



THE FUNCTIONAL AND HEALTH RELATED
QUALITY OF LIFE OUTCOME ON SEVERE
TRAUMATIC BRAIN INJURY IN TWO EAST COAST
HOSPITALS: A COHORT STUDY

BY

NOR'AIN ABDUL RASHID

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International Islamic University Malaysia

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ABSTRACT

Traumatic brain injury (TBI) is the most important medical and socioeconomic problem and is the top cause of death in the young adult. Severe TBI survivors show physical and functional improvement but remain with cognitive and psycho-social problem throughout recovery. However, the long-term impact of severe TBI survivors in Malaysia is still lacking. The main objective of this study is to measure the functional and health related quality of life outcome of severe TBI survivors within 6 months post-injury. A cohort study was done on 33 severe TBI survivors from Hospital Tengku Ampuan Afzan (HTAA) Kuantan, Pahang and Hospital Sultanah Nur Zahirah (HSNZ) Kuala Terengganu. The functional assessment of Glasgow Outcome Scale Extended (GOSE) and Quality of Life after Brain Injury (QOLIBRI) were measured within a 6 months period. The participants mean age was 31.79 ranging from 16 to 73 years old. The result of this study shows that GOSE score and QOLIBRI result improved within 6 months post-injury. The GOSE score showed that within 3 months after discharge from the hospital, all the participants were still poorly recovered, $n=33$ (100.0%). Meanwhile, after 6 months being discharged from the hospital, 48.5% of the participants scored a good recovery score. Logistic regression analysis was conducted to look for predicting factors in the TBI survivors' functional outcome. The full model was statistically significant, χ^2 (5, $N=33$) = 29.09, $p < 0.001$, and the LOS in the ICU ($p=0.049$, odds ratio = 6.062) and the duration of being on the ventilator ($p=0.048$, odds ratio = 0.083) become the predictors for the functional outcome. In the QOLIBRI result, age and duration on the ventilator showed a negative correlation to the QOLIBRI result. Independent T-test showed a significant difference in the GOSE scores for poor recovery ($M=31.88$, $SD=23.65$) and good recovery ($M=75.63$, $SD=14.23$; $t(26.49) = -6.48$, $p < 0.001$ (two-tailed) to the QOLIBRI result. The good recovery group has high QOLIBRI resulted due to the satisfied health related quality of life. TBI survivors often have a long-term recovery process that may be influenced by different factors. In order to assist the TBI survivors to go through their recovery, the outcome measure with a more holistic assessment should be emphasized to enhance more useful results. Furthermore, it would be beneficial in the future to undertake longitudinal research studies on the TBI survivors' to gain a more accurate result on their long-term outcome following the injury

