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Exploring coping mechanisms among traumatic brain injury survivors: A phenomenological study

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Abstract

Objective: The goal of this study was to investigate and comprehend the coping strategies used by traumatic brain injury (TBI) survivors to adjust to the changes that occur after the injury in an Asian rehabilitation set up. *Methods:* The study used a qualitative phenomenological design. Twenty participants, including TBI survivors and their family members, were recruited using purposive sampling. In-depth semi-structured interviews were used to gather data, and thematic analysis was used for analysis. *Results:* Twenty participants were interviewed, 16 were TBI survivors, 6 were relatives of the survivors. Two primary themes emerged: emotion-focused coping (e.g., seeking social support, religious practices) and problem-focused coping (e.g., physical aids, behavioural modifications). The individuals' reactions to the changes and difficulties they faced were reflected in these coping mechanisms**.**
Conclusion: The integration of religious and spiritual coping strategies in the rehabilitation phase is particularly important in a cohort of Asian TBI survivors.

Keywords: Traumatic brain injury, coping mechanisms, phenomenology, rehabilitation, holistic care.

INTRODUCTION

There are an estimated 64 to 74 million new cases of traumatic brain injury (TBI) yearly reported worldwide.[1] TBI survivors may have emotional, cognitive, and functional changes after the trauma. TBI survivors may experience disruption of their lives, feeling disconnect from their previous life and other people, that in turn, changes their life perspective and spiritual belief, as well as having emotional changes, low self-esteem, depression, anxiety, and low quality of life (QOL).[2-8] Furthermore, TBI survivors may experience psychosocial problems, which include stigma from other people, relationship problems, the need of support from others and proper post-hospital follow-up.[3,8-10]

Hence, TBI survivors may utilize various types of coping practices to manage those changes. Some TBI survivors may obtain support from others to help them in their life after the trauma[2], whereas others may adopt positive thinking and are looking forward to starting a new life and learning to accept the changes.[2-4]

Coping styles may be different based on culture, religious practice, and ethnicity. A previous qualitative study performed in Malaysia to explore the psychosocial and spiritual coping strategies used by motor vehicle accident (MVA) victims among Malaysian Malay Muslim, showed that all participants applied psychological, social, and spiritual coping strategies to reduce their post-traumatic stress after an accident.[11] The participants employed positive thinking and rationalisation as psychosocial coping. Meanwhile, they also have strong family support and they applied religious practice in their daily life to reduce their post-traumatic stress symptoms. However, participants of this study were not specifically limited to Malay Muslim, but to other ethnicity and faith to understand the coping practice used by the TBI survivors.

To understand the various perceptions of the

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personal experiences on coping strategies among TBI survivor, both quantitative and qualitative study design have their own strength. In a qualitative study design, the investigators can build a closer relationship to the participants, who may reveal more their experience and feeling, which may help in their nursing care. In this study, we thus chose a qualitative approach. As suggested by Abdullah *et al*, there are need to investigate whether religious participation, family and social support, perception of symptoms and functional capacity related to cultural differences may contribute to difference in psychiatric outcomes of TBI population.[6] There is gap of knowledge in the Asian cultural context, thus the justification of this study.

METHODS

A hermeneutic phenomenology approach was used in this study. The TBI survivors were interviewed with a semi-structured interview to understand their experience of lived changes and coping strategies that they applied towards the changes that they experience.

TBI survivors were chosen as the target population for this study because TBI is the most complicated injury that causes major impact to a survivor's life after the injury and/or accident. The population was purposively sampled and the inclusion criteria for participants of this study were: (1) survivors that were diagnosed with mild, moderate, or severe TBI; (2) survivors aged 18 years and above; (3) survivors who passed cognitive test measured by Mini-Mental State Examination (MMSE); this test is to ensure that they do not have language problem and severe cognitive deficit due to TBI, whereby the outcome of the test should score more than 17 out of 30[12]; (4) residency located in Malaysia only; and (5) survivors who understand Malay and/or English language. Meanwhile, the exclusion criteria were TBI survivors with an underlying history of senile or mental retardation before the injury.

