

**Determinants of the Quality of Life of Patients** 

with Traumatic Brain Injury in Indonesia

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A Thesis Submitted in Partial Fulfillment of the Requirements for the Degree of

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#### ABSTRACT

Traumatic Brain Injury (TBI) is a leading cause of death and disability worldwide that has several impacts on a patient's life. An individual's quality of life (QoL) is often used as an outcome measure following TBI. Numerous studies have documented the decrease of QoL and the various factors affecting QoL after TBI.

This cross sectional survey aimed to assess the level of QoL and to determine the predictive factors of QoL in patients with TBI in Indonesia. One-hundred and three adults with mild, moderate or severe TBI and who had been discharged from hospital for at least one month were purposively selected for interview. The instruments used were a set of questionnaires consisting of demographic and health-related data, physical factors (GCS and DRS), psychosocial factors (MOS SSS and HADS), and QoL (QOLIBRI) questions. The reliability reported by Cronbach's alpha coefficient for MOS SSS, HADS, and QOLIBRI were .99, .89, and .98, respectively. Test-retest of DRS yielded an intraclass correlation coefficient of .99. Descriptive statistics and hierarchical multiple regression were used to analyze the data in this study.

It was found that more than half of the subjects (65%) had a moderate level of QoL, followed sequentially by those with a high level of QoL (18%) and a low level of QoL (17%). Regarding the predictive factors, 32% of the total variance in predicting QoL was accounted for by severity of injury, functioning and disability, social support, anxiety, and depression combined. Depression was the most powerful variable that could explain QoL significantly (B = -2.11,  $\beta$  = -.63, t = -5.33, p = .000). The findings would be helpful in the outcome evaluations or development of interventions to prevent or reduce depression and improve QoL for patients with TBI after discharge from hospitals.

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# **CHAPTER 1**

#### **INTRODUCTION**

#### **Background and Significance of the Problem**

Traumatic brain injury (TBI) is a leading cause of death and disability worldwide. The majority of TBI cases are due to road traffic injuries, which account for nearly 60% of all cases of TBI (Gururaj as cited in Hyder, Wunderlich, Puvanachandra, Gururaj, & Kobusingye, 2007). The World Health Organization (WHO) projected that road traffic injuries will rise from currently being the ninth leading cause of death globally to become the fifth by 2030 (WHO, 2008). The increase in road traffic injuries is also projected to become the third leading cause of global disease and the second leading cause of disease for low- and middle-income countries by 2020 (WHO, 2004). Road traffic injuries kill nearly 1.3 million people annually with approximately 90% occurring in low- and middle-income countries (WHO, 2012). The incidence of TBI in the United States was found to be between 180 and 250 per 100,000 of the population per year (Bruns & Hauser, 2003) and an estimated 1.4 million deaths, hospitalizations, and emergency department visits are attributed to TBI per year (Langlois, Rutland-Brown, & Thomas as cited in Hyder et al., 2007). The Australasian Traumatic Brain Injury Study (ATBIS) found that the 12month mortality rate of TBI patients requiring admission to intensive care units was 26.9%, while the favorable outcome rate at 12 months was 58.8% (Myburgh et al., 2008). The burden of TBI is manifested in all regions of the world, and is especially prominent in low- and middle-income countries (Hyder et al., 2007). In Indonesia, based on the Indonesia Health Profile by the Ministry of Health Republic of Indonesia (MoHRI) (2012), TBI is currently included in the top ten diseases in hospitalized patients. The number of TBI patients in 2010 was 25,281 (MoHRI, 2012).

The effects of TBI can significantly disrupt the lives of those who are injured and survive. Long-term physical, cognitive, psychological and emotional outcomes following a TBI can affect the injured person's capacity to engage in meaningful work (Corrigan, Bogner, Mysiw, Clinchot, & Fugate, 2001), relationships and leisure activities (Hawthorne, Gruen, & Kaye, 2009; Huebner, Johnson, Bennett, & Schneck, 2003), while also resulting in limitations to daily-life activities (Andelic et al., 2010; Dikmen, Machamer, Powell, & Temkin, 2003; Mailhan, Azouvi, & Dazord, 2005). Moreover, the outcomes of TBI can affect a person's self-image (Sasse et al., 2012; Vickery, Gontkovsky, & Caroselli, 2005), coping strategies (Tomberg, Toomela, Pulver, & Tikk, 2005; Tomberg, Toomela, Ennok, & Tikk, 2007), and ultimately their health-related quality of life (HRQoL) (Lin et al., 2010).

An individual's quality of life (QoL) is recognized as a critical indicator of the outcome following TBI. Numerous studies have documented low levels of both objective and subjective QoL after TBI. For example, the low level QoL in patients with TBI occurs from the acute phase (after discharge to one year after TBI) (Emanuelson, Holmkvist, Björklund, & Stålhammar, 2003; Pagulayan Temkin, Machamer, & Dikmen, 2006; Upadhyay, 2007) and remains low until more than one year after injury (Hawthorne et al., 2009; Huebner et al., 2003; Kalpakjian, Lam, Toussaint, & Merbitz, 2004; Nestvold & Stavem, 2009; Pagulayan et al., 2006). Despite the same low QoL results, it seems difficult when comparing one study to another because of the differences in terms of study design, sampling strategy, and conceptualization of the approach and tools for measuring of QoL, including the time of the study approach. Moreover, many studies used a cross-sectional survey although perceived health-related functioning in both physical and psychosocial domains may change over time because the recovery from TBI is a complex and lengthy process (Pagulayan et al., 2006). Another context of the differences is related to the care environment for TBI victims, such as family care and services available after discharge, particularly in low- and middle-income countries.

The various factors affecting QoL have been identified in individuals with TBI. These are (1) demographic factors, (2) physical factors, and (3) psychosocial factors. Some demographic factors have an association with QoL, such as gender (McCarthy et al., 2006; Steadman-Pare, Colantonio, Ratcliff, Chase, &Vernich, 2001; Truelle et al., 2010), age (McCarthy et al., 2006; Nestvold & Stavem, 2009; Truelle et al., 2010), and time after injury (Hu, Feng, Fan, Xiong, & Huang, 2012; Lin et al., 2010; Pagulayan et al., 2006). However, other studies do not confirm these findings (Breed, Flanagan, & Watson, 2004; Kalpakjian et al., 2004; Mailhan et al., 2005; Pierce & Hanks, 2006; Teasdale & Engberg, 2005). Physical factors have been found to be related to QoL, especially the severity of an injury (Dikmen et al., 2003; Lin et al., 2010; Truelle et al., 2010; Upadhyay, 2007). Greater initial severity as measured by the Glasgow Coma Scale (GCS), Post Traumatic Amnesia (PTA), length of hospital stay, and Glasgow Outcome Scale (GOS) at discharge appear to predict poorer outcomes in terms of time returning to work, family and social relationships, and leisure activities (Teasdale & Engberg, 2005). However, results for the relationship between QoL and the severity of an injury remain inconsistent as some studies found no statistically significant relationship between the initial injury severity and QoL (Pierce & Hanks, 2006; Tomberg et al.,

2005; Vickery et al., 2005). In terms of the relationship between disability and QoL, it was found that a lesser degree of disability was related to higher QoL (Huebner et al., 2003). Cognitive dysfunction, the activity of daily living (ADL) dysfunction, and GOS at the time of hospital discharge for TBI patients related significantly to QoL (Teasdale & Engberg, 2005). Congruent with previous studies, patients with lower functional independence have significantly more decreased rates of life satisfaction than patients with greater functional independence (Resch et al., 2009).

It is evident that psychosocial factors are associated with QoL (Corrigan et al., 2001; Eriksson, Kottorp, Borg, & Tham, 2009; Kalpakjian et al., 2004; Petchprapai, 2007; Steadman-Pare et al., 2001; Tomberg et al., 2005). These include social support (Kalpakjian et al., 2004; Petchprapai, 2007; Tomberg et al., 2005) and depressive moods (Corrigan et al., 2001; Eriksson et al., 2009; Steadman-Pare et al., 2001). A study of the psychosocial outcome after TBI showed that subjects with TBI had a significantly lower QoL and lower social support compared with standardization and other non-disabled samples (Kalpakjian et al., 2004). Kalpakjian also found that social support was one of the most strongly associated variables for QoL in a regression analysis. Satisfaction with the level of social support for TBI patients also demonstrated a correlation with QoL (Tomberg et al., 2005; 2007). That study revealed a maladaptive change in the profile of coping strategies. Inadequate social support and low satisfaction with the level of support are associated with QoL. It has been revealed that social support is an important factor for adjusting after TBI (Tomberg et al., 2007). Congruent with previous studies, Petchprapai (2007) found that social support was the only significant factor predicting QoL in patients with TBI. In addition, social support has a beneficial effect on well-being that is explained by the concept of the buffering model (Cohen & Wills, 1985).

Other related factors to QoL among patients with TBI include depressive moods. Depression is associated with diminished QoL among survivors of TBI (Underhill et al., 2003). In a multivariate analysis, it was found that the presence of a depressive mood was one of the influential variables in predicting QoL. The absence of a depressive mood contributed significantly to greater QoL (Eriksson et al., 2009). Similarly, Steadman-Pare et al. (2001) found that general mental health was the primary predictor of perceived QoL, accounting for a large portion of the variance ( $R^2 = 43\%$ ). Individuals with TBI who experienced more depressive feelings reported significantly lower QoL ratings.

However, the previous studies were generally favorable in developed countries where access to necessary resources and a caring environment is not limited. It is unclear which factors may affect the QoL of patients with TBI living in Indonesia where there are quite different contexts of care provision after discharge. A systematic review of prognostic models in TBI by Perel, Edwards, Wentz, & Roberts (2006) also concluded that only a few of the prognostic models were developed using populations from low- and middle-income countries, where most of the trauma occurs, and the generalizability to these settings is limited. Moreover, in a study of developing practical prognostic models in patients with TBI based on a large cohort of international patients including TBI patients from Indonesia, it was found that several predictors differed in the significant level of association with outcomes according to the income of the country. It is considered inappropriate to extrapolate from models for high income countries to poorer settings (Perel et al., 2008).

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In Indonesia, family relationship and support remain high with regard to their living in an extended families and adult offspring living in the same house as their parents. Relatives visit each other frequently, especially when one of the family members becomes sick or injured. This reflects the social norm of 'tolong-menolong' (helping one another), which is well established within Indonesian village society (Higgins & Higgins as cited in Goodwin & Giles, 2003). Moreover, Indonesia was ranked 47th out of the 53 countries and regions assessed on the level of individualism across cultures (Hofstede as cited in Goodwin & Giles, 2003), which reflects that social support remained high. On the other hand, the number of hospitals which provide rehabilitation programs for TBI patients after discharge is limited and those with injuries can gain access only in central referral or tertiary hospitals. Although QoL was associated with several factors, findings from previous studies regarding key determinants of QoL in poor developed countries remain inconclusive. Clearly, to enhance QoL among patients with TBI is challenging, while the evidence supporting the predictive factors of QoL in Indonesia is unknown. Further investigation concerning the determinants of QoL, including severity of injury, functioning and disability, social support, and depressive mood, may target different patient characteristics and the care process particularly in countries with limited resources but high social support, such as Indonesia. Therefore, this study will explore the QoL of patients with TBI and its determinants in Indonesia.

#### **Objectives of the Study**

The objectives of this study were as follows:

1. To describe the level of QoL after discharge of patients with TBI in Indonesia

 To determine the predictive determinants (severity of injury, functioning and disability, social support, and depressive moods) of QoL in patients with TBI in Indonesia

### **Research Questions**

The research questions in this study were:

1. What is the level of QoL of patients with TBI in Indonesia?

2. What determinants (severity of injury, functioning and disability, social support, and depressive moods) are powerful in predicting QoL in patients with TBI in Indonesia?

#### **Conceptual Framework**

The World Health Organization Quality of Life Group (WHOQoL Group) (1993 p.153) defined QoL as "an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goal, expectations, standards and consent. It is a broad-ranging concept, incorporating in a complex way the person's physical health, psychological state, level of independence, social relationships, and their relationship to salient features of their environment". Health-related quality of life (HRQoL), a sub-set of this QoL concept, explicitly relates to those aspects of life affected by health (Kaplan & Bush; Patrick & Elinson as cited in Truelle et al., 2010). Health-related quality of life refers specifically to the effects of illness or other health conditions on quality of life and is a particularly important concept in health conditions (von Steinbuechel, Petersen, Bullinger, & the QOLIBRI Task Force, 2005). Since this study determined the QoL in a TBI population, a specific HRQoL in TBI was needed.

The model of HRQoL in TBI patients requires specific conditions regarding the pathophysiology of TBI and its sequele. It needs to include their particular health condition, which is generally accompanied by cognitive impairments. von Steinbuechel, Petersen, et al. (2005) proposed an HRQoL assessment model in patients with TBI. This HRQoL model represents a person's perspective on his or her subjective health condition, functioning, and well-being in the domains of physical, psychological (emotional and cognitive), social and daily life. The HRQoL needs to be assessed in four areas: physis (physical), psyche (psychological), social life and daily life. In the psychological domain, emotional and cognitive aspects have to be assessed explicitly. The person is viewed as the best expert on his or her own QoL (von Steinbuechel, Petersen, et al., 2005). The final assessment model of HRoL added one domain, namely "self" (von Steinbuechel et al., 2010a; 2010b). This conceptual assessment model of HRQoL was used in this study.

Determinants of QoL in this study were guided by the conceptual assessment model proposed by von Steinbuechel, Petersen, et al. (2005). There are two component variables of predictors. First, the self-rated predictor including medical-psycho-social predictor variables, which consist of (1) disease and treatment, (2) personality characteristics and resources, and (3) life situation and autonomy. Second, the observer-rated predictor include bio-psycho-medical variables which are comprised of (1) medical data, (2) ratings of emotion, (3) neuropsychological testing, (4) sociograms, and (5) activities of daily living (von Steinbuechel, Petersen, et al., 2005). The first component, self rated medical-psycho-social predictor variables, guided the determinants of QoL with modified variables based on a literature review of the studies on factors associated with QoL in patients with TBI.

The first variable, disease and treatment, is regarded as the severity of injury. The relationship of the severity of injury and QoL has been documented (Dikmen et al., 2003; Hu et al., 2012; Lin et al., 2010; Truelle et al., 2010; Upadhyay, 2007). The second variable, personality characteristics and resources, is regarded as depressive moods and social support. Due to the psychological reaction to disability and trauma after TBI, there is risk of the development of mood disorders, such as depression and anxiety, which have been shown to be common among TBI survivors (Whelan-Goodinson, Ponsford, & Schonberger, 2009). Depressive moods are shown as an association with QoL among survivors of TBI (Corrigan et al., 2001; Eriksson et al., 2009; Hawthorne et al., 2009; Lin et al., 2010; Steadman-Pare et al., 2001). The resources variable is recognized as social support. The perceived availability of the functional component of social support will buffer (protect) persons from the potentially pathogenic influence of a stressful illness experience (Cohen & Wills, 1985). TBI patients' perceive availability of support was significantly associated with QoL (Kalpakjian et al., 2004; Petchprapai, 2007; Tomberg et al., 2005; Tomberg et al., 2007).

The last variable, life situation and autonomy, is regarded as functioning and disability. The WHO International Classification of Functioning, disability, and health (ICF) is a universal reference framework for functioning and health. It addresses three components: impairment, activity limitation, and participation restriction. The association of functioning and disability with QoL in patients with TBI has been documented (Huebner et al., 2003; Resch et al., 2009; Teasdale & Engberg, 2005).

The severity of injury and functioning and disability are classified as physical factors. Social support and depressive moods are classified as psychosocial factors. The schema of the conceptual framework in this study is described in Figure 1.



