CHANGES ON LIVED AND COPING PRACTICE EXPERIENCES AMONG TRAUMATIC BRAIN INJURY SURVIVORS AND CAREGIVERS IN MALAYSIA

By

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Chair : Assoc Prof Lee Khuan, PhD
Faculty : Medicine and Health Sciences

Traumatic brain injury (TBI) imparts a long-term effect on the survivors' lives. Given those changes, survivors apply several coping practices to continue their activities of daily living. Limited studies have been conducted in a Malaysian setting related to changes in the lived experiences and coping practices of TBI survivors and caregivers. This study also discusses the gap in the International Classification of Functioning, Disability and Health (ICF) Model, which contains only a limited assessment of the emotional changes in disabled people, especially TBI survivors. The purpose of this study was to understand the changes in the lived experiences and coping practices of post-TBI survivors and their caregivers. A hermeneutic phenomenology approach was applied in this study. Participants were recruited at a rehabilitation hospital in Malaysia after approval had been obtained from the National Medical Research Registry (NMRR), Jawatan Kuasa Etika UPM (JKEUPM) and the hospital ethics board, while consent was obtained from the participants. A total of 20 participants were involved, of which 14 were TBI survivors and six were caregivers of survivors. Data collection was done using semi-structured interviews with both TBI survivors and their caregivers. Other data collection methods were also used, such as field notes, a reflective journal and the story completion technique. All the raw data collected using these methods were triangulated to obtain rich and thick description. Thematic analysis was applied in the data analysis process using Nvivo software version 1.0. Two themes were identified for changes in lived experiences as described by the participants: direct and indirect changes. The former was defined as changes in lived experiences that survivors had directly undergone after an injury; these changes could be identified by others and included physical changes, cognitive changes, behavioural changes, post-injury trauma and fatigue. Indirect changes were defined as changes in survivors' lived experiences that people could not see directly, although these changes affected the survivors in terms of emotions, stigma, role changes and financial difficulties. In regard to coping practices experiences, two themes were described

by the participants: problem-focused and emotional-focused coping. The former refers to coping with the direct changes that affected the participants, while the latter refers more to addressing emotions and finding support from others. Some participants had withdrawn from society and avoided taking any risks because of the post-injury changes in lived experiences. TBI survivors often have a long-term recovery process that might be influenced by internal and external problems. To assist and improve the care of TBI survivors throughout their recovery period, understanding their changes in lived experiences and coping practices is an important aspect that healthcare providers and family members must recognise

Keyword: Interview, live experience, changes, coping, phenomenology, traumatic brain injury, qualitative, survivor

Abstrak tesis yang dikemukakan kepada Senat Universiti Putra Malaysia sebagai memenuhi keperluan untuk ijazah Doktor Falsafah

PENGALAMAN PERUBAHAN HIDUP DAN STRATEGI MENGATASI PERUBAHAN YANG DIALAMI OLEH MANGSA KECEDERAAN TRAUMA DI OTAK DAN PENJAGA DI MALAYSIA

Oleh

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Kecederaan trauma di otak (TBI) memberikan kesan jangka panjang kepada kehidupan mangsa yang terselamat. Memandangkan perubahan tersebut, mangsa yang terselamat menggunakan beberapa strategi untuk mengatasi demi meneruskan aktiviti kehidupan seharian mereka. Di Malaysia, kajian berkaitan dengan perubahan dalam pengalaman hidup selepas trauma dan strategi untuk mengatasi perubahan tersebut di kalangan mangsa TBI dan penjaga adalah terhad. Kajian ini juga membincangkan jurang di dalam Model "the International Classification of Functioning, Disability and Health (ICF)", yang mempunyai penilaian terhad terhadap perubahan emosi di kalangan orang kurang upaya, terutamanya mangsa TBI. Tujuan kajian ini adalah untuk memahami perubahan dalam pengalaman hidup dan strategi untuk mengatasi perubahan tersebut di kalangan mangsa TBI dan penjaga mereka. Pendekatan "hermeneutic phenomenology" telah digunakan di dalam kajian ini. Peserta telah diambil di hospital rehabilitasi di Malaysia selepas mendapat kelulusan daripada Pejabat Pendaftaran Perubatan Kebangsaan (NMRR), Jawatan Kuasa Etika UPM (JKEUPM) dan lembaga etika hospital, manakala persetujuan diperolehi daripada peserta. Seramai 20 peserta terlibat di dalam kajian ini, di mana 14 daripadanya adalah mangsa TBI dan enam adalah penjaga mangsa. Pengumpulan data telah dilakukan secara temu bual separa berstruktur dengan kedua-dua mangsa TBI dan penjaga mereka. Kaedah pengumpulan data lain juga telah digunakan, seperti nota lapangan, jurnal reflektif dan teknik melengkapkan cerita. Semua data yang dikumpul menggunakan kaedah ini telah ditriangulasi untuk mendapatkan penerangan baik. Analisis tematik telah digunakan di dalam proses menganalisis data dengan menggunakan perisian Nvivo versi 1.0. Dua tema telah dikenal pasti untuk perubahan di dalam pengalaman hidup seperti yang diterangkan oleh peserta: perubahan secara langsung dan tidak langsung. Perubahan secara langsung dimaksudkan sebagai perubahan dalam pengalaman hidup yang dialami secara langsung oleh mangsa

