, other relatives, partners, friends and neighbors (National Alliance for Caregiving, 2010). A family caregiver is someone who provides a vast array of emotional, financial, nursing, social, homemaking and other services on a daily or intermittent basis. They volunteer their time without pay to help with the care needs of a loved one, including the provision of personal care, cooking, feeding, toileting,

dressing, bathing, performance of routine medical procedures and household management (KGaA, 2017). Formal caregivers, including home health care providers and other professionals, are trained and paid for their services (National Alliance for Caregiving, 2010).

Family caregivers may be motivated to provide care for several reasons including a sense of love or reciprocity, spiritual fulfillment, duty, guilt, social pressure or, in rare instances, greed. Caregivers who are motivated by a sense of duty, guilt, or social and cultural norms are more likely to resent their roles and suffer greater psychological distress than caregivers with more positive motivations. Caregivers who identify more beneficial components of their roles experience less burden, better health and good relationships with more social support (Brodaty & Donkin, 2009).

The majority of family caregivers among stroke patients are females rather than males, and most of them are adult children, spouses, parents and daughters-in-law, respectively (Badaru et al., 2017; Gbiri et al., 2015; Jaracz et al., 2014; Limpawattana et al., 2015; Nolan, 2015). The ages of family caregivers are between 17 and 74 years (Asiret & Kapucu, 2013; Badaru et al., 2017; Gbiri et al., 2015; Limpawattana et al., 2015; Nolan, 2015). Documents on caregiving among different ethnic groups of the National Alliance for Caregiving (2010) have reported that Hispanic caregivers are typically younger than Caucasian and African-American caregivers. African-American caregivers are more likely to have a lower household income, while Asian-American caregivers are equally likely to be males or females. In Thai families, “natural caregiving” precedes the care of dependent older persons (dependent caregiving). Dependent caregiving begins when dependency is first noticed and care needs are identified (Wongsawang, Lagampan, Lapvongwattana, & Bowers, 2013). Although the pattern of long-term care is changing due to changing social and changing family structure, more people will take the role of informal caregiver with multiple actors in various contexts (van Groenou & De Boer, 2016). Family members continue to take the major responsibilities of caregiving for stroke survivors. In this study, the caregivers were composed of all types of family caregivers, including parents, adult children, spouses, daughters, sons, siblings and other family members.

Family caregiver responsibilities

In general, the duties family caregivers typically perform involve transportation, housework, grocery shopping, meal preparation, financial management, helping with medication (administering pills, giving oxygen, wound care or tube feedings, as required), entertainment in hospital and rehabilitation (Goldberg & Rickler, 2011). Furthermore, half of all the caregivers in this study also reported assisting with the difficult tasks associated with personal care, including getting in and out of bed and chairs, getting dressed, helping bathe or shower, getting to and from the toilet, feeding, dealing with incontinence and changing diapers (National Alliance for Caregiving, 2010).

Stroke family caregivers are a very important part of the recovery process for stroke survivors, because stroke involves sudden onset and multiple impairments for survivors. After discharge, it becomes the responsibility of family caregivers to take care of stroke survivors at home (Kumar et al., 2016). The responsibilities of stroke family caregivers depend on the needs and functional status of stroke patients. Commonly, stroke family caregivers should be accountable for improving well-being, rehabilitation and prevention of a second stroke (National Stroke Association, 2012).

Improving the well-being of stroke patients is an important family caregivers' role. Stroke caregivers may perform some of the following throughout the recovery process: planning treatment and coordinating appointments with healthcare professionals; helping with everyday tasks such as meal preparation, bathing, toileting, walking and transportation; and monitoring stroke survivor health (National Stroke Association, 2012). Gbiri et al. (2015) reported that nearly half of informal caregivers care for stroke patients' daily tasks, including grooming, mobility and other activities.

Rehabilitation is a key caregiver role that may help stroke survivors maintain physical and mental health. Support and encouragement are key parts of stroke patients' recovery. Family caregivers assist survivors with movement and exercise, encouraging survivors to speak with few words, encouraging survivors to get dressed to maintain self-image, doing things stroke patients enjoy and relieving stress (National Stroke Association, 2012).

Family caregivers of stroke survivors should help identify risk factors in order to prevent a second stroke. There are some risk factors for stroke recurrence that caregivers and stroke patients can do nothing about. These include gender, age and family history. Family caregivers have to provide care for stroke patients following the advice of healthcare professionals and controlling risk factors such as hypertension and high cholesterol levels. In addition, caregivers support survivors in their efforts to quit smoking, because smoking doubles the risk for stroke (National Stroke Association, 2012).

Impacts of providing care for stroke survivors

Providing care for stroke survivors has several effects on family caregivers. In the physical dimension, family caregivers experience physical symptoms such as stomach pain, high blood pressure, fatigue, physical pain and constipation (Zhang & Lee, 2017). Since the caregivers feel obligated to respond and take responsibility for their loved ones, they put all of their strength into caring for the stroke survivors day and night. Caregiving can also affect caregivers' sleep and contribute to sleep disturbance. Arber and Venn (2011) conducted in-depth interviews with 24 older men and women in England who had provided night-time care, finding that the sleep of spouse caregivers was particularly affected, particularly among those who had been heavily involved in caring for their spouses for many years.

In the psychological dimension, negative emotions were the most common consequence in caregivers. Zhang and Lee (2017) reviewed several studies exploring the meaning of caregiving among stroke family caregivers. The studies found that caregivers interpreted caregiving as suffering. Woodford, Farrand, Watkins, and LLewellyn (2018) showed that caregivers who had been in a caregiving role for a mean of five years felt uncertainty about the future health of the stroke survivors with anxiety, fear, frustration, grief and hopelessness. Moreover, some stroke caregivers reported having experienced emotional stress and depressive symptoms as a result of caregiving (Pesantes et al., 2017). A survey study in the USA by Musich, Wang, Kraemer, Hawkins, and Wicker (2017) reported that caregivers felt moderate to severe loneliness.

In terms of social life and roles, family caregivers experience difficulty adapting to changes in their social life situations (Woodford et al., 2018). Stroke is a sudden disability, and the responsibility family caregivers of stroke survivors undertake related to daily living activities is without any preparation (Gbiri et al., 2015). Accepting caregiving-related roles by the family involves hardships including loss of independence, autonomy and ability to plan daily living properly as well as loss of normal patterns of relationships with survivors and role exchange (Hesamzadeh, Dalvandi, Maddah, Khoshknab, & Ahmadi, 2015). Woodford et al. (2018) conducted a qualitative investigation of difficulties experienced by informal caregivers of stroke survivors who reported that caregivers felt unable to engage in activities such as socializing with friends, pursuing hobbies, taking vacations, visiting restaurants, going on walks or engaging in sporting interests. Andrew et al. (2015) also reported that the greatest impact of providing care for stroke survivors for more one year involved work, leisure and friendships.

Caregivers face many obstacles as they balance caregiving with other demands, including child rearing, careers and relationships. These caregivers are at increased risk for burden, stress, depression and a variety of other health complications. The effects on caregivers are diverse and complex. Furthermore, there are many other factors that may exacerbate how caregivers react and feel as a result of the caregiving role (Brodaty & Donkin, 2009).

Although informal caregiving may be considered burdensome, many caregivers also report satisfaction with their roles. Mackenzie and Greenwood (2012) investigated the positive experiences of caregiving in stroke survivors in the form of a systematic review finding that caregivers were able to identify positive experiences of caregiving such as strengthened relationships, feeling appreciated and increased self-esteem. Some caregivers even considered focusing on the positive aspects of caregiving as an effective coping mechanism to reduce caregiver burden (Rodriguez, 2017).

Family caregivers' burden

The concept of family caregiver burden has been widely used in the literature on health care, because it is a concept that has been useful for researchers in understanding how caregivers are affected by the caregiving role. This concept was the first described in the early 60s by Grad and Sainsbury (1963) who stated that this concept involved perceived negative outcomes by family caregivers who provided care for their family members' illness with dementia. Later on, Hoenig and Hamilton (1966) gave a different meaning of burden by dichotomizing burden into objective burden and subjective burden, defining the objective burden as events and activities related to disadvantageous outcomes of caregiving and the subjective burden as feelings stimulated in family caregivers.

However, Zarit et al. (1980) defined burden as the extent to which caregivers perceive their emotional and physical health, social life, and financial status as a result of caring for their relatives. Researchers more or less agree that there are dichotomized, objective and subjective burdens. Family caregiver burden is no unique concept, but encompasses multiple dimensions (Carretero, Garcés, Ródenas, & Sanjosé, 2009; Chou, Chu, Tseng, & Lu, 2003). The dimension of burden includes physical, psychological or emotional, social and financial problems could be experienced by family members caring for impaired older adults (George & Gwyther, 1986). In early reviews, other authors modified the concept of burden. Chou (2000) defined family caregiver burden as an individual's subjective feelings including four dimensions (subjective perception, multi-dimensional pheno, dynamic changes and overload). At the same time, one researcher attempted to develop the dimensions of objective and subjective burdens by examining the objective and subjective dimensions of family burden. A recent review by Byun and Evans (2015) interpreted family burden as the objective and subjective aspects, time spent caring for stroke survivors and uncertainly about the future for stroke survivors and caregivers.

As previously stated, the two dimensions of burden are objective and subjective. In general, the direct care tasks from the illness are referred to as the objective burden. These include mandatory activities the caregiver has to perform (helping, supervising, controlling, paying, etc.), experiences (disturbed family and/or social relations) or activities no longer allowed (hobbies, clubs, careers, work) as a

consequence of the caregiving task. Moreover, objective burden could be defined as ‘the time and effort required of one person to attend to the needs of another. Sales (2003) divided objective burden into four dimensions including the direct tasks of care, indirect tasks of care, dealing with emotional needs of patients and the effects of caregiving on other life roles. At the same time, subjective burden was defined as distress or emotional strains experienced, such as worrying, anxiety, stigma, shame, and guilt, by the caregiver in dealing with objective stressors. Although caregiving has such broad emotional effects, it is not surprising that many caregiving burden measures include more items dealing with subjective strains than objective strains.

Several studies have been conducted to investigate the burden of stroke caregivers. Most of these studies have found the majority of stroke caregivers to have high levels of burden (Gorgulu et al., 2016; Kamel et al., 2012; Ogunlana et al., 2014). Gbiri et al. (2015) investigated informal caregivers’ burdens in providing care for stroke survivors in Nigeria, finding that 79.2% of informal caregivers had mild subjective burdens. Jaracz et al. (2014) reported that 47% of Polish primary caregivers experienced moderate or severe burdens. Kumar, Kaur, and Reddemma (2015) revealed that stroke caregivers reported higher levels of burden in financial areas (51.14%) and strained relationships (50.76%). It was also reported that caregivers had suffered a loss of control in life (43.75%) with personal strain (42.52%), emotional disturbance (32.14%) and role strain (28.79%). In Thailand, 34.7% of stroke caregivers have reported mild burdens (Limpawattana et al., 2015) and 41.01% have reported high levels of burden (Kunyodying et al., 2015).

Consequences of caregiver burden

Quality of life

Quality of life [QoL] is defined as caregivers' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns (The WHOQOL Group, 1996). In a prospective study conducted by Chuluunbaatar et al. (2016) in Mongolia, stroke patients and their caregivers were interviewed within 10 days of stroke onset with follow-up after one year. The findings indicated that the psychological health and social relationship domains of QoL among caregivers improved, but the physical health domain declined. Vincent-Onabajo et al. (2013) studied the QoL of caregivers

of stroke survivors who had suffered stroke within one year in Nigeria, finding the QoL of caregivers in the physical domain to be lowest, while QoL in the environment domain was highest. In Thailand, Seesuy (2007) found that 70.8% of stroke caregivers at King Chulalongkorn Memorial Hospital had moderate QoL in all aspects. Kunyodying et al. (2015) found the overall QoL of elderly primary caregivers of elderly stroke patients and all sub-dimensions among elderly caregivers to be low. Although the results of these studies reveal that family caregivers rate their quality of life from moderate to fairly well, long-term provision of care for stroke survivors affects quality of life and requires continuous improvement.

One study by Jeong et al. (2015) investigated the effects of caregiver burden based on the characteristics of patients and caregivers and the level of caregiver burden in hospital settings. The results showed that caregiver burden had a modifying effect on caregivers' QoL. Specifically, caregivers with high burden and poor health status were negative predictors of caregivers' QoL. At the same time, caregivers with low burden and poor health status were negative predictors of caregivers' QoL after controlling for the effects of the other variables. Similarly, Tsai et al. (2016) found that caregivers with higher caregiver burdens and lower self-rated health were significant predictors of lower caregiver QoL. Furthermore, poor or fair self-rated-health was found to have direct negative effects on caregiver QoL mediated by caregiver burden. Caregiver burden which had been found to be the strong determinant of QoL of family caregiver. As the results of Kumar et al. (2015) revealed that level of burden was negatively associated with four domains of QoL (physical ($r = -0.565$); psychological ($r = -0.796$); social ($r = -0.599$) and environmental ($r = -0.763$). Moreover, the relationship between caregiver quality of life and burden by Spearman's correlation shows that caregivers' quality of life is dependent on level of burden. In conclusion, the QoL and burdens of caregivers are related.

Theory guiding the model of stroke family caregiver burden

The conceptual framework for this study was the modified stress process model [MSPM] of Roland and Chappell (2017) which was adapted from the stress process model of Pearlin et al. (1990). The modified stress process model is a

conceptual framework focused on the relationship between care experiences and stress processes (Roland & Chappell, 2017). The four core components of this model include caregiver characteristics referring to the characteristics of the caregiver (socio-demographic characteristics) and giving contexts. The specific characteristics are related to risk for caregiver stress and have influence throughout the stress process. The second set of components includes primary and secondary stressors. Pearlin et al. (1990) indicated that stressors are conditions, experiences and activities that are threatening and difficult for individuals. Primary stressors include the cognitive level and problematic behavior of care recipients and the types of activities in which the care recipient depends on the caregiver. The third component, moderators, may directly reduce the intensity of stressors and limit deleterious outcomes. The fourth component, outcome, is defined as the consequences of the caregiving experience on the caregiver and involves the well-being of people, their physical and mental health and their ability to sustain themselves in their social roles.

Roland and Chappell (2017) extended the stress process theoretical framework for use with spouse caregivers among three neurodegenerative diseases, namely Alzheimer's disease, Parkinson's disease and Parkinson's disease dementia. In their model, the caregiving experiences of burden, depression and/or life satisfaction are influenced by the interaction of the caregiving background, stressors and supports. Caregiver characteristics are predisposing factors that may directly influence stressors, moderators or outcomes. Primary and secondary stressors have direct effects on outcome and moderators are expected to have direct effects on primary and secondary stressors and outcome.

In this study, caregiver burden was directly influenced by several factors, including caregiver age, caregiver health, hours of care, duration of caregiving, functional status of patients, duration of stroke, self-efficacy and social support. In this study, quality of life was directly influenced by caregiver burden, functional status of patients, social support and self-efficacy. Moreover, the functional status of patients may indirectly affect family caregiver burden through hours of care and duration of caregiving. Caregiver age may indirectly affect family caregiver burden through caregiver health and social support may indirectly affect family caregiver

burden through caregiver health and self-efficacy. Hours of care may indirectly affect family caregiver burden through caregiver health.

Factors affecting the burdens of stroke family caregivers

Several factors have been reported to impact caregiver burden and quality of life among family caregivers. However, this section focuses on family caregiver and stroke patient demographics as well as caregiving characteristics. More details are described as follows:

Caregiver age

Campbell (1981) stated that “age” was an irresistible force. It moves humankind through the life cycle, changing our appearance, attitudes, roles, values, behaviors and circumstances of our lives. Campbell (1981) also concluded that the early years of adult life are characterized by strong affective experience, while many pleasant and unpleasant events punctuate the lives of young people. As people grow older, these events are less common as life becomes more bland (Campbell, 1981). Thus, caregiver age is a significant predictor of burden and quality of life among family caregivers.