Figure 1. Study Framework of Determinants of QoL in Patients with TBI

### **Hypothesis**

The hypothesis of this study were as follows:

1. Physical factors (severity of injury and functioning and disability)

have a direct effect on QoL in TBI patients

2. The psychosocial factors (social support and depressive moods)

have a direct effect on QoL in TBI patients

### **Definition of Terms**

*Physical factors* refer to the severity of injury and the functioning and disability of TBI patients.

Severity of injury refers to the classification of the severity of TBI as measured by GCS at the first admission post injury, which includes mild TBI (GCS 13-15), moderate TBI (GCS 9-12), and severe TBI (GCS  $\leq 8$ ).

*Functioning and disability* refers to the level of impairment, activity limitation, and participation restriction after the injury of TBI patients. It was measured by the Disability Rating Scale (DRS) and consists of an 8- item scale (Rappaport, Hall, Hopkins, Belleza, & Cope, 1982).

*Psychosocial factors* refer to the social support and depressive moods of TBI patients.

*Social support* refers to the perception of TBI patients about the degree of support availability at home and in the community after discharge. Social support includes 4 domains: tangible support, affection, positive social interaction, and informational and emotional support. It was measured by the Medical Outcomes Study Social Support Survey (MOS SSS) (Sherbourne & Stewart, 1991) which consists of 19 items on a 5-point scale.

Depressive mood refers to a self report of the current mental state that occurred during the past week which may or may not be probable for mood disorder. It was measured by the Hospital Anxiety and Depression Scale (HADS) (Zigmond & Snaith, 1983), a 14-item scale which consists of two subscales: anxiety scale and depression scale. *Quality of life* refers to a self report of perceived satisfaction and feeling bothered by his or her subjective health condition, functioning, and wellbeing, which are typically caused by TBI. Six domains are included to evaluate the satisfaction (the Cognition, Self, Daily Life and Autonomy, and Social Relationships) and bothered feelings (Emotions and Physical Problems) of the TBI patients. The QoL was measured by the QOLIBRI (von Steinbuechel et al., 2010a; 2010b), which consists of 37-items across six domains. A high score means a high level of QoL.

#### **Scope of the Study**

This study was a cross-sectional survey to describe and determine the QoL of patients with TBI in Indonesia. The study subjects included mild, moderate, and severe TBI patients recruited from Dr. Kariadi Hospital, Central Java Indonesia. Data were collected from interviews conducted between January and March 2013.

### Significance of the Study

The results of this study will enable nurses and health care teams to have a better understanding of the factors influencing QoL among adults living with TBI after being discharged from hospital. The findings can be used as baseline data for the development of a nursing intervention to improve the QoL of patient after discharge or for further interdisciplinary research of TBI.

## CHAPTER 2

## LITERATURE REVIEW

This research was the study of the determinants of QoL of patients with TBI in Indonesia. Related literature, textbooks and research were reviewed and are presented in the following order:

- 1. Traumatic Brain Injury (TBI)
  - 1.1. Definition of TBI
  - 1.2. Types of TBI
  - 1.3. Impact of TBI on patients
  - 1.4. Treatment and care for patients with TBI after discharge
  - 1.5. Health care services for people with TBI in Indonesian context
- 2. QoL in patients with TBI
  - 2.1. Concept and definition of QoL in patients with TBI
  - 2.2. QoL after discharge in patients with TBI
  - 2.3. Assessment of QoL in patients with TBI
  - 2.4. Factors associated with QoL in patients with TBI
- 3. Summary

### **Traumatic Brain Injury (TBI)**

#### **Definition of TBI**

TBI is defined as an alteration in brain function which manifest as confusion, an altered level of consciousness, seizure, coma, or focal sensory or motor neurologic deficit resulting from a blunt or penetrating force to the head (Bruns & Hauser, 2003). The WHO has defined TBI as an acute brain injury resulting from mechanical energy to the head from external physical forces. The operational criteria for the clinical identification of TBI include >1 of: (1) confusion or disorientation; (2) loss of consciousness; (3) post-traumatic amnesia; and (4) other neurological abnormalities such as focal neurological signs, seizure, intracranial lesion (Carroll, Cassidy, Holm, Kraus, & Coronado, 2004).

# **Types of TBI**

Classically, TBI has been divided into two distinct periods: primary and secondary brain injury (Moppett, 2007). The primary injury is the result of the initial, mechanical forces, resulting in the shearing and compression of neuronal, glial, and vascular tissue. Axonal tissue is more susceptible to the injury than vascular tissue. Thus, focal injuries are usually superimposed upon more diffuse neuronal injury. The consequences of the initial injury include physical disruption of cell membranes and infrastructure, and disturbance of ionic homeostasis secondary to increased membrane permeability. This in turn may lead to astrocytic and neuronal swelling, relative hypoperfusion, and a cascade of neurotoxic events because of increased intracellular calcium. The secondary injury is described as the consequence of further physiological insults, such as ischaemia, re-perfusion and hypoxia, to areas of 'at risk' brain in the period after the initial injury. This demarcation of periods of injury is now viewed as excessively simplistic (Moppett, 2007).

TBI are often classified by one of three main systems: (1) clinical indices of severity, used most often in clinical research to compare patients among centers; (2) pathoanatomic type, used most often to describe injuries for acute management; and (3) physical mechanism (i.e., causative forces associated with the injury), used most often in the biomechanics and prevention fields (Saatman et al., 2008).

*Classification by severity of injury*. The 15-point Glascow Coma Scale (GCS) developed by Teasdale and Jennett (1976) is the most widely used clinical measures of TBI severity (Brain Trauma Foundation, American Association of Neurological Surgeons, 2000, p. 163), because of its high inter-observer reliability and generally good prognostic capabilities (Narayan et al., 2002). The severity of TBI can be classified into three types based on GCS: mild, moderate, and severe TBI, (Table 1). The guideline of NSW classifies patients with initial GCS scores of 13 in the moderate head injury group due to the patients having similar patterns of intracranial injury and cognitive behavioural sequelae (Reed, 2011). Moreover, the WHO collaboration center task force on mild TBI recommend an operational definition of mild TBI with one of operational criteria is GCS score of 13–15 after 30 minutes post-injury (Carroll et al., 2004).

# Table 1

	GCS scores		
Guidelines/Authors	Mild	Moderate	Severe
Scottish Intercollegiate Guideline Network (SIGN) (2009)	13-15	9-12	≤8
The European Federation of Neurosurgeon (EFNS) (2002)	13-15	9-12	$\leq 8$
Adult trauma clinical practice guideline of NSW Institute of Trauma and Injury Management (2011)	14-15	9-13	3-8

Severity of TBI Classified by the GCS

Other neurological severity scales include the Brussells Coma Grades, Grady Coma Grades, Innsbruck Coma Scale, and the FOUR score scale (Brihaye et al.; Fleischer et al.; Gerstenbrand et al.; Wijdick et al. as cited in Saatman et al., 2008). A number of scales are also available to assess extracranial injury and physiologic instability which can influence outcome, including the Abbreviated Injury Scale (AIS) (Medicine AftAoA. as cited in Saatman et al., 2008) and the Injury Severity Score (ISS) (Baker, O'Neill, Haddon, & Long, 1974). The AIS is a detailed injury scoring system for each of six body regions; the ISS is designed to quantify the severity of multiple body region injuries. The Trauma Score is a simplified scale which includes the GCS, respiratory rate, respiratory expansion, systolic blood pressure, and capillary refill in order to give an overall score (1-16) to assess injury severity (Champion et al. as cited in Saatman et al., 2008).

*Pathoanatomic classification*. A pathoanatomic classification describes the location or anatomical features of the abnormality to be targeted by a treatment, and generally falls into the scheme of "where and what" terminology. The majority of patients with more severe injuries have more than one injury type when classified in this way. Going from the outside of the head and working inwards, injury types include scalp laceration and contusion, skull fracture, epidural hemorrhage, subdural hemorrhage, subarachnoid hemorrhage (SAH), brain contusion and laceration, intraparenchymal hemorrhage, intraventricular hemorrhage, and focal and diffuse patterns of axonal injury. Each of these entities can be further described by their extent, location, multiplicity, and distribution (Saatman et al., 2008).

*Classification by physical mechanism*. Etiological classification of TBI by physical mechanism of injury has certain advantages in understanding how specific forces at specific magnitudes result in predictable patterns of injury. Thus, injuries can be classified according to whether the head is struck or strikes an object (contact or "impact" loading) and/or the brain moves within the skull (non-contact or "inertial" loading). The magnitude and direction of each type or combination of loading forces may predict type and severity of injury. There is considerable correlation between physical mechanism of injury and pathoanatomic injury type. For instance, most focal injuries, such as skull fractures, brain contusion, and epidural hematoma, result from impact loading, whereas inertial loading generally causes more diffuse injuries such as concussion, subdural hematoma and diffuse axonal injury (DAI) (Saatman et al., 2008).

In summary the TBI can be classified by one of three main systems; clinical indices of severity, pathoanatomic type, and physical mechanisms. However, this study used injury severity classification by the GCS because it is the most widely used clinically and has high inter-observer reliability.

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### **Impact of TBI on Patients**

TBI can affect patients in the physical, cognitive, behavioral, and emotional domains which appear from the acute phase and can remain long-term.

### **Physical impact**

In a study by Lundin, de Boussard, Edman, & Borg (2006), which assesses the symptoms and disability until three months after mild TBI, it was found that 86% of patients reported one or more symptoms the day after the injury and about half reported at least one symptom persisted at three months after injury. The symptoms reported were headache 21%, dizziness 18%, nausea-vomiting 7%, fatigue 21%, and blurred vision 8% (Lundin et al., 2006).

Cantor et al. (2008) found that fatigue was more severe and prevalent in individuals with TBI, and more severe among women. Fatigue was found to be very high in the TBI group, even when compared to a control group in whom fatigue was somewhat elevated. Fatigue was also related to the impact of physical health on functioning. Thus, increased fatigue was associated with greater perceived negative impact of health issues on a variety of daily activities (Cantor et al., 2008).

Moreover, the physical impact of TBI did not recover after one year even in accepted early active rehabilitation (Andersson, Emanuelson, Björklund, & Stålhammar, 2007). At a year outcome after rehabilitation, the mild TBI patients still reported symptoms such as headache 42%, fatigue 41%, dizziness 31%, neck pain 35%, visual impairment 27%, extremity weakness 22%, and hard of hearing 15%.

In a study by Andelic et al. (2010), which assesses disability and the physical and health status 1 year after TBI, the results demonstrated that a significant proportion of TBI survivors face substantial disability and impaired overall health one

year after injury. Compared with the general population, overall health as measured by the SF-36, forty-six percent of the patients reported poor physical health (Andelic et al., 2010).

The activity limitation as measured by the Functional Independence Measure (FIM) showed that 25% of patients reported disability requiring personal assistance in physical activity daily life (ADL). In accordance with the previous study, a longitudinal study from 1 month to 3-5 years after injury of 133 persons with mild to severe TBI (Pagulayan et al., 2006) showed that TBI was associated with broad and significant perceived limitations in most aspects of everyday life, including physical functioning. Moreover, not being able to perform the activity or needing help from others partially or totally occurs in all areas (Dikmen et al., 2003). It was documented that the independence for basic ADL skills, as assessed with the Barthel index showed that 48% (n = 75) of patients with TBI needed at least some assistance for more complex ADL (Mailhan et al., 2005).

#### **Cognitive impact**

The cognitive impairments and behavioral changes of patients with severe TBI after 2 years following injury, as assessed by the Neurobehavioural Rating Scale-Revised (NSR-R), has been well described and mainly involved memory and executive functions (Mailhan et al., 2005). The NRS-R items regarded as the most impaired (mean score of 1.0 or more) were memory difficulties, difficulty in mental flexibility, difficulty in planning and self appraisal difficulties. Similarly, a study by Dikmen et al. (2003) which investigated neuropsychologic, and emotional status 3 to 5 years after moderate to severe TBI in 210 TBI patients, found approximately 60% reported cognitive problems in their daily activities or needed partial or total help from others because of their cognitive difficulties. It is concluded that the results provide representative estimates of long-term morbidity in patients with TBI and indicate that the magnitude of morbidity is high (Dikmen et al., 2003).

Long-term intellectual impairment was also present in 74 patients with moderate and severe TBI at 16 years after injury (Wood & Rutterford, 2006a). The result showed that there was a significant difference (p < .001) in IQ scores between pre-injury and post injury. Consistent with those results, Senathi-Raja, Ponsford, and Schonberger (2010) studied 112 patients with mild to severe TBI and was found that cognitive impairment was greater with years after injury.

#### **Behavioral impact**

Behavioral impacts including psychosocial functioning can occur after the injury. The previous study showed that many patients reported productivity restrictions 1 year post injury (Andelic et al., 2010). Social integration is a high concern as measured by Community Integration Questionnaire (CIQ) was not achieved. Roughly, 66% of the patients reported at least two problems regarding social integration. Thirty-five percent of patients were considered to have major problems with social integration (Andelic et al., 2010). A longitudinal study from 1 month to 3-5 years after injury of 133 persons with mild to severe TBI by Pagulayan et al. (2006) also showed that TBI was associated with broad and significant perceived limitations in psychosocial functioning. Similar to those studies, Dikmen et al. (2003) found functional limitation in the social integration of 210 TBI patients at follow up 3 to 5 years after injury. Another behavioral impact was employment status. It is documented that TBI patients encounter problem with employment. The vocational status had changed dramatically after an accident. Mailhan et al. (2005) reported that before the injury, 60 % of the TBI patients were employed in a full-time job and 28% at school. At the time of study, 60 % of the TBI patients had no activity at all (Mailhan et al., 2005). Others studies also found that at 1 year after injury, 42% TBI patients were not working (Andelic et al., 2010). Consistent with those results, Mc. Carty et al. (2006) found that TBI patients have role limitation at work and school after injury. Moreover, alcohol use (Draper, Ponsford, & Schönberger, 2007) and substance use disorder (Whelan-Goodinson et al., 2009) were also reported as a sequelae in TBI patients after injury.

#### **Emotional impact**

The emotional consequence after TBI has been demonstrated in a study of 53 patients with mild to severe TBI at 10 years following injury (Draper et al., 2007). It showed that long-term emotional problems encountered by patients with TBI with the prevalence of anxiety 20%, depression 46%, and aggression 12 %. Another study also found that depression occurs in 28% of patients with TBI at 3 years after injury (Underhill et al., 2003). In a review on the evidence of depression after TBI (Moldover , Goldberg, & Prout, 2004), it was found that depression represents a major source of disability among individuals who have suffered a TBI, with estimates of prevalence in this population ranging over 50%. Moreover, a high frequency of post injury psychiatric disorders was evident up to 5.5 years post injury, with many novel cases of depression and anxiety (Whelan-Goodinson et al., 2009). In summary, TBI can result in physical, cognitive, behavioral, and emotional impacts, with the majority of TBI patients needing long-term care particularly after discharge.

### Treatment and Care for Patients with TBI after Discharge

TBI stands as a major public health problem and one of the most important challenges for neurological rehabilitation and neurosurgical nursing.

There are three phases in post-traumatic evolution. First, acute rehabilitation takes place during coma and arousal states. The specific aims are to prevent cutaneous, orthopedic, respiratory and other visceral complications, and to provide sensory stimulations with the hope of accelerating arousal. Secondly subacute (generally in patients) rehabilitation is designed to facilitate and accelerate recovery of physical and cognitive impairments, and to compensate for disabilities. A third, post acute rehabilitation phase includes outpatient therapy for achieving physical, domestic and social independence, reduction of handicaps and re-entry into the community: returning home, obtaining financial independence, driving, returning to work, participating in social relationships and leisure activities (Mazaux & Richer, 1998).