TBI selepas kecederaan; perubahan ini boleh dikenal pasti oleh orang lain, ia termasuk perubahan fizikal, perubahan kognitif, perubahan tingkah laku, trauma selepas kecederaan dan keletihan. Perubahan secara tidak langsung dimaksudkan sebagai perubahan dalam pengalaman hidup magsa TBI yang tidak dapat dilihat secara langsung oleh orang ramai, perubahan ini mempengaruhi mangsa TBI dari segi emosi, stigma, perubahan peranan dan kesukaran kewangan. Berkenaan dengan pengalaman cara mengatasi perubahan hidup selepas trauma, dua tema telah dinyatakan oleh peserta: daya tindak berfokuskan masalah dan berfokuskan emosi. Yang pertama merujuk kepada menghadapi perubahan langsung yang menjejaskan peserta, manakala yang kedua merujuk lebih kepada menangani perubahan emosi dan mencari sokongan daripada orang lain. Sesetengah peserta telah menlakukan pengasingan diri daripada masyarakat dan mengelak daripada mengambil sebarang risiko kerana perubahan selepas kecederaan trauma. Orang yang terselamat dari TBI selalunya mengalami proses pemulihan jangka panjang yang mungkin dipengaruhi oleh masalah dalaman dan luaran. Untuk membantu dan meningkatkan penjagaan mangsa TBI yang terselamat sepanjang tempoh pemulihan mereka, memahami perubahan mereka di dalam pengalaman hidup dan strategi mengatasi perubahan hidup selepas trauma adalah aspek penting yang patut di utamakan oleh pihak hospital dan ahli keluarga.

Kata kunci: Temu bual, pengalaman hidup, perubahan, mengatasi, phenomenology, kecederaan trauma di otak, kualitatif, mangsa yang terselamat

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I certify that a Thesis Examination Committee has met on 16 December 2022 to conduct the final examination of Nor'ain Abdul Rashid on her thesis entitled "Changes on Lived and Coping Practice Experiences among Traumatic Brain Injury Survivors and Caregivers In Malaysia" in accordance with the Universities and University Colleges Act 1971 and the Constitution of the Universiti Putra Malaysia [P.U.(A) 106] 15 March 1998. The Committee recommends that the student be awarded the Doctor of Philosophy.

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LIST OF ABBREVIATIONS

ICU	Intensive Care Unit
ICF	The International Classification of Functioning, Disability and Health Model
HRQOL	Health Related Quality of Life
MVA	Motor Vehicle Accident
PCC	Patient Center Care
PTSD	Post-Traumatic Stress Disorder
PTA	Post Traumatic Amnesia
QOL	Quality of Life
TBI	Traumatic Brain Injury
WHO	World Health Organization

CHAPTER 1

INTRODUCTION

1.1 Introduction

This thesis reports a study exploring changes in lived experiences and coping practices among traumatic brain injury (TBI) survivors. More specifically, this chapter contextualises changes in the lived experiences of TBI survivors, outlines global issues that arise post-injury and provides an overview of the current Malaysian landscape. The chapter also explains the long-term repercussions that TBI survivors may experience. The contextualisation presented in this chapter helped to guide the development of the research questions and the literature review, which led to the study being initiated. An outline of this thesis is presented at the end of the chapter.

