Feasibility Study Of M-Health Transition Care Program for Traumatic Brain Injury Caregivers

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ABSTRACT

Background: Caring in discharge transition for patients with moderate to severe traumatic brain injury (TBI) has impacted caregivers. MHealth has become popular for communication between a patient/caregiver and a health profession integrated into numerous public well-being programs in low-middle income countries but is limited for TBI caregivers.

Purpose: This study aims to assess the feasibility of the mHealth supportive care transition program based on transitional care theory for improving discharge readiness and reducing caregivers’ transition stress and burden of caregiving and the patient's readmission rate.

Methods: Seven family caregivers who met inclusion criteria were recruited. The mHealth supportive care transition program includes education and face-to-face information assisted by an android-based application, skill demonstration, assessment of the readiness of hospital discharge, and weekly monitoring and follow-up after the patient’s discharge is given. The outcomes were evaluated using a validated and standardized scale designed to measure transition stress and the burden of caregiving at the baseline, two weeks, and one-month post-discharge, including the patient’s readmission one month (within 28 days) after discharge. Feedback through the mHealth satisfaction questionnaire on the trial feasibility was also collected.

Results: The initial findings showed that all subjects experienced a decrease of stress transition and caregiver burden at two weeks and one-month post-discharge follow-up. High satisfaction scores on mHealth were also reported and no patient was readmitted within 28 days.

Conclusion: This feasibility study showed the mHealth supportive care transition program is feasible for implementation, but it is required to test the effectiveness in the next phase on RCT with a larger sample size.

Keywords: caregiver’s stress, burden, mHealth care transitional program, readmission rate, traumatic brain injury

1. Introduction

Traumatic brain injury (TBI) is a non-degenerative and non-congenital disorder of the brain that results from external mechanical forces, which can cause long-lasting or brief disability of mental, physical, and
psychosocial capacities (Savitsky et al., 2016). TBI causes numerous critical problems worldwide (Roozenbeek et al., 2013). Approximately 69,000,000 people are estimated to experience TBI every year, with various causes (Dewan et al., 2019). Moreover, the World Health Organization (WHO) has released the Global Status Report on Road Safety, which shows that approximately 1.35 million people die each year from road traffic accidents and are diagnosed with severe head injuries (World Health Organization, 2018).

Indonesia has reported a high incidence of traumatic brain injury (TBI). A total of 1377 people experienced TBI and were admitted to the neurosurgery unit at Hasan Sadikin Hospital, the Referral Hospital of West Java Province, Indonesia, in 2019 and increased to 1479 people in 2020 (Arifin et al., 2021). Also, TBI diagnoses were included in the top 10 diseases in Hasan Sadikin Hospital for three consecutive years from 2017 to 2019. Based on statistical data on the classification of traumatic brain injury, in each of these years, there were 59-60% cases of mild head injury, 25-27% cases of moderate head injury, and 14-15% cases of severe head injury. TBI patients come to the neurosurgery unit in the emergency department, intensive care unit, ward, and outpatient department.

TBI patients can experience a wide variety of impacts due to neurological deficits (Blennow et al., 2016). The physical impact caused by TBI can interfere with the fulfillment of patients' daily needs, such as the need to eat, dress, bathe, or mobilize because of the symptoms. Patients can encounter headaches, vision loss, loss of capacity to walk, mental weakness, cognitive decline, and different circumstances that are the outcome of harm to part of the brain because of TBI. These handicap conditions can persist after the patient's release from the medical clinic and are related to critical constraints in different aspects of regular daily existence (Alghnham et al., 2017), such as psychological and cognitive impairment, and decreased social functioning (Semple et al., 2019).

The diversity and complexity of problems and needs suggest a high demand of care for patients with TBI, especially during the transition to home to lead satisfying lives regardless of the consequences of brain injury (Stiekema et al., 2020). Patients with TBI need a caregiver to assist them in the schedule and type of medication to be consumed, provision of food, social security, and access to health services (Dillahunt-Aspillaga et al., 2013). Several tasks are undertaken, including fulfilling daily living activities, assisting in mobilization and medication, and overcoming other problems experienced by patients, such as psychological, social, and cognitive problems (Karpa et al., 2020). Moreover, caregivers have another essential role to provide mental and emotional support to TBI patients facing changes in all aspects of life (Turner et al., 2010).

