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The Effect of Self-Management Support Interventions for Adults with Mild Traumatic Brain Injury and Family Caregivers

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Abstract

Purpose: This study aimed to examine the effect of a self-management support program for individuals with mild traumatic brain injury (mTBI) and their family caregivers.

Design: The study design was a two-group randomized control trial.

Method: A total of 73 mTBI patients and their primary family caregivers were randomly assigned to either the intervention group (n=36) receiving the self-management support program plus usual care or the control group (n=37) receiving only usual care. The self-management program was developed based on the Individual and Family Self-management theory, and relevant clinical practice guidelines. The program consisted of self-management support assessment at the hospital, and four weekly telephone follow-ups to the patients’ home to provide mTBI-related education, symptom monitoring and management, emotional support to individuals with mTBI tailored to the patients’ needs assessed. The primary outcomes including post-concussion symptom severity, individuals’ self-management behaviors, health-related quality of life, and family caregivers’ self-management support behaviors were measured at baseline and week 6 after hospital discharge. Chi-square and t-tests were used to compare demographic data at baseline. Independent sample t-tests were used to compare outcome variables.

Findings: There were no significant difference in post-concussion symptom severity between the intervention and the control groups, but the number of post-concussion symptoms. The intervention group had significantly greater individuals’ self-management behaviors, health-related quality of life, and caregivers’ self-management support behaviors than the control group (p < .001).

Conclusions: The self-management support program had beneficial effects on reducing the number of post-concussion symptom severity and improving individuals’ self-management behaviors, and health-related quality of life and caregivers’ self-management support behaviors.

Clinical Relevance: The scope of care for individuals with mTBI should be expanded beyond acute care settings to their home to promote proper self-management behaviors and improved outcomes, especially during the transition from hospital to home care.

Keywords: Self-management support, post-concussion symptoms, quality of life, mild traumatic brain injury
CHAPTER 1

This chapter consists of the following topics: background/significance of using self-management approaches in supporting mild traumatic brain injury (mTBI) soon after the injury. Included will be the definition and classification of TBI, characteristics of TBI, the definition and development of self-management and self-management support approach, cultural contexts influencing self-management, the significance of family involvement, and recommendations of current clinical practice guidelines including key recommended discharge instructions. The theoretical framework aims, and methods of the study will be discussed. An overview of the three dissertation manuscripts the connections between the three manuscripts and their current status will be described.

Background / Significance of the problem

Mild traumatic brain injury (mTBI) accounts for 70-84% of all TBI cases (Siman-Tov, 2016; Tavender et al., 2014), and the annual incident is 300-500/100,000 people (Marshall et al., 2015). The incident of TBI, especially for mild cases, is likely to be underreported because about 25% of these patients did not seek medical care at all after injuries (Numminen, 2011). The estimated direct and indirect cost of each mild head injury was $33,284-35,951 (Hunt et al., 2017). Even though most mTBI cases achieve a full recovery in weeks or months, a significant portion of these patients are at high risk of developing post-traumatic complications such as intracranial hemorrhage leading to higher mortality and morbidity rates and healthcare burden (Panthong, 2012). Mild TBI is a frequent cause of presentation to emergency departments (EDs). Approximately 20% of all mTBI cases suffer from persistent symptoms that can lead to difficulties returning to routine work or daily life activity, decreased productivity, and absence from work, with
deteriorating economic conditions for both the individuals and the nation (Bosch et al., 2014; Marshall et al. 2015).

TBI has been a leading cause of death and disability and Thailand was ranked the 2\textsuperscript{nd} highest number of people killed by traffic accidents among all countries in the world, and 70\% of all traffic accidents were from motorcycle accidents (Phuenpathom & Srikitwilaikul, 2019). In 2012, the total number of 13,766 deaths and 825,096 injured cases due to traffic accidents had an estimated impact of 268,207 million Thai Baht accounting for 2.97\% of the Gross Domestic Product (GDP). Traumatic brain injury was reported as the most leading cause of death and disability in traffic accidents (Thailand Status of Road Safety, 2012). The evidence indicated that this public concern has caused tremendous healthcare and economic burden and should not be overlooked.

Most prior studies paid great attention to those with moderate to severe TBI in hospital settings and only limited studies focused on improving the quality of care or patient outcomes for individuals with mTBI during the transition from the emergency department to home care. Previous efforts were on initiatives such as the development of clinical pathway, evidence-based care bundle and evidence-based protocols for patients with moderate to severe TBI during acute care phase in hospital settings, leaving those with mTBI inadequately investigated and supported (Damkliang et al. 2015; Kutzleb, 2012; Mohamed et al. 2018; Thaiprom, 2018). Healthcare providers also paid more attention to patients with more severe TBI in clinical practice, which may be a rationale explaining lower satisfaction of information and services among patients with mTBI and their caregivers compared to those with more severe brain injury (Biester et al., 2016). Patients with this critical condition should not be overlooked because mTBI may lead to
severe complications without proper management throughout the continuum of the condition. Mild repetitions could result in severe long-term deficits of cognitive, psychological, and behavioral outcomes and more severe brain injuries, which could be fatal when experiencing the next concussions (Selassie et al., 2013).

The literature indicated that the needs of patients with mTBI and their family are inadequately addressed. For example, studies reported that approximately 40% of the patients were discharged without specific recommendations for their condition, causing dissatisfaction with healthcare services received. Further, current discharge instructions failed to address essential elements of care specific to mTBI, such as possible symptoms and how to manage the symptoms and detect warning signs indicating needs for emergency care and further investigations (Biester et al., 2016). Also, the current discharge criteria from the hospital mainly focus on patients’ condition and specific discharge procedures rather than their readiness and skills to manage their health at home (Ryan & Sawin, 2009). Consistently, a study found that significant post-discharge challenges in patients with TBI were inadequate self-management instructions, feeling unprepared before discharge, pressure on the family to support patients without enough preparation, and poor communication with healthcare providers (Pugh et al., 2019).

The evidence indicated that mTBI survivors have been suffering from many post-injury effects, including physical, cognitive, and psychological symptoms. Physical symptoms include headache, dizziness, sleep disturbance, fatigue, and visual difficulties. Emotional symptoms reported were depression, mood disturbances, irritability, and post-traumatic stress. The patients are also at risk of cognitive symptoms such as amnesia and attention deficit and behavioral changes. These symptoms vary and may last from days to
months. These long-term deficits are mismatched with expectations of their family members, and lack of knowledge and understanding of these possible symptoms may even result in spousal and parental relationship problems, such as family distress, diminished family function, and even separation and divorce (Hyatt, 2014). The literature review on the health consequences of TBI is shown in chapter 2.

A great effort of previous research and clinical practice relevant to brain injury was on improving the care process in the acute phase of brain injury with little emphasis on the care during sub-acute or chronic periods. The results from Galveston Brain Injury Conference recommended that the ultimate goals of caring for patients with brain injury are to improve quality of life and achieve community reintegration (Malec et al., 2013). These goals necessitate healthcare system redesign that moves beyond acute settings to ensure appropriate care throughout the continuum of this condition. Patients with mTBI are usually admitted and cared for by healthcare providers for 24 hours or less at an emergency department. The identified needs are unlikely to be met in a limited time, and a fast-paced working environment in acute care settings and continuing care for the patients is usually interrupted after hospital discharge. This condition is an invisible wound, and its consequences can be complicated and persistent, requiring adequate preparation that strengthens knowledge and skills to self-manage their health challenges appropriately to bridge the gap of continuing care during the transition from hospital to home for the target population.

This chapter explains the current situation of the problems related to mTBI and provides evidence that the burden of the condition is not mild. The impacts of mTBI are complicated, and self-management skills require proper training and preparation. Early
interventions to reduce the consequences of mTBI and promote brain recovery would be beneficial to reduce the burden of this health concern. Many patients with mTBI are not aware of their deteriorating symptoms and behavioral changes at the early stage of brain injury due to compromised cognitive function. The need for family involvement in supporting the patients in understanding and complying with critical discharge instructions for self-management at home to prevent serious complications and promote recovery (Pugh et al., 2019). Unfortunately, none of the current interventions reviewed targeted family involvement in supporting self-management in adults with mTBI. Strong evidence of effective interventions on some mTBI-specific outcomes, such as post-concussion symptoms reduction, self-management behaviors, and quality of life after brain injury, is limited (see the manuscript of the review in chapter 3). Therefore, research with a robust study design examining the efficacy of self-management support programs for patients with mTBI and their family caregivers on such outcomes is needed.

**Definition and classification of TBI**

Traumatic brain injury (TBI) is defined as “alteration of brain function or other evidence of brain pathophysiology caused by an external force” (Menon et al., 2010, p. 1637). TBI is classified into mild, moderate, and severe cases (Mohamed et al., 2018). Mild TBI is considered when the Glasgow Coma Score (GCS) is 13-15, loss of conscious (LOC) ≤ 30 minutes and having post-traumatic amnesia (PTA) less than 24 hours. Moderate TBI means the brain trauma cases with GCS 9-12, LOC 30 minutes - 24 hours, and/or PTA 1-7 days. Severe TBI refers to the brain injury with GCS 3-8, LOC longer than one day, or PTA longer than seven days (Department of Veterans Affairs & Department of Defense, 2016).
Characteristics of TBI

Traffic accidents and falls are the top-two primary causes of brain injuries, and the etiology of TBI varied depending on age groups. Adolescents and younger adults aged 15-40 were most affected by road accidents (Leibson et al., 2011; Siman-Tov et al., 2016). Children aged 0-3 years were more likely to suffer from TBI caused by accidents at home, and children aged 4-11 years experienced more head traumas due to sports and playing outdoors (Danielle van Pelt et al., 2011). Individuals aged 12-18 years had the highest incidence of sport related TBI (Haring et al., 2015; Selassie et al., 2013).

Although some developed countries have been successfully implementing strategies to reduce road-fatality brain injuries, they have been experiencing an increasing trend of TBI from other circumstances such as falls and sports/recreation activities (Numminen, 2011; Perez et al., 2012;). Traffic accidents remain a critical cause of TBI around the world, especially in developing countries including Thailand with the intensive use of motorcycles (Fakharian et al., 2016; Guerrier et al., 2015; Nguyen et al., 2016; Thailand Status of Road Safety, 2012). One study found that almost half of motor-vehicle-related TBI cases were screened positive for alcohol above 0.5 g/L (Guerrier et al., 2015).

The majority of all TBI are mild (70-84%), and the rest 20-30% are moderate or severe TBI (Benner, 2011; Siman-Tov, 2016). There are more male than female victims in all ages ranging from 59.3% to 79.5% (Numminen, 2011). However, some studies found no significant difference in TBI incidence rates between males and females among older adults aged 65 and older (Leibson et al., 2011; Siman-Tov, 2016). The higher occurrence among males may result from more intensive exposure to more risky
behaviors for TBI, such as riding a motorbike and playing contact sports (Haring et al., 2015).

Although TBI occurred more often in working ages (15-64 years), elderlies (aged 65 and older) were more prone to severe injuries, higher mortality rates (Moorin et al., 2014; Selassie et al., 2013) and total care cost (Scholten et al., 2015). Older people have more possibility to have comorbidities, which are associated with increased severity of brain traumas, leading to increased mortality risk. Repetitive TBI was relatively frequent (more than 6% in sport related TBI). Even mild repetitions could result in severe long-term deficits of cognitive, psychological, and behavioral outcomes and more severe brain traumas, which could be fatal when experiencing subsequent concussions (Selassie et al., 2013). The epidemiological data signify the necessity of developing interventions to reduce the incidence and improve the quality of care throughout the continuum of brain injury from pre-hospital, emergency care, intensive care, and long-term rehabilitation to manage the public health issue successfully. Effective initiatives should be designed based on epidemiological contexts of each setting and tailored to address a specific age group for optimal outcomes. Interventions and further studies addressing factors associated with traffic accidents, fall hazards at home, and sports-related injuries are vital to reducing events causing TBI and preventing reinjury.

Self-Management

The definition and historical development of self-management

In the 1960s, the term “self-management” was first introduced to refer to a person’s active participation in the treatment of disease (Lorig & Holman, 2003). The concept has become more recognized by healthcare professionals because it has been
integrated into the health system/provider component, which is a core element of the well-known Chronic Care Model (Malec et al., 2013). Since then, it has been commonly used in the chronic care field. Self-management is defined as “The ability of the individual, in conjunction with family, community and health professionals, to manage symptoms, treatment, lifestyle changes and psychosocial, cultural and spiritual consequences of health conditions” (Richard and Shea, 2011 p.261). The definition covers an individual’s capability, family support, and the role of healthcare professionals to facilitate optimum self-management for their chronic health issues. Based on the general definition of self-management proposed by Richard and Shea (2011) and relevant literature, self-management for individuals with mTBI refers to “the individual’s capability, with support from family, community and healthcare providers, to manage post-concussion symptoms and consequences of brain injury and prevent subsequent TBI.” Post-concussion symptoms cover physical, psychological, and cognitive difficulties following mTBI.

**Self-management support approach**

Self-management support is an essential strategy that shifts the roles of patients and their family caregivers from a passive healthcare receiver to a more active and corroborative manner (Ryan & Sawin, 2009). Using this approach, healthcare providers perform their role as a facilitator to support patients and family caregiver in identifying their issues or challenges related to their health conditions, their strengths/barriers to proper care, available resources in the community, and strategies to solve their problems at home. This approach has been accepted as an effective pathway to support persons
with chronic conditions during the transition from hospital to community settings and support persons and their families to regain power in achieving their health goals.

Self-management support has been widely recognized as a cost-effective approach for patients and their families to perform their duties in managing their symptoms and solving health-related problems outside hospital settings that can maintain the quality of life for people with chronic conditions (Grady & Gough, 2014). The care emphasis for this approach is on empowering patients and their families to deal with condition-specific symptoms and consequences of their health concerns for each person at home (Ryan & Sawin, 2009). The patient/family-centered approach has contributed to promising outcomes, such as decreased disease-specific symptoms, healthcare costs, and healthcare service utilization, and increased quality of life (Grady & Gough, 2014; Ryan & Sawin, 2009). The approach is suitable for adults with mTBI after receiving emergency treatment because they do not require intensive healthcare, but proper preparation to perform self-management activities at home (Makela, 2018; Malec, 2013). However, this approach remains insufficiently used in the mTBI population due to the traditional view of the condition as an acute condition.

**Cultural contexts influencing self-management**

Cultures shape people's behaviors, perceptions, and interpretations of self-management (Millis et al., 2017; Udlis, 2011). For example, the Spanish-origin population trend to prefer a more extended period of care by physicians and may perceive a short visit and rapid transition to self-management preparation as inferior or unsatisfying care (Lorig & Holman, 2003). Self-management in Western countries is more independent and individual-focused, whereas family involvement and social
support play a primary role in enhancing persons to self-manage their health concerns in Asian cultures (Chayaput et al., 2014; Ishikawa et al., 2010). In the context of Thailand, characteristics of Thais and Buddhism have greatly influenced the perception and self-management of a health condition (Somattanakoon et al., 2009).

Approximately 94% of all Thai population is Buddhist, and one of the critical religious teachings is everything occurs for a reason and staying with the present to focus on solutions and not a problem (Lundberg, 2000). This piece of belief can be helpful for individuals to rapidly accept critical life events, including sudden injury and readiness to manage their health issues. On the other hand, the belief of self-dependence rather than relying on others may lead some individuals to solve a problem by themselves rather than seeking proper care. Thai people have been nurtured to be respectful to seniors and authorities of certain professional positions including healthcare professionals, leading to the typical nature of Thais: silence and hesitance to have inquiries about their health or ask for help (Burnard & Naiyapatana, 2004, Jongudomkarn et al., 2012). These factors, if not addressed, could cause delays in medical treatment when managing health concerns at home.

Regarding the caregiving dimension, people in many Asian countries, including Thailand, have a strong belief in filial practice toward parents both in healthy and sick conditions. Filial behaviors have been highly valued in Thai culture. Ignoring parents is unacceptable behavior in Thai norms and maybe socially sanctioned. Thai family caregivers perceived the role of taking care of their family member with a chronic condition as a “willing burden and unavoidable duty” (Limpanichkul & Mcgilvy, 2004). Family caregivers reported that Buddhist beliefs and spiritual practice facilitated their
coping with critical challenges, including sickness of their loved ones (Knodel et al., 2018).

Piyakong (2014) investigated challenges experienced by Thai family members of individuals with TBI and reported that Buddhism was integrated into how they provided care to the patients. The belief served as spiritual support for caregivers to overcome the critical life event. Religious beliefs also encourage people to look at the positive sides of undesirable life events and belief in the law of karma: doing good, the good returns (Limpanichkul & Mcgilvy, 2004). Hence, these beliefs can be valuable for healthcare providers to help caregivers cope with stress and enhance favorable caregiving performance. Overall, cultural contexts could either positively or negatively influence a person’s healthcare. Therefore, contextual assessment and addressing these issues is imperative in providing culturally sensitive self-management support for clients.

The significance of family involvement

Family and caregivers play vital roles in observing the patient’s symptoms and deteriorating signs for urgent care. Family caregivers also suffer from this unpredicted illness of their family members and need support for appropriate coping and enhanced ability to care for the patients (Chayaput et al., 2014). Several researchers underlined the importance of taking the family’s needs and concerns into consideration to promote self-care for individuals (Falk, 2012; Hyatt, 2014; Hyatt et al. 2015). A qualitative study to exploring experiences of family members of persons with TBI found that they had a desire to engage in the care of the patients actively, and they needed essential knowledge and skills to perform their significant roles. Family caregivers participated in many crucial functions of patient care, such as evaluating the patient symptoms, behavior
change, level of consciousness, and providing routine care (Ishikawa et al., 2010). Family’s understanding of changes and their involvement in patient care are crucial, considering possible remaining cognitive, mental, and behavioral issues after mTBI.

Some evidence has revealed an association between family factors and patient outcomes. Family functioning has been associated with level of independence and disability scores of TBI survivors. Physically and psychologically healthy caregivers were related to significantly higher recovery from disability than those with unhealthy caregivers (Chayaput et al., 2014). Hahn-Goldberg et al., (2018) reported that family involvement is the key to a successful transition from hospital to home care and adherence to discharge instructions for patients with complicated health issues. Thus, interventions promoting the knowledge and skills necessary to resume caregiving role effectively is needed for greater self-management support behaviors, resulted in improved patients’ outcomes.

**Recommendations of current clinical practice guidelines**

Current clinical practice guideline recommendations include a comprehensive assessment of post-concussion symptoms, and early education and interventions. The critical content to include in verbal and written discharge advice are warning signs and symptoms for emergency care, common symptoms they may experience and management strategies, the reassurance of expected recovery for most mTBI cases, and a gradual return to normal activities as tolerated by the individual in a stepwise progression. Patients should take a brief period of rest for 24-48 hours in the acute symptomatic period and then progressively return to regular activities as tolerated. Individuals after experiencing concussion should be screened for relevant factors causing
persistent symptoms and delaying recovery to consider proper management strategies.

