

## Caring for Thai Traumatic Brain Injury Survivors in a Transitional Period: What Are the Barriers?

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### Abstract:

**Objective:** We aimed to explore the situations and experiences of Thai traumatic brain injury (TBI) caregivers and nurses who care for TBI patients during their transition from hospital to home.

**Material and Methods:** A descriptive qualitative study was conducted in a tertiary hospital, in Songkhla province, Thailand. Five TBI family caregivers and nine nurses, who cared for TBI patients from admission to discharge, were selected for in-depth interviews and focus group discussions. Reviews of existing documents related to caring for someone during a transition period; such as: the caregiver's booklet manual, nurse's guideline, discharge education, and the service plan were also analyzed. Content analysis was used to explore caring for someone during a TBI situation, within the Thai context.

**Results:** The findings revealed six main barriers in the current care system for TBI caregivers and nurses. These included: (1) inadequate discharge teaching information, (2) less time in caregiver's supervision and support, (3) lack of a comprehensive discharge plan, (4) lack of coordination and communication in follow-up care, (5) less confidence in providing care without support at home, and (6) poor availability of resources and time for consultation.

**Conclusion:** Caregivers require more information and supportive care in order to enhance their adaptation in taking care of TBI patients in the long term. Developing a tele-nursing based caregiver transitional support program among TBI caregivers is suggested.

**Keywords:** caregiver, traumatic brain injury, transitional support program

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## Introduction

The Brain Injury Association of America (BIAA) defines traumatic brain injury (TBI) as: *“an alteration in brain function, or other evidence of brain pathology, caused by an external force.”*<sup>1</sup> TBI is a major health problem in the world, including in Thailand, where TBIs are often caused by motorcycle accidents.<sup>2</sup> People with TBI experience a variety of complications that can affect mobility, memory, perception, social engagement, economic security and consciousness, such that continuing care is required. Uncertainty of patients' prognosis and symptoms is an implicit dimension of TBI, directly affects family members, resulting in feelings of stress and vulnerability.<sup>3,4</sup>

Nowadays, medical advances permit TBI patients to survive to more advanced ages than in the past. The added years, however, involve extending not only periods of good health, but also periods of frailty, complications and disability when routine personal care is required. Most caregivers of TBI patients are family members, who provide home-based care for these patients.<sup>5</sup> Caregivers are given discharge instructions in order to be prepared for hospital discharge as part of the routine nursing intervention.<sup>5</sup> Once TBI patients return home, there is an impact of long-term responsibilities in caring of TBI patients, mostly in rural areas, with limited rehabilitation support from local resources.<sup>6</sup> In addition, patients with TBI often have neurobehavioral and/or physical deficits that remain present even 6–12 months post-injury. This requires them to be more dependent on their caregivers.<sup>7,8</sup> As a result, TBI caregivers play a major role in fulfilling the demanding mission of facilitating both recovery and rehabilitation.<sup>5,9</sup>

The physical and psychological impact of TBI survivors can be distressing for the entire family, who commonly describe a combination of insufficient information and an overwhelming burden of care.<sup>3,10,11</sup> After TBI survivors are discharged from hospital many close relatives assume the position of providing care.<sup>10</sup> Many family care-

givers are then faced with a grieving process when they think about their own future. This can include: having to redefining themselves, fear, a situation of uncertainty and their expectations.<sup>12</sup> Moreover, caregiver stress can occur when the caregiving experiences are known or evaluated as threatening. This can be particularly true in patients with TBI, due to the nature of the TBI.

A study<sup>9</sup> regarding Thai TBI survivors, and their caregivers was conducted in the transition phase, following hospital discharge. The findings from the previous study<sup>9</sup> indicated that: during the early period following hospital discharge, social support was related to the disability of TBI patients, or patients' recovery. Therefore, the intervention enhancing the healthcare system support was unclear. It is thus timely to analyze the current evidence related to giving care for TBI survivors, particularly given that the experiences of care are based on interpersonal understandings and interchanges between the healthcare team and family caregivers (FCs).<sup>5,14,15</sup> In order to improve TBI care in the transition period, this study aimed to analyze caring situations, and discharge planning in caring for TBI survivors.

## Material and Methods

### Design

A descriptive qualitative study was used, which helped the researcher to understand the context of care and services that were specific to the barriers in caring for TBI survivors during the transition from hospital to home.