In Indonesia, caregivers play a role when patients with TBI are admitted to the hospital, up to treatment at home in the transition phase. In hospitals, caregivers assist nurses in meeting the needs of patients' daily living activities, such as mobilization and personal hygiene, aimed to prepare caregivers to treat patients at home. These conditions can certainly affect the burden experienced by caregivers. The results of study showed that the caregivers of patients with TBI who were hospitalized and helped treat patients had a higher burden (Potter et al., 2017). A review of studies in Indonesia and LMIC revealed that most caregivers do not feel confident or are ready to care for TBI patients at home, and need to gain more support in the transition period.
Caring for someone with TBI has been shown to negatively impact on caregivers, particularly in the transition period from hospital to home, which is regarded as a critical period for TBI care. The conditions that occur in caregivers of moderate to severe TBI patients require more TBI care and support systems which integrate essential services to reduce morbidity and mortality rates and the incalculable human suffering that results from neurotraumatic events with appalling sequelae (Huffman et al., 2011). Most caregivers for TBI patients reported high levels of stress and burden when caring for patients with TBI at home (Lieshout et al., 2020). A qualitative study also mentioned that the TBI caregivers experienced less satisfaction to support successful discharge (Piccenna et al., 2016).

To reduce stress transition, caregiver burden, and prevent hospital readmission, there needs to be therapeutic intervention focusing on problem-solving coaching and embodying proper caregiver education before the discharge of patients with TBI from the hospital, which can reduce the chance of developing psychological symptoms in caregivers in the future (Qadeer et al., 2017). In addition, providing information about TBI patients will help reduce tension and stress in caring for TBI patients (Blake, 2017). Also, the education and training of TBI caregivers through demonstrations is essential to reduce caregiver burden and prevent complications in TBI patients after discharge from the hospital (Verma et al., 2018). However, currently available nursing interventions in Indonesia’s hospitals only focus on patients with TBI, not TBI caregivers.

We developed and assessed the feasibility of the mHealth supportive care transition program based on transitional care theory for improving discharge readiness and reducing caregivers' transition stress and burden of caregiving and the patient's readmission rate. The purpose of this paper is to describe the design, method, and characteristics for our feasibility study.

2. Method

2.1 Study overview

This feasibility study was conducted at a single center at Hasan Sadikin Hospital, Bandung, Indonesia. The pilot study was conducted from June 12 to August 12, 2022, as part of a quality improvement project in the hospital. This study was approved by The Research Ethics Committee of Center for Social and Behavioral Science IRB (Document Number: 2022-St-Nur-St-35), and The Research Ethics Committee of Dr. Hasan Sadikin General Hospital Bandung (Document Number: LB.02.01/X.6.5/459/2022). Our research team consisted of nurses and a neurosurgeon.

2.2 Conceptual framework

Meleis' transitional theory was used as a guide in developing programs and achieving the expected outcomes. The transition experience starts before an event and has an ending point that varies based on numerous variables. The transitional period from hospital to home among patients with TBI and their caregivers has attracted great attention.
Understanding the idea of and reactions to change, working with the arrangement and answering its various stages, and advancing well-being and prosperity previously, during, and toward the end of the change occasion prompts the use of Transitions Theory. It affords a system that creates research questions and guides viable consideration prior, during, and post transition care. Transition theory evolved from clinical practice is supported by research evidence and provides a framework for application in practice, research, and theory building.

Transitioning patients with TBI from hospital to home is the health-illness event from nursing interventions to caregiver intervention. This condition necessitates additional attention from nurses to optimize the patient’s well-being. The transition from hospital to home is crucial to innovate patients with TBI and their caregivers. Nurses have helped patients, families, and communities to address transitions by anticipating responses, providing prevenient steering, ameliorative symptoms, enhancing health and well-being, and supporting the implementation of self-care actions (Meleis, 2010).