For persistent psychological and cognitive difficulties interfering with daily functions for
longer than four weeks, referral to a neuropsychological specialist should be arranged
(Department of Veterans Affairs & Department of Defense, 2015; Ontario Neurotrauma
Foundation, 2018).

Patients should be informed that symptom exacerbations are common with
increased activities and, if the issues occur, slower progression is necessary with careful
symptom monitoring. Clinical guidelines recommend continuous follow-up by telephone
or in-person addressing symptom management and a gradual return to activities after
discharge for at least 4 weeks. The guidelines also provide a standardized assessment
tool, educational materials that are consistent with the recommendations, and algorithms
to manage some common symptoms. Other recommendations are relevant to the
management for those readmitted to the emergency department, strategies to prevent
reinjury, use of healthy lifestyles to booster recovery and family participation
(Department of Veterans Affairs & Department of Defense, 2015; Ontario Neurotrauma
Foundation, 2018).

Key recommended discharge instructions

Before hospital discharge, patients with mTBI and their families should receive
oral instructions with written information on warning signs indicating needs for
emergency care including worsening headache, seizures, repeated vomiting, slurred
speech, disorientation, increased agitation or confusion, weakness/paresthesia in arms or
legs, and altered behaviors and level of consciousness. Also, the use of computers,
gaming devices, and phones for texting may worsen the symptoms, and these activities
should be limited in the early period of post-injury. Medication related recommendations are also essential, especially related to those causing bleeding disorders such as Aspirin and Coumadin. These medications should be avoided immediately after injury until intracranial bleeding can be ruled out by the physician. The patients should take only prescribed medications and avoid over-the-counter medications or herbs, which could induce intracranial hemorrhage. Return to work/usual activity needs to be in a stepwise fashion. That is, patients should gradually increase their activity to the next step with symptoms-free for 24 hours under careful monitoring. If the symptoms reoccur, stepping back to the previous level is required. Discharge and follow-up instructions should include repetitive injury prevention, which can delay the recovery process and lead to life-threatening complications, such as avoiding contact sports after an injury, fall prevention, and safe driving practice (Hyatt et al., 2015; Marshall, 2015).

**Individual and Family Self-Management Theory**

Individual and Family Self-Management Theory (IFSMT) was used as a theoretical framework to design a self-management support program. The section includes a description of the theory, the theoretical model, the concepts definitions, and the propositions. Cultural contexts influencing self-management were also added to support the need for adapting the theory before use to address the Thai and the mTBI contexts. Strengths and limitations of the theory as a theoretical basis of research in this field and studies directed by the theory in TBI and other populations with chronic health issues were discussed respectively.
Description of the theory

IFSMT is a new middle-range theory developed by Ryan and Sawin in 2009 using both deductive and inductive approaches and was revised by the Self-Management Science Center Working Group in 2014. The theory was derived from various behavioral change theories and Family Systems theory. The theorists recognized the importance of individuals and their families to self-management, especially when healthcare delivery and health conditions are shifted from in-hospital to non-hospital settings and from acute to chronic. The notion of this theory is that the primary responsibility is on an individual and the family under the support of healthcare providers to achieve personal health goals. Self-management is a complex, multidimensional, and dynamic phenomenon affecting persons and their families in all ages and requires time, repetition, and reflection (Ryan & Sawin, 2009).

This theory consists of three major concepts: self-management context, process, and outcomes with the sub-concepts of each dimension. Contextual factors include condition-specific, physical, and environmental factors and family characteristics (Bonis & Sawin, 2016). The self-management process consists of the development of knowledge and beliefs, self-regulation skills and abilities, and social facilitation. Knowledge and beliefs can be addressed using strategies such as health-related information, self-efficacy enhancement, outcome expectancy, and goal congruency. Self-regulation skills and abilities can be strengthened through developing skills required for a health condition such as goal setting, self-monitoring, reflective thinking, decision making, planning and action, self-evaluation, and emotional control. Social facilitation includes social influence, social support (emotional, instrumental, and informational), and negotiated
collaboration. The final key concept is self-management outcomes, which are divided into proximal (self-management behaviors and cost of health services) and distal outcomes (health status, quality of life, and total cost of health), as shown in the theoretical model below (Figure 1).

Concepts definitions

1. Context (risk and protective factors) is defined as “factors that challenge or protect individuals and families engagement in self-management. Condition-specific factors refer to “physiological, structural, or functional characteristics of the condition, its treatment, or prevention of the condition that impacts the behaviors needed to manage the condition.” These factors included the complexity of condition or treatment trajectory, physiological stability, and physiological transitions. Physical and Social Environments refer to “factors such as access to health care, transition in health care provider or setting, transportation, neighborhoods, schools, work, culture, and social capital that enhance or present barriers to individual and family self-management.” Individual & family factors are “characteristics of the individual and family that enhance or diminish self-management; for example, individual cognitive status, perspectives, information processing, developmental stages, individual and family capabilities to self-manage” (Ryan & Sawin, 2009, p. 225).
2. Processes of self-management are critical pathways that can be used to enhance self-management consisting of condition-specific knowledge and beliefs, acquisition and use of self-regulation skills/abilities, and social facilitation.

2.1 Knowledge & Beliefs depend on information relevant to particular health, self-efficacy, outcome expectancy, and goal congruence (Ryan & Sawin, 2009).

2.2 Self-regulation is “an iterative process people engage in to achieve a change in health behaviors. The skills required for self-regulation include goal setting, self-monitoring, and reflective thinking, decision-making, planning for, and participating in specific practices, self-evaluation, and emotional control” (Ryan & Sawin, 2009).
2.3 Social facilitation is social factors facilitating individuals’ ability to change or perform a desired behavior, including social influence, social support (informational, instrumental, and emotional), and negotiated collaboration.

3. Outcomes refer to the expected results of engagement in self-management. The outcomes are classified into two categories: proximal (self-management behaviors such as engagement in activities/treatment regimens, symptom management, use of recommended medications and cost of healthcare services), and distal outcomes (health status, quality of life and total cost covering both direct and indirect expenses (Ryan & Sawin, 2009, p. 225).

**The relationships between the concepts**

The context component (risks and protective factors) influences the capability and desire of individuals and families to engage in the self-management process and have a direct impact on both proximal and distal outcomes. The theoretical model depicts the connection between constructs in the context and process dimensions. Self-management processes also affect the outcome component. The outcomes are explained by both self-management context and the self-management process. The model also indicates the link between the short-term and long-term outcomes, that is, distal outcomes are partly determined by the extent to which a person achieves proximal outcomes. For example, if individuals and their families successfully participate in the desired behaviors, distal outcomes such as improved quality of life, health status, and reduced cost of health can be expected. The model reveals that interventions for individuals and families to enhance self-management should be based on the context and process dimensions. The context component can be addressed by reducing potential barriers and strengthening the
facilitators to self-management. The self-management process component guides some useful strategies to achieve the desired goals.

**Strengths and limitations of the theory**

The theory guides the importance of both individuals and their families to engage in their care actively. The theoretical approach combines both individual and family perspectives in the management of health conditions. The theory’s perspective is “individuals and families who can manage their health and healthcare needs can achieve improved health outcomes, enhanced quality of life and a reduction in the need for costly healthcare services” (Bonis & Sawin, 2016, p. 568). The assumptions are suitable for adults with mTBI in Thailand as family members are one of the most important social support resources in performing self-management activities at home.

The theory was also specifically designed to guide nursing interventions to promote self-management. The relationships between its concepts have been tested and found significant associations between the proposed concepts, proving evidence of its propositions (Verchota & Sawin, 2016; Casida et al., 2018). The theory is considered sound for its significance, testability, and generalizability based on Fawcett’s theory evaluation criteria (2005). Limitations of using the theory lie with the lack of specification for the mTBI population and the fact that the middle-range theory is not designed to address any specific environmental and cultural background. The theory also provides a wide range of skills and outcomes of self-management, and some are more relevant to other chronic conditions rather than mTBI, necessitating modification before use.
**Research directed by the theory in patients with chronic conditions**

The newly developed IFSMT has been used to guide research designs, healthcare interventions and development of the measurements of the proposed concepts and tested across many chronic diseases, age groups and cultural contexts such as diabetes (Verchota & Sawin, 2016), cancer (Baydoun et al., 2018), and heart disease (Casida et al., 2018). The theory is commonly used as a theoretical framework for clinical research to prepare individuals and their family caregivers to manage their chronic conditions at home after hospitalizations. A systematic review showed that the theory has been a theoretical basis in 16 experimental studies that involved diabetes, hypertension, asthma, stroke, and others. Most of these studies found that the interventions guided by the theory were effective as measured by self-management behaviors, objective biomarkers, and self-reported outcomes (Yi et al., 2018).

**Research directed by IFSMT in the TBI population**

In a review of current self-management support interventions, none of the studies reviewed used any theoretical framework to guide their interventions (see chapter 3). Many theorists recommended using theory-based interventions as a critical tool to achieve desired goals in nursing practice. However, the application of nursing theory in developing nursing interventions to improve patients and their family’s self-management in the mTBI population remains lacking. IFSMT is a newly developed middle-range theory that has the potential to apply in self-management research for chronic conditions, including persons with mTBI. The theory provides relatively clear directions in designing self-management support intervention by working on three main pathways: knowledge and ability enhancement, the development of essential skills, and social facilitation. The
theory was selected to use as a theoretical framework for this study because it focuses not only on an individual but also family and environmental contexts influencing self-management process and outcomes. The theory also guides components of essential interventions and outcomes to be measured as the results of receiving self-management support. The theory is not too complicated to apply into actions for nurses as it consists of steps similar to the nursing process to care for patients: assessment, diagnosis of health issues, providing interventions and evaluation as shown in the theoretical model.

Research Aim

The purpose of the study was to examine the effects of a self-management support program tailored to the contexts of Thailand for individuals with mTBI plus usual care and their family on the patient outcomes (self-management behaviors after mTBI, post-concussion symptom, health-related quality of life, and the caregivers’ outcome: (caregivers’ self-management support behaviors) as compared to those in the control group receiving only usual care.

Research questions

1) What is the effect of the self-management support program plus usual care on self-management behaviors after mTBI compared to the control group receiving only usual care?

2) What is the effect of the self-management support program on post-concussion symptoms plus usual care compared to the control group receiving only usual care?

3) What is the effect of the nursing interventions plus usual care on health-related quality of life after mTBI compared to the control group receiving only usual care?
4) What is the effect of the self-management support program plus usual care on caregivers’ self-management support behaviors compared to the control group receiving only usual care?

**Research hypotheses**

1) Individuals with mTBI in the intervention group receiving the self-management support program plus usual care would report better self-management behaviors after mTBI than those in the control group receiving only usual care.

2) Individuals with mTBI in the intervention group receiving the self-management support program plus usual care would report less post-concussion than those in the control group receiving only usual care.

3) Individuals with mTBI in the intervention group receiving the self-management support program plus usual care would report greater health-related quality of life after mTBI than those in the control group receiving only usual care.

4) Family caregivers of individuals with mTBI in the intervention group receiving caregiver support interventions plus usual care would have better caregivers’ self-management support behaviors than those in the control group receiving only usual care.

**Variables/operational definitions/measures**

The independent variable of this study was the self-management support program for adults with mTBI and their families. The dependent variables were post-concussion symptoms, self-management behaviors after mTBI, health-related quality of life, and caregivers’ self-management support behaviors. These independent variables were operationalized and measured as follows:
Post-concussive symptoms are common symptoms that occur after brain injury. The symptoms are divided into three parts: physical (headache, blurred vision, nausea, dizziness, fatigue, sleep disturbance, noise hypersensitivity), cognitive (amnesia, decreased concentration, and delayed thinking) and emotional (irritability, restlessness, frustration, and depression symptoms). Post-concussion symptoms were assessed by the Rivermead Post-Concussion Questionnaire, which includes 16 common symptoms after brain injury. The research participants are asked to rate the 16 symptoms over the past 24 hours using a 4-point Likert scale ranging from 0 (absent) to 4 (severe), and the score of each item is summed to obtain the total score. A sample item is “over the past 24 hours, what would you rate the severity of your headache on the scale of 0 to 4? The possible points range from 0 to 64. A higher score indicates more post-concussion symptom severity. The instrument has been used in many studies with good to excellent internal consistency (Cronbach α = 0.94). The inter-rater reliability was 0.91, the test-retest reliability was 0.87, and the factor loadings were 0.44-0.85 (Hermann et al., 2009; Potter et al., 2006).

Self-management behaviors after mTBI are an individual’s capability, with support from the family, community, and healthcare providers, to manage post-concussion symptoms and consequences of brain injury and prevent subsequent TBI. The variable was measured using the Self-management Behaviors after mTBI Scale developed by the researcher from a list of key patient discharge instructions recommended by the Center for Disease Control and Prevention (CDC, 2020). Some items were adapted from the Active Coping Scale and Self-management Performance Scale (Kendall & Terry, 2008; Muenchberger et al., 2011). The newly developed scale
assesses persons with mTBI regarding their performance in 13 self-management activities, including symptom management, compliance with discharge instruction, brain recovery strategies, and re-injury prevention. Participants rate each activity using a 5-point Likert scale ranging from 1 (Never) to 5 (Regularly). A sample item is “in the past seven days, how often you alleviate symptoms after brain injury and avoid things that make the symptoms get worse? The scale was tested for its content validity and construct validity before use.

Health-related quality of life (HRQoL) refers to specific effects of health conditions on a person’s well-being and functioning (Steinbuchel et al., 2017). HRQoL is the concept reflecting individuals’ perception of how illness and the treatment affect the physical, psychological, and social domains of life. Health-related quality of life in this study was measured using Quality of Life after Brain Injury Scale-Overall Scale (QOLIBRI-OS). The original QOLIBRI consists of 37 items with a 5-point Likert format, and it has been translated into many languages with good internal consistency (Cronbach $\alpha = 0.84$), and the factor loadings are .30-.90 (Steinbuchel et al., 2017). The QOLIBRI-OS is a short-form of the original scale consisting of six items using the 5-point Likert, ranging from 1 (not at all) to 5 (very). The measure is used to assess overall satisfaction with physical, emotional, and cognitive conditions, function personal/social life, and current situation/prospects for persons with TBI. A sample item is “overall, how satisfied are you with your physical condition?”. The scale means are converted to 0-100 percentage using the formula (Mean-1) x 25, where 0 indicates the lowest, and 100 represents the highest health-related quality of life. The QOLIBRI-OS revealed good construct validity in the TBI population. The reliability of the QOLIBRI-OS was good
(Cronbach’s α = .86, test-retest reliability = .81). The overall version was correlated highly with the total score of the full scale (r = .87), indicating its applicability as a brief version of HRQoL for the target group (Steinbuchel et al., 2017).

Caregivers’ self-management support behaviors refer to the performance of family caregivers in caring or supporting self-management for individuals with mTBI after being discharged from the emergency department. This outcome in the study was measured using Caregiving Performance for Individuals with mTBI Scale. The scale was adapted from Caregivers’ Performance Questionnaire, which was used in caregivers of persons with mTBI in Indonesia with acceptable reliability (Cronbach’s α = .70) (Firmawati et al., 2015). Items in this scale were in parallel with the Self-management Behavior after mTBI Scale. The wordings were adjusted to reflect caregivers’ role in caring or supporting the patients to perform self-management activities. The newly developed scale includes 13 items and participants rate each item using a 5-point Likert scale, ranging from 1 (never) to 5 (regularly) in performing self-management support activities. A sample item is “in the past seven days, how often do you help the patient to alleviate symptoms after brain injury and avoid things that make the symptoms get worse? The scale was tested for its content validity and construct validity before use.

Methods

The study design was a two-group randomized control trial. Eligible participants with mTBI and their primary family caregivers (n = 80 dyads) were randomly assigned to either the intervention group (n=40) receiving the self-management support program plus usual care or the control group (n=40) receiving only usual care. The self-management program was developed based on the Individual and Family Self-management theory,
previous studies, relevant current clinical practice guidelines. The program consisted of self-management support assessment at the hospital, and four weekly telephone follow-ups to the patients’ home to provide mTBI-related education, symptom monitoring and management, emotional support to individuals with mTBI tailored to the patients’ needs assessed. Outcome data were collected by week 1 as baseline data and 2 weeks after program completion (week six after discharge for the control group). The data from 73 dyads who completed the program were analyzed using descriptive statistics, and independent sample t-tests. The details of the methods and the interventions of the dissertation research were described in chapter 4.

**Overview of the Three Study Manuscripts,**

This alternative (manuscript-style) dissertation includes three manuscripts. The first manuscript’s title is “Health-related Consequences of Traumatic Brain Injury: A Scoping Review” (Chapter 2). The purpose of this review was to understand the impact individuals’ physical, cognitive, psychosocial, and behavioral health following mTBI. The insights of its consequences and challenges after mTBI is fundamental to guide clinical practice, nursing interventions, and further research in adults with mTBI. The results of this review contributed to improved understanding that the negative impacts of various aspects of patient’s health are not mild as its name. TBI resulted in multifaceted health consequences: physical, psychological, cognitive and health behavioral, necessitating assessment and appropriate approaches. The findings in this review revealed that post-concussion symptoms and challenges can be persistent in some cases after injury.
The results of this review ignited the researcher’s interest to identify supportive interventions to assist these individuals to deal with post-concussion consequences identified. This review also underlined that symptom management, social support, problem-solving skills, healthy lifestyle interventions, and repetitive injury prevention for patients after TBI should be top priorities to address their unmet needs. The traditional clinical attention on urgent care in healthcare settings may be inadequate to cover their needs, especially after discharge from the hospital, necessitating more proactive approach and expanding scope of nursing delivery to cover subacute phase after injury at their home. Rapid shifting patients and family’s roles from care receivers to self-care and caregivers requires support for smooth transition. Self-management support has been reported as an effective way to reduce symptoms and manage health challenges in patients with many chronic conditions in the literature. The researcher was interested in developing self-management support interventions that are designed to address unique needs of adults with mild traumatic brain injury who are more likely to resume self-management roles compared to those with moderate to severe TBI.

Before developing such interventions, it is essential to review previous relevant studies to learn what was done effectively for this target group and vice versa. The second manuscript was a synthesis of the state of the science of current studies on self-management support for individuals with mild traumatic brain injury covering definition of self-management support, characteristics and key components of self-management support interventions, and outcomes. The results revealed that the studies in this field were limited. Experimental or quasi-experimental studies investigating the effectiveness of self-management support interventions in this target group reported some benefits but
were largely ineffective. There was a lack of theory-driven family-involved self-management support interventions. None of these studies focused on specific strategies to prevent repetitive mTBIs. Thus, the researcher developed a self-management support program for adults with mTBI and their family caregivers which were theory-driven using the Individual and Family Self-Management Theory (IFSMT) and more family-involved. Some components of the interventions were based on the gaps of current studies identified, clinical practice guidelines and cultural contexts of Thailand.