1.2 The Aetiology of TBI

Traumatic brain injury (TBI) has been defined as a change in the brain function due to forces that happen in the brain, which can be caused by, for example, motor vehicle crashes, falls, a direct blow to the head or sports injuries (Centers for Disease Control and Prevention, 2021). The most common causes of TBI are motor vehicle accidents (MVA) (Brazinova et. al, 2016; Ludin et. al., 2018). The type of injury determines its effect on the brain. In general, TBI is divided into two discrete types: primary and secondary brain injury. The former involves the parenchyma, which contains tissues and vessels, being physically damaged during a traumatic event, resulting in the shearing and compression of the surrounding brain tissues. Meanwhile, secondary brain injury results from the complex process that follows a complicated primary brain injury; it occurs over a long period of time that may be hours or days (Lazaridis, C., et. al, 2019). The severity of TBI can be classified using the Glasgow Coma Scale (GCS). The best eye-opening, motor and verbal responses are determined based on a score ranging from 3 to 15 (EMV-score). The scores are calculated based on the total of all the categories. A TBI with a GCS of 13-15 is called a mild TBI, a GCS of 9-12 refers to a moderate TBI and a GCS of 3-8 is classified as a severe TBI (Centers for Disease Control and Prevention (CDC), 2021). However, the GCS has limited ability to predict the outcome.

Other than the GCS, TBI severity can be classified by considering CT scan results, post-traumatic amnesia (PTA) and loss of consciousness (LOC). For a mild TBI, the GCS score is 13-15, the PTA duration is up to 1 day, the LOC duration is up to 30 minutes and a normal CT scan result should be returned. For

a moderate TBI, the GCS score is 9-12, the PTA duration is between 1 to 7 days, the LOC duration is between 30 minutes to 24 hours and a normal or abnormal CT scan reading could be returned. For a severe TBI, the GCS score is 3-8, the PTA duration is more than 7 days, the LOC duration is more than 24 hours and a normal or abnormal CT scan outcome could be returned (Lefaivre, 2015).

Two types of consequences generally follow TBI: primary and secondary loss. Primary loss describes organic, physical and cognitive loss as a direct result of a brain injury (Lefaivre, 2015). Examples of primary loss include physical disability, as well as cognitive, communication, taste and sensory problems. Meanwhile, secondary loss, which occurs in response to TBI but subsequent to primary loss (Lefaivre, 2015), refers to emotional and psychological changes. These may include depression, anxiety, stress, relationship problems and poor health-related quality of life. Primary and secondary losses often co-occur.

Furthermore, TBI is also a leading cause of death and disability (Centers for Disease Control and Prevention, 2021). Many people suffer years of disability and have their productive life affected after a brain injury. Moreover, TBI increases the economic burden on the individuals affected, their families and society. A person suffering from TBI can face financial problems, as well as issues with their cognitive, physical, mental, emotional, psychological and spiritual functions (Freeman et al., 2015). This can have major negative impacts, resulting in interpersonal relationship issues, depression, financial troubles and other difficulties, affecting TBI survivors as well as their families and society (Lefevre-Dognin C, et. al, 2021; Abdullah et al., 2018; Gregorio et al., 2014; McPherson et al., 2018; Grill et. al., 2011).

Chen et al. (2019) argued that by 2020, the MVA would be the third-largest global health burden. TBI has well-known and considerable impacts on the functioning and HRQOL of TBI survivors. The outcome of TBI depends on the severity, which can be divided into mild, moderate and severe. Most studies focus on the outcomes of moderate and severe TBI because most mild TBI cases are not hospitalised. Most recovery periods are within six months post-injury, after which only minimal changes occur (Centers for Disease Control and Prevention, 2021). The changes that do happen can have a drastic impact on the daily lives of TBI survivors.