### Participants

Five TBI caregivers and nine nurses, who cared for TBI patients from admission to discharge, were purposively selected for in-depth interviews and focus group discussions. FCs were primary caregivers, who provided direct care for moderate or severe head injury patients. These caregivers had a close relationship with the patients, and

were usually the parents, spouses, or other relatives. They provided unpaid care to their TBI patients during their hospital stay as well as continuity of care at home. The nine nurse participants were registered nurses, working in the Neurological Ward or Neurological Intensive Care Unit, and were involved with discharge planning, or home visits and willing to participate in this research.

### Setting

A regional hospital, under the Ministry of Public Health, which serves as a referral centre for nearby community hospitals within Songkhla, and other nearby provinces was selected to be in this study. It has a capacity of 700 beds; however, as is often the case with most regional hospitals, there are problems of overcrowding, and most of the time it is often over capacity. The TBI patients were admitted in the Neurosurgical Ward (24 beds), or Neurosurgical Intensive Care Unit (10 beds).

### Data collection

The data were collected by observation, both environment in caring and routine care from hospital to home, nurses' focus groups and in depth interviews with the FCs. This took place in a tertiary hospital in southern Thailand, during the transition period from hospital to home. The semi-structured interview guidelines related to caring for a patient with TBI, nursing care, care coordination, their current living conditions, and activities that caregivers do for these patients was used. Example questions for the nurses: *"How do you think about nursing care, caring, and care coordination?"* *"What kinds of things do you do to care for TBI patients?"* *"How do you evaluate the current caring which is provided to the person with TBI, and his/her caregiver?"* and so forth. TBI caregivers were interviewed at home and the focus group of nurses was conducted at the hospital. The interviews were recorded using digital

audiotape, after obtaining participants' permission. Each interview was about 40–45 minutes in duration. Moreover, existing documents, especially discharge planning, related to caring for TBI patients during their transition from hospital to home and the community setting were analyzed. These included: the caregiver's booklet manual, nursing guidelines, discharge educational materials and service plans.

### Ethical considerations

Approval was obtained from the Research Ethics Review Committee of the Faculty of Nursing, Prince of Songkla University (PSU IRB 2017 – NSt 005), and the Ethics Committee of Hatyai Hospital (ID 55 Protocol number 55/2560, ID 58 Protocol number 58/2561). Participants were given written information explaining the purpose of the study, procedures and plans to maintain confidentiality. Participants were also informed about their right to withdraw from the study at any time without interfering with health service benefits. Consent was provided both verbally and in writing.

### Data analysis

Content and thematic analysis<sup>16</sup> was used to explore the care planning for TBI situations within the Thai context by coding and interpreting textual material and transcripts. Data were transcribed verbatim in Thai, deleting frequent repetitious, pauses and emotional expressions. To get an overview of the themes, transcripts were first read through while listening to the tape recording. The analysis then moved into meaning condensation and coding, this allowed the researcher to extract words into fewer content related categories.<sup>17</sup> Data from observation and documentation were also combined, for instance interviews as well as focus groups ('data triangulation'), so as to gain a context for each meaning unit and categorization which emerged.

Several criteria were used to support the methodological rigor in this study by credibility or the truth value of the study, transferability or its applicability, dependability or the consist of procedures and confirmability or the neutrality of the findings.<sup>18-20</sup> Peer debriefing among the researchers was used to enhance the credibility of both data collection and analyses. The study characteristics of the participants, contexts and settings were clearly described to ensure transferability. The transcriptions of the audiotape records and memos from observation were kept for an audit trial. Two researchers, with professional nursing backgrounds, individually checked the transcriptions and frequently checked to validate the meaning categorization, so as to agree on the emerging contents. If the two researchers found any disagreement, a third researcher rechecked the transcriptions. Confirmability was also performed using member checking.

## Results

Five, female FCs participated in this study. Their ages were between 33 and 65 years of age. The relationships between FCs of TBI patients were: 1 mother, 2 spouses, 1 daughter, and 1 sister. Three (58.7%) had a primary school education. Most caregivers had a family income ranging from 1,000 to 10,000 baht per month (77.5%). Four of the FCs lived in the same house with patients without caregiver assistance. The nursing participants, all female, were aged between 26 and 54 years of age. More than half of them had bachelor degrees, and two of them had master degrees. They had experience in caring for TBI patients ranging from 2 to 22 years.

