# Development of Telenursing Based Caregiver Transitional Support Program for Thai Caregivers of Persons with Traumatic Brain Injury

**Duangsuda Siripituphum**

**A Thesis Submitted in Partial Fulfillment of the Requirements for the**
**Degree of Doctor of Philosophy in Nursing (International Program)**
**Prince of Songkla University**
**2020**

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I hereby certify that this work has not been accepted in substance for any degree, and is not being currently submitted in candidature for any degree.

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## บทคัดย่อ

การวิจัยเชิงปฏิบัติการนี้มีวัตถุประสงค์เพื่อพัฒนาโปรแกรมสนับสนุนการดูแลด้วยระบบพยาบาลทางไกลสำหรับญาติผู้ดูแลผู้บาดเจ็บศีรษะในระยะเปลี่ยนผ่าน กระบวนการศึกษาเป็นไปตามแนวคิดทฤษฎีการดูแลในระยะเปลี่ยนผ่าน และการวิจัยเชิงปฏิบัติการทั้งสามขั้นตอน คือ (1) ระยะศึกษารายละเอียดของปัญหา (2) วงจรของการวิจัยเชิงปฏิบัติการเพื่อพัฒนาโปรแกรมสนับสนุนการดูแลด้วยระบบพยาบาลทางไกลสำหรับญาติผู้ดูแลผู้บาดเจ็บศีรษะในระยะเปลี่ยนผ่าน (ชื่อย่อว่า TCTS) และ (3) การประเมินผลลัพธ์คือภาวะแทรกซ้อนของผู้ป่วย ความเครียดของผู้ดูแล และ ภาระของผู้ดูแล ซึ่งเก็บรวบรวมข้อมูลจากการทำสนทนากลุ่ม การสัมภาษณ์ ผู้มีส่วนร่วมในโครงการ ได้แก่ ผู้ป่วยบาดเจ็บศีรษะและญาติผู้ดูแล 14 คน พยาบาล 9 คน จากโรงพยาบาลตติยภูมิแห่งหนึ่งทางภาคใต้ ข้อมูลที่ได้นำมาวิเคราะห์ข้อมูลด้วยการวิเคราะห์เนื้อหา

ในระยะศึกษารายละเอียดของปัญหา พบอุปสรรคหลักในการดูแลผู้บาดเจ็บศีรษะในระยะเปลี่ยนผ่านซึ่งมีความเกี่ยวข้องกับระบบสนับสนุนการดูแลที่บ้าน เช่น การไม่มีเวลาในการให้คำแนะนำ การที่ไม่มีนักวางแผนจำหน่าย การขาดการติดต่อประสานงานและการสื่อสาร รวมทั้งญาติผู้ดูแลยังขาดความมั่นใจในการดูแล ขาดแหล่งสนับสนุนด้านอุปกรณ์ในการดูแล (เช่น เครื่องดูดเสมหะ เตียงลม และ อุปกรณ์ทำแผล)

โปรแกรมสนับสนุนการดูแลด้วยระบบพยาบาลทางไกลสำหรับญาติผู้ดูแลผู้บาดเจ็บศีรษะในระยะเปลี่ยนผ่าน ได้รับการพัฒนาโดยสร้างความร่วมมือและการสื่อสารระหว่างนักวิจัยและพยาบาล 9 คน ซึ่งเป็นกลุ่มผู้ทำงานหลัก ประกอบด้วย หัวหน้าหอผู้ป่วย 1 คน พยาบาลนักวางแผนจำหน่าย 2 คน พยาบาลชุมชน 1 คน และ พยาบาล 5 คน เพื่อพิจารณากิจกรรมที่เหมาะสมและกำหนดลำดับความสำคัญของกิจกรรมที่จะทำ รูปแบบจำลองการสนับสนุนดูแลเบื้องต้นได้ดำเนินการโดยบูรณาการการระบบการสื่อสารบนแอพลิเคชั่นที่เรียกว่า “We Care You”

หรือ “เราดูแลคุณ” ในการเพิ่มความรู้และทักษะของผู้ดูแลผู้บาดเจ็บศีรษะ กับการดูแลตามปกติ รูปแบบได้มีการปรับเปลี่ยนเพื่อพัฒนาการจัดการดูแลที่บ้านได้อย่างปลอดภัย มีวงจรของการพัฒนาระบบสนับสนุนใน 3 ระยะ ได้แก่ การส่งเสริมศักยภาพและพลังอำนาจของญาติผู้ดูแล การเพิ่มการเข้าถึงทรัพยากรและการประสานงานการดูแล การสนับสนุนการจัดการการดูแลในสถานการณ์ฉุกเฉิน

ในด้านผลลัพธ์ พบว่า ผู้ป่วยไม่มีภาวะแทรกซ้อน ญาติมีความเครียดในการดูแล และ ภาระในการดูแลลดลง โปรแกรมสนับสนุนการดูแลด้วยระบบพยาบาลทางไกลสำหรับญาติผู้ดูแลผู้บาดเจ็บศีรษะในระยะเปลี่ยนผ่าน ที่เน้นการเสริมพลังอำนาจในบทบาทและศักยภาพของญาติผู้ดูแลผ่านการสื่อสารบนแอพลิเคชั่นจึงมีความจำเป็น การศึกษานี้ได้เสนอแนะสำหรับพยาบาลในการนำโปรแกรมสนับสนุนการดูแลด้วยระบบพยาบาลทางไกลไปใช้ ควรพิจารณาถึงปัจจัยที่เกี่ยวข้องกับการมีส่วนร่วมของญาติผู้ดูแลและพยาบาลชุมชน ได้แก่ การจัดหาแหล่งทรัพยากร การประสานการดูแลและการสื่อสารที่ต่อเนื่อง เพื่อเชื่อมระบบบริการที่บ้านและชุมชนในการเพิ่มทั้งความมั่นใจของผู้ดูแลและความปลอดภัยของผู้ป่วยบาดเจ็บศีรษะ

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## ABSTRACT

The purpose of the action research was to develop the telenursing based caregiver transitional support program for Thai caregivers of persons with traumatic brain injury (TBI). The study process was based on the transitional care concept and included three phases of action research; (1) reconnaissance phase; (2) spiral action research process to develop the Telenursing Based Caregiver Transitional Support Program (TCTS Program); and (3) final phase to evaluate the outcomes such as patients' complications, caregiver stress and caregiver burden. Data were obtained from focus group discussions and interviews among participants comprising of 14 persons with traumatic brain injury and their family caregivers, 9 nurses, from a tertiary hospital in a southern Thai province. Content analysis was used for data analysis.

Regarding the reconnaissance phase, the main barriers of TBI care in the transitional period were related to the caregiving support system at home such as a lack of time for giving advice, a lack of a discharge planner, and a lack of care coordination and communication. In addition, the family caregivers' felt a lack of confidence in caring, lacked resources (such as intermittent suction, air bed, and dressing set) for caring, and had no health care provider to consult in emergency situations.

The TCTS program development was employed through the collaboration and communication among the researcher and nine nurses who acted as a core working group, including one head nurse, two discharge planner nurses, one community nurse and five nurses to consider appropriate activities and set priorities for practical activities. The tentative care model was implemented by integrating “We Care You” application to enhance caregiver’s knowledge and skill in TBI care with the usual care plan in the transitional period. The model was refined in enhancing safely TBI care management at home. Three cycles were found as supportive system of TBI caregivers namely, enhancing and empowering the family caregiver, maximizing resources and care coordination, and supporting care management in emergency situations.

In the outcomes, there was no patient’s complication, less caregiver stress, and care burden after discharge home. The TCTS program focusing on empowering family caregivers’ role and capability through “We Care You” application within adequate resources and supportive care at home is necessary. It is recommended for nurses in applying TCTS program, factors related to caregiver and community nurse’s participation should always be considered such as arrangement of resources, continuing care coordination and communication in order to bridge the services at home and community which enable to increase both TBI caregiver’s confidence and TBI patient’s safety at home.

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# CHAPTER 1

# INTRODUCTION

## Background and significance of the problem

Traumatic Brain Injury (TBI) is a silent epidemic nowadays which is costly and considered a health problem, especially in young adults. TBI is also a large health problem in Thailand, often originating from motorcycle accidents (Kitisomprayoonkul, 2010; Petchprapai, 2007; Prateepwanit, 2008). The consequences of TBI can affect change in many aspects not only mobility, memory, perception and consciousness but also social engagement and economic status. Uncertainty is a tacit dimension of TBI and can quickly affect family members making them feel vulnerable and stressed (Hawley & Joseph, 2008; Verhaeghe, Defloor, & Grypdonck, 2005).

Despite advances in medical development and campaigns to raise public awareness in accident prevention, the number of persons with brain injuries has almost doubled in the past 10 years (Kitisomprayoonkul, 2010). Most of the head injuries in adults (83.7%) are of a mild to moderate severity (Petchprapai, 2007). In addition, more than 80% of the survivors from head injuries experience disabilities and are unable to return to work or take care of themselves (Gan, Campbell, Gemeinhardt, & Mcfadden, 2006; Khiewchaum, Thosingha, Chayaput, & Utriyapasit, 2011; Kneafsey & Gawthorpe, 2004). Thus, one’s family, as well as his/her family environment, has been found to play an important role in caring and improving long-term outcomes for TBI survivors (Gan et al., 2006; Khiewchaum et al., 2011; Kneafsey & Gawthorpe).

After discharge from hospital, many TBI survivors return home and live with family members in the community, who assume the role of primary caregiving (Grant, Weaver, Elliott, Bartolucci, & Newman-Giger, 2004; Hankey, 2004; McPherson, Pentland, & McNaughton, 2000). The TBI family caregivers may experience much more uncertainty for a long period of time (Bond, Draeger, Mandleco & Donnelly, 2003; Crisholm & Bruce, 2001; Duff, 2002). Degeneffe (2001) reported that stress and burden often occur in close relatives and do not lessen over time. Sometimes the responsibility in caring and the other demands of life are disabling for TBI family caregivers (Duff, 2002; Simpson et al., 2000).

Caregiver stress is poor emotional and physical health as experienced by the caregiver as a result of continually caring for someone with a chronic illness (Kuipers, Onwurnere, & Bebbington, 2010). After TBI survivors discharge from hospital, many close relatives assume the position of providing care (Degeneffe et al., 2011). Many family caregivers are faced with a grieving process when they think about the future that includes redefining themselves, fear, a situation of uncertainty and their expectations (Backhaus & Ibarra, 2012). Moreover, caregiver stress can occur when the caregiving experiences are known or evaluated as threatening.

Behavioral and personality changes of patients with TBI may ruin the functioning of the family. A family’s conflict in managing the behavior of a TBI survivor may occur as a primary determinant of caregiver burden. The lack of caregiver preparation in order to deal with the afterward personality and TBI behavioral changes is a major complaint. Family members may lack the skills to provide and manage care which can result in negative experiences that increase caregiver stress. Thus, psychological problems in caregivers after caring for TBI survivors are common (Hawley et al., 2003; Kreutzer et al., 2009).

Adequate support is required since the care demands of people with TBI after discharge are unpredictable and dynamic. Literature on family needs supports the importance of hope (Smith & Smith, 2000) and the need for essential information, combined with the need for practical skills and emotional support (Bond et al., 2003; Smith & Smith, 2000). Many studies reported that family caregivers also felt they did not get sufficient information or support for their needs (Paterson, Kieloch, & Gmiterek, 2001; Smith & Smith, 2000). Smith and Smith (2000) also found that family caregivers usually feel the health care system is very complex and no one has a duty to inform and support them, especially when the TBI survivors return home. The caregivers also reflected that health care providers and others did not have an understanding of their problems (Swift & Wilson, 2001).

Support and education programs prior to hospital discharge aim to improve the transition to home and community for people with TBI, as well as those who care for and interact with them. Few studies support or even evaluate the types of caregiving interventions (programs supporting caregivers), however, a number of studies confirm the impact of brain injury on families (Oddy & Herbert, 2003). Many family members and caregivers report that their difficulties increased when access was limited to follow-up support for their caregiving (Lefebvre, Cloutier, & Levert, 2008).

Moreover, nurses should play an important role in transitional care as they support and advocate for TBI patients and their caregivers and provide continual direct care.

Due to the various demands of caregiving, the accessibility of information, care communication and relationships between care supporters (nurses) and caregivers for patients are important. The use of technology to help and support caregivers has shown some benefits. For example, technology-based interventions by utilizing telephones, mobile phones, videophones, computers, and the internet have resulted in improving the caregiver's ability to access information and assistance (Dyer et al., 2012). A Thai study among TBI caregivers found that caregivers who used the internet to access necessary information and used the Line application to informally consult about their family members' condition with health care providers improved discharge readiness (Narkthong et al., 2014). Furthermore, more than 80% of Thai TBI caregivers from the two tertiary hospitals in the southern part of Thailand used the internet to access necessary information (Narkthong et al.).

The trend of using technology aids such as telenursing for faraway patient monitoring to improve management in chronic disease was reported to decrease readmitting rate and emergency department revisits (Boden & Da Costa, 2004; Schwartz & Britton, 2011). Telenursing may help the patients and their caregivers optimize devotion to threat and encourage early detection of signs and symptoms of cardiac decompensation (Doughty et al., 2008). For Telenursing, Doughty and colleagues also advise that definitions usually change as the purpose and services that are based on this growing technology are always improving. In addition, nurses also play an important role in the success of telenursing interventions (Dias et al., 2009;

Naditz, 2009). Telenursing can help people with disabilities and those who provide care for them, such as the caregivers of the elderly or disabled people or those people with chronic illnesses, to live independently by providing them with early assessments, telephone triage/telephone advice, consultation, early emergency management and support, symptom management, and home health care (Naditz; Jonsson & Willman, 2008; Lorentz, 2008). Therefore, telenurses need to have advanced competencies to convey information based on technology that improves the efficiency of disease management in patients with family caregivers and to provide evidence-based professional consulting and supportive care (Dias et al.; Hoglund & Holmstrom, 2008; Snooks et al., 2008).

However, the healthcare resources available to Thai survivors with TBI and their caregivers may be limited compared to those in other countries where previously mentioned studies were conducted on the services and coverage offered. A few studies conducted in Thailand on TBI survivors and their caregivers were focused in the transition stage following discharge from the hospital. Additionally, in regards to Thai culture and support, it is the duty of the family to care for ill family members with TBI and this remains a critical determinant of the successful outcomes of TBI survivors which is different from the situation in western countries (Khiewchaum et al., 2011; Narkthong et al., 2014; Samarkit, Kasemkitvattana, Thosingha, & Vorapongsathorn, 2010; Utriyaprasit, Bootcheewan, Chayaput, & Thosingha, 2012).

Due to the complexity of the caregiving situation for a patient with TBI, a flexible telenursing intervention during transition is necessary. Currently, no published studies have described the transition to home using telenursing interventions for Thai caregivers. Meleis' transitional theory (Meleis, 2010), which points out four major components, was selected for use because it can cover the transition experiences of caregivers from the hospital to home setting. Moreover, Hatyai Hospital is a tertiary hospital with 900 beds which is a central referral center for all hospitals in southern Thailand. Due to the neurosurgical specialist and faollw up care system available, this study had been conducted in this setting. However, the content in telenursing must be suited to each individual patient and caregiver to resolve any immediate problems, as well as continued education and the involvement of the multidisciplinary team with patients and families to help them feel more confident and have readiness for discharge. Telenursing services could be an alternative to improve Thai TBI patient care with lower costs in order to reduce stress and burden at home among caregivers of persons with TBI, and to reduce any patient complications. Ultimately, nurses are enabled to communicate directly with caregivers, and caregivers gain more support to improve patient care after discharge.

## Objective of the study

To develop the telenursing based caregiver transitional support program for Thai caregivers of persons with traumatic brain injury

## Research Questions

1. What is the model's relevance to the telenursing based caregiver transitional support program for Thai caregivers of persons with traumatic brain injury?
    1.1. What are the roles of nurses and caregivers in the telenursing based caregiver transitional support program?

1.2. What strategies can the nurses use to help the caregivers in the telenursing based caregiver transitional support program?
1.3. What are the components of the telenursing based caregiver transitional support program?
1.4. How can the telenursing based caregiver transitional support program reduce caregiver stress, caregiver burden, and patient complications?

## Theoretical framework of the study

This study was developed and guided by Meleis' transition theory (Meleis, 2010), and related literature regarding caregiving and TBI survivors. The action research approach was utilized as the methodological basis to develop the telenursing based caregiver transitional support program for Thai caregivers of persons with traumatic brain injury.

Changes in the health and disease status of people are involved in the process of transition, and clients in transition tend to be more insecure to risks that may affect their health and their families. Nurses can be the key person to provide support and assurance that these transition processes are successful (Meleis, 2010; Meleis et al., 2000). Discharge to home can be a substantially stressful situation for the family of a person with TBI especially for Thai family caregivers (Narkthong et al., 2014; Khiewchaum et al., 2011; Sawasdinaruenart, Sae-Sia, & Songwathana, 2013; Utriyaprasit et al., 2012).

Chick and Meleis (1986 cited in Meleis et al., 2000) define transitions as, "The passage or movement from one state, condition or place to another." Transition regularly requires an individual to merge new knowledge or alter behaviours, thus changing the definition of self in the new environment (Meleis et al., 2000; Meleis, 2010). According to Meleis and colleagues (2000), there are numerous principles of a successful transition, including awareness, engagement, change and difference. The challenges for nurses include understanding the transition process and developing interventions that are successful in helping patients and caregivers recover steadiness and a sense of well-being (Meleis et al., 2000). This theory is based on four main components, which are characterized as follows: nature (type, patterns, and properties of transition), transition conditions (process facilitators or inhibitors related to the person, the community, and society), patterns of response (process indicators and outcome of the transition, conductors of the nursing therapeutics), and therapeutic interventions in nursing.

In the transitional theory of Meleis, the transition is identified by different dynamic stages, milestones, and turning points and can be defined through processes and/or existing outcomes (Meleis, 2010). It is a route from such a life stage or state to another so as to reach sufficient adaptation to the new role and/or event. Consequently, there are various concepts taking on the elements of process, time span, and perception (Chick & Meleis, 2010). Based on this assumption, there are several factors that can be facilitators or inhibitors of an effective transition, such as knowledge and skills, personal meaning, beliefs and attitudes, socioeconomic status, and available community and societal resources. Thus, the responses of caregivers to this process, their involvement, confidence and coping strategies are process indicators, which are likely to be adequate so that outcome indicators (mastery and integration of the new role) are as efficient and healthy as possible.

The family caregivers may face much uncertainty with a transitional situation (Meleis, 2010). This kind of transition includes unexpected situations which happen through the life cycle and this needs a redefinition of their roles and/or assimilation of new roles. Transition is shown in different sections such as the health care area. Within this perspective, nurses are one of the health care professionals who are often experienced in several processes of transition in different situations and are usually the primary caregivers of persons undergoing transitions. The caregivers are focused on the changes and demands resulting from the patients' needs concerning the caregiving tasks and the achievement of the caregiver's role. In this situation, the nurses are one of the health care professionals who prepare the caregiver to facilitate in the transition process and to adapt well for the caregiver role, promoting and inspiring the achievement of knowledge and caring skills and abilities related to their caring situation (Meleis, 2010).

During this transition period, the focus and concern of the nurse should be on the appropriate intervention according to the patient's and family's personal and societal resources, skills, knowledge and availability, and the family caregiver's expressed set of needs. These health care professionals should create interventions to appropriately meet these needs, therefore obtaining the desired gains for caregivers' well-being and their health. In summary, it is important to begin partnerships among the health care professionals and family caregivers, but also to plan appropriate interventions to promote and develop the quality of care and reduce the readmission rates of patients.

There are four major components of transition: nature of transition, transition conditions, nursing therapeutics and patterns of response (Meleis et al., 2000). Each of the concepts of Meleis' transition theory (Meleis et al., 2000) is represented by the study variables. The first component, nature of the transition, is defined as the descriptor of the type, pattern, and property of a transition and is operationalized as the patient's hospitalization and caregiver's characteristics in this study. The second component, transition conditions, is the personal or environmental conditions that facilitate or hinder progress toward achieving a healthy transition. Transition conditions are operationalized as the community and healthcare system. The third component, nursing therapeutics, focuses on the prevention of unhealthy transitions, and deals with the experience of transitions. Nursing therapeutics, the critical role played by nurses in preparing families for transition, is operationalized as the Nurse-led Telehealth Based Caregiver Support Program. The fourth component, patterns of response, attempts to understand how patients manage their diagnosis, treatment, and recovery. Patterns of response has four major components: feeling connected, interacting, location and being situated, and developing confidence and coping (Meleis et al., 2000).

Two of the four dimensions from the patterns of response (feeling connected, and developing confidence and coping) are important outcomes measured in this research. Feeling connected to the health care team means that caregivers are comfortable connecting with the health care team using the Telenursing Based

Caregiver Transition Support Program to receive education, emotional support, and care coordination. The connection to the health care team is an important indicator of a positive transition experience (Meleis et al., 2000). Improving confidence and coping is another component that reflects the nature of the transition process and is manifested by the mastery of treatment and recovery, the level of resource utilization, and strategies for managing the illness over time (Meleis et al., 2000).

Family members who are caring for TBI patients had marked the existence of communication collapse between the caregivers and patients, which has led to a decreasing quality of the relationship and their interaction. Caregivers display the challenge of holding relationships with TBI persons who have physically changed and may had social or verbal swaps. Deteriorating communication may build and result in family dysfunction. Family caregivers are commonly averse to expressing their opposition feelings. Especially, as this is dependent on the cultural obligation. Thus, caregivers need the health care team’s help in understanding and improving family communication (Blake, 2008).

From the previous studies, many censorious family needs were identified; the main needs are relying on health or disease information and rehabilitation information, financial expenses and helpers, and social and emotional support. Moreover, the caregivers also have a need for psychological support and consultation. In order to provide care for TBI survivors, family members also repeated a need for health care professional direction, support and consideration.

Action Research (AR) is a research method of carrying out studies in critical science. The critical social theory virtual reality is assumed to be understandable, but over time has become shaped by social, political, cultural, economic, ethical, and gender values and factors focusing on changes and conflicts of social relations or institutions (Guba & Lincoln, 1994). Action research aims at empowering people, especially less powerful people and oppressed groups, to gain equality (Neuman, 1997; Small, 1995). It therefore transforms the subject-object relationship of the traditional medical model into a subject-subject relationship (Reason, 1994), empowering people to have more autonomy and control over their own healthcare (Webb, 1991). Action research intends to produce knowledge that can change individuals and the culture of the groups, institutions, and societies to which they belong. These are viewed as a process for personal empowerment, emancipation, and social transformation, which mean that the political change can be achieved and sustained.

Action research was well suited for this study because it assisted the participants to better understand the research process that required collaboration between the family caregivers and nurses in sharing information via the telenursing program. As the care provider, there is a strategy to maximize caregivers’ competency to provide effective care to patients and caregivers themselves in both the institutional setting and transitional care from hospital to home.

| Pre-discharge | Hospital discharge | Post discharge |
|---|---|---|
| **TBI Caregiver Problems**<br>-Lack of information related to<br>* Rehabilitation<br>* Patient management in emergency situations<br>-Poor communication related to patient needing support<br>-Lack of emotional support | **- Telenursing Based Caregiver Transitional Support Program**<br>+Education support<br>*Patient's rehabilitation program<br>* Patient management in emergency situations<br>+Emotional support<br>* Support network<br>+Care coordination<br>* Health care team | **Outcome**<br>***Patient***<br>- Complication<br>***Caregiver***<br>- Stress<br>- Burden |

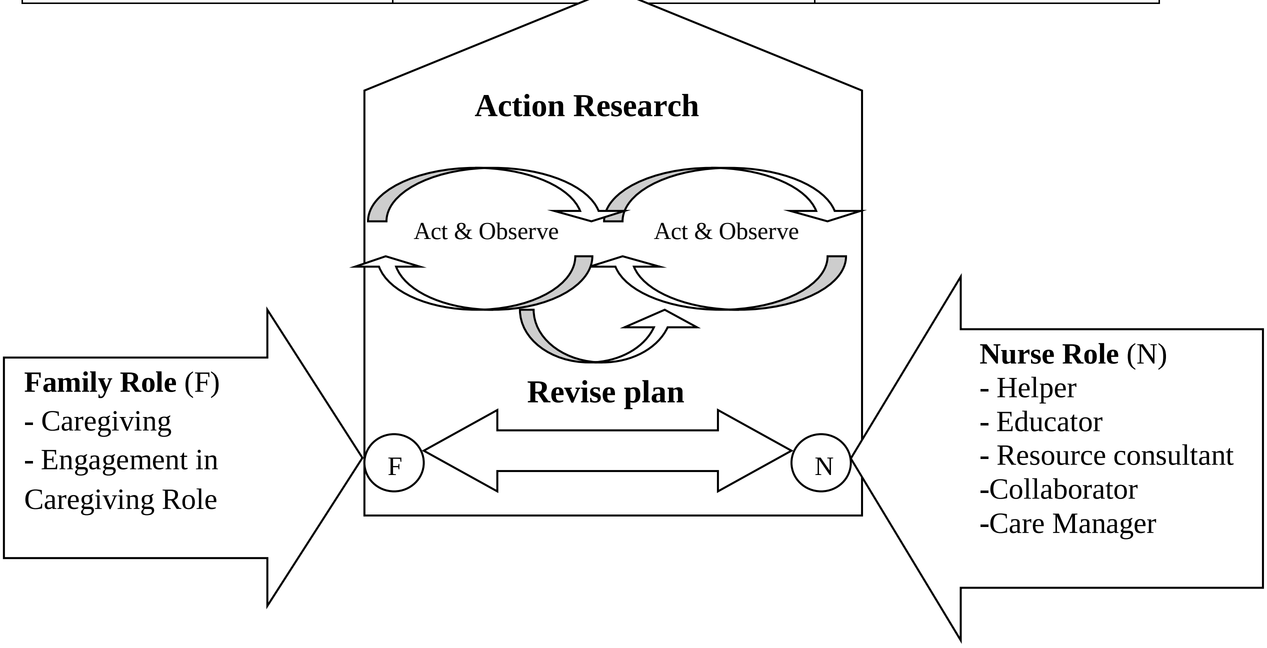

**Figure 1 Conceptual Framework**

## Definition of Terms

**1. Telenursing Based Caregiver Transitional Support Program.** Telenursing based caregiver transitional support program refers to a supportive program initiated by nurses for the caregivers of persons with traumatic brain injury which was developed based on Meleis' transitional care using telenursing as a bridge between nurses and caregivers and this includes the community to be part of the care in order to enhance educational support, emotional support, and care coordination after hospital discharge.

2. **Caregiver Stress**. Caregiver stress is the perception of the TBI caregiver about her/his condition of exhaustion, anger, rage, or guilt that results from unrelieved caring for a TBI patient. Caregiver stress was measured by a self-report numeric rating scale from the family caregiver. The score range was from 0 to 10, 0 = no stress and 10 = very stressful.

3. **Caregiver Burden**. Caregiver burden is the distress that a family caregiver perceives of their experience as a result of the changes that they observe in the person with TBI. Caregiver burden was measured by a self-report numeric rating scale from the family caregiver. The score range was from 0 to 10, 0 = no burden and 10 = heavily burdened.

**4. Patient Complications.** Patient complications are the TBI patient's signs and symptoms that induce readmission to an acute care facility for a hospital stay in any hospital within 30 days before the follow up date (Saverino et al., 2015).

### *Significance of the Study*

The nursing program can be used as a guideline for nurses in providing a telenursing care intervention for caregivers. It helps the family caregiver to adapt well in the transitional period to reduce caregiver stress and caregiver burden. Moreover, this program also helps the caregivers to manage the situation of the patients with TBI to reduce patient complications. This program also helped nurses to develop a supportive care system services under the plan for Thai caregivers of persons with traumatic brain injury.

# CHAPTER 2

# LITERATURE REVIEW

The literature reviews in relation to the major concepts of the study are described in the following.

1. Traumatic Brain Injury (TBI) Caregiving Demands and its Impacts on the Caregiver

2. Family Caregiver's Stress and Burden in the Caring of TBI Patients during the Transition Period

    2.1 Concept of Stress and Burden among Caregivers

    2.2 Factors Related to Caregiver Stress and Burden

3. Care System in Thailand for TBI survivors

4. Caregiver Supportive Program

5. Meleis' Transitional Theory

6. Telenursing

7. Action research

8. Summary

## Traumatic brain injury (TBI) caregiving demands and its impacts on the caregiver

Traumatic brain injury severity ranges from mild, defined as “a brief change in mental status or consciousness,” to severe, defined as “an extended period of unconsciousness or amnesia post-injury” (Brain Injury Association of America [BIAA], 2008; NINDS, 2009; Van Baalen et al., 2007). Traumatic brain injuries happen at nearly 75% each year and include mild traumatic brain injury and concussion or other forms of brain injury (Centers for Disease Control and Prevention [CDC], 2013).