Several studies have indicated an association between caregiver age and caregiver burden. According to the findings of Han et al. (2017) in a prospective longitudinal study in Chinese family caregivers during a six-month period, caregiver age was a determinant of caregiver burden. Most studies revealed that younger caregivers might perceive higher burden than older caregivers. For instance, Kruihof et al. (2016) studied partners of stroke, finding that younger aged partners experience high burden at two months post-stroke. Metzeltin et al. (2017) revealed that younger caregivers are associated with an increased burden and/ or a decrease in quality of life. Moreover, Bhattacharjee et al. (2012) found that caregivers who younger age were related with high caregiving burden. However, perception of burden might not depend on caregiver’s age. The result of Gbiri et al. (2015) showed that there was no significant correlation between caregiver’ age

In summary, caregiver age has a direct effect on caregiver burden and an indirect effect on caregiver burden through caregiver health. However, some studies

have found no significant relationship between caregiver age and caregiver burden (Jaracz, Grabowska-Fudala, & Kozubski, 2012). Thus, there is a need to gain better understanding of the relationship between caregiver age and caregiver burden.

Caregiver health

Caregiver health is defined as perception of current and future conditions in addition to understanding of health. When stroke family caregivers exert their efforts toward providing care for a long time, there may be physical and mental health effects on family caregivers. For older family caregivers in particular, physical health is subject to greater impact than that of younger family caregivers. Therefore, physical decline can lead to many health problems. Most family caregivers lack time to rest, which leads to tiredness, fatigue and burden in giving care. The results of Asiret and Kapucu (2013) revealed that 67% of family caregivers of stroke survivors had health problems and nearly half (47.8%) claimed that their health problems were associated caregiving duties. Similarly, two studies showed that 86.4% of family caregivers reported health problems associated with caregiving (Tosun & Temel, 2017) and 86.2% had poor health (Gorgulu et al., 2016). Stroke survivors are subject to several physical health problems including hypertension, low back-pain, stomach ulcers and headaches (Asiret & Kapucu, 2013; Gbiri et al., 2015). The effects of caregiving are not only on physical health problems, but mental health problems as well.

The symptoms of mental health are stress, depression and anxiety (Asiret & Kapucu, 2013; Bulley, Shiels, Wilkie, & Salisbury, 2010; Chayawatto, 2016; Denno et al., 2013; Guo & Liu, 2015; Kamel et al., 2012; Pakpakorn, 2014).

According to these results, when family caregivers have health problems, they will have burdens in caregiving. According to the literature review for the development of the concept of burden, caregivers in poor health are consistently found to have higher burden levels than those in good health (Chou, 2000). Previous studies have been conducted to investigate the caregiver burden and its determinants. Thus, it has been reported that caregiver health is related to caregiver burden ($r = -.35$) (Jaracz et al., 2014). Hanh et al. (2017) also found that caregivers' general health perception was negatively related to caregiver burden ($r = -.31, p < .01$).

In conclusion, caregiver health is a predictor of caregiver burden. Older family

caregivers with poor health have high burdens. Therefore, caregiver health has negative direct effects on caregiver burden and could be affected by caregiver age.

Hours of care

Hours of care is defined as the amount of time family caregivers spend in providing care for stroke survivors. Lack of breaks from the caring role lead to difficulties with exhaustion, fatigue and boredom (Woodford et al., 2018). Family caregivers spend a long time taking care of stroke patients with low functional status every day. One study attempted to assess continued long-term home care in Japan from 1999-2010, finding most patients to require less than three hours of care per day (Watanabe et al., 2015). In contrast, family caregivers devoted to caregiving in stroke patients spend an average of approximately 4.15 - 8.32 hours/ day in providing care (Chang et al., 2010; Jaracz et al., 2014; Kamel et al., 2012). For instance, Chang et al. (2010) reported that over half of male caregivers in southern Taiwan spend 12.5 hours in providing care per day. Asiret and Kapucu (2013) showed that Turkey female caregivers administered 13.5 hours each day, while family caregivers in Jordan reported that they spent 4.15 hours each day in assisting the ADL of stroke patients (Kamel et al., 2012). Most studies have reported over half of caregivers spending more than six hours caring for stroke survivors daily (Choi-Kwon, Kim, Kwon, & Kim, 2005; Gbiri et al., 2015; Jaracz et al., 2014). According to Seesuwat (2007), half of caregivers provide care for stroke survivors for more than 15 hours per day. Several studies have attempted to find the relationship between hours of caregiving and caregiver burden. The results of these studies have revealed that hours per day devoted to caregiving could be a predictor of caregiver burden (Asiret & Kapucu, 2013; Chuyingsakultip, Chayvimol, Purananon, & Srichannil, 2016; Hanh et al., 2017). When family caregivers spend long hours in providing care for stroke patients, the level of burden increases (Gbiri et al., 2015). In conclusion, the number of daily hours spent taking care of stroke patients has positive direct effects on caregiver burden and could be affected by the functional status of stroke patients.

Duration of caregiving

Duration of caregiving is defined as the length of time caregivers have spend as a family caregiver. Stroke patients with low functional status still need long-term care assistance from family caregivers. Thus, family caregivers remain in the role of

caregiver. The tasks include assisting movement, elimination, bathing and dressing for stroke patients and most of these tasks are done by family caregivers daily. Their daily lives are greatly affected by caregiving duties (Asiret & Kapucu, 2013). When family caregivers provide care for stroke patients with longer care durations, caregivers are likely to face difficulty of movement. Hanh et al. (2017) found that most stroke caregivers who had been family caregivers for a duration of 9.53 months. Asiret and Kapucu (2013) found that the average caregiving duration of stroke caregiver was 29.7 months. Tosun and Temel (2017) found that most family caregivers had taken care of stroke survivors for 1 to 5 years. Kamel et al. (2012) found the duration of caregiving to range from 3 to 8 years. Longer care-related tasks can lead to increasing health problems among caregivers for every year of care provided (Unuigbo et al., 2017) and make caregivers feel a reduction in personal time to take care their life needs with feelings of loneliness. Tosun and Temel (2017) and Asiret and Kapucu (2013) reported that caregivers perceived high burden when they had longer care durations. However, Hanh et al. (2017) found the level of perceived burden to be lower in family caregivers who had long durations of caregiving, because caregivers adapt and accept their new roles as providers as they become more familiar with their role of caregiving.

In summary, the duration of caregiving is associated with the functional status of patients and caregiver burden. The duration of caregiving has a direct effect on caregiver burden and could be affected by the functional status of stroke patients.

Self-efficacy

Self-efficacy is defined as caregivers' beliefs in their own ability to respond to difficult situations and deal with any obstacles involved (Schwarzer & Jerusalem, 1995). Kruithof et al. (2016) revealed that stroke caregivers' high self-efficacy is associated with lower burden at two months post-stroke. People with high self-efficacy set themselves higher goals, invested more effort and persisted longer than those with low self-efficacy. In other studies, the results revealed that family caregivers aged 65 with dementia behavior disturbance perceived that they had the least self-efficacy, but they had higher levels of care burden (Uei, Sung, & Yang, 2013). Meanwhile, one study indicated that caregivers of cancer patients had

moderate self-efficacy in a negative relationship between caregiver burden and self-efficacy (Yildiz, Karakaş, Güngörmüş, & Cengiz, 2017).

To date, little is known about family caregivers' level of self-efficacy and their perceived burden in caring for relatives with stroke. Nevertheless, the results from many studies have reported self-efficacy to be associated with caregiver burden. Therefore, the causal relationship needs to be investigated in this study.

Social support

Social support is defined as perceived support from family, friends and significant others (Zimet et al., 1988). Social support is a major source of assistance to help caregivers cope with the challenges they face. However, family caregivers are not always well-prepared to take on new tasks. Many stroke caregivers lack basic information about stroke, strategies applicable to caring for stroke survivors and methods for preventing complications and future attacks of stroke (Kumar et al., 2016). The findings from a study by Rodriguez (2017) suggested that encouraging high social support may be the strongest protective factor against caregiver burden. Previous studies have shown social support to have tremendous impact on caregiver burden. In other words, caregivers who receive more social support have reported an inversely significant correlation (the higher the burden, the lower the social support score) (Jaracz et al., 2014; Kruithof et al., 2016; Rigby, Gubitz, & Phillips, 2009; Tosun & Temel, 2017). In conclusion, social support has direct effects on caregiver burden.

Functional status of stroke patients

Functional status is defined as an individual's ability to perform the normal daily activities required to meet basic needs, fulfill routine roles and maintain health and well-being (Leidy, 1994). Stroke is known to be the most common cause of physical disability with potential impact on ability to perform the activities of daily living (ADL). Hilton et al. (2013) stated that many stroke patients still require rehabilitation and assistance from family caregivers for six months to three years. The activities of daily living (basic and instrumental) are reliable indicators of the functional status of patients affected by stroke. Difficulties in ADL could decrease the quality of life [QoL] of stroke patients. Previous studies have examined the relationship between the ADL performance and quality of life [QoL] of stroke

survivors by using the Barthel Index [BI] to assess daily function status. The results show that more half of stroke patients are highly dependent on assistance in the activities of daily living [ADL] and that functionality is better in male patients than females (Haghgoo, Pazuki, Hosseini, & Rassafiani, 2013). A recent study by Gorgulu et al. (2016) found that 41.3% of the patients in the study were fully dependent and 23.8% were severely dependent after stroke. In another study, the researcher used the short form of the World Health Organization Disability Assessment Schedule [WHODAS 2.0] to assess disability among stroke survivors. According to the findings, 47.1% of stroke survivors had post-stroke disability, but there were no differences in gender and prevalence or level of post-stroke disability, while the level of disability increases with age, though only for male stroke survivors (Oyewole et al., 2016).

Caring for disabled stroke survivors may be a cause of chronic stress since the gap between caregiving demands and caregivers' ability to provide care. Moreover, providing care for chronically ill persons could be harmful to caregivers' physical and emotional health and lead to the serious negative consequences referred to as burden and low quality of life of family caregivers (Jaracz et al., 2014; Kamel et al., 2012). Several studies have shown that caring for stroke survivors, particularly those with disabling conditions, places burdens on caregivers and affects the quality of life of family caregivers. For instance, Asiret and Kapucu (2013) found that decreased mobility of stroke patients increased the family caregiver burden. Kamel et al. (2012) reported that the functional disabilities of the stroke survivors had influence on caregiver burden. Ogunlana et al. (2014) found that lower functional status of stroke survivors was significantly associated not only with higher caregiver strain, but also lower quality of life among caregivers. Similarly, the literature review of Badaru et al. (2017) reported that the functional status of stroke survivors was a determinant of burden and quality of life among caregivers. In conclusion, the functional status of stroke patients was a main factor influencing the burden and QoL of stroke caregivers with direct effects on the burden and QoL of stroke caregivers. Moreover, the functional status of stroke patients had indirect effects on caregiver burden through hours of care and duration of caregiving.

Duration of stroke

Duration of stroke is defined as the post-stroke period. Stroke recovery time is different. It can take weeks, months, or years (Coccia & Provinciali, 2017). Vincent-Onabajo et al. (2013) reported that caring for stroke patients who had suffered stroke within one year was associated with better quality of life compared with longer post-stroke periods. The ability of caregivers to cope well with their role in the initial period after onset of stroke was due to the fact that they still had support, which might have helped cushion the burden of caregiving (Vincent-Onabajo et al., 2013). Gbiri et al. (2015) revealed that caregivers experienced great burden in the early stage of stroke care and that this burden progressively decreased with post-stroke duration as the functional status of patients improved. In long-term care, however, Watanabe et al. (2015) found that stroke patients' pathology, excretory control, verbal expressions, verbal comprehension and range of activities significantly decreased. If the degrees of dependent self-care, excretory control, transfer and gait are high, the QoL of family caregivers will decrease. In conclusion, the evidence supports the hypotheses that duration of stroke has direct effects on stroke caregiver burden.

Summary of the literature review

Stroke is a global health issue that has negative impact on survivors, family and society. Post-stroke disability is a huge problem for survivors. Most have no ADL performance and family caregivers have to take responsibilities in providing care for stroke patients until normal functional status is restored. However, recovering from stroke may take a long time or survivors may be unable to recover. There are several physical and psychological problems in family caregivers due to caregiving duties. Caregivers often experience burden. Caregiver burden has been shown to be associated with lower caregiver QoL. The modified stress process model in this study can be used to evaluate caregiving burden, including caregiver characteristics (caregiver age, caregiver health, hours of care and duration of caregiving); primary stressors (functional status of stroke patients and duration of stroke), moderators (self-efficacy and social support) and outcomes (caregiver burden and quality of life).

CHAPTER 3

RESEARCH METHODOLOGY

This study aims to test the causal model of burden among family caregivers of stroke patients. This chapter covers research design, population, sample, sampling, research instruments, protection of human rights, data collection procedures, and data analysis.

Research design

This study employed a cross-sectional design. The structural equation modeling [SEM] was used to examine the simultaneous interrelationships of predictors and caregiver burden among stroke family caregivers. It was appropriate to identify factors influencing burden of stroke family caregivers because SEM was a collection of statistical techniques that allowed sets of relationships between one or more independent or dependent variables to be examined, no matter they were continuous or discrete.

Population and sample

The population of this study were informal caregivers who provided direct care for stroke patients. They were recruited from Neurological and Medical outpatient department [OPD] of Saraburi Hospital and Phra Nakhon Si Ayutthaya Hospital, Thailand.

A sample was family members who mainly took care of stroke patients.

The inclusion criteria of participants were as follows:

Family caregiver

1. Being a family caregiver of stroke patient for at least a month after discharged from the hospital
2. Age more than 18 years
3. Person who had relationship with stroke patient such as parents, spouse, offspring or others living with stroke patients
4. Be able to communicate and understand Thai language

Stroke patients

1. Being diagnosed with first time ischemic stroke and hemorrhagic stroke
2. Being in the period of post stroke, 1 - 6 months

Sample size

Hair, Black, Babin, and Anderson (2010) stated that sample size of Structural Equation Modeling [SEM] must be made based on a set of factors. Kline (2016) suggested that a “typical” sample size for studies using SEM was about 200 cases corresponding to the approximate median sample size. Therefore, the sample size in this study were 200 stroke family caregivers.

Setting of the study

The study was conducted in Regional Health 4 which was found the highest mortality rate of stroke patients in Thailand (Regional Health 4, 2017). Saraburi hospital and Phra Nakhon Si Ayutthaya Hospital represented Tertiary Care in this region. Saraburi Center Hospital had a capacity of 700 beds and Phra Nakhon Si Ayutthaya Hospital had a capacity of 524 beds (Technology and information, 2017). Mortality rate of patients with stroke in Saraburi Province were reported decreasing from 16.19 % to 14.59% from 2016 to 2018. Moreover, 25.18% of stroke patients were 60-69 years old, 22.25% were 50-59 years old, and 18.74% were 70-79 years old (Kanoksilp & Kaewnann, 2018).

Sampling method

Family caregivers for stroke patients were recruited by convenience sampling technique as follows:

1. The researcher met with a staff nurse at OPD of Saraburi Hospital and Phra Nakhon Si Ayutthaya Hospital to review patients’ medical records.
2. During the follow-up visits, the researcher asked to meet with the stroke patients’ caregivers. If they were primary caregivers, they would be screened as eligible participants.

Research instruments

Data were collected through seven instruments:

1. Demographic record form included

1.1 Family caregiver information namely gender, age, marital status, education, occupation, family income, relationship with patient, underlying disease, work experience, work hour per day, and number of patients under care.

1.2 Stroke patient information namely gender, age, type of stroke, duration of diagnosed with stroke, co-morbidity.

2. The Zarit Burden Interview [ZBI], the ZBI developed by Zarit et al. (1980). It was used to measure caregiving burden experienced by the primary caregivers of older persons with senile dementia and disabled persons. It was blind back translated to Thai by Toonsiri et al. (2011). It was found that caregivers for patients with chronic illness might experience these four dimensions that were personal strain, privacy conflict, guilt, and uncertain attitude. Participants were requested to respond on a 5- point scale with 0 = never to 4= nearly always. A total burden score was obtained by adding the scores for 22 items with a range of 0-88. Higher scores indicated greater caregiver burden.