The mHealth application plays a role in improving patient care in the transition period from hospital to home and reducing the prevalence of preventable disease complications. Information and communication available to caregivers in patients with TBI through the mHealth application are targeted, relevant, and supported during all care stages, especially in the transition period. This education and personalization results in higher engagement, better patient outcomes, and lower readmission rates. The following is a research conceptual framework based on the transitional theory model from Meleis (Meleis, 2010).
Figure 1. Conceptual framework

### Nursing Therapeutic

#### Assessment of readiness
- Physical ability for care of the patient
- Adequate support for care after hospital discharge
- Emotional stability of caregivers
- Sufficient information and knowledge to answer common problems

#### Providing education and information
- How to treat patients with TBI at home, which includes wound care and how to provide nutrition
- Recognize signs of infection in wounds of craniotomy
- Recognize emergencies in cases of TBI patients at home
- Stress management
- How to arrange a schedule for the care of patients with TBI at home

#### Role supplementation of nurse
- Provide information and skill during discharge
- Preparing caregivers to manage the patient with TBI
- Empower caregivers through clarity, knowledge, skill, and resources
- Counseling the problems of caregiver
- Support to help caregivers manage wound and nutrition
- Facilitate consultation with neurosurgeons when there are medical problems of patients with TBI

### Monitoring and follow-up

**Coordination with nurses at the Community Health Center around the patient’s residence**

<table>
<thead>
<tr>
<th>Caregiver’s domain</th>
<th>Patient’s domain</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stress transition</td>
<td>Sign and symptoms</td>
</tr>
<tr>
<td>Caregiver burden</td>
<td>Patient’s readmission</td>
</tr>
</tbody>
</table>

**Outcome**
- Mastery
- Fluid and integrative identity
- Resourcefulness
- Healthy interaction
- Perceived well-being (Reducing the transition stress, and caregiver burden, prevention of patient’s readmission)
2.3 Development of intervention

The development of this program consists of five stages, including: (1) searching the literature regarding the problems and caregiver needs in caring of TBI patients during the transition from hospital to home and interventions that can be provided; (2) developing the program, which includes educational modules and mHealth applications adapted to caregiver conditions; (3) test the program content and educational modules by three experts (2 experts from Indonesia and one expert from Thailand); (4) refinement of modules and programs according to suggestions from experts; and (5) test the feasibility of applications.

2.4. Interventions

Two stages in the six-day period before the patient discharge consisted of 1) preparation for TBI caregivers’ readiness and
2) monitoring and follow up. Details of the activities of researchers and caregivers at the hospital are explained in Table 1.

Table 1. The activities of researchers and caregivers at the hospital

<table>
<thead>
<tr>
<th>Time</th>
<th>Duration</th>
<th>Place</th>
<th>Activities</th>
</tr>
</thead>
</table>
| Day 1  | 20 minutes |       | • Ask the head nurse of neurosurgical wards to select the caregivers based on the inclusion criteria
• Head nurse introduces the researcher
• Ask the caregivers regarding the willingness to join in the study
• Explain the objective of the study and ask the caregivers to sign the informed consent form
• Ask the research assistant to conduct the randomization
• The caregiver will actively participate in the session
• The caregiver will sign the informed consent form |
| Day 3  | 30-45 minutes |       | • The researcher visits the caregivers to download the program and teach them how to operate it
• After the program is successfully downloaded, the researcher guides the program until the caregiver clearly understands
• Start with the first session of education regarding how to provide nutrition for patients with TBI at home using flipchart and demonstration
• Download the program in the cellphones
• Actively participate in the session |
| Day 4  | 45 minutes   |       | • The researcher evaluates the caregiver's knowledge and abilities related to the first session and then repeats the explanation if there are some parts that the caregiver does not understand or remain unclear
• Continue the second session of education regarding craniotomy wound care and recognize signs of wound infection using flipchart and demonstration
• Actively participate in the session |
| Day 5  | 45 minutes   |       | • The researcher evaluates the caregiver's knowledge and abilities related to the second material
• Actively participate in the session |
The researcher reviews and repeats the explanation regarding the first meeting if there are parts that the caregiver does not understand.

Continue the third session of education regarding how to recognize emergencies in cases of TBI, stress management, and how to arrange a schedule for the care of patients with TBI at home.