Post acute brain injury rehabilitation includes a number of specialized programs appropriate for individuals able to benefit from further rehabilitation. These programs consist of 3 programs including: (1) neurobehavioral program, (2) community integration program, and (3) comprehensive day treatment program. Neurobehavioral programs are residential programs that provide intensive behavioral treatment to TBI patients with severe behavioral disturbances. Residential community reintegration programs provide integrated cognitive, emotional, behavioral, physical, and vocational rehabilitation to patients who cannot participate in outpatient programs either because of severe cognitive and behavioral impairments or the unavailability of outpatient services. Comprehensive (holistic) day treatment programs offer integrated, multimodal rehabilitation. Comprehensive day treatment programs emphasize improvement in self-awareness after TBI. Patients with awareness of their impairments and disabilities may benefit from outpatient community re-entry programs, which typically focus on circumscribed rehabilitative treatment and vocational and social reintegration. Persons with TBI may also be involved with a variety of short- or long-term community supports, including brain injury associations, support groups, vocational services, independent living services, social services, and public or private financial supports (Malec & Basford, 1996).

The TBI person who is admitted in a post acute rehabilitation program may have a better outcome. High, Roebuck-Spencer, Sander, Struchen, & Sherer (2006) examined the outcome of TBI persons admitted to a post rehabilitation program at early admission (less than 1 year post injury) versus late admission. It was found that all groups showed improvements between admission and discharge on measures of overall disability, independence, home competency, and productivity, and these gains were maintained at follow-up. In addition, the greatest gains were obtained in persons entering a post rehabilitation program within 6 months post injury (High et al., 2006). Similarly, Svendsen and Teasdale (2006) also found that post acute neuropsychological rehabilitation can have long-term beneficial effects. The rehabilitation group showed significantly lower levels of brain injury symptoms and higher levels of competency. They also rated internal locus of control and general self-efficacy as significantly higher, anxiety and depression levels significantly lower, and QoL significantly higher in the rehabilitation group (Svendsen & Teasdale, 2006).

Moreover, a systematic review of the effectiveness of multidisciplinary rehabilitation following acquired brain injury in adults of working age (Turner-Stokes, 2008) showed strong evidence that more intensive programs were associated with more rapid functional gains. Braunling-McMorrow, Dollinger, Gould, Neumann, and Heiligenthal (2010) examined the impact of multifaceted rehabilitation services on functional outcomes after TBI for individuals with significant physical and cognitive difficulties, as well as those with added behavioral complications. The result showed that the rehabilitation treatment model achieved significant functional gains for neuropsychologically-impaired adults with and without associated behavioral and substance problems (Braunling-McMorrow et al., 2010).

It is estimated that although over 80% of the world's people with disabilities live in low and middle income countries only 2% have access to rehabilitation services (Jamison et al. as cited in Hyder et al., 2007). In low and middle income countries such as Indonesia, access to rehabilitation units is limited. The management of patients with TBI in Indonesia has focused more on acute treatment. This lack of treatment and long-term care service calls for comprehensive rehabilitative facilities based on trained manpower to enable and empower people affected by TBI in order to increase quality of life (Hyder et al., 2007).
# Health Care Services for People with TBI in Indonesian Context

Implementation of health development in Indonesia refers to the document 'Sistem Kesehatan National' (National Health System) that contains the planning and implementation of methods and means of health in Indonesia. The basic health development in Indonesia, as stated in Law No. 17 Year 2007 in the Long Term National Development Plan Year 2005-2025, aims to increase awareness, willingness and the ability of having a healthy life for every person to ensure the improvement of health as high as possible can be materialized (MoHRI, 2009).

Since the year 2011, based on ownership, hospitals in Indonesia have been grouped into public hospitals and private hospitals. This grouping by the Minister of Health No. 147/Menkes/PER/I/2010 is about Hospital Licensing. Public hospitals are government-run hospitals, local governments and non-profit legal entities, and the private hospital is a hospital run by the material law with the goal of a profit limited liability company or limited company. In 2011 the number of public hospitals in Indonesia was as much as 1406 units, comprising of general hospitals amounting to 1127 units and special hospitals amounting to 279 units. Public hospitals are managed by the Ministry of Health, provincial government, district/city government, military/police, other ministries and the private non-profit organizations. While the number of private hospitals as much as 315 units, consists of general hospitals totaling 245 units and specialty hospitals totaling 70 units. Private hospitals are managed by state-owned and private enterprise. These number of hospitals is a hospital that has been recorded and get the codes hospitals through the Hospital Information System (MoHRI, 2012). In the community setting, there is a community health care in each subdistrict which provides primary care for individuals and the community. Some of the community health care centres have facilities for inpatient obstetric and neonatal care in accordance with the government's program to reduce maternal and child mortality (MoHRI, 2012).

The Indonesian government sets the health budget which has been increasing from year to year. However, the percentage still ranges from 2.6 to 2.8% of the total national budgets. Health financing has increased from year to year. The percentage of national health sector expenditures are increasing from year to year, although it has not reached 5% of the Gross Domestic Product as recommended by WHO. The contribution of government expenditure on health is still small, and is at 38% of total health financing (MoHRI, 2009).

Financing of public health services is a public good which is the responsibility of the government, while for individual health services are private financing, unless funding for the poor and unable people is the government's responsibility. Financing health care for the poor and unable people is held through health insurance with the social insurance mechanisms (*'jamkesmas'*) (MoHRI, 2009)

In Indonesia, besides modern medicine, there are traditional treatments that have been lasted a long time and are entrenched in the community. Traditional health care in Indonesia continues to grow and has began to receive special attention from the government. In Act No. 36 of 2009 on Health, it is stated that traditional health care is the treatment and/or care and drugs by referring to the experience and skills hereditary empirically accountable and applied in accordance with the norms prevailing in society (MoHRI, 2012). However, the implementation of traditional health care in the formal health care setting is still limited.

In 2011, TBI was included in the top ten of disease in hospitalized patients. However, TBI has not been included in any of the Health Ministry's strategic objectives (MoHRI, 2012). Caring for patients with TBI is provided by public and private hospital type A and B who have facilities for neurosurgery. However, the poor people which is under the social insurance scheme only have access to public hospitals. After patient discharge, they can access rehabilitation programs in hospitals which provide a rehabilitation program for TBI patients. Commonly it is provided by tertiary or central referral hospitals in each province.

In the community, TBI patients can access services from a community health center. However, community health centers only provide primary care for simple diseases or symptoms. Caring for TBI patients after the acute phase, like other disabled groups, is mostly done at home with family. Because traditional medicine has become part of Indonesian culture and is also more available, it is more likely to be used for curing patients. As reported in WHO-South East Asia regional (Chaudhury & Rafei, 2001), traditional medicine and traditional practitioners in Indonesia, who have developed in line with community needs, are to provide the alternative health services. These practitioners are very popular and familiar in the community, because they are easily accessible and valuable, and have been proved empirically safe (Chaudhury & Rafei, 2001).

# **QoL in Patients with TBI**

### Concept and Definition of QoL in Patients with TBI

The term QoL historically has mainly been used in politics. The term QoL has also been introduced to medicine, some authors relate the introduction to early work from 1967, others refer it to the increase of publications relating to QoL (Spilker as cited in Bullinger, 2002). The term health-related quality of life has been coined differentiating the medical from the more sociological oriented QoL concepts, since in medicine specifically health aspects of well-being and function were to be represented (Patrick & Erickson as cited in Bullinger, 2002). The term health-related quality of life reflects the way in which patient's view their health state and has gained recognition as an evaluation criterion for medical treatments (Bullinger, 2002). Later, in this study the term HRQoL will be used to refer to QoL.

While research efforts and empirical results are available in several areas of medicine, QoL investigations in patients with traumatic brain injury has only just extensively been explored (Bullinger, 2002). The WHO defines QoL as "an individual's perception of their position in the life in the context of the culture and value systems in which they live and in relation to their goal, expectations, standards and consent. It is a broad concept affected in a complex way by the person's physical health, psychological state, level of independence, social relationships, and their relationship to salient features of their environment" (WHOQoL Group, 1993 p. 153).

A review by Bullinger in 2002 in health-related quality of life in medicine determined the concept of QoL that consists of three concepts. First, QoL is individually centered and implies that QoL is principally not measurable across persons because it varies from person to person in its dimensionality. Secondly, the definition QoL is viewed as evaluable using a defined number of different dimensions which are relevant for all people. These dimensions pertain in accordance with earlier definitions of the WHO to physical, psychological and social well-being. A third concept maintains that QoL cannot be measured directly neither intraindividually nor interindividually. In contrast, QoL is viewed as an implicit construct in which the implicit measurement of patient preference rather than direct questions oriented towards well-being are used. That is the approach of so called health economical or cost utility approaches to the quality of life assessment.

These concepts of quality of life by Bullinger (2002) are in accordance with the conception by Dijkers (2004) in his review of QoL after TBI. The concept of QoL was determined in 3 aspects, as subjective well being, as achievement, and as utility. Firstly, the conceptualization of QoL is that of the psychologists and social scientists who study life satisfaction and affect: QoL is equivalent to subjective wellbeing (SWB), the cognitive and emotional reactions to the balance of achievements and expectations. SWB includes such phenomena as life satisfaction, morale, happiness, and (nonpathologic) negative affect. The term QoL, meaning feeling of "well-being as influenced by the good things in life," is so commonplace that investigators can even ask subjects for a direct rating of their QoL. Second, if Bullinger (2002) viewed that QoL as individually centered, Dijkers (2004) determined that from the individual center or individual expectations can be assumed in that there is so much communality in people's expectations and priorities that it is superfluous to investigate idiosyncratic needs and wishes or individual reactions. They reason that once achievements are known, reactions can be virtually predicted; therefore, a careful inventory of achievements in the major domains of life is all that is needed to

assess QoL. Thus, the conceptualization of QoL is one's share of those characteristics that many people consider essential to "the good life" and that can be determined with a large degree of objectivity. This conceptualization concludes QoL as achievements. The third conceptualization of QoL is the preference for, or utility of, a health status or even a life as a whole. This QoL stems from the applications of economic and management decision-making theories. To evaluate the expenses and benefits of one health care program or medical intervention relative to another, common metrics for costs and outcomes are needed.

Another component in the QoL conceptualization is approaching to the assessment of QoL. Johnston and Miklos's review study (2002) determined 3 approaches to the assessment of QoL. First, the objective approach, which uses functional outcome as a scale for the assessment of QoL. Second is the subjective approach which is based on global QoL that has been defined as the individual's judgment of his/her life experience as a whole along a positive to negative continuum. SWB, life satisfaction, and subjective QoL all involve an appraisal of the affective tenor of life with the person. The third approach is the mixed approach. There are approaches to the assessment of QoL and experience that allow a degree of objectivity into their largely subjective items. These approaches query specific aspects of life experience as specific aspects of health or the experience of illness or need fulfillment that are more objective than global life satisfaction or general feelings.

Brown, Gordon, and Haddad (2000) have compared the utility of needs and the International Classification of Impairment, Disability and Handicap (ICIDH)based models in predicting QoL in persons with TBI. Needs-based models using

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subjective indicators predicted subjective QoL markedly better than models that relied on objective indicators of severity of impairment or disability.

The studies that are included in this review can be defined as three groups of conceptual framework based on Dijkers's conception (2004). Regarding the approaches for assessing QoL, most of the studies in this review use a mixed approach. The group of mixed approach studies used HRQoL as the domain for measure QoL.

A summary of the conceptualization of QoL and its domains for measurement from other studies in this review is described in Table 2.

Table 2

		Tools for	
Authors	Definition of QoL	measurement QoL	Type of Approach
Andersson et al. (2011)	Achievement	SF-36,	Mixed
	SWB	LiSat-11	Subjective
Bedard et al. (2003)	Achievement	SF - 36	Mixed
Breed et al. (2004)	Achievement	LLATBI, SF - 36	Subjective, mixed
Brown et al. (2000)	SWB	QOL Interview	Mixed
Chiu et al. (2006)	Achievement	WHOQOL-BREF	Mixed
Dikmen et al. (2003)	Achievement	SF-36,	Mixed
	SWB	PQOL	Subjective
Emanuelson et al. (2003)	Achievement	SF - 36	Mixed
Eriksson et al. (2009)	SWB (life satisfaction)	LiSat	Subjective
Guilfoyle et al. (2010)	Achievement	SF-36	Mixed
Hawthorne et al. (2009)	Utility	SF-36V2, AQoL,	Mixed
		SF6D	
Huebner et al. (2003)	SWB	QOLR	Subjective
Johnston et al. (2005)	SWB	SWLS	Subjective
		CIQ-2	Objective
Kalpakjian et al. (2004)	SWB	QOL Inventory	Subjective
Lin et al. (2010)	Achievement	WHOQOL-BREF	Mixed
Mailhan et al. (2005)	SWB	SQL Profile	Subjective
Mar et al. (2011)	Utility	SF-36	Mixed
		EQ-5D	
Nestvold & Stavem (2009)	Achievement	SF-36,	Mixed
		GHQ-30	Objective
Pagulayan et al. (2006)	Achievement	SIP	Objective

Conceptualization of QoL in TBI

Table 2 (Continued)

		Tools for	
Authors	Definition of QoL	measurement QoL	Type of Approach
Steadman-Pare et al. (2001)	Achievement	SF-36,	Mixed
	SWB	Self-rated Quality	Weighted
		of Life Scale	
Teasdale & Engberg (2005)	Achievement	EBIQ	Objective
Thomas et al. (2009)	SWB	QOLI	Subjective
Truelle et al. (2010)	Achievement	QOLIBRI	Mixed
Upadhyay (2007)	Achievement	WHOQOL-BREF	Mixed
von Steinbuechel et al. (2010a)	SWB	QOLIBRI	Mixed
von Steinbuechel et al. (2010b)	SWB	QOLIBRI	Mixed

*Note.* SWB = Subjective Well-Being; SF-36 = Short Form-36 health survey; LiSat-11 = Life Satisfaction-11; LLATBI = Living Life After TBI; WHOQOL-BREF = World Health Organization Quality of Life-BREF; PQOL = Perceived Quality of Life; AQoL = Assessment of Quality of Life; QOLR = Quality of Life Rating; SWLS = Satisfaction with Life Scale; CIQ = Community Integration Questionnaire; SQL Profile = Subjective Quality of Life Profile; EQ-5D = Euro Quality of Life-5D; GHQ-30 = General Health Questionnaire-30; SIP = Sickness Impact Profile; EBIQ = European Brain Injury Questionnaire; QOLI = Quality of Life Inventory; QOLIBRI = Quality of Life after Brain Injury.

From Table 2 above, it is shown that 12 studies equated QoL with

subjective well-being, another 14 studies defined QoL as achievement involving an external rater forming a judgement about the quality the person of interest enjoys on key aspects of life such as their health, work, leisure activities, place of residence, financial status and relationships. Only two studies (Hawthorne et al., 2009; Mar et al., 2011) use utility as a conception of QoL. Truelle et al. (2010) and von Steinbuechel et al. (2010a; 2010b) studies which used QOLIBRI as the measurement tool for QoL also used the concept of SWB to define the QoL.

von Steinbuechel, Petersen et al. (2005) proposed a conceptual model of an HRQoL assessment (Figure 2). In this model, HRQoL needs to be assessed in four areas; physis (physical), psyche (psychological), social life and daily life (center line in Figure 2). In the psychological domain emotional and cognitive aspects have to be assessed explicitly. Relevant predictor variables (first and third row) should be measured along with the self-rated core HRQoL variables. Only in cognitively severely impaired persons after TBI, observers (proxies) should serve as raters (von Steinbuechel, Petersen, et al., 2005). This HRQoL assessment model guided the development of QOLIBRI by an international multi-disciplinary group (the TBI Consensus Group, later the QOLIBRI Task Force) which formed in 1999. The domain in the QOLIBRI consists of 5 domains from von Steinbuechel, Petersen, et al. (2005) HRQoL conceptual model added with the self domain. The final QOLIBRI instrument consists of 6 domains which include (1) cognition, (2) self, (3) daily life and autonomy, (4) social relationships, (5) emotions, and (6) physical problem (von Steinbuechel et al., 2010a, 2010b).