The third manuscript is a data-based manuscript reporting on the effect of developed self-management support program on patient outcomes (post-concussion symptoms, self-management behaviors after mTBI, health-related quality of life, and a caregivers’ outcome: (caregivers’ self-management support behaviors) as compared to those in the control group receiving usual care (Chapter 4). The study used a two-group randomized controlled trial design to answer the research questions. The third manuscript which is a result report of the dissertation research is currently in preparation (Chapter 4).
Chapter 2

Health-related Consequences of Traumatic Brain Injury: A Scoping Review

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Abstract

Traumatic brain injury (TBI) is a global public health issue, causing tremendous healthcare and economic burden. The purpose of this review is to examine the consequences of TBI on individuals’ health across all levels of severity to guide nursing practice and future research. This review looks at the entire continuum of TBI. A total of 24 studies that met the inclusion criteria were included in this review. The results show that TBI had adverse effects on individuals’ physical, cognitive, psychosocial, and behavioral health. This review also found that repetitive TBI, which complicates the consequences and delays the brain healing process, is not adequately addressed.

Supportive interventions for persons with TBI to deal with these challenges after TBI is essential. Symptom management, social support, problem-solving skills, healthy lifestyle interventions, and repetitive injury prevention for TBI patients should be top priorities for nursing research, education, and clinical practice.

Keywords: Traumatic brain injury/ Health-related consequences/ Adults
Introduction

Traumatic brain injury (TBI) is defined as “alteration of brain function or other evidence of brain pathophysiology caused by an external force”\(^1\). TBI is classified into mild, moderate, and severe cases\(^2\). TBI is a global public health issue, causing great healthcare and economic burden. Each year, around 1.7 million U.S. citizens experience TBI. Approximately 25% require hospitalizations, and about 52,000 victims die, accounting for almost one-third of injury-related deaths\(^3\). The critical injury affected people in all age groups especially adolescent and younger adults who are significant for workforces and economic growth. The estimated total direct and indirect costs of TBI including loss of productivity are over $76 billion a year\(^3\). A Romanian study found a sizable portion of severely injured individuals die at the injury sites, and about 25% of severe TBI decease within day seven of injury. A significant portion of TBI patients (43%) have a long-term disability and chronic symptoms\(^4\). Thailand is ranked the second country for the most reported car accidents in the world, traumatic brain injury has been reported as the most leading cause of death and disability in traffic accidents\(^5\). Overall, the negative on economic and public health impact in the literature is clear. However, its direct health-related impact on individuals after TBI requires further investigation. The purpose of this review is to analyze current studies on various aspects of health-related consequences of TBI among adults to guide nursing practice, appropriate interventions, and further research in this field.
Methodology

Search strategy and outcomes

Four key databases: PubMed, CINAHL, MEDLINE, and Cochrane Library were used to identify peer-reviewed primary research. The search terms: “traumatic brain injury” OR “TBI” OR “head injury” AND “effect” OR “impact” OR “consequence” were utilized to identify primary research to answer the research question systematically. The search was intended to target only adult individuals with TBI. Therefore, NOT “Child*” OR Pediatric OR Adolescent were used in the searching process. Additional studies were also manually searched from the relevant journal articles. The review includes only studies written in English published between January 2009 and December 2021. The initial search yielded 355 records. During the screening process from titles and abstracts, 307 items were eliminated using the inclusion and exclusion criteria, remaining 48 items at this stage. After six duplicates were removed, full-text of 42 studies were assessed for eligibility. Additional 20 records that failed to meet the inclusion criteria were excluded, resulting in 22 studies to be reviewed. Two articles were added from hand search, resulting in the total of 24 included studies for this review (See Prisma Flow Diagram in figure 1). Selected studies represent research from 9 countries.

Data extraction and research quality assessment

The data, including study designs, settings, sample sizes, consequences of TBI, and the findings, were extracted using a data extraction form. The criteria developed by the U.S. Agency for Health Research Quality for reviewing observational/non-randomized studies were used as a guideline to evaluate the quality of the identified studies\(^6\). There was a variety of study designs used to investigate the consequences of
TBI in the 24 studies included for this review. Most studies used a cross-sectional design (n = 9; 37.5%), followed by a retrospective and prospective approaches (n = 4; 16.67% for each approach). The other studies utilized a longitudinal qualitative, and secondary analysis design (n = 2; 8.33% for each design). Only one study was a case-control study (4.17%). All studies were non-experimental research providing level-three evidence and used sound research methodology and methods. Most of the identified studies (n = 17; 70.83%) included a relatively large sample size (greater than 100). Among these studies, eight studies can be considered having very large sample sizes (greater than 1,000). The largest sample size was 139,254 patients with TBI recruited from a national research database. Seven studies had a small sample size (n < 100) including two qualitative studies.

**Results**

Overall, the studies focused on various aspects of health effects of TBI and used different measurements for the targeted outcomes. The health-related consequences of TBI can be classified into four dimensions: physical, cognitive, psychological and health behavioral sequels.

**The Physical Health Consequences**

The most common physical symptoms after the brain injury included headache, fatigue, sleep disturbance, bodily pain, dizziness, tiredness, and nausea.\(^4,7,8-11\) Neurological symptoms reported by the patients included paralysis, spastic disorder, epilepsy, and fine motor deficits.\(^11\) Physical limitations/disabilities, especially movement and balance were also a critical difficulty experienced by TBI patients.\(^9,10-14\) Several studies reported the impact relative to sensory impairments.\(^10,11,15\)
The mortality rate of TBI was relatively high: almost 6% of severe TBI cases died on the first day of injury and one-fourth of severely injured case deceased within 7 days after injury. The mortality statistics could be even higher when TBI patients developed post-injury complications. That is, individuals with TBI had around 1.5 times higher risk of developing bacterial infections, pneumonia, and septicemia; two times greater possibility of developing deep vein thrombosis (DVT) and pulmonary embolism (PE); three folds higher risks of cellulitis, device-related infection and non-healing wound compared to general patients. In a study with the largest sample size, the top five post-TBI complications were intracerebral hemorrhage (ICH), acute respiratory tract infection (URI), dizziness, constipation, and urinary tract infection (UTI) respectively. Pneumonia, acute respiratory failure, and UTI was the most common complication grouping, increasing the mortality rate. When septicemia was combined with respiratory complications, the risk of death increased to nearly two folds compared to TBI patients without the complications. Patients with TBI also had over ten times higher risk of having an acute ischemic stroke compared to the overall population (2.5% vs. 0.2%).

The Cognitive Health Consequences

The cognitive sequels seem more persistent than other health aspects. Compared to persons without a history of TBI, Patients with TBI had higher risks of cognitive impairments included poor memory, concentration, and comprehension. Some studies reported that brain trauma resulted in speech deficits and slow thinking process. Patients with TBI were more likely to have difficulties in learning, orientation, planning and making decisions which significantly affected their daily living. Post-traumatic memory loss was found in more than 50% of TBI patients in
different extents. TBI individuals revealed 3.8 times more self-reported overall cognitive impairments than the non-TBI controls. Cognitive problems persisted years after brain trauma. While physical and emotional symptoms substantially improved at four years after brain injury, cognitive deficits remained when compared to the control counterparts. However, a study with relatively small sample size (n = 84) found no significant difference in cognitive functions between military services members with TBI and the controls. However, this study included only participants with mild TBI who are likely to have less severe and persistent cognitive issues compared to individuals with moderate to severe TBI.

The Psychosocial Health Consequences

The psychosocial effects of TBI gained considerable attention among the research in the studies reviewed as 75% of the studies investigated the impact of TBI on this health aspect. In relation to psychological effects, many investigators found that TBI was associated with post-traumatic stress disorder (PTSD) and depression. These studies showed that incidence rates of PTSD and depression were significantly higher than the general population. Persons who had a positive screening test for TBI presented more than 4.5 times risk for PTSD. TBI individuals also experienced other negative emotional issues such as anxiety, anger or irritation, and mental fatigue.

Besides, persons with a history of TBI had significantly poorer self-reported overall mental and emotional health compared to those who did not. Two studies reported increased risks of potential psychiatric disorders in TBI persons such as panic disorder, social phobia, and agoraphobia and schizophrenia. However, when considering only newly diagnosed psychiatric problems, no significant difference in these
outcomes was observed between TBI and non-TBI groups. The association remains unclear, necessitating additional studies to explore and explain this point. Within the social dimension, patients with TBI were more likely to be single or divorced, especially for those with a high level of TBI severity. Individuals with a history of brain injury also reported having more family problems, decreased social functions, and less social connections or community participation compared to the controls. A qualitative study also reported fewer social interactions among individuals after having brain trauma.

**The Health Behavioral Consequences**

Nine out of 24 studies reported on behavioral sequels following TBI. Most of these studies found associations between brain trauma and alcohol misuse and substance use. Individuals with TBI were found to be four folds more likely to have alcohol-related problems such as drunk driving, traffic accidents, participating in violent behaviors and drinking-related health concerns compared to those without TBI. Individuals with TBI also experienced more difficulties controlling their aggressive or violent behaviors compared to those without a history of TBI.

**Discussion**

The results of this review indicated that TBI had adverse effects not only on physical health but also cognitive, psychosocial, and behavioral health. The findings were consistent with the lower perceived health-related quality of life (HRQoL) which reflects overall subjective health conditions among this group. This review addressed that the consequences after brain injury were dependent on the severity of TBI and level of disability. That is, persons with higher severity of TBI reported more physical limitations, mental problems, and social isolation than those with lower TBI severity. Those with
more severe disability presented more depressive symptoms than non-TBI controls. Thus, the severity of injury should be taken into consideration when assessing the patients. The findings of this review also pointed out that TBI and its consequences may have intertwining relationships. For instance, TBI increased the risk for depression, and at the same time, depression also led to difficulty performing daily activities which could in turn delay recovery from TBI. Furthermore, sensory impairments resulted from TBI also had a negative impact on functional improvements. Immobility and decreased consciousness and use of invasive monitoring after TBI may partly account for increased possibility of developing additional post-injury complications such as pneumonia and infections. The findings underlined the importance of post-TBI complications prevention. Importantly, various aspects of TBI consequences seemed complicated and may have synergic effects in developing undesirable outcomes. For example, PTSD after TBI could lead to alcohol dependence which then caused relationship conflicts, mental issues and repeated injuries. These combined effects could even worsen functional outcomes.

Some studies in this review reported different health effects following TBI in women and men. Females were likely to report more post-concussion symptoms, psychosocial impairments and chronic mental fatigue than males. The rationale explaining the variation remains unclear and requires further research. Importantly, repetitive brain injuries increase mortality and morbidity rates and tended to cause detrimental consequences. We found that multiple injuries increased the likelihood of PTSD and stress reactions after TBI. Thus, gender and injury repetitions are essential components in patient assessment. For psychosocial aspect, there was adequate evidence...
that TBI resulted in PTSD, depression, and other negative emotions such as anxiety, frustration, anger, and poor self-reported mental health. However, the connections between TBI and severe psychiatric disorders such as schizophrenia, panic and phobia disorders could not be determined based on the available evidence. Our findings indicated that TBI patients were at high risk of social isolation. Lack of social support and interactions were associated with some physical and mental health concerns which may hinder long-term functional improvements. This social consequence should be assessed and promoting social support and connections may be useful for long-term outcomes.

Implications for Nursing Practice and Further Research

1. The health-related consequences of TBI are complicated and multifaceted, signaling the need of multidisciplinary approaches and effective interventions to manage these consequences.

2. Consequences of TBI, especially cognitive and psychosocial aspects, may persist for years after injury, requiring long-term supportive program to improve patients’ functions and quality of life. Future research should focus on developing and evaluating evidence-based interventions or supportive programs to reduce consequences of TBI and improve patients’ functions and health-related quality of life.

3. Unhealthy behaviors such as binge drinking and substance misuse were common in persons with brain trauma, suggesting problem-solving skills and healthy lifestyle interventions for TBI patients need to be prioritized.
4. Repetitive brain injuries worsen patients’ function and delay recovery. Risk factors should be assessed to design proper prevention strategies. Research on effective nursing interventions to prevent repetitive TBI is needed.

5. TBI is associated with social isolation and lack of social support which may hinder patients’ recovery. Nurses should include this social factor when assessing patients and reinforce connecting with community resources and strengthening social support for optimal outcomes.

**Conclusion**

TBI resulted in multifaceted health consequences: physical, psychological, cognitive and health behavioral, necessitating early comprehensive assessment and appropriate multidisciplinary approaches to deal with this global-concern injury. The findings in this review revealed that post-concussion symptoms including physical, psychosocial, and cognitive complaints might be persistent for years after injury. Therefore, interventions or strategies to prevent and reduce post-concussion consequences are crucial. Even mild brain injury when occurring repeatedly, can be life-threatening. Social support is essential to promote functional recovery and improve health-related quality of life among TBI survivors. Health-related consequences of TBI are multifaceted, synergically worsening the quality of life of the patients. TBI and its consequences have intertwining relationships, that is, addressing the consequences would positively affect recovery from TBI and vice versa. Repetitive TBI, which complicates the consequences and delays the brain healing process, is not adequately addressed. Supportive interventions for persons with TBI to deal with these challenges after TBI is essential. Symptom management, social support, problem-solving skills, healthy lifestyle
interventions, and repetitive injury prevention for TBI patients should be top priorities for nursing research, education, and clinical practice. The limitations of this review lie in its scope including the publication period, the specific language (English only) and the focus on the consequences of TBI in adult patients. Therefore, the application of the findings with caution is recommended.
Figure 1: PRISMA Flow Diagram

- Identification process
- Screening procedure
- Duplicates removal
- Eligibility assessment
- Additional study identification
- Final included decision

Studies identified from databases searching (PubMed, MEDLINE, CINAHL and Cochrane Library) (n = 355)

Records after title/abstract screening (n = 48)

Duplicates removed (n = 6)

Records after full-text assessment for eligibility (n = 22)

Records excluded using inclusion/exclusion criteria (n = 20)

Items after removing duplicated (n = 42)

Articles excluded using inclusion/exclusion criteria (n = 307)

The studies included for the review (n = 24)

Hand search to identify additional studies (n = 2)
References


Chapter 3

(Second manuscript)

Self-management Support Interventions for Adults with Mild Traumatic Brain Injury: The State of the Science

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Abstract

Purpose: To provide a synthesis of the state of the science of self-management support for individuals with mild traumatic brain injury (mTBI) to guide future research.

Design: The paper includes the definition of self-management support, characteristics and key components of self-management support interventions, and outcomes.

Methods: A comprehensive literature review was conducted using standard reporting guidelines.

Findings: Studies varied regarding inclusion criteria, study design, details of interventions, and outcomes, making a comparison across the studies challenging. In only two of six randomized controlled trials were beneficial effects reported. Quasi-experimental studies showed some benefit but were largely one-group studies, so the results must be viewed with caution. There was a lack of theory-driven family-involved self-management support interventions, and no studies about specific strategies to prevent repetitive mTBIs.

Conclusions: Based on RCTs reviewed, the interventions in mTBI patients showed minimal effectiveness. The components of the interventions were judged to be largely
inadequate, based on the current clinical guidelines. Supportive interventions should be theoretically based.

**Clinical relevance:** Education given to patients with mTBI needs to be more comprehensive, covering all key content necessary for self-managing their health after discharge. The emphasis of current clinical practice has been placed on acute care symptoms and problems, whereas the ultimate goals for mTBI patients should be centered on interventions pertaining to self-management support to improve patients’ recovery and long-term outcomes after returning home. Future research priorities for the mTBI patient are development of more interactive, comprehensive interventions, more family caregiver involvement, and reinjury prevention.
Introduction

Traumatic brain injury (TBI) results primarily from traffic accidents and falls (Siman-Tov et al., 2016) and is defined as an alteration in brain function or other evidence of brain pathophysiology caused by an external force, resulting in concussion (Menon, Schwab, Wright, & Mass, 2010). Mild traumatic brain injury (mTBI) accounts for 70% to 84% of all TBI cases (Siman-Tov et al., 2016). The World Health Organization mTBI criteria are (a) a Glasgow Coma Scale score of 13 to 15 at 30 minutes after injury or at presentation for health care and (b) at least one of the following: disorientation, loss of conscious ≤ 30 minutes, post-traumatic amnesia < 24 hours, or other transient neurological abnormalities not requiring surgery (Carroll et al., 2004).

The annual incidence of mTBI ranges from 100 to 500 per 100,000 people (Marshall et al., 2015), yet mTBI is underreported given that about 25% of patients do not seek medical care after injury (Numminen, 2011). About 20% of mTBI patients suffer from persistent symptoms. patients’ struggles are compounded by the injury’s negative influence on daily life activity, productivity, and return to work, issues that affect both individuals and society. Also, the economic burden associated with mTBI is $35,000 to $40,000 per case (Marshall et al., 2015).

Significant post-discharge challenges of patients with mTBI are poor communication with health care providers, inadequate self-management instructions, and feeling unprepared at discharge (Pugh et al., 2019). This situation results in patients not knowing about, not being able to articulate, and not performing desirable behaviors at home. The premise of this paper is that there is too much focus on acute care symptoms and problems; the ultimate goals for mTBI patients should be centered on interventions
pertaining to self-management support to improve their recovery and long-term outcomes after returning home (Malec et al., 2013).

The intricacies of self-management support interventions in the context of mTBI remain poorly understood. This state of the science paper reviews the (a) definition of self-management support, (b) characteristics and key components of self-management support interventions, and (c) outcomes. By understanding the impact of mTBI on the patient and examining the strengths of the research, nurses might be better able to help patients meet their long-term needs during recovery and suggest future research questions regarding this important neurological condition.

**Methods**

**Literature Search Strategies**

A comprehensive search was conducted for studies using the search terms: self-management, self-care, intervention, program, strategies, traumatic brain injury, mild TBI, mild head injury, and concussion. The Cumulative Index of Nursing and Allied Health Literature (CINAHL), Medline, PubMed, PsycInfo, Embase, and Web of Science databases were used. Recommendations from the current clinical practice guidelines also were reviewed.

**Selection Criteria**

The inclusion criteria were (a) peer-reviewed intervention research articles published in English between January 2009 and June 2021; (b) randomized controlled trials (RCTs) or quasi-experimental studies; (c) adults with mTBI; and (d) nonpharmacological or non-invasive interventions. Studies were excluded that focused on children or adolescents.
Data Extraction and Quality Assessment

Data describing the study setting, sample, and design; methods and interventions; and findings were extracted using a form (see Tables 1 and 2). Johns Hopkins Criteria for Evidence Level and Quality Guide was used to evaluate the quality of the studies. Among the 11 high-quality articles, six were RCTs providing level 1 evidence, and five were quasi-experimental, providing level 2 evidence (Johns Hopkins Hospital/Johns Hopkins School of Nursing, 2017).