3. The Health Perception Scale for Thai adults [HPS-T] was used to measure the caregivers' health. It was developed by (Rojpaisarnkit, 2001) using focus group interview and Delphi technique for exploring construct and content validity. HPS-T was based on Health Perception Questionnaire [HPQ] developed by Health Insurance Study [HIS] in USA being recognized as a worldwide construct of health perceptions (Brook et al., 1979). HPS-T was tested for reliability by Cronbach's coefficient alpha and for discriminant power by Levene's test of equality of variance in three times of try-outs. Testing of construct validity was performed by Exploratory Factor Analysis [EFA] and Confirmatory Factor Analysis [CFA]. HPS-T consisted of 9 domains, 27 items. The researcher used this instrument to assess caregivers' health perceptions consisted of 6 domains including current health, future health, health concern, resistance or susceptibility to illness, health threat, and sickness orientation 18 items. Fourteen positive items were scored from 1 (definitely false) to 5 (definitely true) and four negative items were reversed score. Total scores ranged from 18 to 90. Higher scores indicated higher health concern.

4. The Barthel Index [BI] was used to measure the patients' functional status variable. The BI was developed in 1965 by Mahoney and Barthel (1965).

Its Thai version was modified by Department of Health, Ministry of Public Health, Thailand. The BI included 10 items of ADL. The score of each item was as follows;

1. Feeding (0 = unable, 5 = need help, 10 = independent)
2. Bathing (0 = dependent, 5 = independent)
3. Grooming (0 = need to help, 5 = independent)
4. Dressing (0 = dependence, 5 = need help but can do, 10 = independent)
5. Bowels (0 = incontinent, or need to be given enemas, 5 = occasional accident, 10 = continent).
6. Bladder (0 = incontinent, or catheterized, 5 = occasional accident, 10 = continent).
7. Toilet use (0 = dependent, 5 = need some help but can do, 10 = independent).
8. Transfers (0 = dependent 5 = need some help but can do something, 10 = minor help, 15 = independent)
9. Mobility (0 = immobile, 5 = wheelchair independent, 10 = walks with help, 15 = independent).
10. Stair (0 = unable, 5 = need help, 10 = independent).

Total score ranged from 0-100 scores. Higher scores indicated more independent of stroke patients' functional status.

5. The General Perceived Self-efficacy Scale [GSES] was used to measure family caregivers' self-efficacy variable. It was developed by Schwarzer and Jerusalem (1995). In 2002, it was translated into a Thai version by Sukmak et al. (2002). The back translation was done by bilingual speakers. Exploratory and Confirmatory Factor Analyses were also performed. It was used to assess a general sense of perceived self-efficacy in coping as well as adapting after experiencing all kinds of daily life stress. The construct of GSES reflected an optimistic self-belief that one could perform difficult tasks, or cope with adversity. Perceived self-efficacy facilitated goal setting, effort investment, persistence in face of barriers and recovery from setbacks. There were 10 items. Each item was scored from 1 (not at all true) to 4 (exactly true). Total scores ranged from 10 to 40. Higher scores indicated higher self-efficacy.

6. A revised Multi-Dimensional Scale of Perceived Social Support [rMSPSS] was used to measure the social support variable. It was originally developed by Zimet et al. (1988). Its Thai version was translated by Wongpakaran & Wongpakaran in 2011, with back-translation performed by a bilingual school teacher. Exploratory factor analysis [EFA] and confirmatory factor analysis [CFA] were employed to test construct validity. In 2012, the modified version by Nahathai Wongpakaran & Tinakon Wongpakaran had been tested for its psychometrics in both clinical and non-clinical samples using Confirmatory Factor Analysis. This revised version had better and more suitable psychometrics properties for Thai people. It measured social support from three sources: family members, friends, and significant others. Each source was comprised of four items with total 12 items. Each item was scored from 1 (very strongly disagree) to 7 (very strongly agree). Total scores ranged from 12 to 84. Higher scores indicated higher social support.

7. The World Health Organization Quality of Life- BREF (WHOQOL-BREF-THAI Version) was used to measure caregivers' quality of life variable. The WHOQOL-BREF was a 26-item-version of the WHOQOL-100 assessment (WHO, 2004). It measured life positions perception of each individual in the context of a culture they lived in related to their goals, expectations, standards and concerns. This instrument had four domains of QOL which were physical health, psychological health, social relationship, and environment. In 2004, it was translated into a Thai version by Department of Health, Ministry of Public Health, Thailand. Participants were requested to respond on a 5-point Likert scale with positive items 1 = Never to 5= always and negative items were reversed score. A total score was obtained by adding the scores of 26 items with a range of 26-130. Higher scores indicated higher QoL.

Psychometric properties of instruments

Validity

All questionnaires including ZBI, HPS-T, BI, GSES, rMSPSS, and WHOQOL-BREF were acceptable content validity as standard instruments. These instruments had permission from original developers.

Reliability

The reliability of all study instruments was tested with 30 stroke family caregivers at Saraburi hospital before conducting this study, but they were not included in the actual study. The internal consistency reliability was presented in Table 1.

Tables 1 Reliability of study instruments

Questionnaire	Number of items	Cronbach's alpha		
		Original	Pilot	Current
Zarit Burden Interview [ZBI]	22	.90	.82	.81
Health Perception Scale for Thai adults [HPS-T]	18	.83	.76	.77
Barthel ADL Index [BAI]	10	.84	.94	.89
General Self-efficacy Scale [GSES]	10	.80	.86	.90
The Multidimensional Scale of Perceived Social Support [MSPSS]	12	.87	.88	.86
WHOQOL- BREF-THAI	26	.90	.89	.85

Protection of human rights

The research proposal was approved, by the institutional review board [IRB], Faculty of Nursing, Burapha University (IRB # 03-11-2561) and the Committee of Rights for Human Research of Saraburi Hospital and Phra Nakhon Si Ayutthaya Hospital, before data collection. After obtaining the permission from the hospitals' directors, participants would be carefully screened according to the inclusion criteria by the researcher. Then, the researcher would clearly inform family caregivers who met the criteria regarding research objectives, procedures, risks, and benefits of participation. Family caregivers would be informed that they had the right to withdraw from this study at any time without any consequences, that their information was unidentified, that their data were defined code numbers and kept in lock cabinet, and that the data would be eliminated when the study was completed and published. Finally, participants were asked to sign consent forms.

Data collection procedures

Data collection was started after the IRB approved from Faculty of Nursing, Burapha University, Saraburi Hospital and Phra Nakhon Si Ayutthaya Hospital.

1. The researcher contacted directors of Saraburi Hospital and Phra Nakhon Si Ayutthaya Hospital to ask for a permission to collect data.
2. Then, the researcher contacted directors of outpatient department at Saraburi Hospital and Phra Nakhon Si Ayutthaya Hospital.
3. The researcher visited to Medical outpatient department and informed the objectives of the study to staff nurses. Then the researcher recruited stroke patient and their caregivers who met the inclusion criteria from the patient follow-up list.
4. The researcher informed stroke caregivers about objectives, procedures, and protection of human rights of this study.
5. Later, family caregivers who agreed to participate in this study were asked to sign a consent form.
6. The researcher asked family caregivers to spend 25-30 minutes to fill out the following questionnaires; demographic data, Zarit Burden Interview [ZBI], Health Perception Scale for Thai adults [HPS-T], Barthel Index [BI], General Perceived Self-Efficacy Scale [GSES], WHOQOL- BREF-THAI Version, and A revised Multi-Dimensional Scale of Perceived Social Support [rMSPSS] in a private area near the medical examination room.
7. After the questionnaires were completed, the researcher would check for the completion. The items with no responses were confirmed. If family caregivers insisted on no response, the researcher would respect and ended the procedure.

Data analysis

Data were analyzed as follows;

1. Descriptive statistics was employed to analyze the caregivers' demographic data by using frequencies, means, and standard deviations.
2. Assumptions including outlier, normality, linearity, multicollinearity and homoscedasticity were tested.

3. Structural equation modeling [SEM], AMOS software, was used to test the relationships between caregivers' health status, patients' functional status, hours of caregiving, duration of caregiving, self-efficacy, social support, quality of life, and caregivers' burden at significance level at $p < .05$. The researcher tested measurement model before the structural model was evaluated.



CHAPTER 4

RESULTS

This chapter presents the results from data analyses in three sections. The first section describes the characteristics of the sample's demographic. The second section is assumption testing and the descriptive statistics of the study variables. The last section presents the model testing of the hypothesized model and the final model burden of stroke caregivers.

Characteristics of the caregivers

Their demographic characteristics were shown in Tables 2 and Table 3. For caregivers, most of them (79.5%) were female. Half of them were between 41 to 60 years old (50.0%) and 42% were younger. More than half of the participants (70.0%) were married. Most stroke caregivers had completed primary school (31.5%), secondary school, and obtained a diploma, (26.5% and 23.5%, respectively). More than one-third of participants (36.0%) were merchants. The mean family income was 25,587.50 baht/month ($SD = 18,045.76$). Nearly half of caregivers (44.0%) were sons and daughters. Fifty-two percent reported being healthy; the remaining 48% reported having chronic diseases. Most caregivers (53.5%) spent 4 to 8 hours caring for the stroke survivor per day. The mean age was 44.55 ($SD = 11.75$) years. The average duration of caregiving was 3.29 ($SD = 1.34$) months with a range of 1 to 6 months. Average number of hours was 7.12 ($SD = 2.92$) hours with a range of 2 to 13.

Tables 2 Demographic characteristics of stroke family caregivers ($n = 200$)

Characteristics	<i>n</i>	%
Gender		
Male	41	20.5
Female	159	79.5
Age (years) ($M = 44.55, SD = 11.75$)		
20-40	84	42.0
41-60	100	50.0
> 60	16	8.0
Marital status		
Single	51	25.5
Married	140	70.0
Widow	3	1.5
Divorce	6	3.0
Education		
Illiteracy	7	3.5
Primary school	63	31.5
Secondary school	53	26.5
Diploma	47	23.5
Baccarelata	29	14.5
Higher than baccarelata	1	0.5
Occupation		
Unemployed	31	15.5
Government/ Public enterprise	9	4.5
Merchant/ Trade/ Commercial	72	36.0
Hire	55	27.5
Agriculture	21	10.5
Employee	12	6.0

Table 2 (continued)

Characteristics	<i>n</i>	%
Family income (bath/ month) (<i>M</i> =25,587.50, <i>SD</i> = 18,045.76)		
<10,000	38	19.0
10,001-20,000	65	32.5
20,001-30,000	50	25.0
30,001-40,000	21	10.5
40,001-50,000	16	8.0
>50,000	10	5.0
Relationship with stroke patient		
Spouse (husband/ wife)	71	35.5
Father/ Mother	8	4.0
Son/ Daughter	88	44.0
Son-in-law/ Daughter-in-law	11	5.5
Sibling	12	6.0
Grandchild/ cousin	10	5.0
Underlying/ chronic diseases		
None	104	52.0
Hypertension	70	35.0
Dyslipidemia	26	13.0
Diabetes mellitus	16	8.0
Asthma	5	2.5
Gastritis	3	1.5
Heart disease	2	1.0
Gout	2	1.0
Disk hernia	1	0.5
Length of caregiving (<i>M</i> = 3.29, <i>SD</i> = 1.34)		
1 month	20	10.0
2 months	37	18.5
3 months	59	29.5

Table 2 (continued)

Characteristics	<i>n</i>	%
4 months	49	23.0
5 months	26	13.0
6 months	12	6.0
Hour per day of caregiving (<i>M</i> = 7.12, <i>SD</i> = 2.92)		
1-3 hours	21	10.5
4-6 hours	70	35.0
7-9 hours	58	29.0
≥ 10 hours	51	25.5

Characteristics of the stroke survivors

Of the total 200 stroke survivors, half of them (58.5%) were male. Most of them were between 41 to 60 years old (54.0%) with the mean age of 59.24 (*SD* = 12.53) years between the ages of 23 to 90 years. The majority of stroke survivors (88.0%) had ischemic strokes. The average time duration since their stroke was 3.43 (*SD* = 1.61) months with a range of 1 to 6 months. Equal number of survivors were found to have hypertension and dyslipidemia (73.0%). See Table 3.

Tables 3 Demographic characteristics of stroke survivors ($n = 200$)

Characteristics	<i>n</i>	%
Gender		
Male	117	58.5
Female	83	41.5
Age (years) ($M = 59.24$, $SD = 12.53$)		
20-40	16	8.0
41-60	108	54.0
> 60	76	38.0
Type of stroke		
Ischemic stroke	176	88.0
Hemorrhage stroke	24	12.0
Duration of post stroke ($M = 3.43$, $SD = 1.61$)		
1 month	19	9.5
2 months	26	13.0
3 months	46	23.0
4 months	50	25.0
5 months	29	14.5
6 months	30	15.0
Underlying/ chronic diseases		
Hypertension	146	73.0
Dyslipidemia	146	73.0
Diabetes mellitus	48	24.0
Heart disease	19	9.5
Gout	5	2.5
Chronic kidney diseases	5	2.5
Thyroid	3	1.5
Benign prostatic hyperplasia	2	1.0
Cancer	1	0.5
Rheumatoid	1	0.5

Descriptive statistic of the study variables

Stroke survivors were able to perform their daily activities at moderate level of functional status which ranged from 0 to 90 ($M = 44.73$, $SD = 22.70$). Duration of stroke indicated that stroke survivors were post-stroke between acute and sub-acute phrases ranging from 1 to 6 months ($M = 3.43$, $SD = 1.61$). Family caregivers spent from 2 to 13 hours per day ($M = 7.12$, $SD = 2.92$) caring for stroke survivors. The duration of caregiving ranged from 1 to 6 months ($M = 3.29$, $SD = 1.34$). Caregivers perceived their health at high. Caregivers perceived moderate self-efficacy to provide care stroke survivors. Social support indicating that caregiver perceived of received assistant from family, friend, and other at moderate level. The total score for caregiver burden indicated that stroke family caregiver had mild to moderate level of burden. Quality of life of caregivers indicated that they had good quality of life. The continuous variables in this study are presented in Table 4.

Tables 4 Descriptive statistic of study variables ($n = 200$)

Variable	Possible Range	Actual Range	<i>M</i>	<i>SD</i>
Caregiver's age	20-72	20-72	44.55	11.75
Functional status of patient	0-100	0-90	44.73	22.70
Duration of stroke (month)	1-6	1-6	3.43	1.61
Hour of care	0-24	2-13	7.12	2.92
Duration of caregiving	1-6	1-6	3.29	1.34
Caregiver's health	18-90	59-84	72.59	5.32
Self-efficacy	10-40	20-40	29.61	4.83
Social support	12-84	37-66	51.00	7.62
Caregiver burden	0-88	3-60	29.89	12.50
Personal strain	0-36	0-28	9.92	7.09
Privacy conflict	0-16	0-12	5.44	3.45
Guilt	0-20	0-18	9.58	4.01
Uncertain attitude	0-16	0-13	4.96	2.97

Table 4 (continued)

Variable	Possible Range	Actual Range	<i>M</i>	<i>SD</i>
Quality of Life of caregiver	26-130	89-123	105.17	6.99
Physical health	0-35	18-28	22.69	1.95
Mental Health	0-30	16-28	21.34	2.07
Socio relationship	0-15	9-15	12.26	1.11
Environment	0-40	24-40	31.82	2.57

Assumption testing

Before analyzing Structural Equation Modelling, ten variables were screened. Missing data, outlier, normality, linearity, and multicollinearity were checked to maintain values in data. However, no missing data were detected among those 200 questionnaires. All variables were screened for univariate outliers and multivariate outliers. Cases with standardized scores (Z score) of greater than 3.29 were potential univariate outliers (Tabachnick, Fidell, & Ullman, 2007). For this study, the results of the Z score was less than 3.29. Therefore, it concluded that the samples were not univariate outlier. Then, multivariate outliers were detected. The criterion for multivariate outliers was Mahalanobis distance at $p < .001$ (Tabachnick et al., 2007). Also, it could be evaluated by χ^2 with degrees of freedom equal to the number of variables (Tabachnick et al., 2007). These variables included caregivers' age, duration of caregiving, hour of care, duration of stroke, patients' functional status, caregiver's health, self-efficacy, social support, burden, and quality of life. Critical values of Mahalanobis distance with 10 variables $\alpha = .001$ was 29.588. In this study, maximum value of Mahalanobis distance was 24.318 and a probability value of the chi-square distribution was less than .001. Therefore, there had no multivariate outlier.

The normal distribution could be estimated from skewness and kurtosis. If it was a normal distribution, the value of skewness and kurtosis would be zero (Tabachnick et al., 2007). If skewness and kurtosis were a non-zero, this indicated that a distribution "lean" one way or the other and had an asymmetric tail.