This study was done in a rehabilitation hospital in the central region of peninsular Malaysia. (Hospital Rehabilitasi Cheras, Kuala Lumpur) There are 20 participants who received written and verbal information and were invited to participate in this study.

Ethics

The researcher explained the aim of the study to the participants. Subsequently, should the participants agree to participate in the study, they are requested to read and sign the informed consent prior to their enrolment in the study. Participants were periodically reminded that their participation is voluntary and that they have the right to stop participating at any time. The participants were given a copy of informed consent for their reference. All participants are kept anonymous.

Data collection process

To achieve the research objectives, the study selected in-depth interviews for data collection. Participants were asked to describe in detail about their experience, which relates to the questions asked. The interview was conducted individually at a time and venue convenient to each of the participants. The interview session was around 30 to 40 minutes per session. The interview session was conducted for at least three sessions for each participant. In addition, to gain a comprehensive data, the researcher also interviewed the relatives of TBI survivors.

Data analysis

Prior to result analysis, the audio recording of the interview was transcribed and converted into analysable text. The data were analysed based on thematic analysis. The NVivo software version 1.0 was used in the data analysis to assist the researcher in analysis process. Data collection and analysis were done continuously and parallel to each other. It allows a deep understanding of the description given by participants, thus aiding the process of establishing saturation point that demonstrates the result obtained by the researcher had meet the research objectives.

Throughout the study, the multilingual nature was carefully controlled to ensure accuracy and cultural sensitivity. To facilitate semantic equivalency between languages, a thorough strategy was taken during the translation process, which included back-translation techniques. To preserve the integrity of participant responses, certified translators who were knowledgeable about the study's background were hired, and all translations were cross-checked.

Although gathering data in multiple languages presented inherent difficulties, steps were taken to reduce the possibility of bias. This involved triangulating results to improve dependability, iterative conversations among team members who were proficient in the languages being utilized, and keeping thorough records of translation procedures. We believe that the study's

multilingual component did not result in a major obstacle; rather, it enhanced the analysis's depth by bringing in views from different cultural background.

RESULTS

For this study, 20 participants were interviewed; from the total numbers of the participants, 14 were TBI survivors and 6 were relatives to those TBI survivors. The participants' age range for this study was between 19 and 60 years old. Seven participants were female and thirteen were male. Of the TBI survivors, seven of them were married; from that number, half of them do not have any children. Fourteen survivors suffered TBI due to motor vehicle accident (MVA), including two due to assault and one to fall. At the time of interview, only five participants were working, one was still studying, five were unemployed, and three were pensioners. Majority of the participants were TBI survivors for more than six (6) months.

The finding highlights two main themes of coping practices used by the participants, which were problem-focused coping and emotion-focused coping.

Problem-focused coping

Majority of the participants used problem-focused coping as their response to changes in their life after the trauma. This problem-focused coping theme were derived from two subthemes, which were the need for physical aid and behavioural coping.

Six participants were utilising either a wheelchair or a walking frame to assist their mobility.

In addition, participants from this study reported to have poor memory, hand and leg weakness, hand stiffness, pronunciation problem, and fatigue. Therefore, we created a category for this coping practice as behavioural coping. The behavioural coping practice is defined by how the survivors act or behave to cope with their lived changes. Thus, these survivors (n = 13) employed behavioural coping as a coping mechanism. Furthermore, participants shared that they created a memo to cope with poor memory problem, taking a short rest when experiencing excessive fatigue, put all important things such as wallet, car key, and phone in one beg and always carrying that beg to avoid misplacement due to forgetfulness. Meanwhile, some of them seek traditional massage for their hand or leg weakness.

"I write things down in a notebook. Because I would often forget if I had completed something, like sweeping the floor." (P9)
"I put all my things in one bag, so all my important belongings are in that specific bag. I carry the bag with me everywhere I go so that I don't misplace anything." (P7)

This was one of the coping practices they used due to short-term memory problems. Another participant shared his experience that when he was in the exercise room in the rehabilitation centre, he made a schedule for the whole week, where he made a note of his must-do activities and what to wear on the specific day due to his short-term memory problem.