TBI is well known in the disability rank with high prevalence and has a sizable and direct impact on TBI survivors and their families. The impact of TBI is various and extended and may implicate a range of physical, cognitive, and/or psychosocial problems.

### *Physical health problems*

Physical health problems of TBI include reduced tolerance, abnormalities of muscle strength, headaches, seizures, abnormal vision, hearing loss, and problems with smell, taste, and speech. These physical problems can causes limitations in daily life activities such as preparing meals, driving a car or riding a motorcycle, or working in a previous position. If hemiplegia after injury is not aggressively treated, this can become a struggle and lead to an unfunctional useless limb. This usually occurs in 1-4 months after an injury and the signs include a decreased range of motion, lower limb swelling, and pain similar to that experienced during a fever

(Tronhill et al., 2000). Rehabilitation services are difficult to access, in addition, all rehabilitation activities and the outcomes usually depend on their TBI caregivers' ability in caring.

Moreover, urinary incontinence also can be a common problem and often occurs after a brain injury. Catheterization can be used to solve this problem in the short term. However, if an impairment of bladder emptiness remains then the technique of intermittent catheterization by patients or caregivers can be used (Tronhill et al., 2000).

### *Cognitive problems*

Changes in cognition is a common prevalent problem at moderate to severe levels in TBI survivors and such changes include difficulties in memory recall, difficulties in making decisions, difficulties in communication, memory loss, fatigue, and poor concentration. These changes are a large barrier for TBI persons returning to independent daily living or previous working positions. The results from a study by Kersel and colleagues (2001) showed up to 74% of TBI patients had some degree of cognitive impairment. Most TBI patients at both six months and one year post injury, in this study were affected in their normal perception, intelligence, and other aspects of attention and controlled functioning. Moreover, those TBI patients with a severe disability are unable to verbally communicate and need help to effectively communicate (Brewin & Lewis, 2001). These TBI survivors also are dependent on care from their family caregivers.

### *Psychosocial health problems*

Psychosocial health problems include emotional, personality and controlling behaviors and these can also occur in TBI patients. Such health problems include impatience, isolation, physical aggressiveness, impulsiveness, depression, and an inability to show empathy (Hickey, 2003; Roy, 2000). The consequences of psychosocial health problems for TBI persons can result in a change or loss of work, being ostracized from society and in the performance of role functions. Also, TBI survivors will feel a lack of self confidence, self esteem, self control, powerlessness or helplessness and may experience social stigma (Glenn, O'Neil-Pirozzi, Goldstein, Burke, & Jacob, 2001; Samartkit et al., 2010). All of these problems mentioned tend to result in increasing distress six months after the injury which is more than in the acute phase (Franulic, Carbonell, Pinto, & Sepulveda, 2004). These problems can have a direct effect on a person's daily life, work, friends, and family.

After TBI, there can be a mass of physical, cognitive and emotional changes which may result in distress for the TBI survivors and their families. The caregiver role is continually shown in many research studies as creating too much strain and burden on the caregiver, resulting in poor well-being, including poor physical health, mental health and overall health (Langlois, Rutland-Brown, & Wald, 2006; Marsh et al., 2002; Paterson, Kieloch, & Gmiterek, 2001; Pinquart & Sorensen, 2003). These TBI caregivers have been quoted as the "hidden patients" as up until three decades ago, the understanding of caregiving experiences and interventions to meet the caregivers' needs also have had little awareness (Hart et al., 2005; Kim et al., 2007; Pickelsimer et al., 2006).

TBI survivors usually need long term care and rehabilitation, therefore, they may rely on their caregivers for a long time. For the family who take on the role of caring for TBI patients, this can be a staggering experience. Lefebver and Colleagues (Lefebver, Pechat, & Levert, 2007) found that after the first crisis ended, patients would move into a transition point from hospital to rehabilitation or long-term care facilities and their families may face a difficult time during this period. It is so difficult because families have to adjust to becoming a caregiver, as well as adjust to changes in the care providers they have come to trust, change in the caregiver's work position, and any changes in appraisal actions due to delays in assessments by medical professionals. These changes can cause the family to feel that their needs are unmet and they tend to feel uncertain about the future which can cause families' to grieve. In addition, miscommunication in the hospital can cause families to feel anger (Lefebver, Pechat, & Levert, 2007).

Caregivers perceived TBI-caregiving as a burden, although some of them expressed satisfaction which is greater than the disadvantage. Certainly, caregivers experienced problems such as anxiety, depression, as well as other financial and practical problems. The majority of the studies about family caregiving experiences, since families consist of the primary TBI-caregivers, have been conducted in the Asian countries. Caregivers also reflected on the lack of relevant information and resources about the treatment, patients' progress, patients' conditions and prognosis (Hawley, Ward, Magnay, & Long, 2003). Healthcare professionals especially nurses often provided inadequate explanations to families in understanding the extent of the TBI injuries, their sequelae and consequences (CDC, 2013). During the initial phase after injury, such inadequacy causes distress. Consequently, in the later phases, due to the complexity in adapting and adjusting to a changed living style, the function of the family and daily life may become disrupted.

### *Caregiving Demands*

Patients with any severity of TBI may require assistance with activities of daily living (ADLs), such as bathing, dressing, managing medications, and feeding. Some patients may need help with instrumental ADLs, such as meal preparation, grocery shopping, household chores, child care, getting to appointments or activities, coordination of educational and vocational services, financial and benefits management, and supportive listening. The caregiving demands for TBI are therefore depended on the process of recovery.

The process of recovery following a TBI can be long and demanding for both the survivor and the family. Caregivers typically progress through several phases of recovery following a family member’s TBI. During the acute-care hospital stay, caregivers often omit their home and work responsibilities, and may have difficulty transitioning back to their activities before injury. They may have to take a practical approach, or pull together with friends and family for support to meet basic needs. Emotions reported include disbelief, grief and difficulty with acceptance.

Once the survivor transitions to a rehabilitation program, caregivers tend to report hopes for a rapid recovery, but may also have decreased social support and an increased level of awareness that some changes in the survivor may be permanent. As is often the case, many caregivers assume the responsibility of providing the majority of care for the TBI survivor once rehabilitation is complete (Degeneffe et al., 2011). When thinking about the future, many caregivers experience a grieving process that includes redefining themselves, fear of long-term caregiver stress, and redefining their expectations (Backhaus & Ibarra, 2012).

Due to the high demands of TBI care, several impact of TBI family caregivers are reviewed and found in four aspects as follows;

*1) Psychological impact*

The most common psychological impact of TBI on family caregivers is stress (Ganesalingam et al., 2007; Prigatano, 2005; Testa et al., 2006). As a caregiver, individuals are faced with specific stress related to their families, which impacts on their employment and financial status, and changes within their social functioning. The stress or burden on family caregivers of TBI survivors may affect the entire family system. Individuals who become caregivers are often more isolated than their non-caregiving counterparts, which has been shown to decrease a person's ability to cope with stressful situations (Ergh, Rapport, Coleman, & Hanks, 2002; Malec, Testa, Rush, Brown, & Moessner, 2007). A study by Samartkit and colleague (2010) found that TBI family caregivers experienced their own psychological health problems such as anxiety, depression, and role strain.

Another family crisis is the medical crisis over rehabilitation which can be a long, and slow process (Uomoto & Uomoto, 2009), therefore, it is also essential to know the signs of caregivers' fatigue, depression and distress. Harris and colleagues (2001) found that although caregivers feel they have support, they can also feel depressed. The depression also affected how the family adapted to the TBI survivors and the TBI survivors adapted to the long term outcomes of being a TBI survivor. Similarly to the study of Rivera and colleagues (2007), they reported that if the caregivers had their own physical problems or ineffective problem solving skills, the caregiver was at risk for greater levels of depression. In addition, the consumption of tranquilizers, sleeping pills and alcohol were reported by the caregivers as a way to cope with new and long term stress (Testa et al., 2006). It is suggested that long term stress is particularly risky for both the physical and mental health of caregivers of a low socio-economic status.

2) *Physical impact*

The physical impacts have been found in most TBI caregivers. Marsh, Kersel, Havill, and Sleigh (2002) found that TBI caregivers reported a change in sleeping patterns and physical illness. Some caregivers are also at a risk for getting communicable diseases. Furthermore, common caregiving tasks with the demands of daily activities may be a reason for muscle strain, skeletal injury, arthritis and other physical discomfort and pain. Poor emotional and physical health was predicted by the modification of exercise patterns, diet, and a substantially-burdened life. Moreover, family caregivers who were looking after patients with TBI with high levels of disability also reported physical fatigue and exhaustion (McPherson, Pentland, & McNaughton as cited in Samartkit, Kasemkitvattana, Thosingha, & Vorapngsathorn, 2010).

### *3) Socioeconomic impact*

Long-term caring can involve high costs in both direct and indirect care for recovery or rehabilitation. The socioeconomic impact is evident in previous studies (Bond, Draeger, Mandleco, & Donelly, 2003; Hawley et al., 2003; Sawasdinaruenart et al., 2013). Sawasdinaruenart et al. (2013) found that post injury, some family caregivers need to find extra money in order to pay for the use of advanced technology for TBI patients such as CT scans, surgery, and so on in order to take care of the patient during the hospital period. Additional expense is needed to purchase rehabilitation and life-adaptive devices. Many parents quit their job to care for their child in hospital and to take on the caregiver role after discharge from hospital. Thus, the impact of TBI patients can result in a lack of income for families. In addition, extra transport costs due to hospital visits, rehabilitation sessions, and school transport for a TBI schooled child are also financial burdens for the family (Bond et al., 2003; Hawley et al., 2003; Marsh et al., 2002).

### *4) Family function*

In regards to the impacts on the function of a family; many studies have documented about less problem solving, communication, role functioning, affective involvement, affective responsiveness, behavioral control and effective coping as interrupting family functions (Curtis, Klemz, & Vanderploeg, 2000; Ergh et al., 2002; Gan & Schuler, 2002; Testa et al., 2006).

In summary, the impact of TBI on family caregivers can be looked at in the following four aspects; psychological impact, physical impact, socioeconomic impact, and impact on the function of the family. Moreover, from previous studies in long-term recovery and TBI patients' rehabilitation period, the most impact of TBI on the family caregiver is psychological impact especially stress and burden.

## Family Caregiver's Stress and Burden in the Caring of TBI Patients during the Transition Period

### *Concept of Stress Among Caregivers*

The Merriam-Webster dictionary (2013) defined caregiver as an individual who provides direct care to children, elderly people, or the chronically ill. Stress is defined as "a physical, chemical, or emotional factor that causes bodily or mental tension and may be a factor in disease causation" (Merriam-Webster, 2013). The definitions of caregiver stress means an individual who provides direct care to another, and feels bodily or mental tension resulting from factors that tend to alter an existing stability. The National Women's Health Information Center (NWHIC), on the other hand, defines caregiver stress as "the emotional strain of caregiving" (NWHIC, 2006, p. 1). In addition, caregiver stress is the caregiver's perceived poor emotional and physical health as a result of continually caring for a chronically illness person (Kuipers, Onwurnere, & Bebbington, 2010). Caregiver stress can occur when the caregiver experiences are perceived or appraised as threatening, which can become worse due to the progressive nature of TBI.

### *Concept of Burden Among Caregivers*

Hiseman and Fackrell (2017) defined caregiver burden as as the strain or load borne between the patient's disability and the impact that caregiving has on the lives of the caregivers and their families. Caregiver burden is one construct used to classify the types of difficulties associated with caregiving for a chronic illness person, such as brain injury. Caregiver burden has been described as both objective and subjective burden; the objective difficulties of work (for example; financial strain) are the same as the subjective problems connected with caregiving demands (for example; emotional strain) by an individual who cares for a chronically ill person, disable person, or elderly family member (Jaisri, 2014). Caregiver burden is a multiple dimensional reaction to physical, psychological, emotional, social, and financial stressors connected with the caregiving experience. The caregiver perceives the burden rather than the other family members or healthcare providers, and this perceived burden determines the impact on the caregiver's life (Carretero, Garces, Rodenas, & Sanjose, 2009). The perceived burden level has been associated with greater risks of depression and lower caregivers' quality of life (Flesch, Batistonia, Neria, & Cachionia, 2017).

In summary, caregiver stress and burden all involve a negative association for being a caregiver. There is a difference between the caregivers' needs and their ability to cope with the needs. The caregiver's assessment of the difficulties, caregiver strain, or objective burdens of caring establish the level of perceived caregiver stress and/or subjective caregiver burden.

### *Factors Related to Caregiver Stress and Burden*

Various factors may affect the stress of a caregiver. These are patient related factors such as neurobehavioral disturbance and emotional states in a patient with TBI

(Testa et al., 2006), changes in behavioral management and cognitive complexity (Ergh et al., 2002). Ganesalingam and colleagues (2007) found that post-concussion symptoms were associated with a greater level of family stress at 3 months. In addition, the family caregivers' stress can influence a patient's rehabilitation (Sady et al., 2010; Sander, Carosellis, Becker, Neeses, & Scheibel, 2002). Family caregivers who report stress may not be of valuable assistance in the rehabilitation period (Sander et al., 2002). Not only stress, but also caregivers' burden was found at three months post injury (Ganesalingsam et al., 2007). Additionally, some family caregivers reported that loss of personal free time was connected to caregiver burden (Marsh et al., 2002).

Behavioral and personality changes of TBI patients may ruin a family's functioning. The problems a family may have in handling the TBI-patient's behavioral changes may become a principal determinant of family burden. The lack of caregivers and patients' preparation to deal with the later behavioral and personality changes is a main complaint. Family members may not have the skills to handle, manage, cope and provide care in TBI rehabilitation. As a result, psychological problems that occur in TBI caregivers are common (Hawley et al., 2003; Kreutzer et al., 2009). These emotional problems may continue and in some lead to higher stress, thus affecting the caregiver as distress symptoms.

### *Gender*

Because of greater female life expectation and constant sex role differences, women are much more likely to provide direct care than men. Many studies reported the relationship between gender and burden. The higher level of burden on female caregivers has been described as ‘‘the sandwich generation’’ and ‘‘women in the middle’’ (Chou, 2000; Samartkit et al., 2010) which refers to the various roles of women such as mother, worker, household leader, and primary counseling and emotional supporter. The result of role socialization by gender differences can be traced to caregiver burden (Lippa et al., 2014). Similarly, many studies reported women made up the majority of family caregivers (more than 60%) and they perceived their burden higher than men (Chou, 2000; Samartkit et al., 2010).

*Socioeconomic Status.*

Economic status plays a key function in a family's perception of stress and burden. Family income also has been found to be the crucial determinant in the types of services families can afford as well as the load of burden the family carry in regards to caregiving (Sawasdinaruenart et al., 2013). It has been shown that inadequate family income decreases the access to resources that might make caregiving more suitable.

*Social Support*

Social support was a key autonomous predictor of caregiver burden (Rodakowski, Skidmore, Rogers, & Schulz, 2012). The primary caregivers role are mainly to provide care to patients, including direct, interpersonal, and general care over time, thus, this role can result in physical stress, fatigue, psychological stress, and less relaxation time (Rigby, Gubitz, & Phillips, 2009). Therefore, having assistance to care for the patients could decrease the caregiver burden. This is a similar result to Rigby and colleagues' (2009) study which explained that having an assistant caregiver of patients with cardiovascular accident accounted for 37.6% of variance in the caregiver burden.

### *Caregiver's Health*

Healthy caregivers were always found to have considerably lower burden levels than those in poor health (Samartkit et al., 2010; Sisk, 2000). According to Samartkit and colleagues (2010), they found the relationships between burden and a caregiver's health can adjust over time as the condition of the patient being cared for becomes more troublesome.

Many factors were identified in a previous study which related to caregivers burden. These included: gender, socioeconomic status, social support, and a caregiver's health (O'Donovan et al., 2011; Gan et al., 2010; Jorgensen et al., 2010; MacKenzie et al., 2009; Nabors Seacat, & Rosenthal, 2002; Padmini Yeleswarapu & Curran, 2010; Stancin et al., 2010). A previous study of assault victims of the unrest situation in the southern border provinces of Thailand showed that having an assistant caregiver and the patients' ability to do daily activities were important predictors of caregiver burden (Saesia, Songwathana, & Suwanmanee, 2014).

### *Caregiver Need of Support*

Family needs change over time as care settings, functioning, and personal roles change. Previous studies of family needs have focused on the progress of needs over time. Rotondi and colleagues (2007) described caregiver needs in multiple phases of care such as acute care, rehabilitation in hospital, transition to home and long term living in the community.

In the acute care, family members mainly use their time in the intensive care unit or rehabilitation in a hospital. During this period, the family caregiver stated the need to know and understand about the injured patient's condition, prognosis and expectations information. They also desired to totally understand the needed medical care for the patients. Caregivers also found greater understanding of the patients' changes in the long term and the implications of the patients including the process of rehabilitation and compensation (Bond et al., 2003). Therefore, the family caregiver would be trained in the skills to cope with the patient's impairments, and deficits, as well as the sequelae of TBI patients (Bond et al.).

After discharge, family members need to get continuous reassessments of the TBI survivor to measure recovery progress. For advice and direction, caregivers are required to communicate with health care professionals to respond to the medical questions and the patient's condition and to seek support and encouragement. Caregivers need help to provide a good environment for their TBI patients.

In the later phase, some families explained they their needs had been met about the health information, however, they also reported unmet needs about emotional support, instrumental support, and professional support. Support needs are mostly required from other family members and friends and other caregivers to share experiences. Social and/or community support groups are required for assistance. This service is essential to facilitate a family to cope with the sequelae of TBI and prevent emotional problems arising due to the situation. Family caregivers may also need recommendations for the appropriate legal assistance organization to deal with insurance claims and other legal issues. Family caregivers also need help in verifying reliable sources of financial help such as charities, social organizations and foundations (Bond et al., 2003).

TBI caregivers may face situation changes over time. Nurses should provide support and education programs prior to hospital discharge aimed at improving the transition to home and the community for people with TBI, as well as those who care for and interact with them.

### Care System in Thailand for TBI survivors

In Thailand, there is not a law or policy specific for TBI survivors. There is only an act for persons with disabilities in general. Since 2007, the Persons with Disabilities Empowerment Act has come into power, taking over the Rehabilitation of Disabled Persons Act of 1991 and allied Ministerial Regulations, which formerly had been the core legal instruments (Thailand, Ministry of Labour, 2017). The Rehabilitation Act of 1991 set the basis for the rights of persons with disabilities to receive public services. Other acts also have involved entitlements for persons with disabilities, for example, the Social Security Act provides registered persons with disabilities a subsistence allowance of 500 baht per month, and the National Education Act defends the rights of persons with disabilities to gain education. However, the continuation of payment and other support tend to be the smallest amount compared to the current standard of living in Thailand with the daily lowest wage fixed at 300 baht in 2018.

Although the quality and amount of services for disabilities persons are not enough and are not advanced when compared to other developed countries, these Acts ensure that Thai persons with disabilities have the right to receive medical, rehabilitative, and educational services, employment support and financial assistance. As a condition to receive these services, a person with a disability needs to be registered at their nearest Public Welfare Office, with a medical diagnosis of his/her impairment. District Public Welfare Offices and Health Centers provide services directly to persons with disabilities, and Provincial Special Education Centers are in arraign of educational services for children with disabilities.

The present TBI care system in the Thai context still lacks a comprehensive discharge planner and care coordination between both the hospital and community. Due to the complexity of TBI injury, continued care is needed from the acute phase to the rehabilitation phase. Lack of information and documentation during the transitional period was acknowledged, in addition to the health care systems in both the hospital and community which are separate and directly affects quality of care (Songwathana, Sae-sia, Kitrungrote, & Manoonya, 2014). Furthrmore, discharge preparedness programs are not performed as needed. Some TBI patients returned to hospital with common and recurrent problems. In a tertiary hospital in southern Thailand, the home visit program was being managed without an organized plan. Due to lack of cooperation and communication about patient conditions and caregiving needs associated to discharge planning and inconsistent follow ups, complications in patients and problems for caregivers have occurred.

### Caregiver Supportive Program

In general, the hospital discharge program is designed to enable a patient or/and family caregiver to manage the treatment and prevent any patient complications, while maintaining quality of life.

A systematic review on caregiver and supportive programs for TBI caregivers was performed by searching existing research evidence for quasi experimental research, randomized controlled trails (RCTs), and a systematic review from 1999-2018 using (1) CIHNAL, (2) PubMed, (3) The Cochrane Library, (4) Sciencedirect, and (5) ThaiLIS database. The key words were caregiver, caregiving, brain injury, head injury, intervention, program, supportive program, and family caregiver. Using Google, online resources were also assembled, such as the websites of telenursing.

The interventions developed for TBI caregivers are described in terms of components, duration, and outcomes. The main components of the interventions from nine studies composed of education, psycho-education, skills training, and emotional support (Table 1) in hospital (Backhuas et al., 2010; Morris, 2001; Narkthong, Songwathana, Kitrungrote, 2014; Prabripoo, Wongvatunyu, & Junhavat, 2013; Sawasdinaruenart, Sae-sia, & Songwathna, 2013) and community (Brown et al., 1999; Carnevale, Anselmi, Busichio, & Millis, 2002; Petranovich et al., 2015; Rivera, Elliott, Berry, & Grant, 2008).

#### *Educational interventions*

The educational interventions were mainly focused on health conditions related to TBI, its impact, a patient's recovery process, solving problems and managing stress. Booklets and documents for individual learning after teaching or training were distributed without any system to follow up or for individual counseling and support as needed.

#### *Psycho-education*

The group interventions were combined using psycho-education, and the teaching of stress management and problem solving strategies. Most types of material used for teaching were power-point and visual aids. Moreover, all groups were led by a clinical psychologist.

#### *Skills training*

The skills training topics were mainly focused on nursing techniques that included nutrition care, respiratory care, excretion care, exercise and daily care, rest care, medication care, preventing accidents and complications procedures, and hygiene care. These were conducted in groups by nursing professionals (researchers).

#### *Emotional support*

The emotional support intervention was conducted in groups of caregivers of patients with TBI (two to three persons/group) through training workshops about stress management, problem solving, having control of intense emotions, coping strategies and anger management. This session took only 30-45 minutes.

Table 1 shows the duration of the interventions which are mostly designed for during hospitalization within a short term period (less than 3 months) rather than a long term period (more than 3 months). Seven studies conducted in the short term

**Table 1** Interventions for Caregivers of TBI Patients

| **Authors** | **Level of evidence** | **Sample** | **Effect Size** | **Intervention** | **Duration** |
|---|---|---|---|---|---|
| Morris, K. C. (2001). | 2d | 1 group | .14 to .21 (small) | Combination (1,2) | 4 weeks |
| Brown, et al. (1999) | 2c | 2 groups | 1.2 (large) | Single(1) , *distance education<br>**face to face intervention | 10 weeks |
| Sawasdina-ruenart, et al. (2013) | 2c | 2 groups | 1.27 (large) | Combination (1,2,4) | 1week |
| Prabripoo, et al. (2013) | 2c | 2 groups | 1.28 (large) | Combination (1,3) | 1week |
| Narkthong, et al. (2014) | 2c | 2 groups | .74to1.05 (large) | Combination (1,2) | 4weeks |
| Carnevale, et al. (2002). | 1c | 3 groups | 0.07 to.39 (Small to medium) | Combination (1,2) | 4weeks |
| Rivera et al., (2008) | 1c | 2 groups | -.62 to.30 (small) | Combination (2,4) | 1year |
| Backhaus, et al. (2010) | 1c | 2 groups | .8 (large) | Combination (2,4) | 14weeks |
| Petranovich et al. (2015) | 1c | 2 groups | 0.36-0.55 (medium) | Combination (2,4) | 1.5years |

Remarks [1] Educational intervention [2] Psycho-education

[3] Skills Training [4] Emotional Support

ranged from 1 week (Prabripoo et al., 2013; Sawasdinaruenart et al., 2013), 4 weeks (Carnevale et al., 2002; Morris, 2001; Narkthong et al., 2014), 10 weeks (Brown et al., 1999), and 14 weeks (Backhaus, et al., 2010). Two studies conducted in the long term included 1 year (Rivera et al., 2008), and 1.5 years (Petranovich et al., 2015). However, four weeks is often the time period given for an intervention for TBI caregivers.

A wide range of outcome scales were used focusing on reducing caregivers' psychological problems to improve their psychological health. The most common outcomes of these interventions were caregiver stress (Carnevale et al., 2002; Rivera et al., 2008; Sawasdinaruenart et al., 2013), caregiver burden (Brown et al., 1999; Carnevale et al., 2002; Rivera et al., 2008), depression (Morris, 2001; Rivera et al., 2008; Petranovich et al., 2015), distress (Backhuas et al., 2010; Brown et al., 1999; Petranovich et al., 2015), stress impact (Sawasdinaruenart et al., 2013), anxiety (Morris, 2001), patient not ready to discharge (Narkthong et al., 2014), and poor well-being (Rivera et al., 2008).

Regarding the outcomes of the interventions, some similar findings were shown. The mean score of the psychological problems in the intervention group (receiving combined methods) was significantly lower than those in the control group and a better result was gained than before (Backhuas et al., 2010; Brown et al., 1999; Morris, 2001; Narkthong et al., 2014; Petranovich et al., 2015; Rivera et al., 2008; Sawasdinaruenart et al., 2013). However, only one study (Carnevale et al., 2002) showed no significant change in psychological problems after receiving an educational program. Moreover, Brown and colleagues (1999) found that those who received an intervention either face to face or by telephone had no significant change in the mean score of psychological problems.

Although there was evidence of the interventions in reducing psychological problems or improving psychological health among the caregivers of patients with TBI, these were administered in a short term period. Evaluation was mainly assessed at the hospital level which acknowledged the importance of comprehensive education for TBI caregivers. However, adequate support is required since the care demands of persons with TBI after discharge are unpredictable and dynamic.

Nurses are the largest group of health care professionals who play a central role in discharge education. It is important for nurses to provide information packages for caregivers. Combined interventions are more effective than a single method, so comprehensive guidance for caregivers should be developed for caregivers to be better able to care for people with moderate to severe TBI living in the community. However, a further method needs to be developed to maintain psychological health and follow up in the long term. In addition, the caregiver intervention must be integrated with the available resources such as hospital discharge and community support programs to enable patients or/and family caregivers to manage care and prevent patient complications, while maintaining psychological health. Moreover, the intervention studies from the literature review did not measure any patient outcomes.

After hospital discharge, the common problems of TBI survivors are memory loss, seizure, headaches and difficulties in daily living. Most brain damage in the survivors are in the moderate range of visible behavioral change which is a sign of temporal and/or frontal injury (Lerzak, 1995). Because of damage to the brain, TBI can induce the risk of seizures, Alzheimer’s disease, Parkinson’s disease, and other related brain disorders. The physical or psychological change may depend on the area of the brain that was damaged.

The complications after a traumatic brain injury especially a moderate to severe traumatic brain injury dramatically increase the risk of more serious complications. Physical complications include posttraumatic seizures, hydrocephalus, facial paralysis, loss of feeling, loss of eyesight, swallowing dysfunction, cognitive problems, deep vein thrombosis, wound infection, pressure sores, urinary tract infections, and urinary incontinence (Narkthong et al., 2014; Pangilinan, 2015). TBI patients also experience emotional changes such as mood swings, stress, anxiety, depression, irritability, lack of sensitivity for others, are easily angered, suffer insomnia, and changes in self-esteem (Riggio, 2011).

These complications may be life-threatening and also may interfere with the participation of patient readmission (Boutin et al., 2013). About 20% of those who receive Medicare benefits will return to the hospital after a discharge, and be readmitted within 30 days after discharge from the hospital and about 90 % of those patients are unplanned readmissions (Saverino, et al., 2015).

## Meleis’ Transition Theory

Meleis et al. (2010) and other researchers (Golan, 1981; Selder, 1989; Tyhurst, 1957; Walker, 2001) have affirmed that transitions are complicated and multidimensional. This transitional theory is based on four main concepts, which are described as nature (type, patterns, and properties of transition), transition conditions (process facilitators or inhibitors and related to the person, the community, and society), patterns of response (process indicators and outcomes of the transition, conductors of the nursing therapeutics), and therapeutic interventions in nursing.

According to the Meleis transitional theory, the transition is identified by different dynamic stages, milestones, and turning points and can be defined through processes and/or existing outcomes (Meleis, 2010). It is a route from such a life stage or state to another so as to reach the sufficient adaptation to the new role and/or event. Consequently, it is a variety of notions taking on the elements of process, time span, and perception (Chick & Meleis, 2010).