Medical-psycho-social predictor variables: self- or observer-rated						
Disease and the e.g. severity duration of unconscious	reatment degree, on ousness	Per	sonality character and resources e.g. coping strategi	r <b>istics</b> es	istics Life situation, autonomy e.g. self-care, dependence on help	
	TT 1/1			e (11D		
Health-Related Quality of Life (HRQOL)						
HRQOL variables: self-rated						
Physis		Psy	rche	Social life		Daily life
e.g. physical functioning, symptoms	Emotions e.g. self-este self-awaren	s em, ess	Cognition e.g. memory, executive functions	e.g. relationship to family and friends		e.g. hobbies, leisure, activities, mobility
<u> </u>	<b></b>		<b>≜</b>	<u>+</u> <u>+</u> <u>+</u>		T.
<b>Medical data</b> e.g. EEG, MR, laboratory data	Ratings o emotion e.g. anosogne scale	<b>f</b> osia	Neuropsychologica testing e.g. memory, executive functior	u So e re	ociograms e.g. social elationship scale	Activities of daily living e.g. ADL
Bio-psycho-medical predictor variables: observer-rated						

*Figure 2*. Measurement Model of HRQoL in Persons after TBI. Adapted from "Assessment of health-related quality of life in persons after traumatic brain injury – development of the Qolibri, a specific measure," by N. von Steinbuechel, C. Petersen, M. Bullinger, and the QOLIBRI Task Force, 2005, *Acta Neurochirurgica, S93*, p. 47. Copyright 2005 by the Springer-Verlag.

In summary, two important definitions of QoL were used in the studies related to TBI namely achievement and subjective well being. Despite the different approach, appropriate domains of QoL seem essential particularly the cognitive domain in TBI patients which is generally accompanied by cognitive impairment. Since HRQoL model from von Steinbuechel, Petersen, et al. (2005) integrates disease-specific issues of TBI patients such as cognition in the assessment, this model was used in this study for the QoL conception.

# **QoL after Discharge in Patients with TBI**

QoL has become a priority outcome in research and clinical practice. QoL is a useful frame of reference to measure outcome after TBI. Among 24 studies reviewed, it showed that the majority of patients with TBI have lows of QoL (Table 3). Although the results of QoL were similar in showing low QoL in TBI patients, it seems difficult to compare because of the differences in terms of study design, sampling strategy, conceptualization to approach QoL, the tool for the measurement of QoL, and the inclusion criteria when approached. The summary of studies in this review is in Table 3.

lors	Inclusion Criteria	Data Collection Method	Subjects and Sample Size	Study Design	Result of QoL
	$\geq 1$ year post injury	Home interview	All (mild, moderate & severe TBI), 13	Intervention, pre- post study	Moderate
	4 years post injury	Telephone interview	All, 191	Descriptive survey	Low
ŝ	> 3 years after injury	Not state	All, 210	Descriptive	Slighty worse
	injury				year were significantly lower and no significant difference between 3 months and 1 year
	1 – 4 years after injury	A postal survey	All, 116	Cross-sectional	Low
(6	> 3 months post injury	Interview ; at home or another nominated location, telephone	All, 66	Cross-sectional	Low
	> 1 year post injury	Telephone interview	All, 25	Cross-sectional	Low
	> 1 month after rehabilitation discharge	Telephone interview	All, 162	Longitudinal	Low at 1 month and no improvement at12 months
<del>(</del> )	<1 year	Telephone interview	All, 50	Cross-sectional	Low

Study in QoL after Discharge in Patients with TBI

Table 3

Authors	Inclusion Criteria	Data Collection Method	Subjects and Sample Size	Study Design	Result of QoL
Lin et al. (2010)	After discharge	Telephone interview	All, 158	Longitudinal	Decline at discharge, followed at 6 months slight increase at 12 months.
Mailhan et al. (2005)	>2 year after injury	Home or hospital interview	Severe TBI, 75	<b>Cross-sectional</b>	Low
Mar et al. (2011)	> 12 months after hospital admission	Interview	All, 68	Cross-sectional	Low
Nestvold & Stavem (2008)	22 years after injury	Postal survey	All, 259	Cohort study	Low
Pagulayan et al. (2006)	> 1 month after TBI	Not stated	All, 133	Longitudinal cohort	Pattern of endorsed difficulties at 6 months, 1 year, and 3 to 5 years nearly the same
Steadman-Pare et al. (2001)	8 - 24 years after injury	Home interview	Moderate to severe TBI, 275	Cross-sectional	High
Teasdale & Engberg (2005)	> 5 year post injury	Postal questionnaire	All, 257	Cross-sectional	Low
Truelle et al. (2010)	> 3 months after injury	Postal questionnaire/ face- to face interview/ telephone interview	All, 795	Cross-sectional	Low
Upadhyay (2007)	> 3 months post injury	Not stated	All, 30	Cross sectional	Low
<i>Note</i> . All = mild, moderat	e, and severe TBI				

Table 3 (Continued)

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Table 3 shows that most of the studies related to QoL of patients with TBI used cross-sectional design. Regarding the outcome measured, it can be divided into two groups. First, the short-term outcome that measured the QoL less than one year (ranged from discharge at 1 month) (Johnston, Goverover, & Dijkers, 2005; Lin et al., 2010; Pagulayan et al., 2006) until 12 months after injury (Bedard et al., 2003). Second, the long-term outcome of approaches to QoL in patients with TBI is accounted of more than 1 year after injury.

Most of the studies used cross-sectional design. Congruent with Pagulayan et al. (2006), there are relatively few studies that have evaluated outcome at multiple points over an extended period of time after injury. Perceived healthrelated functioning in both physical and psychosocial domains may change over time because recovery from TBI is a complex and lengthy process. The rate of recovery may vary because of a number of factors, including the severity of the brain injury, time since the injury, the domain of functioning that is being assessed, and measures used for their assessment. Given the multiplicity of contributing factors and the difficulties in performing longitudinal studies, particularly in the TBI population, the literature is limited on the trajectory of HRQoL over time after a TBI (Pagulayan et al., 2006). Even so, there are recommendations for a longitudinal study on QoL after TBI to see the changes over time regarding QoL (Bullinger & TBI Concensus Group, 2002; Dijkers, 2004). However, a cross-sectional study with an appropriate QoL assessment using a valid specific instrument for patients with TBI can overcome the shortcoming of a longitudinal study. This study used a cross sectional survey and approach patients after one month post injury since there are very few data sources for base line information in Indonesia.

# Assessment of QoL in Patients with TBI

To assess trauma severity and the clinical outcome after TBI, there are now well-established and widely-used TBI-specific instruments available. The instruments including the Glascow Coma Scale (GCS) (Teasdale & Janet, 1976), the Coma Remission Scale and the Coma Recovery Scale to measure recovery from a coma, the Glascow Outcome Scale (GOS) (Jennett & Bond, 1975) or its extended version, GOSE (Jennett, Snoek, Bond, & Brooks, 1981), the Disability Rating Scale (Rappaport et al., 1982), the Functional Status Examination (Dikmen, Machamer, Miller, Doctor, & Temkin, 2001) and the Mayo-Portland Inventory (MPAI) to index disability, the Community Integration Questionnaire (CIQ) (Willer, Rosenthal, Kreutzer, Gordon, & Rempel, 1993) to assess social reintegration, the Functional Independence Measure (FIM) (Granget as cited in Laxe et al., 2012), the Trail Making Test (TMT) (Reitan & Wolfson as cited in Laxe et al., 2012), and finally the International Classification of Functioning, Disability and Health (ICF) (WHO, 2001) as a framework for describing functioning and health.

On the contrary, for outcomes after TBI-related QoL such conditionspecific tools do not exist, and clinicians and researcher are still developing such tools (Bullinger, 2002; Dijkers, 2004; Truelle, 2010). There are two main types of QoL instruments: generic and disease-specific. Generic instruments do not take a particular condition into account and therefore, allow comparisons with healthy individuals along with comparisons across various disease states. Disease-specific instruments take into account a patient's specific health condition and therefore, may be more sensitive to the consequences of the condition and more relevant to patients (Bullinger et al., 2002; Nichol et al., 2011). The tool that has been used in studies of this review are shown in Table 4.

# Table 4

# Overview for Measurement of QoL in Patients with TBI

Tool	TBI references	Number of studies	Type of tool
SF - 36	Bedard et al., 2003;	4	Generic
	Emanuelson et al., 2003;		
	Guilfoyle et al., 2010;		
	Nestvold & Stavem, 2009		
LLATBI	Breed et al., 2004	1	TBI-specific
SIP	Pagulayan et al., 2006	1	Generic
WHOQOL-BREF	Chiu et al., 2006; Lin et al.,	3	Generic
	2010; Upadhyay, 2007		
PQOL (perceived quality of life)	Dikmen et al., 2003	1	Generic
Self Rated Quality of	Steadman-Pare et al., 2001	1	Generic
Life Scale		-	
AOoL	Hawthorne et al., 2009	1	Generic
LiSat-11	Andersson et al., 2011;	2	Generic
	Eriksson et al., 2009		
QOLR	Huebner et al., 2003	1	Generic
SWLS	Johnston et al., 2005	1	Generic
QOL Inventory	Kalpakjian et al., 2004	1	Generic
EBIQ	Teasdale & Engberg, 2005	1	<b>TBI-specific</b>
QOL Interview	Brown et al., 2000	1	Generic
SQL Profile	Mailhan et al., 2005	1	<b>TBI-specific</b>
QOLI	Thomas et al., 2009	1	Generic
EQ-5D	Mar et al., 2011	1	Generic
QOLIBRI	Truelle et al., 2008; 2010;	4	TBI-specific
	von Steinbuechel et al.,		-
	2010a; 2010b		

*Note*. SF-36 = Short Form-36 health survey; LLATBI = Living Life After TBI; SIP = Sickness Impact Profile; WHOQOL-BREF = World Health Organization Quality of Life-BREF; PQOL = Perceived Quality of Life; AQoL = Assessment of Quality of Life; ; LiSat-11 = Life Satisfaction-11; QOLR = Quality of Life Rating; SWLS = Satisfaction with Life Scale; SQL Profile = Subjective Quality of Life Profile; EQ-5D = Euro Quality of Life-5D; GHQ-30 = General Health Questionnaire-30; EBIQ = European Brain Injury Questionnaire; QOLI = Quality of Life Inventory; QOLIBRI = Quality of Life after Brain Injury.

Based on Table 4, it shows that 19 out of 26 studies in this review

measure QoL using a generic instrument. Four studies used a version of generic

medical outcome study-short form 36 (SF-36) health survey (Bedard et al., 2003; Emanuelson et al., 2003; Guilfoyle et al., 2010; Nestvold & Stavem, 2009). Other studies used a variety of other global QoL measures, such as WHOQOL-BREF (Chiu et al., 2006; Lin et al., 2010; Upadhyay, 2007), LiSat-11 (Andersson et al., 2011; Eriksson et al., 2009), and other QoL measurement (SIP, PQOL, Self Rated Quality of Life Scale, AQOL, QOLR, SWLS, QOL Inventory, QOL Interview, QOLI, and EQ-5D). Only a few studies used a disease-specific instrument such as LLTBI (Breed et al., 2004), EBIQ (Teasdale & Engberg, 2005), SQL Profile (Mailhan et al., 2005), and QOLIBRI (Truelle et al., 2008; 2010; von Steinbuechel et al., 2010a; 2010b). For the last one, QOLIBRI, is the specific QoL measurement in TBI which has been recently developed.

### **Generic instruments**

Short Form 36 Health Status Questionnaire (SF-36) and Short Form 12 Health Status Questionnaire (SF-12). The SF-36 is a 36-item questionnaire (as the name suggests) that covers eight dimensions of health related quality of life (HRQoL): physical functioning, social functioning, physical role, emotional role, mental health, vitality, bodily pain and general health. Each dimension yields a score ranging from 0 to 100 (where 100 represents best health). The eight dimensions can be further summarized into two summary scales – mental health and physical health (Guilfoyle et al., 2010). The reliability and validity of the SF-36 have been established in a TBI population (Guilfoyle et al., 2010) and it has been widely used in TBI research. In their study, Findler, Cantor, Gordon, and Ashman (2001) noted that the SF-36 may be a more sensitive measure of health-related problems in patients with mild TBI than in those with moderate-severe TBI, as the correlations between the SF-36 scales and measures of health problems associated with TBI were weaker and more uniform in the moderate-severe TBI group (compared to the correlations in the mild TBI group). The SF-12 is a shorter version of the SF-36 containing 12 items. It covers the summary of physical health and mental health scales, but does not provide information about each of the eight dimensions of the SF-36. The SF-12 has begun to be more commonly used in the TBI population, however its psychometric properties in this population have not been specifically assessed (Nichol et al., 2011).

World Health Organization Quality of Life Brief Questionnaire (WHOQOL-BREF). The WHOQOL-BREF is a 26-item questionnaire that is a short version of the 100-item WHOQOL developed by focus groups in numerous countries. It is available in over 20 different languages. Each item uses a scale from 1 to 5, where a higher score indicates a higher HRQoL. It covers four domains of HRQoL: physical health, psychological health, social relationships, and environment (The WHOQoL Group, 1998).

# *European Quality of Life-5 Dimensions (EQ-5D).* The EQ-5D (previously known as the EuroQoL questionnaire) is a five dimensions, five item questionnaire developed in Europe in 1990. The dimensions measured are mobility, self-care, usual activities, pain/discomfort and anxiety/depression. Each item represents a single dimension with three levels: no problems, some problems, and unable or extreme. The EQ-5D can be used to generate a single health index (a utility), and is therefore useful in economic evaluations as it can be used to calculate quality adjusted life years (QALYs). It is available in many languages and there is usually no fee for its use for non-commercial purposes. A criticism of the EQ-5D for

use in TBI patients is that it does not contain a cognitive dimension (Nichol et al., 2011). A systematic review of studies using the EQ-5D after injury, found that all studies that included TBI patients added a cognitive question or cognitive specific measure to the questions they asked of participants (Derrett, Black, & Herbison, 2009).

# **TBI-specific instruments**

*The Subjective Quality of Life Profile (SQLP).* The SQLP is a patient's self assessment and relative assessment form to be included in rehabilitation and long-term cases. It has been constructed for TBI patients, and has been tested for psychometric criteria, it contains 38 items, it needs 20 minutes to fill out, and is available in English and French. The questionnaire has a generic part which contains a life satisfaction questionnaire with 10 specific questions added for TBI patients. In its core form, it resembles a more generic life satisfaction questionnaire (Bullinger et al., 2002).

### The Living Life with Traumatic Brain Injury (LLTBI). The LLTBI

questionnaire is a structured interview system concerning five areas of the impact of TBI on patients. It contains one QoL part with several items on cognition, physical well-being and social function, and has been applied in over 1000 patients. However, the psychometric criteria are not available yet. It is available in English and has been constructed for descriptive purposes (Bullinger et al., 2002).

*European Brain Injury Questionnaire (EBIQ).* The EBIQ was developed in 1997 as a measure of the subjective experience of cognitive, emotional and social difficulties experienced by people with brain injury. There are two parallel versions of the EBIQ available: one to be completed by the patient and another to be completed by a close relative/proxy. It is a 63-item questionnaire that is reported to take around 15 min to complete. Each item has three response categories: not at all, a little, and a lot. The questionnaire covers a global scale and eight subscales: somatics, cognition, motivation, impulsivity, depression, social isolation, physical activities of daily living (ADL) complaints, and communication. It has not been widely used since it was first developed, but its reliability and validity in a TBI population have been established. However, a recent study to assess the construct validity of the self-rating version of the EBIQ found that some items and overall scales did not meet expectations (using Rasch analysis) (Nichol et al., 2011).