1.3 Research Background

The occurrence of traumatic events could lead to further medical, cognitive, functional, social and/or emotional complications, even death. In fact, Lefaivre (2015) reported TBI to be a major medical problem and a leading cause of death among children and young adults globally. Individuals who survive the ordeal

frequently face a loss of productivity and years of disability post-TBI. Every year, millions of TBI patients are discharged from intensive care units (ICU). These individuals and their families often report a wide range of issues, like impaired psychosocial, cognitive, physical and/or psychological health, which could last for months, if not years, post-discharge. TBI entails trauma to the brain leading to changes in brain function, possibly due to a force, blow or other injury as a result of a direct blow to the head; a motor vehicle crash; a fall; or the most common cause, a sports injury (Lefaivre, 2015). Thus, TBI creates lifelong repercussions that affect not only TBI survivors but also their caregivers, family members, community and country.

TBI incidences appear to be increasing, especially in developing countries. More than 50 million people worldwide report TBI annually, and projections have revealed that half the world's population experiences TBI at least once in their lifetime (Maas et al., 2017). An estimated 2.5 million individuals in America have experienced TBI (Centers for Disease Control and Prevention, 2014), while approximately 790 cases of TBI were reported per 100, 000 individuals in New Zealand (Feigin et al., 2013) annually. Several countries, including Asian nations, have been affected by the high global and regional burden posed by TBI, which appears to be the leading cause of death, morbidity and socio-economic problems in India, where the main and second most common causes of TBI were MVA and falls, respectively (Ambika et. al, 2020). Meanwhile, in China, population-based mortality related to TBI was estimated to be 13 cases per 100,000 people, with motor vehicle accidents (MVA) as the most common cause of TBI (Jiang et. al., 2019).

There is a general lack of data on TBI-related incidence and admission rates in Malaysia. According to reports by Abdullah (2011), accidental brain injuries accounted for approximately 6,872 deaths out of 28,269 injuries in 2010. Furthermore, head injuries appeared to be the third most commonly diagnosed condition leading to intensive care unit (ICU) admission in Malaysia over the previous nine years (Geok et al., 2016; Rai et al., 2017). According to Noor Fatimah et al. (2018), about 247 TBI cases were referred to Hospital Rehabilitasi Cheras between 2012 and 2018. Motor vehicle accidents (MVA) accounted for the majority of TBI cases in Malaysia. A study by Ludin et al. (2018) conducted at two tertiary hospitals in East Coast Malaysia found that 96.9% of their participants had severe TBI attributed to MVA - parallel to figures from the Department of Statistics Malaysia (2019), which reported transport accidents to be the fourth leading cause of death in 2018. Nevertheless, brain injury research is crucial to obtain updates on recent incidence and admission rates, as well as assess post-injury outcomes among TBI survivors.

Brain injuries are highly complex healthcare challenges that impact all aspects of life and functioning. Individuals affected may experience changes in function, personal identity and social relationships. Although some TBI survivors return to

normal functioning, this could take months or years, while others struggle with TBI repercussions for their whole life. Machamer and colleagues (2022) reported that the prevalence of TBI symptoms was higher in the first year following the injury. Thus, early rehabilitation is crucial for not just only patients but also their families and clinicians so that any long-term effects can be mitigated.

Individuals with TBI often undergo changes in their lived experience, such as functional changes (Sandhaug et al., 2015; Ludin et. al., 2018), cognitive changes (Freeman et al., 2015; Adams & Dahdah, 2016), changes in their health-related quality of life (Soberg et al., 2013; Forslund et al., 2013) and self-identity changes (Freeman et al., 2015; Adams & Dahdah, 2016). Studies focusing on the experiences of TBI survivors also found that most could face problems linked to their interpersonal, social, cognitive and physical states after injury (Freeman et al., 2015; McPherson et al., 2018; Adam & Dahdah, 2016). Therefore, changes in the lived experiences of TBI survivors post-injury and how these experiences shape their life outcomes must be better understood. Research is especially needed on the lived experiences of TBI survivors during the rehabilitative phase so that communities can be better informed about developments in rehabilitative approaches and the support services available, which could promote successful community transitions.