Also, kurtosis increased with peakedness and decreased with flatness (Cain, Zhang, & Yuan, 2017).

It was impractical to assess violation of multivariate normality. However, many instances of multivariate non normality were detected through inspection of univariate distributions (Kline, 2016). There were more methods to measure skew and kurtosis. A simple test of normality could also be done by using a standardized score (z) for skewness and kurtosis value, if z value was greater than the specified critical value (c.r.) with ± 2.58 (at .01 significance level) and ± 1.96 (at .05 significance level), it indicated that the distribution was non-normal (Hair et al., 2010).

One guideline could be evaluated by interpreting absolute values of skewness and kurtosis. If skew index > 3 , described as severely skewed and kurtosis index > 10 , suggested a problem (Kline, 2016). In this study, the result revealed that ten variables had the values of skewness and kurtosis and met the criteria. Thus, the distribution was normal.

Linearity assumption was examined by using Pearson correlation coefficient (Schumacker & Lomax, 2010; Tabachnick et al., 2007) which demonstrated a non-zero. As shown in Table 4-5, the bivariate relationship between the study variables did not show a non-zero correlation. For multicollinearity, this problem could occur if the variables were highly correlated greater than .90. Another statistic was the variance inflation factor [VIF]. The variable in question may be redundant, if $VIF > 10.0$. Also, Tolerance values $< .10$ may indicated extreme multivariate collinearity (Kline, 2016). The results showed that no variables were multicollinearity.

Quality of measurements

The researcher examined measurement models of six variables including caregivers' age, duration of caregiving, hour of care, duration of stroke, functional status, caregiver's health, self-efficacy, social support, burden, and quality of life. If the initial model did not show good fit, exploratory factor analysis [EFA] using principle components analysis was performed, followed by confirmatory factor analysis [CFA] to examine the fit indices. The results showed that these variables were good construct. Then, each measurement model was examined internal consistent using Cronbach's alpha. The results were presented in Table 5.

Tables 5 Summary of measurement models of studied variables

Variable name	Instruments	Items	Factor loading	Fit Indices							Cronbach's alpha	
				CMIN	df	p	CMIN /df	GFI	AGFI	CFI		RMSEA
Functional status	Barthel Index [BI]	10	.61 - .71	8.78	5	.12	1.76	.98	.95	.99	.06	.88
Self-efficacy	General Perceived Self-Efficacy Scale [GSES]	10	.69 - .79	32.2	19	.03	1.7	.96	.92	.96	.06	.88
Caregivers' health	Health Perception Scale for Thai adults [HPS-T]	18	.54 - .82	50.62	27	.00	1.88	.95	.92	.96	.07	.70
Social support	A revised Multi-dimensional Scale of Perceived Social Support [rMSPSS]	12	.63 - .85	56.21	32	.01	1.76	.95	.91	.97	.06	.85
Caregiver burden	Zarit Burden Interview [ZBI]	22	.45 - .86	126.57	74	.00	1.71	.92	.88	.94	.06	.80
Quality of life	WHOQOL-BREF-THAI	26	.51 - .89	49.28	27	.01	1.83	.95	.92	.97	.06	.74

Correlation among study variables

Tables 6 Correlation matrix of study variables

Variable	1	2	3	4	5	6	7	8	9
1. Duration of stroke	.03								
2. Functional status of patient	.01	-.14							
3. Caregiver's age	.77*	-.02	.15*						
4. Duration of caregiving	.08	-.15*	-.02	.05					
5. Hour of care	-.08	.03	-.02	-.01	-.05				
6. Caregiver's health	-.21**	.12	-.04	-.25**	-.01	.05			
7. Self-efficacy	-.09	-.04	-.05	-.03	.03	.02	.21**		
8. Social support	.24**	-.35**	-.06	.29**	.22**	-.03	-.28**	-.06	
9. Caregiver burden	-.16*	.09	-.09	-.22**	.01	.05	.31**	.07	-.29**

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

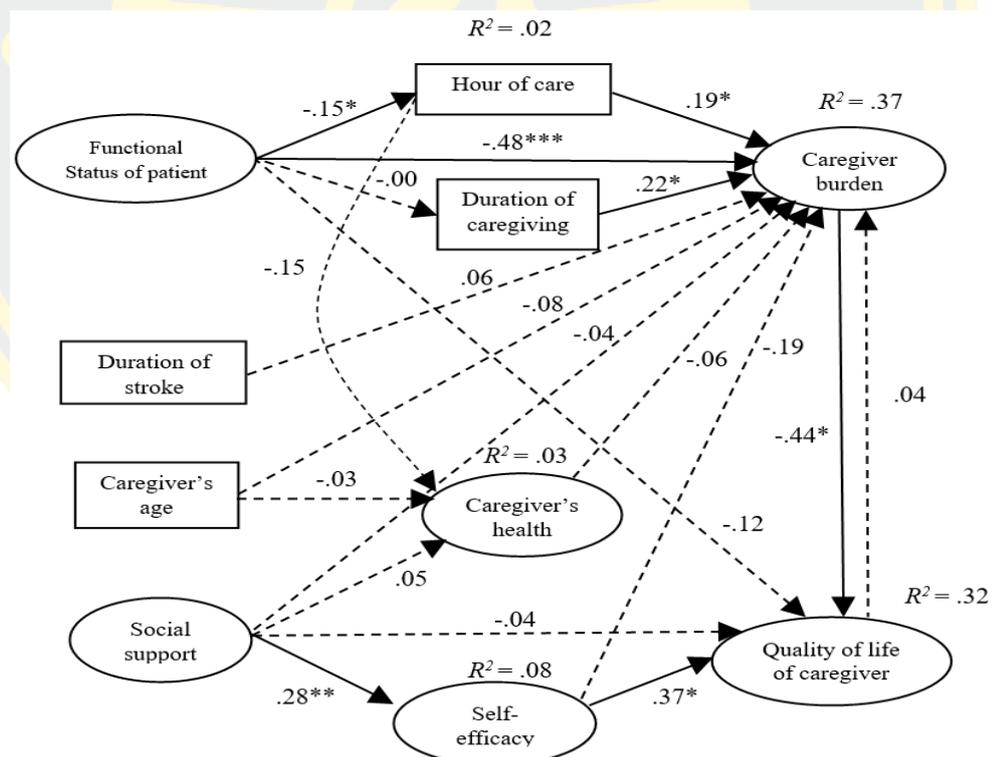
Result of model testing

In this section, the researcher examined the factors influencing burden of stroke family caregivers and effect of burden on caregivers' QoL. Therefore, there were two testing models.

1. Model of factors influencing QoL of stroke family caregivers

1.1 The hypothesized model

The hypothesized model consists of exogenous variables including duration of stroke, caregiver's age, and social support. Endogenous variables were caregiver burden and quality of life. Moreover, there are five variables were exogenous variables; endogenous variables included hour of care, duration of caregiving, caregivers' health, self-efficacy, and caregiver burden as presented in Figure 2.



* $p < .05$, ** $p < .01$, *** $p < .001$

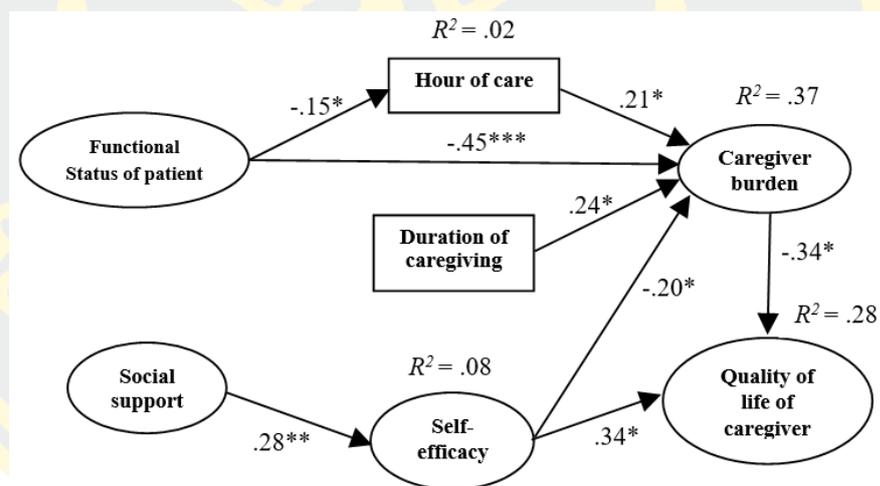
Figures 2 The hypothesized model of factors influencing QoL of stroke family caregivers

The initial results of SEM analysis showed that seven parameter's estimates were significant paths. Goodness fit indices showed that $CMIN = 447.02$, $df = 219$, $p < .001$, $CMIN/df = 2.04$, $GFI = 0.86$, $AGFI = 0.82$, $CFI = 0.80$, and $RMSEA = 0.07$.

1.2 The modified model

The hypothesized model did not fit the data well. Consequently, the researcher modified the hypothesized model by considering the conceptual and modification indices. The model trimming was used in the hypothesized model with low standardized factor loading and non-significant parameter. Eleven path estimates were removed. Finally, the modified model fitted the data well as presented in Figure 3.

1.3 The final model



* $p < .05$, ** $p < .01$, *** $p < .001$

Figures 3 Final model of factors influencing QoL of stroke family caregivers

The results of a final acceptable model revealed that $CMIN = 182.35$, $df = 131$, $p < .001$, $CMIN/df = 1.39$, $GFI = 0.91$, $AGFI = 0.88$, $CFI = 0.95$, and $RMSEA = 0.04$. It indicated that the modified model fit the data well. Goodness of fit indices between the hypothesized model and the modified model are presented in Table 7.

Tables 7 Fit indices of model of factors influencing QoL of stroke family caregivers

	CMIN (χ^2)	CMIN	GFI	AGFI	CFI	RMSEA
	<i>/ df</i>					
Acceptable levels	$p > .05$	< 2	.90-1.0	.90-1.0	.90-1.0	$< .08$
Hypothesized model	$\chi^2 = 447.02,$ $p < .001$ ($df = 219$)	2.04	.86	.82	.80	.07
Modified model	$\chi^2 = 182.35,$ $p = .002$ ($df = 131$)	1.39	.91	.88	.95	.04

There were direct, indirect, and total effect between exogenous and endogenous variables in the modified model. Four independent variables had direct effects to caregiver burden included functional status ($\beta = -.45, p < .001$), duration of caregiving ($\beta = .24, p < .01$), hour of care ($\beta = .21, p < .05$), and self-efficacy ($\beta = -.20, p < .05$). Moreover, there were two variables had direct effects to QoL of caregiver included caregiver burden ($\beta = -.34, p < .05$) and self-efficacy ($\beta = .34, p < .05$).

One variable indirectly influenced QoL of caregivers through caregiver burden. It was self-efficacy (.07). In addition, functional status indirectly effected caregiver burden through hour of caregiving (-.03).

Total direct effect, for caregiver burden, functional status had the strongest effect on caregiver burden ($\beta = -.48, p < .001$). Next, positive effect on caregiver burden were duration of caregiving ($\beta = .24, p < .01$), hour of caregiving ($\beta = .21, p < .05$), and self-efficacy ($\beta = -.20, p < .05$). Furthermore, self-efficacy was the highest total effect on QoL of caregiver ($\beta = .41, p < .05$) then caregiver burden ($\beta = -.34, p < .05$). See Table 8.

Tables 8 Effects of variables in the final model of factors influencing QoL of stroke family caregivers

Variable	HO			SE			BU			QoL		
	DE	IE	TE	DE	IE	TE	DE	IE	TE	DE	IE	TE
Functional status	-.15*	-	-.15*	-	-	-	-.45***	-.03*	-.48***	-	-	-
Duration of caregiving	-	-	-	-	-	-	.24**	-	.24**	-	-	-
Hour of care	-	-	-	-	-	-	.21*	-	.21*	-	-	-
Social support	-	-	-	.28**	-	.28**	-	-	-	-	-	-
Self-efficacy	-	-	-	-	-	-	-.20*	-	-.20*	.34*	.07*	.41*
Burden	-	-	-	-	-	-	-	-	-	-.34*	-	-.34*

Note. DE = Direct effect, IE = Indirect effect, TE = Total effect, FU = Functional, DC = Duration of caregiving, HO = Hour of care,

SS = Social support, SE = Self-efficacy, BU = Burden, QoL= Quality of life

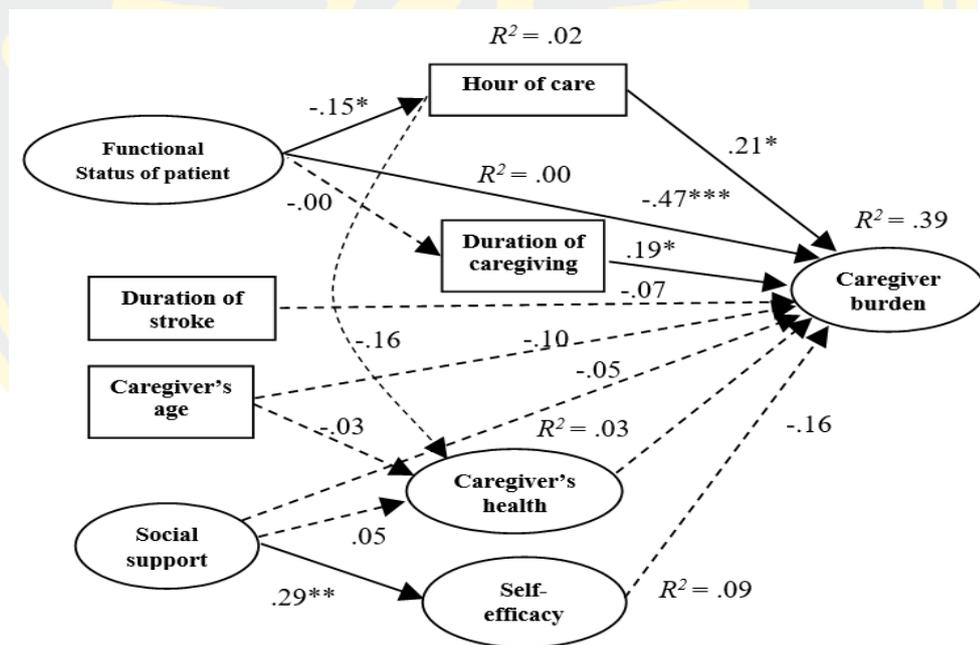
* $p < .05$, ** $p < .01$, *** $p < .001$

However, the result of model testing revealed that QoL of caregivers was the outcome of caregiver burden. For improving quality of care for stroke survivors, therefore, the researcher would drop QoL of caregivers variable and examine influencing factors of caregiver burden. The hypothesized model of caregiver burden with the same set of variable in the original hypothesized model was examined as follows.

2. Model of factors influencing burden among stroke family caregivers

2.1 The hypothesized model

The goodness fit indices showed that $CMIN = 379.66$, $df = 162$, $p < .001$, $CMIN/df = 2.34$, $GFI = 0.86$, $AGFI = 0.82$, $CFI = 0.80$, and $RMSEA = 0.08$ as presented in Figure 4. However, the results showed that hypothesized model did not fit the data well as follows.



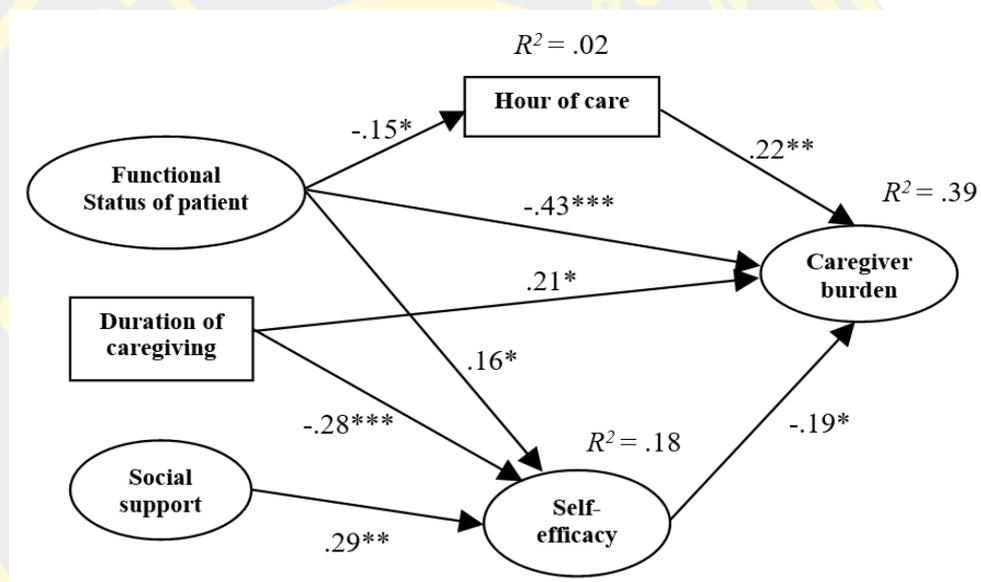
* $p < .05$, ** $p < .01$, *** $p < .001$

Figures 4 The hypothesized model of factors influencing burden among stroke family caregivers

2.2 The modified model

In this hypothesized model, the researcher modified model by considering the conceptual and modification indices. The model trimming was used with low standardized factor loading and non-significant parameter. The model was modified by adding 2 parameters including the path from functional status of patient to self-efficacy and the path from duration of caregiving to self-efficacy. Finally, the final modified model was data fitted well as presented in Figure 5.