Day 6 15 minutes

- The research assistant (RA) measures the readiness of hospital discharge, stress transition and caregiver burden.
- The researcher informs the Community Health Center around the patient’s residence of the patient’s discharge from the hospital.

Fill the questionnaire

Monitoring and follow-up

After the patient returns home, the researcher continues monitoring and follow-up via online chat in the mHealth and telephone. Each participant can ask questions through the online chat regarding caring for patients with TBI at home and the problems caregivers face. Also, researchers monitor whether participants use the mHealth application regularly at home and will contact caregivers via online chat to remind caregivers to keep using the application. Follow-up calls are made every week for four weeks after the patient's discharge. Details of the activities of researchers and caregivers are in Table 2.

Table 2. The activities of researchers and caregivers during monitoring and follow up

<table>
<thead>
<tr>
<th>Time</th>
<th>Duration</th>
<th>Activities</th>
</tr>
</thead>
</table>
| Follow up twice at one week (week 1) and two weeks (week 2) after hospital discharge | 5-10 minutes | - Researchers begin each call by asking open-ended questions to ascertain any issues since the last call.  
- Researcher uses a problem-solving approach to address the situation.  
- Researcher then asks a series of open-ended questions to help the caregiver apply the problem-solving steps of problem definition, goal setting, solution generation, solution |
|                           |          | - Each caregiver is then asked to identify the concern they wish to address on the call.  
- Actively participate in the session |

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Supposing there is a problem that the researcher cannot resolve during the consultation via phone, then, in that event, the researcher will consult with a neurosurgeon at Hasan Sadikin Hospital. If the patient cannot reach the hospital, the researcher will coordinate with the nurses at the Community Health Center around the patient’s residence for home visits. The research assistant will measure transition stress and caregiver burden in the second and fourth weeks after discharge. During the study period, researchers will evaluate readmission cases and their causes by the online questionnaire via Google Forms. The scheme of intervention is shown in Figure 3.

2.5. Sample

Seven family caregivers who met inclusion criteria were recruited. The inclusion criteria included: age 18 or older, family members who identified themselves as a responsible person in caring for patients at home or main caregiver who has been assigned by other family members in caring for patients, caregivers who provide care of patients with moderate or severe TBI, able to communicate, read, write and speak Indonesian well, willing to be involved in research, readiness for hospital discharge score <16, and have an android phone and can operate it well.

The exclusion criteria in this study were caregivers for patients with TBI with comorbidity (heart disorders, kidney
Figure 3. Scheme of intervention

- Day 1: Randomization by a research assistant
  - Intervention group
  - Control group

- Day 2: The researcher will obtain informed consent and demographic data
  - Six days before hospital discharge
    - Receive the routine care
    - Researcher will visit the caregivers to download the program and teach them
    - The first session of education regarding how to provide nutrition for TBI at home
  - Four days before hospital discharge
    - The second session of education regarding craniotomy wound care and how to recognize signs of infection in wounds
  - Three days before hospital discharge
    - The third session of education regarding recognizing emergencies in cases of TBI, stress management, and how to arrange a schedule for the care of patients with TBI
  - One day before hospital discharge
    - The research assistant will collect baseline data: Stress transition and caregiver burden, Readiness of hospital discharge (only for the intervention group)
    - Monitoring and peer group support via Online Chat Room by the researcher
    - No action from the researcher
    - Telephone follow-up by the researcher
    - No action from the researcher
    - Telephone follow-up on intervention group; research assistant will collect Stress transition and caregiver burden via google forms
    - No action from the researcher
    - Telephone follow-up and evaluation of readmission by the researcher
      - A research assistant will collect the following:
        - Stress transition and caregiver burden
      - Evaluation of readmission by researcher
        - The research assistant will collect the stress transition and caregiver burden
2.6. Data collection & instruments

Researchers used three types of instruments (questionnaire A-C) in data collection, including data on respondent characteristics, stress transition, and caregiver burden. The validity test used the content validity test. In addition, three experts carried out the face validity test—one from Thailand and two from Indonesia. The results of the face validity test showed that all questionnaires are suitable to measure the outcomes in this study.

**Questionnaire A: Demographic data**

This questionnaire contains data on the characteristics of the patients and caregivers, consisting of age, gender, relationship with the patient, length of care for the patient, level of job education, and income level.