1.4 Problem Statement

A highly complex healthcare challenge, TBI impacts almost all aspects of life and functioning. It may change the physical, cognitive and communicative capacities of survivors, as well as affect their activities of daily living. Numerous studies have been conducted to observe the functional, cognitive, emotional and health-related quality of life (HRQOL) outcomes among TBI survivors. Life changes are inevitable upon TBI diagnosis, and survivors often struggle to regain normal living. A survivor's experience from the point of injury until normal living resumes is highly significant. Qualitative studies have been conducted to explore such experiences, with the findings indicating that TBI survivors reported a sense of abnormality, disconnection from the social world and the feeling they were being treated differently by others, while they also perceived TBI as a hidden injury (Freeman et al., 2015; McPherson et al., 2018). Survivors may utilise several coping practices in response to these experiences, such as religion and spirituality (Waldon-Perrine et al, 2011; Johnstone et al, 2009). Some choose to withdraw from social settings, emphasise staying positive (Freeman et al., 2015) or seek support from others (McPherson et al., 2018; Adams & Dahdah, 2016). However, most existing studies have been conducted in Western countries.

In Malaysia, a study conducted in the northern region of Malaysia found that 25% TBI survivors were diagnosed with depression and 14% had anxiety after their injury (Abdullah et al., 2018). Meanwhile, another study reported that among MVA victims, social, psychological and spiritual coping methods helped to

diminish post-trauma distress signs after their accident (Bahari et al., 2016). Nonetheless, limited studies have been undertaken on the lived experiences and coping practices employed by TBI survivors. Therefore, it was important to understand how TBI survivors perceived their experience and determine the psychological, social and/or spiritual coping practices they used to address the changes to their lived experience. The cultural differences between Malaysia and other countries, especially those in the West, could present new findings concerning the changes in lived experiences and coping practices among TBI survivors. Besides, in Malaysia, most studies have focused on clinical outcomes, with a lack of qualitative studies focusing on the lived experiences and coping practices of TBI survivors. Therefore, more researchers should explore the core problems experienced by TBI survivors by trying to understand, for example, their lived experiences and how they cope with changes.

The study findings could provide new result on the theoretical gap especially in assessment on emotional part for disable people in the International of Functioning, Disability and Health (ICF) model. In addition, perhaps this study also could provide new finding on coping practices because the study was done in Asian country and have multi-ethnicity and religious practices. Moreover, this study could improve TBI survivors' quality of life and assist researchers to plan future intervention studies to help survivors, especially during their rehabilitation.

1.5 Aim of Study

The aim of this hermeneutic phenomenological study was to understand changes in lived and coping practices experiences used among TBI survivor's and caregiver's in Malaysia.

1.6 Research Questions

"How" and "what" were interrogative questions which could help thoroughly capture the changes in lived experience of and coping strategies used among TBI survivors. Hence, research questions for this study were;

1) What were the changes in lived experiences of post-injury TBI survivors'?
2) How did post-trauma TBI survivors cope with changes in their life?

1.7 Significance of the Study

This study has great significance to society, health practitioners, TBI survivors and caregivers. In terms of their societal significance, the findings help by

accurately depicting TBI survivors' experiences and advocating empathy towards them. Therefore, the general public should become better educated about how to best help survivors, especially in terms of welfare, career, vocational and/or group support. In addition, understanding how the lived experiences of TBI survivors change should help to remove negative public perceptions of such individuals.

The study also offers medical practitioners, nurses and rehabilitation teams new, local insights on changes in the lived experiences of and coping strategies used by TBI survivors. It also serves as a guide for healthcare professionals, especially nurses, that should develop a better understanding of the psychological and psychosocial post-injury experiences of TBI survivors. In addition, the findings offer baseline knowledge on individual experiences during rehabilitation, which is crucial for improving support services and rehabilitation approaches to promote successful community transitions and ensure the smooth administration of treatment and rehabilitation. Further, the study also highlights the presence of post-traumatic symptoms among survivors, thus enabling medical practitioners to better understand the contributing role played by post-traumatic stress disorder (PTSD) symptoms in life after trauma among TBI survivors. Meanwhile, healthcare providers such as nurses and occupational therapists could use the findings to offer the counselling support required by TBI survivors during their rehabilitation. Nurses would also be able to provide future TBI survivors with valuable guidance on the best coping practices.

Next, the study emphasises the need for nursing management teams to continue TBI patient follow-ups upon their discharge from a hospital and/or rehabilitation unit, eespecially considering the long-term repercussions faced by TBI survivors. Thus, follow-up calls would keep nurses updated on the physical, psychological and psychosocial condition of a TBI survivor.