*Quality of Life in Brain Injury (QOLIBRI).* The QOLIBRI has been recently developed by an international collaboration, and has been evaluated in its psychometric properties. The results of the psychometric evaluation indicate favorable psychometric properties of the QOLIBRI. In spite of the variation in demographic and clinical characteristics, internal consistency and test-retest reliability are acceptable to good, both in the total sample and in different language groups. Although there is one strong HRQoL factor, a six-scale structure explaining additional variance was validated by exploratory and confirmatory factor analyses, and with Rasch modeling. The QOLIBRI is a new cross-culturally developed instrument for assessing HRQoL after TBI that fulfills the standard psychometric criteria. It is potentially useful for clinicians and researchers conducting clinical trials, for assessing the impact of rehabilitation or other interventions, and for carrying out epidemiological surveys (von Steinbuechel et al., 2010a). It also has been evaluated in clinical use. The QOLIBRI final version comprises of 2 parts with a total of 37 items across six sub-scales. The first part assesses the level of satisfaction within four domains: cognition (seven items), self (seven items), daily life and autonomy (seven items), and social relationships (six items). The second part asks respondents how 'bothered' they are in relation to two domains: emotions (five items) and physical problems (five items). The completion mean time was reported at 11 minutes for self-completion and 20 minutes for face-to-face interview, although this is likely to vary by disability level. The QOLIBRI total scores were obtained by a simple summation of 37 item scores (graded 1–5), after reversal of 10 'bothered' items in order to have a 'satisfaction global score'. Then, the maximum score is  $37 \times 5 = 185$ . Afterwards, the QOLIBRI scores are presented on a 0 (worst possible score on the QOLIBRI) to 100 (best possible score) scale (although this is a percentage scale it is more common among HRQoL instruments to describe this as a 0–100 point scale) (Truelle et al., 2010).

The QOLIBRI was first validated in German, Finnish, Italian, French, English and Dutch. The development of QOLIBRI in Asia already starts with meeting of the researchers to perform the first steps towards languages harmonization with researchers. The QOLIBRI also has been translated into 14 languages: Chinese (Mandarin and Cantonese), Danish, Dutch, English, Finnish, French, German, Italian, Japanese, Polish, Spanish, Norwegian, and Malayan (Truelle et al., 2008). Currently, validation of QOLIBRI in Australian population has been documented (Hawthorne et al., 2011).

Most of the studies used the HRQoL instrument to assess QoL in TBI patients (Andersson et al., 2011; Bedard et al., 2003; Chiu et al., 2006; Dikmen et al.,

2003; Emanuelson et al., 2003; Guilfoyle et al., 2010; Hawthorne et al., 2009; Lin et al., 2010; Nestvold & Stavem, 2009; Pagulayan et al., 2006; Steadman-Pare et al., 2001; Upadhyay, 2007). HRQoL is a concept that reflects a patient's subjective view of their disease, treatment and the impact these have on their life. HRQoL covers numerous dimensions, including physical, social, psychological, and daily life. Whilst HRQoL as an outcome measure in medicine has been used for over 30 years, its use in TBI patients has only commenced in the past decade.

Measurement of QoL in patients with TBI is conceptually difficult due to the need to obtain the patient's viewpoint for a condition which often leaves patients with impaired cognition and an inability to communicate effectively. To assess QoL a patient must be conscious, able to express themselves, and have sufficient cognitive functioning to be able to understand and respond to questions. As some (or many) TBI patients may not fulfil these requirements, the perceptions of others such as family members or carers is often used (proxy respondents). These responses however, cannot fully substitute for a patient's own report (Nichol et al., 2011).

Bullinger et al. (2002) also discuss that issue. They are stating that only some of the instruments measure perceived health status by the patient, and lack an additional evaluation of the importance of health status information from the patients' perspective. Therefore, a distinction between patients' perceived health and family perceived health was made, which was relevant also for the question whether or not proxy assessment should be used. They consented that the proxy assessments are not suited to assess the patients' QoL.

There are specific criteria which should be met when developing QoL instruments. They should be specific, feasible, brief, and should take less than 20 min to complete (better 10–15 min.). They should be comprehensive, include the four main dimensions of QoL (physical, social, functioning, psychological) and also include cognitive and existential dimensions (for existential dimensions items needed to be formulated). They should be usable for the patient and for significant other (i.e., not to use the significant other's information as proxy but as the family perceived patient's health). They should have acceptable psychometric quality, that is reliability, validity and sensitivity, and they should tap the "quality" of the QoL and not just consist of the recollection of behavior or function. Instruments should be easily scorable, they preferably should be accompanied by a profile sheet in which an individual patient as well as patient groups can be depicted. They should cover both, rehabilitation phases (T2) and long term (T3) (at least T3), and they should assess the relative importance of the questions for each patient. They should have room for qualitative data, that is open answers to open questions, which gives the patient a possibility to express his or her view of QoL in his or her own words (this can be done in a structured way by leaving a space for the patient to complete and rate subjectively relevant dimensions). They should be available in several languages and should be accompanied by generic questionnaires for comparison (with other disease states, other representative populations) and they should also include information about the patients' previous life. Since the latter is difficult to achieve in terms of premorbid personality or previous life assessment, it thought that devising or developing an existential dimension to assess QoL could incorporate the perceived change in

comparison of now to the prior state, the feeling of loss, mourning, and future outlook (Bullinger et al., 2002).

Moreover, Riemsma, Forbes, Glanville, Eastwood, and Kleijnen (2001) evaluated the degree to which general health status measures have been evaluated for use with people with cognitive impairments, including TBI. It was reported that of the 34 measures used in samples with cognitive impairments, only 6 have been validated in these groups. Riemsma et al. (2001) concluded that there are no validated instruments available for use in cognitively impaired respondents and existing measures for use in general populations, should be used cautiously in studies of persons with cognitive impairment (Riemsma et al., 2001). A review by von Steinbuechel, Richter, Morawetz, & Riemsma (2005) on the assessment of HRQoL in acquired or degenerative brain injury also confirm that there are only a few measures that have been developed and validated for respondents with cognitive impairment. HRQoL assessment should therefore be validated in the specific disease and if necessary, combined with a neuropsychological evaluation and a disease-specific HRQoL measure (von Steinbuechel, Richter, et al., 2005). As noted in prior studies (Bullinger et al., 2002; Daggett, Bakas, & Habermann, 2009; Petchprapai & Winkelman, 2007) various generic measurements have been used to measure HRQOL in TBI patients, and there is lack of TBI-specific HRQOL instruments.

In summary, there were various generic QoL measurement used in most of the studies in this review. Only a few of the studies used disease-specific QoL measurement. The QOLIBRI is a new disease specific QoL measurement in patients with TBI thorough conceptual and psychometrical analysis. The QOLIBRI seems feasible and uses a valid approach for the assessment of QoL in TBI. Therefore, it was used in this study for the QoL assessment.

## Factors Associated with QoL in Patients with TBI

# Age group and QoL

There was a different result for the association between age and QoL in patients with TBI, although not all of the studies have investigated this. Only four studies examined the relationship between age and QoL. One group found that there was no correlation between age and QoL (Breed et al., 2004; Kalpakjian et al., 2004; Mailhan et al., 2005; Resch et al., 2009; Steadman-Pare et al., 2001; Teasdale & Engberg, 2005) and also no significant difference between younger and older TBI subjects with QoL (Breed et al., 2004).

Breed's study (2004) provides insight into the effects of TBI versus no disability as well as the effects of age. It found that the TBI effect (i.e., the difference between subjects with TBI and controls) was stronger than the age effect (i.e., the differences between older and younger subjects). However, the literature has documented poorer outcome and greater morbidity for older people with TBI. Several reasons may account for this finding. First, the current study interviewed only subjects living in community. It is possible that older subjects with TBI and multiple health issues are not as likely to be "living independently in the community". Thus, who survive and return to the community may represent a select group of older adults with relatively few health problems. A second issue was related to the influence of normative perceptions of the effect of aging on health. Older adults with TBI may perceive their altered health or their symptoms as part of normal aging rather than being secondary to their TBI. In contrast, younger adults generally have good health, and changes in their health status are likely to be viewed as aberrations (Breed et al., 2004).

The other studies showed that there is an association between age and QoL (Hu et al., 2012; Nestvold & Stavem, 2009; Truelle et al., 2010). The study by Truelle et al. (2010) break the scales of the QOLIBRI, as a measurement to assess HRQoL, scores down by age group and was found that the QOLIBRI scores systematically varied by age on four scales (cognition, self, daily life and autonomy, and physical problems). It was also found that the QOLIBRI total score with those aged 35-54 obtained the lowest scores and the highest scores were obtained by the youngest participants aged 17-34. Similarly, Nestvold, and Stavem (2009) break the SF-36, as a measurement to assess QoL, by age below and above the median and found there were lower scores among individuals above the median age (<40.7 years). In the same ways, Hu et al. (2012) adjusted age group into older than 30 and younger than 30. They found that patients older than 30 had lower scores of QoL (OR = 1.6, 95% CI: 1.1-2.6).

In summary, there are contrasting views regarding the role of age associated with QoL in patients with TBI. Therefore, age needs to be further explored in QoL of patients with TBI.

# Gender and QoL

Even though almost all of the studies showed that men were more likely to be diagnosed with TBI (Anderson et al., 2011; Breed et al., 2004; Brown et al., 2000; Chiu et al., 2006; Emanuelson et al., 2003; Eriksson et al., 2009; Guilfoyle et al., 2010; Hawthorne et al., 2008; Huebner et al., 2003; Johnston et al., 2005; Kalpakjian et al., 2004; Lin et al., 2010; Mailhan et al., 2005; Nestvold & Stavem, 2009; Steadman-Pare et al., 2001; Teasdale & Engberg, 2005; Thomas et al., 2009; Truelle et al., 2010; von Steinbuechel et al., 2010a) only a few studies examined the relationship between gender and QoL. Gender was associated with QoL as demonstrated in a study by Steadman-Pare et al. (2001), whereby women tended to report higher QoL perceptions than men. This result may be skewed, because the TBI population is predominantly male, it needs to provide statistical power to assess differences. When separating the QOLIBRI scale by gender, it was found that one of the scales (physical) statistically significantly varied by gender with males obtaining scores higher than females (Truelle et al., 2010). Consistent with the last findings, Hu et al. (2012) found that female patients had lower mental component scores of QoL than the male patients(OR = 1.8, 95% CI : 1.1-2.9). Contrast finding that gender was not significant factors in predicting QoL has also been documented (Resch et al., 2009; Teasdale & Engberg, 2005)

Due to its inconsistent findings, gender may be one factor required to be further explored with QoL in patients with TBI.

### Time after injury and QoL

Perceived health-related functioning in both physical and psychosocial domains may change over time because recovery from TBI is a complex and lengthy process. The rate of recovery may vary because of a number of factors including the time after an injury (Pagulayan et al., 2006). The relationship between time after injury and QoL in TBI patients has been well documented as discussed below. Hu et al. (2012) study of 358 patients with moderate to severe TBI with 2 years follow up and found that at 6 months after discharge, there was statistically significant improvement of QoL as measured by SF-36 in all four physical health domains and two mental health domain. After 1 year from discharge, all eight domains of QoL had significant improvement compared with measurements at discharge. The statistically significant time effects were observed from ANOVA for repeated measures in all eight domains of QoL (Hu et al., 2012).

Another study, Lin et al. (2010) who study of QoL during the first year after injury in 158 TBI patients, concluded that during the first year after TBI, the magnitude of QoL recovery differed across different QoL domains. The result showed that the scores on all QoL domains, as measured by WHOQOL-BREF, except for social relationships greatly improved over the first 12 months after the injury. All four domains of QoL had the lowest scores at discharge and these slightly increased over a 12 month post injury period. Among those 4 domains, physical capacity had the largest score changes at any time after injury and was the only domain that had not recovered to the preinjury level at 12 months after injury. The linear mixed-effect model analysis that threats each domain of the QoL as an outcome revealed that: (1) the score on physical domain at discharge had significantly increased by 4.2 (95% CI, 1.0 to 7.4) points at 6 months and by 9.5 (95% CI, 6.2 to 12.8) points at 12 months after injury, (2) the score on the psychologic domain at discharge significantly increased by 4.9 (95% CI, 0.3 to 9.4) points at 6 months and by 8.4 (95% CI, 4.0 to 12.9) points at 12 months after injury, and (3) the score on the environmental domain at discharge significantly increased by 3.6 (95% CI, 1.0 to 6.2) points at 6 months and by 4.5 (95% CI, 1.9 to 7.1) points at 12 months after injury (Lin et al., 2010).

Similar to those studies, Pagulayan et al. (2006) investigate the longitudinal recovery of QoL as measured by SIP from 1 month up to 3 to 5 years post injury. The result showed that in general, there was significant improvement between 1 month and 6 months post injury, and then the recovery levels off. Moreover, Andersson et al. (2011) found that changes over time of life satisfaction remain change at 10 years after injury. The result showed that comparisons of data at baseline (3 weeks after injury) and 10 years after injury revealed a decrease in life satisfaction with the mean decrease of 0.32 (95% CI, 0.13 – 0.53, Z (133) = -3.1, p = .002).

In summary, it can be concluded that the time after injury is one of the factors that is associated with QoL in patients with TBI.

# Severity of injury and QoL

Another variable that had variety in result was the severity of TBI. Several studies have shown an association between the severity of TBI with QoL (Dikmen et al., 2003; Hawthorne et al., 2009; Hu et al., 2012; Lin et al., 2010; Truelle et al., 2010; Upadhyay, 2007). People with severe TBI tends to rate QoL lower than those with less severe TBI (Dikmen et al., 2003; Upadhyay, 2007). The severity of injury has an impact on the physical aspect and psychological domain of QoL. In comparison to mild TBI patients, moderate and severe TBI patients have many adverse effects on all the four domains of QoL (physical, psychological, social, and environment) (Upadhyay, 2007). Patients with severe TBI had lower scores in both the physical component summary (OR = 1.9, 95% CI: 1.2-3.1) and mental component summary (OR = 1.6, 95% CI: 1.0-2.6) of QoL compared with those with moderate TBI (Hu et al., 2012). Dikmen et al. (2003) found that brain injury severity assessed within 24 hours of injury with a modified Abbreviation Injury Scale (AIS)-head measure was related to neuropsychologic and functional outcomes at 3 to 5 years after injury. Severity of TBI as measure by coma length also predicted QoL (Hawthorne et al., 2009). Moreover, Teasdale, and Engberg (2005) found that QoL outcome was fairly well predicted by the severity of injury. However, contrast findings that show there was no association between the severity of injury with QoL have also been documented (Nestvold & Stavem, 2009; Steadman-Pare et al., 2001).

In summary, regarding the inconsistency of finding in the relationship of the severity of injury with QoL in patients with TBI, this needs further exploration.

# Functioning and disability and QoL

The WHO developed the International Classification of Functioning, Disability, and Heath (ICF) (2001) framework for describing heath and health-related states. The ICF development went through multiple revisions, including the original International Classification of Impairments, Disabilities, and Handicaps (ICIDH) and the intermediate working draft, International Classification of Functioning and Disability (ICIDH-2) before reaching its current form (Pierce & Hanks, 2006). In the ICF, "disability" was replaced with the simpler and more general term "activity". Handicap has been replaced with "participation restriction". Handicap and participation are different words for similar constructs, the latter designed to have a more positive slant (Johnston & Miklos, 2002). In the ICF framework, a person's functioning is conceived as a dynamic interaction between health condition (disease, disorder, injuries, trauma) and contextual factor using bio-psycho-social approach. The ICF consists of two parts including (1) functioning and disability and (2) contextual factor. Functioning and disability has two components; (1) body structure and (2) activity and participation. It can be used to indicate problems with a three components outcome; (1) impairment, (2) activity limitation, and (3) participation restriction (WHO, 2001). The relationship of functioning and disability with QoL are presented in the discussion below.