**Questionnaire B: Stress transition**

The stress transition questionnaire used the Caregiver Stress Self-Assessment from Dr. Steven Zarit, a modified version containing a list of 20 statements that reflect how people sometimes feel when taking care of another person (Zarit et al., 1998). This questionnaire was first developed in the 1980s by Dr. Zarit to evaluate caregiver stress. After each statement, participants are asked to indicate how often they feel that way: never, rarely, sometimes, quite frequently, or nearly always. The answer scores are Never = 0, Rarely = 1, Sometimes = 2, Quite Frequently = 3 Nearly Always = 4. Total scores are summarized and categorized. If the score is 0-20, the caregiver is declared Little/No Stress, 21-40 = Mild/Moderate Stress, 41-60 = Moderate/Severe Stress, and 61-80 = Severe Stress. The reliability coefficient alpha was 0.88.

**Questionnaire C: Caregiver burden**

This study used the Short-Zarit Burden Interview (ZBI), which gives a complete evaluation of each goal and subjective burden. It is one of the most customarily used burden measures and verified in many culturally or ethnically exclusive populations (Luo et al., 2010). The Short-Zarit Burden Interview (ZBI) is a 12-item instrument for measuring the caregiver’s perceived burden of providing family care. The 12 items are assessed on a 5-factor Likert scale. Items 1 to ten have positive statements so that the value ranges from 0 = 'never' to 4 = 'nearly continually.' Items 11 and 12 have negative questions, the value ranges from 0 = 'nearly continually' to 4 = 'never.' Item ratings are introduced to give a complete rating ranging from 0 to 48, with higher scores indicating extra burden. The final score is grouped into 0-10: no to the mild burden, 10-20: mild to the moderate burden, and >20: high burden. The Pearson's correlation coefficient was 0.53 to 0.73. The Cronbach's alpha value for the ZBI items was 0.93.

**Readmission rate**

The readmission rate in patients with TBI was monitored through the hospital's medical record database.
mHealth satisfaction

The mHealth Satisfaction Questionnaire modified from Melin (2020) consists of 14 items where the respondents were asked to rate of what extent they agreed on using mHealth transition care program application on a 5-point Likert scale (Melin et al., 2020). A higher rating corresponds to a higher agreement (i.e., 1 = strongly disagree, 5 = strongly agree); 10 items are positively stated, while four items are negatively stated. The negatively stated items were reversed in the analyses; accordingly, higher values correspond to higher leniency. The Cronbach's alpha value for the mHealth Satisfaction Questionnaire items was 0.84.

Back translation technique

The instruments were translated into the Indonesian language through the lower back-translation by a qualified team of translators who are native speakers of the target language. This is the forward translation process and involves a translator, editor, and proofreader. Once the forward translation is complete, this is translated back into the source text language by another translator who has not read the original text. Next, the researcher reviewed the back translation against the source text, one sentence at a time. Again, we use another individual who has had no part in any of the previous translation steps, typically using a senior bilingual translator.

Validity and reliability of Indonesian version of instruments

Item validity is the degree to which an individual item measures what it purports to measure. Item validity was carried out on 30 caregivers of patients treated at Hasan Sadikin Hospital before the study period. The item validity test has been analyzed using SPSS version 26.0 with the following results.

Table 3. Validity and reliability of Indonesian version of instruments

<table>
<thead>
<tr>
<th>Questionnaire</th>
<th>Validity and reliability</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caregiver Stress Self-Assessment</td>
<td>The range of the corrected item-total correlation from 0.77 to 0.95. The Cronbach’s alpha value was 0.91.</td>
</tr>
<tr>
<td>The Short-Zarit Burden Interview</td>
<td>The range of the corrected item-total correlation from 0.69 to 0.93. The Cronbach’s alpha value was 0.88.</td>
</tr>
<tr>
<td>The Preparedness for Caregiving</td>
<td>The range of the corrected item-total correlation from 0.77 to 0.95. The Cronbach’s alpha value was 0.90.</td>
</tr>
</tbody>
</table>

2.7. Statistical analysis

Data were analyzed using descriptive analysis and inferential statistics. The numerical data types, namely age, length of patient care, income, and readiness of hospital discharge, were presented in the form of mean, median, standard deviation, minimum value, and maximum value. Meanwhile, for the presentation of categorical data, namely gender relationship with patients, education level, stress transition, caregiver burden, and the incidence of readmission, patients were presented in percentages/proportions. One-way repeated-measures analysis of variance (one-way RM-ANOVA) was compared to
the difference stress transition and caregiver burden across the three time points.