Results

Search Outcomes and Demographic Characteristics of the Included Studies

The initial search yielded 667 records. Twenty-five articles were assessed for eligibility. Eleven studies were included in this review (see Supplemental Material). The reviewed studies included a total of 690 participants. Studies had sample sizes ranging from 21 to 173.

Definition of Self-management Support in mTBI Patients

Self-management support for individuals with mTBI refers to strategies used to equip patients with required knowledge, skills and capabilities, and resources to deal with post-concussion symptoms and health challenges due to remaining deficits, as well as to reduce risks of reinjury. This approach encourages patients to actively engage and understand their responsibility in the management of their health concerns (Grady & Gough, 2014).

Self-management Support Intervention Characteristics

Regarding the mode of intervention delivery, studies used a group (n = 5), individual (n = 2), internet (n = 2), or telephone-based approach (n = 2). The intervention
varied from one session of 20 to 30 minutes to five 1-hour sessions a week for 12 weeks. Most studies used a single-session or a self-paced approach (n = 5), followed by weekly/biweekly interventions (n = 4) and daily delivery (n = 2). None of the studies reported using a theoretical framework to design self-management support interventions for persons with mTBI.

**Key Components**

Components of effective interventions focused on providing mTBI-specific knowledge, developing self-management skills, and reinforcing social support. Education included general information about brain injury, common symptoms after brain injury, the usual pattern of recovery, and practical strategies to manage post-concussion symptoms or deal with possible problems after returning home (Belanger et al., 2015; Kannan et al., 2017; Varner et al., 2017; Vikane et al., 2017). Some studies, focusing on strengthening essential self-management skills after mTBI, included post-concussion symptom management, goal setting, problem solving, and adapting and coping with remaining issues after brain injury (Huckans et al., 2010; Kannan et al., 2017; Vikane et al., 2017). Self-management support programs facilitated by health care personnel served as essential social support resources in these studies. This component was strengthened through informational support such as self-care booklets at discharge (Matureviciene et al., 2016), instrumental support such as symptom monitoring tools, and emotional support such as reassurance of favorable recovery (Huckans et al., 2010; Moore et al., 2014; Vikane et al., 2017). However, none of the studies emphasized developing knowledge and caregiving skills for family members.
Outcomes

Various time points for outcome measurement were used. Most studies measured post-intervention outcomes immediately after program completion (n = 4), whereas others used 4 weeks (n = 1), 12 weeks (n = 2), or multiple time points (n = 4), with the longest follow-up at 12 months after program completion. The outcomes of these programs also varied across studies. Most studies investigated post-concussion symptom severity, and some studies focused on physical function such as return to work and usual activities (Huckans et al., 2010; Vikane et al., 2017). A few studies that measured psychological outcomes included depressive and anxiety symptoms, psychological distress, and post-traumatic stress disorder (Huckans et al., 2010; Moore et al., 2014), whereas others examined cognitive function (Azulay et al., 2013; Kannan et al., 2017) and social dimensions such as community reintegration and community functioning (Huckans et al., 2010; Moore et al., 2014). A few studies evaluated the impact of an intervention on perceived general health, quality of life, and life satisfaction (King et al., 2013; Matusviciene et al., 2016). Only one study investigated the intervention’s effect on self-efficacy (Azulay et al., 2013). Other outcome measures included time off from work and school, and health care utilization such as health care provider revisits (Varner et al. 2017). Few studies investigated self-management behaviors or skills as intervention outcomes: use of problem-solving skills (Azulay et al., 2013), cognitive compensation strategies (Huckans et al., 2010), pain medication (Suffoletto et al., 2013), and alcohol (Moore et al., 2014).
Discussion

Comparing the effectiveness of interventions across studies is challenging due to the use of different inclusion criteria, especially concerning symptoms and time after initial injury. The studies also varied in mode of delivery, length and intensity of intervention, outcomes, and follow-up measurement time points. Based on the RCTs overall, supportive interventions for mTBI patients showed few benefits. For example, one RCT demonstrated significantly fewer post-concussion symptoms in the 4-week intervention versus the control group (Vikane et al., 2017). This RCT has the advantage of using multiple components including education, multidisciplinary assessment to identify an individual’s needs, and an emphasis on strategies to deal with the challenges or consequences identified at home. One other RCT, emphasizing both providing mTBI-related education and strengthening problem-solving skills, reported significant improvements in psychological distress, post-traumatic stress disorder, sleep quality, overall health perception, and perceived physical health status compared to the control group at 6 months (Bell et al., 2017). However, significant differences in these outcomes were not found at the 12-month follow-up, demonstrating desirable short-term effects that were not sustained.

The current clinical guidelines relevant to intervention research for patients with mTBI include reinjury prevention strategies, approaches such as healthy lifestyles to support recovery, family involvement, and stress management strategies. In addition, critical content of verbal and written discharge advice should include warning signs and symptoms for emergency care, common symptoms patients may experience and management strategies, reassurance of expected recovery for most mTBI cases, and plan
for gradual return to normal activities as individuals’ tolerance increases in a stepwise progression (Department of Veterans Affairs & Department of Defense, 2016; Ontario Neurotrauma Foundation, 2018; Silverberg et al., 2020). However, the comprehensiveness of interventions reviewed was inadequate. For example, three studies had interventions that focused solely on education, the emphasis of one study was on gradual return instructions to usual activities (Varner et al., 2017), and one study’s intervention only focused on symptom management strategies (Suffoletto et al., 2013). None of the interventions reviewed were as comprehensive as those recommended by the current clinical guidelines.

Regarding the modes of intervention delivery, most of the RCTs used one-way communication approaches such as a self-paced internet-based intervention (Belanger et al. 2015) or text messaging (Suffoletto et al., 2013). The one-way approaches may not allow for active participation, interactive communication, and addressing individual needs. Education is a primary component of most trials, yet it may not be sufficient to reduce post-concussion symptoms (Belanger et al., 2015; Suffoletto et al., 2013; Varner et al., 2017) and distress, depression, and anxiety (Belanger et al. 2015; Suffoletto et al. 2013).

Optimal self-management support in this target group requires encouraging patients to learn by doing from their own experience and also repeating the knowledge and skills until they become confident in performing self-management activities (Azulay et al., 2013). Moreover, the current guidelines recommend follow-up by telephone or in-person for at least 4 weeks, addressing symptom management and a gradual return to activities after discharge. However, only one of five RCTs had weekly follow-ups to
allow repetition and reinforcement of optimum learning and self-management skill development (Vikane et al., 2017), which is critical for patients with mTBI who commonly experience cognitive compromise after brain injury.

Although the quasi-experimental studies added new knowledge, potential limitations were lack of randomization, small sample sizes, and no comparative group (in many studies), which could have influenced the interpretation of the findings. Natural recovery may have affected the results. King (2013) corroborated the findings of Vikane et al. (2017), who reported significantly fewer post-concussion symptoms in the intervention versus the control group.

The quasi-experimental studies included many outcomes of interest not found in the RCTs. Combining educational intervention and essential skill enhancement resulted in favorable outcomes in quasi-experimental studies, such as significantly reduced symptom severity (Huckans et al., 2010), improved cognitive function (Kannan et al., 2017), and reduced alcohol consumption (Moore et al., 2014). Mindfulness interventions contributed to improving quality of life, but their effect on symptom reduction remains unclear (Azulay et al., 2013; Huckans et al., 2010). Interventions examined in the quasi-experimental research need further scrutiny.

Optimal care of mTBI patients is extremely challenging, requiring both self-management and support. No study focused on both patients and family caregivers. No study explicitly stated an underlying theoretical framework for their interventions. Yet, the Individual and Family Self-Management Theory (Ryan & Sawin, 2009) is highly applicable to the care of mTBI patients and their family caregivers. Application of relevant theories may be useful to direct future intervention research and clinical practice
for patients with mTBI. A limitation is that the review included only adults with mTBI, so the results are not generalizable beyond this target population. A major strength of this review is that it provides a specific definition of self-management support in mTBI patients, and a detailed synthesis of interventions implemented in research settings.

**Conclusions and Implications for Further Research**

Based on the RCTs, the interventions in mTBI patients showed minimal effectiveness. Quasi-experimental studies, largely one group designs, showed some benefits from the interventions, but the results should be viewed with caution. The components of the interventions were largely inadequate based on current clinical guideline for mTBI patients. Supportive interventions should be theoretically based. Future research priorities for the mTBI patient are more comprehensive interventions, family caregiver involvement, and reinjury prevention.

**Clinical Resources**

- Centers for Disease Control and Prevention. HEADS UP to Health Care Providers https://www.cdc.gov/headsup/providers/index.html
References


Chapter 4 (Third Manuscript)

The Effect of a Self-Management Support Program for Adults with Mild Traumatic Brain Injury and Family Caregivers: A Randomized Controlled Trial

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Abstract

Purpose: To examine the effect of a self-management support program for individuals with mild traumatic brain injury (mTBI) and their family caregivers

Design: The study design was a two-group randomized control trial.

Method: This study employed a randomized control trial. A total of 73 mTBI patients and their primary family caregivers were randomly assigned to either the intervention group (n=36) receiving the self-management support program plus usual care or the control group (n=37) receiving only usual care. The self-management program was developed based on the Individual and Family Self-management theory, and recommendations of relevant clinical practice guidelines. The program consisted of self-management support assessment at the hospital, and four weekly telephone follow-ups to the patients’ home to provide mTBI-related education, symptom monitoring and management, emotional support to individuals with mTBI tailored to the patients’ needs assessed. The primary Outcomes including post-concussion severity, individuals’ self-management behaviors, health-related quality of life, and family caregivers’ self-management support behaviors were measured at baseline and week 6 after hospital discharge. Chi-square and t-tests were used to compare demographic data at baseline.
Independent sample t-tests were used to compare outcome variables between the intervention and the control groups.

**Findings:** There were no significant difference in post-concussion symptom severity between the intervention and the control groups. The intervention group had significantly greater individuals’ self-management behaviors, quality of life after brain injury, and caregivers’ self-management support behaviors than the control group ($p < .001$).

**Conclusions:** The self-management support program had beneficial effects on improving individuals’ self-management behaviors, and caregivers’ self-management support behaviors, and quality of life after brain injury.

**Clinical Relevance:** The scope of care for individuals with mTBI should be expanded beyond acute care settings to their home to promote proper self-management behaviors and improved outcomes, especially during the transition from hospital to home care.

**Keywords:** Self-management support, post-concussion symptoms, quality of life, mild traumatic brain injury

**Introduction**

Mild traumatic brain injury (mTBI) accounts for 70-84% of all TBI cases (Siman-Tov, 2016). The annual incident is 300-500/100,000 population and the estimated direct and indirect cost of each mild head injury was $35,000-40,000 (Marshall et al., 2015). About 20% of all mTBI cases suffer from persistent symptoms that can lead to difficulties returning to routine work or daily life activity, decreased productivity, and absence from work (Bosch et al., 2014). In Thailand, TBI has been a leading cause of death and disability as the nation was ranked the 2nd highest number of people killed by traffic accidents among all countries in the world, and 70% of all traffic accidents were
from motorcycle accidents. Adolescents and adults aged 15-44 years old were the most affected group from traumatic brain injury (Phuenpathom & Srikitwilaikul, 2019). This age group is very important to the nation’s workforces. The literature indicated that this public concern causes tremendous healthcare and economic burden for both for the injured individuals and the nation.

The literature revealed that the needs of patients with mTBI and their family were inadequately addressed. Patients with mTBI are usually admitted and cared for by healthcare providers for 24 hours or less at an emergency department, allowing only a short period of time to adjust during the transition from hospital to home care. Approximately 40% of the patients were discharged without specific recommendations for their condition, causing dissatisfaction with healthcare services received. They reported lower satisfaction of information and services among patients with mTBI and their caregivers compared to those with more severe brain injury (Biester et al., 2016). Traditional discharge instructions failed to address essential elements of care specific to mTBI, such as possible symptoms and how to manage the symptoms and detect warning signs indicating needs for emergency care and further investigations (Biester et al., 2016). The discharge criteria from the hospital mainly focus on the patients’ condition and specific discharge procedures rather than their readiness and skills to manage their health at home (Ryan & Sawin, 2009). Significant post-discharge challenges in patients with TBI included inadequate self-management instructions, feeling unprepared before discharge, pressure on the family to support patients without enough preparation, and poor communication with healthcare providers (Pugh et al., 2019).
A review of previous studies published found that research focusing on the effect of self-management support after mTBI is limited. Only a few randomized controlled trials reported beneficial effects. Quasi-experimental studies showed some benefit but were one-group design with limitations in showing effects of the interventions. Most studies solely focused on providing knowledge on mTBI and warning signs to return to emergency department. Many educational interventions did not cover all critical components for self-management after mTBI recommended by the current clinical guidelines such as symptom management, return to usual activities, healthy lifestyle to promote brain recovery, and repetitive injury prevention. There was a lack of theory-driven family-involved self-management support interventions and only a few studies focused on enhancing essential skills necessary to self-manage their symptoms or challenges after mTBI at home. and the focus of this study was to examine the effects of interventions that were theory-directed with the emphasis on knowledge and skill development, family involvement and repetitive brain injury prevention as suggested by the literature.

**Methods**

**Study design:** A two-group randomized control trial was conducted.

**Setting and Sample:** The study setting was a 1200-bed tertiary care hospital with a trauma center in an urban area of Thailand. The study samples were adults with mTBI and their primary family caregivers. The inclusion/exclusion criteria were 1) Glasgow Coma Score (GCS) = 13-15, loss of conscious (LOC) ≤ 30 minutes, and having post-traumatic amnesia (PTA) less than 24 hours; 2) aged ≥18 years; and 3) have and able to use a telephone. The exclusion criteria consist of 1) moderate to severe TBI, 2) unable to
communicate in Thai 3) severe psychotic disorders, and 4) patients with other brain-related conditions such as stroke and dementia. Convenient sampling technique was used to select the samples. The inclusion criteria for family caregivers were 1) identified by the patient with mTBI as a primary caregiver who stay with or has regular contact with the patient at least once a week 2) aged ≥18 years; and 3) have and able to use a telephone.

**Sample size determination**

A priori power analysis was conducted using G-Power software to estimate the required sample size to ensure adequate statistical power (Malone et al., 2016). The sample size (n = 67) was calculated based on the previously reported effect size of .33, a power of 80% and alpha level = .05 (Huckans, 2010). The average dropout rate informed by prior studies was approximately 20% (Matuseviciene et al., 2016; Varner et al., 2017). Thus, 80 dyads (40 for each arm) were recruited to account for the anticipated attrition rate.

**Recruitment of participants and randomization**

The total of 93 dyads were screened for study eligibility using the specified inclusion/exclusion by a research assistant trained on recruitment procedure. Eligible patients and their family caregivers were asked if they would like to participate in the study when a patient is planned to discharge from the emergency department to avoid interruption with the treatment in the acute phase and ensure that they were clinically stable. Thirteen eligible dyads declined, and eighty dyads agreed to participate in the study. Written informed consent was obtained from all participants before discharge from the hospital by a research assistant. The recruited dyadic participants were randomly
assigned to either experimental or the control groups (n = 40 for each arm) using a preset computer-generated list by the research assistant. There were four dropouts (10%) in the intervention group and three dropouts (7.50%) in the control group. The total of 73 dyads: 36 dyads in the intervention group and 37 dyads in the control groups completed the program (see figure 1).

**Outcome measures**

Post-concussion symptoms were measured by the Rivermead Post-Concussion Questionnaire, which includes 16 common symptoms after brain injury. The research participants were asked to rate the 16 symptoms over the past 24 hours using a 4-point Likert scale ranging from 0 (absent) to 4 (severe), and the score of each item was summed to obtain the total score. The possible points range from 0 to 64. A higher score indicates more post-concussion symptom severity (Hermann et al., 2009). A sample item is “over the past 24 hours, what would you rate the severity of your headache on the scale of 0 to 4?

Self-management behaviors were measured using the Self-management Behaviors after mTBI Scale developed by the researcher from a list of key patient discharge instructions recommended by the Center for Disease Control and Prevention (CDC, 2020). Some items are adapted from the Active Coping Scale and Self-management Performance Scale (Kendall & Terry, 2008; Muenchberger et al., 2011). A sample item is “in the past seven days, how often you alleviate symptoms after brain injury and avoid things that make the symptoms get worse? The measure includes 13 items that participants complete using a 5-point Likert scale ranging from 1 (Never) to 5 (Regularly). The scale was evaluated for content and construct validity before use.
Health-related quality of life (HRQoL) was measured using Quality of Life after Brain Injury Scale-Overall Scale (QOLIBRI-OS). The QOLIBRI-OS is a short-form of the original QOLIBRI scale consisting of six items rated by participants using a 5-level Likert, ranging from 1 (not at all) to 5 (very). The scale means were converted to 0-100 percentage using the formula \((\text{Mean}-1) \times 25\), where 0 indicates the lowest, and 100 represents the highest health-related quality of life (Steinbuchel et al., 2017). A sample item is “overall, how satisfied are you with your physical condition?”.

Caregivers’ self-management support behaviors were measured using Caregiving Performance for Individuals with mTBI Scale. The scale is adapted from Caregivers’ Performance Questionnaire, which was used in caregivers of persons with mTBI in Indonesia. (Firmawati et al., 2015). This scale was also designed in parallel with the Self-management Behaviors after mTBI Scale. The wordings were adjusted to reflect caregivers’ roles in caring or supporting the patients to perform self-management activities. The newly developed 13 item scale uses a 5-level Likert scale, ranging from 1 (never) to 5 (regularly) in performing self-management support activities. A sample item is “in the past seven days, how often do you help the patient to alleviate symptoms after brain injury and avoid things that make the symptoms get worse? The scale was evaluated for content and construct validity before use. All instruments were translated into Thai using translation and back translation techniques and validated by three bilingual experts to assess cultural relevance.

**Interventions**

The multicomponent self-management support interventions were directed by the Individual and Family Self-management Theory (Ryan & Sawin, 2009) and useful
elements informed by previous studies and the current clinical practice guidelines for managing mTBI. The critical components of the program in this study included context assessment using self-management support assessment form adapted from acute concussion evaluation form (Ontario Neurotrauma Foundation, 2018) to identify facilitators and potential barriers to self-management for both individuals with mTBI and their family caregivers and follow-up telephone-based interventions were individually tailored based on the information emerged from the assessment.