### *1) Awareness*

Chick and Meleis (1986) affirmed that in order for a person to begin transition, they must initially be aware of the transitional situation. The starting process of the transition is awareness in which the person is reminded that he or she is not well and looks for health care. The transition may not be associated with individual choice such as the case of persons with both a chronic illness and an added acute illness who are not given the decision to stay in hospital until recovery. Throughout this event of transition from the hospital to home setting, the patients and their family members may suffer from feeling unsafe, feeling confused, and feeling helpless (Weaver, Perloff, & Waters, 1998).

### *2) Engagement*

The talent of the caregiver or patient to engage relies on the awareness of the transitional situation (Meleis et al., 2000). Engagement is the point to which the individual is occupied in the transition process. This is the stage in which he or she is looking for information and is proactive. Nurses can assess in the caregiver and patient’s needs, and responding to this information need is significant during the proactive stage of the transitional process

### *3) Time Span*

Time span is the move and change over time that results in transition. Bridges (1991) points out that a transition is like a process in which there are combined rites, rituals, and ceremonies. He also describes three distinctive phases as endings described by various negative characteristics, a reassessment, and new starting or a time of steadiness. His conceptualization applies to both grown and event types of transition.

After discharge from the hospital, the TBI patients and family caregivers recognize the need to start the primary transitional process. Performing telenursing as the caregiver starts to find information and engages would be helpful. This time span is frequently in a state of flow or change and would need the nurse to repeatedly assess how the patients and family caregivers are affected throughout their illness transition. Meleis et al. (2000) recognized the significance of reactivation in explaining hidden transitions and the need to constantly reassess the patients’ health outcomes.

### *4) Critical Points*

Critical points and situations are the eras of exposure a patient and/or family caregivers using telenursing may face during the transitional period (Meleis et al., 2000). Selder (1989) verifies that when truth has been interrupted, there often is a common sense of being unsafe and of feeling threatened. This is common in the literature on the topic of caregiving, but little attention has been faithful to the important era at immediately following hospitalization. In one study on mothers cared for by their children, there were less difficulties in caring for their mother post-discharge when the children were able to gain information and solve any problems with the healthcare providers that arose in their daily life. They also felt more likely to have established routines (Bull & Jervis, 1997). In Meleis' transition theory, transition is an adjustment in health and illness that tends to generate a period of of vulnerability (Meleis et al., 2000). Transition is both a process and outcome of complicated interactions that change over time (Meleis & Trangenstein, 1994). As mentioned previously, there are four key components of transition: nature of transition, transition conditions, nursing therapeutics and patterns of response (Meleis et al., 2000).

Each of the four components of Meleis' transitions theory (Meleis et al., 2000) is described by the study variables. The nature of the transition is the first component which is defined as the descriptor of the type, pattern, and property of a transition and is functionalized as the TBI patient's hospitalization and the caregiver's characteristics in this study. A transition condition is the second component and is the personal or environmental conditions that simplify or prevent progress to perform a good transition. The community and healthcare systems are the transition conditions in this study. The nursing therapeutics is the third component that focuses on the avoidance of frail transitions, and deals with the experience of transitions. The Telenursing Based Caregiver Transitional Support Program is the one important nursing therapeutics role for preparing families before transition to home. The patterns of response is the fourth component that attempts to understand how patients and their caregivers handle the illness, treatment, and rehabilitation. Moreover, the patterns of response have four main dimensions which are feeling connected, interacting, location and being situated, and developing confidence and coping (Meleis et al., 2000).

Two of the four dimensions from the patterns of response (feeling connected and developing confidence and coping) are significant outcomes measured in this study. Feeling connected to the health care providers means that caregivers and patients feel they are easily connected with the health care provider in order to find the answers to their questions by using the Telenursing Based Caregiver Transitional Support Program. The connection to the health care providers is an important indicator of a good transition experience by caregivers and their patients (Meleis et al., 2000). Developing confidence and coping is another dimension that considers the nature of the transition process and is visible by the mastery of treatment and rehabilitation, the level of resource utilization, and the tactics for organizing the illness over the time (Meleis et al., 2000). Patterns of response are commonly considered in the short term period. The short term period is 28 days or four weeks following the hospital discharge which in this study is indicated by caregiver burden, caregiver stress, and patient readmission rate.

## Telenursing

Telenursing as an openly easily reached resource that can facilitate these critical points outline above while promoting caring strategies and support for the caregivers on daily care (Meleis et al., 2000). Schumacher et al. (2000) identified that caregivers need professional assessment and guided direction to build confidence in their caregiver roles in a critical event in caregiving.

Telenursing is one component of telehealth that occurs when nurses meet the health needs of patients and/or caregivers using information, communication and web-based systems. Telenursing has been defined as “the delivery, management and coordination of care and services provided via information and telecommunication technologies” (College of Nurses of Ontario, 2009). Technologies that are used in telenursing nowadays may include telephones, personal digital assistants (PDAs), tablets, video and audio conferencing, and so on.

The involvement of several technological resources can also show good outcomes. In Jelin and colleagues’ (2012) study, the results showed the telephone care was used for the delivery of care for fibromyalgia patients by an education support program through the Web which included consultation and support care for the patients' chronic pain. One of the studies used Facebook groups for diabetes which was one of the largest groups that used technology to deliver information on a medical condition. The patients and family members use these spaces for sharing experiences and for searching for information needs on the disease for care and emotional support (Greene, Choudhry, Kilabuk, & Shrank, 2011). In regard to the individual, it is assumed that telenursing is primarily significant for attending to situations or events. This is generally for patients with chronic illnesses, where there is a difficulty to maintain the treatment. Notionally, these technologies should be applied to home care, especially, to the launching of post-acute care, and may improve the quality, efficiency, safety and ability of health care systems. Caregivers participating in telenursing services can receive appropriate care at all times from a nurse who provides crucial information via their mobile phones to handle illness management. Caregivers are also able to consult their nurse via telecommunications such as the Line application to achieve advice/counselling with a 24-hour service. Currently, no published studies have described the transition to home using telenursing interventions for Thai caregivers in caring for patients with TBI at home.

In conclusion, the use of telenursing is already published and well known in international research studies. Moreover, in Thai society, technologies have become more important in our daily life, especially in the health care system. There are two popular telehealth applications that Thai people are familiar with and these are the Thai EMS 1669 application on the mobile phone and the mental health hotline consultation.

The telenursing based caregiver transitional support program is a support program initiated by nurses for TBI caregivers which has been developed based on Meleis' transitional care (Meleis, 2010) using technology as a bridge between nurses and caregivers which can be integrated in discharge planning. Caregivers participating in telenursing services can access suitable care at all times from nurses who provide essential informative via their mobile phones to help in illness management.

Caregivers are also able to consult their nurse via telecommunications such as the Line application to obtain advice.

## Action Research

Action Research has existed for over 60 years and has long been used in a variety of disciplines (Mayer, 2000). Action research is nowadays used as a broad term covering several types of research and, relies on the author, and unusual classifications. Particularly designed to close the gap among theory, practice, and research, action research is improving credibility in health care, particularly with nursing. The principle purpose of action research is to implement a change to solve a nursing practice problem.

Three common definitions for action research are: a "systemic inquiry that is collective, collaborative, self-reflective, critical and undertaken by participants in the inquiry" (McCutcheon & Jung, 1990:148). "A form of collective self-reflective inquiry undertaken by participants in social situations in order to improve the rationality and justice of their own social or educational practices, as well as their understanding of these practices and the situations in which these practices are carried out" (Kemmis & McTaggert, 1990:5). "Action research aims to contribute both to the practical concerns of people in an immediate problematic situation and to the goals of social science by joint collaboration within a mutually acceptable ethical framework" (Rapoport, 1970:499 as cited in McKernan 1991:4).

Grundy (1988) identified three modes of action research: technical, practical, and emancipatory. The technical approach was been used in this study in order to check an exacting intervention based on a specified theoretical framework, in regards to the nature of the cooperation between the researcher and the health care providers which are technical and facilitator. The researcher verifies the barriers and a specific intervention, then if the health care providers are of the same opinion, they can facilitate in the delivery of the intervention (Holter & Schwartz-Barcott, 1993). The communication circulated within this type of research is generally between the facilitator/researcher and the group, so that the concepts may be conveyed to the group (Grundy, 1988).

A spiral diagram shows the nature of developing action research, even though modifications show the cycling possibility of a long process. The cycles occupy four phases of planning, acting, observing and reflecting (Kemmis & McTaggart, 1989; Zuber-Skerrit, 1995). These can be either worked simultaneously or orderly throughout the process until participants' appropriation and satisfaction of the model are gained.

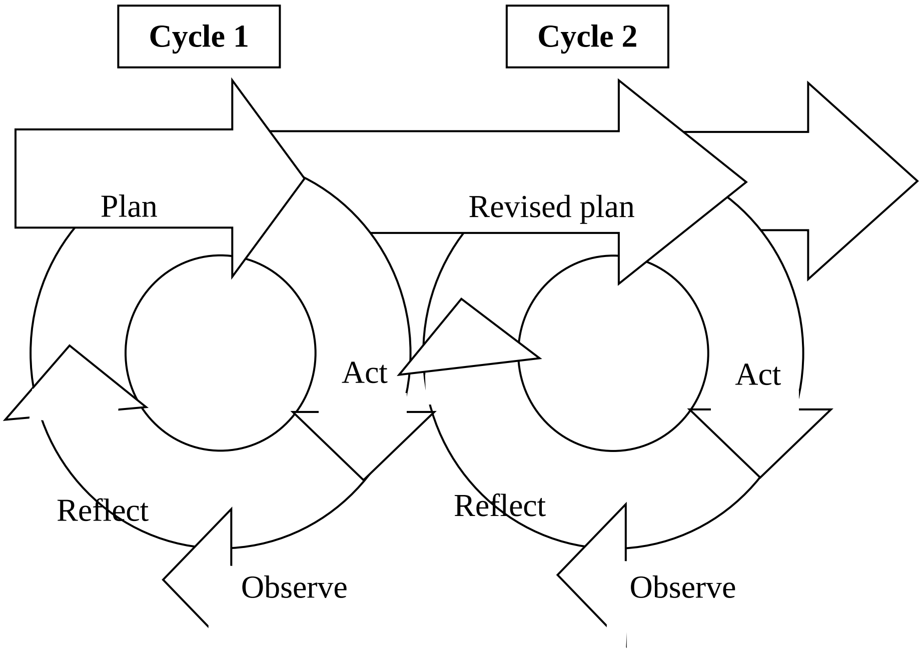

**Figure 2: The Action Research Process**

## Summary

The occurrence of TBI significantly influences the lives of the patient and their family and usually results in dependent living**.** After discharge from hospital, many TBI survivors return to home and live with their family members who assume the primary caregiving role. Transitioning TBI patients from the hospital to home can be a stressful situation for TBI family caregivers. Caregiver burden and caregiver stress are the most common experiences which are contributed to by gender, socioeconomic status, social support, and a caregiver's level of health.

Nurses are a key person in providing specific discharge planning for TBI patients and their caregivers. However, the TBI caregivers need a more convenient way to access information such as through the use of modern technology to help them in using less time as well as less transporting of patients which is more convenient for caregivers. A support program using commonly used technology is necessary to educate TBI caregivers and to provide them with consultations and advice, primary assessments, disease management, telephone triage, emergency support and management, and homecare.

# CHAPTER 3

# RESEARCH METHODOLOGY

This chapter presents the research design and method consisting of research design, study participants and research setting, research instruments and the process of data collection, and data analysis.

## Research Design

The design of this study is action research. The approach relies on the collaborative process between the family caregivers and nurses to develop a telenursing based caregiver transitional support program for Thai caregivers of persons with traumatic brain injury**.**

## Setting

The study included nurses and family caregivers of moderate to severe traumatic brain injured patients at Hatyai Hospital located in Southern Thailand. This hospital is a tertiary hospital with 900 beds which is a central referral center for all hospitals in southern Thailand. TBI patients are admitted to the neurosurgical ward or neurological intensive care unit

The neurological ward and neurological intensive care unit at Hatyai Hospital were selected for the research setting because this hospital has specialist doctors in neurology who are responsible for taking care of neurological patients in

Southern Thailand. Many neurological patients, especially traumatic brain injury patients are referred to this hospital for further treatment.

The discharge planning that is provided in these two units is similar. The nurse or neurosurgeon instructs the patients and their families about the health conditions, current treatments, and impacts on the patients' lives. Moreover, the nurse or education nurse provides a formal general educational program and common nursing skills as routine services in these units before a patient is discharged.

### Participants

The key participants in this study were the nurses, the community nurse and the family members who are the primary caregivers providing direct unpaid care to TBI patients.

1. Nurses

The participants consisted of registered nurses who are working in the neurological ward or neurological intensive care unit or community nurse and who were willing to participate in this research.

2. Family caregivers

Family members who were primary caregivers and who provided the majority of care for moderate or severe head injury patients. These caregivers also have a close relationship with the TBI patients, and are usually the parents, spouse, or other relatives who provide unpaid care to their TBI patients during hospitalization and transition to home.

A sample following the inclusion criteria was used to enlist caregivers who identified themselves as the major providers for TBI patients. The inclusion criteria for selecting the sample is defined as follows:

**Inclusion criteria for TBI patients**

1. TBI patients who were aged more than 18 years old
2. Has been diagnosed as moderate to severe TBI, who has a disability and Glasgow outcome score evaluated by The Extended Glasgow Outcome Scale (GOSE) at level 2 to 5 (Appendix A).

**Inclusion criteria for caregivers**

1. At least 18 years old
2. Provide direct care for TBI patient both during hospitalization and at home
3. Communicate in Thai or the local Thai language
4. Had and was able to use a smart phone

## Instruments

The study instruments consist of 1) instruments for the research procedure and 2) instruments for data collection.

*Instruments for research procedure*

The instrument needed for this study were the researcher and telenursing.

1) Researcher

The researcher was a key person in the data collection. While the researcher had little experience in conducting qualitative research, the thesis advisor suggested conducting a pilot study to gain more experience. This was conducted to assist the researcher in gaining confidence and skills in collecting, summarizing, and analyzing data. The researcher had experienced in trauma patients caring who had multiple trauma including brain injury and taught nursing student about brain injury for five years. The researcher conducted a pilot study in the Neurosurgical ward. One nurse and one TBI caregiver participated in the process through the action research steps, which was composed of plan, action, observation, reflection, and revised plan.

2) Telenursing

From the five experienced TBI caregivers interview and Literature review, the result was used to develop a tentative telenursing model for this study.

*Instruments for data collection*

The instruments used in this study consisted of 1) general information questionnaires, 2) A question guideline for participants, 3) Patient complications, 4) Caregiver Stress, and 5) Caregiver burden

1) General information questionnaires for each participant (Appendix A)

1.1) Family caregiver's general information questionnaire contains a checklist of demographic and socioeconomic characteristics of a primary caregiver. These include age, gender, education, marital status, occupation, monthly income, economic status, and relationship with the patient. The family caregiver was asked to answer questions about her/his experience as a caregiver, her/his self-defined caregiver role, assistant person, and her/his hometown.

Patient general information inventory contains a checklist of demographic and socioeconomic characteristics of the patient. These include age, gender, education, marital status, occupation, monthly income, and economic status. The questions also include information about traumatic injury history, the patient's condition, and medical history.

1.2) Nurse demographic questionnaire contains a checklist of nursing duties, gender, age, education, marital status, employment in nursing, work experience in caring for patients with TBI, and economic status.

2) A question guideline for participants (Appendix B)

2.1) Caregivers

An interviewing guide was conducted to gain an understanding of the participants' perceptions and needs in transitional care. This was a semi-structured interview with a combination of open ended questions followed by more specific probes. Three experts who were a neurosurgeon, neurology nurse and one surgical nursing instructor reviewed the interview for content validity.

Data from individual interviews were collected since the participant initially entered the study through the time they were discharged from the study (post-discharge period). Interviews were audio recorded, and complete written transcriptions were made immediately after each interview.

2.2) Nurses

Focus group discussions (FGD) were conducted to gain an understanding of the participants' perceptions and needs in transitional care led by the researcher. FGD were audio recorded, and complete written transcriptions were made immediately after each FGD.

3) Patient complications

Patient complications were measured by a patient's readmission rate. These are common complications that can occur in the transition period such as respiratory infection, urinary tract infection, pressure sores, and others.

4) Caregiver Stress

Caregiver stress was the perception of the TBI caregiver about her/his condition of exhaustion, anger, rage, or guilt that results from unrelieved caring for a TBI patient. Caregiver stress was measured by a self-report numeric rating scale from the family caregiver. This scale is only one question that is an easy and quick access for caregiver stress. The score range was from 0 to 10, 0 = no stress and 10 = very stressful. The data was collected 4 times; in discharge day, day 7, day 14, and day 21.

5) Caregiver burden

Caregiver burden was the distress that a family caregiver perceived of their experience as a result of the changes that they observe in the person with TBI. In this study, caregiver burden was measured by a self-report numeric rating scale from the family caregiver. This scale is only one question that is an easy and quick access for caregiver burden. The score range was from 0 to 10, 0 = no burden and 10 = heavily burdened. The data was collected 4 times; in discharge day, day 7, day 14, and day 21.

## Data collection process

The process of data collection using action research was divided into 3 steps: 1) preparation, 2) action, and 3) evaluation. Maximum variety sampling (Morse, 1994) was utilized to describe high quality cases and identify significant share patterns of commonalities existing across the participants.

### 1. Preparation Step

This step aimed to engage the participants, build rapport with them and understand the context of TBI caregivers.

1.1 Building rapport and recruitment

The researcher kept in touch with the nurses before conducting this action research.

1.2 Assessing the context

The nurses' caring activities for TBI patients in the hospital focusing on atmosphere, the interpersonal relationship between the nurse and caregiver, the clinical practice and the discharge planning from hospital were explored through participatory observation and focus group discussion with the nurses of the main working group. Moreover, information taken from informal discussions with the nurses and community nurses where it was managed in another way was collected. Information from the literature review was included in the overview of the current research since it provided the researcher with some areas of concern.

### 1.3 Development of the Telenursing Application

The data gathered through clinical experience, baseline data and the literature review were used as the baseline data for constructing the application "We Care You". The researcher trained in order to use the application. The contents in the application were proved by three nurses who provided direct care to TBI patients. A meeting among the researcher and the nurses was held to discuss the current situation, to share the information, to explain about the application and to seek their agreement to provide care. The result was used to develop the tentative models for the telenursing based caregiver transitional supportive program among caregivers of persons with traumatic brain injury.

## 2. Action Step

This part was conducted following the five phases of action research consisting of the initiative reconnaissance phase, and the spiral of four phases (planning, acting, observing, and reflecting).

### 2.1 Reconnaissance phase

The in-depth interviews were conducted in the group of nine TBI caregivers who took care of moderate to severe TBI patients to disclose the daily living activities of the caregiver with a TBI patient in the hospital and at home, and this included care provided from the nurses, seeking information and technology used. Informal interviews and reviewing medical records were undertaken to understand a patient's present illness, health status, problems, concerns, needs, expectations and resources. The group discussions were conducted in the group of nurses to reveal their caring experience, routine care, discharged plan, their perception about caregiver needs, their expectations and the technology used.

### 2.2 Spiral of four phases

#### *2.2.1 Planning phase*

Several strategies were identified to guarantee the achievement of goals/aims involving:

(1) Building rapport in relationships with the caregivers

(2) Empowering the caregiver to perform care by providing information and inspirational support

(3) Encouraging the family caregivers to provide the patients with proper assistance and support in the hospital setting

(4) Providing bed side skills training and individual education in caring and preventing complications to the caregiver.

#### *2.2.2 Acting and 2.2.3 Observing phases*

A tentative care model was developed by integrating the literature review, qualitative data from the reconnaissance phase, and suggestions from the nurses, community nurses and the head nurse. The tentative care model was introduced to the nurses of the main working group in a group meeting. The tentative care model was implemented. Usual care plan in each cycle focused on the TBI family caregivers in the transitional period from hospital to home. The model was refined or modified based on the data collected during the implementation in 3 cycles.

### *2.2.4 Reflecting phase*

Reflection was performed with all participants to evaluate the process of outcomes by in-depth interviews or FGDs of implementing this model.

## 3. Final evaluation step

Process evaluation investigated the participants’ satisfaction with the process of executing the telenursing based caregiver transitional support program via participatory observation, in-depth interviews, and group meetings. The evaluation was performed at the post-discharge period. Data were analyzed to summarize a final model and the knowledge gained. Family stress and burden were evaluated using a numeric rating scale (0-10), individual interviews and observations. A patient’s complications were evaluated using related questionnaires. The results were discussed among the researcher and participants in the meeting.

**Table 2** *Role of researcher and participants in each phase*

| | **Phase 1**<br>Reconnaissance phase | **Phase 2**<br>Planning phase | **Phase 3**<br>Acting and observing phase |
|---|---|---|---|
| **Researcher** | ➢ Introducing this study<br>➢ Building rapport and recruitment<br>➢ Gaining relevant information to the setting<br>➢ Interviewing the experienced caregivers<br>➢ Conducting FGD with health care team<br>➢ Collecting and analyzing data<br>➢ Reviewing literature<br>➢ Developing a tentative care model<br>➢ Introducing this model to participants<br>➢ Testing and refining the tentative model<br>➢ Collecting and analyzing data | ➢ Testing and refining the tentative model<br>➢ Collecting and analyzing data | ➢ Testing and refining the tentative model<br>➢ Collecting and analyzing data<br>➢ Summarizing the actual care model and presenting it<br>➢ Investigating the outcome from this model |
| **Nurse** | ➢ Understanding this study<br>➢ Signing informed consent form<br>➢ Providing suggestions on the tentative model<br>➢ Mutual goal-setting and decision-making on telenursing among health care team and caregiver | ➢ Testing the tentative model<br>➢ Providing suggestions on the tentative model | ➢ Testing the tentative model<br>➢ Providing reflection on the tentative model |
| **Caregiver** | ➢ Understanding this study<br>➢ Signing informed consent form<br>➢ Providing suggestions on the tentative model<br>➢ Mutual goal-setting and decision-making on telenursing among health care team and caregiver | ➢ Testing the tentative model<br>➢ Providing suggestions on the tentative model | ➢ Testing the tentative model<br>➢ Providing reflection on the tentative model |

## The role of researcher

During the data collection, the researcher played the role of a facilitator, consultant, and researcher to help participants evaluate their practice, plan, and implement the program. This included self reflective discussions, goal setting, and other changes to evaluate the program’s outcome.

## Ethical Consideration

This study was approved by the Research Ethics Review Committee of the Faculty of Nursing, Prince of Songkla University, Thailand (PSU IRB 2017 - NSt 005). Permission was obtained from the institutional review board to conduct the study at Hatyai Hospital (ID 55 Protocol number 55/2560, ID 58 Protocol number 58/2561). (Appendix D)

The written objective procedures of the study were given to each subject and a written informed consent was provided. The subjects were assured that their human rights were respected. Potential subjects were able to explain the purpose of the study and how they were involved. In order to decrease the issue of the potential harm, if the participants felt depressed or uncomfortable, the researcher also refers them to the psychologist soon. It was also explained to the participants about the possibility to stop or withdraw from the action research process any time based on their own reasons without fear of any negative consequences in the caring process of TBI patients. They also were informed that they had the right to subject confidentiality and that anonymity was maintained (Appendix E). In addition, the disable person right would be respected.

## Data Analysis

l. Qualitative data

The researcher used the technique of content analysis (Morse & Field, 1995). The researcher initially transcribed the interviews or FGD then made brief notes in regards to interesting or relevant information. After that, the researcher read through the list and categorized each item. Finally, the researcher wrote descriptive paragraphs about the categories and looked for associations between each category. These relationships could be concurrent, antecedents or consequences of a preliminary category.

2. Quantitative data

2.1 The descriptive statistics were used to describe the general information.

2.2 Patient's complications at the post-discharge period (1 month) were analyzed by frequency, percentage, mean, and standard deviation.

2.3 Caregiver stress and burden were analyzed by mean and standard deviation.

## Trustworthiness

Several criteria supported the methodological rigor in this study and assist the reader in evaluating the trustworthiness of qualitative research which can be evaluated by credibility or the truth value of the study, transferability or its applicability, dependability or the consistency of the procedures, and confirmability or the neutrality of the findings (Lincoln & Guba, 1985; Munhall, 2007; Sandelowski, 1986).

*Credibility*. The certainty value of qualitative inquiry usually resides in the finding of human phenomena or experiences as the same as they are lived and perceived by those involved, rather than in the certification of a previous conception of those experiences (Sandelowski, 1986). Guba and Lincoln (1981) suggested that credibility is the principle against which the certainty value of qualitative research is measured. Qualitative research should present such authentic descriptions or interpretations of human experience that the individual having that experience would instantly distinguish as their own from reading the descriptions or interpretations (Sandelowski).

In this study, the researcher adapted these modes of improving the probability so that the findings and interpretations were creditable. Prolonged engagement was used in order to identify constructions and to facilitate immersion into and understanding of the context's culture (Lincoln & Guba, 1985). Although it was not an easy task, developing a trusting relationship in spending time to establish rapport with the participants was more possible for the researcher because she is a southern native Thai. When participants felt that they were acquainted with the researcher, they felt more comfortable in describing their own experiences.

Member checking was another method that the researcher used to maximize credibility. The researcher checked out the selected hunch and preliminary interpretations by asking participants to read stories and provide their feedback. Checking by participants gave them a chance to correct errors of fact or the researcher's interpretations. This provided the participants the opportunity to provide additional data, place the accuracy of their responses and the researcher's "on record", and gave the researcher the opportunity to summarize and assess the overall adequacy of the interviews and focus group discussions.

*Transferability*. Transferability refers to the degree of detail provided about the context of the situation so that it can be judged, and using thick descriptions of the interviews address transferability. In order to glean all the information from the interviews and observations, all senses were engaged as much as possible. The reader is able to understand the context in which it was said for a fuller understanding of the phenomena.

In the process of data analysis, selected precise expressions and exemplars from the interviews were used throughout the presentation of the data to provide a thick description of the experiences of the participants in this study.

*Dependability*. Dependability, as a criterion similar to reliability, refers to the clarity and reproducibility or consistency of the researcher's methodological and analytic decisions and interpretations of the data (Sandelowski, 1986; Woods & Catanzaro, 1988). The reproducibility of the methodology of the study was achieved through the auditing process (Lincoln & Guba, 1985).

During data analysis, the researcher consulted with advisors to verify data interpretation and provide feedback to prevent premature closure.

*Confirmability*. The evaluation of confirmability is based on the characteristics of the data rather than the investigator. A confirmability audit is a major technique for establishing confirmability (Lincohn & Guba, 1985). The assessment of confirmability primarily aims to ascertain whether the findings are grounded in the data.

In this study, the researcher kept audit trail linkages and a personal journal throughout the process to explore impressions of the interviews and focus group discussions (audio tapes and transcripts), the setting, field notes, collaborative data, current events and methodological decisions which might affect interview responses. Likewise, peer debriefing memos, data analysis sheeting, letters of solicitation, and Human Subjects Review paperwork were maintained in the researcher's log.

# Chapter 4

# Findings and Discussion

The Telenursing Based Caregiver Transitional Support Program was conducted among Thai caregivers of persons with traumatic brain injury, the nurses and the researcher using the methodology of action research. The findings of this study relied on both qualitative and quantitative data analysis and are shown as follows.

1. Demographic Characteristics of the Participants
2. Process in Development of the Telenursing Based Caregiver Transitional Support (TCTS) Program
    - 2.1 Reconnaissance phase
        - 2.1.1 Establishing partnership to understand the health care services for TBI patients
        - 2.1.2 Assessing caregiving activities for TBI patients perceived by both the family caregivers and nurses
        - 2.1.3 Identifying main barriers or problems in the TBI care system during transition
        - 2.1.4 Planning the tentative TCTS program
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        - 2.2.1 Cycle 1 - Enhancing and empowering the family caregiver
        - 2.2.2 Cycle 2 - Maximizing resources and care coordination
        - 2.2.3 Cycle 3 - Supporting care management in emergency situations

2.3 Reflection

3. Components, Stages and Strategies of the TCTS Program

4. Discussion

## 1. Demographic Characteristics of the Participants

The participants of this study consisted of 14 primary family caregivers (5 caregivers of experienced patients and nine caregivers of novice patients), and nine nurses of the core working group.

### Primary family caregivers

A total of 23 primary family caregivers (FCG) were included in this study. However, only 14 FCG participated in this study because the condition of the TBI patients was better than GOSE 5. In the reconnaissance phase, five family caregivers of experienced patients were interviewed. In the following phases, 9 family caregivers of novice patients were recruited by this way of one family caregiver versus one patient as a couple, so as to refine the tentative Telenursing Based Caregiver Transitional Support Program.