خلاصة البحث

تعد إصابات الدماغ الرضحية (TBI) من أهم المشاكل الطبية والاجتماعية والاقتصادية، وتعتبر السبب الرئيسي للوفاة بين الشباب البالغين. يُظهر المتعافون من الـ TBI الشديد تحسنا جسديا ووظيفيا ولكنهم لا يزالون يعانون من مشاكل إدراكية ونفسية اجتماعية طوال فترة الانتعاش . وبالإضافة إلى ذلك فإن المعلومات على الآثار طويلة المدى للمتعافين من الـ TBI الشديد في ماليزيا لا يزال غير كافيا. الهدف الرئيسي لهذه الدراسة هو قياس النتائج الوظيفية ونتائج جودة الحياة للمتعافين من الـ TBI الشديد في غضون 6 أشهر بعد الإصابة. أجريت دراسة تعرض على 33 متعافٍ من الـ TBI الشديد من مستشفى تنكو أميوان أفران (HTAA) في كوانتان بولاية باهانغ، ومستشفى السلطانة نور زاهرة (HSNZ) في كوالا تيرينجانو. تم قياس التقييم الوظيفي لمقياس غلاسكو للنتائج الموسع (GOSE) وقياس نوعية الحياة بعد إصابة الدماغ (QOLIBRI) خلال فترة 6 أشهر. متوسط أعمار المشاركين كان 31.79 سنة، بأعمار تتراوح بين 16 و 73 سنة. أظهرت نتائج هذه الدراسة أن نقاط GOSE ونتائج QOLIBRI تحسنت في غضون 6 أشهر بعد الإصابة. أظهرت نقاط GOSE أنه في غضون 3 أشهر بعد الخروج من المستشفى، كان جميع المشاركين في حالة تعاف متدنية، $n=33$ (100%)، أما بعد 6 أشهر من خروجهم من المستشفى، سجل 48.5% من المشاركين نقاط تعاف جيدة. تم إجراء تحليل الانحدار اللوجستي للبحث عن عوامل تنبؤية في النتائج الوظيفية للمتعافين من الـ TBI. كان لدى النموذج الكامل دلالة إحصائية $\chi^2 (5, n=33) = 29.09$ ، $p > 0.001$ ، و في الـ LOS في وحدة العناية المركزة ($p=0.049$ ، نسبة الأرجحية = 6.062)، ومدة المكوث على جهاز التنفس الصناعي ($p=0.048$ ، نسبة الأرجحية = 0.083)، والتي أصبح تنبؤات للنتائج الوظيفية. العمر والمدة على جهاز التنفس الصناعي في نتائج الـ QOLIBRI أظهرت علاقة سلبية فيها. أظهر اختبار تي المستقل (t-test) فرقا كبيرا في نقاط GOSE للتعافي المتدني (المتوسط: 31.88، الانحراف المعياري: 23.65) والتعافي الجيد (المتوسط: 75.63، الانحراف المعياري: 14.23؛ $t (26.49) = -6.48$ ، $p > 0.001$ (ذو ذيلين) إلى نتائج الـ QOLIBRI. كان لدى مجموعة التعافي الجيد نتيجة QOLIBRI عالية بسبب نوعية الحياة المرضية. غالبا ما يمر المتعافين من الـ TBI بعملية تعاف طويلة الأمد والتي قد تتأثر بعوامل مختلفة. من أجل مساعدة المتعافين من الـ TBI في فترة الاستشفاء ينبغي التشديد على قياس النتائج بإجراءات تقييم أكثر شمولية لتعزيز نتائج أكثر فائدة. وعلاوة على ذلك، سيكون من المفيد في المستقبل إجراء دراسات بحثية طويلة على المتعافين من الـ TBI للحصول على بيانات أكثر دقة حول نتائجها الطويلة المدى بعد الإصابة.

APPROVAL PAGE

I certify that I have supervised and read this study and that in my opinion, it conforms to acceptable standards of scholarly presentation and is fully adequate, in scope and quality, as a thesis for the degree of Master in Nursing Science.

.....
Asst. Prof. Dr. Salizar Mohamed
Ludin
Supervisor

.....
Assoc. Prof. Dato' Dr. Mohd
Basri Mat Nor
Co-Supervisor

.....
Assoc. Prof. Datuk Dr. Mohamed
Saufi Awang
Co-Supervisor

I certify that I have read this study and that in my opinion it conforms to acceptable standards of scholarly presentation and is fully adequate, in scope and quality, as a thesis for the degree of Master in Nursing Science.

.....
Asst. Prof. Dr. Mohd Said
Nurumal
Internal Examiner

.....
Prof. Dr. Lim Pek Hong
External Examiner

This thesis was submitted to the Kulliyah of Nursing and is accepted as a fulfilment of the requirement for the degree of Master in Nursing Science.

.....
Asst. Prof. Dr. Mohd Said
Nurumal
Dean, Kulliyah of Nursing

DECLARATION

I hereby declare that this dissertation is the result of my own investigations, except where otherwise stated. I also declare that it has not been previously or concurrently submitted as a whole for any other degrees at IIUM or other institutions.