The component of knowledge and belief was enhanced through providing essential information of mTBI: common symptoms, symptom management, expected recovery, warning signs for emergency care, a gradual return to daily activities, healthy lifestyles to promote brain recovery and repetitive injury prevention and use of reassurance technique as informed by previous studies. The intervention also focused on strengthening essential skills for self-management after mTBI including symptom monitoring, symptom management coping/ problem-solving skills, and repetitive injury prevention. Regarding the social support component, the patients and their caregivers receive informational and emotional support from the interventionists who were experts in care for adults with mTBI with an intensive training. In parallel, the program also aimed at strengthening knowledge and skills for the family caregivers who are one of the most valuable social support resources to properly support individuals with mTBI to self-manage at home. The program was given by two interventionists who received 40-hour training on the research and knowledge related to the program delivery to ensure fidelity of the study.
At discharge, the participants in the intervention group received usual care plus the self-management support program consisting of self-management assessment and an educational booklet which was developed for people with grade-6 education level to understand, followed by 4 weekly scheduled telephone interventions. The control group received usual care and a phone contact at week three to schedule outcome measurement at week six after hospital discharge without any additional interventions. After post-test outcomes were measured, the participants in the control group were given a self-management booklet by post or email, depending on their preference and convenience (see Table 1 in appendix).

**Data Collection Procedure**

The patients’ demographic data, patients’ clinical variables, and family caregivers’ characteristics were collected from the medical records and direct interviews from patients or family members by research assistants using the demographic data questionnaires. Participants from both groups were asked to answer baseline assessments of all four outcomes of interest by week one after hospital discharge. The research assistant team read the questionnaires for the patient to prevent symptoms induced by text reading. The outcome data were collected via telephone after program completion using the measures (Thai version) by a research assistant who is blinded to the study and participants’ group assignment to minimize bias 2 weeks after the program or week 6 after discharge for the control group.

**Data Analysis**

SPSS program version 26.0 was used for data analysis. Frequency, percentage, mean, and standard deviation were used to describe the participants’ characteristics.
T-tests for continuous variables with normal distribution, chi-square tests for categorical variables, were used to compare the difference of participants’ characteristics between two groups at baseline. Independent sample t-tests were used to compare the differences in mean scores of post-concussion symptom severity, self-management behaviors, health-related quality of life and caregivers’ self-management support behaviors at baseline and week 6 after hospital discharge. The significance level is set at .05.

The assumptions for independent sample t-test including independence, normality, homogeneity, and random sampling were examined. The data collected were from two different groups randomly assigned to either intervention or control groups, Thus, the independence and random sampling assumptions were met. The normality assumption was tested using histograms, kurtosis and skewness and the results showed that the data from both groups were approximately normally distributed. Homogeneity of variance was tested using Levene’s test for equality of variance. The data analysis was adjusted according to the Levene’s tests.

**Ethical Considerations**

IRB approval was obtained before conducting the study. Adequate information was given before receiving written informed consent from the participants (both through verbal explanation and patient information sheet). Written informed consent was ensured by a research assistant and the consent process was voluntary. The participants were informed that not participating in the study would have no negative consequences to their care, and they had their right to withdraw from the study anytime. Confidentiality and anonymity were maintained throughout the study.
**Figure 1** Flow of study participants

- **Enrollment**
  - Assessed for eligibility (n=93 dyads)
    - Not meeting inclusion criteria (n = 8, 8.70%)
    - Decline to participate (n = 5, 5.43%)
  - Recruited (n=80 dyads)

- **Allocation**
  - The experimental group receiving the self-management support program (n=40 dyads)
  - The control group receiving usual care (n=40 dyads)

- **Follow-up**
  - Dropout rate = 10% (n=4 dyads)
    - Do not answer the phone (n=2)
    - Do not have time (n=1)
    - Illness / health issues (1)
  - Dropout rate = 7.5% (n=3 dyads)
    - Do not answer the phone / change contact number

- **Analysis**
  - Analyzed (n=36 dyads)
  - Analyzed (n=37 dyads)
Results

All baseline demographic characteristics and health-related data between the participants in the control and intervention groups were not statistically difference ($p > .05$). The mean age of the intervention group and the control group was 34.1 and 34.7 years, respectively. Most participants in both groups were: male, single, educated at high school level. Most of them had Glasgow coma score = 15, major causes of mTBI were motor vehicle accidents and falls. Most of them had no history of previous TBI, post-traumatic amnesia, underlying diseases or taking any medications. Most participants were classified as moderate risk mTBI. In terms of caregivers’ demographic data, the mean age of family caregivers in the intervention and the control group were 38.64 and 36.14 respectively. Most of them were female, married, educated at bachelor’s degree or higher, followed by high school level, employed, and related to the patient as a husband or wife (see Table 1 and 2). Attrition bias was checked by comparing the demographic data, health-related data, and the studied independent variables at baseline among those all cases recruited (N=80) and those who completed the program (N=73). The results show no significant difference.
Table 1
Comparisons of the demographic characteristics and health-related data of participants randomized to each arm at baseline

<table>
<thead>
<tr>
<th>Demographic</th>
<th>Intervention (n=36)</th>
<th>Control (n=37)</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>n (%)</td>
<td>n (%)</td>
<td></td>
</tr>
<tr>
<td>Mean Age in year (SD)</td>
<td>34.06 (15.47)</td>
<td>34.06 (16.17)</td>
<td>.868&lt;sup&gt;b&lt;/sup&gt;</td>
</tr>
<tr>
<td>Range</td>
<td>21-74</td>
<td>20-76</td>
<td></td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>28 (77.80)</td>
<td>27 (73.00)</td>
<td>.634&lt;sup&gt;a&lt;/sup&gt;</td>
</tr>
<tr>
<td>Female</td>
<td>8 (22.20)</td>
<td>10 (27.00)</td>
<td></td>
</tr>
<tr>
<td>Marital Status</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Single</td>
<td>19 (50.20)</td>
<td>19 (51.40)</td>
<td>.519&lt;sup&gt;a&lt;/sup&gt;</td>
</tr>
<tr>
<td>Married</td>
<td>13 (36.10)</td>
<td>11 (29.70)</td>
<td></td>
</tr>
<tr>
<td>Widowed</td>
<td>4 (11.10)</td>
<td>5 (13.59)</td>
<td></td>
</tr>
<tr>
<td>Divorced</td>
<td>0 (0.00)</td>
<td>2 (5.4)</td>
<td></td>
</tr>
<tr>
<td>Education</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Primary School or less</td>
<td>6 (16.70)</td>
<td>4 (10.80)</td>
<td>.669&lt;sup&gt;a&lt;/sup&gt;</td>
</tr>
<tr>
<td>High school/ diploma</td>
<td>20 (55.60)</td>
<td>24 (64.90)</td>
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</tr>
<tr>
<td>Bachelor’s degree or higher</td>
<td>10 (27.80)</td>
<td>9 (24.30)</td>
<td></td>
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<tr>
<td>GSC</td>
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<td></td>
</tr>
<tr>
<td>14</td>
<td>13 (36.10)</td>
<td>14 (37.80)</td>
<td>.436&lt;sup&gt;a&lt;/sup&gt;</td>
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<tr>
<td>15</td>
<td>23 (63.90)</td>
<td>24 (62.20)</td>
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</tr>
<tr>
<td>Cause of injury</td>
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<td></td>
</tr>
<tr>
<td>Motor vehicle accidents</td>
<td>23 (63.90)</td>
<td>26 (70.30)</td>
<td>.542&lt;sup&gt;a&lt;/sup&gt;</td>
</tr>
<tr>
<td>Fall</td>
<td>9 (25.00)</td>
<td>4 (10.80)</td>
<td></td>
</tr>
<tr>
<td>Sports</td>
<td>1 (2.80)</td>
<td>2 (5.40)</td>
<td></td>
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<tr>
<td>Physical assaults</td>
<td>2 (5.60)</td>
<td>4 (10.80)</td>
<td></td>
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<tr>
<td>Work-related accidents</td>
<td>1 (2.80)</td>
<td>1 (2.7)</td>
<td></td>
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<tr>
<td>History of previous TBI</td>
<td></td>
<td></td>
<td>.331&lt;sup&gt;a&lt;/sup&gt;</td>
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<td>Yes</td>
<td>8 (22.20)</td>
<td>5 (13.50)</td>
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<td>No</td>
<td>28 (77.80)</td>
<td>32 (86.50)</td>
<td></td>
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<tr>
<td>Post-traumatic Amnesia</td>
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<td>11 (29.70)</td>
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<td>No</td>
<td>23 (63.90)</td>
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<td>11 (29.70)</td>
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<tr>
<td>No</td>
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<tr>
<td>Currently taking any medications</td>
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<td>.634&lt;sup&gt;a&lt;/sup&gt;</td>
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<td>10 (27.00)</td>
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<td>28 (77.80)</td>
<td>27 (73.00)</td>
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<td>Risk classification</td>
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<td>Low risk</td>
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<tr>
<td>Moderate risk</td>
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<td>30 (81.10)</td>
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<tr>
<td>High risk</td>
<td>7 (19.40)</td>
<td>4 (10.80)</td>
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Note: <sup>a</sup> = Chi-square test, <sup>b</sup> = independent t-test, Significance at p < .05
Table 2
Comparisons of the demographic characteristics of family caregivers randomized to each arm at baseline

<table>
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<tr>
<th>Demographic</th>
<th>Intervention (n=36)</th>
<th>Control (n=37)</th>
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<tr>
<td></td>
<td>n (%)</td>
<td>n (%)</td>
<td></td>
</tr>
<tr>
<td>Age</td>
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</tr>
<tr>
<td>Mean age in years (SD)</td>
<td>38.64 (12.52)</td>
<td>36.14 (10.06)</td>
<td>.349^b</td>
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<tr>
<td>Range</td>
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<td>21-54</td>
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<td>Gender</td>
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<td>Male</td>
<td>11 (30.60)</td>
<td>12 (32.40)</td>
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<tr>
<td>Divorced</td>
<td>2 (5.60)</td>
<td>1 (2.70)</td>
<td></td>
</tr>
<tr>
<td>Education</td>
<td></td>
<td></td>
<td>.768^a</td>
</tr>
<tr>
<td>Primary School or less</td>
<td>3 (8.30)</td>
<td>1 (2.70)</td>
<td></td>
</tr>
<tr>
<td>High school/ diploma</td>
<td>15 (41.70)</td>
<td>16 (42.30)</td>
<td></td>
</tr>
<tr>
<td>Bachelor’s degree or higher</td>
<td>18 (50.00)</td>
<td>20 (54.00)</td>
<td></td>
</tr>
<tr>
<td>Working status</td>
<td></td>
<td></td>
<td>.124^a</td>
</tr>
<tr>
<td>Unemployed / retired</td>
<td>6 (16.70)</td>
<td>2 (5.40)</td>
<td></td>
</tr>
<tr>
<td>Employed</td>
<td>30 (83.30)</td>
<td>35 (94.60)</td>
<td></td>
</tr>
<tr>
<td>Relationship with the patient</td>
<td></td>
<td></td>
<td>.616^a</td>
</tr>
<tr>
<td>Husband/wife</td>
<td>14 (38.90)</td>
<td>10 (27.00)</td>
<td></td>
</tr>
<tr>
<td>Mother/father</td>
<td>9 (25.00)</td>
<td>9 (12.30)</td>
<td></td>
</tr>
<tr>
<td>Child</td>
<td>4 (11.10)</td>
<td>8 (21.60)</td>
<td></td>
</tr>
<tr>
<td>Sibling</td>
<td>9 (25.00)</td>
<td>10 (27.00)</td>
<td></td>
</tr>
</tbody>
</table>

Note: ^a = Chi-square test, ^b = independent t-test, Significance at p < .05

For post-concussion symptoms, independent sample t-tests showed that there was no significant difference in post-concussion symptoms severity between the intervention (M = 14.89, SD = 6.30) and the control group (M = 14.11, SD = 5.33) at baseline t (71) = .572, p = .60. There was also no statistical difference between the intervention (M = 7.86, SD = 3.58) and the control groups (M = 9.43, SD = 4.36) six weeks after injury t (71) = -1.68, p = .097. Cohen’s d was estimated -.394, which is a small effect size. Although the mean score of post-concussion symptoms in the control group was higher at baseline and lower after receiving the program, both groups had a decrease trend in the post-
concussion symptoms compared to baseline (Table 3). Thirty participants (41.10%) in the total sample reported having at least one persistent symptom at week 6 after hospital discharge. Physical symptoms including headache and dizziness were the most dominant symptoms reported by the participants. Our additional analysis showed that there was no significant difference in number of post-concussion symptoms between the intervention (M = 68, SD = 2.65) and the control group (M = 5.89, SD = 1.97) at baseline $t(71) = .16$, $p = .11$. However, there was a statistical difference between the intervention (M = .86, SD = 1.31) and the control groups (M = 2.86, SD = 2.12) after receiving the program; $t(60.27) = -4.86$, $p < .001$ (Table 3). Cohen’s $d$ was estimated -1.13, which is a large effect size.

Regarding individuals’ self-management behaviors, independent sample t-tests revealed that there was no significant difference in this independent variable between the intervention (M = 3.04, SD = .30) and the control groups (M = 3.10, SD = .25) at baseline $t(71) = -.90$, $p = .35$. After receiving the program, the intervention group (M = 4.28, SD = .21) reported significantly higher self-management behaviors than the control group (M = 3.13, SD = .35) who received only usual care; $t(60.18) = 17.31$, $p < .001$ (Table 3). That means the self-management support program had an effect on improving self-management behaviors. Cohen’s $d$ was estimated 4.03, which is a large effect size.

For quality of life after brain injury, independent sample t-test showed that there was no significant difference in the outcome variable between the intervention (M = 61.00, SD = 12.00) and the control groups (M = 65.54, SD = 10.38) at baseline $t(71) = -1.73$, $p = .088$. However, there was a significant difference in quality of life after brain injury between the intervention (M = 80.21, SD = 9.09) and the control groups (M =
70.61, SD = 9.87) after receiving the program; \( t(71) = 4.32, p < .001 \) (Table 3). In other words, the self-management program had an effect on increasing quality of life after brain injury. Cohen’s \( d \) was estimated 1.01, which is a large effect size.

For caregivers’ self-management support behaviors, independent t-test showed that there was no significant difference in this dependent variable between the intervention (\( M = 3.00, \ SD = .39 \)) and the control group (\( M = 3.11, \ SD = .28 \)) at baseline \( t(71) = -1.35, p = .18 \). However, there was a significant difference in this outcome between the intervention (\( M = 4.42, \ SD = .20 \)) and the control groups (\( M = 3.09, \ SD = .36 \)) after receiving the program; \( t(50.46) = 19.45, p < .001 \) (Table 3). That means the self-management support program had an effect on improving self-management support behaviors among family caregivers in the control group. Cohen’s \( d \) was estimated 4.52, which is a large effect size.

Table 3

Independent sample t-tests of outcome variables between the intervention and the control groups at baseline and 2 weeks post-intervention

<table>
<thead>
<tr>
<th>Time</th>
<th>Intervention Group</th>
<th>Control Group</th>
<th>Mean difference</th>
<th>( p )-value (^a)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>( M (SD) )</td>
<td>( M (SD) )</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Post-concussion symptoms</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Baseline</td>
<td>14.89 (6.30)</td>
<td>14.11 (5.33)</td>
<td>.78</td>
<td>.569</td>
</tr>
<tr>
<td>Post-intervention</td>
<td>7.86 (2.18)</td>
<td>9.43 (2.28)</td>
<td>-1.57</td>
<td>.097</td>
</tr>
<tr>
<td><strong>Individuals’ Self-management behaviors</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Baseline</td>
<td>3.04 (.30)</td>
<td>3.10 (.27)</td>
<td>-.06</td>
<td>.369</td>
</tr>
<tr>
<td>Post-intervention</td>
<td>4.28 (.25)</td>
<td>3.13 (2.82)</td>
<td>1.15</td>
<td>&lt;.001*</td>
</tr>
<tr>
<td><strong>Quality of life after brain injury</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Baseline</td>
<td>61.00 (12.0)</td>
<td>65.54 (10.38)</td>
<td>-4.54</td>
<td>.088</td>
</tr>
<tr>
<td>Post-intervention</td>
<td>80.21 (9.09)</td>
<td>70.61 (9.87)</td>
<td>9.60</td>
<td>&lt;.001*</td>
</tr>
<tr>
<td><strong>Caregivers’ self-management support behaviors</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Baseline</td>
<td>3.00 (.39)</td>
<td>3.11 (.28)</td>
<td>-.11</td>
<td>.180</td>
</tr>
<tr>
<td>Post-intervention</td>
<td>4.41 (.20)</td>
<td>3.09 (.72)</td>
<td>1.32</td>
<td>&lt;.001*</td>
</tr>
</tbody>
</table>

Note: \( M= \) mean, \( SD = \) standard deviation, Significance at \( p < .05 \)
Discussion

The self-management support program did not have significant effect in reducing post-concussion symptom severity, but number of symptoms. The results showed its beneficial effect on improving individuals’ self-management behaviors, patients’ self-management behaviors, health related quality of life, and caregivers’ self-management support behaviors.

There was no significant difference in post-concussion symptom severity between the intervention and the control groups after receiving the program. This finding is consistent with many previous studies (Azulay et al, 2013; Belanger et al, 2015; Bell et al, 2017; Matuseviciene et al., 2016; Moore et al, 2014; Suffoletto et al., 2013; Varner et al. 2017). Two studies reviewed reported beneficial effect in symptomology aspect. However, one study found positive effect in reducing number of symptoms, not the severity (King et al., 2013; Vikane et al., 2017) and one of these studies were a 1-group quasi-experimental design without a control group. Additional analysis also found significant difference in number of post-concussion symptoms. The result found that the intervention group reported higher number of symptoms than the control group at baseline and a lower number of symptoms than the control group after receiving the program, showing greater improvement in overall number of symptoms. Natural healing after mTBI made interpretation of the somatology outcomes challenging. However, this finding can be considered clinically significance. Although the program did not find a statistically significant reduction in the symptom severity for individuals with mTBI compared to the control group, it may facilitate them to adjust and live with the symptoms they experienced after mTBI during the critical transition of care.
This study found that the program had an effect on improving both individuals’ self-management behaviors and family caregivers’ self-management support behaviors. Providing knowledge and developing essential skills increases their self-efficacy to self-manage their health issues and perform caregiving roles after returning home (Azulay et al., 2013; Belanger et al, 2015). Increased self-efficacy contributes to improved health-related behaviors (Ryan & Wall, 2009). The findings were consistent with the results of a previous study reporting a desirable behavioral outcome of similar interventions which was decreased alcohol consumption.