The five family caregivers of the experienced patients involved one mother, two spouses, one adult child and one sibling (sister). All of them were female, ranging in age from 37 years to 70 years (*M* = 55.2, *SD* = 12.13). Five of them were married. Two were retired, one was a vendor and two were rubber farmers. Three of them had finished their study in a primary school, one had a diploma and the other one had a bachelor degree. Four lived with the patients in the same houses, and one did not live in the same house but lived nearby.

Table 3 *Characteristics of the Experienced Family Caregivers*

| | Characteristics | n |
|---|---|---|
| Gender | Female | 5 |
| Age | | |
| (*M* = 55.2, *SD* = 12.13) | 30-39 years | 1 |
| | 40-49 years | 0 |
| | 50-59 years | 2 |
| | 60-70 years | 2 |
| Religion | Buddhist | 4 |
| | Muslim | 1 |
| Marital status | Married | 5 |
| Education level | Primary | 3 |
| | Diploma | 1 |
| | Bachelor | 1 |
| Occupation | Retired | 2 |
| | Vendor | 1 |
| | Rubber Farmer | 2 |
| Relationship with Patient | Mother | 1 |
| | Spouse | 2 |
| | Adult child | 1 |
| | Sibling (Sister) | 1 |
| Monthly Family Income | 10000-20000 Baht | 3 |
| | 20000-30000 Baht | 2 |
| Living place | Own house | 4 |
| | Rental house | 1 |
| Living with patient | Yes | 4 |
| | No | 1 |

The nine family caregivers of the novice patients involved 5 spouses, 3 adult children and one sister. All of them were female, ranging in age from 27 years to 53 years (*M* = 42.21, *SD* = 10.17). Seven of them were married, and only two were single. One was a farmer, two were retired, one was unemployed, two were businesswomen and three were vendors. One had graduated from a primary school, one had finished their study in high school, and seven had a bachelor degree. All of them lived in the same house with the TBI patient.

Table 4 *Characteristics of the Novice Caregivers*

| | Characteristics | n |
|---|---|---|
| Gender | Female | 9 |
| Age | | |
| (*M* =42.21, *SD* = 10.17) | 20-29 years | 1 |
| | 30-39 years | 4 |
| | 40-49 years | 3 |
| | 50-59 years | 1 |
| Religion | Buddhist | 8 |
| | Muslim | 1 |
| Marital status | Single | 2 |
| | Married | 7 |
| Education level | Primary | 1 |
| | High school | 1 |
| | Bachelor | 7 |
| Occupation | Farmer | 1 |
| | Retired | 2 |
| | Unemployed | 1 |
| | Businesswoman | 2 |
| | Vendor | 3 |
| Relationship with Patient | Spouse | 5 |
| | Adult child | 3 |
| | Sibling (Sister) | 1 |
| Monthly Family Income | 10000-20000 Baht | 3 |
| | 20000-30000 Baht | 4 |
| | >30000 Baht | 2 |
| Living place | Own house | 5 |
| | Rent house | 3 |
| Living with patient | Yes | 9 |
| | No | 0 |

**Nurses of the core working group**

Nine nurses working in this selected unit were part of the core working group. The members of this group consisted of one head nurse, two discharge planner nurses, one community nurse, and five ward nurses. The ages of the nurses ranged from 26 to 53 years of age and 5 of them were married. Seven of them had a Bachelor degree and two of them had a Master degree. Their work experience of TBI care ranged from 2 years to 21 years (*M* = 10.70, *SD* = 8.41).

Table 5 *Characteristics of the Nurses*

| | Characteristics | n |
|---|---|---|
| Gender | Female | 9 |
| Age | | |
| (*M* =40.23, *SD* = 14.02) | 20-29 years | 2 |
| | 30-39 years | 3 |
| | 40-49 years | 2 |
| | 50-59 years | 2 |
| Religion | Buddhist | 9 |
| Education level | Bachelor | 7 |
| | Master | 2 |
| Year of TBI care experiences | 1-10 years | 5 |
| (*M* = 10.70, *SD* = 8.41) | 11-20 years | 3 |
| | >20 years | 1 |

## 2. Process in Development of the Telenursing Based Caregiver Transitional Support (TCTS) Program

Following the five steps of action research starting from the initiative reconnaissance phase and the spiral of planning, acting, observing, and reflecting, the development of the TCTS Program for Thai caregivers of persons with traumatic brain injury was reported through three phases: (1) reconnaissance phase; (2) spiral action research process to develop the Telenursing Based Caregiver Transitional Support Program; and (3) final evaluation.

### 2.1 Reconnaissance phase

Reconnaissance was conducted to understand the caregiving situations and identify problems that needed to be resolved.

2.1.1 Establishing a partnership is the first step aimed at finding a team of core members in the working group from the hospital and community to make a mutual commitment to participate in the research. The researcher presented the project with a head nurse and a nursing director who helped to formulate a core working group. The core working group was comprised of one head nurse, two discharge planner nurses, one community nurse, and five ward nurses. The role of the core team was to design and set a mutual plan with the researcher and participate in the development of the program and help coordinate with the participants.

#### ***1) Health care services for the TBI patients***

The study was observed in a tertiary hospital in Songkhla province. A regional tertiary hospital under the Thai Ministry of Public Health, this hospital is a referral centre for nearby community hospitals principally within Songkhla, although the hospital also serves for other nearby provinces. It has a facility of 900 beds, but it often faces problems of overcrowding and is over capacity most of the time. Moreover, the hospital policy allows only one family caregiver to provide care to the patient during the day in the general wards only and not in the ICU. The TBI patients were admitted in the Neurosurgical Ward (40 beds) or the Neurosurgical Intensive Care Unit (10 beds). Normally, visiting hours for the Neurosurgical Ward are from 11 a.m. to 1 p.m. and 3 p.m. to 7 p.m. In the day shift, there are 7 nurses on duty in the Neurosurgical Ward. In addition, visiting hours for the Neurosurgical Intensive Care Unit are from 12 p.m. to 2 p.m. and 4 p.m. to 7 p.m. In the day shift, there are 7 nurses on duty in the Neurosurgical Intensive Care Unit. Only one discharge planning nurse takes responsibility for both units.

Information gained in participant observation revealed that nursing staff provide patient care. The main provision of care involves physical care, and the management of the physician’s treatment plans. Most of caregivers obtain information from nurses emphasizing hospital policy, hospital setting, cost of inpatient care, and what the family was allowed to perform in the hospital, whereas a few caregivers obtain general information from the nurse aids. The majority of nursing staff are uncertain about the patients’ conditions and progression. Nursing procedures are emphatically described in terms of “what to do” and “how to do”, but they rarely explain “why these procedures have to be done”. Most medical procedures performed are explained to the family caregivers, and are without family participation in decision making.

The focus group of nine nurses, who had responsibility to perform TBI care, also noticed that the existing TBI care system still lacked comprehensive discharge planning and care coordination in both the hospital and community. Lack of information and documentation during the transitional period was recognized and the health care system after discharge into the community was separate from hospitalization, which affected the quality of care. In addition, a discharge preparedness program was not performed as much as the caregivers’ needed. Some patients returned to hospital with preventable complications, as a nurse reflected “some patients were recurrently admitted to the hospital due to a caregiver’s lack of knowledge and skills for caring, as a result, patients often returned with preventable complications”. The home visit program was also undertaken without an organized plan; it just depended on the individual rather than the health care team that needed to visit a TBI patient after discharge from hospital. All of the pathways were based upon the principle that continuing care would be provided to all patients (home health care nurses visit within 14 days after patient discharge from hospital). There was a lack of care coordination and communication about current problems of patients and caring needs related to discharge plans as well as unpredictable follow ups and patient outcomes were often not identified.

#### 2.1.2 Assessing caregiving activities for TBI patients perceived by both the family caregivers and nurses

The five experienced TBI caregivers and nine nurses who were taking care of the TBI patients from admission to discharge were purposively selected for in-depth interviews and focus group discussions. A review of existing documents related to caring in the transition period such as the caregiver's booklet manual, the nurse's guideline, discharge education and service plan were also analyzed. Content analysis was used to explore caring in the TBI situation in the Thai context.

The family caregivers' tasks involved in the patients' daily living activities were those such as bathing, grooming, feeding, and preventing other complications by changing a patient's position and exercising the patient's range of motion, as well as supervision and surveillance in order to avoid dangerous accidents.

*"The nurse taught me about my relative's daily living caring activities such as total bathing, nasogastric tube feeding, tracheostomy tube care and how to remove secretion from the patient's mouth and tracheostomy tube, preventing bed sores by changing the patient position, doing a range of motions to prevent joint stiffness, and*

*supervising and caring in order to avoid dangerous accidents".* (Family caregiver: FCG 1, FCG 5)

*"Mostly the caring activities in the hospital were done by nurses on the ward. The nurses also taught my sister and me while we were switching places to care for him. At home, sometimes we felt less confident. I thought and hoped that if the nurse was here and came to teach us again or we had instructions to do caring tasks, it would be good for us."* (FCG2)

In addition, they also lacked supervision and evaluation about continuity of care. Traditional attitudes and routine clinical practice induced the barrier to enhancing family enhancement. Consequently, nursing staff and family caregiver interaction is task-orientated, superficial and routine. Moreover, family caregivers might be too shy, too considerate, or too insecure to approach nursing staff. They are afraid to disturb the nurses when they are working. The caregivers reflected that caregiving procedures are emphatically taught about "do this thing" and "how to do", but they rarely explain "why these procedures have to be done."

*"At that time, I could remember. It is the third day after the surgery day, the nurses told me I should do these caregiving tasks, to do this and to do that. However, the nurse didn't tell me in detail when I need to do this or I can do it if necessary or not. I wasn't ready. How can I do this thing without the guidance of nurses? I have no previous experience [about caring for TBI patients].*" (FCG1)

*"When the nurse taught me how to do caring activities, I could do that in that moment. However, when the time flies, I cannot remember something and I feel unconfident to do it, I was too self-conscious to ask the nurses more than one time*

*because they looked very busy all the time. I just seek to learn how to do that thing from other caregivers, the internet and sometimes from YouTube.*" (FCG4)

Most medical procedures performed are explained to the family caregivers, and are without family participation in decision making. The family caregivers, therefore, acquire knowledge and skills to care for the TBI patients by self learning, self awareness, past experience in caregiving, observation of health care personal and other caregivers, and trial and error practice. Some family caregivers are not concerned, and lack appropriate participation in the caregiving process.

*"The first time, when I just visited my husband, the nurse came to do A, B, C tasks and to do this and to do that. She just told me to do these A, B, C, and D tasks only however I just thought in my mind why do I need to do these tasks. She didn't tell me anymore.*" (FCG2)

Due to the short hospital stay policy and a large number of nursing duties, the discharge planning program is informally learned and only occasionally arranged. The nursing staff and/or discharge planning nurse who arranges the trainer role quickly taught discharge planning in the acute phase to the family caregivers by either assessing a family caregiver's readiness or choosing the appropriate way to enhance their competency. Lack of caring information and documentation during the transition from hospital to home was noticed and the care system after discharge was separate from hospitalization.

### Staff nurses

A staff nurse is a registered nurse who takes care of patients in each unit and provides routine nursing care. The main care provision included physical care, and care management under the physician's treatment plans. The nurse also emphasized care quality and safety based on hospital policy, considered the cost of inpatient care, and the role of the family in the patient care at the hospital. Due to the uncertainty of patients' conditions and progression, nursing procedures were emphatically described as "what to do" and "how to do", but the nurses rarely explained to the caregivers about "why these nursing procedures have to be done". Most medical procedures were explained to the family caregivers with less family participation in decision making.

*"At the beginning, the nurse explains about the hospital setting, hospital policy, expense of inpatient care, and what the relative was allowed to do in the hospital to TBI relatives. Then they usually provided the patient's routine care which involves physical care, and administering the neurosurgeon's treatment plans."* (FGD Nurses)

**Discharge planner**

Discharge planner is a nurse who prepares the knowledge and skills for the readiness of the caregiver and patient before discharge to be able to continue care in the home setting. In addition, the discharge planning nurse usually prepares the family caregivers earlier from the acute phase by either assessing the family caregiver's readiness or choosing an appropriate way to enhance their competency.

*"My main job is providing the discharge plan in order to prepare the readiness of the caregiver and patient before they go back home. When the patient's health conditions are stable, I usually teach the main caregiver as soon as possible. I teach them all about TBI and their patient's conditions, I also provide caregiving knowledge and teach skills to the caregivers.*" (Discharge planning nurse: DN1)

**Community nurse**

Community nurse is a nurse who follows the patient in the home setting. In general, a patient was followed up within 14 days after discharge. The continuing visit would be planned depending on the patient's problems and demands of care at home as reflected by a community nurse.

*"Normally, I and my team (nurses) will go to visit the patients within 14 days. However, we have all name lists of the patients and we will visit as soon as possible. Sometimes we also cannot visit all patients within this timeline. In addition, we also try to rapidly visit as much as we can, and queue by patients' severity. When we go to visit a patient, we have our checklist that of the patient needs and complications and whether the patient is needed for another follow up or not. If she/he needs continuing help, we will visit each patient for the next 1 month.*" (Community Nurse: CN1)

### *2.1.3 Identifying main barriers in the TBI care system during transition*

The findings revealed four main barriers in the current TBI care system that were perceived by caregivers and nurses; 1) lack of support from health care systems because of limited care manager/ discharge planner 2) ineffective communication among multidisciplinary teams and caregivers due to lack of guidelines or pathways used 3) lack of care coordination between each unit related to discharge programs and 4) incomplete follow up system after discharge.

The Family Caregivers mentioned their needs of support from the health care team in the community on the discharge day. However the family caregiver reported that they did not how to communicate with the community health care service. After discharge from hospital, the caregiver also needs to be able to communicate with the health care team to ask for help and support. Moreover, the caregiver needs to be able to ask for some assistances from the health care provider in providing care for the TBI patients at home. The caregiver also told the ward nurses that they also need the support from the health care provider in the home setting. The caregiver did not know how to adapt themselves in taking care of their TBI patients.

Table 6 *Barriers in the TBI Care System Frequently Mentioned by the Family Caregivers and Nurses*

| | On discharge day | | 1 week after discharge | | 1 month after discharge | |
|---|---|---|---|---|---|---|
| | FCG | Nurses | FCG | Nurses | FCG | Nurses |
| Support | ✓ | ✓ | ✓ | ✓ | - | - |
| Communication | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ |
| Care coordination | - | ✓ | - | ✓ | - | ✓ |
| Follow up System | - | ✓ | - | ✓ | - | ✓ |

In addition, the health care system also lacked of the formal communication between the health care provider and the TBI caregiver. The routine follow up visit by the community health care team is to be held a patient’s home within 14 days post discharge. However, the TBI caregiver also required the assistance as early as possible. The caregivers often called back to the ward to ask for some help and expected a quick response from the nurse when asking any question.

### 2.1.4 Planning for the tentative program

After assessing the caring activities and problems, the researcher obtained information related to TBI care and reflected this to the core working group. This helps to refine the elements of the tentative model guiding this study by initiating the plan, approaches, participation, influence, and individual and group abilities on discharge planning. In addition, participants were encouraged to share ideas and experiences. These approaches also helped develop trust between the researcher, nurse and caregiver who were key factors in this study.

## 2.2 Spiral action research process to develop the Telenursing Based Caregiver Transitional Support (TCTS) Program

The process of TCTS program development consisted of three cycles which were employed through collaboration and communication among the researcher, 9 primary family caregivers (3 in cycle 1, 4 in cycle 2, 2 in cycle 3) and nine nurses. The new caregivers of TBI patients were recruited before discharge and followed up for one month after discharge. These caregivers were called novice caregivers who were recruited by the method of one patient to one caregiver as a couple. The nine nurses were organized as a core working group, consisting of one head nurse, two discharge planner nurse, one community nurse and four nurses, to consider appropriate activities and set priorities for practical activities.

A tentative care model developed by integrating the literature review and the qualitative data from the reconnaissance phase was initially presented in a group meeting. The suggestions from the nurses and the head nurse were introduced to the nurses of the core working group. The main barriers were identified. The barriers identified by nurses towards the care systems were less time for giving advice, lack of discharge planners, lack of care coordination and communication. In addition, the family caregivers' felt unconfident in caring, lacked resources for caring instruments (such as intermittent suction, air bed, dressing set), the health care provider had no time for consultation, the caregivers needed believable and quickly accessed resources for retrieving knowledge and skills in caring, they lacked knowledge in the common complications of TBI patients and how to prevent and manage those symptoms, and they lacked help in emergency situations.

Due to the four barriers related to support, communication, coordination and follow up system (Table 6) as mentioned earlier, discussions among the researcher, nurses and community nurses were arranged to make a decision on the prioritization of the tasks or the important concerns to tackle.

*"I know that they need more time to learn the caring tasks. However, we have limited time for each family. If I were them, I will feel unconfident to do these tasks. It needs time to practice. ……..The family caregiver's readiness and confidence to take care of TBI patients can be the key to improve quality of care."* (FGD Nurses)

Finally, improving the knowledge and skills of family caregivers in caring for TBI patients which they can use for self- learning. The provision of the application was introduced comprising of the basic caring knowledge and essential skills for the family caregiver, the assessment of a patient's complications (respiratory system, gastrointestinal system, muscle and skeletal system), and strategies to manage or solve any problems they faced. In addition, caregiver stress (numeric rating scale) and caregiver burden (numeric rating scale) and some simple management techniques were included for the caregivers to heal by themselves.

The tentative care model was implemented by integrating with the usual care plan in each cycle for TBI care targeting the family caregivers in the transitional period. The model was refined or modified based on the data collected during implementation. There were three cycles, namely, enhancing and empowering the family caregiver, maximizing resources and care coordination, and supporting care management in emergency situations. The process of each cycle is described as follows.

### 2.2.1 Cycle 1 - Enhancing and empowering the family caregiver

In the first cycle, the activities were focused on enhancing and empowering the three family caregivers in the transitional period. This cycle started when the family caregivers were suddenly assigned to learn how to care for the TBI patient. They mostly feel confused and less confident to provide care. Seeing the situation and change of their loved ones and the unfamiliar environment in the hospital aggravated the stress and anxiety among family caregivers. They were informed about the care and treatment that were often complicated and unfamiliar to them which caused them high levels of anxiety. In addition, they were shocked from the unexpected patient’s situation due to no ability to communicate and acquire information properly. This made family caregivers feel vulnerable in handling or managing care for the TBI patient. The lack of confidence to provide care for TBI patients after discharge was of concern by family caregivers.

Upon discussions with the nurses, community nurse and family caregiver, the researcher realized the problems of the family caregivers and the needs to enhance knowledge and skills in the care of TBI patients. The researcher was a facilitator in the discussion and provided support for all participants in order to enhance or promote the family caregiver's confidence. The TBI family caregivers were inspired to acknowledge their patient's conditions and situations.

They reported that they were not familiar with the instruments and environment in caring at home.

*"The nurse in the ward provided a good discharge care plan. The nurse was doing caring activities such as dressing wounds, feeding, and passive exercising for my relative. I can remember some and try to do my best. However, when I went back home, I felt obstructed. I could not do anything. Everything was new for me, new environment, new (different) equipment, etc. Also, I didn't have an instructor, I didn't feel confident."* (FCG 7, FCG8)

Some of the TBI caregivers did not continue providing care at home. Sometimes the main caregiver could not come to learn at the hospital, sometimes the main caregiver changed over time.

*"The nurse called me as she wanted to teach me about caring tasks but I told her to wait, I needed to ask my family member to pick me up. She told me that she didn't have free time on another day and really wanted to teach these caregiving tasks today and would arrange the appropriate time to repeat. Luckily on that day, my sister came to visit my brother, she had a chance to learn and the nurse asked that she teach me later. My sister cannot remember all, she could do somethings. I tried to do*

*my best in caring, somethings that I did, I watched and followed from the internet. I felt unconfident to do the tasks but I must do those things. I think, on that discharge day, if I had a nurse to stay with me at home it would be good.*" (FCG 6)

Mostly caregivers reflected that they felt unconfident when they took care of the patient on their own. The main concern in this cycle was the confidence in caring for the patient at home. The interaction process among the family caregivers and nursing staff begin as soon as the patients were not in an acute phase to enhance and empower the family caregiver by collaborating with nursing staff. At the hospital, the TBI caregivers were given routine education and discharge planning from the nurses. The important role of the nurse is to provide care for patients as well as empower family caregivers. These activities included: 1) saving life and preventing patient's complications, 2) providing information and education to the family caregivers based on their readiness, 3) developing a training course and manual for enhancing the capacity of family caregivers such as how to assess the risk, identify abnormal symptoms and prevent patient complications, 4) training the family caregiver by using a scenario, 5) providing emotional and psychological support, and 6) providing a discharge plan according to background knowledge and skills in the caring of the TBI patient. In this cycle, the researcher introduced "We Care You" application that the caregiver can use to seek more knowledge in caring. The caregiving manual in a leaflet format was also given. Moreover, the researcher tested the caregivers' knowledge and skills in the discharge plan by using a scenario to simulate the situation which a caregiver might face in order to improve their own confidence and empower their caregiving activities.

To ensure their confidence, the researcher also encouraged the TBI caregivers to perform caring activities by themselves without the help of a nurse. The researcher observed their activities, provided support, assistance and advice when they had missed any points. In this process, it helped the caregiver to feel confident in the transition care period.

### Factors influencing a family caregiver's confidence

Several factors have influenced the caregivers' confidence during this cycle.

#### 1) Trust and a supportive environment

Trust occurred in family caregivers when they believed that the nurses could help their relative. Their beliefs come from witnessing the collaboration among nurses and other health care providers in trying to save the life of their patient. The routine care, the concerns, the assistance for any problems and continuous information given from the nurses comforted the mind of the caregivers and gradually they came to trust the nurses. Furthermore, the therapeutic relationship between the nurses and family caregivers increased the feelings of trust in that the family caregivers could do things following the nurses' instructions. Communicating in a comfortable atmosphere assists the family caregivers to enhance their ability to learn knowledge and skills in caring for TBI patients. This trust consequently relieves their stress and makes them ready to care for their TBI patients.

### 2) Sharing information from one another

One of the important factors which relieves the family caregivers' stress and burden was sharing and receiving information from the nurses. The nurses gave information regarding the nursing interventions, regulations and proper performance. Moreover, family members could participate in caring for their loved ones. The nurses also supported and assisted in some processes and some caring activities. Family caregivers received information related to care for the patient as well as advice from other family members. The advice from other family members could be clarified by seeking information from nurses, believable persons, and online resources such as those found relevant websites and the YouTube channel.

### 3) Easy access to information via technology

The most important aspect was access to health information via technology. Nowadays, the smart phone is used in our daily lives. The TBI caregiver also used a smart phone to find out the necessary information in caring for TBI patients. However, the caring information was not received from a medical school or medical textbook or hospital, or health care system website, so the caregiver needed to be able to justify the medical information regarding caring tasks for a patient, patient complications, primary assessment, and primary management in emergency situations. Therefore, consultation with a nurse via technology is necessary in caring for a patient at home. The caregivers reflected that the application on their smartphone was a good way to access the correct caring information and to learn from it.

### 4) Support each other

The family caregiver participated throughout the hospitalization transition period to home. The success in caring is the caregiver being able to do caregiving activities and stay with the TBI patient in the same house. Moreover, all of the family caregivers have extended family in that they had other family members in the same house who could help in switching the caring when they needed. In addition, all the family members could help in the psychological and economic support for both the family caregiver and TBI patient. The family caregiver did not have the duty to earn the income for their family. The caregivers could take full time care of the TBI patients.

## The outcomes of the first cycle

### 1. Patient complications

The outcomes could be classified according to the patient complications that can cause the patients to be readmitted to the hospital within 3 weeks. These complications were assessed by the family caregivers. The researcher introduced the family members to checking the condition of the patient that affected the respiratory system, and cardiovascular system, as well as muscle and skeletal systems complications, by using “We Care You”. All three family caregivers also reported that their TBI patients did not have any complications. Moreover, all of the TBI patients’ conditions were not complicated and their family caregivers took full time care of them.

### 2. Caregiver stress and caregiver burden

After the first cycle finished, the three TBI caregivers reported strong confidence, less stress (3-4/10), but the same burden when they changed to the home setting. However, one of the family caregivers could not come to learn about discharge planning at the hospital because she could not drive and there was no relative available during office hours to take her. So she could not come to the hospital in the daytime to learn. The researcher used video conferencing through the Line application for teaching her instead. Also, the TBI caregivers were encouraged to communicate with the nurses and community nurses when they felt unconfident in caring for their patients at home. However, the caregivers needed more resources such as an intermittent suction, air bed, dressing set, etc and care coordination in the community and home setting.

*"The nurse taught daily caregiving activities to me and I could do it at that time. After discharge, I did it alone, they didn't ask me when I arrived home if I could do it or not. Did I have any problems? I didn't feel confident. The community nurse came to visit us 2 weeks later. If they came on the first day I think it would be perfect.*" (FCG6, FCG7)

Although, 3 of the family caregivers stated that they felt confident to care for the patients on the day before discharge., they also felt unconfident on discharge day when they arrived home because they did not know whether the caring activities they did were right or wrong. They needed some health care provider to stay with them to make sure that they did the right things in caring. In that situation, they can feel more confident and can continue care at home.

### 2.2.2 Cycle 2 - Maximizing resources and care coordination

Upon discussions with the nurses, community nurse and family caregiver, the researcher realized the problems of the family caregivers in cycle 1. In cycle 2, the activities were added on maximizing resources and care coordination. This cycle began when the caregivers needed to communicate with the nurses and community nurses when they felt unconfident in caring for their patients at home. They reflected that they needed more in caring resources such as intermittent suctions, air bed, and dressing sets, and needed care coordination with the community health care provider before the discharge of the TBI patients to the home setting.

In general, the nurses communicated by electronic mail with the health care provider in the community before discharge. The health care provider usually visited the patients who required assistance after discharge within 14 days. The family caregivers also reflected that they needed immediate assistance when the TBI patients arrived home.

*"After discharge, I did caregiving activities alone. I wasn't familiar with the new caring environment, and strange equipment. They didn't ask me when I arrived home whether I could do it or not. Did I have any problems? I didn't feel confident. The community nurse came to visit us 2 weeks later. If they came on the first day I think it would have been perfect.*" (FCG 6, FCG7)

*"Before discharge, I needed to prepare the home for my relative. I wasn't familiar with caring at home it seems like the new environment for caring. I didn't feel confident. If the community nurse came to help and check the home environment*

*and equipment whether it was ready for the patient or not, I think it will be good.*" (FCG 7)

*"I felt difficulty to find the equipment for caring such as suction equipment, and air bed equipment. I asked for help from the nurse at the ward about where I can get suction equipment, where I can get air bed equipment. She said I could use a normal bed instead of an air bed and turn my TBI patient's position every 2-3 hours, no need to waste money for this thing. I believed in her, so if she could come to help and check the home environment also"* (FCG6, FCG8)

There were three activities in this cycle.

1) Providing assistance by linking the person in the community

Before TBI patients' discharge, the researcher helped the family caregivers to directly contact the community nurse who was responsible in the same area. The assistance was based on the condition of the TBI patients and the request or need of assistance from the caregivers. The appropriate person in the community was contacted.

2) Creating a supportive environment in caring at home

Regarding communication, the community nurses kept in touch with family caregivers by asking about their needs and providing help in the first few days after discharge. Providing support and time was observed by seeking the necessary resources such as a suction machine or bed including helping the family caregivers to prepare the home environment for the patient. The community nurses knew exactly what the caregivers and patients' care demands were in the home setting. Moreover, the community nurses and the team first visited to these TBI patients' homes to provide support as soon as possible on day 1 and day 2. This could support and encourage the confidence of the caregivers to perform caregiving activities. They felt they received supportive care not only for themselves but also for the TBI patients who were their loved ones

3) Enhancing family and community collaboration.

By implementing this cycle, the program could help promote collaboration in TBI care management at home. The researcher facilitated the link of information and coordinated the care between the caregivers and community nurses by making a phone call on the discharge day to provide an update on the condition of the patient and caregiver needs. The TBI caregivers stated that they felt strongly confident in taking care of the TBI patients at home.

### Factors influencing good care coordination

### 1) Trust and a caregiver's friendly assistance

The trust occured in family caregivers when they believed that the community nurse could help their relative. Their beliefs come from witnessing the collaboration among the nurses and community nurse in trying to help the patient in the transitional period. The concerns and the assistance for any resources and problems, continuous care according to the condition of the patient from the community nurse supported the caregivers helping to alleviate any fear which gradually turned to trust. Furthermore, the therapeutic relationship between the community nurses and family caregivers increased the level of trust and closeness with each other in that the family caregivers could easily contact and consult the community nurse when the TBI patient or caregiver needed help. They also used the “We Care You” application in order to consult the researcher and health care providers any time they wanted. Communicating in a comfortable atmosphere assisted the family caregivers to enhance their ability in caring for the TBI patients. This trust consequently relieved their stress and burden. Moreover, this atmosphere helped the caregivers to ready themselves to care for their TBI patients in their home.