Nor'ain Bt Abdul Rashid

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LIST OF ABBREVIATION

GCS	Glasgow Coma Scale
ICU	Intensive Care Unit
TBI	Traumatic Brain Injury
LOS	Length of Stay
GOS	Glasgow Outcome Scale
GOSE	Glasgow Outcome Scale Extended
QOLIBRI	Quality of Life After Brain Injury
ICF	The International Classification of Functioning, Disability and Health Model
QOL	Quality of Life
HRQOL	Health Related Quality of Life
SOFA	Sequential Organ Failure Assessment Score
SAPS II	Simplified Acute Physiology Score II

CHAPTER ONE

INTRODUCTION

1.1 INTRODUCTION

This chapter explained the background of the severe traumatic brain injury (TBI) survivors and problems related to the functional outcome and health related quality of life (HRQOL) globally and also the current situation in Malaysia. The data that leads to the admission to the intensive care unit (ICU) in a tertiary hospital in Malaysia and the description of the long-term functional outcome concept in severe TBI survivors are provided. The background to the problem presented in this chapter was directed to the development of the research questions that guided to the literature review and initiation of this study.

1.2 STUDY BACKGROUND

Traumatic brain injury (TBI) is an alteration in the brain function due to the forces that happen in the brain, for example, a direct blow to the head, motor vehicle crashes, falls and the most common cause which is sports injuries (Needham *et al.*, 2012). Besides that, TBI also is a major medical and socioeconomic problem and the leading cause of death in children and young adult. The productive life was lost and many people have suffered years of disability post-TBI (Lefaiivre, 2015). In addition to that, Gordon, Flanagan, Brown and Connors (2008) said that TBI is a global health epidemic that has harmful consequences to the TBI survivors, their family and subsequently to the society.

In Europe, 1.6 million patients with TBI are admitted to the hospital and 66,000 dies annually. The health care costs related to TBI are estimated to be €2.9 billion per year. Besides that, Europe estimated 8 million people to experience some level of disability caused by TBI (Willemse-van Son, 2009). In the USA, 1.6 million people tolerated with TBI each year in which, approximately 50,000 people die from TBI and 125,000 were disabled one year after injury. In 2000, it was estimated that the economic burden of TBI of all severities in the USA was about 60 million dollars (Finkelstein, Corso & Miller, 2006).

Moreover, TBI also causes high global and regional burden to all countries including Asia. In India, for example TBI becomes the leading cause of death, morbidity and socioeconomic problem. The calculated incidence was 120 per 100 000. The same goes to Eastern China, which indicates that TBI is the leading cause of trauma injury and it became the 5th leading cause of mortality in adults less than 40 years old (Puvanachandta & Hyder, 2009). In Malaysia, TBI also has been reported to cause serious problems of mortality and morbidity in the community. Abdullah (2011) showed that in 2010, the data on accidental brain injuries indicated that there were 6,872 deaths out of 28,269 injuries in that year with most of them were males between 16 to 30 years old. Out of that, 4,035 died on the spot at the accident site and the rest were managed by both government and private hospital. This finding was consistent with the data from Malaysian Institute of Road Safety Research in which, the age characteristic for rider fatalities was between 20 years to 29 (first quartile), age 30 years to 50 (second quartile) and age above 50 years (last quartile) (Sarani, Roslan & Saniran, 2011). Ponsford (2013) on the other hand, reported that the highest incident of TBI is at the age of 15 to 24 years with other peaks in the early childhood and in the elderly.

Every year, millions of TBI patients were discharged from ICU all over the world. These ICU survivors' and their family regularly report a wide range of impairments in their health status, which may last for months and years after hospital discharge. In Malaysia, head injury is top three admission rates to the ICU and motor vehicle crashes being the major cause of it (Jenny *et al.*, 2015). Over the past 9 years, dengue infection, sepsis and head injury have remained the three most commonly diagnosed leading to ICU admission (Jenny *et al.*, 2015).

However, the statement shown underestimates the actual problem. This is because the indirect costs, such as the loss of productivity and intangible costs due to the reduced quality of life are not taken into account. Furthermore, the figure is only based on the hospital admission while most of the patients, especially those with mild TBI do not refer to the emergency departments and are not hospitalized (Ribber, 2010). In addition to that, the detail on the severity of the head injury was not clearly stated. Thus, this study will use samples taken from patients who had been admitted to the ICU and were diagnosed with a severe TBI.