Figure 4. M-health transition care program application
3. Result

3.1. Demographic characteristics of caregivers

Generally, family caregivers were different in some characteristics including age, gender, relationship with the patient, length of care for the patient, level of job education, and income level (Table 4).

Table 4. Characteristics of age and income of caregivers (N = 7)

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Mean</th>
<th>SD</th>
<th>Min-Max</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>41.43</td>
<td>9.73</td>
<td>22-50</td>
</tr>
<tr>
<td>Income (US)</td>
<td>195</td>
<td>634.72</td>
<td>128.23-301.33</td>
</tr>
</tbody>
</table>

Based on Table 4, the average age of caregivers is 41.43 years, with a standard deviation of 9.73. At the same time, the mean caregiver income is around 195 US dollars. The characteristics of sex, relationship with the patient, and level of education are shown in Table 5.

Table 5. Characteristics of gender, relationship with the patient, and the level of education of caregivers (N = 7)

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td>7</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>4</td>
<td>57.1</td>
</tr>
<tr>
<td>Female</td>
<td>3</td>
<td>42.9</td>
</tr>
<tr>
<td>Relationship with the patient</td>
<td>7</td>
<td></td>
</tr>
<tr>
<td>Husband/wife</td>
<td>1</td>
<td>14.3</td>
</tr>
<tr>
<td>Child</td>
<td>4</td>
<td>57.1</td>
</tr>
<tr>
<td>Parents</td>
<td>2</td>
<td>28.6</td>
</tr>
<tr>
<td>Level of education</td>
<td>7</td>
<td></td>
</tr>
<tr>
<td>Higher degree</td>
<td>2</td>
<td>28.6</td>
</tr>
<tr>
<td>Bachelor degree</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Based on Table 5, 57.1% of caregivers are men and are husbands of patients with TBI. In addition, 71.4% of the participants have a higher degree education level.

3.2. Readiness of hospital discharge

The following is the mean value of readiness for hospital discharge for both caregivers (Table 6).

Table 6. Readiness of hospital discharge of caregivers (N = 7)

<table>
<thead>
<tr>
<th>Variable</th>
<th>Mean</th>
<th>SD</th>
<th>Min-Max</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Readiness of hospital discharge</td>
<td>14</td>
<td>1.15</td>
<td>12-15</td>
<td>0.0001</td>
</tr>
<tr>
<td>Before intervention</td>
<td>18.86</td>
<td>1.07</td>
<td>17-20</td>
<td></td>
</tr>
</tbody>
</table>

Both patients had a readiness for hospital discharge score of less than 16, so they were included in the pilot study. However, after face-to-face education with the help of mHealth was carried out, the readiness for hospital discharge score
increased by 6 points to 20 and 19, respectively, before discharge.

3.3. Stress transition

The following is the value of stress transition at discharge and two weeks after discharge for both caregivers (Table 7).

<table>
<thead>
<tr>
<th>Variable</th>
<th>Pre-discharge score</th>
<th>Two weeks after discharge score</th>
<th>One month after discharge score</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean</td>
<td>SD</td>
<td>Mean</td>
<td>SD</td>
</tr>
<tr>
<td>Stress transition</td>
<td>40.14</td>
<td>1.215</td>
<td>28.86</td>
<td>2.79</td>
</tr>
</tbody>
</table>

Based on Table 7, we can see that both sets of subjects experienced a decrease in the stress score during the transition at follow-up of two weeks and one month after hospital discharge. Although both still experienced mild-moderate stress level, the values obtained showed that the stress transition was reduced two weeks after discharge, and achieving the minimum score for the mild-moderate stress level in one month post-discharge from the hospital.

3.4. Caregiver burden

The following is the value of caregiver burden at discharge and two weeks after discharge for both caregivers (Table 8).