2.3 The final model



* $p < .05$, ** $p < .01$, *** $p < .001$

Figures 5 Final model of factors influencing burden among stroke family caregivers

The results of a final acceptable model revealed that $CMIN = 99.0$, $df = 84$, $p = .13$, $CMIN/df = 1.18$, $GFI = 0.94$, $AGFI = 0.91$, $CFI = 0.98$, and $RMSEA = 0.03$. It indicated that the modified model fit the data well. Goodness of fit indices between the hypothesized model and the modified model were presented in Table 9.

Tables 9 Fit indices in model of factors influencing burden among stroke family caregivers

	CMIN (χ^2)	CMIN / df	GFI	AGFI	CFI	RMSEA
Acceptable levels	$p > .05$	< 2	.90-1.0	.90-1.0	.90-1.0	$< .08$
Hypothesized model	$\chi^2 = 379.66,$ $p < .001, df = 162$	2.34	.86	.82	.80	.08
Modified model	$\chi^2 = 99.0,$ $p = .13, df = 84$	1.18	.94	.91	.98	.03

There were four independent variables had direct effects to caregiver burden included functional status ($\beta = -.43, p < .001$), duration of caregiving ($\beta = .21, p < .05$), hour of care ($\beta = .22, p < .01$), and self-efficacy ($\beta = -.19, p < .05$). Functional status and duration of caregiving had indirect effects to caregiver burden through self-efficacy ($\beta = -.06$ and $\beta = -.05, p < .05$). Total direct effect, functional status had the strongest effect on caregiver burden ($\beta = -.49, p < .001$). Next, hour of caregiving ($\beta = .22, p < .01$), duration of caregiving ($\beta = .21, p < .05$), and self-efficacy ($\beta = -.19, p < .05$) as presented in Table 10.

Tables 10 Effects of variables in final model of factors influencing burden among stroke family caregivers

Variable	HO			SE			BU		
	DE	IE	TE	DE	IE	TE	DE	IE	TE
Functional status	-.15*	-	-.15*	.16*	-	.16*	-.43***	-.06*	-.49***
Duration of caregiving	-	-	-	-.28***	-	-.28***	.21*	-.05*	.16*
Hour of care	-	-	-	-	-	-	.22**	-	.22**
Social support	-	-	-	.29**	-	.29**	-	-	-
Self-efficacy	-	-	-	-	-	-	-.19*	-	-.19*

Note. DE = Direct effect, IE = Indirect effect, TE = Total effect, HO = Hour of care, SE = Self-efficacy, BU = Burden

CHAPTER 5

DISCUSSION AND CONCLUSION

This chapter consists of three parts. The first part is a summary of the study and the results. The second part discusses the findings of the study. Lastly, there is the discussion of study limitations, strengths, and recommendations.

Summary of the study

The purpose of the study was to test the model of caregiver burden of stroke family caregivers. The researcher used convenience sampling to recruit a sample of caregivers who were taking care of stroke survivors during the first six months after a stroke. There were 200 stroke family caregivers from Saraburi hospital and Phra Nakhon Sri Ayutthaya hospital. Research instruments included a form to collect demographic information of stroke caregivers and stroke survivors, the Zarit Burden Interview [ZBI], the Health Perception Scale for Thai adults [HPS-T], the Barthel Index [BI], the General Perceived Self-efficacy Scale [GSES], the revised Multi-dimensional Scale of Perceived Social Support [rMSPSS], and the WHOQOL-BREF-THAI Version. The Cronbach's alphas of ZBI, HPS-T, BI, GSES, rMSPSS, and WHOQOL-BREF-THAI were .80, .70, .88, .88, .85, and .74, respectively.

Most of the caregivers were female (79.5%) and married (70.0%). Less than half reported having offspring (44.0%). The caregivers' mean age was 44.55 years ($SD = 11.75$), ranging between 41 and 60 years old (50.0%), completed primary school (31.5%), and were merchants (36.0%) with a mean family income of 25,587.50 baht/month ($SD = 18,045.76$). The average length of time of caregiving was 3.29 months ($SD = 1.34$) and the average number of hours per day spent for caregiving was 7.12 ($SD = 2.92$). Half of the caregivers reported no chronic or underlying disease.

Over half of the stroke survivors were male (58.5%). The majority of stroke survivors had sustained an ischemic stroke (88.0%). Most had underlying conditions of hypertension and dyslipidemia (73.0%). The mean age was 59.24 years ($SD = 12.53$) and average time post stroke was 3.67 months ($SD = 1.50$).

The results showed that the hypothesized model of caregiver burden did not fit the data well (CMIN = 379.66, $df = 162$, $p < .001$, CMIN/ $df = 2.34$, GFI = 0.86, AGFI = 0.82, CFI = 0.80, and RMSEA = 0.08). After modification, the final caregiver burden model showed that the functional status of stroke survivor, number of hours of caregiving, duration of caregiving, and self-efficacy had a significantly direct effect on caregiver burden. The functional status of the stroke survivor had a significantly indirect effect on caregiver burden through the number of hours of caregiving and self-efficacy. Moreover, the duration of caregiving had a significantly indirect effect on caregiver burden through self-efficacy. Goodness of fit indices were CMIN = 99.0, $df = 84$, $p = .13$, CMIN/ $df = 1.18$, GFI = 0.94, AGFI = 0.91, CFI = 0.98, and RMSEA = 0.03.

The results of the hypothesized model of caregivers' quality of life [QoL] also did not fit the data well (CMIN = 447.02, $df = 219$, $p < .001$, CMIN/ $df = 2.04$, GFI = 0.86, AGFI = 0.82, CFI = 0.80, and RMSEA = 0.07). After modifying the caregivers' QoL model, the final model showed that the functional status of the stroke survivors, number of hours of caregiving, duration of caregiving, and self-efficacy had a significantly direct effect on caregiver burden. Caregiver burden and self-efficacy of caregivers had direct effects on the caregivers' QoL. Also, self-efficacy had an indirect effect on caregivers' QoL through caregiver burden. Goodness of fit indices were CMIN = 182.35, $df = 131$, $p < .001$, CMIN/ $df = 1.39$, GFI = 0.91, AGFI = 0.88, CFI = 0.95, and RMSEA = 0.04. The final model explained 37% ($R^2 = .37$) of the variances.

Discussion of research findings

The purpose of this study was to test a causal model of the burden of stroke on family caregivers. Thus, the researcher discusses the findings below.

Level of burden among family caregivers of stroke patients

Providing care to stroke survivors after 6 months of the occurrence can lead to caregiver burden. From this study's findings, family caregivers of stroke survivors reported that they perceived burden ($M = 29.89$, $SD = 12.50$). The result is consistent with previous studies in that stroke families experience a mild burden in giving care (Gbiri, 2015; Limpawatta, 2015) or a mild to moderate burden of care Kumar et al.

(2015). This can be explained that having a stroke is an unexpected situation for a family and requires an adjustment for caregivers. Undertaking caregiving tasks with responsibilities for survivors requires effort from caregivers. Caregivers have to arrange their time to take care of survivors throughout the day and also manage their lifestyle limitations. As time passes, caregivers may become more uncomfortable with their life (Gorgulu, 2016). This might explain why the mean scores of personal strain dimension of caregiver burden in this study were high ($M = 9.92$ and 7.09 , respectively).

However, the results of this study showed that the mean of family caregivers' burden did not high level. It can be explained that most caregivers were a son or daughter (44%) or a spouse (37%), therefore family caregivers not only had negative aspects to their lives but also had positive views of giving care. Akosile et al. (2011) and Asiret and Kapucu (2013) also found that the majority of caregivers were a child or a spouse. They reported positive and strong relationships and the children said they could express gratitude to their parents by giving care. Although new roles can emerge out of the initial caregiving relationship, children and spouses take loving care of the survivors with positive attitudes, beliefs, and expectations about their duty to provide care (Montgomery & Kosloski, 2009). Mackenzie and Greenwood (2012) found in a systematic review of the literature that stroke caregivers often reported satisfaction with caregiving. They saw their activities and responsibilities as reciprocation for past caring and felt they were a better person for doing so. In Thailand, Jantayananont et al. (2011) also reported that some stroke caregivers had positive thinking in taking care of their stroke survivor, and they felt no burden because they had compassion and believed it was their responsibility to do.

For duration of caregiving, because the average duration of caregiving in this study was 3.29 months ($SD = 1.34$), it might be that the relatively short time period produced less burden. Jaracz et al. (2015) reported that after 6 months of a person having a stroke, caregivers experienced severe strain. In the early months after a stroke, many caregivers may require increased attention and assistance from health care providers in order to mitigate their current difficulties.

Factors influencing QoL of caregivers

Findings from this study showed that self-efficacy had a direct effect on caregiver burden and the QoL of caregivers. Moreover, self-efficacy had an indirect effect on the QoL of caregivers through caregiver burden. The functional status of the stroke survivor and social support did not have a direct effect on the QoL of caregivers. This indicates that caregiver burden mediated the relationship between self-efficacy and QoL of caregivers, thus demonstrating that family caregivers with high self-efficacy had low levels of burden and high levels of QoL.

Based on Modified Stress Process Model [MSPM], caregiver burden as an outcome of caregiving had a direct effect on their QoL. Moreover, caregiver burden was affected by several factors as stressors. These results are consistent with previous studies (Caro et al., 2018; Jeong et al., 2015; Rawat et al., 2017; Tsai et al., 2016) in that high burden was a predictor of low levels of QoL. An explanation might be that most of the caregivers in that study were either a son or daughter ($n = 88$) or a spouse ($n = 71$) who lived with the stroke survivor. During each day, family caregivers have responsibilities to assist their relatives in dressing, mobility, and movement. However, they still need private time to manage their own lives and work within a limited timeframe. Caregivers can experience strain in post subacute phases of stroke because the first few months of caregiving are the most difficult (Jaract et al, 2015). If they perceive their circumstance to be poor, their QoL will probably be affected.

In terms of self-efficacy in this study, family caregivers with a strong sense of self-efficacy were associated with a better QoL. The result is consistent with the findings of Warapornmongkholkul, Howteerakul, Suwannapong, & Soparattanapaisarn (2017) who showed that self-efficacy had a direct effect on the QoL of caregivers. This can be explained because caregivers who believe in their own ability to respond to difficult situations and to deal with any associated obstacles believe they can manage their life problems.

However, the functional status of patients did not have a direct effect on the QoL of caregivers. This finding contrasts with the study of Ogunlana et al. (2014) who found that a lower functional status of stroke survivors was significantly related to a lower QoL of caregivers. A possible explanation could be that some family caregivers are less dependent on the stroke survivor's functional status. It indicates

that stroke survivors may be more able to perform activities of daily living and manage their basic needs without monitoring or assistance. Therefore, functional status of the stroke survivor in this study did not influence QoL of caregivers.

Social support was not significantly correlated with QoL of caregivers in this study, contrary to expectations. This finding might be because the majority of family caregivers were either children or a spouse. They were more willing to take care of their spouse or parents with a positive attitude. Also, half of the caregivers had no underlying or chronic diseases, so it might have been possible that family caregivers did not feel the need to seek help from others. They felt confident in their ability to provide support to their father, mother, or spouse. Hence, social support had no effect on the QoL of caregivers

Factors influencing family caregiver burden

In this study, the functional status of stroke survivors, the number of hours of care, duration of caregiving, and self-efficacy had a direct effect on caregiver burden. Furthermore, the functional status of stroke survivors had an indirect effect on caregiver burden through the number of hours of care and self-efficacy. Duration of caregiving had an indirect effect on caregiver burden through self-efficacy. This indicates that the number of hours of care and self-efficacy were mediators. A caregiver's age and the duration of stroke also did not have a direct effect on caregiver burden.

The findings partially support the Modified Stress Process Model [MSPM] in that stroke family caregiver burden as an outcome was directly affected and interrelated among components by two caregiver characteristics (number of hours of care and duration of caregiving) and two stressors (functional status of the stroke survivor and self-efficacy).

Functional status of stroke survivors had a direct effect on family caregiver burden. This is consistent with previous studies that have shown that stroke survivors who have lower functional status also have a significantly higher caregiver burden (Asiret & Kapucu, 2013; Badaru et al., 2017; Çelik & Kara, 2019; Han et al., 2017; Ogunlana et al., 2014). One explanation might be that after having a stroke, survivors are disabled and need assistance. Family caregivers have many difficult tasks to do for stroke survivors, including assisting with mobility, walking, and rehabilitation in

order to improve the survivors' functioning. It is possible that more responsibilities and time to take care of disabled survivors affects caregiver burden.

The results also showed that functional status of stroke survivors indirectly influenced family caregiver burden through the number of hours of care and self-efficacy. Stroke survivors with a low functional status may require more assistance. In this study, caregivers averaged 7.12 hours per day in providing care to stroke survivors. Caring for stroke survivors with high functional dependency has been associated with poor physical, mental health for the caregiver (Em et al., 2017) and cause more stress for the caregiver (Ogunlana et al., 2014). Thus, when caregivers spend more time in taking care for survivors, they may perceive a higher burden.

The findings are congruent with researchers who have shown that the number of hours and duration of caregiving are associated with caregiver burden (Asiret & Kapucu, 2013; Han et al., 2017). There were likely to be many hours of care and responsibilities for the caregivers. Studies conducted in countries, such as Taiwan, Turkey, Nigeria, and Poland, have shown that time duration of providing care at home average 4.15-13.5 hours each day (Asiret & Kapucu, 2013; Chang et al., 2010); Gbiri et al., 2015; Jaracz et al., 2012). Gbiri et al. (2015) reported the number of hours of caregiving to be a main factor that influences caregivers' burden especially when initial care of someone having a stroke requires constant attention, causing caregivers to be tired, exhausted, and quickly burn out (Woodford et al., 2018). Thus, long hours of caregiving increase caregiver burden.

Duration of caregiving had a directly effect on family caregiver burden. This finding is consistent with several studies showing duration of caregiving associated with caregiver burden (Asiret & Kapucu, 2013; Chang et al., 2010; Tosun & Temel, 2017). In this study, although the average length of time for being a caregiver was 3.29 months ($SD = 1.34$), the caregivers perceived a burden. The role of family caregiver during the first phase after a stroke occurrence requires caregivers to adjust to new duties and responsibilities of taking care of the stroke survivor. This reduces their personal time to take care of their own life needs and time to participate in social activities (Chang et al., 2010; Kamel et al., 2012).

Additionally, the duration of caregiving had a negative indirect influence on family caregiver burden through self-efficacy. It is possible that caregivers who had a

long duration of caregiving had low self-efficacy due to the pathology of post stroke. In the sub-acute phase, most stroke survivors have spasticity in their upper or lower limbs. There is a risk of joint stiffness (Malhotra et al, 2011; Sackley et al, 2008). This problem affects the ability to move for stroke survivors. Although caregivers attempt to provide care and assist stroke survivors, it is slow and difficult to recover limb mobility because of the long recovery process. Therefore, caregivers who have low confidence in their ability to adequately take care of the survivors could also experience high levels of burden. On the other hand, caregivers who have high self-efficacy experience lower levels of burden (Kruithof, 2016).