The majority of the survivors have physical problems, where they would attend to in the rehabilitation programme. For example, one of the patients has muscle stiffness on his hand. He also exercised at home, following what he had learnt at the rehabilitation unit. As a result, his hand showed improvement; as described in the excerpt below:

"After the accident, my body became too weak, especially my hand. I am doing physiotherapy at the hospital as scheduled, but I also do some exercises at home, for example, lifting a small mineral water bottle. I lift it up and down for hand physio." (P12)

Emotion-focused coping

The participants in this study also applied emotion-focused coping mechanism. This coping mechanism is defined as participants controlling their emotional reaction as a result of their TBI.[14] In this study, some of the problems that they experienced were depression, shyness, stigma from others, and easily agitated. There were several coping practices under this emotion-focused coping theme, including seeking social support, self-positive motivation, avoidance, and religious practices.

Seeking social support

The participants shared their emotional coping practices by seeking social support from spouse, family, and people around them. They attempted to seek support from these people, especially for emotional support, such as encouragement and positive words. The participants reported that having encouragement make them stronger in facing their difficulties.

"My family and friends have been supportive. They give me words of encouragement during my physiotherapy. They give me the motivation to be strong. They said that I have to be strong so that I can be my old self again." (P5)

One of the participants shared his experience of creating social support group to share his experience and information, especially on his lived changes. From that action, he found social support from others and at the same time, he also gave courage to other group members.

Self-positive motivation

Other than seeking social support, the participants also searched for positive self-motivation to cope with changes in their lives. They tried to have self-motivation to keep moving forward, always think positive, start a new life, move on, and try to find a motivational source to make them strong after the injury. Some of the participants shared that they had to accept their changes of a new life. One of the participants said that before the trauma, he was a naughty boy, but he wants to start a new life after the trauma and become a good son to his parents. Meanwhile, some participants revealed they listen to motivational videos, Instagram, YouTube channel and read motivational books; this is explained by the excerpt below.

"I see a lot of motivational speech from YouTube channel, such as motivational talk. One of the motivators was from Western country. He gave a good motivational speech on how to be talented and so on. It felt like I was self-motivated. I must keep looking forward and keep it positive to cope with changes on post-TBI life." (P1)

Religious practices

The next subtheme for emotion-focused coping was religious practices. This was when most participants applied religious practices to cope with their changes. This coping practice could calm them and help them start accepting those changes that had happened to them. The survivors would make a prayer (*du'a* in Malay) and seek help from God. As stated in the demographic data of the participants, ten of the participants were Muslim, three participants were Hindu, and one participant was Christian. Regardless of their religious belief, most participants applied religious practices to cope with their life after the injury. They believe that through prayer, making a *du'a*, and reciting the Holy verses, they tend to feel calmer and reflect the incidents and thought of some positive reason. They also make a prayer to God to heal their injury soon.

Avoidance coping

The last finding for emotional coping practice theme was avoidance coping. The researcher defines avoidance when participants avoid people and isolate themselves from community around. This coping practice was more inclined towards negative coping because they try to withdraw from people around. Four participants said they isolated themselves because of their changes.

"At school, I keep to myself and stay silent. If there are meetings that are not important, I skip them because I have trouble listening to many people talking at the same time." (P13)

Nevertheless, there were also still positive aspects to this coping mechanism, where the participants would avoid taking risk that may give rise to problems because of their deficit.

In brief, the participants shared their coping practice by implementing the problem-focused and emotion-focused coping methods. The problem-focused method focuses more on direct response to when a problem occurs, while the emotion-focused method addresses the emotional reaction that comes from the problem or stressor.

DISCUSSION

Due to TBI, the survivors may have long-term recovery process that can be influenced by internal and external factors. Therefore, to maintain the QOL, having good coping practices is an important factor that must be given attention. A previous study reported that the survivors' ability to cope with problems or stressors is important to maintain a good QOL.[13]

Coping is declared as a person's constantly changing cognitive and behavioural efforts to manage specific external and internal difficulties that are perceived as demanding or exceeding the resources of the person.[14]

As discussed by Lazarus and Folkman, problem-focused coping mechanism has been defined as managing stress by actively seeking a solution to the problem.[14] This may involve define the problem, find a solution, weigh the alternative solution, choose the best solution, and apply the best solution to cope with the problem. Meanwhile, emotion-focused coping mechanism

is defined as managing emotional reaction that transpires from the problems. However, managing stress with emotion could be a positive or a negative approach.

