

# Coping with Traumatic Brain Injury Using the Preparation Program among Caregivers of Patients in the Intensive Care Unit

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## ABSTRACT

**Background:** After sustaining severe traumatic brain injury (TBI), most patients suffer both physical and mental disabilities. Caregivers of those critically ill patients have to deal with crises not only from unexpected injury, but also from difficult situations in giving care to them. The preparation program (PP) which assists caregivers to cope by enhancing the participation in care during intensive episode is needed.

**Objective:** To examine differences between mean coping scores of TBI patients caregivers who received the PP and those receiving the usual nursing care.

**Methods:** A quasi-experimental research design was conducted. The sample included 40 caregivers of ICU patients with severe TBI, 20 for a control group and 20 for an experimental group, was recruited. The Preparation Program (PP) implemented in the experimental group was developed based on an extensive review of related literature. The Thai version of the Coping and Adaptation Processing Scale Short Form (TCAP-SF) was administered before and after the training of caregivers with PP to determine their coping ability. Data were analyzed using Chi-square and t-test.

**Results:** Caregivers who received the PP had a higher mean of coping score ( $\bar{X}$  = 98.50, SD = 8.32) than those receiving the usual care did ( $\bar{X}$  = 79.55, SD = 12.20) at  $p < .001$ .

**Conclusion:** Caregivers were able to cope better after receiving the PP. The PP facilitated them to deal with a crisis episode of a family member with TBI in the ICU by getting more participation in their care. However, the coping of caregivers after patient discharge from the ICU to ward and after returning home should be evaluated.

**Keywords:** Caregiver, coping, critically ill patient, preparation program, traumatic brain injury

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**T**raumatic brain injury (TBI) not only has direct effects on patients physically, psychologically, emotionally, and socially, but also involves caregivers and other family members.<sup>1</sup> Especially, patients with critical conditions in the intensive care unit (ICU) cause their caregivers stress, worry, and uncertain feelings about prognosis and treatment.<sup>2</sup> If caregivers do not receive any timely and suitable help, they are likely to subsequently suffer from loss of balance in life and be unable to adjust themselves to cope and respond to any unexpected situation.<sup>1,3,4</sup>

A review of literature has illustrated that another important factor which affects caregivers coping is suitable responses to caregivers needs. In other words, the actual needs of caregivers should be responded to appropriately since the critical period is after a patients admission to the ICU.<sup>4</sup> The provision of information to caregivers during this critical period, particularly, when it is systematically introduced as a properly designed program, can reduce the stress and anxiety of caregivers,<sup>5</sup> and at the same time increase their satisfaction with the service of the healthcare team.<sup>6</sup>

Nonetheless, the program to enhance the coping of TBI patients caregivers by preparing them to take part in the care of family member with TBI relating to their needs and readiness is essential. Since this kind of program has not existed in Thailand, the researchers developed a preparation program to equip caregivers to deal with this

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difficult situation of taking care of critically ill TBI patients. The preparation program consisted of dissemination of information and necessary skills practice for caregivers to provide care in order to meet patients needs during this difficult period. Therefore, the effectiveness of the program on caregivers coping needs to be explored in this study.

### Research objective

To examine the differences between the mean coping scores of TBI patients caregivers in the ICU who received the preparation program and those who received the usual nursing care.

### Research hypotheses

1. The caregivers of TBI patients in the ICU will cope significantly better after receiving the preparation program.
2. The caregivers of TBI patients in the ICU who receive the preparation program will cope significantly better than those who receive the usual nursing care.

## MATERIALS AND METHODS

This quasi-experimental research with 2 groups pre-post test design was employed. The inclusion criteria were caregivers of patients with moderate to severe TBI in the ICU at a tertiary care hospital in Thailand. They were primary informal caregivers, such as father, mother, spouse, and patients relatives, who did not receive any remuneration in return for their caregiving duties, and at least 18 years of age or older. For the critically ill TBI patients, they had Glasgow Coma Scores (GCS) of 3-12 points with no previous history of physical and mental impairment. The present study was approved by Mahidol University Institution Review Board (MU-IRB 2008/021.2205) and the Ethical Committee of the hospital study site.