Mailhan et al. (2005) in a cross-sectional study of 75 patients 2 years or more after a severe TBI, assessed the relationship between life satisfaction and disability. The result found that life satisfaction significantly inversely correlated with global measures of disability as measured by DRS and GOS. In order to further assess the relationships between life satisfaction and disability, the satisfaction scores were compared in the different DRS and GOS categories by two separate analysis of variance (ANNOVAs) with the mean satisfaction score as the dependent variable and the DRS (or GOS) category as between-subject factor. In relation to the DRS, this statistical analysis revealed a significant effect of the DRS category (F(4,70) = 7.13, p < .0001) that was due to lower satisfaction score in participants with partial or moderate disability as compared to no disability. The box plot illustrated the mean satisfaction score against the category of DRS, showing a trend for a U-shaped curve. The same was found for the distribution of life satisfaction with the GOS (Mailhan et al., 2005).

Similarly, Huebner et al. (2003) examined outcomes after TBI and found that less disability as measured by the Activity Limitation Survey (ALS) was related to higher QoL. It was also found that participation was associated with higher QoL (Huebner et al., 2003). Lin et al. (2010) found that the domain of QoL measurement at discharge were significantly associated with GOS level. This association significantly influenced longitudinal changes in the QoL. Resch et al. (2009) prospectively examined varying predictors of rate of change in life satisfaction in the first 5 years of living with TBI. Multilevel modelling techniques revealed a consistent pattern. The trajectory of long-term life satisfaction was significantly associated with functional impairment (Resch et al., 2009). Moreover, Pierce's study (2006) found that the combination of ICF components (body function and structure, activities, and participation) significantly predicted life satisfaction of TBI persons.

The DRS (Rappaport et al., 1982) is one of the instruments to measure functioning and disability of TBI patients. It has the ability to describe disability for individuals in a variety of settings, from acute care hospital to community settings (Rappaport et al. as cited in Bellon, Wright, Jamison, & Kolakowsky, 2012). Measurement across a wide range of recovery is possible because the various items of DRS address all three WHO categories: impairment, activity limitation, and participation restriction. The first three items of the DRS ("Eye Opening", "Communication Ability", and "Motor Response") are a slight modification of the GCS and reflect impairment ratings. Cognitive ability for "Feeding", "Toileting" and "Grooming" reflect the level of activity limitation. The "Level of Functioning" and "Employability" reflects participation restriction (Shukla, Devi, & Agrawal, 2011; Wright, 2000).

Inter-rater reliability of in-person assessments with the DRS has been established (r = .97-.98). The test-retest reliability of the DRS has also been established (Spearmen  $\rho = .95$ ) (Rappaport et al. as cited in Bellon et al., 2012). Novack et al. as cited in Wright (2000) reported the inter-rater reliability of DRS

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ratings by family members vs. rehabilitation professionals yielding significant correlations for both rehabilitation admissions (r = .95) and discharge (r = .93) ratings. Concurrent validity was established in the initial publication on the DRS by Rappaport et al. as cited in Wright (2000), which compared DRS scores with ratings of abnormal evoked potentials (r = .35-.78). Evidence of good admission and discharge concurrent validity and superior levels of predictive validity has been demonstrated by Gouvier et al. as cited in Bellon et al. (2012). Moreover, a study by Hall et al. as cited in Nichol et al. (2011) demonstrated the validity of DRS against other TBI disability and physiological derangement scales. Eliason and Topp (1984) have established the predictive validity of the DRS predicting length of hospital stay and discharge status.

In summary, it can be concluded that functioning and disability is one of the factors that is associated with QoL in patients with TBI.

### **Psychosocial factors and QoL**

Of all injuries, TBI most frequently affects every domain of a person's health including psychosocial limitations (McCarty et al., 2006). Common psychosocial health problems following TBI include depression, anxiety, decreased social contact, and lack of social integration (Draper et al., 2007; McCarty et al., 2006; Wood & Rutterford, 2006b; Wood & Rutterford, 2006c). Studies that have focused on the psychosocial outcome after TBI have consistently demonstrated that persons with TBI commonly experience long-term psychosocial problems (Draper et al., 2007; Wood & Rutterford, 2006b; Wood & Rutterford, 2006c). Studies that look for factors associated with QoL in patients with TBI showed that the psychosocial factor was the most associated with QoL (Corrigan et al., 2001; Huebner et al., 2003; Johnston et al., 2005; Kalpakjian et al., 2004; Steadman-Pare et al., 2001). The psychosocial factor included social support (Kalpakjian et al., 2004; Petchprapai, 2007; Steadman-Pare et al. 2001; Tomberg et al., 2005; 2007), and depressive mood (Corrigan et al., 2001; Eriksson et al., 2009; Hawthorne et al., 2009; Lin et al., 2010; Steadman-Pare et al.).

# Social support

Perceived social support (Barrera as cited in Yu, Lee, & Woo, 2004), the cognitive appraisal of connection to others, was one of the most common conceptualizations of social support which has received the greatest acceptance (Yu et al., 2004). Social support has a beneficial effect on well-being. This process was explained by the buffering model (Cohen & Wills, 1985). The buffering model postulates that social support "buffers" (protects) persons from the potentially pathologic influence of stressful events or illness (Cohen & Wills, 1985). Perceived social support emphasizes on the measurement of the perceived availability of functional support because it is believed that a person's perception about available support is important (Sherbourne & Stewart, 1991). The fact that a person does not receive support during a given time period does not mean that the person is unsupported. Received support is confounded with need and may not accurately reflect the amount of support that is available to a person. This emphasis on the function of perceived social support resulted in social support being categorized into five dimensions; (1) emotional support (the expression of positive affect, empathetic understanding, and the encouragement of expressions of feelings), (2) informational support (the offering of advice, information, guidance or feedback), (3) tangible support (the provision of material aid or behavioral assistance), (4) positive social interaction (the availability of other persons to do fun things with you), and (5) affectionate support (involving expressions of love and affection) (Sherbourne & Stewart, 1991).

A study by Steadman-Pare et al. (2001) showed that receiving social support was strongly related to QoL. Receiving social support positively related to QoL. Individuals who were married or in a partner relationship reported significantly higher QoL than those who were single. Getting along with people, the availability of emotional support, and availability of help with tasks positively related to QoL (Steadman-Pare et al., 2001). Another study also found that social support as measured by the Social Support Survey was significantly associated with QoL (Lin et al., 2010). Moreover, a regression analysis found that social support as measured by The Social Provision Scale (SPS) has the strongest association with QoL (Kalpakjian et al., 2004). Similar to those studies, Tomberg et al. (2005) found that the correlation for satisfaction with social support for eighty-five persons with moderate TBI was moderate in the majority of QoL domains. The social support of those TBI persons still significantly correlated at the follow up of 5 to 6 years later (Tomberg et al., 2007). It found that there was no significant change in the number of total supporters T1 and T2 while the mean scores for satisfaction with social support showed a tendency of decrease. Social support is considered an important factor for adjustment after TBI. The availability of persons on whom one can rely and who provide care significantly correlated with general health status (Tomberg et al., 2007).

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# **Depressive** mood

Sometimes an emotional disorder is a result of the stress caused by a physical disability which manifest as anxiety or depressive states and have no basis in organic pathology. A neurosis may coexist with a physical illness causing the patient to be more distressed by the symptoms of the illness (Zigmond & Snaith, 1983). The relation between a depressive mood and QoL in patients with TBI is described below.

Steadman-Pare et al. (2001) explored the factors associated with perceived QoL, and found that mental status was the primary predictor of perceived QoL. It accounted for a large portion of the variance;  $R^2 = 43\%$  (p < .0001). Individuals who experienced more depressive feelings significantly reported lower QoL (Steadman-Pare et al., 2001). Another study reported that the absence of a depressed mood at 2 years post discharge correlated with higher QoL (Corrigan et al., 2001) and depressive symptoms were associated with lower QoL ratings in patients with TBI more than 3 years after their injury (Vickery et al., 2005). In a longitudinal study of QoL in the first year after TBI in Taiwan, showed that depressive status was significantly associated with QoL (Lin et al., 2010). Anxiety, worry, or depression as measured by HADS showed to significantly contribute to poor QoL (Hawthorne et al., 2009). Eriksson et al. (2009) explored the relationship between depressive mood and life satisfaction in 116 persons with TBI, and found that the absence of a depressive mood as measured by HADS contributed significantly to greater life satisfaction. In the final regression model, the presence of a depressive mood explained 6% of the total variance in life satisfaction (Eriksson et al., 2009). Underhill et al. (2003) also confirmed the association between depression with life satisfaction.

HADS (Zigmond & Snaith, 1983) is one of the instruments for measuring depressive moods. The development of HADS was primarily conducted in the setting of a hospital medical outpatient clinic (Zigmond & Snaith, 1983). Furthermore, a review of 747 identified studies by Bjelland, Dahl, Haug and Neckelmann (2002) concluded that HADS was acceptable in assessing severity and caseness of anxiety disorders and depression in both somatic, and psychiatric cases not only in hospital practice (for which it was first designed) but also in primary care patients and the general population. In a commentary report, Snaith (2003) mentioned that HADS was designed to provide a simple yet reliable tool for use in medical practice. The term 'hospital' in its title suggests that it is only valid in such a setting but many studies conducted throughout the world have confirmed that it is valid when used in community settings and primary care medical practice (Snaith, 2003). Moreover, Whelan-Goodinson et al. (2009) who examined the validity of HADS in the TBI population concluded that the HADS was a reliable measure of emotional distress in this TBI sample. They showed that the depression subscale had a sensitivity of 62% and a specificity of 92%, while the anxiety subscale had a sensitivity of 75% and a specificity of 69% (Whelan-Goodinson et al., 2009).

In summary, psychosocial factors including social support, and depressive mood have an association with QoL in patients with TBI. Therefore, the study in the determinants of QoL should include these factors.
## **Summary**

TBI is an alteration in brain function resulting from external physical forces to the head. The classification of TBI is most widely by the injury severity using GCS which consists of three types; mild, moderate, and severe TBI.

The impact of TBI can result in physical, cognitive, behavioral, and emotional consequences among TBI survivors which occur in the acute phase after injury and persist in long-term after injury. A post acute rehabilitation program for the care and treatment of TBI persons after discharge is beneficial in having better outcomes. Moreover, in the low and middle income countries such as Indonesia, patients have limited access to the rehabilitation program.

QoL in individuals of patients with TBI is recognized as a critical indicator of outcome following TBI. Two important definitions of QOL have been used in studies related to TBI namely achievement and subjective well being. The majority of studies in this review used generic measurements to measure QoL in patients with TBI, and there is lack of a TBI-specific QoL instrument. The QOLIBRI as a new disease-specific QoL measurement in TBI seems a feasible and valid approach for the assessment of QoL in TBI. The QOLIBRI includes the cognitive domain which is a specific condition in patients with TBI and its thorough in its conceptual and psychometric analysis.

Several factors have been shown to have an association with QoL in patients with TBI including demographic factors (age and gender), injury and disability factors, and psychosocial factors (social support, and depressive mood). Moreover, those studies were generally favorable in developed countries. It was unclear which factors may affect the QoL of patients with TBI in Indonesia where there are different contexts.

#### **CHAPTER 3**

#### **RESEARCH METHODOLOGY**

#### **Research Design**

This study was a cross-sectional survey to describe the level of QoL and determine the predicting factors of QoL in patients with TBI in Indonesia.

#### Setting

This study was conducted at Dr. Kariadi Hospital, Central Java, Indonesia. Dr. Kariadi Hospital is a teaching hospital with 925 beds and a central referral center for all hospitals in Central Java Province. Due to the specialist available at this hospital, adults with TBI from different areas come to use the services in both the in- and out-patient departments (OPD) including the emergency department. The estimated number of patients with TBI (from mild to severe head injury) each year is about 1,000. The number of TBI patients who are admitted to the neurological unit is approximately 25 patients per month. A week after discharge from this unit, TBI patients often have a follow-up appointment in the neurosurgical OPD. Moreover, a medical rehabilitation center in the hospital has served TBI patients who require short- and long-term rehabilitation after their discharge from the hospital. This service is paid for by the Social Security Scheme.

## **Population and Sample**

### **Target Population**

The population was adult patients with TBI who come to use the services in Dr. Kariadi Hospital, Central Java, Indonesia.

## Sample and Sample Size

Power analysis was used to determine the sample size of this study. To determine the effect size, a few studies related to the determinants of HRQoL were used. For example, in a study of QoL among patients from 22 years of follow ups after hospitalization, an  $R^2$  of 68% of the variance of QoL was found (Nestvold & Stavem, 2009). Calculation of an effect size  $(f^2)$  yielded a large effect size  $(f^2 = 2.12)$ . In another study that explores the factors associated with perceived QoL after TBI (Steadman-Pare et al., 2001), an  $R^2$  of 54% of the variance of QoL was shown with a large effect size ( $f^2 = 1.17$ ). With regard to Kalpakjian et al. (2004), who studied the OoL and psychosocial outcomes after TBI, an  $R^2$  of 49% of the variance of OoL was found, which also gave the large effect size of 0.96. However, those studies were conducted in resources-rich western countries. Since there is no known study to determine the QoL of patients with TBI in Indonesia, the medium effect size of 0.15 (Cohen, 1988 p. 413) was used. The sample size was estimated by using Cohen's equation (Cohen, 1988 p. 445) and table (Cohen, 1988 p. 452). Based on this calculation, the minimum sample size is 82 (Appendix F). Twenty five percent was added to anticipate incomplete questionnaire. Thus, a total of 103 subjects was used in this study.

# **Inclusion Criteria**

The inclusion criteria of the sample included (1) patients being aged 18–65 years old; (2) at least 1 month having passed since discharge from hospital and patients being available for follow up; (3) patients having been diagnosed with mild to severe TBI, and being oriented to time, place and person at the time approached; and (4) patients having no spinal cord injury, history of or current psychiatric disease, terminal illness, and cormorbidity such as MI, COPD and gout.

## Instrumentation

# **Data Collection Instrument**

The instrument used for data collection was a questionnaire which is composed of four parts.

Part 1. Demographic and health status questionnairePart 2. Physical factors questionnairePart 3. Psychosocial factors questionnairePart 4. QoL questionnaire

## Part 1. Demographic and health status questionnaire

The demographic and health status questionnaire developed by the researcher included questions about gender, age, religion, marital status, educational level, average income, previous occupation, present occupation, family status, time after injury, access to rehabilitation, and current symptoms. (Appendix B)

#### Part 2. Physical factors questionnaire

The physical factors questionnaire consisted of question about the level of severity of TBI and functional status using an existing instrument. The severity of injury was measured by the GCS score conducted by the physician at the time of the patient's admission. The severity of injury was classified by the sum score of three components: the best eye-opening response (four levels), the best verbal response (five levels), and the best motor response (six levels). It was classified as mild TBI with GCS 13-15, moderate TBI with GCS 9-12, and severe TBI with GCS  $\leq$  8 (AANS, 2000; EFNS, 2002; SIGN, 2009). The GCS has high inter-observer reliability and generally good prognostic capabilities (Narayan et al., 2002). (Appendix C)

Functioning and disability were measured by the Disability Rating Scale (DRS) (Rappaport et al., 1982). It consists of 8 items with a 29-point measure. The DRS was designed to measure changes in recovery levels of adults with TBI, where the total scores are meant to reflect the level of disability. The total score was the sum of the 8 items. Different scoring weights were attached to different items. Eye opening, employment, and cognitive ability for self care activities were scored on a scale of 0 to 3, whereas communication ability was scored on a scale of 0 to 4, and motor response on a scale of 0 to 5. A score of zero meant the person had no disabling impairments detected by the scale, while the maximum score of 29 indicated vegetative death (Rappaport et al. as cited in Bellon et al., 2012). Total scores have been used to describe different clinical levels of disability as follows: none (0), mild (1), partial (2-3), moderate (4-6), moderately severe (7-11), severe (12-16), extremely severe (17-21), vegetative state (22-24), and extreme vegetative state (25-29) (Bellon et al.). The inter-rater reliability of in-person assessments with the DRS has been established (r = .97-.98) and the test-retest reliability of the DRS has also been established (Spearmen  $\rho = .95$ ) (Rappaport et al. as cited in Bellon et al., 2012). (Appendix C)

#### Part 3. Psychosocial factors questionnaire

There were two parts in this questionnaire: social support and depressive mood. Both of these used existing instruments. (Appendix D)

Social support was measured by the Medical Outcomes Study Social Support Survey (MOS SSS) (Sherbourne & Stewart, 1991). The development of MOS SSS was for patients with prevalent and treatable chronic conditions. It consists of 19 items on a 5-point rating scale (1 = none of the time, 5 = all of the time) with 4 subscales as follows: (1) emotional/informational support, (2) tangible support, (3) affectionate support, and (4) positive social interaction. A higher score for an individual scale or for the overall support index indicated more support. To obtain a score for each subscale, the average of the scores for each item in the subscale was calculated. To obtain an overall support index, the average of the scores for all 19 items included in (1) the four subscales and (2) the score for the one additional item were calculated. There has been validation in Asian countries, and it has demonstrated good reliability and validity when it was applied to an adult sample in Taiwan with Cronbach's alpha coefficients above .80 (Shyu, Tang, Liang & Weng, 2006). The psychometric properties in China showed the Cronbach's alpha for the overall scale of .98 and test–retest reliability as measured by the intraclass correlation coefficient of .84 (Yu et al., 2004). The application in the TBI population has been documented (Lin et al., 2010).