Kruithof et al. (2016) found that self-efficacy among caregivers was directly and negatively associated with burden during the sub-acute phase. Perhaps, the perception of self-efficacy directly affects the ability to set goals and carry them out. The expected outcomes are dependent on self-efficacy judgments (Resnick, 2013). People's expectations help direct how much dedication they will apply to the task at hand. If people believe more in their abilities, they will apply more effort. They can change their behavior and are able to handle the situation (Bandura, 1977). Because most of the caregivers in this study were sons and daughters, they made an effort to provide care their parents coupled with a set of positive beliefs and expectations (Montgomery & Kosloski, 2009). Thus, caregivers with high self-efficacy expect more of themselves, spend more effort, and endure longer than those with low self-efficacy Kruithof et al. (2016) in order to recover/ maintain the health of their love one. Finally, when caregivers recognized that they could handle the situation, they perceived a lower burden. According to the study's findings, social support was an important resource that helped individuals cope with stress and enhance their self-confidence to control or manage then problems. Caregivers could have high self-efficacy when they received social support.

However, there was a statistically non-significant relationship between caregiver's age and caregiver burden. This is similar to the studies by Gbiri et al. (2015) and Jaracz et al. (2012). They found that the age of the caregiver was not related to caregiver burden. This finding contrasts, however, with Watanabe et al. (2015) who reported that caregivers' age had a positive correlation with caregiver burden. Han et al. (2017) also found that caregivers' age was a determinant of

caregiver burden. This could be explained by 42% of caregivers in this study who were 20-40 years old. It is possible that people in this stage of life are mature minded to assume more responsibilities of their life and their family. When they face a difficult task, they might understand problems and have the ability to find solutions. Thus, they believe in their ability to continue caregiving (Kruithof, 2016). Moreover, because participants were in their early to middle adulthood ($M = 44.6$, $SD = 11.8$), their health was good, and the risk of chronic diseases was relatively low. Therefore, providing care for six months did not produce caregiver burden. As Nir, Greenberger, and Bachner (2009) found, during the six months of caring for stroke survivors, the caregivers' health remained stable.

It was found that there was not statistical relationship between caregivers' age and caregivers' health status. This result contrasts with Long, Pinyopasakul, Pongthavornkamol, and Panitrat (2019) who reported that caregiver's age was a predictor of a caregiver's health status. One explanation might be that caregivers perceived their health as good because they were relatively young in middle age and 52% of caregivers had no underlying disease. Moreover, half of the caregivers had a relatively narrow range of health status, likely reducing its relationship with the number of hours in caregiving. Furthermore, within 6 months of caregiving they were still adjusting to their new role. Health status would likely have had little effect on burden because middle-aged caregivers have a relatively low risk for health problems. Therefore, the number of caregiving hours did not have an indirect effect on caregiver burden through caregivers' health.

According to the findings, social support did not have a direct effect on caregiver burden. The stroke survivors were post stroke from 1- 6 months. Thus, family caregivers were in their role for 6 months or less. There was little statistical variability in the duration of the stroke and, at this point, had little influence on caregiver burden. Moreover, social support did not have a direct effect on health status of these caregivers. This can be explained that half of the caregivers had no underlying or chronic diseases and they perceived themselves to be in good health. This result contrasts with Clay et al. (2013) and Yu et al. (2013). In their studies, they found that social support was linked to the caregivers' health.

Conclusion

According to the main objectives of this study, there were eight factors that would influence family caregiver burden of stroke survivors. However, after modification of model structures, four factors remained. Functional status of stroke survivors was the strongest factor influencing family caregiver burden. Self-efficacy of caregivers and the number of hours of caregiving were mediators of caregiver burden.

The results of this study are partially explained by the Modified Stress Process Model [MSPM]. By model testing, it was shown that caregiver characteristics, primary and secondary stressors, moderators, and outcomes were interrelated. However, the statistical models did not show the interrelationships among caregivers' age, caregivers' health status, duration of stroke, caregiver burden, and the QoL of caregivers. Therefore, further research with larger sample sizes may be needed to show more interrelationships as proposed by the MSPM.

Limitations of the study

There were limitations in this study. A convenience sample and small geographical setting limited the ability to generalize to other populations. In this study, the researcher used the minimum sample size that was sufficient to test the statistical models because of the difficulty in finding first time stroke occurrences. Moreover, the sample was selected from two hospitals in the central region of Thailand. Therefore, it might inadequately represent other populations of interest in other settings.

Some questionnaires were developed in Western context and some were not specific to Thai stroke caregivers. The Zarit Burden Interview [ZBI] questionnaire was focused on subjective burden but it did not cover all aspects of caregiver burden. This may have been one reason that the results of this study did not correlate with some factors in the model.

Recommendations for future research

1. Because the functional status of a stroke survivor was the strongest factor that contributed to caregiver burden, nurses in hospitals and the community should evaluate the level of functional status of stroke survivors before they are discharged. Moreover, confidence and self-efficacy among family caregivers should be enhanced so that they can learn to solve problems in taking care of stroke survivors. Healthcare providers should pay attention to how to decrease the number of hours of care per day and the duration of caregiving by caregivers by fostering family support. Other family members should be involved in providing care in order to decrease feelings of isolation and to increase the personal time of family caregivers during the caregiving process.

2. The findings of this study extend the current knowledge of caregiver burden of stroke family caregivers and provide direction to develop intervention programs for stroke family caregivers to decrease caregiver burden, such as a self-efficacy training program to be offered during the first six months after a stroke occurrence.

3. Further research could be conducted with larger sample sizes and randomly sampled participants, if possible, in several settings to have a better understanding of the burden and QoL of caregivers.

4. Nursing interventions for increasing the self-efficacy of caregivers to reduce caregiver burden and enhance the quality of life of stroke caregivers should be developed based on this finding.

5. It would be useful to develop a caregiver burden tool to assess all aspects of burden more suitable to understand stroke family caregivers in Thai context.

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APPENDICES



APPENDIX A

Institution review board



**THE INSTITUTIONAL REVIEW BOARD (IRB) FOR GRADUATE STUDIES
FACULTY OF NURSING, BURAPHA UNIVERSITY, THAILAND**

Thesis Title Factors Influencing Burden among Stroke Family Caregivers

Name Ms. Suneerat Boonsin
ID: 59810013
Doctor of Philosophy in Nursing Science (International Program)

Number of the IRB approval 03 – 11 – 2561

The Institutional Review Board (IRB) for graduate studies of Faculty of Nursing, Burapha University reviewed your submitted proposal. The contingencies have been addressed and the IRB **approves** the protocol. Work on this project may begin. This approval is for a period of one year from the date of this letter and will require continuation approval if the research project extends beyond **December 7th, 2019**.

If you make any changes to the protocol during the period of this approval, you must submit a revised protocol to the IRB committee for approval before implementing the changes.

Date of Approval December 7th, 2018

Chintana Wacharasin, R.N., Ph.D.

Chairperson of the IRB
Faculty of Nursing, Burapha University, THAILAND

Tel.: 66-038-102823
Fax: 66-038-393476
E-Mail: naruemit@buu.ac.th



คณะกรรมการจริยธรรมการวิจัยในมนุษย์ โรงพยาบาลพระนครศรีอยุธยา
46/1 หมู่ 4 ถ.อุทอง ต.ประตู่ชัย อ.พระนครศรีอยุธยา จ.พระนครศรีอยุธยา
โทร 035-211888 ต่อ 2318

เอกสารรับรองโครงการวิจัย

คณะกรรมการจริยธรรมการวิจัยในมนุษย์ โรงพยาบาลพระนครศรีอยุธยา ดำเนินการให้รับรองโครงการวิจัยตามแนวทางหลักจริยธรรมการวิจัยในมนุษย์ ที่เป็นมาตรฐานสากลได้แก่ Declaration of Helsinki, The Belmont Report, CIOMS Guideline และ International Conference on Harmonization in Good Clinical Practice หรือ ICH-GCP

ชื่อโครงการ : ปัจจัยที่มีอิทธิพลต่อภาวะการดูแลในญาติผู้ดูแลผู้ป่วยโรคหลอดเลือดสมอง
เลขที่โครงการวิจัย : 035/2561
ผู้วิจัยหลัก : นางสาวสุนีย์รัตน์ บุญศิลป์
สังกัดหน่วยงาน : คณะพยาบาลศาสตร์ มหาวิทยาลัยบูรพา
วิธีทบทวน : คณะกรรมการเต็มชุด (Full Board)
รายงานความก้าวหน้า : ส่งรายงานความก้าวหน้าอย่างน้อย 1 ครั้ง/ปี หรือส่งรายงานฉบับสมบูรณ์หากดำเนินโครงการเสร็จสิ้นก่อน 1 ปี / ส่งรายงานความก้าวหน้าอย่างน้อยทุก 6 เดือน / ส่งรายงานความก้าวหน้าอย่างน้อยทุก 3 เดือน
เอกสารรับรอง : - โครงร่างวิจัย / - แบบยินยอมเข้าร่วมการวิจัย / - แบบสอบถามเพื่อการวิจัย

ลงนาม.....
(ดร.พญ.ประกายทิพ สุศิลป์รัตน์)

ประธานคณะกรรมการจริยธรรมการวิจัยในมนุษย์

ลงนาม.....
(นายธีร์รัฐ พงศ์เลิศอารี)

กรรมการและเลขานุการ
คณะกรรมการจริยธรรมการวิจัยในมนุษย์

วันที่รับรอง : 12 S.A. 2561

วันหมดอายุ : 11 S.A. 2562

ทั้งนี้ การรับรองนี้มีเงื่อนไขดังที่ระบุไว้ด้านหลังทุกข้อ (ดูด้านหลังของเอกสารรับรองโครงการวิจัย)

นักวิจัยทุกท่านที่ผ่านการรับรองจริยธรรมการวิจัยต้องปฏิบัติดังต่อไปนี้

1. ดำเนินการวิจัยตามที่ระบุไว้ในโครงร่างการวิจัยอย่างเคร่งครัด
2. ใช้เอกสารแนะนำอาสาสมัคร ใบยินยอม (และเอกสารเชิญเข้าร่วมวิจัยหรือใบโฆษณาถ้ามี) แบบ สัมภาษณ์ และหรือ แบบสอบถาม เฉพาะที่มีตราประทับของคณะกรรมการพิจารณาจริยธรรมเท่านั้น และ ส่งสำเนาเอกสารดังกล่าวที่ใช้กับผู้เข้าร่วมวิจัยจริงรายแรกมาที่.....เพื่อเก็บไว้เป็นหลักฐาน
3. รายงานเหตุการณ์ไม่พึงประสงค์ร้ายแรงที่เกิดขึ้นหรือการเปลี่ยนแปลงกิจกรรมวิจัยใดๆ ต่อคณะกรรมการ พิจารณาจริยธรรมการวิจัย ภายใน 5 วันทำการ
4. ส่งรายงานความก้าวหน้าต่อคณะกรรมการจริยธรรมการวิจัย ตามเวลาที่กำหนดหรือเมื่อได้รับการร้องขอ
5. หากการวิจัยไม่สามารถดำเนินการเสร็จสิ้นภายในกำหนด ผู้วิจัยต้องยื่นขออนุมัติใหม่ก่อนอย่างน้อย 1 เดือน
6. เอกสารทุกฉบับที่ได้รับการรับรองครั้งนี้ หมดอายุตามอายุของโครงการวิจัยที่ได้รับการรับรองก่อนหน้านี้ (หมายเลขโครงการ.....)

คู่มือการดำเนินงานของคณะกรรมการจริยธรรมการวิจัยในคน โรงพยาบาลสระบุรี ฉบับที่ ๒

18 ถนนเทศบาล 4

อำเภอเมือง จังหวัดสระบุรี



โทรศัพท์ 036-343500

โทรสาร 036-211624

เอกสารรับรองโครงการ

คณะกรรมการจริยธรรมการวิจัยในคน โรงพยาบาลสระบุรี

หมายเลข 174/2018

ชื่อโครงการภาษาไทย : ปัจจัยที่มีอิทธิพลต่อการดูแลในญาติผู้ดูแลผู้ป่วยโรคหลอดเลือดสมอง "Factors influencing burden among stroke family caregivers"

รหัสโครงการ : EC198/02/2018

หัวหน้าโครงการ : นางสาวสุนีย์รัตน์ บุญศิลป์

สถานที่ทำวิจัย : โรงพยาบาลสระบุรี

เอกสารที่รับรอง :

1. แบบเสนอโครงการวิจัยเพื่อขอรับการพิจารณาจากคณะกรรมการจริยธรรมการวิจัยในคน
2. โครงร่างการวิจัย
3. แบบสอบถาม
4. ประวัติผู้วิจัย

วันที่รับรอง : 26 ธันวาคม 2561

วันหมดอายุ : 26 ธันวาคม 2562

คณะกรรมการจริยธรรมการวิจัยในคน โรงพยาบาลสระบุรี ดำเนินการให้การรับรองโครงการวิจัยตามแนวทางหลังจริยธรรมการวิจัยในคนที่เป็นสากล ได้แก่ Declaration of Helsinki, The Belmont Report, CIOMS Guidelines และ The International Conference on Harmonization in Good Clinical Practice (ICH-GCP)

.....
 (นายแพทย์ณรงค์ศักดิ์ วัชรโรจน)
 ประธานคณะกรรมการจริยธรรมการวิจัยในคน

28 ธ.ค. 2561

วันที่

.....

(นายแพทย์อนันต์ กมลเนตร)

ผู้อำนวยการโรงพยาบาลสระบุรี

08 ม.ค. 2562

วันที่

กลุ่มงานพัฒนาทรัพยากรบุคคล
 รับวันที่... 7 มิ.ย. 2562
 เลขที่... 00085
 เวลา..... น.

โรงพยาบาลพระนครศรีอยุธยา
 รับวันที่... 7 มิ.ย. 2562
 เลขที่... 00181
 เวลา..... น.



ที่ ศร ๒๒๐๖/๒๕๖๒

มหาวิทยาลัยบูรพา คณะพยาบาลศาสตร์
 ๑๖๙ ถนนลงทาดบางแสน ตำบลแสนสุข
 อำเภอเมือง จังหวัดชลบุรี ๒๐๑๓๑

๒๓ ธันวาคม ๒๕๖๑

เรื่อง ขออนุญาตเผยแพร่หนังสือเก็บรวบรวมข้อมูลเพื่อดำเนินการวิจัย

เรียน ผู้อำนวยการโรงพยาบาลพระนครศรีอยุธยา

- สิ่งที่ส่งมาด้วย ๑. ผลการพิจารณาจริยธรรมการวิจัย
 ๒. เครื่องมือที่ใช้ในการวิจัย

ด้วย นางสาวสุนีย์รัตน์ บุญศิลป์ นิสิตหลักสูตรปรัชญาดุษฎีบัณฑิต สาขาวิชาพยาบาลศาสตร์ (หลักสูตรนานาชาติ) คณะพยาบาลศาสตร์ มหาวิทยาลัยบูรพา ได้รับอนุมัติเค้าโครงดุษฎีนิพนธ์ เรื่อง "FACTORS INFLUENCING BURDEN AMONG STROKE FAMILY CAREGIVERS" โดยมี รองศาสตราจารย์ ดร.อาภรณ์ ตีนาน เป็นอาจารย์ที่ปรึกษาดุษฎีนิพนธ์หลัก

ในการนี้ คณะฯ จึงขออนุญาตจากท่านอำนวยความสะดวกให้นิสิตเก็บรวบรวมข้อมูลจากกลุ่มตัวอย่างคือ ญาติผู้ดูแลหลักที่มีอายุ ๑๘ ปีขึ้นไป ได้ดูแลผู้ป่วยโรคหลอดเลือดสมอง อย่างน้อย ๑ เดือน ณ ห้องตรวจอายุรกรรม แผนกหอผู้ป่วยนอก โรงพยาบาลพระนครศรีอยุธยา จังหวัดพระนครศรีอยุธยา จำนวน ๕๐ ราย ระหว่างวันที่ ๔ กุมภาพันธ์ - ๓๑ กรกฎาคม พ.ศ. ๒๕๖๒

จึงเรียนมาเพื่อโปรดพิจารณาให้ความอนุเคราะห์ด้วย จะเป็นพระคุณยิ่ง

- เรียน ผู้อำนวยการ () เพื่อโปรดอนุมัติ
 () เพื่อโปรดพิจารณา
 () เพื่อโปรดทราบ

ขอแสดงความนับถือ

(ผู้ช่วยศาสตราจารย์ ดร.พรชัย จุลเมตต)
 คณบดีคณะพยาบาลศาสตร์ ปฏิบัติการแทน
 ผู้ปฏิบัติหน้าที่อธิการบดีมหาวิทยาลัยบูรพา

- ร. บูรพา คณะพยาบาลศาสตร์ ขอความอนุเคราะห์
 ให้นำหนังสือเก็บรวบรวมข้อมูลเพื่อ ดำเนินการวิจัย
 จากกลุ่มตัวอย่าง ญาติผู้ดูแลโรคหลอดเลือดสมอง
 ณ แผนกผู้ป่วยนอก อ.ม.อยุธยา
 ให้ครบถ้วน - กก. จริยธรรมวิจัยฯ มทบ.๒๕

ส่งกลุ่มงาน พรศ.