### Subjects and sample size

The sample size was calculated based on a review of research previously carried out with similar populations from the study of Sinnakaruppan, Downey, and Morrison.<sup>7</sup> The formula used in determining the effect size (Effect size =  $d$ ) was adopted from Glass, McGaw, and Smith.<sup>8</sup> The power analysis was accomplished with a level of significance ( $\alpha$ ) of .05. The power of the test was set at .08. The calculated effect size was 50. The table of Cohen<sup>9</sup> indicated a possible minimum sample size of 25 subjects for each group. However, the number of subjects enrolled in this study was 56. For these, a simple random sampling with block randomization and random number table was performed. The sample was divided into two groups: 27 in the experimental group and 29 in the control group. During the data collection, 16 TBI patients passed away: 7 in the experimental group and 9 in the control group. Caregivers of those 16 patients were, then, excluded from the study with no recruitment substitution. Finally, the total number of subjects with complete data for subsequent analysis was equal to 40: 20 in the experimental group and 20 in the control group.

### The preparation program

The preparation program (PP) was developed based on an extensive review of related literature and research<sup>10</sup>. It was composed of giving information, daily nurse-caregiver meetings, and skill practice for caring for TBI patients

which was adapted to the patients conditions and progress. The care activities were discussed and scheduled. Therefore, choices of care activities were decided on daily basis. In order to reinforce the skill training, 12 patient care manuals on different topics were included in an educational package for caregivers which were established by the researchers. The essential care activities for TBI patients were contained in a caregiver manual, for example, general hygiene care, feeding, suctioning, prevention of complications, chest physical therapy, and rehabilitation. They were delivered to caregivers individually with concern for each patients problems, specific needs in patient care, and caregivers need and readiness. The content validity of manuals and the PP were also examined. The PP was introduced as a 7-consecutive day skill training for giving TBI patients care in the ICU by their caregivers.

### Measurement

The Thai version of the Coping and Adaptation Processing Scale Short Form (TCAP-SF) was used to evaluate the coping of caregivers in this study which was based on the Roy adaptation model and the Roy's nursing model of cognitive processing.<sup>3,11,12</sup> A twenty seven item questionnaire which consisted of 3 modes of coping strategies including physiologic-physical, self-concept, and interdependence was used.<sup>12,13</sup> The higher score indicated the better coping. The Cronbachs alpha correlation coefficient of the TCAPS-SF was equal to 0.85.

### Data collection

#### The experimental group

1. The pretest score of caregivers' coping was gathered using the TCAPS-SF within 72 hours after TBI patient admission to the ICU, but before the preparation program was started (Coping<sub>pre-exp</sub>).
2. The PP was engaged. The researchers provided information about patients' conditions, nursing care activities, and caregivers' participation in care about 30 minutes a day. A daily caregiver-nurse meeting was pursued according to caregivers' convenience. The need and readiness of caregivers to take part in patient care were evaluated.
3. If caregivers were ready to participate in patients care, the researchers asked caregivers to prioritize and arrange what care activities they wanted to do for patients on each day during the ICU stay. The skills related to patients care were tailored and coached by the researchers regarding the needs of each caregiver. After the 7-day PP training was completed, the posttest score of caregivers coping was collected using the TCAPS-SF (Coping<sub>post-exp</sub>).

#### The control group

1. Pretest score of caregivers' coping was obtained using the TCAPS-SF within 72 hours after TBI patient admission to the ICU (Coping<sub>pre-con</sub>).
2. Caregivers received the usual nursing care from nursing staff. After 7 days from the day of pretest coping score collected, posttest score was completed using the TCAPS-SF (Coping<sub>post-con</sub>).

### Data analysis

Frequency, percentage, mean, and standard deviation were applied to analyze the demographic characteristics of TBI patients and caregivers. Chi-square and t-test were employed to investigate the differences in demographic characteristics of patients and caregivers between the experimental group and the control group.

A paired t-test was used to determine the differences between the mean coping scores of caregivers who received the PP before program implementation (Coping<sub>pre-exp</sub>) and after program completion (Coping<sub>post-exp</sub>).

An independent t-test was utilized to examine the differences between the mean coping scores of caregivers who received the PP (Coping<sub>post-exp</sub>) and those who received the usual nursing care (Coping<sub>post-con</sub>).