The depressive mood was measured by the Hospital Anxiety and Depression Scale (HADS) (Zigmond & Snaith, 1983). It is a 14-item self-report measure with seven items forming a depression subscale and another seven measuring anxiety. Each item is rated on a 4-point scale ranging from 0 to 3, with 3 indicating higher symptom frequency. Total scores for each subscale range from 0 to 21, categorized as follows: normal (0–7), mild (8–10), moderate (11–14) or severe (15– 21). Results for the Depression "D" scale and Anxiety "A" scales were examined. For the overall HADS scale and the depression and anxiety subscales, Cronbach's alpha was .94, .88, and .92, respectively, indicating homogeneity of the scales (Whelan-Goodinson et al., 2009).

#### Part 4. QoL questionnaire

The QOLIBRI, a specific TBI QoL tool developed by von Steinbuechel et al. (2010a; 2010b) was used. The QOLIBRI consists of four domains to measure satisfaction (the Cognition, Self, Daily Life & Autonomy, and Social Relationships scales) and an additional two domains to measure bothered feelings (the Emotion and Physical Problem scales). A total of 37 items in six domains and measured on a 5-point Likert scale were included. Each item of the satisfaction domains is rated at 1-5, where 1 = not at all satisfied and 5 = very satisfied. Responses to the 'feeling bothered' items were reversed to correspond with the satisfaction items, where 1 = very bothered and 5 = not at all bothered. The responses on each scale were summed to give a total, and then divided by the number of responses to give a scale mean. The scale means have a maximum possible range of 1 to 5. The mean can be computed when there are some missing responses, but was not calculated if more than one third of the responses on the scale were missing. In a similar manner the QOLIBRI total score was calculated by summing all the responses, and then dividing by the actual number of responses. The scale means were converted to the 0-100 scale by subtracting 1 from the mean and then multiplying by 25. This produced scale scores which had a lowest possible value of 0 (worst possible quality of life) and a maximum value of 100 (best possible quality of life). The psychometric properties of the QOLIBRI were documented by von Steinbuechel et al. (2010b) with internal consistency of  $\alpha = .75$ -.89 and test-retest reliability of  $r_{tt} = .78$ -.85. The score was interpreted by using standard deviation (*SD*) with the assumption data in normal distribution. The three levels categorized are as follows: (1) low QoL, if the score is less than -1 *SD*; (2) moderate QoL, if the score is in the range of means  $\pm 1SD$ ; and (3) high QoL, if the score is more than + 1*SD* (Polit & Beck, 2012, p.388).

## **Translation of the Instruments**

Since this study was conducted in Indonesia and there was no available instrument, the original English versions of the instruments were translated into the Indonesian language through a back translation technique. Three bilingual translators who are literate in both the English and Indonesian languages assisted in this process to ensure the accuracy of the content and identify any discrepancies between the two versions. The qualifications of the translators were as follows: (1) two of the translators were lecturers at the English College in Semarang, Central Java, Indonesia, and (2) the last translator was a lecturer at the emergency and critical care nursing department at a state university in Semarang, Central Java, Indonesia. The procedure for the back translation was as follows. First, the original English version of the instruments were translated into an Indonesian version by a bilingual translator. Second, another bilingual translator blindly back translated the Indonesian version into English. Third, the last bilingual translator reviewed both of the completed back translated versions and the English versions to determine the appropriateness of their meaning and equivalence (Hilton & Skrutkowski, 2002).

### Validity and Reliability of the Instruments

The instruments were tested for quality through validity and reliability testing before being used in the actual study.

## Validity

The instruments including DRS, MOS SSS, HADS, and QOLIBRI were tested for content validity. Five experts in caring for TBI patients were involved as follows: (1) a neurosurgeon from Thailand, (2) a neurosurgeon from Indonesia, (3) an advanced practice nurse in neurosurgical or trauma from Thailand, (4) a nurse in neurosurgical care from Indonesia, and (5) the lecturer of the surgical nursing department from Thailand. A content validity index (CVI) score was used in this process. The results of Items-CVI (I-CVI) and Scale-CVI (S-CVI) were as follows. The I-CVI and S-CVI values for DRS were both 1, while the MOS SSS had I-CVI values ranging from .80 to 1 and the S-CVI value was .98. The HADS had an I-CVI value of 1 and an S-CVI value of 1. Lastly, QOLIBRI yielded I-CVI values ranging from .80 to 1 and an S-CVI value of .99. Thus, the results show that all questionnaires were valid with of I-CVI and S-CVI values within the acceptable range. An I-CVI score of at least .80 was considered an acceptable value, and an S-CVI of .90 was the standard for establishing excellent content validity (Polit & Beck, 2012, p.337).

#### Reliability

All Indonesian version measurements were piloted with 20 TBI patients. The internal consistency was assessed using Cronbach's alpha coefficients for the four instruments including MOS SSS, HADS and QOLIBRI. An alpha coefficient greater than .80 is required for existing instruments (Burns & Grove, 2005, p.374). The value of Cronbach's alpha coefficients for MOS SSS, HADS, and QOLIBRI were .99, .89, and .98 respectively. Another instrument, DRS, was tested using test-retest reliability. Reliability coefficients above .80 are considered good (Polit & Beck, 2012, p.333). Test-retest of the DRS was evaluated by correlating the scores from two administrations separated by a1-week interval. The total score of DRS was normally distributed. The intraclass correlation coefficient between the total score of DRS1 and DRS2 yielded a value of .99.

## **Data Collection Procedure**

## **Preparation Phase**

The procedures for data collection in this phase were as follows:

 Approval was sought from both the Research Ethics Committee of the Faculty of Nursing at Prince of Songkla University and the Health Research Ethics Committee of Dr. Kariadi Hospital, Central Java, Indonesia, as well as from Dr. Kariadi Hospital, Central Java, Indonesia.

- 2. Two research assistants (RAs), who had a bachelor's degree or higher qualification in nursing, were trained in the objectives of the study, the data collection processes, expected research outcomes, human subject rights, the types of questionnaires, expected time of the completion of data collection, and the detailed method of collecting data. Before conducting the data collection, the RAs were asked to observe the researcher's data collection method. Then the RAs performed the data collection by her/himself under the observation of the researcher and, in the last step, the RAs received feedback from the researcher.
- The name lists of the patients with TBI who met the sampling criteria from medical records were obtained.

#### **Implementation Phase**

The procedures for data collection in this phase were as follows:

- Permission was asked from the subjects. For those who were not in the hospital, the researcher contacted them by telephone or home visit and explained the purpose and the data procedure for this study. All who agreed to participate in this study were asked when was a convenient time for an appointment to either meet at either the Out Patient Department (OPD) or another convenient place. The majority of subjects chose to have the interview at their home.
- 2. The subjects were asked to sign a consent form.
- 3. The subjects were interviewed to gather their demographic and health related data, and they were then asked the question from the physical

factor questionnaire. However, this data set was initially collected and reviewed from patient's medical records before face-to-face interview.

- 4. The psychosocial factors and QoL questionnaires were administered. Each individual was asked to complete the questionnaire by his or herself. During this procedure, the researcher/RAs read the questionnaire verbatim to any subjects who had difficulty in reading. The questionnaires took approximately 30-45 minutes to be completed.
- 5. At the end of each day of data collection, the researcher/RAs checked the completion of data before processing the data ready for data analysis.
- 6. In addition, the researcher stopped the process of the interview if the subjects felt tired and could not continue with the interview. In such cases, the subjects were given time to relax. After resting, the subjects were asked if they wanted to continue or postpone the interview.

## **Ethical Consideration**

The subjects who agreed to participate in this study were sought and informed consent was obtained. The researcher had contacted each subject prior to their participation to explain the purpose and details of the study and assure them that all data would be kept confidential. They were also allowed to make a free and independent decision on whether to participate or refuse to take part without any coercion. Also, the subjects were allowed to ask any questions related to this study and had the right to withdraw from the study at any time without penalty. The coding system was used for each subject to assure anonymity and the confidentiality of all information. The researcher stopped interviewing if the subjects felt stressed or any discomfort and gave time for them to relax before asking them if they want to continue or postpone the interview. In addition, the phone number, email, and mailing address of the researcher were provided to participants and they were reassured that they could contact the researcher any time as needed. (Appendix A)

#### **Data Analysis**

The descriptive and inferential statistics were used in this study. First, descriptive statistics were used to describe the demographic data and clinical characteristics using frequency, percentage, median, and mean. Secondly, the inferential statistics were used to examine the correlation between the identified factors and QoL. Hierarchical multiple regression was used to determine the strongest predictors of QoL. The confounding variables (demographic variable) were entered as the first step of hierarchical multiple regression. In the second step, physical and psychosocial variables were entered into a regression analysis. Testing the underlying assumptions of multiple regression analysis were examined as follows.

## Normality

Normality of variables can be detected by either statistical or graphical methods. For this study, univariate normality was detected by examining skewness and kurtosis. The distribution of data is normal when the values of skewness divided by the standard error of skewness and kurtosis divided by the standard error of kurtosis were in the range  $\pm$  3. For this study, the criterion (QOLIBRI) was normally distributed, while for the predictive variable found that three of them including MOS SSS, HADS\_A and HADS\_D were in the range of  $\pm$  3 (Appendix G). The GCS

variable had negative skewness (skewness = -3.2, kurtosis = -.69) and the DRS had positive skewness (skewness = 11.74, kurtosis = 16.5). Thus the researcher used transformation of variables to improve their normality.

According to Tabachnick and Fidell (2001), the best strategy for the transformation of the data with negative skewness is to reflect the variable and then apply the appropriate transformation for positive skewness. To reflect a variable, the largest score in the distribution should be found and then one should be added to this score in order to form a constant that is larger than any score in the distribution. Then a new variable should be created by subtracting each score from the constant. In this way, a variable with negative skewness is converted to one with positive skewness prior to transformation. Subsequently, the square root transformation was performed for the GCS variable. After transformation, the skewness and kurtosis of GCS were 1.4 and -2.3, respectively. For DRS, since the distribution differs substantially with 0, a log 10 with constant was applied. A constant was added to each score so that the smallest score was 1. After transformation, the skewness and kurtosis of DRS were 7.9 and 4.7, respectively. However, the result showed the violence of normality; thus the DRS was changed to be the dummy coded variable.

## Linearity

Linearity is the assumption that there is a straight line relationship between two variables. Linearity between two variables (each independent variable and dependent variable) was assessed roughly by the inspection of bivariate scatterplots. Scatterplots were used to determine whether or not the relationship between each independent variable (predictor) and dependent variable (criterion) was linear. It was found that the relationship between each independent variable and dependent variable was represented by a straight line. Furthermore, the scatterplot of the regression standardized residual and regression standardized predicted value was used to check the assumption of linearity. (Appendix H)

## Homoscedasticity

The assumption underlying homoscedasticity is that the dependent variable exhibits similar amounts of variance across the range of values for an independent variable. This assumption was checked by visual examination of a plot of the standardized residuals by the regression standardized predicted value (Appendix H). If the linearity and the homoscedasticity assumption are met, the plot of points will appear as a rectangular band in a scatterplot (Tabachnick & Fidell, 2001).

## Multicollinearity

Multicollinearity occurs when one independent variable is strongly correlated with one or more of the other independent variables ( $r \ge .90$ ) (Tabachnick & Fidell, 2001). Furthermore, multicollinearity was detected by examining the tolerance value for each independent variable. Tolerance is the amount of variability in one independent variable that is not explained by the other independent variables. Multicollinearity was tested by computing tolerance and Variance-Inflating Factor (VIF). If tolerance is less than .20, a problem of multicollinearity may be indicated (Tabachnick & Fidell, 2001). In this model, tolerance for each independent variable ranged from .40 – .99, and there was no problem of multicollinearity. Moreover, the VIF in this study ranged from 1.01 - 2.48, and all were less than 10, indicating that no multicollinearity was found in this model.

# Autocorrelation

Residual analysis for the regression model was conducted. The Durbin-Watson statistic for correlation between errors was 1.42, indicated that errors were not correlated.

## **CHAPTER 4**

#### **RESULTS AND DISCUSSION**

#### Results

In this chapter, a description of the sample and the results of the analysis corresponding to the objectives are presented. There are three parts presented as follows: (1) demographic characteristics, (2) the level of QoL after discharge, and (3) the predictive factors (severity of injury, functioning and disability, social support, and depressive mood) of QoL.

## Part I. Demographic Characteristics of the Samples

The demographic characteristics of the 103 subjects are shown in Table 5. The mean (*M*) age of the subjects was 32.48 years old (SD = 12.27) with ages ranging from 18-59 years old. The majority of subjects in this study were male (77%) with the average time after injury being 13.76 (SD = 6.79) months and a range of 2-24 months. About half (57%) of the subjects were married and 39% had educational levels lower than junior high school. Although more than half of the subjects worked as laborers (66% before injury and 60% after injury), the number of unemployed increased after injury from 12% of the subjects to 21%. The majority of subjects were Muslim, while 93% lived with their family, which ranged in size from 1 member to 9. The TBI in the majority of subjects was due to traffic accidents. More than half of the subjects reported having current symptoms, which included headaches (57%), problems with memory (12%), fatigue (5%), and problems with seeing (1%).

# Table 5

Itoms	Frequency	Percentage	Moon (SD)
Itellis	(n)	(%)	Weath $(5D)$
Gender	70	77	
Male	79	11	
Female	24	23	22.40
Age, year			32.48
(Minimum-Maximum=18-59)	10	20	(12.27)
18 - 25 years	40	39	
26-40 years	36	35	
>40 years	27	26	
Religion			
Muslim	101	98	
Christian	2	2	
Marital status			
Single	41	40	
Married	59	57	
Widow/Widower	3	3	
Level of education			
No schooling	4	4	
Elementary school	16	16	
Junior high school	19	18	
Senior high school	55	53	
Diploma/ Bachelor	9	9	
Occupation before injury			
Student	19	18	
Government employee	4	4	
Laborers	68	68	
No occupation	12	12	
Occupation after injury			
Student	16	16	
Government employee	3	3	
Laborers	62	62	
No occupation	22	21	
Time after injury, month			13.76
(Minimum-Maximum= 2-24)			(6.79)
1-6 months	21	20	
7 - 12 months	26	25	
13 - 18 months	18	18	
19-24 months	38	37	

Frequency, Percentage, and Mean of Demographic and Health Status Characteristics of Study Participants (N = 103)

Table 5 (Continued)

	Frequency	Percentage	
Items	(n)	(%)	Mean (SD)
Living together with family			
No	7	7	
Yes	96	93	
Number of family members			3.6
living together			(1.7)
(Minimum-Maximum=1-9)			
Current symptoms			
No	33	32	
Yes	70	68	
Headaches*	59	57	
Memory problems*	12	12	
Fatigue*	5	5	
Vision problems*	1	1	
Access to rehabilitation			
No	84	82	
Yes	19	18	
Use of complementary therapy			
No	86	84	
Yes	17	16	
Cause of injury			
Motorcycle accident	70	68	
Traffic accident	27	26	
Falling	4	4	
Violence	2	2	

*Note*. \* = some patients reported more than one symptom.