Most of the patient will be admitted to the ICU for critical illness therapy. Critical illness survivors have reported problems during recovery; however, patients in recovery or rehabilitation are receiving more attention due to the increased survival rate. Few of the patients also may experience physical, emotional and cognitive issues after an ICU stay (Needham *et al.*, 2012) which includes sleep difficulties, polyneuropathies, poor appetite and many more, which can reduce the overall functional capacity (Walker & Pickett, 2007). Therefore, it is vital to have a nurse to help these ICU survivors and to measure the outcome after discharging them to ensure that the ICU survivors will minimize the limitation during recovery.

1.3 PROBLEM STATEMENT

Brain injury is the most complex health care challenge and it gives an impact on all aspects of life and functioning. Functional outcome recovery after TBI is important for the healthcare professional to predict the long term management and rehabilitation for the TBI survivors'. Defining and evaluating the predictors that influence the functional outcome has been the goal of clinical treatment within the rehabilitation medicine (Brown *et al.*, 2005). The major problem for many people with TBI is to be able to perform daily life activities, thus failure to return the productive roles becomes a great economic and personal cost to people with TBI, their family and the society (Gordon *et al.*, 2008). Besides, data from the Colorado TBI registry stated that 50% of those who were severely injured failed to return to work at one year post-injury while the other 20% of those with mild injuries were unemployed. This result includes hospitalized TBI patients (Whiteneck *et al.*, 2001). Most of the study stated that many people with TBI were not able to return to their normal lives that they once had before the injury.

Several studies focused solely on the severe TBI and are trying extensively looking at the factors in predicting the global outcome for example in neuropsychological performance (Sinha, Gunawat, Nehra & Sharma, 2013), functional status, cognitive skills, and quality of life (Green *et al.*, 2008) at 6 to 12 months. A long-term predictive study of patients with severe TBI post-rehabilitation by Hoofien, Gilboa, Vakil and Donovanick (2002) found that the pre-injury socioeconomic status as defined by the education, numbers of siblings and the quality of military service predicted the cognitive, psychiatric, vocational, and social/familial functioning an average of 14 years post-injury. In the same study, the severity of the

injury as measured by the duration of stay in the rehabilitation and duration of coma was predictive and functioning in activities of daily living (ADL).

TBI has the significant impact on the survivors and their relatives. Medical advances have improved the survival rate after severe TBI but the survivor still facing lifetime disability, which in turn affects their family. The long-term outcome for this population is indeed important for the patients and also their family but also to the clinicians in order to provide prognostic information to the insurance companies as well as the healthcare providers who bear most of the cost for the care.

The effectiveness studies in the past generally focused on whether better outcomes were associated with receiving services or otherwise. The “Yes/No” global assessments typically showed that this vocational rehabilitation (VR) services help some clients (Gordon *et al.*, 2008). In Malaysia, Kementerian Kesihatan Malaysia (KKM) developed a program called ‘Perkhidmatan Perawatan Domiciliary’ in primary care clinic, which measures the outcome and the predictor of the discharged patient (Kementerian Kesihatan Malaysia (KKM), 2014). This program covered all cases but not specifically to TBI survivor and will be the first to generate data since there is no proper documentation on the functional and health related quality of life (HRQOL) outcome after severe TBI.

Furthermore, it can be seen from the limited work on documenting of functional outcome and quality of life on severe TBI in Malaysia. Besides, Sim, Lim, Lee, Liew and Wong (2011) suggested having a proper documentation on these issues. Thus, it will have a baseline data on the functional outcome and HRQOL on severe TBI population in Malaysia.

Nevertheless, although various studies have documented the findings and information from around the world on the functional outcome of severe TBI and the

impact of the patients' recovery, to date, the status and the long-term functional and HRQOL outcome of severe TBI in Malaysia after discharge is still unknown. Thus, the aim of this study is to measure the functional and HRQOL of life outcome of severe TBI survivors during their recovery period.