## RESULTS

### Demographic characteristics of patients with TBI

Most of the patients with TBI in both experimental and control groups were adult males aged between 26-60 years (50% in the experimental group and 75% in the control group), with the mean age of 33.2 years (SD = 14.64) and 41.7 years (SD = 18.63), respectively. Most of the patients had GCSs on the day of ICU admission ranging from 3 to 8 points (85% in the experimental group and 90% in the control group). There were no differences in gender ( $\chi^2 = .229, p = .633$ ), age ( $t = .112, p = .117$ ), and level of injury severity (GSC) ( $\chi^2 = .229, p = .633$ ) between the two groups of subjects.

### Demographic characteristics of caregivers

Most of the caregivers of TBI patients in both groups were adult females aged between 26-60 years (80% in the experimental group and 65% in the control group), with the mean age of 41.6 years (SD = 11.48) in the experimental group and 38.7 years (SD = 14.53) in the control group. Furthermore, most of the caregivers had completed primary education and were mothers or children of the patients (55% in both groups). There were no differences in gender and age of both groups of caregivers ( $\chi^2 = .902, p = .342$  and  $t = .70, p = .488$ , respectively).

### Coping of caregivers

#### Hypothesis 1.

The mean coping score of caregivers after receiving the PP was higher than that obtained before program implementation ( $\bar{X}_{\text{Coping post-exp}} = 88.85, SD = 12.79, \bar{X}_{\text{Coping pre-exp}} = 72.45, SD = 17.04, t = -3.727, p = .001$ , respectively). The present finding illustrated that caregivers of TBI patients in the ICU coped significantly better after receiving the preparation program (Table 1).

**TABLE 1.** Comparison of mean scores of coping before and after receiving program in experimental group.

TCAPS-SF	Mean	SD	t	p-value
Before program implementation (Coping <sub>pre-exp</sub> )	72.45	17.04		
After program completion (Coping <sub>post-exp</sub> )	88.85	12.79	-3.727	.001 *

(\*  $p < 0.001$ )

**TABLE 2.** Comparison of mean scores of coping between experimental and control groups after program completion.

TCAPS-SF	Mean	SD	t	p-value
Experimentals (Coping <sub>post-exp</sub> )	98.50	8.32		
Controls (Coping <sub>post-con</sub> )	79.55	12.20	5.737	.000 *

(\*  $p < 0.001$ )

#### Hypothesis 2.

Caregivers who received the PP had a mean coping score higher than those receiving the usual care ( $\bar{X}_{\text{Coping post-exp}} = 98.50, SD = 8.32, \bar{X}_{\text{Coping post-con}} = 79.55, SD = 12.20, t = 5.737, p = .000$ , respectively). This result indicated that caregivers of TBI patients in the ICU who received the preparation program coped significantly better than those who received the usual nursing care (Table 2).

## DISCUSSION

As the results of the PP implementation, the critically ill TBI patients caregivers were able to cope better by taking an active part in patient care while their family members stayed in the ICU. Since the demographic data of caregivers showed that most of the caregivers were 26-60 years of age, the individuals in this age range play the major role in taking care of family members and help in raising children in the family.<sup>2,13</sup> Generally, caregivers in adulthood have many duties relating to their secondary roles, such as the roles of parents, spouses, and children who have to take care of parents and/or other siblings.<sup>3,13</sup> Moreover, most of the caregivers were females and the patients mothers like other studies.<sup>1,2,6,14</sup> Caregiving duty in the family also has been labeled as a female responsibility.<sup>1,2,15</sup> It seemed that they were unable to let go of these roles and needed the existing sources of social support to help them deal with the new problems they faced.<sup>6,15</sup> In addition, caregivers in this age tended to have some previous life experiences relating to managing the problems in their daily life, family, and crisis.<sup>13,15</sup> Therefore, they were more likely to be able to better take a new direction in order to cope with a serious episode which was caused by the TBI patients needing ICU admission.<sup>2,3,6</sup>

Caregivers perceived the situation as it was happening at that time when the researchers daily informed them, discussed about the patients condition, and gave the choices on how to participate in the care concerning the patients specific problems and caregivers needs. Then, they could easily follow a new way for a new solution that might work for them in that situation quickly.<sup>16,17</sup> The findings of the present study were consistent with the findings of previous studies<sup>18</sup> that mothers were able to easily take on what happened to their children with less distress than fathers. Mothers who had caring experience could settle themselves to become primary caregivers of patients to some extent. Thus, caregivers were more likely to respond to the patients needs and effectively take care of patients after the PP was introduced as a new solution were needed to manage the TBI patients crises. After the PP, the caregivers could cope even better for their family members with severe TBI who were critically ill in the ICU.