- ๗ มิ.ย. ๒๕๖๒

7/๖๒

๓/๗๗๗

8/11/11

งานบริการการศึกษา (บัณฑิตศึกษา)
 โทรศัพท์ (๐๓๘) ๑๐๒๘๓๖, ๑๐๒๘๐๘
 โทรสาร (๐๓๘) ๓๑๓๔๙๖
 ผู้วิจัยโทร ๐๘-๑๒๑๖-๓๒๔๓

ส่งผู้เกี่ยวข้อง... ทาว Email. นาง กนก ธีรวิญ ทรน

ที่ ศธ ๖๒๐๖/๒๕๖๓



มหาวิทยาลัยบูรพา คณะพยาบาลศาสตร์
๑๖๙ ถนนลงหาดบางแสน ตำบลแสนสุข
อำเภอเมือง จังหวัดชลบุรี ๒๐๑๓๑

๒๓ ธันวาคม ๒๕๖๑

เรื่อง ขอความอนุเคราะห์ให้นิสิตเก็บรวบรวมข้อมูลเพื่อตรวจสอบคุณภาพเครื่องมือการวิจัย และเพื่อดำเนินการวิจัย
เรียน ผู้อำนวยการโรงพยาบาลสระบุรี

- สิ่งที่ส่งมาด้วย ๑. ผลการพิจารณาจริยธรรมการวิจัย
- ๒. เครื่องมือที่ใช้ในการวิจัย

ร.พ. สระบุรี
เลขที่ 0000๖๖
วันที่ 3 ธ.ค. 2562
เวลา

ด้วย นางสาวสุนีย์รัตน์ บุญศิลป์ นิสิตหลักสูตรปริญญาตรีบัณฑิต สาขาวิชาพยาบาลศาสตร์ (หลักสูตรนานาชาติ) คณะพยาบาลศาสตร์ มหาวิทยาลัยบูรพา ได้รับอนุมัติเค้าโครงดุษฎีนิพนธ์ เรื่อง "FACTORS INFLUENCING BURDEN AMONG STROKE FAMILY CAREGIVERS" โดยมี รองศาสตราจารย์ ดร.อารักษ์ ตีนาน เป็นอาจารย์ที่ปรึกษาดุษฎีนิพนธ์หลัก

ในการนี้ คณะฯ จึงขอความอนุเคราะห์จากท่านอำนวยความสะดวกให้นิสิตเก็บรวบรวมข้อมูลจากกลุ่มตัวอย่างคือ ญาติผู้ดูแลหลักที่มีอายุ ๑๘ ปีขึ้นไป ได้ดูแลผู้ป่วยโรคหลอดเลือดสมอง อย่างน้อย ๑ เดือน หวังตรวจอายุรกรรม แผนกหอผู้ป่วยนอก โรงพยาบาลสระบุรี จังหวัดสระบุรี โดยกำหนดการเก็บรวบรวมข้อมูล ๒ ช่วงเวลาดังนี้

- ๑. เก็บรวบรวมข้อมูลเพื่อตรวจสอบคุณภาพเครื่องมือ จำนวน ๓๐ ราย ระหว่างวันที่ ๒-๓๑ มกราคม พ.ศ. ๒๕๖๒
- ๒. เก็บรวบรวมข้อมูลเพื่อดำเนินการวิจัย จำนวน ๑๕๐ ราย ระหว่างวันที่ ๔ กุมภาพันธ์ - ๓๑ กรกฎาคม พ.ศ. ๒๕๖๒

จึงเรียนมาเพื่อโปรดพิจารณาให้ความอนุเคราะห์ด้วย จะเป็นพระคุณยิ่ง

เรื่อง ขอ เพื่อโปรดทราบ

ม.บูรพา คณะพยาบาลศาสตร์
ขอความอนุเคราะห์ให้นิสิตเก็บรวบรวม
ข้อมูลเพื่อตรวจสอบคุณภาพเครื่องมือ
การวิจัย ระหว่างวันที่ 2-31 ม.ค. 62
และเพื่อเก็บรวบรวมข้อมูลดุษฎีนิพนธ์วิจัย

266172 ระหว่างวันที่ 4 กพ - 31 ก.ค. 62
งานบริการการศึกษา (บัณฑิตศึกษา)
โทรศัพท์ (๐๓๘) ๐๑๒๘๓๖, ๐๑๒๘๐๘
โทรสาร (๐๓๘) ๓๙๓๔๗๖
ผู้วิจัยโทร ๐๘-๑๒๕๒-๓๒๕๑

ขอแสดงความนับถือ

(ผู้ช่วยศาสตราจารย์ ดร.พรชัย จุลเมตต์)
คณบดีคณะพยาบาลศาสตร์ ปฏิบัติการแทน
ผู้ปฏิบัติหน้าที่อธิการบดีมหาวิทยาลัยบูรพา

ผู้ส่งแทน รองคณบดี
3 พ.ค. 62
ว.134.

๖๐๐
๗
3 ม 62



APPENDIX B

Permission instruments



619561/24711
24 ธ.ค. 2561
15.36.H.

9134
24 ธ.ค. 2561
10.30

คณะสาธารณสุขศาสตร์ มหาวิทยาลัยมหิดล
๔๒๐/๑ ถนนราชวิถี เขตราชเทวี กรุงเทพฯ ๑๐๔๐๐

โทร. ๐ ๒๓๕๔ ๘๕๕๗ ต่อ ๓๖๐๔

โทรสาร ๐ ๒๖๔๔ ๘๙๙๙

ที่ ศธ ๐๕๑๗.๑๔/๐๔๐๓๑

วันที่ ๒๑ ธันวาคม ๒๕๖๑

เรื่อง อนุญาตให้ใช้เครื่องมือวิจัย

เรียน คณบดีบัณฑิตวิทยาลัย

ตามหนังสือที่ ศธ ๐๕๑๗.๐๒/๑๒๒๗๕ ลงวันที่ ๖ ธันวาคม ๒๕๖๑ บัณฑิตวิทยาลัย มหาวิทยาลัยมหิดล ขออนุญาตใช้เครื่องมือวิจัย ของ นางกุลวดี โรจน์ไพศาลกิจ นักศึกษาหลักสูตรสาธารณสุขศาสตรดุษฎีบัณฑิต สาขาวิชาเอกสุขศึกษา คณะสาธารณสุขศาสตร์ มหาวิทยาลัยมหิดล โดยมี รองศาสตราจารย์ ดร.วสันต์ ศิลปสุวรรณ เป็นอาจารย์ที่ปรึกษาหลัก ดังความละเอียดแจ้งแล้วนั้น

ในการนี้ คณะสาธารณสุขศาสตร์ พิจารณาแล้ว ไม่ขัดข้อง ยินดีอนุญาตให้ใช้เครื่องมือวิจัยดังกล่าวได้

จึงเรียนมาเพื่อโปรดทราบ

ดร. สุนีย์ ละกำปັນ

(รองศาสตราจารย์ ดร. สุนีย์ ละกำปັນ)
รองคณบดีฝ่ายบัณฑิตศึกษา
ปฏิบัติหน้าที่แทนคณบดี คณะสาธารณสุขศาสตร์



คณะพยาบาลศาสตร์
มหาวิทยาลัยบูรพา
ที่ ๐๐๑๒๔
วันที่ 16 มี.ค. 2๖๖2
เรื่อง 14.26 %

งานบริการการศึกษา บัณฑิตวิทยาลัย
๒๕/๒๕ ถ.พุทธมณฑลสาย ๔ ศาลายา นครปฐม ๗๓๑๗๐
โทร. ๐-๒๔๔๑-๔๑๒๕ ต่อ ๑๐๐-๑๐๗ โทรสาร ๐-๒๔๔๑-๔๘๓๔

-วาน พินิจ

ที่ ศธ ๐๕๑๗.๐๒ / ๐๐๑๐๘
วันที่ ๓ มกราคม ๒๕๖๒
เรื่อง อนุญาตให้ใช้เครื่องมือวิจัย

เรียน คณบดีคณะพยาบาลศาสตร์ มหาวิทยาลัยบูรพา

ตามหนังสือที่ ศธ ๖๒๐๖/๒๒๔๔ ลงวันที่ ๒๗ พฤศจิกายน ๒๕๖๑ คณะพยาบาลศาสตร์ มหาวิทยาลัยบูรพา แจ้งว่า

ผู้ขอใช้เครื่องมือวิจัย : น.ส. สุนีย์รัตน์ บุญศิลป์ นักศึกษาหลักสูตรปรัชญาดุษฎีบัณฑิต สาขาวิชาพยาบาลศาสตร์ (หลักสูตรนานาชาติ) คณะพยาบาลศาสตร์ มหาวิทยาลัยบูรพา

งานวิจัยของผู้ขอใช้เครื่องมือ : “FACTORS INFLUENCING BURDEN AMONG STROKE FAMILY CAREGIVERS” โดยมี รศ.ดร. อารมณ์ ตีนาน เป็นอาจารย์ที่ปรึกษาหลัก

เครื่องมือวิจัยที่ขอใช้ : แบบวัดการรับรู้ภาวะสุขภาพสำหรับคนไทยวัยผู้ใหญ่

เครื่องมือวิจัยนี้พัฒนาโดย : นาง กุลวดี โรจนไพศาลกิจ ซึ่งเป็นส่วนหนึ่งของวิทยานิพนธ์ เรื่อง “การพัฒนาเครื่องมือวัดการรับรู้ภาวะสุขภาพสำหรับคนไทยวัยผู้ใหญ่” (พ.ศ. ๒๕๔๔) หลักสูตรสาธารณสุขศาสตรดุษฎีบัณฑิต สาขาวิชาเอกสุขภาพ คณะสาธารณสุขศาสตร์ มหาวิทยาลัยมหิดล โดยมี รศ.ดร. วสันต์ ศิลปสุวรรณ เป็นอาจารย์ที่ปรึกษาหลัก

บัณฑิตวิทยาลัยได้รับแจ้งจาก คณะสาธารณสุขศาสตร์ มหาวิทยาลัยมหิดล ว่าไม่ขัดข้อง และยินดีอนุญาตให้ น.ส. สุนีย์รัตน์ บุญศิลป์ ใช้เครื่องมือวิจัยดังกล่าวได้

จึงเรียนมาเพื่อโปรดทราบ และดำเนินการต่อไปด้วย จักขอบพระคุณยิ่ง

(รองศาสตราจารย์ ดร. วรารณ อัครปฐมวงศ์)

รองคณบดีฝ่ายวิชาการ

ปฏิบัติหน้าที่แทน คณบดีบัณฑิตวิทยาลัย

ที่ ศธ ๖๕๙๓(๘).๗/ ๑๒๐๒



ภาควิชาจิตเวชศาสตร์ คณะแพทยศาสตร์
มหาวิทยาลัยเชียงใหม่ ๕๐๒๐๐



ดร. วัฒนาทิพย์

๗ ธันวาคม ๒๕๖๑

เรื่อง อนุญาตให้ใช้เครื่องมือวิจัย

เรียน คณบดีคณะพยาบาลศาสตร์ มหาวิทยาลัยบูรพา

อ้างถึง หนังสือเลขที่ ศธ ๖๒๐๖/๒๒๙๗ ลงวันที่ ๒๗ พฤศจิกายน ๒๕๖๑

สิ่งที่ส่งมาด้วย แบบวัดความรู้สึกลากหลายมิติเกี่ยวกับความช่วยเหลือทางสังคม (ฉบับปรับปรุงภาษาไทย)
พร้อมวารสารอ้างอิง จำนวน ๑ ชุด

ตามที่ นางสาวสุนีย์รัตน์ บุญศิลป์ นิสิตหลักสูตรปรัชญาดุษฎีบัณฑิต สาขาวิชาพยาบาลศาสตร์ (หลักสูตรนานาชาติ) คณะพยาบาลศาสตร์ มหาวิทยาลัยบูรพา กำลังดำเนินการจัดทำเค้าโครงดุษฎีนิพนธ์ เรื่อง “FACTORS INFLUENCING BURDEN AMONG STROKE FAMILY CAREGIVERS” โดยได้ขอความอนุเคราะห์ใช้แบบสอบถามเครื่องมือวิจัย คือ แบบวัดความรู้สึกลากหลายมิติเกี่ยวกับความช่วยเหลือทางสังคม (ฉบับปรับปรุงภาษาไทย) จากรายงานการวิจัยเรื่อง A revised Thai Multi-dimensional Scale of Perceived Social Support (rMSPSS) ของ ศ.พญ.ณททัย วงศ์ปการันย์ มาใช้ในประกอบการทำวิทยานิพนธ์ ความแจ้งแล้วนั้น

ในการนี้ข้าพเจ้า ศ.พญ.ณททัย วงศ์ปการันย์ พิจารณาแล้วไม่ขัดข้อง อนุญาตให้ใช้เครื่องมือวิจัยดังกล่าวได้ ทั้งนี้ได้แนบตัวอย่างแบบวัดความรู้สึกลากหลายมิติเกี่ยวกับความช่วยเหลือทางสังคม ฉบับปรับปรุง และเอกสารอ้างอิงมาพร้อมนี้แล้ว อนึ่งขอให้อนุญาตใช้เครื่องมือ MSPSS จาก Prof. Zimet ด้วย

จึงเรียนมาเพื่อทราบและดำเนินการต่อไป

ขอแสดงความนับถือ

(ศาสตราจารย์ แพทย์หญิง ณททัย วงศ์ปการันย์)
ศาสตราจารย์ประจำภาควิชาจิตเวชศาสตร์

ภาควิชาจิตเวชศาสตร์ คณะแพทยศาสตร์

โทร ๐ ๕๓๙๓ ๕๔๒๒

โทรสาร ๐ ๕๓๙๓ ๕๔๒๖

Zimet, Gregory D <gzimet@iu.edu>

Oct 11, 2018, 7:17 PM

to me

Dear Suneerat Boosin,

You have my permission to use the Thai version of the Multidimensional Scale of Perceived Social Support (MSPSS) in your research. I have attached the original English language version of the scale (with scoring information on the 2nd page), a document listing several of the articles that have reported on the reliability and validity of the MSPSS, and a chapter that I wrote about the scale. Also attached is a copy of the Wongpakaran translation.

Best regards,
Greg Zimet

Gregory D. Zimet, PhD, FSAHM
Professor of Pediatrics & Clinical Psychology
Co-Director, IUPUI Center for HPV Research
Division of Adolescent Medicine | Department of Pediatrics

410 W. 10th Street | HS 1001
Indianapolis, IN 46202
317.274.8812 tel
317.274.0133 fax
gzimet@iu.edu



4 Attachments

0732 Zimet - MSP...

MSPSS References...

MSPSS.pdf

MSPSS - Thai MSP...

Request #154025_ZBI Inbox x



Sakellaropoulou, Foteini <Foteini.Sakellaropoulou@mapi-trust.org>

Thu, Oct 11, 9:09 PM



to eProvide, me ▾

Dear Ms Boonsin

Thank you for contacting Mapi Research Trust.

I am pleased to inform you that you can download free of charge the ZBI using our online distribution, as a not funded academic user.

https://eprovide.mapi-trust.org/instruments/zarit-burden-interview#online_distribution

I attach here instructions for your guidance.

I hope you will find what you need.

Best regards

Foteini Sakellaropoulou

Information Resources Specialist

PROVIDE
PROVIDE™

Mapi Research Trust

27 rue de la Villette | 69003 LYON | France

Please note my new email address : Foteini.Sakellaropoulou@mapi-trust.org

www.mapi-trust.org

Mapi
Research Trust

Think environmentally, please only print if necessary.