#### 2) Home visit as needed

The caregiver also needs help in the first few days after discharge. The community nurses and team firstly visited to the three TBI patients’ home for support on day 1 and day 2. These visits could provide psychological and caring material support and encourage the confidence of the caregivers to perform caregiving activities. The family caregiver felt that the TBI patient was receiving the best care.

### The outcomes of the second cycle

#### 1. Patient complications

According to patient complications that can cause patients to be readmitted to hospital within 3 weeks, no TBI patients were readmitted in this study. All the family caregivers (n=4) learned from discharge planning such as caregiving tasks, primary management in some situations (by case scenarios) from the nurses, the researcher and the “We Care You” application. They also reported their TBI patients did not have any complications. However, one family caregiver reported the patient was coughing while feeding and she still kept feeding because the meal was nearly finished. It was luckily that the TBI patient suffered no complication.

*"While I was tube feeding, my husband moved from the high fowler position to lie down. My husband coughed many times. The food was nearly finished, I continued feeding and he was still OK"* (FCG 12)

The above case reflected the need of the family caregiver to learn appropriate management for emergency situations. This case was discussed in the team meeting (the nurses, community nurses and the researcher), and the outcome was that there needs to be clarification for the family caregivers in regards to emergency situations and how to manage the most common types of emergency situations.

#### 2. Caregiver stress and caregiver burden

After the second cycle finished, the four TBI caregivers reported feeling confident, more appreciative, less burdened (3-4/10) and less stressed (2-4/10) when they provided care in the home setting. In addition, the TBI caregivers were encouraged to communicate with the nurses and community nurses when they felt unconfident while taking action in caring tasks or had problems in caring for their patients.

### 2.2.3 Cycle 3 - Supporting care management in emergency situations

Upon discussions with the nurses, community nurse and family caregiver, the researcher realized the problems of the family caregivers in cycle 2. In cycle 3, the goal was added on supporting care management in emergency situations. From the previous cycle, one TBI caregiver also reported her patient was coughing and aspirating during feeding via enteral nutrition but she still kept feeding because the meal was nearly finished. From this caring situation, the caregivers, the researcher and the nurses also thought about emergency situations and the primary care management of caregivers.

In this cycle, the researcher continued to support the family caregivers by using the telenursing "We Care You" application for assessing any early complications of the patients, providing TBI emergency care education and communicating with the health care providers. The "We Care You" application was the caregiver's self assessment tool to evaluate patient complications, caregiver stress and caregiver burden, however, this tool can help in care management in emergency situations and provide direct contact with the help care provider when the result of an assessment is abnormal.

Moreover, the researcher was monitoring "We Care You" in action to see the practically of the application and the caregivers reflected whether this application was easy to use or not.

*"This application could help me in order to primarily assess my patient's condition. I can be reminded of some tasks that I wasn't sure about and I can follow the application."* (FCG 13)

*"If I was not sure of my patient's condition then I used the application for a primary assessment. If it showed the yellow color then I called you (researcher) to make sure and to ask what I should do next."* (FCG 14)

*"We think the application is easy to use. However when the result is yellow, we suggested it would be good if it shows the nearest hospital phone number."* (FGD Nurses)

### Factors that support care management in emergency situations

#### 1) Caregiver's Assessment Skill

The key point is the right assessment. The family caregivers needed to train in how to assess and early detect any patient complications. The family caregivers would be the best to know as well as attend to the needs and changes in a patient. The family caregivers usually provided direct care and were very close to the TBI patients compared to others throughout the hospitalization period and continued care at home with love. So the family caregivers could quickly detect any change in with their TBI patients. Therefore, the caregivers could be a good helper to prevent patient complications through caring and the early detection of any abnormal symptoms.

#### 2) Immediate response to caregivers' demands

In this transitional time, the family caregivers need support from health care provider to answer them all questions. The data from previous cycles and reconnaissance phase was used to find strategies to manage common problems together with the family caregivers. However, caregiver demand in improving patient safety was high because of the better relationship with the health care provider.

### The outcomes of the third cycle

The evaluation of the results in the third cycle demonstrated that the TBI patients did not develop any patient complications, so the family caregiver reported a low level of caregiver stress (2/10) and a low to moderate level of caregiver burden (3-5/10). In addition, it means the caregivers had knowledge and skills and could provide good quality care to TBI patients to prevent patient complications.

## 2.3 Reflection

In taking care of TBI patients who had the Extended Glasgow Outcome Scale (GOSE) at level 2 to 5, patients usually were at risk of complications. However, the patient's illness conditions of patients in this study were not complex. The three family caregivers, using one patient to one caregiver as a couple, were prepared well in providing care. In addition, there were other family members who were able to help and support. All of the family caregivers also used a smart phone in their daily lives. The easy to use the "We Care You" application as part of caring for TBI patients would assist in the confidence level of the caregivers.

However, caregiver stress and caregiver burden did not reach the zero because of many factors from both external and internal demands of the caregivers themselves. These factors were those such as providing the most extensive and comprehensive care, maintaining the caregiving role longer, larger disruption in lifestyle from competing demands, and patient needs may restricting caregivers' usual activities. The patient complications did not occurred because the caregivers could detect early signs and were able to manage the signs and symptoms by themselves.

After finishing the last cycle, the nursing staff had developed a telenursing model and adapted the new preparation strategies in discharge planning according to the model. The new preparation strategies were those such as the nurse using scenarios similar to a home situation and following the capability of the family caregiver. The community nurse also taught the family caregiver by using the patient complications checklist and primary management in emergency situations. The discharge planner (nurse) contacted the community nurse by phone before a patient's discharge. The nurses gained perception and satisfaction on the model.

Nursing discharge service systems involve cooperation with other health care settings. Ward nurses also encouraged family caregivers to care for TBI patients and gave the first priority to TBI patients and family caregivers. This seemed to build good relationships and trust between the ward nurses and the family caregivers of TBI patients. With this atmosphere, family caregivers are more likely to talk, share their opinions and their needs. From this study, this atmosphere led to a better cooperative environment in caring for patients. The caregivers' and the patients' needs were met. From this situation, the caregiver could provide good caring for the TBI patient. Since these TBI patients required continuous care at home, good training in caregiving activities is necessary. In addition, the assessment for any abnormal signs in patients was needed to prevent patient complications.

Throughout the research process, the nurses suggested that the "We Care You" application should be revised in regards to the reporting time of any the abnormalities in each body system rather than reporting the patient’s overall status without recognizing what the abnormal signs are. The nurses then suggested reporting any abnormalities directly to the nearest hospital and call for 1669. As a result from this study, the nurses strongly agreed in the transitional telenursing model that the caregivers could help to assess any abnormal signs in the patients. They were satisfied with the condition of the patients which could then be managed by them and there were no more readmissions. Data from the interviews with the family caregivers also revealed that they were satisfied with the “We Care You” application that could help them in caring for the TBI patients at home. In addition, with the cooperation and continued support of the health care providers in the transitional period, the caregivers felt confident in TBI care at home.

The researcher thought that this application was useful in helping for TBI family caregiver management of care at home. In addition, most of the TBI patients did not have complicated conditions so most of the family caregivers felt more confident in order to continue caring. Moreover, the application “We Care You” should be encouraged for use by integrating it with the normal care system for practiced use in both the family caregiver and the nurse.

### 3. Component, Stage and Strategies of the TCTS Program

The model of TCTS program (Figure 4) was developed through three cycles of action research (Figure 3). The period of one month after discharge from hospitalization to the home setting was set for systemic data collection.

The first component was TBI caring education which aimed to emphasize caregiver’s knowledge and skill by enhancing and empowering the caregivers to feel confident in TBI care at home. The goal in the first cycle was for enhancing and empowerment the family caregiver. The nurse took the main responsibility to prepare the family caregivers of TBI patients before discharge, and continued providing nursing support in the hospital as routine care. In addition, the researcher provided the caregiving manual flipchart then introduced the “We Care You” application and showed the caregivers how to use the application to seek knowledge. Using simulation situations for greater care confidence was also implemented. All of these activities could promote a caregiver’s self confidence and empower the family caregiver to provide care in the transitional period. After finishing the program, no patients had any complications and the caregivers showed up more confidence in caring, there was less caregiver stress even through the burden remained the same.

In the initial realization of the situation and early in the first cycle, the researcher performs the two nursing strategies: 1) emphasizing a caregiver’s knowledge and skill, and 2) enhancing and empowering the caregiver to feel confident. There were seven activities as follows:

1. Establishing a trusting relationship. The researcher created trusting relationships by respecting the caregivers’ individual differences, listening to the participants’ need about knowledge and skill in caring.

2. Understanding caregivers’ background, their readiness and ability before learning.

3. Providing information, knowledge and practicing skills.

4. Introducing the TCTS program and “We Care You” application before discharge from hospital.

5. Establishing mutual goals for caring for TBI patients.

6. Enhancing and empowering the caregiver to feel confident. The researcher and the ward nurse let the caregiver to care for TBI patients by themselves under close observation from the nurse.

7. Asking for suggestions for revising the TCTS program and “We Care You” application.

At the end of the first cycle, two revisions of the process were needed.

1. Flexible time in preparing a family caregiver’s knowledge and caregiving skills in TBI care. Each caregiver needs a time that is flexible for them to learn knowledge and skills.

2. Although all caregivers reported strong confidence after receiving the knowledge and skills training, they reported being unconfident in caring for the patients on the first day they arrived home because they did not know whether the actual caring activities they did were right or wrong. So, close supervision and support were provided.

The second component was the nurse’s care management in the transition period by maximizing resources, facilitating daily care at home and encouraging care coordination via telenursing. The goal in this cycle was aimed for maximizing resource and care coordinates by starting with; 1) emphasising the educational and skills training via a VDO conference and teaching how to use the “We Care You” application. 2) the researcher used a direct phone call to the community nurse for patient care coordination in order to support a family caregiver’s readiness in care and to help them to prepare the environment and equipment at home. Throughout the process in this cycle, patients' complications were not reported. Additionally, the family caregivers reflected on the ability to care with more confidence to care which reduced their stress and care burden.

In cycle two, the researcher used three nursing strategies: 1) maximizing resources in the transition period, 2) facilitating daily care at home, and 3) encouraging care coordination via telenursing. There were seven activities as follows:

1. Maintaining a trusting relationship. The researcher maintained trusting relationships by respecting the caregivers' individual differences, listening to the participants' need for knowledge and skills in caring.
2. Understanding caregivers' readiness and new environment at home.
3. Reviewing information, knowledge and practicing skills.
4. Maximizing resources, facilitating the caregiver in doing daily care.
5. Introducing the TCTS program and the "We Care You" application. Encouraging care coordination via telenursing.
6. Establishing mutual benefits for caring for TBI patients.
7. Asking about any issues and suggestions for revising the TCTS program and the "We Care You" application.

At the end of the second cycle, one activity was required and added in the program to focus on care management in an emergency. One caregiver reported they need immediately help when they had an urgent problem.

The third component was a system to support care management in emergency situations which helps the caregiver in the transitional period. The goal in the last cycle was for supporting care management in emergency situations, the community nurse was took responsibility to prepare the team and supplier for caring in the home setting. In addition, an evaluation of the TBI patients' and caregivers' needs and complications was done. The family caregivers had often provided direct care and were closed to the TBI patients throughout the hospitalization period and continued the care at home. The caregivers could be the good helpers in preventing any patients' complications by providing care and detecting any early abnormal symptoms. Additionally, the family caregiver learned to evaluate any changes in the patient so they had confidence in detecting any minimal changes in their TBI patients.

In the cycle 3, the researcher used a strategy of care management in emergency situations. There were seven activities as follows:

1. Maintaining a trusting relationship. The researcher maintained trusting relationships by respecting the caregivers' individual differences, listen to participants' needs about knowledge and skills in caring.

2. Understanding a patient's condition and caregivers' problems/ needs of TBI care at home.

3. Facilitating information, knowledge and practicing skills in relation to TBI emergency care.

4. Enhancing primary care management in emergency situation and communicating with health care providers.

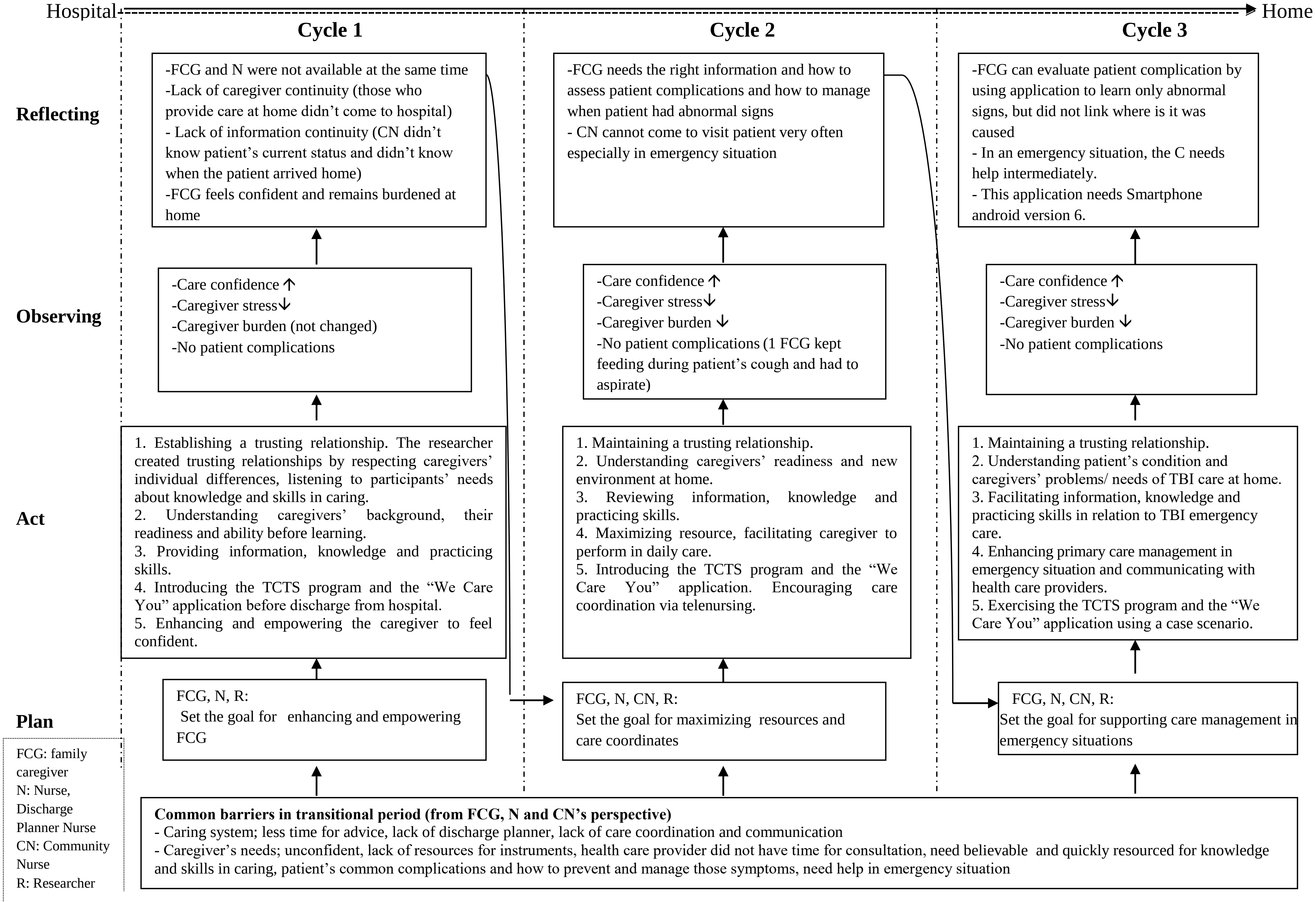
5. Exercising the TCTS program and the "We Care You" application using case scenario.

6. Establishing mutual benefits for caring for TBI patients.

7. Asking about any issues and suggestions for revising the TCTS program and the “We Care You” application.

The development process of TCTS for TBI care was performed in three cycles as shown in figure 3. This TCTS program can help family caregivers to notice their abilities and value in their caregiving roles. It also makes family caregivers consider their care in taking care of their TBI patients and themselves, including enhancing their observation towards their power and control of related factors. The program assists them to autonomously make decisions in employing several means to take care of their TBI patients in either routine daily or emergency situations. Finally, they can live happy without stress and burden, feel confident in providing care and have successful lives with their TBI patients.

The researcher discussed the final TCTS program (figure 4) with nurses and the representative caregiver to make it easily accessible in the implementation of TBI care at home. The TCTS program consisted of 3 strategies in 3 phases during the transition care. These are 1) enhancing and empowering of the FCG before the discharge phase, 2) maximizing resources and care coordinates after discharge in a 7 days phase, 3) supporting care management in emergency situations for 21 days after discharge.



**Cycle 1**

Reflecting:
-FCG and N were not available at the same time
-Lack of caregiver continuity (those who provide care at home didn't come to hospital)
- Lack of information continuity (CN didn't know patient's current status and didn't know when the patient arrived home)
-FCG feels confident and remains burdened at home

Observing:
-Care confidence ↑
-Caregiver stress↓
-Caregiver burden (not changed)
-No patient complications

Act:
1. Establishing a trusting relationship. The researcher created trusting relationships by respecting caregivers' individual differences, listening to participants' needs about knowledge and skills in caring.
2. Understanding caregivers' background, their readiness and ability before learning.
3. Providing information, knowledge and practicing skills.
4. Introducing the TCTS program and the "We Care You" application before discharge from hospital.
5. Enhancing and empowering the caregiver to feel confident.

Plan:
FCG, N, R:
Set the goal for enhancing and empowering FCG

**Cycle 2**

Reflecting:
-FCG needs the right information and how to assess patient complications and how to manage when patient had abnormal signs
- CN cannot come to visit patient very often especially in emergency situation

Observing:
-Care confidence ↑
-Caregiver stress↓
-Caregiver burden ↓
-No patient complications (1 FCG kept feeding during patient's cough and had to aspirate)

Act:
1. Maintaining a trusting relationship.
2. Understanding caregivers' readiness and new environment at home.
3. Reviewing information, knowledge and practicing skills.
4. Maximizing resource, facilitating caregiver to perform in daily care.
5. Introducing the TCTS program and the "We Care You" application. Encouraging care coordination via telenursing.

Plan:
FCG, N, CN, R:
Set the goal for maximizing resources and care coordinates

**Cycle 3**

Reflecting:
-FCG can evaluate patient complication by using application to learn only abnormal signs, but did not link where is it was caused
- In an emergency situation, the C needs help intermediately.
- This application needs Smartphone android version 6.

Observing:
-Care confidence ↑
-Caregiver stress↓
-Caregiver burden ↓
-No patient complications

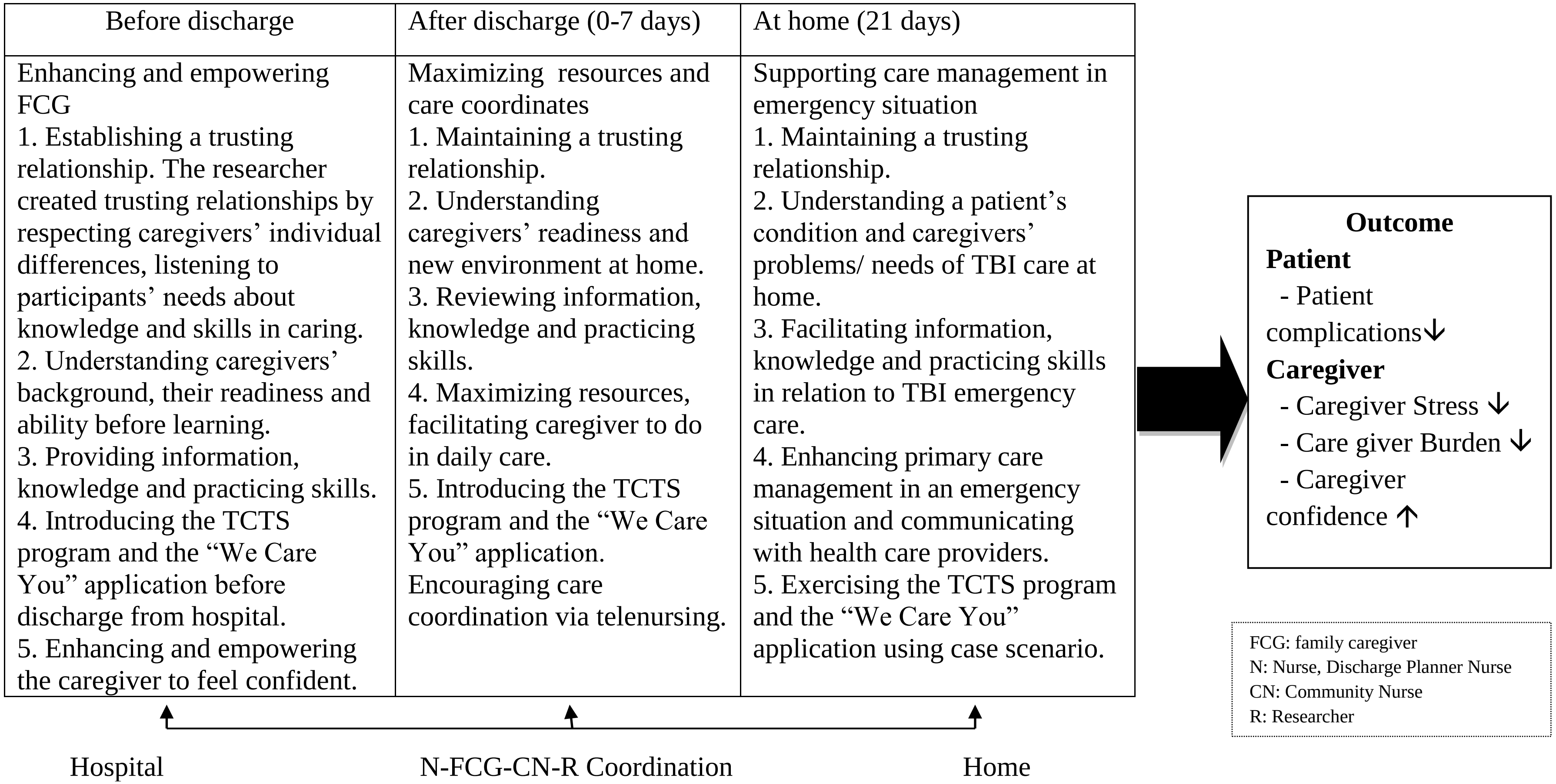
Act:
1. Maintaining a trusting relationship.
2. Understanding patient's condition and caregivers' problems/ needs of TBI care at home.
3. Facilitating information, knowledge and practicing skills in relation to TBI emergency care.
4. Enhancing primary care management in emergency situation and communicating with health care providers.
5. Exercising the TCTS program and the "We Care You" application using a case scenario.

Plan:
FCG, N, CN, R:
Set the goal for supporting care management in emergency situations

**Common barriers in transitional period (from FCG, N and CN's perspective)**
- Caring system; less time for advice, lack of discharge planner, lack of care coordination and communication
- Caregiver's needs; unconfident, lack of resources for instruments, health care provider did not have time for consultation, need believable and quickly resourced for knowledge and skills in caring, patient's common complications and how to prevent and manage those symptoms, need help in emergency situation

FCG: family caregiver
N: Nurse, Discharge Planner Nurse
CN: Community Nurse
R: Researcher

**Figure3** ***The three Cycle of Action Research*** **in this study**



| Before discharge | After discharge (0-7 days) | At home (21 days) |
|---|---|---|
| Enhancing and empowering FCG<br>1. Establishing a trusting relationship. The researcher created trusting relationships by respecting caregivers' individual differences, listening to participants' needs about knowledge and skills in caring.<br>2. Understanding caregivers' background, their readiness and ability before learning.<br>3. Providing information, knowledge and practicing skills.<br>4. Introducing the TCTS program and the "We Care You" application before discharge from hospital.<br>5. Enhancing and empowering the caregiver to feel confident. | Maximizing resources and care coordinates<br>1. Maintaining a trusting relationship.<br>2. Understanding caregivers' readiness and new environment at home.<br>3. Reviewing information, knowledge and practicing skills.<br>4. Maximizing resources, facilitating caregiver to do in daily care.<br>5. Introducing the TCTS program and the "We Care You" application. Encouraging care coordination via telenursing. | Supporting care management in emergency situation<br>1. Maintaining a trusting relationship.<br>2. Understanding a patient's condition and caregivers' problems/ needs of TBI care at home.<br>3. Facilitating information, knowledge and practicing skills in relation to TBI emergency care.<br>4. Enhancing primary care management in an emergency situation and communicating with health care providers.<br>5. Exercising the TCTS program and the "We Care You" application using case scenario. |

**Outcome**

**Patient**

- Patient complications ↓

**Caregiver**

- Caregiver Stress ↓
- Care giver Burden ↓
- Caregiver confidence ↑

FCG: family caregiver
N: Nurse, Discharge Planner Nurse
CN: Community Nurse
R: Researcher

Figure 4 *Nursing care model for telenursing based caregiver transitional supportive program among caregivers of persons with traumatic brain injury (TCTS program)*

The researcher, the nurses, and community nurses all recognized such a program potentially would support and facilitate FCG to remain confident and management in TBI caring at home.

### 4. Discussion

The results demonstrated how the telenursing based caregiver transitional support program among caregivers of persons with traumatic brain injury (TCTS program) helped to improve a caregiver's confidence and reduce caregiver stress and caregiver burden. Although the TBI caregiver felt stressed and burdened in caring for their TBI patient in the initial stage of the transitional process, they were able to seek help from around themselves by asking, searching or trying something whether it was right or wrong before asking for some help from the health care providers. The nurses, discharge planner nurse, community nurse and family caregivers joined in the process of analyzing the problems, selecting, and coordinating in the transitional period.

The TCTS program development discussion consists of: 1) setting and participants, 2) TBI patients impacts on caregivers, 3) transitional care, 4) nursing approaches, 5) outcome evaluation, 6) factors influencing the TCTS program, and 7) modified the TCTS program.

1) Setting and participants

All participants were willing to participate in this study because all of them needed to see change in the transitional care system for TBI patients who are their loved ones. Moreover, this setting agrees with the requirement of the TCTS program for changing routine care in the hospital. In addition, most of the caregivers are family and lived in the same house which is why most of them had the main responsibility in caring for TBI patients. Moreover, all participants were educated and used smart phones in their daily life. This may be one reason why they easily responded in this TCTS program.

2) Caregivers needs on discharge day

The caregiver needs on discharge day were found in this study. Most of the TBI patients were adult and had the main responsibility of family income that was involved in the family structure as it was involved with family income. Moreover, the TBI patients' condition was most reported in many studies as increasing a caregiver's need of support (Backhaus & Ibarra, 2012; Degeneffe et al., 2011). The family caregiver did not feeling ready to care for the TBI patient's at home. The family caregiver was also fearful in facing any unpredicted situation at home and fearful of not knowing how to manage such a situation as well as knowing who they could turn to and ask for help.

3) Transitional care.

In this study, the transitional care concept (Meleis, et al., 2000) was used to guide the development process. The transitions occur in the context of the transitioning role from family member to family caregiver, and these conditions exist within persons, communities, and society. These conditions may facilitate successful transitioning or they may inhibit one's ability for successfully transiting in TBI caregivers. Personal conditions are most influential on the individual caregiver's role attainment and transition outcome, since these conditions include the meaning one attaches to the transition, cultural beliefs and attitudes (confidence in caring), socioeconomic status (resources and challenges), and preparation and knowledge needed to deal with the transition period (Meleis, et al., 2000).

Moreover, the key points were composed from the phenomenon of the caregiving process of TBI family caregivers' caregiving process. The factors that may facilitate effective TBI transitional care are caregiver knowledge and skills, a caregiver's confidence, the care coordination with the community nurse, support in care management in emergency situation, and accessibility to caring information.

4) Nursing approaches and facilitators.

A carefully evaluation of the TCTS program outcomes and influencing factors was undertaken in the three cycles of the TCTS program. This is one of the essential activities of the action research process. The activity was respecting participants' feedback of change. Participants' conscious reflections helps them gain direct problem solving strategies which were coverage, conciseness, and relevance to the TCTS program. In addition, data from a participant's reflection increased personal knowledge beyond expectation. Moreover, conscious suggestions for program revision for transitional care directly affected programming changes.