This study also found a beneficial effect of the self-management program on increasing the individuals’ quality of life in the intervention group compared to the control group. Some strategies in the program such as reassurance of usual brain recovery, and emotional support throughout the program could positively impact psychological health. The self-management support program in this study provided continuing care and strengthened family caregivers’ ability to support individuals with mTBI at home. Decreased post-concussion symptoms, perceived self-efficacy in managing their own health issues and social support both by healthcare providers and their family caregivers may explain the favorable outcome. Other studies also reported positive effect of self-management support interventions on quality of life or life satisfaction among individuals with mTBI (Azulay et al., 2013; Huckans, 2010).

This study also underlined the importance of family involvement because the literature indicated that they participate in many crucial functions of patient care, such as evaluating the patient symptoms, behavior changes, level of consciousness, and providing routine care, considering possible remaining cognitive, mental, and behavioral issues
after mTBI (Ishikawa et al., 2010). Family involvement is key to a successful transition from hospital to home care and adherence to discharge instructions for patients with complicated health issues (Hahn-Goldberg et al., 2018). A previous study also found that a caregivers’ educational support program was effective in improving caregivers’ confidence and performance in caring for persons with mTBI (Firmawati et al., 2015).

In this study the major causes of mTBI were from motor vehicle accidents in younger adults and falls in elderlies aged ≥ 60 years. About 17.81% had the history of previous mTBI and most of them did not seek medical care after their first mTBI. A sizable portion of mTBI incidents in this study were related to drunk driving (20.55%) and not wearing a helmet (16.44%) while riding a motorcycle. This may contribute to why repetitive brain injury is quite common and sustainable prevention measures are needed to reduce the incident. Our study found that more than one third of all participants reported having at least one persistent symptom at week 6 after discharge, necessitating continuing support to solve long-term impact. In this study, we observed that many physical symptoms such as headache, dizziness and nausea vomiting were mostly resolved in the first 2 weeks after mTBI. Sleep disturbance and fatigue lasted longer to recover. Cognitive (such as poor memory and concentration) and psychological symptoms (such as feeling frustration and being irritable) once occurred were more persistent.

**Limitations**

The outcomes of this study were based on self-reported measures rather than objective measures. This study involved only those with mTBI and their family caregivers in a single study setting. The study results should be interpreted with caution.
The research findings only investigated short-term outcomes at week 6 after hospital discharge; hence sustainability of outcomes is unknown.

**Implications**

Use of theory-guided multicomponent interventions, current clinical practice guidelines, experienced interventionists, family involvement and continuing telephone-based interventions are keys to achieve positive outcomes. Persistent symptoms and challenges after mTBI are common and mTBI patients and their family need adequate support for proper self-management during the transition from hospital to home care. This study underlined that the scope of clinical practice for patients with mTBI should be expanded beyond acute care settings to cover their needs when they return home by providing adequate preparation that strengthens knowledge and skills to self-manage appropriately to bridge the gap of continuing care for the patients for greater patient outcomes. Repetitive brain injury prevention is essential since it could result in severe long-term deficits of cognitive, psychological, and behavioral outcomes and more severe brain injuries, which could be fatal when experiencing the next concussions. Future campaigns to minimize risky behaviors such as drunk driving and not wearing a helmet is needed to reduce the incident. Future research is needed that focuses on investigating the effects of a self-management support program on different patient outcomes such as rate of emergency department revisit, time in returning to normal activities, and rate of repetitive brain injury and family caregivers’ outcomes such as self-efficacy and psychological impacts. Investigating which symptoms are most impacted by a self-management program would also contribute to furthering knowledge in this area. Further studies for long-term follow-up at three or six months
Acknowledgment

The gratitude shall be given to all participants involved in this study, the interventionists, research assistant team, all experts who involved in instrument translation and validation. The designer of the self-management booklet, and the University of Missouri-St. Louis, College of Nursing O’Grady Fellowship for providing financial support to conduct this research.

Clinical Resources

- Centers for Disease Control and Prevention. HEADS UP to Health Care Providers https://www.cdc.gov/headsup/providers/index.html
References


Chapter 5

Summary

The chapter consists of 5 parts 1) a summary of the findings of the dissertation research based on the research questions, 2) a summary of the three dissertation manuscripts, 3) a summary of what has learned as a result of this body of work, 4) implications for nursing education, research, practice and/or policy, and 5) overall contribution to science.

Summary of the findings of the dissertation research

1) What is the effect of the self-management support program on post-concussion symptoms plus usual care compared to the control group receiving only usual care?

The study found no significant effect in reducing post-concussion symptom severity in the intervention compared to the control groups. Natural healing after mTBI made interpretation of the somatology outcomes challenging. Although the research did not find a statistically significant reduction in the symptom severity for individuals with mTBI who completed the self-management program compared to the control group, the results did show a greater reduction in the intervention group than in the control group that may be considered clinically significant. The program may facilitate individuals with mTBI to accept, adjust and live with the symptoms they experienced after mTBI during the critical transition of care. The mean symptom severity score of the intervention group was higher than the control group at baseline and the mean score of the intervention group after receiving the program were lower than those in the control group. Further, a significant difference in the number of post-concussion symptoms was found according to our additional analysis. The intervention group reported higher number of symptoms
than the control group at baseline but had significantly fewer number of symptoms than the control group after receiving the program.

2) *What is the effect of the self-management support program plus usual care on self-management behaviors after mTBI compared to the control group receiving only usual care?*

This study found that the self-management support program had a positive effect on improving individuals’ self-management behaviors. Key components of the program were providing knowledge and developing essential skills which may in turn increase their self-efficacy to perform proper behaviors to deal with their health issues after discharge from the hospital. The most improved behaviors among the participants in the intervention group were having physical rest after mTBI, performing actions to prevent repetitive brain injury, and managing stress respectively. On the other hand, self-management behaviors among the control counterparts were largely the same compared to baseline. Importantly, the control group tended to perform some self-management behaviors less over time, especially symptom monitoring, seeing the doctor as scheduled, and activities that delay brain recovery such as smoking and alcohol consumption. Thus, it can be concluded that the self-management program is effective to improve individuals’ self-management behaviors after mTBI.

3. *What is the effect of the nursing interventions plus usual care on health-related quality of life after mTBI compared to the control group receiving only usual care?*

Our study found a beneficial effect of the self-management program on increasing the individuals’ health-related quality of life in the intervention group compared to the control group. The participants rated considerably greater health-related quality of life
than those in the control group. The three most positively changed aspects of health-related quality of life were satisfaction in their ability to perform daily activities, their cognitive functions and physical condition respectively. Whereas the control group reported slightly increase in overall health-related quality of life compared to baseline. Hence, the self-management support program is effective in increasing health-related quality of life.

4) What is the effect of the self-management support program plus usual care on caregivers’ self-management support behaviors compared to the control group receiving only usual care?

The results revealed that there was a statistically significant difference in family caregivers’ self-management support behaviors between the intervention and the control group. Family caregivers in the intervention group reported greater performance in providing care and supporting individuals with mTBI after hospital discharge. Top three most improved performance were preventing repetitive brain injury, providing emotional support, and problem-solving support respectively. On the other hand, self-management support behaviors of those in the control group were approximately at the same level as baseline. It should be noted that some actions tended to decline overtime, especially patient’s symptom monitoring, ensuring that the patient follow-up with the doctor as scheduled, and providing emotional support for individual with mTBI respectively. Therefore, the self-management support program strengthened family caregivers’ self-management support behaviors.
A summary of the three dissertation manuscripts

This alternative dissertation consisted of three manuscripts. The first one was a scoping review on health-related consequences of mTBI (Chapter 2). The results of this review provided insights on intricacies of negative impacts on individuals with mTBI in various dimensions: physical, cognitive, psychosocial and health behavioral dimensions. The review highlighted the need to properly manage these consequences which could be persistent in some cases. Some individuals experienced family conflicts due to lack of understanding of emotional and behavioral changes after brain injury. The consequence of this invisible wound is relatively complicated and not mild as its name. Without proper support and preparation, patients with mTBI were at risk of delayed recovery, subsequent issues, and developing post-concussion complications such as cerebral hemorrhage which could be fatal. This manuscript was submitted in February 2022 to the Journal of The Royal Thai Army Nurses and is currently accepted for publication. The manuscript is expected to get published by May 2022.

The second manuscript is a state of the science on self-management support interventions specifically designed for adults with mTBI (Chapter 3). The results indicated that more research in this area is needed. The review also pointed out some essential components and effective strategies to facilitate self-management and resulted in desirable outcomes. The gaps of the literature in developing such interventions were identified. The results of this manuscript indicated the need of theory-driven, family involved, more comprehensive and continuing educational interventions strengthening knowledge and skills required for self-management after mTBI and the emphasis on repetitive brain injury prevention. Studies investigating the effect of self-management
interventions using a robust design with a control group was highly needed to prove the effect among this target group. Previous studies published were largely ineffective. This manuscript was submitted to the Journal of Nursing Scholarship and was not accepted for publication and some comments were received from the reviewers. The feedbacks have been used to improve the manuscript and will be submitted to Rehabilitation Nursing Journal.

The self-management support program in this dissertation research was developed from integration of the knowledge products gained from the first two manuscripts. The third manuscript is a data-based article reporting the results of the self-management support program (Chapter 4). The manuscript will be submitted to a peer-reviewed journal, the proposed journal is the Journal of Nursing Scholarship.

**Summary Discussion**

The main knowledge products gained from this dissertation were synthesizing results from various studies and integrating knowledge from courses learned throughout the Ph.D. program into research focused on evaluating the effectiveness of a self-management program for individuals following a mTBI. Selecting a theory to use as a theoretical framework and turning a theory into practice to inform intervention development and how to evaluate the outcomes were a new skill set learned from the body of this work. Knowledge was developed on how to choose research instruments to measure the variable outcomes that best fit with the research purpose, cultural contexts, and the nature of the studied population. When instrument particularly designed for the target group did not exist, knowledge from psychometrics course, relevant articles on instrument development, and suggestions from bilingual experts were integrated to
develop new research instruments which required including modifying some items from existing tools, using translation-back translation technique, and evaluating validity and reliability testing.

Physical symptoms can be early and mostly recognized by individuals with mTBI and their family caregiver, but they did not realize having cognitive, psychological, or behavioral changes when assessed at the emergency department. Unlike people with other health issues, persons with mTBI usually noticed these challenges when they returned to their work, study, or daily living. Perhaps, this may be one of the reasons making symptomology outcome measurement in patients with mTBI compared to baseline challenging. This emphasizes the importance of continuing follow-ups. The research experience reinforced that self-management is a dynamic process depending on several factors including individuals’ and family caregivers’ contexts, the nature of their health issues, their beliefs and culture, and acquired knowledge and skills and support received from various resources. Optimal self-management in this target group requires learning by doing from one’s experience and repeating the knowledge and skills until they become confident in performing self-management activities.

The findings from this research confirmed the concerning results reported by previous studies, especially in terms of frequent repetitive brain injury rate, underreported of mTBI incidents since post participants reporting the history of brain injury in the past did not seek medical attention. The finding indicates the need to provide education and campaigns to increase awareness to receive proper assessment and care from healthcare providers and prevent subsequent brain injury since it can cause delayed brain recovery, complicated issues and even life-threatening conditions. We found a relatively large
portion (approximately 40%) of persistent post-concussion symptoms among the research participants. Long-term intervention for those with persistent symptoms after mTBI for 3-6 months may be beneficial.

**Implications for nursing education, research, practice, and/or policy, as relevant.**

In terms of nursing education, nursing curriculum related to the care of mTBI patients should address not only acute symptoms and care during emergency phase but also their needs in subacute and chronic phases. Knowledge on theory development and application theories into clinical practice should be continually encouraged in all levels of nursing education. Nurses need to learn about how to prepare patients with mTBI and their family caregivers to resume their responsibility in managing their health after returning home. In the era of increasingly limited resources and nursing shortage, it is crucial to educate nurses to shift their roles from healthcare providers to a healthcare facilitator or supporter by equipping them with essential knowledge and skills related to their health conditions after hospital discharge.

Similarly, the scope of clinical practice when caring for patients with mTBI needs to be in parallel with nursing education reform by expanding our attention to look beyond acute care settings to cover their needs when they return home. The result of this study found that persistent symptoms are common. Hence, they should be adequately prepared to deal with possible long-term challenges by strengthening their knowledge and skills necessary for smooth transition and greater continuing care. Use of telephone-based interventions are not to substitute usual care, but an additional support to ensure proper self-management. This approach is also suitable during the COVID-19 pandemic era when healthcare resources are seriously limited, and face-to-face interventions may put
participants at risk of the infection disease. The quality of care and discharge instructions for patients can be compromised, especially among patients with mTBI which is usually seen as a non-life-threatening condition in emergency department.

Family involvement in the care for persons with mTBI is crucial, given that mTBI patients’ readiness to understand detailed instructions may be compromised due to physical conditions and decreased cognitive functions. Repetitive brain injuries are relatively frequent and result in delayed brain recovery and detrimental patient outcomes. Many incidents of mTBI cases in this study were related to risky behaviors which were preventable such as drink driving, wearing a helmet when riding a motorcycle, having fall hazards at home, or not wearing protective equipment at work. Road accident prevention policy or measures such as drink-don’t-drive, fall reduction or safety workplace campaigns may be helpful to reduce the incidents at the first place.

Future research should focus on examining effect of self-management support program in other outcomes not covered in this research such as rate of emergency department revisit, time in returning to normal activities, cost, and rate of repetitive brain injury. Alternatively, investigating the effect of such interventions on caregiver outcomes such as self-efficacy and psychological impacts would expand the body of knowledge in this field. Long-term follow-up studies at three or six months may be useful, especially for those with persistent post-concussion symptoms and to study sustainability of the outcomes. The number of post-concussion symptoms at emergency department should be taken into consideration to better understand the effect of self-management interventions on severity of the symptoms.
The overall contribution to science

This study is robust empirical evidence regarding pragmatism of the Individual and Family Self-management Theory as a theoretical framework in developing self-management support program for individuals with mTBI and family caregivers. According to the literature reviewed, none of previous studies had used the relatively new middle-range theory as a theoretical base of their interventions for individuals with mTBI. This research used the concept of self-management, which was commonly applied to those with other chronic conditions, to promote a continuing of care after returning to their home. The research highlighted the need for healthcare reform to expand beyond acute care settings to cover the entire continuum of the brain injury to minimize consequences of the critical injury and support them to return to their normal. Persistent symptoms and long-term challenges after mTBI are common, necessitating a more proactive and continuing approach to improve patient outcomes and quality of healthcare.

The study developed a program with the emphasis of family involvement, culturally tailored strategies, and repetitive brain injury prevention which bridged some gaps of the literature in this field. Family involvement was addressed in children and adolescents with mTBI. This study underlined that family involvement is one of the most important social support and resources for adults after mTBI too, given that cognitive remaining cognitive deficits are common and readiness to learn detailed discharge instructions at once before discharge is compromised among the patients.

Part of this dissertation research was the development of two research instruments: Self-Management Support behaviors after mTBI Scale and Caregiving Performance for Individuals with mTBI Scale. Most instrument in the literature measured
general health behaviors or behaviors for persons with other conditions, not specifically for individuals with mTBI. The researcher also translated all four instruments used to measure the outcome variables using translation - back translation technique. The instruments were content and culturally validated before use. Thus, the instruments can be useful for other researcher who are interested in conducting studies in this area using these instruments (both Thai and English versions), especially in Thailand. Having research instrument available for researcher may facilitate research production and knowledge development in self-management support science.

The results of this study provided strong evidence of some desirable effects of the self-management support program that culturally and individually tailored based on self-management assessment. The researcher also pointed out areas to further expand knowledge in this field including additional investigation on other interesting outcomes that were not covered in this dissertation research such as hospitalization, cost, self-efficacy in managing their symptoms or health conditions, return to normal activities, rate of repetitive mTBIs, and family caregivers’ psychological outcomes. Extended interventions for individuals with persistent post-concussion symptoms and multiple long-term outcome evaluations are recommended.
References


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doi:10.1089/neu.2013.2952


doi:10.1016/j.apnu.2014.03.001


Appendices
### Appendix A

**Table 1**

*The 4-week Self-management Support Interventions*

<table>
<thead>
<tr>
<th>Interventions</th>
<th>For individuals with mTBI</th>
<th>For family caregivers</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>At discharge</strong></td>
<td>□ Patient assessment identify self-management barriers/facilitators</td>
<td>□ Assess caregivers’ barriers and facilitators in supporting the patient at home</td>
</tr>
<tr>
<td>(1 hour)</td>
<td>□ Self-management booklet for patients (general information of mTBI, common symptoms, symptom management, expected recovery, warning signs for emergency care, a gradual return to daily activities, healthy lifestyles to promote brain recovery and repetitive injury prevention and reassurance of desirable recovery)</td>
<td>□ Self-management support booklet for the family caregiver (essential content is as in the patient booklet with additional patient observation tool and family roles in observing changes/consequences of mTBI and how to support the patients)</td>
</tr>
<tr>
<td><strong>Schedule telephone</strong></td>
<td>□ Assess post-concussion symptoms and provide strategies to manage symptoms each patient is experiencing and warning signs</td>
<td>□ Follow-up the use of a tool provided to monitor the patient’s symptoms and warning signs</td>
</tr>
<tr>
<td><strong>intervention</strong></td>
<td>□ Addressing physical and cognitive rest, use of cognitive compensatory techniques, how to return to daily activities safely and gradually</td>
<td>□ Providing strategies that the family caregivers can do to alleviate the symptoms the patient is having</td>
</tr>
<tr>
<td>(Week 1)</td>
<td>□ A brief mindfulness practice</td>
<td>□ Motivate caregivers to encourage the patient to practice mindfulness</td>
</tr>
<tr>
<td>(15-30 minutes)</td>
<td>□ Emotional support: accepting the condition, stay with the present, a reassurance of favorable recovery, and addressing their inquiries/concerns</td>
<td>□ Emotional support by addressing their inquiries/concerns</td>
</tr>
<tr>
<td><strong>Schedule telephone</strong></td>
<td>□ Follow-up post-concussion symptoms and warning signs, and facilitate a gradual return to daily activities</td>
<td>□ Follow-up caregivers’ practice in monitoring the patient’s symptom</td>
</tr>
<tr>
<td><strong>intervention</strong></td>
<td>□ Asking the patient’s experience in managing their health at home in the past week</td>
<td>□ Asking how they support the patient in the past week</td>
</tr>
<tr>
<td>(Week 2)</td>
<td>□ strategies the patient use the reduce the symptoms</td>
<td>□ Healthy lifestyles to promote brain recovery (e.g., diet for brain healing, sleep hygiene, stress reduction)</td>
</tr>
<tr>
<td>(15-30 minutes)</td>
<td>□ Healthy lifestyles to promote brain recovery (e.g., diet for brain healing, sleep hygiene, stress reduction)</td>
<td>□ Motivate caregivers to encourage the patient to practice mindfulness</td>
</tr>
<tr>
<td></td>
<td>□ A brief mindfulness practice</td>
<td>□ Providing positive feedback for desirable performance and response to caregivers’ inquiries/concerns</td>
</tr>
<tr>
<td>Interventions</td>
<td>For individuals with mTBI</td>
<td>For family caregivers</td>
</tr>
<tr>
<td>---------------</td>
<td>----------------------------</td>
<td>----------------------</td>
</tr>
<tr>
<td>Schedule telephone intervention (Week 3)</td>
<td>Follow-up post-concussion symptoms and warning signs and facilitate a gradual return to daily activities</td>
<td>Assess caregivers’ barriers and facilitators in supporting the patient at home</td>
</tr>
<tr>
<td>(15-30 minutes)</td>
<td>Facilitate problem-solving skills using the 6-step approach: define the problem, brainstorm solutions, assess solution options, select the best solution, apply it, and evaluate and modify the plan as needed</td>
<td>Self-management support booklet for the family caregiver (essential content is as in the patient booklet with additional patient observation tool and family roles in observing changes/consequences of mTBI and how to support the patients)</td>
</tr>
<tr>
<td></td>
<td>A brief mindfulness practice</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Addressing their inquiries/concerns</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Follow-up post-concussion symptoms and warning signs, and returning to daily activities</td>
<td></td>
</tr>
<tr>
<td>Schedule telephone intervention (Week 4)</td>
<td>The danger of repetitive brain injury</td>
<td></td>
</tr>
<tr>
<td>(15-30 minutes)</td>
<td>Risk factors identification (behavioral and environmental modification) to prevent subsequent brain injury</td>
<td></td>
</tr>
<tr>
<td></td>
<td>A brief mindfulness practice</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Ask how they apply what have learned to self-manage their health at home (what worked, what did not work and their plan to address remaining issues)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Encourage the patient to continue applying knowledge and skills trained to take care of themselves at home, giving feedback on performance</td>
<td></td>
</tr>
<tr>
<td>Two weeks after completing the program (Week 6)</td>
<td>Post-test outcome measurement by phone (self-management behaviors after mTBI, post-concussion symptom, health-related quality of life)</td>
<td></td>
</tr>
<tr>
<td>20-30 minutes</td>
<td></td>
<td>Post-test outcome measurement by phone (caregivers’ self-management support behaviors)</td>
</tr>
</tbody>
</table>
Appendix B