APPENDIX C

Participant information and consent form



เอกสารชี้แจงผู้เข้าร่วมการวิจัย

การวิจัยเรื่อง ปัจจัยที่มีอิทธิพลต่อการดูแลในผู้ดูแลผู้ป่วยโรคหลอดเลือดสมอง

รหัสจริยธรรมการวิจัย 03-11-2561

ชื่อผู้วิจัย นางสาวสุนีย์รัตน์ บุญศิลป์

การศึกษาครั้งนี้ มีจุดประสงค์เพื่อศึกษาระดับของภาระในการดูแลของผู้ดูแลผู้ป่วยโรคหลอดเลือดสมองและตรวจสอบโมเดลความสัมพันธ์เชิงสาเหตุของกลุ่มปัจจัยได้แก่ อายุของผู้ดูแล สุขภาพของผู้ดูแล สภาพการทำงานที่ของผู้ป่วย ระยะเวลาการเป็นโรคหลอดเลือดสมอง จำนวนชั่วโมงในการดูแล ระยะเวลาการเป็นผู้ดูแล การรับรู้สมรรถนะแห่งตน การสนับสนุนทางสังคม และคุณภาพชีวิตของผู้ดูแลที่มีอิทธิพลต่อการดูแลของผู้ดูแลผู้ป่วยโรคหลอดเลือดสมอง

เมื่อท่านเข้าร่วมการวิจัยครั้งนี้ สิ่งที่ท่านจะต้องปฏิบัติคือ การให้ความร่วมมือในการตอบแบบสอบถาม โดยตอบตามความเป็นจริงเกี่ยวกับข้อมูลส่วนตัวของท่านและผู้ป่วย การรับรู้เกี่ยวกับสุขภาพของท่าน การรับรู้สมรรถนะแห่งตน การสนับสนุนทางสังคม และคุณภาพชีวิตและภาระในการดูแล ซึ่งจะใช้เวลาประมาณ 30-50 นาที ในการตอบแบบสอบถาม โดยใช้พื้นที่บริเวณใกล้ห้องตรวจอายุรกรรมในโรงพยาบาล ทั้งนี้จะไม่มีความเสี่ยงใดๆเกิดขึ้นขณะเข้าร่วมการวิจัยครั้งนี้ ผลที่ได้จากการวิจัยครั้งนี้จะเป็นประโยชน์ในการพัฒนาโปรแกรมที่ช่วยลดภาระในการดูแลของผู้ดูแลผู้ป่วยโรคหลอดเลือดสมองและช่วยส่งเสริมให้ผู้ดูแลผู้ป่วยโรคหลอดเลือดสมองมีคุณภาพชีวิตที่ดี

การเข้าร่วมวิจัยในครั้งนี้จะเป็นไปตามความสมัครใจของท่าน ท่านมีสิทธิ์จะไม่ตอบแบบสอบถาม และขอถอนตัวจากการเข้าร่วมการวิจัยได้ตลอดเวลาโดยไม่ต้องแจ้งผู้วิจัยทราบล่วงหน้า ซึ่งจะไม่มีผลกระทบใดๆ ต่อตัวท่าน ทั้งนี้ชื่อสกุลของท่านจะลงเป็นรหัสแทน นอกจากนี้ผลที่ได้จากการวิจัยจะนำเสนอในภาพรวมไม่มีการแสดงชื่อหรือที่อยู่ที่จะทำให้สืบค้นถึงตัวท่านได้ ข้อมูลทั้งหมดจะถูกจัดเก็บรักษาเป็นความลับในตู้เอกสารและข้อมูลดังกล่าวจะถูกนำไปทำลายเมื่อเสร็จสิ้นการเผยแพร่รายงานวิจัยแล้ว

หากท่านมีปัญหาหรือข้อสงสัยประการใด สามารถสอบถามได้โดยตรงจากผู้วิจัยในวันทำการรวบรวมข้อมูลหรือสามารถติดต่อสอบถามเกี่ยวกับการวิจัยครั้งนี้ได้ตลอดเวลาที่ นางสาวสุนีย์รัตน์ บุญศิลป์ หมายเลขโทรศัพท์ 081-292-3241 หรือที่ รองศาสตราจารย์ ดร.อาภรณ์ ดীনาน อาจารย์ที่ปรึกษาหลัก หมายเลขโทรศัพท์ 081-611-6225

นางสาวสุนีย์รัตน์ บุญศิลป์
ผู้วิจัย

หากท่านได้รับการปฏิบัติที่ไม่ตรงตามที่ได้ระบุไว้ในเอกสารชี้แจงนี้ ท่านจะสามารถแจ้งให้ประธานคณะกรรมการพิจารณาจริยธรรมฯ ทราบได้ที่ เลขานุการคณะกรรมการจริยธรรมฯ ฝ่ายวิจัย คณะพยาบาลศาสตร์ มหาวิทยาลัยบูรพา โทร. 038-102823



ใบยินยอมเข้าร่วมการวิจัย

หัวข้อวิทยานิพนธ์ เรื่อง ปัจจัยที่มีอิทธิพลต่อการการดูแลในผู้ดูแลผู้ป่วยโรคหลอดเลือดสมอง

วันที่ให้คำยินยอม วันที่เดือน.....พ.ศ.

ก่อนที่จะลงนามในใบยินยอมเข้าร่วมการวิจัยนี้ ข้าพเจ้าได้รับการอธิบายจากผู้วิจัยถึงวัตถุประสงค์ของการวิจัย วิธีการวิจัย ประโยชน์ที่จะเกิดขึ้นจากการวิจัยอย่างละเอียดและมีความเข้าใจดีแล้ว ข้าพเจ้ายินดีเข้าร่วมโครงการวิจัยนี้ด้วยความสมัครใจ และข้าพเจ้ามีสิทธิที่จะบอกเลิกการเข้าร่วมในโครงการวิจัยนี้เมื่อใดก็ได้ และการบอกเลิกการเข้าร่วมการวิจัยนี้ จะไม่มีผลกระทบใด ๆ ต่อข้าพเจ้า

ผู้วิจัยรับรองว่าจะตอบคำถามต่าง ๆ ที่ข้าพเจ้าสงสัยด้วยความเต็มใจ ไม่ปิดบัง ซ่อนเร้นจนข้าพเจ้าพอใจ ข้อมูลเฉพาะเกี่ยวกับตัวข้าพเจ้าจะถูกเก็บเป็นความลับและจะเปิดเผยในภาพรวมที่เป็น

การสรุปผลการวิจัย

ข้าพเจ้าได้อ่านข้อความข้างต้นแล้ว และมีความเข้าใจดีทุกประการ และได้ลงนามในใบยินยอมนี้ด้วยความเต็มใจ

ลงนาม.....ผู้ยินยอม
(.....)

ลงนาม.....พยาน
(.....)

ลงนาม.....ผู้วิจัย

(.....)

The Demographic Questionnaire

Direction: This questionnaire asks about demographic data of you and your love one with stroke. Please write or choose the answer that is corrected for you and your loved one.

Demographic characteristics of family caregiver

1. Gender 1. Male 2. Female
2. Age.....years
3. Marital status
 1. Single 2. Married 3. Divorce
 4. Widow 5. Separated 6. Others.....
4. Education
 1. Illiteracy 4. Diploma
 2. Primary School 5. Bachelor's Degree
 3. Secondary School 6. Higher than Bachelor's Degree
5. Occupation
 1. Unemployed 4. Employee
 2. Government/Public Enterprise 5. Agriculture
 3. Trade/ Commercial 6. Others.....
6. Family income.....Baht/ month
7. Relationship with patient
 1. Spouse 4. Son/ Daughter-in-law
 2. Father/ Mother 5. Sibling
 3. Son/ Daughter 6. Others.....
8. Underlying/ chronic diseases
 1. Hypertension 4. Heart disease 7. Others.....
 2. Diabetes mellitus 5. Kidney disease
 3. Dyslipidemia 6. Osteoarthritis
9. Length of caregiving.....month

10. Number of hour per day of caregiving.....hr.

11. Number of patients to take care.....

Demographic characteristics of stroke patient

1. Gender 1. Male 2. Female

2. Age.....years

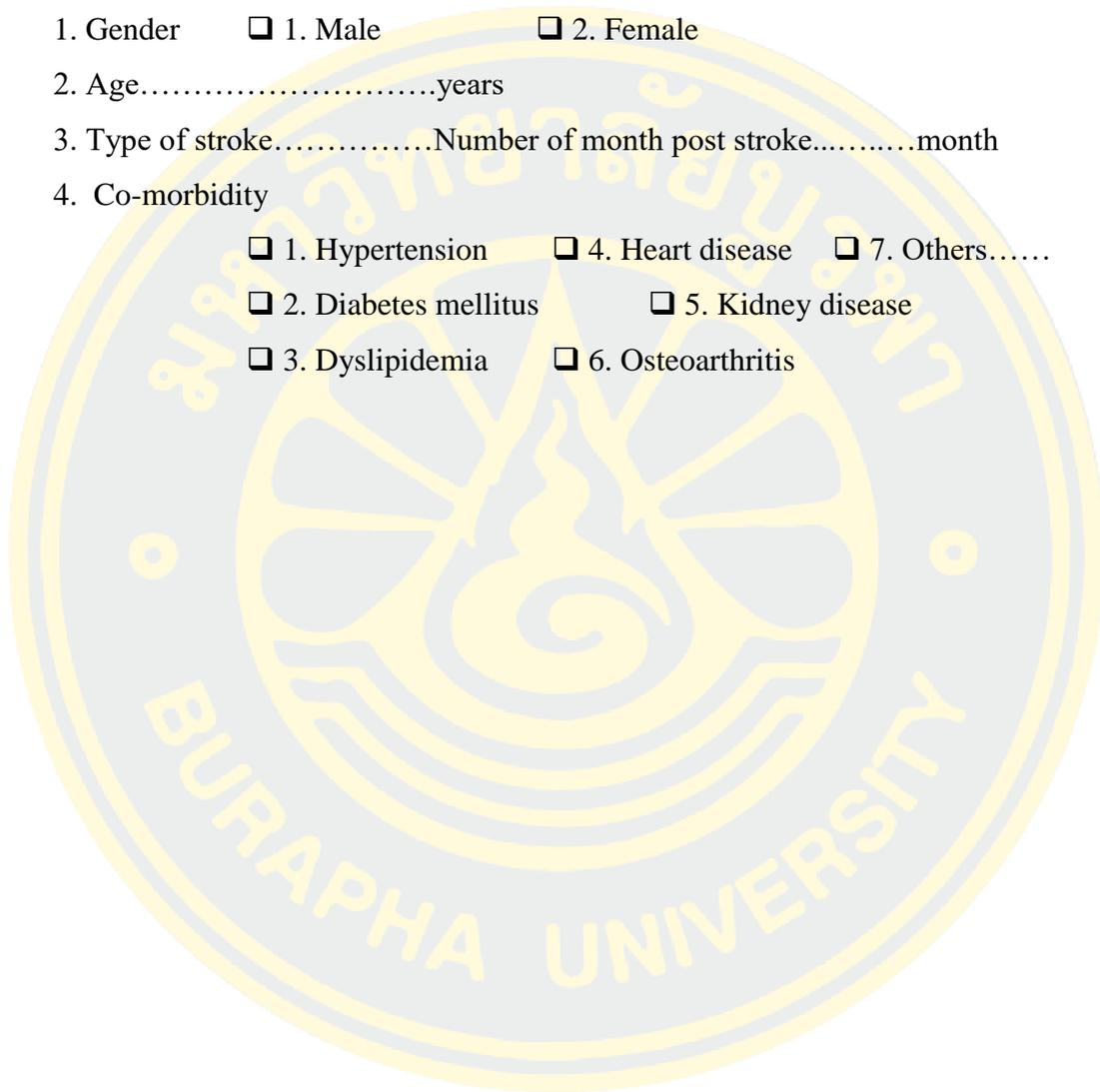
3. Type of stroke.....Number of month post stroke.....month

4. Co-morbidity

1. Hypertension 4. Heart disease 7. Others.....

2. Diabetes mellitus 5. Kidney disease

3. Dyslipidemia 6. Osteoarthritis



The Barthel Index

Direction: Please write the score which exactly states stroke patient's ability to perform the following activities

Activities	Score
Feeding 0 = unable 5 = needs help cutting, spreading butter. Etc., or requires modified diet 10 = independent	
Bathing 0 = dependent 5 = independent (or in shower)	
Grooming 0 = needs to help with personal care 5 = independent face/hair/teeth/shaving (impairments provided)	
Dressing 0 = dependence 5 = needs help but can do about half unaided 10 = independent (including buttons, zips, laces, etc.)	
Bowels 0 = incontinent (or needs to be given enemas) 5 = occasional accident 10 = continent	
Bladder 0 = incontinent, or catheterized and unable to manage alone 5 = occasional accident 10 = continent	
Toilet use 0 = dependent 5 = needs some help but can do something alone 10 = independent (on and off, dressing, wiping)	
Transfers (Bed to chair and back) 0 = unable, no sitting balance 5 = major help (one or two people, physical), can sit 10 = minor help (verbal or physical) 15 = independent	
Mobility (On level surfaces) 0 = immobile or < 50 yards 5 = wheelchair independent, including corners, > 50 yards 10 = walks with help of one person (verbal or physical) > 50 yards 15 = independent (but may use any aid; for example, stick) > 50 yards	
Stair 0 = unable 5 = need help (verbal, physical, carrying aid) 10 = independent	

Activities	Score
Total (0-100)	

General Perceived Self –Efficacy Scale (GSES)

Direction: Please mark the degree to which you agree or disagree with the following statements by circle in the number which best match how you feel.

No.	Items	Not at all true	Barely true	Moderately true	Exactly true
1	I can always manage to solve difficult problems if I try hard enough.	1	2	3	4
2	If someone opposes me, I can find the means and ways to get what I want.	1	2	3	4
-				
-				
-				
9	If I am in trouble, I can usually think of a solution.	1	2	3	4
10	I can usually handle whatever comes my way	1	2	3	4

Zarit Burden Interview

Directions: The following is a list of statements, which reflect how people sometimes feel when taking care of another person. After each statement. Indicate how often you feel that way; never, rarely, sometimes, quite frequently, or nearly always. There are no right or wrong answers.

No.	Items	Nearly Always 4	Quite Frequentl y 3	Some times 2	Rarel y 1	Neve r 0
1	Do you feel that your relative asks for more help than he/she needs?					
2	Do you feel that because of the time you spend with your relative that you don't have enough time for yourself?					
3	Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?					
-					
-					
-					
21	Do you feel you could do a better job in caring for your relative?					
22	Overall, how burdened do you feel in caring for your relative?					

Health Perception Scales for Thai adults (HPS-T)

Directions: Please mark the degree to which you agree or disagree with the following statements by circle in the number which best match your perception

No.	Items	Definitely true 5	Mostly true 4	Don't know 3	Mostly false 2	Definitely false 1
1	Now, I am healthy.					
2	I am, for one, as healthy as other people.					
3	My health is very good.					
-					
-					
-					
17	If I don't go to a doctor, I think I'm not sick.					
18	I will go to see a doctor only when /I have a serious illness.					

Revised Multidimensional Scale of Perceived Social Support

Directions: We are interested in how you feel about the following statements.

Read each statement carefully. Indicate how you feel about each statement.

Circle the “1” if you **Very Strongly Disagree**

Circle the “2” if you **Strongly Disagree**

Circle the “3” if you **Mildly Disagree**

Circle the “4” if you are **Neutral**

Circle the “5” if you **Mildly Agree**

Circle the “6” if you **Strongly Agree**

Circle the “7” if you **Very Strongly Agree**

No.	Items	Very strong disagree	Strong disagree	Mildly disagree	Neutral	Mildly agree	Strong agree	Very strong agree
1	There is a special person who is around when I am in need.	1	2	3	4	5	6	7
2	There is a special person with whom I can share my joys and sorrows.	1	2	3	4	5	6	7
3	My family really tries to help me.	1	2	3	4	5	6	7
-							
-							
-							
11	My family is willing to help me make decisions.	1	2	3	4	5	6	7
12	I can talk about my problems with my friends.	1	2	3	4	5	6	7

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 satisfied nor dissatisfied	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

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

BIOGRAPHY

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