<table>
<thead>
<tr>
<th>Variable</th>
<th>Pre-discharge score</th>
<th>Two weeks post discharge score</th>
<th>One month after discharge score</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean</td>
<td>SD</td>
<td>Mean</td>
<td>SD</td>
</tr>
<tr>
<td>Caregiver burden</td>
<td>17.86</td>
<td>1.46</td>
<td>15.71</td>
<td>1.49</td>
</tr>
</tbody>
</table>

Based on Table 8, we can see that both subjects experienced a decrease in the value of caregiver burden at two weeks follow-up after discharge from the hospital. Although both sets of subjects still experienced mild to moderate burden level, the values obtained showed that the caregiver burden was slightly reduced two weeks after discharge from the hospital. Also, both achieved the minimum score for mild to moderate burden level in one month post-discharge from the hospital.

3.5. The patient’s conditions related to caregiver’s burden

Researchers also monitored the patient's condition before leaving the hospital and the patient's condition two weeks and one month after hospital discharge through telephone monitoring. Before being discharged from the hospital, most patients were conscious, but there were two patients with GCS 14, and the patients sometimes screamed because of headaches. All patients had a craniotomy wound bandaged on discharge and needing a dressing once a day after discharge. All patients were not able to mobilize by walking, except sitting. The activities of daily living such as eating and drinking, bathing and dressing were assisted by the family. Most patients had pain in the craniotomy wound. Two patients had limb weakness, and one patient with visual impairment. A total of five patients still received tube feeding when
discharged.

The majority of patients (5) had conditions improved at the time of follow-up two weeks after discharge. One patient had improved consciousness but was still sleepy and had headaches. The patient's craniotomy wound was dry, and the stitches were removed at two weeks after discharge. Most patients’ activities were still assisted by the family, especially those with mobility difficulties, who required assistance from the family to bathe, change clothes, and move around. However, after one month follow-up discharge, some patients (3) still experienced occasional headaches, and some (4) were already independent in their activities, such as eating and drinking except for bathing and walking where they were still assisted by family members.

3.6. Readmission rate

The hospital's medical record data showed no readmission for the seven patients.

3.7. mHealth satisfaction

Regarding an assessment of caregiver’s satisfaction in using mHealth, the findings showed that all caregivers were satisfied with using mHealth with an average score of 55.6. When caregivers are at home, they use the mhealth application at least once a week. They sometimes re-validate their actions to treat patients with TBI at home. For example, two caregivers asked via Online Chat whether the method of wound care they did was correct. Even though the steps for wound care are already in the application, the two caregivers want to ensure that the steps they are taking are accurate. In general, participants said they found no problems when using the application. They said that it was easy to use and the material contained in the program was easy to understand.

3.8. Subjective evaluation

In general, all caregivers said that the mHealth program was easy to use and helped treat patients with TBI at home. At the beginning of the pilot study, the mHealth application only contained six modules. However, caregivers said that it would be better if they added videos on how to treat wounds and provide nutrition to make it easier to carry out these two procedures. Thus, the researcher improved the mHealth program by adding a video demonstration of how to treat wounds and provide nutrition to patients at home.

4. Discussion

Continuity of care in patients with TBI and caregivers needs particular attention in Indonesia. For patients with moderate and severe TBI who require long-term care, the continuity program of transitional care is a crucial component bridging the in-hospital care program and out-of-hospital follow-up care (Siripituphum et al., 2020). Research also proves that this program effectively increases the caregiver's ability to carry out care, improves the caregiver's psychological condition, and reduces the incidence of re-hospitalization (Shahrokhi et al., 2018; Stiekema et al., 2020). Continuous nursing services in Indonesia are regulated in the Regulation of the Minister of Health in 2012. It is explained that patients who require long-term benefits after receiving treatment are carried out in primary services (Minister of Health of the Republic of Indonesia, 2012).
In practice, in Indonesia, transitional care services for patients with TBI have not been developed.