Moreover, asking for suggestions from the caregiver participants provided information for the program revision and confirmed the real modification aspects that caregiver participants really needed for the next trail. Furthermore, participants consciously reflected and suggested in each cycle, displaying a proper evaluation of the modifications of the TCTS program.

Nursing facilitation including establishing and maintaining a trust relationship, understanding participants' backgrounds, introducing the TCTS program and training knowledge and skills, establishing mutual goals for the TCTS program, providing information, consulting and empowering, recognizing participant abilities and supporting self confidence and monitoring patient' s complications were important not only for increasing the participants' abilities but also for helping participants' with problem solving and confidence in TBI patient care during the transitional period.

5) TCTS program.

A tentative care model developed by integrating the literature review, qualitative data from the reconnaissance phase was initially presented in a group meeting. The suggestions from the nurses and the head nurse were introduced to the nurses of the core working group.

The initial barriers identified by nurses toward care systems were less time for giving advice, a lack of discharge planners, and lack of care coordination and communication. In addition, the family caregivers felt unconfident in caring, lacked resources for caring instruments (such as an intermittent suction, air bed, dressing set), the health care provider had no time for consultation, the caregivers needed believable and quickly accessed resources for retrieving knowledge and skills in caring, they lacked knowledge in the common complications of TBI patients and how to prevent and manage those symptoms, and they lacked help in emergency situations.

The group discussions among the researcher, nurses and community nurses were arranged to make a decision on the prioritization of the tasks or the important concerns to tackle. The researcher introduced ways to improve the knowledge and skills of family caregivers in caring for TBI patients which they can use for self-learning. The provision of the application was introduced comprising of the basic caring knowledge and essential skills for the family caregiver, the assessment of a patient's complications (respiratory system, gastrointestinal system, muscle and skeletal system), and strategies to manage or solve any problems they faced. In addition, caregiver stress (numeric rating scale) and caregiver burden (numeric rating scale) and some simple management techniques were included for the caregivers to heal by themselves.

The tentative care model was implemented by integrating with the usual care plan in each cycle for TBI care targeting the family caregivers in the transitional period. The model was refined or modified based on the data collected during implementation. There were three cycles, namely, enhancing and empowering the family caregiver, maximizing resources and care coordination, and supporting care management in emergency situations.

In the first cycle of TCTS program, the family caregivers needed to acquire the knowledge and skills to promote their confidence in caring activities. To ensure their confidence, the researcher also encouraged the TBI caregivers to perform caring activities by themselves without the help of a nurse. The researcher observed their activities, provided support, assistance and advice when they had missed any points. This process helped the caregiver to feel confident in the transition care period. The engagement and support of family caregivers' participation in the patient care process from the first hospital admission is essential. In this process, the family caregivers had readiness and confidence which decreased caregiver stress and caregiver burden.

At the end of the first cycle, all of the family caregivers stated that they felt unconfident to care for the patients on the first day they arrived home because they did not know whether the caring activities they did were right or wrong. They needed a health care provider to stay with them to make sure that they did the right things in caring. In that situation, they may feel more confident and can continue care at home.

In cycle 2, the activities were focused on maximizing resources and care coordination with nurses and community nurses. This method could help to build trust and create a good atmosphere with family caregivers. The family caregiver felt it was easy to communicate with the heath care provider when they needed help.

Before a TBI patients' discharge, the researcher helped the family caregivers to directly contact the community nurse who was responsible in their home area. The assistance was based on the condition of the TBI patients and the request or need of assistance from the caregivers. The appropriate person in the community was contacted. Then, the community nurses knew exactly what the caregivers and patients' care demands were in the home setting. Moreover, the community nurses and team went directly to the TBI patients' homes for support as soon as possible. This could support and encourage the confidence of the caregivers to perform caregiving activities. They felt they received supportive care not only for themselves but also for the TBI patients who were their loved ones.

Finally, the TBI caregivers were encouraged to communicate with the nurses and community nurses when they felt unconfident while taking action in caring tasks or had problems in caring for their patients. Moreover, in this cycle, one TBI caregiver also reported her patient was coughing and aspirating during feeding via enteral nutrition but she still kept feeding because the meal was nearly complete. From this caring situation, the caregivers, the researcher and the nurses also thought about emergency situations and the caregiver’s primary care management.

In cycle 3, the researcher continued to support the family caregivers by using the telenursing “We Care You” application for assessing any early complications of the patients, providing TBI emergency care education and communicating with the health care providers. The latest TCTS program included scenarios of both common problems and emergency situations which may occur and provided a guide on how to correctly manage each situation. In addition, the program can help family caregivers to notice their abilities and efficacy in their caregiving roles. The program also helped the family caregivers to become more aware when taking care of their TBI patients and themselves, including enhancing their awareness and manageability of related patient factors such as fever, and abnormal breathing. It assisted them to autonomously make decisions in employing several means to take care of their TBI patients in emergency situations. The final outcome in the application of the program was that the family caregivers were happy, confident and successful in the transition of their role of providing care for their family member with TBI as well as in their day to day life**.**

From the process of the TCTS program development above, the conditions of the selected TBI patients were not too severe or complex for the caregivers to manage at home, and there were no urgent complications or emergency situations while caring in the home setting that could have caused any patient's readmission to hospital. Almost all of the caregivers explained about a lack of supervision, experience and evaluation about continuity of care. When the caregiving procedures were explained and reasons were given as to why and when the procedures needed to be done a certain way, the caregivers reflected that knowing and understanding why these procedures have to be done made them feel more relaxed and gave them the courage to be the primary caregiver. Moreover, after the family caregivers had spent some time providing full time care then the feeling of confidence was gained by performing the best tasks for their patients. In providing routine care, they felt that all daily tasks were simple.

The TCTS care model was implemented by integrating with the usual care plan in each cycle for TBI care targeting family caregivers in the transitional period. The model was refined or modified based on the data collected during implementation. The family caregiver participated throughout the hospitalization period and the transition to home. Successful caring was a caregiver who could confidently provide caregiving activities and stay with the TBI patient in the same house. Luckily for these caregivers, they had other family members to take turns in the caring when needed.

Telenursing in this study could ensure the safety of the TBI patient resulting in no need to move a TBI patient with an unnecessary condition to hospital. The program provided consultation with health care professionals where transportation to another facility may cost time, money, or safety, as well as co-operation with healthcare providers in the community resulting in getting help and information from the health care system at any time needed, thus, less time was used in healthcare delivery. The program was readily adaptable to patient and caregiver needs, and improved the intermediate outcomes and satisfaction of the patient.

In this study, the TBI caregivers reported strong confidence, less caregiver stress, and less caregiver burden when they changed to the home setting. The family caregivers usually had provided direct care and were closer than other family members to the TBI patients throughout the hospitalization and continued care at home. Therefore, the family caregivers could detect any minimal change in their TBI patients. The caregivers could be of good help in preventing any patient complications by caring and by the early detection of any abnormal symptoms. Moreover, most patients' conditions were not complicated. Most families presented a one to one ratio of caregiver to patient as a couple was appropriate with the support of other family members who could help with TBI care at home. All family caregivers were trained to be 'smart' caregivers, so they used the smart phone in their daily life. They then found it easy to use the "We Care You" application as a part of caring for their TBI patients. Additionally, the community nurses and team went directly to the homes of TBI patients for support as soon as possible. This could supported and encouraged caregivers' confidence to perform caregiving activities. They felt they had supportive care not only for themselves but also for the TBI patients who were their loved ones.

The telenursing program in this study was of benefit at a personal, system, and program level. The mutual benefit at a personal level was to improve the caregivers' interactions with nurses and gain learning skills through the application. In addition, offering assistance in real time to meet the caregivers' needs at home was the focus of this program, thus, a system approach was helpful. This is similar to the previous study in delivering care after discharge for fibromyalgia patients (Jelin et al., 2012). The results showed the telephone care with an education support program through the Web including consultation and support care was helpful to manage fibromyalgia patients' chronic pain. Another study also used Facebook groups on diabetes care for patients and family members to share experiences and search for information needs related to the disease, proper care and emotional support (Greene, Choudhry, Kilabuk, & Shrank, 2011).

In addition, the reflection from the caregivers' experiences showed that many Thai TBI family caregivers felt hesitant (kreng jai) to ask for nurses' assistance when needed as they thought the nurses were busy and there was a shortage of nursing staff on the ward. So, the telenursing program could be an option for caregivers to ask questions when they need help. A number of studies have recommended the use and application of technology in home care, especially for post-acute care patients, which may improve the quality, quickness in response, safety as well as reduce the gap in health care systems. Caregivers participating in telenursing services can receive appropriate care at all times from a nurse who provides crucial information via a mobile phone to handle illness management (Greene et al., 2011).

Overall, the model's relevance to the telenursing based caregiver transitional support program was derived from undergoing a reflection process among the concerned parties , which was developed over 2 years in this study, can help Thai caregivers of persons with traumatic brain injury was derived from undergoing the reflection process among the concern parties. The researcher, nurses and caregivers were directly responded in the telenursing based caregiver transitional support program. The important strategies which nurses used to help the caregivers in the telenursing based caregiver transitional support program were creating trust, facilitating care coordination and caregiver’s confidence in TBI care that can reduce caregiver stress, caregiver burden, and prevent any patient’s complications.

# Chapter 5

# Conclusion and recommendation

This chapter consists of the conclusion, lesson learned, implication for nursing, the recommendation and limitations of this study.

## Conclusion

This study aimed to develop the telenursing based caregiver transitional support program (TCTS program) among caregivers of persons with traumatic brain injury. TBI caregivers had stress and felt burden due to various transition conditions before and after the TBI patient's discharge to home. The transition conditions among TBI caregivers were the condition of the TBI patient was not complicated, the family caregiver had other family members to support, the family caregiver had to be able to use a Smartphone etc.

The action research was used to develop the TCTS program through a spiral action research process over two years with 5 experienced caregivers, 9 novice caregivers and nine nurses in the main group. The findings showed that the four main barriers in the TBI current care system that were perceived by the caregivers and nurses were 1) lack of support from health care systems because of limited care manager/ discharge planner 2) ineffective communication among multidisciplinary teams and caregivers due to lack of guidelines or pathways used 3) lack of care coordination between each unit related to discharge program 4) incomplete follow up system after discharge. After assessing the caring activities and problems, the researcher obtained information related to TBI care and reflected to the core working group.  This helps to refine the elements of the tentative model guiding this study by initiating the plan, approaches, participation, influence, and individual and group abilities on discharge planning. A tentative care model developed by integrating the literature review, qualitative data from the reconnaissance phase was initially presented in a group meeting as follows.

Firstly, a lack of support care in the home setting educated by the hospital nurse to take responsibilities to prepare TBI caregivers before TBI patients' discharge and provide nursing support after discharge. The concept of empowerment guided the direction of the nurses to build trust with the caregivers, facilitate the ability of TBI patients' care, empower and encourage a caregiver's self confidence. The telenursing "We Care You" application was used to give knowledge in caring. Based on the improvement in ability, the change in this process could be continued.

Secondly, the action of the family caregiver in the hospital was unclear; the caregiver mostly did care under a nurse's instructions. The family caregiver was required to take more responsibility for the care of the TBI patient at home without the instructor (nurse). Through assuming, the TBI caregiver almost felt unconfident in caring as well as stressed. The telenursing "We Care You" application was used to connect with the researcher in order to maximize the resources and care coordination with the community nurse.

Thirdly, they also felt stress when faced with unplanned or emergency situations. The telenursing "We Care You" application was used to handle the common emergency situations which added some of the emergency management and had an emergency channel to contact a healthcare provider.

The family caregivers may perceive strong confidence in the preparedness of the caregiving role before discharge. However, they mostly felt much more stressed and burdened when they cared for the TBI patients at home, they reflected on having less confidence when faced with an unfamiliar environment and equipment. The care coordination with the health care provider was also lacking. The TBI caregivers felt loneliness when they had the main responsibility of being the caregiver. They reflected that they did not know the health care provider in their community who could help their TBI patient, and when they had any questions the caregiver also had to seek answers from other persons or from searching the internet.

The TCTS program, which comprises of facilitation and coordination, the family caregiver, nurse, and the community, enhancing empowerment, maximizing facilitation and care coordination, and hand over in emergency situations, helped the caregiver in the transitional period to reduce patient complications, caregiver stress, and caregiver burden.

## Lesson Learned

Conducting this action research gave the researcher firsthand experience from the beginning of analyzing the problems and barriers during the transitional period, entering the home and community setting, and then starting the program until the findings.

The setting in this study started at the neurosurgical ward and neurosurgical intensive care unit to discharge to home in order to observe the environment, situation, problems and barriers of the TBI patients and family caregivers that helped the researcher recognize that providing care to TBI patients was a complicated situation. The traditional care in a hospital is utilized by health care providers such as doctors, nurses, nurse aids, etc. In Thai society, the caregivers' participation always failed because the power to plan and decide in caring were dependent on the health care provider especially the doctors and nurses. This problem steadily remained until the TBI patient was discharged from hospital. Therefore, the caring at home was at times due to lack of knowledge, lack of skills and confidence of the family caregivers in caregiving activities. Therefore, the participation of caregivers in the hospital period should be encouraged to gain effective caring and reduce patient complications in the home setting.

Conducting the participatory action research was not easy. Many limitations were found as early as starting this study. Tracking along this road to help improve the quality of transitional care of TBI patients, although the researcher put in a lot of effort to encourage the family caregivers and nurses to understand in the same direction. Many times the researcher performed several functions without consulting the nurses in handling the caregivers' and patients' needs. The process of this participatory action research, which includes reflection, evaluation, and the adjustment of the plan among the concerned parties such as the caregivers, researcher, nurses and community nurses, revealed that something were difficult to implement as primarily planned.

Moreover, the researcher was a novice in the participatory action research. The researcher also felt difficulty in analyzing the amount of qualitative data. Also telenursing is new for Thai society, therefore, sometimes it was difficult to use in caring for patients. The main problems were interpreting the data and building up the telenursing. However, the suggestions from the advisors were helpful and useful. This success could not be achieved without help from a programmer to build the “We Care You” application as much as the reflection process and coordination with all the participants. The inspiration and effort of the researcher that this TCTS program would help the caregivers to early access and manage their situation on their own and prevent any TBI patient complications. The facilitator, educator, supporter as the nurse professional was clearly acknowledged.

The scientific knowledge from the study reflected the need to apply the participatory action research into real practice to generate the practical and clinical nursing practice. This TCTS program can add on the traditional model that emphasizes the content and nursing process. The knowledge from this study could be useful to facilitate and renew specific care methods for TBI patients according to the similar context of the TBI caregivers. The study reveals that the lifestyle and environment of people have an impact on the TBI patient’s and caregiver’s individual health status.

## Implications and recommendation

Regarding the differences of the transition conditions which TBI caregivers may face, the following suggestions are required to utilize the model.

### Nursing practice

Nurses can play an important role in justifying the readiness of the family caregiver to participate in caring and the discharge process. Awareness is needed for a preparation program for a family caregiver’s readiness. An appropriate discharge service should include the time from admission until after discharge to home.

Providing simulation situation workshops like the home setting should be increased. During the organization of the workshop journey, the nurse should evaluate the caregiver’s practice, caregiver’s management and continuous support until discharge and follow up at home after discharge.

The Telenursing: “We Care You” application should be integrated in the discharge manual plan for all caregivers which could help in the improvement of a caregiver’s knowledge because of the easy friendly access to information. In addition, the application helps the nursing staff to manage clients when they have a shortage of staff in order to provide repeated knowledge. Moreover, the electronic manual is useful for the family caregivers as they could easily follow and practice the care in their daily life.

### Nurse administration

The findings of this study have suggested that the implementation of TCTS program needs concerted effort from administrative units as well as raise up change in the administrative work.  The nurse administrator should promote related to policy changes, discharge service systems, adequate staff and training as well. Policies concerning the encouragement of the participation and collaboration of the family caregiver in providing care to the patient in the ward should be simply stated to promote the quality of TBI patient care.

The coordination between the hospital and community setting was also important. The referral contact should be required before patient discharge. Although electronic discharge information in the traditional system was sent, in these cases, the nurse should closely coordinate by directly contacting the community nurse before patient discharge. The nurse in the community would then know the exact needs of each patient and could prepare the necessary help on the discharge day. This way could help the family caregiver to not feel lonely and give them more confidence to care for the TBI patient at home.

### Nursing research

Even though some impacts of telenursing in the transitional period were found, the continuation of the care process should be performed to enhance and empower the TBI caregivers at home. Due to the small number of participants, the effectiveness of this telenursing model should be tested by using quasi experimental studies. In addition, the cohort study should have a good design to evaluate the long term outcomes such as caregiver stress, and burden and patient complications.

Finally, the study should include those family caregivers who take care of TBI patients with complex a health status, unconscious patients or neurological patients who are in palliative care.

## Limitation of this study

The TCTS program was drawn based on literature and the data collected from one hospital and community network in Songkhla province. Therefore, the result may not be generalized to other contexts. Moreover, this study had only family caregiver who had the full support from other family members in order to continue taking care of the TBI patient. The model may be limited to those caregivers who had access to information and were able to use the smart phone.

**References**

American Telemedicine Association Telehealth Nursing SIG (2008). *Telenursing: A white paper developed and accepted by the telehealth nursing special interest group.* American Telemedicine Association, Washington DC.

American Telemedicine Association Telehealth Nursing SIG (2011). *Telehealth Nursing Fact Sheet*. American Telemedicine Association, Washington DC, pp. 2.

Andren, S., & Elmstahl, S. (2008). The relationship between caregiver burden, caregivers' perceived health and their sense of coherence in caring for elders with dementia. *Journal of Clinical Nursing*, *17*(6), 790–799.

Backhaus, S., & Ibarra, S. (2012). *Brain injury coping skills: A support and education program for adults with brain injury and their caregivers*. Youngsville, N.C.: Lash & Associates.

Backhaus, S. L., Ibarra, S. L., Klyce, D., Trexler, L. E., & Malec, J. F. (2010). Brain injury coping skills group: A preventative intervention for patients with brain injury andtheir caregivers. *Archives of Physical Medicine and Rehabilitation, 91*, 840–848.

Banik, B. J. (1993). Applying triangulation in nursing research. *Applied Nursing Research, 6*(1), 47-52.

Baptist Community Services (2006). *Smart House & Community Technologies Project*. http://www.alzheimers.org.au/upload/Hoeschke_Technology.pdf Retrieved 2nd September 2015.

Bazarian, J. J., Cernak, I., Noble-Haeusslein, L., Potolicchio, S., & Temkin, N. (2009). Long-term neurologic outcomes after traumatic brain injury. *Journal of Head Trauma Rehabilitation, 24*, 439-451.

Berry, J., Elliott, T., Grant, J., Edwards, G., & Fine, P. (2012). Does problem-solving training for family caregivers benefit their care recipients with severe disabilities? A latent growth model of the Project CLUES randomized clinical trial. *Rehabilitation Psychology, 57*(2), 98–112.

Blake, H. (2008). Caregiver stress in traumatic brain injury. *International Journal of Therapy and Rehabilitation, 15*(6), 263-271.

Boden, M., & Da Costa, O. (2004). Science and Technology Roadmapping: Implications for eHealth (Issue 81). Institute for Prospective Technological Studies, European Commission Joint Research Centre. *Journal of Telemedicine and Telecare, 1*, 32-34.

Bond, A. E., Draeger, C. R., Mandleco, B., & Donnelly, M. (2003). Needs of family members of patients with severe traumatic brain injury. Implications for evidence-based practice. *Critical Care Nurse, 23*(4), 63-72.

Bondanelli, M., De Marinis, L., Ambrosio, M. R., Monesi, M., Valle, D., Zatelli, M. C., Fusco, A., ... Uberti, E. C. (2004). Occurrence of pituitary dysfunction following traumatic brain injury. *Journal of Neurotrauma, 21*(6), 685-696.

Boschen, K., Gargaro, J., Gan, C., Gerber, G., & Brandys, C. (2007). Family interventions after acquired brain injury and other chronic conditions: a critical appraisal of the quality of evidence. *Neurorehabilitation, 22*(1), 19-41.

Boutin, A., Francisque, K., Moore, L., Lauzier, F., Neveu, X . & Turgeon, A. (2013). Hospital readmissions following traumatic brain injury. *Critical Care, 17*(l 2), P331.

Brown, R., Pain, K., Berwald, C., Hirschi, P., Delebanty, R., & Miller, H. (1999). Distance education and caregiver support groups: Comparison of traditional and telephone groups. *Journal of Head Trauma Rehabilitation, 14*(3), 257-268.

Buhse, M. (2008). Assessment of caregiver burden in families of persons with multiple sclerosis. *The Journal of Neuroscience Nursing, 40*(1), 25-31.

Bureau of Non Communicable Disease. (2015). Thai Road Safety Collaboration statistic report. Retrieved 2nd February 2016 from http://thaincd.com/information-statistic/injured-data.php

Burnard, P. (2006). Some attitudes towards teaching and learning in Thai nursing education. Nurse Education Today, 26(3), 253-257.

Burnard, P. & Naiyapatana, W. (2004). Culture and communication in Thai nursing: a report of an ethnographic study. *International Journal of Nursing Studies, 41*, 755-765.

Calvete, E. & deArroyabe, E. L. (2012). Depression and grief in Spanish family caregivers of people with traumatic brain injury: The roles of social support and coping. *Brain Injury, 26*(6), 834−43.

College of Nurses of Ontario. (2009). Telepractice: Practice guideline. Toronto: Author.

Carnevale, G., Anselmi, V., Busichio, K., & Millis, S. (2002). Changes in ratings of caregiver burden following a community-based behavior management program for persons with traumatic brain injury. *Journal of Head Trauma Rehabilitation, 17,* 83–95.

Carretero, S., Garces ,J., Rodenas, F. ,& Sanjose, V. (2009). The informal caregiver‘s burden of dependent people: Theory and empirical review. *Archives of Gerontology and Geriatrics, 49,* 74–79.

Cavallo, M. & Kay, T. (2005). *The family system*. In J. Silver, T., McAllister, & S, Yudofsky. (Eds.), Textbook of Traumatic Brain Injury. (pp. 533-5538). Arlington, VA: American Psychiatric Publishing.

Cavallo, D. N., Tate, D. F., Ries, A. V., Brown, J. D., DeVellis, R. F., & Ammerman, A. S. (2012). A social media-based physical activity intervention: A randomized controlled trial. *American Journal of Preventative Medicine*. *43*(2),527–532.

Chiang, L. C., Chen, W. C., Dai, Y. T., & Ho, Y. L. (2012).The effectiveness of telehealth care on caregiver burden, mastery of stress, and family function among family caregivers of heart failure patients: a quasi-experimental study. *International journal of nursing studies, 49*(10), 1230-1242.

Choowattanapakorn, T. (1999). The social situation in Thailand: the impact on elderly people. *International Journal of Nursing Practice*, *5*(2), 95-99.

Chronister, J, & Chan, F. (2006). A stress process model of caregiving for individuals with traumatic brain injury. *Rehabilitation Psychology*,*51*, 190.

Coco, K., Tossavainen, K., Jääskeläinen, J. E., & Turunen, H. (2011). Support for traumatic brain injury patients' family members in neurosurgical nursing: A systematic review. *Journal of Neuroscience Nursing, 43*,337−348.

Conde-Sala, J.L., Garre-Olmo, J., Turro-Garriga, O., Vilalta-Franch, J., & Lopez-Pousa, S. (2010). Differential features of burden between spouse and adult-child caregivers of patients with Alzheimer's disease: An exploratory comparative design. *International Journal of Nursing Studies, 47*(10), 1262–1273.

Corbin, J. M., & Strauss, A. (1988). *Unending work and care: Managing chronic illness at home*. Jossey-Bass; London, UK.

Corrigan, J., & Hammond, F. (2013). Traumatic brain injury as a chronic health condition. *Archives of Physical Medicine and Rehabilitation,94*, 1199–1201.

Curtiss, G., Klemz, S., & Vanderploeg, R. D. (2000). Acute impact of severe traumatic brain injury on family structure and coping responses. *Journal of Head Trauma Rehabilitation, 15*, 1113-1122.

Davis, L. C., Sander, A. M., Struchen, M. A., Sherer, M., & Nakase-Richardson, R. (2009). Medical and psychosocial predictors of caregiver distress and perceived burden following traumatic brain injury. *Journal of Head Trauma Rehabilitation, 24*, 145–154.

da Costa Melo, R. M., dos Santos Rua, M., & de Brito Santos, C. S. V. (2014). Family caregiver's needs in caring for the dependent person: an integrative literature review. *Revista de Enfermagem Referência*, *4*(2), 143-151.

Degeneffe, C. E. (2001). Family caregiving and traumatic brain injury. *Health and Social Work*, *26*(4), 257–268.

Degeneffe, C. E., Chan, F., Dunlap, L., Man, D., & Sung, C. (2011). Development and validation of the caregiver empowerment scale: A resource for working with family caregivers of persons with traumatic brain injury. *Rehabilitation Psychology, 56*, 243–250.

Dias, V. P., Witt, R. R., Silveira, D. T., Kolling, J. H., Fontanive, P., de CastroFilho, E. D., & Harzheim, E. (2009). Telenursing in primary health care: Report of experience in southern Brazil. *Studies in Health Technology and Informatics, 146*, 202–206.

Douglas, J. M., & Spellacy, F. J. (2000). Correlates of depression in adults with severe traumatic brain injury and their carers. *Brain Injury, 14,* 71-88.

Doughty, K., Monk, A., Bayliss, C., Brown, S., Dewsbury, L., …,Ward, D. (2008). Telecare, Telehealth and assistive technologies: do we know what we're talking about? *Pavilion Journals (Brighton) Ltd, 11*(3), 36-41.

Dyer, K. F. W., Bell, R., McCann, J., & Rauch, R. (2006). Aggression after traumatic brain injury: analyzing socially desirable responses and the nature of aggressive traits. *Brain Injury, 20*(11), 1163-1173.

Dyer, N., Sorra, J. S., Smith, S. A., Cleary, P. D., &Hays, R. D. (2012). "Psychometric properties of the consumer assessment of healthcare providers and systems (CAHPS®) clinician and group adult visit survey". *Medical Care, 50*, 28–34.

Edwards, N. E. & Ruettiger, K. M. (2002). The influence of caregiver burden on patients' management of Parkinson's disease: Implications for rehabilitation nursing. *Rehabilitation Nursing, 27*(5), 182-186.

Elliott, T., Shewchuk, R., & Richards, J. (2001). Family caregiver social problem-solving abilities and adjustment during the initial year of the caregiving role. *Journal of Counseling Psychology, 48*, 223–232.

Ergh, T. C., Rapport, L. J., Coleman, R. D., & Hanks R. A. (2002). Predictors of caregiver and family functioning following traumatic brain injury: social support moderates caregiver distress. *Journal of Head Trauma Rehabilitation, 17* (2), 155–174.

Flesch, L. D., Batistonia, S. S. T., Neria, A. L., & Cachionia, M. (2017). Psychological aspects of the quality of life of caregivers of the elderly: an integrative review. *Geriatrics Gerontology Aging, 11*(3),138-149.

Gan, C., Campbell, K. A., Gemeinhardt, M., & McFadden, G. T. (2006). Predictors of family system functioning after brain injury. *Brain Injury, 20*(6), 587–600.

Gan, C., Gargaro, J., Brandys, C., Gerber, G., & Boschen, K. (2010). Family caregivers' support needs after brain injury: a synthesis of perspectives from caregivers, programs, and researchers. *Neuro Rehabilitation, 27*, 5-18.

Gan, C., & Schuller, R. (2002). Family system outcome following acquired brain injury: clinical and research perspectives. *Brain Injury, 16*(4), 311-322.

Ganesalingam, K., Yeates, K. O., Ginn, M. S., Taylor, H. G., Dietrich, A., Nuss, K., & Wright, M. (2007). Family burden and parental distress following mild traumatic brain injury in children and its relationship to post-concussive symptoms. *Journal of Pediatric Psychology, 33*, 621-629.

Grant, J., Weaver, M., Elliott, T., Bartolucci, A., & Newman-Giger, J. (2004). Family caregivers of stroke survivors: Characteristics of caregivers at risk for depression. *Rehabilitation Psychology, 49*, 172–179.

Greene, R. R. (2008). *Social work with the aged and their families*. (2nd ed.). New York, NY: Aldine de Gruyter.

Hankey, G. J. (2004). Informal care giving for disabled stroke survivors. *British Medical Journal, 32,* 1085-1086.

Hanks, R. A., Rapport, L. J., & Vangel, S. (2007). Caregiving appraisal after traumatic brain injury: The effects of functional status, coping style, social support and family functioning. *Neurologyl Rehabilitation, 22*(1), 43–52.

Harkness, K. & Tranmer, J. (2007). Measurement of the caregiver experience in caregivers of persons living with heart failure: A review of current instruments. *Journal of Cardiac Failure, 13*(7), 577–587.