The results showed both positive and negative aspects in caring during hospital to home. However, this studies findings highlight some barriers when exploring the care plans, and activities derived from all collected data performed during the transitional period of TBI patients;

which include: (1) barriers related to service provision and (2) caregiver's information needs and support at home.

### Barriers related to services provision

Information gained from interviews and participant observation during discharge revealed that the nursing staff provide patient care focusing on physical care and management of care following the physician's treatment plans. Most TBI caregivers obtain information from nurses, emphasizing their hospital policy, hospital setting, cost of inpatient care and what the family was allowed to do in the hospital, whereas a few of them obtained general information from the nurse aids. A few of them were uncertain about the patients' conditions and progression during nursing procedures, partly because they were emphatically told only about "*what to do*" and "*how to do it*", but rarely was it explained "*why these procedures have to be done*." In addition, most medical procedures were explained to the FCs without their participation in the decision-making process. The main barriers were organized into four categories: (1) inadequate discharge teaching and information, (2) less time in caregiver's supervision and support, (3) lack of a comprehensive discharge plan, (4) lack of coordination and communication in follow-up care.

#### 1. Inadequate discharge teaching information

The members of the nursing staff in charge of the discharge plan often perform discharge teaching to the FCs in the acute phase, by assessing family caregiver's readiness and choosing appropriate ways to enhance their competency. The discharge care plan document was occasionally used as a guide in actual practice; discharge information and care plan documentation during the transitional period were then incomplete. In addition, the FCs' tasks involve attending to the patients' daily activities; such as bathing: grooming, and feeding, as well as changing

patient position, body exercise movements for prevention of other complications and close observation to detect (some alert) symptoms in order to avoid risk and accidents.

*“The nurse taught me about my relative’s daily activities; such as bathing; feeding, removing the secretion in his/her mouth by suction, preventing other complications by changing patient position and doing body movement, and supervising and caring in order to avoid dangerous accidents. Moreover, it will be good if the nurses give me the caregiving instruction handbook or any documentation related to caring [for] my loved one”* (FC1–5).

*“When I was visiting my husband, the nurse just told me to do A, B, C, and D procedures; however, she didn’t tell or explain to me why [I] need to do these procedures”* (FC2).

## **2. Less time in caregiver’s supervision and support**

Due to the hospitals short stay policy, and a large amount of nursing duties with patient care demands, the discharge planning program is informally learned and only occasionally arranged without clearly incorporating a teaching method, or allowing enough time in the setting to practice the method. In addition, the different care systems after discharge were separated from hospitalization, which affected both TBI patients and their caregivers in daily life. The family reported their feeling of un-readiness to learn. Most teaching methods as well as information were used for clinical learning, and skilled training with less supervision or monitoring of caregivers’ continuing care by nurses. Traditional attitudes and routine clinical practice without family engagement may lead to some barriers in care provision. Consequently, nursing staff and family caregiver interactions were more task-orientated and performed as routine. Moreover, the FCs were too shy, too considerate or too insecure to communicate to nursing staff. They were afraid of disturbing the nurses when

they were working. Most caregivers, therefore, acquired knowledge and skills for TBI care by self-learning, past experience in caregiving, observation of healthcare personnel and other caregivers’ practice. Some FCs were lacking in the time to spend on the caregiving process.

*“On the third day after surgery, the nurses told me I should do this thing, do that thing. However, they didn’t tell me when to do this or if it was necessary or not. How can I do this thing without the guidance of nurses? I don’t have any previous experience [about caring for TBI patients]”* (FC1).

## **3. Lack of comprehensive discharge planner**

The focus group of nine nurses identified that the existing care system still lacks comprehensive discharge planning and care coordination between setting and out of hospital. Incomplete information and documentation during the transitional period was recognized, and the different care systems after discharge were separated from hospitalization, which affected quality of care. In addition, the discharge preparedness program was not performed as needed. Some patients returned to the hospital with preventable complications, as a nurse reflected: *“Some patients were admitted back into the hospital due to a caregiver’s lack of knowledge and skill in caring, as a result, patients often returned with preventable complications.”*

*“At the beginning, we explained the hospital policy, hospital setting, cost of inpatient care and what the family was allowed to do in the hospital to TBI relatives. Then we usually provided care that involves physical care and management of the physician’s treatment plans. For the discharge planning program, sometimes we did it because we have only 1 discharge planner to serve patients and caregivers”* (nurses: focus group discussion).