Individual changes in lived experience should be reflected in the service delivery, with support services needed to achieve individualised goal settings. Therefore, knowledge of the changes in the lived experiences of TBI survivors would allow future researchers to explore how support services could be tailored to suit the needs of TBI survivors upon their discharge from hospital.

In terms of nursing education, the study highlights the importance of therapeutic psychosocial care among patients. Student nurses need to recognise the importance of communication skills when interacting with TBI patients before they can learn the importance of therapeutic psychosocial care in improving emotional health among such patients. This study also emphasises the cruciality of knowing patient details (e.g., their background, culture and financial status) before delivering treatment. That is, student nurses must recognise the need to

understand how an individual function intrinsically and extrinsically, in relation to other individuals.

The study also provided a platform for the TBI survivor participants to share their post-injury experiences with nurses and healthcare providers, thus enabling them to release the emotional burdens onto which they had been holding. Nurses had opportunities to administer therapeutic nursing care to TBI survivors, communicate with them, listen to their experiences, build a good rapport with them and try to understand their feelings. Therapeutic communication occurs between a nurse and their patient to help advance the latter's physical and emotional health. Nurses are also presented with opportunities to observe verbal and non-verbal cues among TBI survivors. Ultimately, good therapeutic communication helps survivors to feel like they are understood and cared for.

The study also triangulates the data collection methods used with the caregivers. Therefore, sharing their experiences while caring for TBI survivors helped the caregivers to understand the survivors' feelings. Therefore, they gained a deeper understanding of how changes to brain injury affected the survivors' lives and how they coped with those changes.

1.8 Definition of Terms

Mild traumatic brain injury

Patients presenting GCS scores ranging between 13 to 15 during admission, disorientation, loss of consciousness for a maximum of 30 minutes, and post-traumatic amnesia (PTA) below 24 hours (Lefaivre, 2015).

Moderate traumatic brain injury

Patients presenting GCS scores ranging between 9 to 12 during admission, loss of consciousness for more than 30 minutes but less than 24 hours and post-traumatic amnesia (PTA) between 1 to 7 days (Lefaivre, 2015).

Severe traumatic brain injury

Patients presenting GCS score ranging between 3 to 8 during admission, post-traumatic amnesia (PTA) of more than 7 days and loss of consciousness for more than 24 hours (Lefaivre, 2015).

Changes in lived experience

To understand lives of TBI survivors and changes in their sense of identity post-trauma.

Coping Practice

To gain insight on how TBI survivors cope with or respond to changes in lived experience post-trauma.

Problem-Focused Coping

Targeting the root of the problem/stress in a practical manner by delving into the stress/problem causing situation with aim to reduce said stress/problem.

Emotion-Focused Coping

A form of stress management that focuses on reducing negative emotional responses brought about by the stressor.

1.9 Thesis Structure

This thesis is presented in five chapters. The first introduces the thesis and contextualises the study. The chapter also explains the current Malaysian landscape surrounding TBI, leading to the study being initiated. The second chapter provides an overview of the process involved in the literature review, which highlighted gaps in knowledge to justify the study. The third chapter describes the philosophy underpinning this study and the detailed methodology of how the study was conducted. The results and discussion are presented in

chapter four. The final chapter discusses the limitations of the study, recommendations for nursing education and management, as well as suggestions for future research, before concluding the study.

1.10 Summary

TBI survivors encounter long-term effects on their lives, including the physical, cognitive and even emotional changes that occur after the injury. Thus, they need good coping practices to manage those changes. A comprehensive literature review was performed to understand more about personal experiences and coping practices among TBI survivors. The literature revealed there a lack of studies have been undertaken in a Malaysia setting to examine the changes in lived experiences and coping practices of TBI survivors. Therefore, the researcher decided to explore and understand these changes among this group of survivors in Malaysia. This study was expected to help the TBI survivors by allowing them to share their experiences, thus reducing the emotional burden onto which they had been. Besides, healthcare providers would also gain a deeper understanding of these experiences and be able to improve the support services so they suit the survivors' needs. The study should equip community members and caregivers with empathy towards such experiences, while they would also be able to help survivors in the form of social support and lose their negative perceptions of TBI survivors.

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