Hart, T., Brenner, L., Clark, A. N., Bogner, J. A., & Novack, T. A. (2011). Major and minor depression after traumatic brain injury. *Archives of Physical Medicine and Rehabilitation, 90*, 1211–1219.

Hassan, S., Khaw, W., Rosna, A., & Husna, J. (2011). Traumatic Brain Injury: Caregivers' Problems and Needs. *Journal of the Nepal Medical Association, 50,* 53–55.

Hawley, C.A. & Joseph, S. (2008). Predictors of positive growth after traumatic brain injury: A longitudinal study. *Brain Injury, 22,* 427–435.

Hawley, C. A., Ward, A. B., Magnay, A. R., & Long J. (2003). Parental stress and burden following traumatic brain injury amongst children and adolescents. Brain *Injury, 17*(1), 1-23.

Hart, T., Whyte, J., Polansky, M., Kersey-Matusiak, G., & Fidler-Sheppard, R. (2005). Community Outcomes Following Traumatic Brain Injury: Impact of race and pre-injury status. *Journal of Head Trauma Rehabilitation, 20,*158-172.

Hatyai Hospital Annual Report. (2015). Hatyai hospital annual report 2015. Retrieved 2nd February 2016 from http://www.geocities.ws/jarajorn_hadyai.html

Hiseman, J. P.  & Fackrell, R. (2017). Chapter Fourteen - caregiver burden and the nonmotor symptoms of parkinson's disease. *International Review of Neurobiology, 133,* 479-497.

Hoglund, A. T., & Holmstrom, I. (2008). 'It's easier to talk to a woman'. Aspects of gender in Swedish telenursing. *Journal of Clinical Nursing, 17,*2979–2986

Jaisri, M. (2014). Caregiver burden and depression among dementia caregivers. *International Journal of Social Science and Humanities Research, 2*(4), 365-371.

Jonsson, A. M., & Willman, A. (2008). Implementation of  telenursing within home healthcare. *Telemedicine  Journal and E-Health, 14,*1057–1062

Jorgensen, D., Parsons, M., Jacobs, S., & Arksey, H. (2010). The New Zealand informal caregivers and their unmet needs. *The New Zealand Medical Journal, 123*(1317), 9.

Jumisko, E., Lexell, J., & Soderberg, S. (2007). Living with moderate or severe traumatic brain injury: The meaning of family members’ experiences. *Journal of Family Nursing, 13*(3), 353–369.

Kemmis,S., & McTaggert, R., (1990). *The Action Research Planner*. Geelong: Deakin University Press.

Khan, F., Baguley, I. J., & Cameron I. D. (2003). Rehabilitation after traumatic brain injury. *Medical Journal of Australia, 178,* 290-295.

Khiewchaum, R., Thosingha, O., Chayaput, P., & Utriyaprasit, K. (2011). Coping with traumatic brain injury using the preparation program among caregivers of patients in the intensive care unit. *The Siriaj Medical Journal, 63*(4), 128-131.

Kim, H., Chang, M. Rose, K., & Kim, S. (2011). Predictors of caregiver burden in caregivers of individuals with dementia. *Journal of Advanced Nursing, 68*(4), 846-855.

Kim, J., Knight, B. G., & Flynn Longmire, C. V. (2007). The role of familism values in stress and coping processes among African American and White dementia caregivers: Effects on mental and physical health. *Health Psychology, 26*, 564-576.

Kitisomprayoonkul, W. (2010).*Traumatic brain injury rehabilitation.* D. Chaiwanichsiri, W. Kitisomprayoonkul (Eds.), Rehabilitation medicine textbook (2nd ed.), Chulalongkorn University Company, Bangkok, pp. 187–197. (Thai version).

Kneafsey, R., & Gawthorpe, D. (2004). Head injury: Long-term consequences for patients and families and implications for nurses. *Journal of Clinical Nursing, 3*, 601-608.

Kolakowsky-Hayner, S. A., Miner, K., & Kreutzer, J. (2001). Long-term life quality and family needs after traumatic brain injury. *Journal of Head Trauma Rehabilitation, 16*, 374–385.

Kreutzer, J. S., Marwitz, J. H., Godwin, E. E., & Arango-Lasprilla, J. C. (2010). Practical approaches to effective family intervention after brain injury. *Journal of Head Trauma Rehabilitation, 25*(2), 113-120.

Kreutzer, J. S., Stegskal, T. M., Ketchum, J. A., Marwitz, J. H., Taylor, L. A., & Mentzel, J.C. (2009). A preliminary investigation of the brain injury family intervention: impact on family members. *Brain Injury, 23*(6), 535-547.

Kreutzer, J. S., Rapport, L. J., Marwitz, J. H., Harrison-Felix, C., Hart, T., Glenn, M. et al. (2009). Caregivers' well-being after traumatic brain injury: a multicenter prospective investigation. *Archives of Physical Medicine and Rehabilitation, 90*(6), 939-946.

Kuipers, E., Onwumere, J., & Bebbington, P. (2010). Cognitive model of caregiving in psychosis. *The British Journal of Psychiatry: the Journal of Mental Science*, 196(4), 259–265.

Landau, J., & Hissett, J. (2008). Mild traumatic brain injury: Impact on identity and ambiguous loss in the family. *Families, Systems, & Health, 26*(1), 69-85. doi: 10.1037/1091-7527.26.1.69.

Langlois, J. A., Rutland-Brown, W., & Wald, M. M.. (2006). The Epidemiology and impact of traumatic brain injury a brief overview. *Journal of Head Trauma Rehabilitation, 21*(5), 375-378.

Lefebvre, H., & Levert, M. J. (2012). The close relatives of people who have had a traumatic brain injury and their special needs. *Brain Injury, 26*(9), 1084–1097.

Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry*. Beverly Hills, CA: Sage.

Lippa, C., Bowen, K., Robertson-James, C., Nunez,A., & Gonzalez,E. (2014). The role of gender differences in dementia caregiver risk. *Journal of the American Academy of Neurology, 82*, 212.

Lippert-Gruner, M., Kuchta, J., Hellmich, M., & Klug, N. (2006). Neurobehavioral deficits after traumatic brain injury. *Brain Injury, 20*(6), 569-574.

Livingston, D. H., Lavery, R. F., Mosenthal, A. C., Knudson, M. M., Lee, S., & Morabito, D. M. (2005). Recovery at one year following isolated traumatic brain injury: A western trauma association prospective multicenter trial. *Journal of Trauma and Acute Care Surgery, 59*, 1298-1304.

Lorentz, M. M. (2008). Telenursing and home healthcare. The many facets of technology. *Home Healthcare Nurse, 26*, 237–243.

Lui, M., Ross, F., & Thompson, D. (2005). Supporting family caregivers in stroke care: A review of the evidence for problem solving. *Stroke*, *36*, 2514–2522.

MacKenzie, E., Jaffe, K., Paidas, C., Dorsch, A., Christensen, J., Aitken, M., et al. (2009). Family burden after traumatic brain injury in children. *Pediatrics, 123*(1), 199-206.

McCutcheon,G., & Jurg, B., (1990). Alternative Perspectives on Action Research. *Theory into Practice, 20*(3).

McKernan,J., (1991). *Curriculum Action Research. A Handbook of Methods and Resources for the Reflective Practitioner*. London: Kogan Page.

Malec, J. F., Testa, J. A., Rush, B. K., Brown, A. W., & Moessner, A. M. (2007). Self-assessment of impairment, impaired self-awareness, and depression after traumatic brain injury. *Journal of Head Trauma Rehabilitation, 22* (3), 156-166.

Manning, S. (2011). Bridging the gap between hospital and home a newmodel of care for reducing readmission rates in chronic heart failure. *Journal of Cardiovascular Nursing, 26*(5), 368–376.

MAPI Research Institute. (2009). ZBI-22-Thailand/Thai-Version 2009. retrieved 4th December, 2016 from http://mapi-trust.org/our-resources/questionnaires-distributed-by-the-mapi-research-trust/.

Marsh, N. V., Kersel, D. A., Havill, J. A., & Sleigh, J. W. (2002). Caregiver burden during the year following severe traumatic brain injury. *Journal of Clinical and Experimental Neuropsychology, 24*(4), 434-447.

Martin, K. (2012). Carers and traumatic brain injury: A qualitative synthesis. International *Journal of Therapy and Rehabilitation, 19*(9), 504-513.

Martinez-Martin, P., Arroyo, S., Rojo-Abuin, J. M., Rodriguez-Blazquez, C., Frades, B., & de Pedro Cuesta, J. (2008) Burden, perceived health status, and mood among caregivers of Parkinson's disease patients. *Movement Disorders, 23*(12), 1673–1680.

Meleis, A. I. (2010). *Transitions from practice to evidence-based models of care*. In A. I. Meleis (Ed.), Transitions Theory: Middle-range and situation-specific theories in nursing research and practice (pp. 1 – 9). New York: Springer Publishing.

Meleis, A. I., Douglas, M. K., Eribes, C., Shih, R., & Messias, D. K. (1996). Employed Mexican women as mothers and partners: Valued, empowered, and overloaded. *Journal of Advanced Nursing, 23*(1), 82-90.

Meleis, A. I., Sawyer, L.M., Im, E.O., Hilfinger Messias, D. K., & Schumacher, K. (2000). Experiencing transitions: An emerging middle range theory. *Advances in Nursing Science, 23*(1), 12-28.

Meleis, A. I. (1975). Role sufficiency and role supplementation: A conceptual framework. *Nursing Research, 24*, 264-271.

McPherson, K. M., Pentland, B., & McNaughton, H. K. (2000). Brain injury: The perceived health of carers. *Disability and Rehabilitation, 22*(15), 683–689.

Morris, K. C. (2001). Psychological distress in carers of head injured individuals: the provision of written information. *Brian Injury, 15*(3), 239-254.

Murray, H. M., Maslany , G. W., & Jeffery, B. (2006). Assessment of family needs following acquired brain injury in Saskatchewan. *Brain Injury, 20*(6), 575-585.

Nabors, N., Seacat, J., & Rosenthal, M. (2002). Predictors of caregiver burden following traumatic brain injury. *Brain Injury, 16*(12), 1039-1050.

Naditz, A., (2009). Telenursing:Front-line applications of telehealth care delivery. *Telemedicine Journal and E-Health, 15,* 825–829

Narkthong, N., Songwathana, P., & Kitrunrote, L. (2014). *Effect of tailored discharge preparedness program on caregiver's discharge readiness in caring for patients with traumatic brain injury: A preliminary*. Oral presentation from The 2nd NEUNIRC2014 International Conference.

Naylor, M. D., Brooten, D. A., Campbell, R. L., Maislin, G., McCauley, K. M., & Schwartz, J. S. (2004). Transitional care of older adults hospitalized with heart failure: A randomized, controlled trial. *Journal of the American Geriatrics Society, 52*(5), 675-684.

Novak, M., & Guest, C. (1989). Application of a multidimensional caregiver burden inventory. *Gerentologist, 29*,798–803.

Oddy, M. & Herbert, C. (2003). Intervention with families following brain injury: Evidence based practice. *Neuropsychological Rehabilitation, 13,* 259–273.

O'Donovan A., Epel E., Lin J., Wolkowitz O., Cohen B., Maguen S., ... Neylan, T. C. (2011). Childhood trauma associated with short leukocyte telomere length in posttraumatic stress disorder. *Biological Psychiatry, 70,* 465–471.

Olofsson, A., Andersson, A., & Carlberg, B. (2005). "If only I manage to get home I'll get better"—Interviews with stroke patients after emergency stay in hospital on their experiences and needs. *Clinical Rehabilitation, 19,* 433-440.

Padmini Yeleswarapu, S., & Curran, A. (2010). Rehabilitation after head injury. *Pediatrics and Child Health, 20*(9), 424-427.

Pangilinan, P. H. (2015). Classification and Complications of Traumatic Brain Injury. Retrieved 10th January 2016 from http://emedicine.medscape.com/article/326643-overview

Paterson, B., Kieloch, B., & Gmiterek J. (2001). 'They never told us anything: post discharge instruction for families of persons with brain injuries. Rehabilitation Nursing, 26(2), 48-53.

Petchprapai, N. (2007). *Adaptation to mild traumatic brain injury among Thai adults*. Unpublished Doctoral Dissertation of Frances Payne Bolton School of Nursing, Case Western Reserve University.

Petranovich, C. L., Wade, S. L., Taylor, H. G., Cassedy, A., Stancin, T., Kirkwood, M. W., & Brown, T. M. (2015). Long term caregiver mental health outcomes following a predominately online intervention n for adolescents with complicated mild to severe traumatic brain injury. *Journal of Pediatric Psychology, 2,* 1-9.

Phelps, A. C., Maciejewski, P. K., Nilsson, M., Balboni, T. A., Wright, A. A., Paulk, M. E. et al. (2009). Religious coping and use of intensive lifeprolonging care near death in patients with advanced cancer. *The Journal of the American Medical Association, 301*(11), 1140-1147.

Pickelsimer, E.E.; Selassie, A.W., Gu, J.K., & Langlois, J.A. (2006). A population-based outcomes study of persons hospitalized with traumatic brain injury: Operations of the South Carolina traumatic brain injury follow-up registry. *Journal of Head Trauma Rehabilitation, 21*, 491-504.

Pinquart, M., & Sorensen, S. (2003). Differences between caregivers and noncaregivers in psychological health and physical health: A meta-analysis. *Psychology Aging, 18*(2), 250-267.

Potaya, S. (2001). *Model for family caregivers' participation in caring for traumatic brain injured patients*. Unpublished Doctoral Dissertation of Nursing Science, Mahidol University. Bangkok

Prateepwanit, P. (2008). *Introduction of rehabilitation medicine.* Pajaree, K. (Ed.), Rehabilitation Medicine, N.P. Press, Bangkok , pp. 1–8. (Thai version).

Prigatano, G. P. (2005). Disturbances of self-awareness and rehabilitation of patients with traumatic brain injury: A 20-year perspective. *Journal of Head Trauma Rehabilitation, 20*(1), 19–29.

Radhakrishnan, K., & Jacelon, C. (2011). Impact of telehealth on patient self-management of heart failure: A review of literature. *Journal of Cardio-vascularNurse*, 1–11.

Ramkumar, N. A., & Elliott, T. R. (2010) Family caregiving of persons following neurotrauma: Issues in research, service and policy. *Neurology Rehabilitation, 27*, 105–112.

Reinhard, S. C., Given, B., Petlick, N. H., & Bemis, A. (2008) Supporting family caregivers in providing care. In: R.G. Hughes (ed). Patient safety and quality: An evidence-based handbook for nurses. Rockville (MD): Agency for Healthcare Research and Quality (US); 2008 Apr. Chapter 14. Available: http://www.ncbi.nlm. nih.gov/books/NBK2665/. Accessed 2015 November 11.

Rigby, H., Gubitz, G., & Phillips, S. (2009). A systematic review of caregiver burden following stroke. *International Journal of Stroke, 4,* 285-292.

Riggio, H. (2011). Traumatic Brain Injury and Its Neurobehavioral Sequelae. Neurologic Clinics, 29(1), 35-47.

Rinaldi, P., Spazzafumo, L., Mastriforti, R., Mattioli, P., Marvardi, M., Polidori, M.C., ... , & Study Group on Brain Aging of the Italian Society of

Gerontology and Geriatrics. (2005). Predictors of high level of burden and distress in caregivers of demented patients: Results of an Italian multicenter study. *International Journal of Geriatric Psychiatry, 20*(2), 168– 174.

Rivera, P. A., Elliott, T. R., Berry, J. W., & Grant, J. S. (2008). Problem-solving training for family caregivers of persons with traumatic brain injuries: A randomized controlled trial. *Archives of Physical Medicine and Rehabilitation, 89*, 931-941.

Rivera, P., Elliott, T. R., Berry, J. W., Grant, J. S., & Oswald, K. (2007). Predictors of caregiver depression among community-residing families living with traumatic brain injury. *NeuroRehabilitation, 22*, 3-8.

Rodgers, M. L., Strode, A. D., Norell, D. M., Short, R. A., Dyck, D. G., & Becker, B. (2007). Adapting multiple family group treatment for brain and spinal cord injury intervention development and preliminary outcomes. *American Journal of Physical Medicine and Rehabilitation, 86*(6), 482-491.

Rogers, J. M., & Read, C. A. (2007). Psychiatric co-morbidity following traumatic brain injury. *Brain Injury, 21*, 1321–1333.

Roscigno, C. I., Gran, G., Savage, T. A., & Philipsen, G. (2013). Parent perceptions of early prognostic encounters following children’s severe traumatic brain injury: ‘Locked up in this cage of absolute horror’. *Brain Injury, 27*(13-14), 1536-1548.

Rotondi, A. J., Sinkule, J., Balzer, K., Harris, J., & Moldovan, R. (2007). A qualitative needs assessment of persons who have experienced traumatic brain injury and their primary family caregivers. *Journal of Head Trauma Rehabilitation, 22*, 14–25.

Rotondi, A. J., Sinkule, J., & Spring, M. (2005). An interactive web-based intervention for persons with TBI and their families: Use and evaluation by female significant others. *Journal of Head Trauma Rehabilitation, 20*(2), 173-185.

Rotondi, A. J., Sinkule, J., Balzer, K., Harris, J., & Moldovan, R. (2007). A qualitative needs assessment of persons who have experienced traumatic brain injury and their primary family caregivers. *Journal of Head Trauma Rehabilitation, 22*, 14-25.

Sady, M. D., Sander, A.M., Clark, A.N., Sherer, M., Nakase-Richardson, R., & Malec, J. F. (2010). Relationship of preinjury caregiver and family functioning to community integration in adults with traumatic brain injury. *Archives of Physical Medicine Rehabilitation, 91*, 1542-1550.

Sae-sia, W, Songwathana, P., & Suwanmanee, M. (2014). Predicting factors of care burden among caregivers of assault victims of the unrest in southern border provinces of Thailand. *Journal of Trauma Nursing, 21*(4), 194-198.

Samartkit, N., Kasemkitvattana, S., Thosingha, O., & Vorapongsathorn, T. (2010). Caregiver role strain and rewards: Caring for Thais with a traumatic brain

Injury. *Pacific Rim International Journal of Nursing Research, 14*(4), 297 - 314.

Sandelowski, M. (1986). The problem of rigor in qualitative research. *Advance in Nursing Science, 8*(3), 27-37.

Sander, A. M., Carosellis, J. S., Becker, C., Neeses, L., & Scheibel, R. (2002). Relationship of family functioning to progress in post-acute rehabilitation programme following traumatic brain injury. *Brain Injury, 16*, 649-657.

Santos-García, D. & de la Fuente-Fernandez, R. (2015). Factors contributing to caregivers' stress and burden in Parkinson's disease. *Acta Neurologica Scandinavica*, *131*(4), 203-210.

Saverino, C., Swaine, B., Jaglal, S., Lewko, J., Vernich, L., Voth, J. Calzavara, A., & Colantonio, A. (2015). Rehospitalization After Traumatic Brain Injury: A Population-Based Study. *Archives of Physical Medicine and Rehabilitation* (In Press).

Sawasdinaruenat, S., Sae-sia, W., & Songwathana, P. (2013). Effects of Information and Emotional Support Program on Caregivers Stress and Stress Impacts in Caring for Patients with Traumatic Brain Injury in Critical Phase. *Princess of Naradhiwas University Journal, 2*, 1-13.

Schofield, R. S., Kline, S. E., Schmalfuss, C. M., Carver, H. M., Aranda, J. M., Pauly, D. F., … Chumbler, N. R. (2005). Early outcomes of a care coordinationenhanced telehome care program for elderly veterans with chronic heart failure. *Telemed Journal and E-health Health, 1*, 20-27.

Schulz, R., Beach, S. R., Cook, T. B., Martire, L. M., Tomlinson, J. M., & Monin, J. K. (2012). Predictors and consequences of perceived lack of choice in becoming an informal caregiver. *Aging & Mental Health, 16*(6), 712–721.

Schwartz, K.A. & Britton, B. (2011). Use of telehealth to improve chronic disease management. *North Carolina Medical Journal., 72,* 216-218.

Sequeira, C. (2010). *Caring for seniors with physical addiction and mental*. Lisbon: Lidel.

Sisk, R. J. (2000). Caregiver burden and health promotion. *International Journal of Nursing Studies, 37*, 37–43

Snooks, H. A., Williams, A. M., Griffiths, L. J., Peconi, J., Rance, J., Snelgrove, S.,... Cheung , W. Y. (2008). Real nursing? The development of telenursing. *Journal of Advanced Nursing, 61*, 631–640.

Stancin, T., Wade, S., Walz, N., Yeates, K., & Taylor, H. (2010). Family adaptation 18 months after traumatic brain injury in early childhood. *Journal of Development and Behavioral Pediatrics, 31*,317-325.

Testa, J. A., Malec, J. F., Moessner, A. M., & Brown, A. W. (2006). Predicting family functioning after TBI: Impact of neurobehavioral factors. *Journal Head Trauma Rehabilitation, 21*, 326-347.

Thompson, C. A., Spilsbury, K., Hall, J., Birks, Y., Barnes, C., & Adamson, J. (2007). Systematic review of information and support interventions for caregivers of people with dementia. *BMC Geriatrics, 7*, 18 - 29.

Utriyaprasit, K., Bootcheewan, S., Chayaput, P., & Thosingha, O. (2012). The relationship between social support to caregiver and patient's disability from traumatic brain injury. *The Siriaj Medical Journal, 64*(6), 188-192.

Van Baalen, B., Ribbers, G. M., Medema-Meulepas, D., Pas, M. S., Odding, E., & Stam, H. J. (2007). Being restricted in participation after a traumatic brain injury is negatively associated by passive coping style of the caregiver. *Brain Injury, 21*(9), 925-931.

Vanderploeg, R. D., Belanger, H. G., Duchnick, J. D., & Curtiss, G. (2007). Awareness problems following moderate to severe traumatic brain injury: Prevalence, assessment methods, and injury correlates. *Journal of Rehabilitation Research & Development, 44*(7), 937–950.

Vangel, S., Rapport, L., & Hanks, R. (2011) Effects of family and caregiver psychosocial outcomes on persons with traumatic brain injury. *Journal of Head Trauma Rehabilitation, 26*, 20–29.

Verhaeghe, S., Defloor, T., & Grypdonck, M. (2005). Stress and coping among families of patients with traumatic brain injury: A review of the literature. *The Journal of Clinical Nursing, 14*, 1004-1012.

Vreeland, D. G., Rea, R. E., & Montgomery, L. L. (2011). A review of the literature on heart failure and discharge education. *Critical Care Nursing Quarterly, 34*(3), 235–245.

Wade, S. L., Carey,  J., & Wolfe, C. R. (2006). The efficacy of an online cognitive behavioral family intervention in improving child behavior and social competence in pediatric brain injury. *Rehabilitation Psychology, 51*, 179–189.

Wakai, A., Roberts, I., & Schierhout, G. (2005). Mannitol for acute traumatic brain injury. *The Cochrane Database of Systematic Reviews, 4*, CD001049.

Watanabe, Y., Shiel, A., McLellan, D. L., Kurihara, M., & Hayashi, K. (2001). The impact of traumatic brain injury on family members living with patients: A preliminary study in Japan and the UK. Disability and Rehabilitation, 23(9), 370-378.

Webber, G. (2007). The impact of migration on HIV prevention for women: Constructing a conceptual framework. *Health Care for Women International, 28*(8), 712-730.

Woods, N. F., & Catanzaro, M. (1988). *Nursing research: Theory and practice*. St. Louis: C.V. Mosby.

World Health Organization (WHO) (2014). World health statistic 2014. Retrieved from http://apps.who.int/iris/bitstream/10665/112738/1/9789240692671_eng.pdf

Whyte, J., Hart, T., Laborde, A., & Rosenthal, M. (2005). Rehabilitation of the patient with traumatic brain injury. In J. A. DeLisa, B. M. Gans, N. E. Walsh, W. L. Bockenek, & W. R. Frontera (Eds.), Physical medicine & rehabilitation – principles and practice. (4th ed., vol 2., pp. 1680-1693). Philadelphia: Lippincott Williams & Wilkins.

Wongpakaran, N., & Wongpakaran, T. (2010). The Thai version of the PSS-10: An investigation of its psychometric properties. *Biopsychosocial Medicine, 4*(1), 1-6.

Wongvatunyu, S., & Porter, E. (2005). Mothers' experience of helping young adults with traumatic brain injury. *Journal of Nursing Scholarship, 37*(1), 48-56.

Woods, N. F., & Catanzaro, M. (1988). *Nursing research: Theory and practice*. St. Louis: C.V. Mosby.

Yetman, L. (2008). Neuroscience nurses caring for family members of patients with acquired brain injury in acute ward settings: Nursing defensively in a double bind. *Canadian Journal of Neuroscience Nursing, 30*, 26–33.

Zauszniewski, J. A., Picot, S. J. F., Debanne, S. M.. Roberts, B. L., & Wykle, M. L. (2002), Psychometric characteristics of the depressive cognition scale in African American women. *Journal of Nursing Measurement, 10*(2), 83-95.

# Appendices

# Appendix A

## The Extended Glasgow Outcome Scale (GOSE)

The Extended Glasgow Outcome Scale (GOSE) was used to assess the severity of illness of TBI patients. It was developed from The Glasgow Outcome Scale (GOS) constructed by Jennet and Bond (1975). Previously, the GOS had classified the outcomes into five levels. Then Wilson and colleagues developed the GOSE, which classified the outcomes of TBI into eight levels. The reliability value derived from the observation kappa value was .85 (Wilson, Pettigrew, & Teasdale, 1998). Thosingha (2001) translated the GOSE into Thai version and two bilingual linguists were also asked to check the accuracy of the language.

In this study GOSE was used to assess the disability level of TBI patients. The eight levels of GOSE are as follows:

Level 1: There is a very high change of mortality. The Glasgow Coma Scale results have been only 3 or 4 since the very beginning.

Level 2: The patient is in a vegetation state. He or she cannot help him/herself and does not have mindful responses.

Level 3: The patient has the highest degree of impairment. He or she needs constant care from others in performing all or almost all daily life activities.

Level 4: The patient has a very high degree of impairment. He or she needs constant care from others in performing a number of daily life activities.

Level 5: The patient has a moderate level of impairment. He or she can take care him/herself when at home; however, care is required from others when the patient is outside the home.

Level 6: The patient has slight impairment. He or she can take good care of him/herself but requires assistance from others in performing some activities when going out of the house. In addition, the patient can do some work which is lighter than what he or she used to do than before the onset of the neurological condition. However, there are certain limitations in terms of social and recreational activities.

Level 7: The patient has a slight change of recovery. He or she can take good care of him/herself to certain extent. However, the patient still has problems concerning interaction or communication with family members or colleagues. He or she sometime has behavioral and emotional problems but is still able to participate in some social or recreation activities.

Level 8: The patient has a very good chance of recovery. He or she is very likely to live a normal life, be able to take care of him/herself and go back to work.

The total score range from 1 to 8 points, with low score reflecting severe remained disabled and high scores reflecting less remained disabled. This study will conduct with caregivers who take care of patients whose range of GOSE is at level 2 to 5. This is because of the patient in level 1 has high chance of mortality or too severe a disability whereas the patients in level 6-8 are able to take care his/herself.

# Appendix B

# Assessment Tools

## B1 General information questionnaires to each participant

No ……….

Date ………..

### Family Caregivers' General information Questionnaire

Please answer all of the following questions and do not leave any question blank. Please check √ in ☐ that corresponds to your answer, or write your answer in the blank where appropriate.

1. Age …………….. Year
2. Gender
   ☐ 1. Female
   ☐ 2. Male

3. Marital status
   ☐ 1. Single
   ☐ 2. Married
   ☐ 3. Widowed
   ☐ 4. Divorced

4. Religion
   ☐ 1. Buddhist
   ☐ 2. Christian
   ☐ 3. Muslim
   ☐ 4. Others (please specified) …..

5. Education level
   ☐ 1. No education
   ☐ 2. Primary school
   ☐ 3. Secondary school/ Diploma
   ☐ 4. Bachelor's degree
   ☐ 5. Master's degree or higher

6. Occupation
   ☐ 1. No job
   ☐ 2. Labor
   ☐ 3. Farmer
   ☐ 4. Government officer
   ☐ 5. Vendor
   ☐ 6. Retired
   ☐ 7. Other (please specified) ……………

7. Working during caring patient
   ☐ 1. Stop working ☐ 2. Part time

   ☐ 3. Full time

8. Family income ……………….baht/month
9. Sufficiency income
   ☐ 1. Not enough and loans ☐ 2. Enough money
   without saving

   ☐ 3. Enough money with saving

10. Relation with patient (please specified): ……………………..
11. The reason becoming caregiver
    ☐ 1. Duty/responsibility

    ☐2. Love/Attachment

    ☐ 3. No other/ no choice

    ☐ 4. Other reasons (please specified) ……………………………

12. Duration of taking care …………month
13. Time spent for taking care ………hour/day
14. Experience of caregiving
    ☐ 1. No ☐ 2. Yes (please specified) …….