*"I am the only discharge planning nurse in the neurosurgical area. The ward-nurses help me to teach discharge planning in some cases. My duty is preparing caregiver's and patient's readiness before discharge. When the patient's condition is stable, I usually teach the caregiver as soon as possible. I teach them about disease and the patient's condition, including caregiving skills to cover all aspects of the patient's needs"* (nurse, DN1).

#### **4. Lack of coordination and communication in follow up care**

The home visit program was usually managed by nurses, depending on the individual concerns, or assessment for TBI patients who needed to visit after discharge from the hospital. Based upon the principle of continuing care, it is required that all patients are visited by home healthcare nurses within 14 days after discharge. However, issues related to time for follow-up, coordination and communication between nurses and caregivers at home regarding patient problems, caring needs in the discharge plan, and outcome measure were identified.

*"My team (nurses) and I will follow up our patients within 14 days. However, we will have a list of name and arranged by severity, and we will visit patients as soon as possible. Sometimes we cannot visit within the timeline. Moreover, we try to quickly serve as best as we can, and schedule for those who have a severe illness. When we come to visit, we also have a checklist that the patient needs to continue and follow-up. If she/he needs help, we will come around the next month, depending on our available time"* (community nurse 1).

*"There has been little communication between the healthcare team and myself. When I see them, they are always busy. I don't know if I call them, or whether they can or cannot answer me"* (FC1, FC3).

*"I need a communication pathway in which I can contact them (health care professional) easily in order to ask for assistance, support and consult etc. Some-*

*times I felt it was difficult to talk to community nurses who I wasn't close with [the community nurse]"* (FC2).

*"When I called the community nurse for help, she sometimes didn't know my TBI patient's condition. Then I tried to contact the nurse in the hospital again for consultation. I hope to have a pathway in which any nurse can know and understand my patient's condition"* (FC2, FC4-5).

In conclusion, the existing follow up services, and TBI patient care system in the Thai context were less developed. Nursing staff provided patient care, focusing on physical care and management of care following the physician's treatment plans. Although TBI caregivers obtained general information from the nurse, some were uncertain about the patients' condition and prognosis. Discharge planning was performed without guidelines/ instructions and documentation. Moreover, the home visit program was usually performed without adequate coordination or communication in follow-up care.

#### **Barriers related to caregiver's information and support at home**

The results from the interviews of 5 TBI FCs reflected their need for information and support at home, and the current technology used for care at home. The results also identified the problems in the early period, after being discharged to home, due to the TBI patient's disability, which causes limitations in performing the fundamental activities of daily life. Ineffective caregiving, less confidence, or an inability to carry out caregiving tasks, in turn affects the patient's health status and disability rehabilitation.

##### **1. Less confident to provide care without support at home**

Most FCs reported that caring for TBI patients was a difficult task if they lacked support. They also felt less confidence, because they were unable to remember all discharged information.



*“Most caregiving activities at the hospital were done by nurses. The nurses taught me and my sister when we were to switch. At home, sometimes we felt less confident, if the nurse came to teach us again one by one, or used a video conference or had instructions for caregiving tasks it would be a better choice for me” (FC2).*

*“When the nurse taught me how to do caregiving procedures, I was able to do it in that time. However, as time passed, I could not remember something and I felt less confident in doing it. I was too considerate to ask the nurses again, because they looked very busy. I just learned from other caregivers and YouTube. I learned a lot from social media, but I don’t know whether it is right or not. If I could directly communicate with the nurse when I’m not sure I think it would be good” (FC4).*

## **2. Poor availability of resources and time for consultation**

Underlying this relationship undoubtedly is the association between the level of need and age of TBI patients. However, FCs were sometimes faced with many problems and needed some help from others. Most caregivers preferred to use personal telephones to contact a nurse to find a quick way to solve an urgent problem; like: airway obstructions, tracheotomy dislocation and so on. In addition, more hospital-based information was provided, and remained less coordinated or communicated as to the patients condition among the healthcare team and caregivers. Moreover, most TBI caregivers sought TBI care information via individual contact with nurses in the hospital, using the LINE application, or used YouTube, web based sites and web based medical sites based on available resources. However, the FCs avoided disturbing nurses as they reported.