This study was informed by Meleis' transitional theory, a conceptual model theory in developing programs and achieving the expected outcomes. The transition experience starts before an event and has an ending point that varies based on numerous variables. One of them is the transitional period from hospital to home in patients with TBI and their caregivers. Understanding the nature of and responses to change, facilitating the understanding and responding to its different phases, and promoting health and well-being before, during, and at the end of the change event prompts the utilization of transitions theory (Meleis, 2010). It provides a framework that generates research questions and guides effective care before, during, and after the transition.

The feasibility of this program showed a decrease in the value of transition stress in the second and fourth weeks after discharge from the hospital. In addition, statistical tests showed significant differences in the transition stress cycle at pre-discharge, two weeks post-discharge, and the first month post-discharge. Caregiving in TBI is associated with various unfavorable consequences for caregiver health, psychological well-being, and life satisfaction. Substance abuse in TBI people is brought about the higher caregiver stress. The strongest stress allaying factor proved to be a healing intervention in the form of problem-fixing education. Recommendations include proper caregiver education earlier than discharging the TBI sufferers from the health center, which would lessen the opportunities of psychological signs and symptoms performing within the caregivers in the future (Qadeer et al., 2017).

Likewise, for caregiver burdens, this study shows a decrease in caregiver burden score in the second and fourth weeks after discharge from the hospital. Statistical tests showed significant differences in caregiver burden scores at pre-discharge, two weeks post-discharge, and the one month post-discharge. Caregiver burden can be defined as the multifaceted strain the caregiver perceives from caring for a family member with TBI at home after discharge (Coxe et al., 2020). A study highlights distinct aspects of the burden experienced by primary caregivers of adults with TBI (Manskow et al., 2017). In this study, the reduction in the burden on caregivers is likely related to the support provided by researchers in the interventions provided. Also, some caregiver questions and confusion, such as the condition of the craniotomy wound, can be consulted and discussed with the nurse through the program provided. A previous study explained that caregivers of TBI patients with fewer sources of support have a higher risk of experiencing a burden (Griffin et al., 2017).

This program was implemented in a low socioeconomic sample compared to previous studies conducted by involving caregivers with a high level of education (Caplan et al., 2016; Shahrokhi et al., 2018). Meanwhile, in this program, there were various levels of caregiver education. Indonesia's population is the fourth largest in the world. However, only 8.5% managed to graduate from higher education (more than secondary education). From the feasibility results of this study, it is found that even though caregivers have only secondary education, they can easily use this mHealth application. They also said that the online chat feature made it easy to ask questions or consult with nurses. The mHealth application program can also be easily downloaded for free on Google Playstore.
This transitional care program was combined using an educational platform via Android, which was previously explained face-to-face to the caregiver. After the patient with TBI comes home from the hospital and the caregiver takes care of the patient at home, follow up by telephone once a week was performed. The caregivers had the opportunity to discuss through the online chat and were expected to have optimal understanding and skills in caring for patients with TBI. The caregiver's readiness for discharge score increased from the measurement before the intervention was given and the measurement before the patient went home. Some of the question items that have an increased score are caregiver readiness in taking care of the patient's physical condition, dealing with changes in the patient's emotions, and dealing with stress that can be experienced by caregivers while caring for patients with TBI.

MHealth provides information caregivers need in caring for patients, including how to manage stress. They can easily repeat information by opening the application. The literature concluded that information could improve knowledge and recommended active education strategies that included participant involvement and planned and repeated educational episodes for reinforcement and clarification (Ostwald et al., 2014). The caregivers were also satisfied with using mHealth, including it was easy to use, suitable to use, the time spent using it has been accepted, the introduction of how to use it was sufficient, it was not overly time-consuming, and it motivated them to take care of the patient according to the procedure described in the program. They also said that they recommend mHealth to others. This condition can be assumed to be related to the education level of caregivers in this feasibility study, which is middle to high-level education.

This study shows that the mHealth transition care program is feasible for caregivers of Indonesia's moderate and severe TBI patients. However, this study involved a small sample. Furthermore, it was conducted in a single center, so a larger sample size is needed, using a randomized controlled trial method and a control group to identify the program effects in more depth.

5. Conclusion
This pilot study showed the mHealth supportive care transition program is feasible for implementation but there is a need to test the effectiveness in the next phase on RCT with a larger sample size.

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7. Conflict of interest
All authors stated that there was no conflict of interest in this study.
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