15. Caregiver assistant
    ☐ 1. No ☐ 2. Yes (please specified) …….

16. Other persons with caring responsibility
    ☐ 1. No ☐ 2. Yes (please specified) …….

17. Health problem before caring
    ☐ 1. No ☐ 2. Yes (please specified) …….

18. Health problem during caring
    ☐ 1. No ☐ 2. Yes (please specified) …….

19. Common medicine use
    ☐ 1. No

    ☐ 2. Yes (please specified: drug name, dose, frequency) …………………

20. Getting information about caregiving

☐ 1. No ☐ 2. Yes (please specified) …….

21. Getting training on caregiving skills

☐ 1. No ☐ 2. Yes (please specified) …….

22. Place for caring

☐ 1. Own house ☐ 2. Relative's house

☐ 3. Others (please specified) ………………

# Appendix B

## B1 General information questionnaires to each participant

No ……….

Date ………..

### Health Care Team General Information Questionnaire

Please answer all of the following questions and do not leave any question blank. Please check √ in ☐ that corresponds to your answer, or write your answer in the blank where appropriate.

1. Age …………….. Year
2. Gender
   ☐ 1. Female ☐ 2. Male

3. Marital status
   ☐ 1. Single ☐ 2. Married

   ☐ 3. Widowed ☐ 4. Divorced

4. Religion
   ☐ 1. Buddhist ☐ 2. Christian

   ☐ 3. Muslim ☐ 4. Others (please specified) …..

5. Education level
   ☐ 1. No education ☐ 2. Primary school

   ☐ 3. Secondary school/ Diploma ☐ 4. Bachelor’s degree

   ☐ 5. Master’s degree or higher

6. Occupation
   ☐ 1. Nurse ☐ 2. Community Nurse

   ☐ 3. Health care volunteer ☐ 4. Doctor

   ☐ 5. Other (please specified) ……………

7. Experience of taking care TBI patient …………year

# Appendix B

# A question guideline for participants

### 1.1 Guideline of interview with family caregiver

**Goal:** To understand the family caregiver's experience of caring the person with TBI.

**Instruction:** Ask the participant the following questions after getting informed consent.

**1) Pre-discharge period**

1. What do you feel about caring the person with TBI?

2. What do you think about nursing care and caring?

3. What kinds of things do you do to care the person?

4. How do you think about the caring for the person from the health care team? Good aspects? Bad aspects?

5. Do you feel stress and/or burden? If yes, please explain more "why do you feel like that?".

6. What do you expect from the health care team?

**2) Discharge and post-discharge period**

1. What do you feel about caring the person with TBI (first week and now)?

2. What do you think about nursing care, caring, and telenursing?

3. How do you evaluate the person’s current living?

4. What kinds of things do you do to care the person?

5. What can facilitate or inhibit the person to manage own life with TBI?

7. How do you think about the caring for the person from the health care team? Good aspects? Bad aspects?

8. Do you feel stress and burden? If yes, please explain more “why do you feel like that?”.

9. What should be improved in the caring by telenursing?

### 1.2 Guideline of focus group discussion with health care team

**Goal:** To understand the experiences from health care provider of caring the persons with TBI.

**Instruction:** Ask the participants the following questions after getting informed consent.

1. How do you feel about caring the person with TBI?

2. How do you think about nursing care, caring, and telenursing?

3. What kinds of things do you do to care the person?

4. What can facilitate or inhibit the caregiver to manage TBI caring?

5. How do you evaluate the current caring which is provided to the person with TBI and his/her caregiver?

6. What should be improved in the caring in transitional care?

### 1.3 Reflection Guideline

**Instruction:** The researcher should use the guideline for self-reflection and enlightening the participants' reflection during the process of this study.

1. What happened when you performed the action?

2. Who was involved in the plan and the action? How?

3. How do you feel? Do you feel stress and/or burden? If yes, please explain more "why do you feel like that?".

4. What does it mean to you?

5. What is the difference between before and after the action?

6. Have you achieved your goal?

7. What has been changed in your life?

8. What have you learned?

9. What should be improved in the caring in transitional care and telenursing?

# Appendix C

## Observation Record Form

**Instruction:** The researcher should use this form to make field note during the process of participant observation.

Observation record No. ………….. Page ……………

Date…………………………………………….time………………………………..

Location………………………………………………………………………………

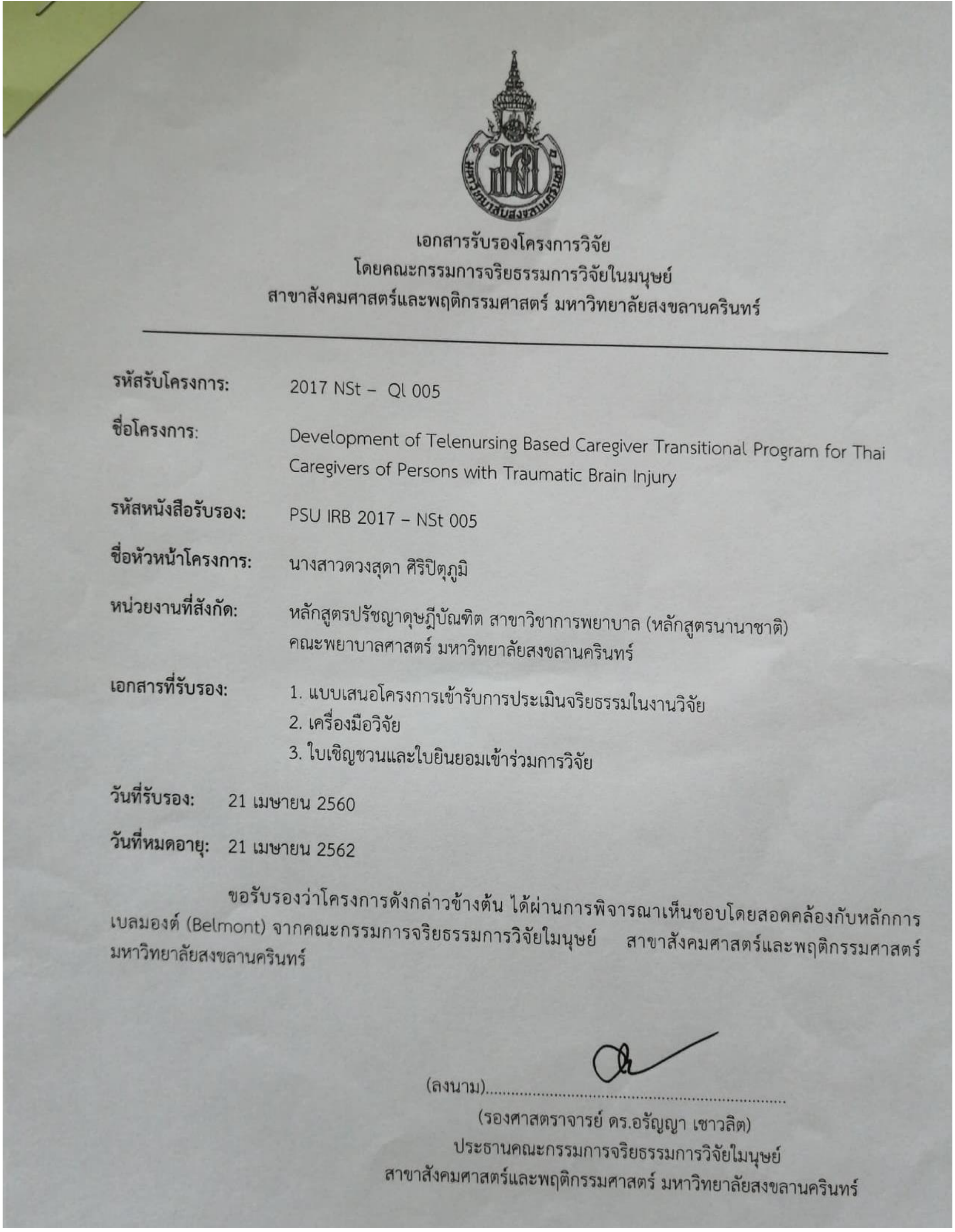
Participants…………………………………………………………………………

| Observed data | Reflection |
|---|---|
| | |
| | |
| | |
| | |
| | |
| | |
| | |
| | |

# Appendix D

## Ethical Permission

IRB from the Faculty of Nursing, Prince of Songkla University
(PSU IRB 2017 - NSt 005)



เอกสารรับรองโครงการวิจัย
โดยคณะกรรมการจริยธรรมการวิจัยในมนุษย์
สาขาสังคมศาสตร์และพฤติกรรมศาสตร์ มหาวิทยาลัยสงขลานครินทร์

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**รหัสรับโครงการ:** 2017 NSt – Ql 005

**ชื่อโครงการ:** Development of Telenursing Based Caregiver Transitional Program for Thai Caregivers of Persons with Traumatic Brain Injury

**รหัสหนังสือรับรอง:** PSU IRB 2017 – NSt 005

**ชื่อหัวหน้าโครงการ:** นางสาวดวงสุดา ศิริปิตุภูมิ

**หน่วยงานที่สังกัด:** หลักสูตรปรัชญาดุษฎีบัณฑิต สาขาวิชาการพยาบาล (หลักสูตรนานาชาติ)
คณะพยาบาลศาสตร์ มหาวิทยาลัยสงขลานครินทร์

**เอกสารที่รับรอง:**
1. แบบเสนอโครงการเข้ารับการประเมินจริยธรรมในงานวิจัย
2. เครื่องมือวิจัย
3. ใบเชิญชวนและใบยินยอมเข้าร่วมการวิจัย

**วันที่รับรอง:** 21 เมษายน 2560

**วันที่หมดอายุ:** 21 เมษายน 2562

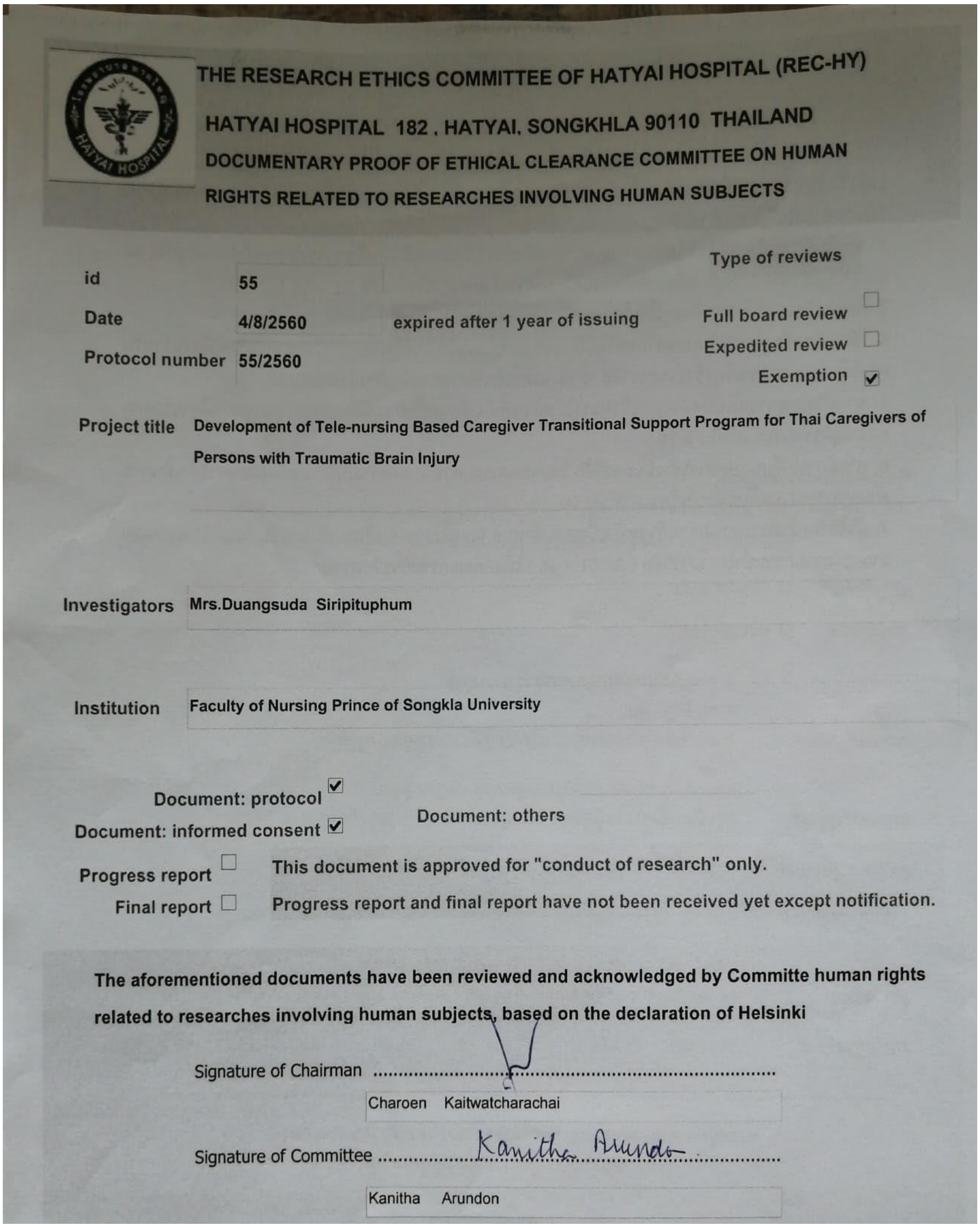
ขอรับรองว่าโครงการดังกล่าวข้างต้น ได้ผ่านการพิจารณาเห็นชอบโดยสอดคล้องกับหลักการเบลมองต์ (Belmont) จากคณะกรรมการจริยธรรมการวิจัยใมนุษย์ สาขาสังคมศาสตร์และพฤติกรรมศาสตร์ มหาวิทยาลัยสงขลานครินทร์

(ลงนาม)..........................................................................
(รองศาสตราจารย์ ดร.อรัญญา เชาวลิต)
ประธานคณะกรรมการจริยธรรมการวิจัยใมนุษย์
สาขาสังคมศาสตร์และพฤติกรรมศาสตร์ มหาวิทยาลัยสงขลานครินทร์

# Appendix D

## Ethical Permission

IRB from Hatyai hospital (ID 55 Protocol number 55/2560)



**THE RESEARCH ETHICS COMMITTEE OF HATYAI HOSPITAL (REC-HY)**

**HATYAI HOSPITAL 182 . HATYAI. SONGKHLA 90110 THAILAND**

**DOCUMENTARY PROOF OF ETHICAL CLEARANCE COMMITTEE ON HUMAN RIGHTS RELATED TO RESEARCHES INVOLVING HUMAN SUBJECTS**

id **55**

Date **4/8/2560** expired after 1 year of issuing

Protocol number **55/2560**

Type of reviews

Full board review ☐

Expedited review ☐

Exemption ☑

Project title **Development of Tele-nursing Based Caregiver Transitional Support Program for Thai Caregivers of Persons with Traumatic Brain Injury**

Investigators **Mrs.Duangsuda Siripituphum**

Institution **Faculty of Nursing Prince of Songkla University**

Document: protocol ☑

Document: informed consent ☑

Document: others

Progress report ☐

Final report ☐

This document is approved for "conduct of research" only.

Progress report and final report have not been received yet except notification.

**The aforementioned documents have been reviewed and acknowledged by Committe human rights related to researches involving human subjects, based on the declaration of Helsinki**

Signature of Chairman ..........................................................................

Charoen Kaitwatcharachai

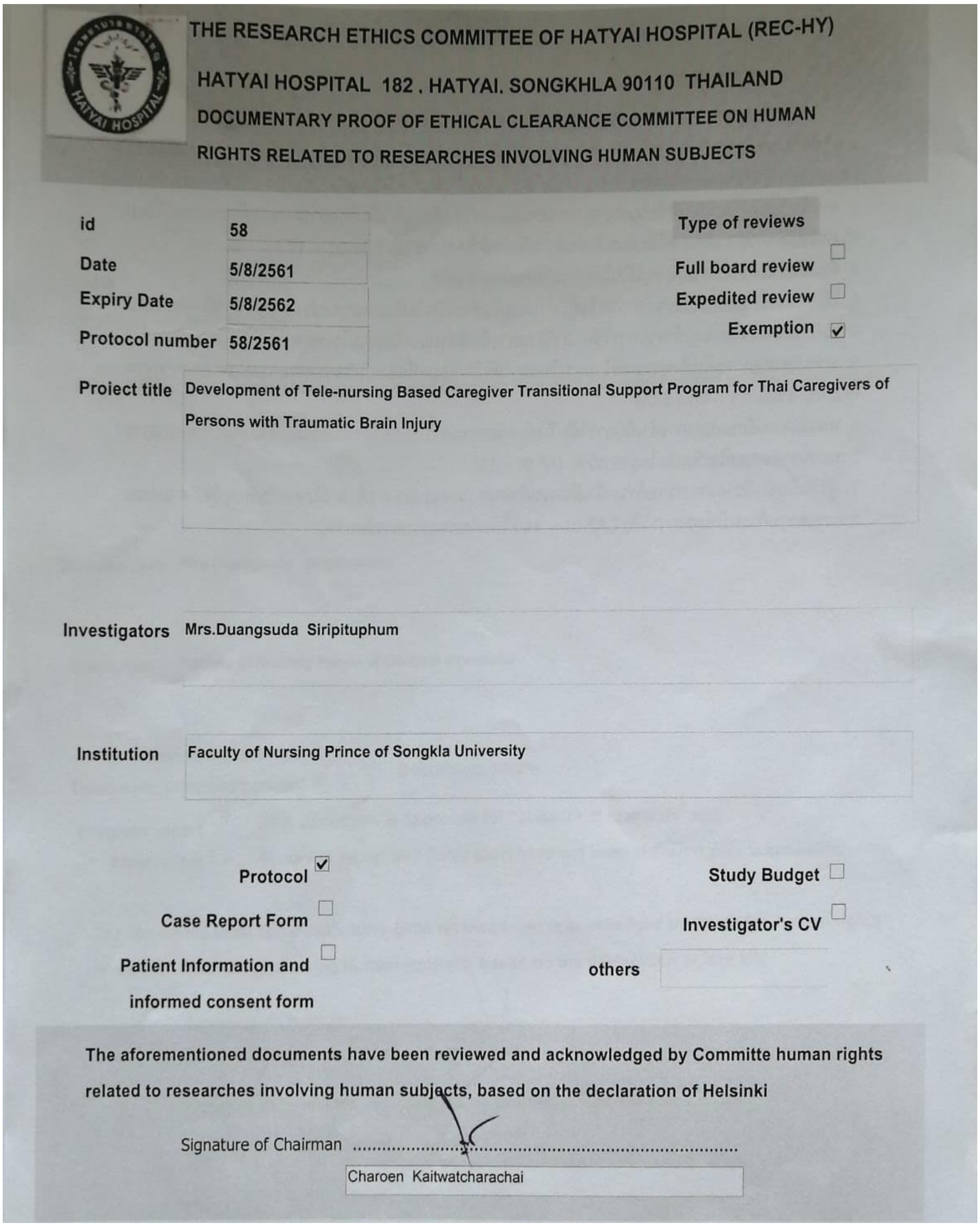
Signature of Committee ....................Kanitha Arundon....................

Kanitha Arundon

# Appendix D

## Ethical Permission

IRB from Hatyai hospital (ID 58 Protocol number 58/2561)



**THE RESEARCH ETHICS COMMITTEE OF HATYAI HOSPITAL (REC-HY)**

**HATYAI HOSPITAL 182 . HATYAI. SONGKHLA 90110 THAILAND**

**DOCUMENTARY PROOF OF ETHICAL CLEARANCE COMMITTEE ON HUMAN RIGHTS RELATED TO RESEARCHES INVOLVING HUMAN SUBJECTS**

**id** 58

**Date** 5/8/2561

**Expiry Date** 5/8/2562

**Protocol number** 58/2561

**Type of reviews**

**Full board review** ☐

**Expedited review** ☐

**Exemption** ☑

**Proiect title** Development of Tele-nursing Based Caregiver Transitional Support Program for Thai Caregivers of Persons with Traumatic Brain Injury

**Investigators** Mrs.Duangsuda Siripituphum

**Institution** Faculty of Nursing Prince of Songkla University

**Protocol** ☑

**Case Report Form** ☐

**Patient Information and informed consent form** ☐

**Study Budget** ☐

**Investigator's CV** ☐

**others**

**The aforementioned documents have been reviewed and acknowledged by Committe human rights related to researches involving human subjects, based on the declaration of Helsinki**

Signature of Chairman ..............................................................................

Charoen Kaitwatcharachai

# Appendix E

## E1 Informed Consent for Family Caregiver

Dear participant,

I am Duangsuda Siripituphum. I am a PhD. student in Faculty of Nursing, Prince of Songkla University, Thailand. Currently I am undertaking a research project entitled “Development of Telenursing Based Caregiver Transitional Support Program for Thai Caregivers of Persons with Traumatic Brain Injury”. You are an important participant who has the experience of caring the person with traumatic brain injury. The study will develop appropriate telenursing supportive program during transition period to reduce caregiver stress, caregiver burden, and patient’s readmission rate.

I would like to ask you to complete the relevant forms, participate in the interviews with the researcher, and collaborate with the nurses. The aim of the interviews is to understand (1) your experience of caring the person with TBI; (2) your needs and expectations about telenursing; (3) your opinion about this developed care model. Several interviews will be performed in hospital or at home and it will take about 30-60 minutes for each interview. I would like to get your permission to tape the interviews by audio-recorder. All information provided will be treated in a confidential manner and no name will appear in the transcripts of interviews. Moreover, I would like you to collaborate with the health care team and contribute your view. We will work together for decision-making and problem-solving in telenursing. In this program, security, confidentiality and privacy are of utmost importance not only in terms of nurses’ interactions with caregivers, but also in ensuring that the technologies themselves are secure (e.g., minimal risk of hacker ‘intrusions’). To ensure your information remains confidential and private, it is vital that your records be adequately protected (e.g., secure in electronic and/or written format).

If you have any question about this study, I will be glad to answer your questions at anytime. You have the rights to make decision whether you would like to participate in this study or not. Moreover, you may withdraw at any time without penalty.

If you have any questions regarding this study, please do not hesitate to contact me.

**Contact Address:**

Duangsuda Siripituphum, a PhD student,
15 Kanjanavanich road, Faculty of Nursing, Prince of Songkla University. Hat Yai, Songkhla, Thailand, 90112.
Mobile: 083-1848403.

Thank you for your collaboration

____________________________
(Mrs. Duangsuda Siripituphum)

**Agreement to participate in this study**

I am invited to participate in this study. I have understood the objective of this study and the procedures that I have to involve.

( ) I am willing to participate in this study.
( ) I am not willing to participate in this study.

____________________________ _______________
( ) Date
Participant’s signature

# Appendix E

## E2 Informed Consent for Health Care Team

Dear participant,

I am Duangsuda Siripituphum. I am a PhD. student in Faculty of Nursing, Prince of Songkla University, Thailand. Currently I am undertaking a research project entitled “Development of Telenursing Based Caregiver Transitional Support Program for Thai Caregivers of Persons with Traumatic Brain Injury”. You are an important participant who has the experience of caring the person with traumatic brain injury. The study will develop appropriate telenursing supportive program during transition period to reduce caregiver stress, caregiver burden, and patient’s readmission rate.

I would like to ask you to complete the relevant forms, participate in the interviews with the researcher, and collaborate with the nurses. The aim of the focus group discussion is to understand (1) your experience of caring the person with TBI; (2) your needs and expectations about telenursing; (3) your opinion about this developed care model. Several group meetings will be conducted to (1) discuss a tentative care model proposed by the researcher before application; (2) implement, evaluate and revise the tentative care model; (3) implement and evaluate the actual care model. I would like to get your permission to tape the focus group discussion and group meetings by audio-recorder. All information provided will be treated in a confidential manner and no name will appear in the transcripts of focus group discussion. Moreover, I would like you to collaborate with the family caregivers of persons with traumatic brain injury. We will work together for decision-making and problem-solving in telenursing.

If you have any question about this study, I will be glad to answer your questions at anytime. You have the rights to make decision whether you would like to participate in this study or not. Moreover, you may withdraw at any time without penalty even though you have participated in this study.

If you have any questions regarding this study, please do not hesitate to contact me.

**Contact Address:**

Duangsuda Siripituphum, a PhD student,
15 Kanjanavanich road, Faculty of Nursing, Prince of Songkla University. Hat Yai, Songkhla, Thailand, 90112.
Mobile: 083-1848403.

Thank you for your collaboration

(Mrs. Duangsuda Siripituphum)

**Agreement to participate in this study**

I am invited to participate in this study. I have understood the objective of this study and the procedures that I have to involve.

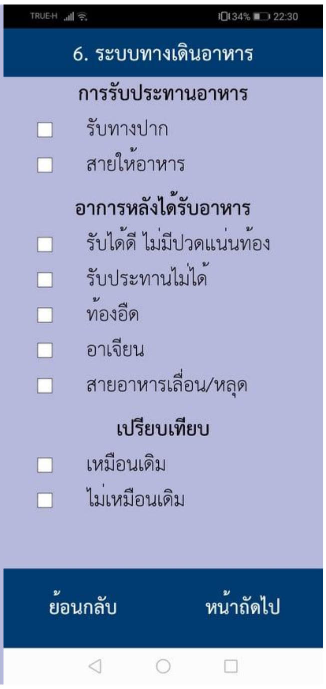
(  ) I am willing to participate in this study.
(  ) I am not willing to participate in this study.

(  )  Date

Participant’s signature

# Appendix F

## “We Care You” Manual Book



**การรับประทานอาหาร**

☐ รับทางปาก
☐ สายให้อาหาร

**อาการหลังได้รับอาหาร**

☐ รับได้ดี ไม่มีปวดแน่นท้อง
☐ รับประทานไม่ได้
☐ ท้องอืด
☐ อาเจียน
☐ สายอาหารเลื่อน/หลุด

**เปรียบเทียบ**

☐ เหมือนเดิม
☐ ไม่เหมือนเดิม

**1.ท่านมีความมั่นใจในการดูแลมากน้อยเพียงใด**

คะแนน : 0

**2.ท่านสามารถแก้ไขปัญหาที่เกิดขึ้นในการดูแลมากน้อยเพียงใด**

คะแนน : 0

**3.ท่านรู้สึกผ่อนคลายมากน้อยเพียงใด**

คะแนน : 0

**4.ท่านได้รับการช่วยเหลือจากครอบครัวมากน้อยเพียงใด**

คะแนน : 0

**1.ถ้าท่อเจาะคอหลุด หรือใส่ท่อเจาะคอชั้นในไม่ได้ ควรทำอย่างไร ?**

-รีบพามาพบแพทย์ทันที หรือติดต่อ 1669 โดยทันที

# VITAE

**Name** Mrs. Duangsuda  Siripituphum

**Student ID** 5710430007

**Educational Attainment**

| **Degree** | **Name of Institution** | **Year of Graduation** |
|---|---|---|
| Bachelor of Nursing | Prince of Songkla University | 2006 |
| Master of Nursing | Prince of Songkla University | 2010 |
| (International Program | . | |

**Scholarship Awards during Enrolment**

Scholarship PhD 50% provided by Faculty of Nursing and Prince of Songkla University.

**Work – Position and Address**

Lecturer, Faculty of Nursing Prince of Songkla University, Thailand 90110

Email: Duangsuda.wo@psu.ac.th

**List of Publication and Proceeding**

Publication

Siripituphum, D., & Songwathana, P. (2017). A program of psychological health improvement for caregivers of patients with traumatic brain injury: an integrative review. *Rajabhat Journal of Sciences, Humanities & Social Sciences, 18*(2), 230-239.

Proceeding

Siripituphum, D., Songwathana, P., & Khupantavee, N. Interventions to Improve Psychological Outcomes Among TBI Caregivers: An Integrative Review. Oral Presentation at the International Nursing Conference Optimizing Healthcare Quality: Teamwork in Education, Research, and Practice, The Empress Hotel, Chiangmai, Thailand, 22-23 June 2016.

Siripituphum, D., Songwathana, P., & Khupantavee, N. Coordinated Transitional Care with Telenursing in Improving Thai TBI Caregiving at Home. Oral Presentation at The 4th International Conference on Prevention and Management of Chronic Conditions: Innovations in Nursing Practice, Education, and Research, The Emerald Hotel, Bangkok, Thailand, 13-15 February 2019.