It was reported in a study that the adoption of maladaptive emotional coping method increased in the first six (6) months after TBI injury and the increase was related to reduced productivity.[15] This report revealed that the survivors used more of emotion-focused strategies on their concern about themselves, self-blame, as well as for ignoring and isolation. Some participants in this study also applied avoidance coping in their practice. They stated that they will isolate themselves for the first few months after the injury just to get courage and accept their lived changes. The participants will try to adapt to their new life and use emotional coping practice in positive light, such as having positive self-motivation and religious practice.

It is important to help the survivors in selecting the best coping practices and help them choose appropriate or suitable coping practices that could help them improve their health-related quality of life (HRQOL). Assisting survivors to choose positive coping practices can also minimise the risk of psychological problems among TBI survivors. Thus, the health care providers need to focus in suggesting the suitable coping approach to the survivors. Moreover, health care providers, especially the nurses, should know the estimated duration for survivors to adapt with their lived changes after the injury; this is so nurses can plan for rehabilitation intervention. Giving TBI survivors a reasonable time for acceptance of the trauma and establish a positive thinking about the current condition is important to them to help them move forward in life.

The study's findings revealed that the participants applied problem-focused coping and emotion-focused coping to cope with their lived changes. Previous study reported TBI survivors using white board, hand-held devices, and sticky note to help them to record, keep note, schedule appointment, and write down phone numbers.[9] It was apparent that this is a common practice among those with memory loss. The patients would jot down what the next schedule or any important notes that they should remember either in their phone, sticky note or white board. Keeping a reminder is useful and can easily be done in their phone.

Other problems faced by TBI survivors from Adam *et al*. from US was fatigue, which is consistent with this study.[9] One practice in coping with fatigue problem was also found with this study, which was the participants will take a rest when they feel fatigued. In addition, Adam et al. also reported that survivors will adjust their schedule, and find a quiet place and sit alone to reduce feeling of fatigue. This coping practice is different with the findings of this study. This may be attributable to the participants from that study who were recruited one year after they were diagnosed with TBI, compared with the participants from this study who were recruited after six (6) months of diagnosis. Therefore, their practices might be different, in which their coping practices can be adjusted in accordance with the experience of the survivors. We found that with time, the TBI survivor may develop good coping practices to handle with his lived changes. The choice of a coping practice can be highly dependent on the situation and the specific phase of the recovery process.[16]

This study also reported that some participants accepted their post-TBI lifestyle and became positive towards the changes in their lives. They thought the changes were their second chance at being a better person. This finding is similar to two previous reports.[3,9] The participants valued their current life and looked forward to the future. Moreover, they valued more time with their spouse and family. Nurses can collaborate with psychologist to plan some intervention to help survivors to have positive thinking and determination to move on with their current condition.

Nevertheless, some survivors may still have negative thinking after the injury. They have internalised stigma and the negative impression projected by others. Therefore, some survivors will resort to avoidance coping, such as isolating themselves and withdrawal from society. This finding was also reported by a previous study, where their participants had responded with social withdrawal because of impaired ability, perceived difference, and sense of abnormality.[3]

We found majority of the participants shared that religious coping can help to regulate their emotional reaction in post-TBI. The participants stated that applying religious coping made them calmer and having faith in God will help them in getting better and through the tough times. Even though the participants in this study come from various religious background, their reason for using this coping practice is similar. Previous study revealed that religious and spiritual belief systems play an important role in rehabilitation outcome.[17] The study also indicated that religious wellbeing was a predictor for life satisfaction,

distress, and functional ability and should be encouraged.

In summary, the participants in this study applied problem-focused coping and emotion-focused coping as their coping practices. These coping practices are closely related with the coping theory by Lazarus and Folkman.[14] However, this coping theory came from North America, it is expected that there may be some differences found in the coping practices used by the participants in the current study, which is from an Asian cultural setting.