Table 2

*Description and Psychometric Properties of Measures*

<table>
<thead>
<tr>
<th>Variables</th>
<th>Name of measures /reference</th>
<th>Item Type /Number of items</th>
<th>Item scale</th>
<th>Cronbach’s alpha/construct validity from previous studies</th>
<th>Cronbach’s alpha/construct validity from this study</th>
</tr>
</thead>
<tbody>
<tr>
<td>Post-concussive symptoms</td>
<td>Rivermead Post Concussion Symptom Questionnaire</td>
<td>Likert/16</td>
<td>0-4 (Absent to severe)</td>
<td>α = .94</td>
<td>α = .84</td>
</tr>
<tr>
<td>Self-management behaviors</td>
<td>Self-management behaviors after mTBI Scale</td>
<td>Likert/13</td>
<td>1-5 (Never to regularly)</td>
<td>Newly developed</td>
<td>α = .77</td>
</tr>
<tr>
<td>Health-related quality of life</td>
<td>QOLIBRI-OS</td>
<td>Likert/6</td>
<td>1-5 (not at all to very satisfied)</td>
<td>α = .86</td>
<td>α = .80</td>
</tr>
<tr>
<td>Caregivers’ self-management support behaviors</td>
<td>Caregiving Performance for Individuals with mTBI Scale</td>
<td>Likert/13</td>
<td>1-5 (Never to regularly)</td>
<td>Newly developed</td>
<td>α = .74</td>
</tr>
</tbody>
</table>

Note: α = Cronbach alpha reliability; mTBI = mild traumatic brain injury; QOLIBRI-OS = Quality of Life After Brain Injury-Overall Scale
Appendix C

Table 3

*Data Collection Summary Table*

<table>
<thead>
<tr>
<th>Variables</th>
<th>Instruments/ Source of data</th>
<th>Data collection time points</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>At baseline (At discharge or by week 1)</td>
</tr>
<tr>
<td>Demographics</td>
<td>Demographic questionnaire</td>
<td>×</td>
</tr>
<tr>
<td>Clinical variables</td>
<td>Medical records</td>
<td>×</td>
</tr>
<tr>
<td>Individuals’ Self-management behaviors</td>
<td>Self-management behaviors after mTBI Scale</td>
<td>× (By week 1)</td>
</tr>
<tr>
<td>Post-concussive symptoms</td>
<td>Rivermead Post Concussion Symptom Questionnaire</td>
<td>×</td>
</tr>
<tr>
<td>Health-related quality of life</td>
<td>QOLIBRI-OS</td>
<td>×</td>
</tr>
<tr>
<td>Caregivers’ Self-management support behaviors</td>
<td>Caregiver’s Self-Management Support Performance for Individuals with mTBI Scale</td>
<td>× (By week 1)</td>
</tr>
</tbody>
</table>

Note: QOLIBRI-OS = Quality of Life After Brain Injury-Overall Scale
Appendix D

Patient Assessment Form for Individualized Self-Management Support Interventions for Adults with mTBI

A. Injury characteristics
1. GCS at admission: E………..M………..V………..
2. Date and time of injury: ________________________________
3. Cause of injury: ( ) Motor vehicle accident   (   ) Fall   ( ) Sports specify:__________   ( ) Assault   (   ) Others, Specify:__________
4. Post-traumatic amnesia: ( ) Yes   (   ) No
5. Risk group classification: ***See the criteria next page*** ( ) Low risk   (   ) Moderate risk   (   ) High risk

B. Symptom Checklist Since the injury, has the person experienced any of these symptoms more than usual today or in the past day? (0 = No, 1 = Yes)

<table>
<thead>
<tr>
<th>Physical (10)</th>
<th>Cognitive (4)</th>
<th>Sleep (4)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Headache 0 1</td>
<td>Feeling mentally foggy 0 1</td>
<td>Drowsiness 0 1</td>
</tr>
<tr>
<td>Nausea 0 1</td>
<td>Feeling slowed down 0 1</td>
<td>Sleeping less than usual 0 1 N/A</td>
</tr>
<tr>
<td>Vomiting 0 1</td>
<td>Difficulty concentrating 0 1</td>
<td>Sleeping more than usual 0 1 N/A</td>
</tr>
<tr>
<td>Balance problems 0 1</td>
<td>Difficulty remembering 0 1</td>
<td>Trouble falling asleep 0 1 N/A</td>
</tr>
<tr>
<td>Dizziness 0 1</td>
<td>Cognitive Total (0-4) ______</td>
<td>Sleep Total (0-4) ______</td>
</tr>
<tr>
<td>Visual problems 0 1</td>
<td>Emotional (4)</td>
<td>Exertion: Do this symptom worsen with:</td>
</tr>
<tr>
<td>Fatigue 0 1</td>
<td>Irritability 0 1</td>
<td>Physical activity ( ) Yes ( ) No ( ) N/A</td>
</tr>
<tr>
<td>Sensitivity to light 0 1</td>
<td>Sadness 0 1</td>
<td>Cognitive activity ( ) Yes ( ) No ( ) N/A</td>
</tr>
<tr>
<td>Sensitivity to noise 0 1</td>
<td>More emotional 0 1</td>
<td>Others, specify:__________________________</td>
</tr>
<tr>
<td>Numbness/Tingling 0 1</td>
<td>Nervousness 0 1</td>
<td>________________________________</td>
</tr>
<tr>
<td>Physical Total (0-10) ______</td>
<td>Emotional Total (0-4) ______</td>
<td>________________________________</td>
</tr>
<tr>
<td>Total score (0-22) ______</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

C. Risk Factors for Protected Recovery

<table>
<thead>
<tr>
<th>Concussion History:</th>
<th>Yes______</th>
<th>No______</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of previous concussions:</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Underlying diseases:</td>
<td>( ) Yes, specify:__________________________</td>
<td>( ) No</td>
</tr>
<tr>
<td>Current medications:</td>
<td>( ) Yes, specify:__________________________</td>
<td>( ) No</td>
</tr>
</tbody>
</table>

D. Red flags for acute emergency management: Refer to the emergency department with sudden onset of any of the following:

- Headaches that worsen
- Can’t recognize people or place
- Changes in state of consciousness
- Seizures
- Increasing confusion or irritability
- Neck pain
- Focal neurologic signs
- Weakness or numbness in arms/legs
- Unusual behavioral change
- Looks very drowsy/ can’t be awaken
- Repeated vomiting

E. Others important information for telephone-based self-management support interventions
- Factors facilitating self-management: ______________________________________________________________
- Barriers / challenges for self-management: ___________________________________________________________
- Risks of repetitive injury: ________________________________________________________________
- Note of self-management support plan: ______________________________________________________________
**Patients’ Demographic and Health and Injury-related Data Form**

**Part 1: Demographic data**

**Instruction:** Please answer the following questions by giving a check mark on the parenthesis or filling in the blanks provided

1. Age_____________ years
2. Gender  
   1 (   ) Male  
   2 (   ) Female
3. Marital status  
   1 (   ) Single  
   2 (   ) Married  
   3 (   ) Widowed  
   4 (   ) Divorced
4. Education level  
   1 (   ) No education / primary school  
   2 (   ) High school / Diploma level  
   3 (   ) Bachelor’s degree  
   4 (   ) Master’s degree and higher

**Part 2: Health and Injury-related data**

1. GCS at admission  
   1 (   ) 13  
   2 (   ) 14  
   3 (   ) 15
2. Cause of injury  
   1 (   ) Motor vehicle accident  
   2 (   ) Fall  
   3 (   ) Sport injury  
   4 (   ) Physical assault  
   5 (   ) Others, specify ________________________________
3. History of previous traumatic brain injury  
   1 (   ) Yes ………………. Times  
   2 (   ) No
3. Post-traumatic amnesia  
   1 (   ) Yes  
   2 (   ) No
4. Underlying diseases (e.g., diabetes, hypertension, health disease)  
   1 (   ) Yes, specify______________________________  
   2 (   ) No
5. Currently taking any medications for medical diseases  
   1 (   ) Yes, specify ________________________________  
   2 (   ) No
Appendix E

The Rivermead Post Concussion Symptom Questionnaire (RPQ)

After a head injury or accident some people experience symptoms that can cause worry or nuisance. We would like to know if you now suffer any of the symptoms given below. Because many of these symptoms occur normally, we would like you to compare yourself now with before the accident. For each symptom listed below please circle the number that most closely represents your answer.

0 = not experienced at all 1 = no more of a problem 2 = a mild problem 3 = a moderate problem 4 = a severe problem

Compared with before the accident, do you now (i.e., over the last 24 hours) suffer from:

<table>
<thead>
<tr>
<th>Symptom</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
</tr>
</thead>
<tbody>
<tr>
<td>Headaches</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Feelings of dizziness</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nausea and/or vomiting</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Noise sensitivity (easily upset by loud noise)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sleep disturbance</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fatigue, tiring more easily</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Being irritable, easily angered</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Feeling depressed or tearful</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Feeling frustrated or impatient</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Forgetfulness, poor memory</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Poor concentration</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Taking longer to think</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Double vision</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Light sensitivity (easily upset by bright light)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Double vision</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Restlessness</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Are you experiencing any other difficulties? Please specify, and rate as above.

1. ___________________________________________ 0 1 2 3 4
2. ___________________________________________ 0 1 2 3 4
Appendix F
Patients’ Self-management Behaviors after mTBI Scale

Instruction: Please marking √ in the column that represents how often you perform each action in the past week. (Never = 0 times a week, rarely = 1-2 times a week, sometimes = 3-4 times a week, often = 5-6 times a week, and regularly = everyday/every time when needed)

<table>
<thead>
<tr>
<th>Items</th>
<th>Never</th>
<th>Rarely</th>
<th>Sometimes</th>
<th>Often</th>
<th>Regularly</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. You rest physically and avoid vigorous activities or doing sports/exercises when having post-concussion symptoms.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. You rest cognitively by practicing mindfulness and avoid overthinking, reading for too long, and remembering complicated things.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. You alleviate symptoms after brain injury and avoid things that make the symptoms get worse.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. You monitor your symptoms and would ask someone to take you to an emergency department if you detect signs of serious problems such as repeated vomiting, worse headache, loss of consciousness, or unable to stay awake, seizure, and weakness or numbness.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. You gradually return to study/work as recommended by healthcare personnel.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. You perform healthy lifestyles that promote recovery of your brain, such as having adequate sleep, eating proper nutrition, using stress reduction, and relaxation techniques.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. You avoid activities that prohibit brain recovery, such as smoking, drinking alcohol, and taking recreational drugs.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. You see the doctor for follow-up/rehabilitation as scheduled.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9. You find information from reliable resources and seek help from your family, healthcare providers, or community resources when experiencing difficulties managing your health at home.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10. You take medications as prescribed by the doctor.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>11. You find strategies/solutions to deal with challenges after brain injuries.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>12. You motivate yourself or seek emotional support when experiencing emotional issues such as stress or anxiety.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>13. You assess the patient’s causes/risk factors of traumatic brain injury and help change the risks/behaviors identified to prevent subsequent brain injury such as wearing a helmet, avoiding drink driving, and preventing fall hazards.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Appendix G

QUALITY OF LIFE AFTER BRAIN INJURY - Overall Scale (QOLIBRI-OS)

We would like to know how satisfied you are with different aspects of your life since your brain injury. For each question, please choose the answer which is closest to how you feel now (including the past week) and mark the box with an “X”. If you have problems filling out the questionnaire, please ask for help.

These questions are about how you feel overall now (including the past week).

<table>
<thead>
<tr>
<th>Questions</th>
<th>Not at all</th>
<th>Slightly</th>
<th>Moderately</th>
<th>Quite</th>
<th>Very</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Overall</strong>, how satisfied are you with your physical condition?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. <strong>Overall</strong>, how satisfied are you with how your brain is working, in terms of your concentration, memory, thinking?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. <strong>Overall</strong>, how satisfied are you with your feelings and emotions?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. <strong>Overall</strong>, how satisfied are you with your ability to carry out day to day activities?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. <strong>Overall</strong>, how satisfied are you with your personal and social life?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. <strong>Overall</strong>, how satisfied are you with your current situation and future prospects?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
### Appendix H

**Caregivers’ Demographic Data Form**

**Instruction:** Please answer the following questions by giving a check mark on the parenthesis or filling in the blanks provided.

1. Age_______________ years

2. Gender
   - 1 ( ) Male
   - 2 ( ) Female

3. Marital status
   - 1 ( ) Single
   - 2 ( ) Married
   - 3 ( ) Widowed
   - 4 ( ) Divorced

4. Education level
   - 1 ( ) No education / primary school
   - 2 ( ) High school / Diploma level
   - 3 ( ) Bachelor’s degree
   - 4 ( ) Master’s degree and higher

5. Employment
   - 1 ( ) Unemployed / retired
   - 2 ( ) Employed

6. Relationship with the patient
   - 1 ( ) Husband
   - 2 ( ) Wife
   - 3 ( ) Mother
   - 4 ( ) Father
   - 5 ( ) Child
   - 6 ( ) Sibling
   - 7 ( ) Others
Appendix I

**Caregivers’ Self-management Support Performance for Individuals with mTBI Scale**

Instruction: Please marking √ in the column representing how often you perform each action for the patient in the past week. (Never = 0 times a week, rarely = 1-2 times a week, sometimes = 3-4 times a week, often = 5-6 times a week, and regularly = everyday)

<table>
<thead>
<tr>
<th>Items</th>
<th>Never</th>
<th>Rarely</th>
<th>Sometimes</th>
<th>Often</th>
<th>Regularly</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. You encourage the patient to rest physically and avoid vigorous activities or doing sports/exercises when having post-concussion symptoms.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. You support the patient to rest cognitively by practicing mindfulness and avoid overthinking, reading for too long, and remembering complicated things.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. You help the patient to alleviate symptoms after brain injury and avoid things that make the symptoms get worse.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. You monitor the patient’s symptoms and would take the patient to the emergency department if you detect signs of serious problems such as repeated vomiting, worse headache, loss of consciousness, or unable to stay wake, seizure, and weakness or numbness.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. You help the patient to gradually return to study/work as recommended by healthcare personnel.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. You encourage healthy lifestyles that promote recovery of your brain, such as having an adequate sleep, eating proper nutrition, using stress reduction and relaxation techniques.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. You encourage the patient to avoid activities that prohibit brain recovery, such as smoking, drinking alcohol, and taking recreational drugs.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. You make sure the patient sees the doctor for follow-up/rehabilitation as scheduled.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9. You find information from reliable resources and seek help from healthcare providers, community resources when experiencing difficulties caring or supporting the patient at home.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10. You make sure the patient takes medications as prescribed by the doctor.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>11. You assist the patients in finding strategies to deal with challenges after brain injuries.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>12. You provide emotional support to the patient.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>13. You assess the patient’s causes/risk factors of traumatic brain injury and help change the risks/behaviors identified to prevent subsequent brain injury such as wearing a helmet, avoiding drink driving, and preventing fall hazards.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Appendix J

Table 4

*Comparisons of the demographic characteristics of participants randomized to each arm at baseline, and those remaining in the study at week 6*

<table>
<thead>
<tr>
<th>Demographic</th>
<th>All participants at baseline</th>
<th>Remaining participants</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Intervention (n=40)</td>
<td>Control (n=40)</td>
</tr>
<tr>
<td></td>
<td>n (%)</td>
<td>n (%)</td>
</tr>
<tr>
<td>Age</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean age (SD)</td>
<td>33.7(15.0)</td>
<td>34.3(15.7)</td>
</tr>
<tr>
<td>Range</td>
<td>20-74</td>
<td>20-76</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>32(80)</td>
<td>29(72.5)</td>
</tr>
<tr>
<td>Female</td>
<td>8(20)</td>
<td>11(27.5)</td>
</tr>
<tr>
<td>Marital Status</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Single</td>
<td>21(52.2)</td>
<td>20(50.0)</td>
</tr>
<tr>
<td>Married</td>
<td>15(37.5)</td>
<td>13(32.5)</td>
</tr>
<tr>
<td>Widowed</td>
<td>4(10.0)</td>
<td>5(12.5)</td>
</tr>
<tr>
<td>Divorced</td>
<td>0(0.0)</td>
<td>2(5.0)</td>
</tr>
<tr>
<td>Education</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No education /Primary School</td>
<td>6(15)</td>
<td>4(10.0)</td>
</tr>
<tr>
<td>High school / diploma</td>
<td>24(60.0)</td>
<td>25(62.5)</td>
</tr>
<tr>
<td>Bachelor’s degree and above</td>
<td>10(25.0)</td>
<td>11(27.5)</td>
</tr>
<tr>
<td>GSC</td>
<td></td>
<td></td>
</tr>
<tr>
<td>13</td>
<td>0(0.0)</td>
<td>0(0.0)</td>
</tr>
<tr>
<td>14</td>
<td>14(35.5)</td>
<td>15(37.5)</td>
</tr>
<tr>
<td>15</td>
<td>25(62.5)</td>
<td></td>
</tr>
<tr>
<td>26(65.0)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cause of injury</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Motor vehicle accidents</td>
<td>26(65.0)</td>
<td>29(72.5)</td>
</tr>
<tr>
<td>Fall</td>
<td>9(22.5)</td>
<td>4(10)</td>
</tr>
<tr>
<td>Sports</td>
<td>1(2.5)</td>
<td>2(5)</td>
</tr>
<tr>
<td>Physical assault</td>
<td>3(7.5)</td>
<td>4(10)</td>
</tr>
<tr>
<td>Others</td>
<td>1(2.5)</td>
<td>1(2.5)</td>
</tr>
</tbody>
</table>

Note: <sup>a</sup> = Chi-square, test, <sup>b</sup> = independent t-test, Significance at p < .05

Table 5
Table 5

Comparisons of the demographic characteristics of participants randomized to each arm at baseline, and those remaining in the study (cont.)