1.4 SIGNIFICANT OF THE STUDY

This study is significant to the nurses in terms of instilling positive outcomes and new knowledge regarding the long-term impact of severe TBI survivors' life in Malaysia, to keep the patients safe and to aid the national strategy to reduce the medical or healthcare cost. Besides, it will increase the knowledge of the health care workers such as the intensive care outreach team on TBI survivors' long-term outcome during recovery.

As for the TBI survivors, it will reduce the sign and symptom of post-TBI complications squeal, death rate and readmission rate to the hospital or ICU. It will also maximize the full cognitive and physical functioning of the TBI survivors and subsequently increases their HRQOL.

For the family members, this study will help them to understand the outcome of the TBI survivors. The knowledge that they gain from the nurses can be utilised to help the survivors to improve their outcome and HRQOL. Family members also will understand more on the pathophysiology and rehabilitation process that were faced by the survivors.

On the other hand, this study is important to the society, economy and national level because the analysis on the TBI recovery allows the real-time tracking and outcome assessment as well as qualitative and quantitative "experiential" documentation of the changes in functional status, living situation, employment status,

social relationship, HRQOL and ongoing behavioral sequel after TBI. It will also enhance the critical illness survivors and family members' satisfaction and quality of life.

1.5 RESEARCH QUESTIONS

1. Are the severe TBI survivors able to function well in their daily life after being discharged from the hospital?
2. What is the range for HRQOL of severe TBI survivors after they discharge from the hospital?
3. Is there any improvement in the functional outcome and HRQOL shown by ICU survivors with a severe TBI after being discharged from the hospital?
4. Is there any relationship between the long-term impact of severe TBI survivors and their demographic characteristic?

1.6 HYPOTHESIS

H1 The ICU survivors with severe TBI show no improvement in the functional outcome and HRQOL after being discharged from the hospital.

1.7 RESEARCH OBJECTIVES

1.7.1 General Objective

The aim of this study is to measure the functional level and HRQOL of the ICU survivors with severe TBI within 6 months after being discharged from the hospital.

1.7.2 Specific objectives

1. To describe the socio-demographic characteristics of severe TBI.
2. To determine the long term impact of severe TBI on functional outcome within 6 months post-injury.
3. To determine the long term impact of severe TBI on HRQOL within 6 months post-injury.
4. To distinguish the association between socio-demographic characteristics and their functional outcome.
5. To distinguish the relationship between socio-demographic characteristics and their HRQOL.
6. To determine the relationship between functional outcome and HRQOL on severe TBI.

1.8 DEFINITION OF TERMS

Traumatic brain injury

Injury caused by a fall, blow or trauma to the head or a penetrating head injury that interrupts the normal function of the brain (Faul, Xu, Wald & Coronado, 2010).

Mild traumatic brain injury

Patients who had GCS score 13-15 during admission, had disorientation, loss of consciousness for 30 minutes or less, and had post traumatic amnesia (PTA) less than 24 hours (Lefaiivre, 2015).

Moderate traumatic brain injury

Patients who had GCS 12-9 during admission, had loss of conscious more than 30 minutes but less than 24 hours and had post traumatic amnesia (PTA) between 1 to 7 days (Lefaiivre, 2015).

Severe traumatic brain injury

Patients who had GCS score 3-8 during admission, had post traumatic amnesia (PTA) more than 7 days and loss of consciousness more than 24 hours (Lefaiivre, 2015).

Functional outcome

A goal that helps a patient to accomplish specific activities of daily living. There are six basic ADLs namely eating, bathing, dressing, toileting, transferring (walking) and continence (Medical Dictionary, 2009).

The quality of life

Broad multidimensional concept that usually subjective evaluation of both positive and negative aspects of life. The satisfaction of an individual regarding a particular style of life and in relation to their goals, expectation, standards and concerns. (Medical Dictionary, 2009).

Health Related Quality of Life

Multidimensional concept that includes domains related to physical, mental, emotional and social functioning. It goes beyond direct measure of population health, life expectancy and cause of death. It was focused on the impact of health status. (Center for Disease Control (CDC), 2016).

1.9 CONCLUSION

Several studies showed that there are limitations on the functional outcome on severe TBI survivors and these become the socioeconomic problem for their family as well