Receiving accurate and appropriate information had a direct effect on individuals coping.<sup>14,15</sup> In addition, the provision of written information should be supplemented to accompany an educational program.<sup>6,19</sup> Caregivers and their family lived with uncertainty and felt vulnerable while their family members were in a serious condition.<sup>20</sup> Many studies<sup>6,15,20-22</sup> have shown that enough and suitable information, active participation in care, nurse advocacy, meaningful conversation, and regular scheduled nurse-family meetings could strengthen individuals hope, fulfill caregivers and family support needs, and promote patients' recovery. These could also facilitate caregivers to learn how to deal with crises they encountered, solve

problems by making decisions from the available choices and resources, and manage the situations effectively.<sup>1,3,15</sup> Therefore, the PP with educational package for caregivers could prepare them to be ready for the ICU discharge of TBI patients, and enable them to adjust their roles more suitably, and cope more effectively.

Most importantly, information should be distributed to caregivers when they are prepared and need it.<sup>5,6,21</sup> The assessment of their readiness should be achieved between 24 and 72 hours after the patients are hospitalized in the ICU.<sup>23</sup> It could be noted that, in the initial phase of caring after patients' first hospitalization, caregivers are faced with the sudden and unexpected experience of TBI to their family member. During the between life and death period, physicians and nurses tended to treat and work most intensively to save the patients life, but pay less attention to the care given to their caregivers. Therefore, caregivers were more likely to develop stress, worry, anxiety, and depression from uncertain conditions which happened to the TBI patients.<sup>1,5,24</sup>

With much anxiety, yet less hope, caregivers struggled to learn what they should do for severe TBI patients, during the first 72 hours of admission.<sup>21</sup> Moreover, after the injury, moderate and severe TBI patients would suffer respiratory problems and neurological deficits.<sup>1,4</sup> Most critical patients had to rely on a ventilator support and other necessary medical equipment. Additionally, the sudden changes in the patients symptoms and treatment plans caused caregivers confusion which resulted in a turmoil of uncertainty.<sup>1,4,20</sup>

All of those could make caregivers who had no or less experience with such equipment felt anxious and they did not understand what was happening to the TBI patients. They kept worrying about the patients future whether patients could make it or not.<sup>20,21,23</sup> As a result, caregivers gained high levels of stress during this critical time, especially, when caregivers found other patients in the ICU dying.<sup>4</sup> Then, those caregivers were left on an edge by being pushed into a huge adjustment in their life where they were in new places, when they learned about uncertain situations, and those they met with unfamiliar faces.<sup>1,13,25</sup>

Thus, caregivers needed to know the useful information about the patients conditions.<sup>26</sup> The administration of an educational package along with advice for caregivers was able to make them understand and learn more about patients conditions, problems, diagnosis, and treatment plans.<sup>5,14,21</sup> At the same time, listening to what caregivers felt and answering specific questions on patients care also reduced their stress and anxiety during nurse-caregiver meetings.<sup>22,24</sup> Moreover, when caregivers received the information about patients condition and the way to comply with caring tasks required, they would feel less distress and were better able to plan for the future. They actually grasped the situation in order to handle each crisis. These resulted in increasing coping scores among caregivers who received the PP which meant that caregivers might more readily accept to live with having a severe TBI patient in the family and coped better by perceiving less threat in caring for their disabled family member.

## CONCLUSION

Even though the study results notes the effectiveness of the PP by enhancing caregivers to cope better through the active participation in patients care, the coping of

caregivers after patient discharge from the ICU to ward and after returning home should be evaluated. The PP is a tailor-made program to suit each caregiver of TBI patients individually. Nurses should respect the decisions caregivers make, know when caregivers are in need, and also be sensitive to what they need to learn about. Additionally, the needs of TBI patients and caregivers should be re-assessed in a timely manner to ensure that caregivers are still able to effectively carry out proper care activities to promote TBI patients recovery.

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