<table>
<thead>
<tr>
<th>Demographic</th>
<th>All participants at baseline</th>
<th>Remaining participants</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Intervention (n=40)</td>
<td>Control (n=40)</td>
</tr>
<tr>
<td></td>
<td>n (%)</td>
<td>n (%)</td>
</tr>
<tr>
<td>History of previous TBI</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>8(20.0)</td>
<td>5(12.5)</td>
</tr>
<tr>
<td>No</td>
<td>32(80.0)</td>
<td>35(87.5)</td>
</tr>
<tr>
<td>Post-traumatic Amnesia</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>14(35.0)</td>
<td>11(27.5)</td>
</tr>
<tr>
<td>No</td>
<td>26(65.0)</td>
<td>29(72.5)</td>
</tr>
<tr>
<td>Underlying diseases</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>14(35.0)</td>
<td>11(27.5)</td>
</tr>
<tr>
<td>No</td>
<td>26(65.0)</td>
<td>29(72.5)</td>
</tr>
<tr>
<td>Taking any medications</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>9(22.5)</td>
<td>10(25.0)</td>
</tr>
<tr>
<td>No</td>
<td>31(77.5)</td>
<td>30(75.0)</td>
</tr>
<tr>
<td>Risk classification</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Low risk</td>
<td>3(7.5)</td>
<td>3(7.5)</td>
</tr>
<tr>
<td>Moderate risk</td>
<td>30(75.0)</td>
<td>33(82.5)</td>
</tr>
<tr>
<td>High risk</td>
<td>7(17.5)</td>
<td>4(10.0)</td>
</tr>
</tbody>
</table>

Note: ^a = Chi-square test, ^b = independent t-test, Significance at p < .05
Table 6

Comparisons of the demographic characteristics of family caregivers randomized to each arm at baseline, and those remaining in the study (cont.)

<table>
<thead>
<tr>
<th>Demographic</th>
<th>All participants at baseline</th>
<th>Remaining participants</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Intervention (n=40)</td>
<td>Control (n=40)</td>
</tr>
<tr>
<td></td>
<td>n (%)</td>
<td>n (%)</td>
</tr>
<tr>
<td>Age (years)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean (SD)</td>
<td>38.83 (12.09)</td>
<td>36.67 (10.36)</td>
</tr>
<tr>
<td>Range</td>
<td>20-65</td>
<td>21-54</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>11 (27.50)</td>
<td>13 (32.50)</td>
</tr>
<tr>
<td>Female</td>
<td>29 (72.50)</td>
<td>27 (67.50)</td>
</tr>
<tr>
<td>Marital Status</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Single</td>
<td>5 (12.50)</td>
<td>7 (17.50)</td>
</tr>
<tr>
<td>Married</td>
<td>33 (82.50)</td>
<td>31 (77.50)</td>
</tr>
<tr>
<td>Divorced</td>
<td>2 (5.00)</td>
<td>2 (5.99)</td>
</tr>
<tr>
<td>Education</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Primary School or less</td>
<td>3 (7.50)</td>
<td>1 (2.50)</td>
</tr>
<tr>
<td>High school/ diploma</td>
<td>17 (45.00)</td>
<td>16 (40.00)</td>
</tr>
<tr>
<td>Bachelor’s degree or higher</td>
<td>17 (42.50)</td>
<td>21 (52.50)</td>
</tr>
<tr>
<td>Working status</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Unemployed / retired</td>
<td>6 (15.00)</td>
<td>3 (7.50)</td>
</tr>
<tr>
<td>Employed</td>
<td>34 (85.00)</td>
<td>37 (92.50)</td>
</tr>
<tr>
<td>Relationship with the patient</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Husband/wife</td>
<td>16 (40.00)</td>
<td>6 (15.00)</td>
</tr>
<tr>
<td>Mother/father</td>
<td>11 (27.50)</td>
<td>10 (25.00)</td>
</tr>
<tr>
<td>Child</td>
<td>4 (10.00)</td>
<td>8 (20.00)</td>
</tr>
<tr>
<td>Sibling</td>
<td>9 922.50)</td>
<td>10 (25.00)</td>
</tr>
</tbody>
</table>

Note: a = Chi-square test, b = independent t-test, Significance at p < .05
Table 7

Comparisons of the demographic characteristics of participants randomized to each arm at baseline, and those remaining in the study (cont.)

<table>
<thead>
<tr>
<th>Demographic</th>
<th>All participants at baseline</th>
<th>Remaining participants</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Intervention (n=40)</td>
<td>Control (n=40)</td>
<td>p-value</td>
</tr>
<tr>
<td></td>
<td>n (%)</td>
<td>n (%)</td>
<td></td>
</tr>
<tr>
<td>Post-concussion symptom severity</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean (SD)</td>
<td>14.4(6.3)</td>
<td>14.13(5.1)</td>
<td>.847b</td>
</tr>
<tr>
<td>Range</td>
<td>4-29</td>
<td>4-23</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>.569b</td>
</tr>
<tr>
<td>Patients’ self-management</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>behaviors</td>
<td></td>
<td></td>
<td>.551b</td>
</tr>
<tr>
<td>Mean (SD)</td>
<td>3.1(.3)</td>
<td>3.1(.2)</td>
<td></td>
</tr>
<tr>
<td>Range</td>
<td>2.5-3.8</td>
<td>2.6-3.9</td>
<td></td>
</tr>
<tr>
<td>Quality of life after brain</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>injury</td>
<td></td>
<td></td>
<td>.186b</td>
</tr>
<tr>
<td>Mean (SD)</td>
<td>62.2(12.2)</td>
<td>65.5(10.0)</td>
<td></td>
</tr>
<tr>
<td>Range</td>
<td>45.8-83.3</td>
<td>45.8-83.3</td>
<td></td>
</tr>
<tr>
<td>Caregivers’ self-management</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>support behaviors</td>
<td></td>
<td></td>
<td>.240b</td>
</tr>
<tr>
<td>Mean (SD)</td>
<td>3.0(.4)</td>
<td>3.1(.3)</td>
<td></td>
</tr>
<tr>
<td>Range</td>
<td>2.2-4.1</td>
<td>2.5-3.8</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>.180b</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Note: * = Fisher’s exact test, a = Chi-square test, b = independent t-test, Significance at p < .05
Table 8

*Independent sample t-tests of the number of post-concussion symptoms between the intervention and the control groups at baseline and 2 weeks post-intervention*

<table>
<thead>
<tr>
<th>Time</th>
<th>Intervention Group</th>
<th>Control Group</th>
<th>Mean difference</th>
<th>p-valuea</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>M (SD)</td>
<td>M (SD)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Number of post-concussion symptoms</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Baseline</td>
<td>6.78 (2.65)</td>
<td>5.89 (1.97)</td>
<td>.89</td>
<td>.293</td>
</tr>
<tr>
<td>Post-intervention</td>
<td>.86 (1.31)</td>
<td>2.86 (2.12)</td>
<td>-2.00</td>
<td>&lt;.001*</td>
</tr>
</tbody>
</table>

Note: M= mean, SD = standard deviation, Significance at p < .05
### Appendix K

#### Table 8

*Randomized Controlled Trials of Self-management Support Interventions for Adults with Mild Traumatic Brain Injury (mTBI)*

<table>
<thead>
<tr>
<th>Author, Year</th>
<th>Setting/Sample/Design</th>
<th>Methods/Interventions</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Belanger et al., 2015</td>
<td>• Military/veteran with symptoms • 158 with mTBI, aged 18-55 years • 2-group RCT (Intervention = 75, Control = 71)</td>
<td>• Educational intervention (TBI severity, expected symptoms, symptom management strategies and expectation of recovery) versus usual care • Self-paced internet-based intervention (5 modules with quiz); 1 session (15-45 minutes) to complete all modules</td>
<td>• NS: Post-concussion symptom severity, self-efficacy, and psychological distress</td>
</tr>
<tr>
<td>Bell et al., 2017</td>
<td>• Military clinics • 356 active duty with clinically confirmed mTBI, aged 20-54 years • 2-group RCT (Intervention = 178, Control = 178)</td>
<td>• Problem-solving treatment plus education intervention (common issues after mTBI and adjustment after return from deployment) versus education only</td>
<td>• Improvement in psychological distress*, PTSD*, sleep quality*, overall health perception*, and perceived physical health status* at 6 months • NS: All the above outcomes at 12 months; no impact on post-concussion symptoms at 6 and 12 months</td>
</tr>
<tr>
<td>Study</td>
<td>Setting</td>
<td>Participants</td>
<td>Intervention</td>
</tr>
<tr>
<td>---------------</td>
<td>--------------------------------</td>
<td>---------------------------------------------------</td>
<td>------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Matuseviciene et al., 2016</td>
<td>7 hospitals</td>
<td>80 patients with mTBI and GCS 14-15 and ≥ 3 post-concussion symptoms, aged 15-70 years</td>
<td>Educational intervention at discharge (written information about mTBI, the reassurance of positive recovery, a gradual return to regular activities, referrals to other specialists if needed), an early visit by a rehabilitation-specialist (anxiety and depression screening, symptom assessment, neurological examination) and versus usual care</td>
</tr>
<tr>
<td>Suffoletto et al., 2013</td>
<td>Emergency department</td>
<td>43 patients with mTBI, aged ≥ 18 years</td>
<td>Educational intervention (symptom management strategies with an emphasis on three symptoms: headache, concentration problem, irritability/anxiety) versus usual care</td>
</tr>
<tr>
<td>Study</td>
<td>Type of intervention</td>
<td>Follow-up measure</td>
<td>Outcome measures</td>
</tr>
<tr>
<td>--------------------</td>
<td>---------------------------------------------------------------------------------------</td>
<td>--------------------------------------------------------</td>
<td>--------------------------------------------------------</td>
</tr>
<tr>
<td>Varner et al., 2017</td>
<td>• Educational intervention (cognitive rest and the gradual return to usual activities instruction) versus usual care&lt;br&gt;Individually based intervention; 1 session at discharge (length of the session not specified)&lt;br&gt;2-group RCT (Intervention = 60, Control = 58)</td>
<td>Follow-up measures: 2 and 4 weeks after discharge from the emergency department</td>
<td>NS: Post-concussion symptom severity, number of physician visits, and time off work/school</td>
</tr>
<tr>
<td>Vikane et al., 2017</td>
<td>• Multidisciplinary assessment and educational intervention (common problems in daily life following mTBI, experience sharing and discussion on strategies to reduce the consequences, reassurance of favorable recovery and developing a plan for gradually returning to work and regular activities) versus usual care&lt;br&gt;Group-based intervention (number/group not specified); 4-week program (1 session/week, length of the session not specified)&lt;br&gt;2-group RCT (Intervention = 81, Control = 70)</td>
<td></td>
<td>Fewer numbers of post-concussion symptoms in the intervention versus the control group*&lt;br&gt;NS: Return to work, disability level, perceived recovery, and psychological distress</td>
</tr>
</tbody>
</table>

*Note. mTBI = Mild traumatic brain injury; RCT = Randomized controlled trial; NS = No statistically significant difference, PTSD = post-traumatic stress disorder; *p < .05.
Table 9

**Quasi-experimental Studies of Self-management Support Interventions for Adults with Mild Traumatic Brain Injury (mTBI)**

<table>
<thead>
<tr>
<th>Author, Year</th>
<th>Setting/Sample/Design</th>
<th>Methods/Interventions</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Azulay et al., 2013</td>
<td>Suburban rehabilitation hospital • 22 patients with mTBI at least 3 months, aged 18-62 years • 1-group QSE</td>
<td>Mindfulness intervention (awareness of emotional and psychological pain, acceptance with experiences with a nonjudgmental attitude, cognitive compensatory strategies, and enhancement of attention skills) • Group-based intervention (6 persons/group) • 10-week program (2 hours/session, 1 session/week) • Follow-up measure: 2 weeks after the program</td>
<td>Improved perceived self-efficacy*, quality of life*, and attention* • NS: Problem-solving skills, post-concussion symptom severity, and mindful attention awareness</td>
</tr>
<tr>
<td>Huckans et al., 2010</td>
<td>Veteran Affairs Medical Center • 21 veterans with mTBI and mild cognitive problems, aged 25-43 years • 1-group QSE</td>
<td>Skill training intervention (cognitive training strategies, e.g., mindfulness exercise use of external aids, goal setting, and problem-solving) • Group-based intervention (6 persons/group) • 6-8-week program (2 hours/week) • Follow-up measure: After completing the program</td>
<td>Increased life satisfaction* • Decreased post-concussion psychiatric symptom severity* and cognitive symptom severity* • NS: Community integration and self-efficacy</td>
</tr>
<tr>
<td>Study</td>
<td>Setting</td>
<td>Participants</td>
<td>Intervention (TBI severity, expected symptoms, normal recovery process, and symptom management strategies)</td>
</tr>
<tr>
<td>------------------</td>
<td>-------------------------------------------------------------------------</td>
<td>-------------------------------------------------------------------------------</td>
<td>-------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Kannan et al.,</td>
<td>Emergency department</td>
<td>66 patients with mTBI and mild memory impairment admitted within 48 hours, aged 20-60 years</td>
<td>Educational intervention (information about TBI), and cognitive retraining and skill training (compensatory cognitive strategies and symptom management skills) versus usual care</td>
</tr>
<tr>
<td>2017</td>
<td>2-group QSE (Intervention = 33, Control = 33)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>King et al.,</td>
<td>3 rehabilitation centers</td>
<td>25 military and civilian participants with both acute and chronic symptomatic mTBI, aged 18-55 years</td>
<td>Educational intervention (TBI severity, expected symptoms, normal recovery process, and symptom management strategies)</td>
</tr>
<tr>
<td>2013</td>
<td>1-group QSE</td>
<td></td>
<td>Self-paced internet-based intervention (education material with quiz); 1 session (20-30 minutes)</td>
</tr>
<tr>
<td>Moore et al., 2014</td>
<td>● Trauma center</td>
<td>● Educational (written information about common symptoms and management strategies, reassurance, and tips for a healthy recovery, expected recovery timeline, alcohol intervention, strengthening essential skills like coping strategies, and suggestions for community resources versus usual care)</td>
<td>● Maintained community functioning in the intervention group versus declined function in the control group*</td>
</tr>
<tr>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td>● 64 patients with mTBI receiving head CT, discharge &lt; 24 hours from the trauma center, aged ≥ 18 years</td>
<td>● 2-group QSE (Intervention = 32, Control = 32)</td>
<td>● Group-based intervention (number/group not specified); 1 session (45-60 minutes)</td>
<td>● Decreased alcohol consumption in the intervention group versus the control group*</td>
</tr>
<tr>
<td>● Follow-up measure: 3 months post-injury</td>
<td></td>
<td></td>
<td>● NS: Symptom severity, depression and anxiety, and post-traumatic stress disorder</td>
</tr>
</tbody>
</table>

*Note. mTBI = Mild traumatic brain injury; QSE = Quasi-experimental; NS = No statistically significant difference; *p < .05.
Appendix L

Individual and Family Self-Management Theory

Context
Risk and Protective Factors
Condition-Specific Factors
- Individual/Family perception of
  - Complexity of condition & treatment
  - Trajectory
  - Condition stability & transitions
Physical & Social Environment
- Health care access
- Transportation
- Culture
- Social capital
Individual & Family Factors
- Developmental stages
- Learning ability
- Literacy
- Family structure & functioning
- Capacity to self-manage

Process
The Self-Management Process
Knowledge & Beliefs
- Factual information
- Self-efficacy
- Outcome expectancy
- Goal congruence
Self-Regulation Skills & Abilities
- Goal Setting, self-monitoring & reflective thinking
- Decision making, planning & action
- Self-evaluation
- Emotional control
Social Facilitation
- Social influence
- Support (emotional, instrumental or informational)
- Negotiated collaboration

Proximal Outcomes
Individual & Family Self-Management Behaviors
- Engagement in activities/treatment regimens
- Use of recommended pharmacological therapies
- Symptom management
Cost of Health Care Services

Distal Outcomes
Health Status
- Prevention, attenuation, stabilization, worsening of the condition
Quality of Life
- Perceived well-being
Cost of Health
- Direct & indirect cost

Intervention: Individual/family centered interventions
The Concept Map of the Self-Management Support Intervention for Adults with mTBI

INDIVIDUAL SM CONTEXTS
FACILITATORS/BARRIERS
• TBI-specific factors (GCS, cause of injury, history of previous mTBI, PTA, other injuries)
• Individual characteristics (age, gender, education, underlying diseases, current medications)

Family Contextual Factors
• Family caregiver characteristics (age, gender, marital status, education, employment, and relationship with the patient)

SM PROCESS AFTER MTBI
Knowledge and beliefs
• Education/information
• Self-efficacy (empowerment, reassurance)

MTBI skills and abilities
• Self-monitoring
• Symptom management (mindfulness and other non-pharmacological approaches)
• Problem-solving and coping with challenges after brain injury
• Reinjury prevention

Social support
(Informational, instrumental & emotional)

INDIVIDUAL SM BEHAVIORS

HRQOL
Post-concussion symptoms

Caregivers’ SM support behaviors

NOTES: Adapted from the Individual and Family Self-Management Theory (Ryan & Sawin, 2009)
Abbreviations: SM = Self-management; MTBI = Mild traumatic brain injury; PCS = Post-concussion symptoms, HRQOL = Health-related quality of life, GCS = Glasgow Coma Score, PTA = Post-traumatic amnesia
Symbols: = negative impact; = positive impact; = increase; = decrease