*“At home, my sisters and I help to take care of my TBI brother. When my brother was not in a good condition, I recognized the time when I was at the hospital. I felt the nurses (neurological nurse) were busy all the time, so I*

*avoided disturbing them. I usually called my friend who is a pediatric nurse to ask for some help. Sometimes, I didn’t want to contact the nurse on duty and would call the nurse who I am familiar with. I think that if I have a guideline for caregiving, it could guide me to do thing right. It will be good” (FC2).*

*“My relative had some physical changes. I didn’t know what I needed to do. That time, I got in trouble. I then called the nurse that I am familiar with, or searched from the internet. I felt that the nurse on duty was very busy” (FC3).*

*“The community nurse didn’t know about my husband’s condition. I needed to explain and give her some documentation from the hospital to her. I usually found caring information from the internet, or called back to the hospital more than consulting with the community nurse. I felt tired, stressed and a physical burden, I need a system that can help or decrease these tasks” (FC1).*

## **Discussion**

The two categories of the six main barriers found in the current TBI care system were (1) inadequate discharge teaching information, (2) less time in caregiver’s supervision and support, (3) lack of comprehensive discharge plan, (4) lack of coordination and communication in follow-up care, (5) less confident to provide care without support at home, and (6) poor availability of resources and time for consultation. The results reflected that the current service provision for TBI patients was still limited in informing and responding to the caregiving demands. The caregivers asked for some assistance in continuing care, and a regular follow up system after patients were discharged. Although, personal telephone contact with nurses was useful for them to solve some urgent problems, TBI care management information and individual contact with the hospital nurses by using technology at home is required.

Our findings also show that the existing TBI care system in the Thai context did not have a clear and comprehensive discharge program, partly because of no systemic documentation after discharge in addition to a lack of effective communication among multidisciplinary teams and caregivers in the transition period. This is similar to previous studies in transitional care.<sup>5,15</sup> The appropriate administration of a discharge plan along with advice for caregivers was essential in making them understand and learn more about the patient's condition, common complications and rehabilitation plans.<sup>21</sup> Therefore, the caregivers needed to learn more about the patient's condition during hospitalization. At the same time, listening to what caregivers felt, and answering specific questions about patient care can reduce their stress and anxiety during nurse-caregiver meetings.<sup>21,22</sup> Due to the high demands of TBI care in transition, it was important for nurses, who worked with TBI patients and their families, to grasp the essential meanings in the specific situations before giving care or teaching discharge planning. Since electronic equipment is used in daily life, the need for telehealth services may be necessary for rural, Thai communities. The technology in healthcare or telehealth has been shown to be relatively effective in rural areas for delivering psychological and medical services.<sup>23,24</sup> It is therefore suggested for nurses to communicate and cooperate with each other by using technology in nursing care or telenursing, and to provide evidence-based professional consulting along with supportive care; in order to enhance caregivers' adaptation to living and taking care of TBI patients along the journey.<sup>25,26</sup>

Developing an evidence-based caregiver transitional support program among TBI caregivers is suggested. Telenursing services could be an alternative. These would help to improve Thai TBI patient care, with lower costs in order to facilitate better communication and cooperation for both caregivers and TBI patients. Moreover, the nurses'

competency in working in these areas should be enhanced. This could be achieved by transitional care training programs, including the use of technology, especially for the young staff nurses, which is required. However, the interpretation of the findings from the care plan might caution nurses due to incomplete documentations of care management information.

In caring for TBI patients, in the Thai context, six main barriers related to services provision and family caregivers' capability for caring in the transitional period. In addition, Thai caregivers required more information and supportive care, in order to enhance their confidence and care management for TBI patients in the long term.

Due to the small number of participants and the convenience of the sample, a limitation of this study was its limited data. The small sample size may not allow the information to be generalizable to other neurological units. However, the findings from this current study suggest important areas for the future development of programs targeted at TBI patients and their families.

## Conclusion

There is a substantial gap in the existing literature regarding the barriers to encompass a successful care plan for Thai TBI survivors during a transitional period. Nonetheless, the previous studies suggested that technology has an important role in facilitating person-centered integrated care. Developments in technology are ongoing, and will continue to provide diverse applications to health-care. However, nursing research in the Thai context is currently limited regarding during transition, with a lack of consistent models of transitional care; which may inhibit the development and implementation of practices. Further research is needed to establish a model of transitional care for those living with a TBI and those taking care of such patients.



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## Conflict of interest

No conflict of interest related to this article was reported.

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