Findings of study related to theoretical framework

Our finding in this study revealed that the participants implemented problem-focused coping and emotion-focused coping as their coping practice. The participants used strategic problem solving to cope with physical problem and memory problem. As explained in coping theory from Lazarus and Folkman[14], some people will cope with stress by finding a social support to talk to and by looking for social connection to help them survive in these difficult times; for example, family and friends while they persevere. This reflects the finding from this study, where participants would establish social support from their family and friends with their motivational encouragement. However, limited knowledge on TBI of the family and friends will place limitations of their help. Hence, it is better if they can find support group to share the knowledge of TBI and their experiences. The support group in a developed country may be more established, the TBI survivors may be able to easily find support group in the hospital or locality-based community. For they may also feel more comfortable to share their feelings with other TBI survivors due to their similar experience and fear of stigma.

Some participants in this study revealed that they have emotional changes, such as depression. They tried to apply emotion-focused coping. Emotion-focused coping has been characterised as managing stress through emotion. Some participants shared that they enjoyed writing a journal and drawing, as it helps them to clarify their thoughts and feeling, and distract them from having negative thoughts.

Our participants in this study come from various religious backgrounds, including Islam, Buddhism, Hinduism, and Christianity. The findings of this study showed that most participants applied religious coping practice to regulate their negative emotional reaction, i.e., seeking help from God as they go through their difficult time. This religious coping mechanism was not mentioned in the classification of the most active coping method used in the Lazarus and Folkman's coping theory.[14] We propose a more comprehensive approach to the coping theory to include religious practice.

Understanding how the coping practices of traumatic brain injury (TBI) survivors influence the implementation of holistic care strategies by nurses.

Nurses can apply holistic care to all patients regardless of their diagnosis, educational background, family background, and religious practice. However, nurses need to understand the coping practices experiences of TBI before delivering holistic care to the survivors. Nurses should recognize the individual person they are dealing with to ensure that the care delivered would achieve the goals that have been set for both the patient and themselves. This would ensure that patients are treated based on their individual self-care interest rather than just based on their illness. When applying holistic care, nurses should notice patient's preferences. Understanding the coping practices experiences among TBI survivors allow for nurses to involve patients in decision-making. Nurses could suggest rehabilitation programs while respecting the requests of the TBI survivor, when considering alternative therapies, such as complementary and alternative medicine.

Moreover, delivering information and education relevant to the patient's disease is an important dimension in holistic care. Understanding the changes in lived experience of TBI survivors can give TBI survivors the right information about their illness and treatment options available. Nurses will need to explain to the survivor on details of the latter's illness and care process. However, the explanation should be comprehensible to the layman. Nurses are also encouraged to distribute any brochures or e-learning material and assist patients and their family members in using internet search to gain more information.

With the current technology, nurses could consider telehealth for TBI survivors by which they can easily access care through email or by logging in a support group created by the hospital. This also means that nurses will need to respond to these emails and telephone calls in a timely manner. Nevertheless, the use of technology comes with its own set of challenges, such as

limited internet coverage and lack of knowledge on smartphone usage. In such cases, nurses in rehabilitation centre should communicate with nurses in community to include home visits and follow-up care.

In understanding the coping practices experience of TBI survivors, it is important to provide emotional support. Survivors may have post-traumatic stress symptoms, where nurses can be a good listener and counsellor. Nurses should provide emotional support and encouragement to patients. This would lead to formulation of positive coping mechanisms among participants. Nurses should also encourage TBI survivors' family members and friends to give support to the survivors. Nurses may advise survivors and their family members to seek emotional support from peer support groups, counselling, motivational talks or books, religious activities, mindfulness, and other forms of therapy to help them control negative emotional responses. In summary, having deeper understanding on holistic care practices helps nurses to adopt the steps of holistic care practices in nursing care.

In conclusion, majority of the TBI survivors are struggling to return to their normal life. Knowing their coping practices will facilitate in improving care of delivery to survivors with TBI, especially in assisting them to choose the best coping practices that suit their preference. Our study revealed that survivors with TBI in Malaysia used problem-focused coping and emotion-focused coping to deal with their lived changes. Future study may explore further on the impact of coping practices that can improve their health-related quality of life, including religious coping practices particularly in a religious society.

DISCLOSURE

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