## **Injury and disability factors**

For the GCS, it was found that 58% of the subjects were classified as mild TBI, while 39% and 3% of the subjects were classified as moderate and severe TBI, respectively. The median score of GCS was 13 with an interquartile range (IQR) = 4 and ranging from 6 to 15. Regarding the disability based on the DRS score, 78% of the subjects had no disability, whereas 6% had a mild disability and 17% had a partial disability (Table 6).

## Table 6

	Frequency	Percentage	Mean	Median	
Items	(n)	(%)	(SD)	(IQR)	Range
GCS on admission			12.79	13 (4)	6 - 15
			(2.21)		
Mild TBI (13 – 15)	60	58.3			
Moderate (9 – 12)	40	38.8			
Severe ( $\leq 8$ )	3	2.9			
DRS			.87	0 (0)	0 - 11
			(.20)		
None (0)	80	77.7			
Mild (1)	6	5.8			
Partial (2-3)	6	5.8			
Moderate (4-6)	6	5.8			
Moderately severe (7-11)	5	4.9			

Frequency, Percentage, Mean, Median and Range of Injury and Disability Factors of Study Participants (N = 103)

*Note*. GCS = Glasgow Coma Scale; DRS = Disability Rating Scale

## **Psychosocial factors**

The psychosocial factors comprised social support and depressive moods. The mean of the overall social support and four domains of social support, including: (1) emotional/informational support, (2) tangible support, (3) affectionate support, and (4) positive social relationship, were in the range of a moderate level  $(M_{\text{social support}} = 3.32, SD = .74; M_{\text{emotional}} = 3.11, SD = .75; M_{\text{tangible}} = 3.43, SD = .79;$  $M_{\text{affectionate}} = 3.63, SD = .95; M_{\text{positive}} = 3.29, SD = .80)$ . These findings reveal that affectionate support had the highest score and emotional/informational support had the lowest score (Table 7).

The depressive moods consist of two scales: (1) anxiety and (2) depression. The majority of TBI subjects reported a normal level of anxiety (77.7%).

In addition, the majority of the subjects in this study also had normal levels of

depression (78.6%) (Table 8).

Table 7

Mean, Median, and Range of Psychosocial Factors of Study Participants (N = 103)

Items	Mean (SD)	Median (IQR)	Range
Social support	3.32 (.74)	3.28 (1.24)	1.95 - 4.44
Emotional/ informational support	3.11 (.75)	3.00 (1.25)	1.63 – 4.38
Tangible support	3.44 (.79)	3.50 (1.25)	2.00 - 5.00
Affectionate support	3.63 (.95)	4.00 (1.33)	1.33 - 5.00
Positive social interaction	3.29 (.80)	3.33 (1.33)	1.67 - 5.00
Depressive mood			
Anxiety	4.47 (.37)	4.00 (6.00)	0 - 18
Depression	4.52 (.32)	4.00 (6.00)	0 - 14

# Table 8

Frequency and Percentage of Depressive Mood of Study Participants (N = 103)

	Frequency	Percentage
Depressive mood	(n)	(%)
Anxiety		
Normal $(0-7)$	80	77.7
Mild (8 – 10)	17	16.5
Moderate (11 – 14)	5	4.9
Severe (15 – 21)	1	1.0
Depression		
Normal $(0-7)$	81	78.6
Mild (8 – 10)	18	17.5
Moderate (11 – 14)	4	3.9

## Part II. The Level of QoL

Table 9 shows the total score and the subscales of QOLIBRI including part 1 (satisfaction domains): cognitive, self, daily life and autonomy, and social relationship; and part 2 (bothered domains): emotions, and physical problems. The domain with the highest score was emotion (M = 72.49, SD = 18.09), while the lowest score was for physical problems (M = 66.75, SD = 21.30). In addition, the mean score of three domains: emotion (M = 72.48, SD = 18.09), self (M = 70.46, SD = 9.2), and social relationships (M = 69.62, SD = 10.89) were above the mean score of the overall QOLIBRI score (M = 69.00, SD = 10.96).

#### Table 9

Scale	Mean (SD)	Median (IQR)	Range
Part 1: Satisfaction			
Cognitive	67.00 (13.28)	67.90 (14)	29 - 100
Self	70.46 (9.2)	71.40 (11)	36 - 93
Daily life and autonomy	67.27 (12.58)	67.90 (14)	32 - 96
Social relationships	69.62 (10.89)	70.83 (12)	33 - 100
Part 2: Bothered			
Emotions	72.48 (18.09)	70.00 (25)	30 - 100
Physical problems	66.75 (21.30)	70.00 (35)	10 - 95
Total QOLIBRI	69.00 (10.96)	69.60 (16)	38 - 92

Mean, Median, and Range of QoL of Study Participants (N = 103)

Note. QOLIBRI= Quality of Life after Brain Injury.

The level of QoL of patients with TBI in Indonesia is interpreted based on the criteria of the QOLIBRI score using standard deviation. It was found that more than half of the subjects (65%) had a moderate level of QoL, followed by those with a high level of QoL (18%) and a low level of QoL (17%) (Table 10).

# Table 10

	Frequency	Percentage
Level of QoL	(n)	(%)
Low (< 58.04)	17	17
Moderate (58.04 – 79.96)	67	65
High (> 79.96)	19	18

*The QoL Level of the Subjects (N=103)* 

## Part III. Predictive Determinants of QoL

In order to determine the predictive determinants, the relationships between QoL and other measured variables were sought.

The relationship among the study variables: age, gender, time after injury, severity of injury, disability and functioning, social support, depressive mood, and QoL

Bivariate correlation was used and presented in Table 11. There were ten pairs of negative relationships: (1) QoL and age, (2) QoL and functioning and disability, (3) QoL and anxiety (4) QoL and depression, (5) time after injury and functioning and disability, (6) time after injury and anxiety, (7) time after injury and depression, (8) social support and functioning and disability, (9) social support and anxiety, and (10) social support and depression. In addition, there were nine pairs of positive relationships: (1) QoL and time after injury, (2) QoL and social support, (3) age and anxiety, (4) age and depression, (5) time after injury and social support, (6) severity of injury and functioning and disability, (7) anxiety and functioning and disability, (8) depression and functioning and disability, and (9) anxiety and depression.

Table 11

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	QoL	Age	Gender <sup>a</sup>	Time after injury	Severity of injury <sup>b</sup>	Functioning and disability <sup>c</sup>	Social support	Anxiety	Depression
QoL	1								
Age	20*	1							
Gender <sup>a</sup>	15	.11	1						
Time after injury	.27**	.07	02	1					
Severity of injury <sup>b</sup>	11	15	.08	01	1				
Functioning and disability <sup>c</sup>	26**	.16	.02	20*	.28**	1			
Social support	.23*	90.	13	.37**	.08	30**	1		
Anxiety	50**	.23*	.10	34**	04	.51**	32**	1	
Depression	66**	.28**	.14	34**	04	.36**	46**	.71**	1
Note. $*p < .05, **p < $ <sup>a</sup> = dummy coded varia	.01 ible (0 = fei	nale, 1 =	male), <sup>b</sup> = s	quare root tra	Insformation w	ith constant was used	l, <sup>c</sup> = dummy	coded vari	able (0 = no

sque disability, 1 = disability) Š a B

## The predictive factors of QoL

Hierarchical multiple regression was performed to determine the strongest predictors of QoL (Table 12). In the first model/step, QoL was tested simultaneously on demographic variables as confounding variables including age, gender, and time after injury. This model was supported (adj.  $R^2 = .11$ , F = 5.07, p = .003). Age, gender, and time after injury explained the variation of QoL for 11% (p = .003). In this model, the most powerful variables that could explain QoL most significantly were time after injury (B = .45, t = 2.97, p = .004) and age (B = -.18, t = -2.14, p = .04).

In the second step, the proposed variables including physical factors (severity of injury and functioning and disability) and psychosocial factors (social support, anxiety and depression) were entered. The overall model was supported (adj.  $R^2 = .43$ , F = 10.44, p = .000). The contribution of the severity of injury, functioning and disability, social support, anxiety, and depression explained the variation of QoL for 32% (p = .000). In this model depression was the most powerful variable that could explain QoL most significantly (B = -2.12, t = -5.33, p = .000). Adjusted  $R^2$  changed in this step was significant (adj.  $R^2$  change = .32, F change = 11.97, p = .000).

Using the information of the regression analysis findings, the predicted equation can be constructed as follows:

$$R^2$$
 QoL = 88.63 + -.02 (age) + -1.40 (gender) + .11 (time after injury) +  
-2.65 (severity of injury) + 1.18 (functioning and disability) + -1.39 (social support) + -.22 (anxiety) + -2.12 (depression).

# Table 12

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		Unstanda	rdized	Standardized			95% C	Lof B
	Predictors	B	SE	β	t	Р	Lower	Upper
Model	Age	18	.08	20	-2.14	.04	35	01
1	Gender <sup>a</sup>	-3.19	2.43	12	-1.31	.19	-8.02	1.64
	Time after injury	.45	.15	.28	2.97	.004	.15	.75
	Model : adj. $R^2$	= .11, df = 3	, 99, <i>F</i> =	5.07, <i>p</i> = .003				
Model	Age	02	.08	03	31	.76	17	.13
2	Gender <sup>a</sup>	-1.40	1.99	05	70	.49	-5.36	2.56
	Time after injury	.11	.14	.07	.83	.41	16	.38
	Severity of injury <sup>b</sup>	-2.65	1.50	15	-1.77	.08	-5.62	.32
	Functioning and disability <sup>c</sup>	1.18	2.53	.05	.47	.64	-3.84	6.19
	Social support	-1.39	1.37	09	-1.01	.31	-4.11	1.33
	Anxiety	22	.35	07	63	.53	90	.47
	Depression	-2.12	.40	63	-5.33	.000	-2.90	-1.33
	Model: adj. $R^2$ =	= .43, df = 8,	94, $F = 1$	10.44, p = .000				
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Adjust  $R^2$  change = .32, df = 5, 94, F change = 11.97, p = .000

*Note.*  $^{a}$  = dummy coded variable (0=female, 1= male),  $^{b}$  = square root transformation with constant was used,  $^{c}$  = dummy coded variable (0 = no disability, 1 = disability)

## Discussion

## **Demographic Characteristics of the Sample**

The majority of the TBI subjects in this study were male, which was similar to previous studies (Anderson et al., 2011; Eriksson et al., 2009; Guilfoyle et al., 2010; Hawthorne et al., 2009; Lin et al., 2010; Nestvold & Stavem, 2009; Thomas et al., 2009; Truelle et al., 2010; von Steinbuechel et al., 2010a). The WHO report (2004) on road traffic injury prevention reported that males account for 73% of deaths and 70% of all disability-adjusted life years (DALYs) lost because of road traffic injuries.

According to the cause of TBI, it was found that the majority of the subjects diagnosed with TBI sustained their injuries in road traffic accidents. This result was consistent with the second global status report on road safety by the WHO (2012) in that 90% of road traffic injuries occur in low- and middle-income countries, such as Indonesia. Similarly, it was also reported that in low- and middle-income countries, motorcycle riders account for a large portions of road traffic injuries (WHO, 2004).

Most of the subjects in this study were young adults (M = 32.48, SD = 12.27) with the median age of 31 years old. This finding was consistent with a previous study which reported that young adults accounted for the majority of TBI subjects (Dikmen et al., 2003; McCarthy et al., 2006). Moreover, a report on the incidence of TBI showed that there was bimodal age distribution in adult populations (Rutland-Brown, Langlois, Thomas & Xi, 2006). The first peak occurs in young adults with motor vehicle crashes being the major cause of TBI. The second peak occurs within the elderly population with falls being the predominant cause of TBI (Rutland-Brown et al., 2006).

Regarding the employment status of TBI patients, it was found that the number of unemployed subjects increased from 12% before injury to 21% after injury. This finding may reflect that some TBI patients could not return to normal life after their injury. The TBI results in physical and functioning limitations which need long-term care. As reported in previous studies, more than a half of TBI patients had changed their vocational status after they encountered problems with employment (Mailhan et al., 2005). Consistent with those results, role limitations at work and school was confronted by TBI patients (McCarthy et al., 2006).

More than a half of the subjects in this study reported having current symptoms such as headaches, memory problems, fatigue, and the vision problems. Some of patient reported having more than one symptom. This finding was consistent with previous studies which reported the physical impact of TBI on patients (Andelic et al., 2010; Andersson et al., 2007; Lundin et al., 2006). After three months, approximately half of the mild TBI subjects reported at least one persistent symptom (Lundin et al., 2006), and the persistence of symptoms continued at one year after injury even though they received early active rehabilitation (Andersson et al., 2007). Among those symptoms reported in this study, headaches were the most common among the TBI subjects, which was consistent with a previous study (Hoffman et al., 2011).

#### **QoL of Patients with TBI**

In general, the QoL in this study was at a moderate level. Moreover, the mean scores under the domain of self, emotion and social relationship were higher than the overall QoL mean score (Table 9). The domain of self consists of satisfaction about aspects of self including energy, motivation, self-esteem, the way you look, achievement, self perception, and own future. The higher rating of the self domain shows that the TBI survivors in this study had a higher view of self. The view of self was associated with QoL (Vickery et al, 2005), which receives a lower rating from subjects who have a poorer view of self. Regarding the view of the others, the domain of social relationships consists of satisfaction with affection towards others, family members, friends and partner, as well as sex life and attitudes of others. The higher rating of the social relationship domain showed that subjects had higher social support. It is evident that social support was positively related with QoL (Table 11), which is similar to the findings of other studies (Kalpakjian et al., 2004; Steadman-Pare et al., 2001: Tomberg et al., 2007). Moreover, it was found that the top three items of satisfaction reported by subjects in this study were (1) the ability to feel affection towards others (partner, family, and friends); (2) the relationships with members of the family; and (3) self-esteem, how valuable you feel. The results may reflect the succesful coping of subjects in this study, as shown in the domain above, and help subjects to report their QoL at a moderate level. This finding may be different from most of the previous studies on the QoL of TBI patients, which showed that the QoL of TBI patients was at a low level (Emanuelson et al., 2003; Hawthorne et al., 2009; Huebner et al., 2003; Kalpakjian et al., 2004; Nestvold & Stavem, 2009; Pagulayan et al., 2006).

In addition, the moderate level of QoL may be from the cultural context of the caring environment that exists in Indonesia, particularly in terms of family support and care environments among TBI patients after discharge. The majority of the subjects in this study were living with family (96.1%) and family care is regarded as social support, which is one of the factors that positively influence the QoL of TBI patients. In Indonesia, family relationships and support remain high with regard to Indonesians living in an extended family and adult offspring living in the same house as their parents. Relatives visit each other frequently, especially when one of the family members becomes sick or injured. These traits reflect the social norm of

*'tolong menolong'* (helping one another), which is particularly well established within Indonesian village society (Higgins & Higgins as cited in Goodwin & Giles, 2003). Perceived availability of social support can exert a buffering effect that attenuates an individual's reaction to the adverse impacts of chronic illness. This buffering function is mediated through a bolstering of patients' confidence so that they appraise the illness experience as being less stressful (Cohen & Wills, 1985). These buffering model confirm that the subjects in this study reported fewer bothered feelings of negative emotion in the domain emotion of QoL (feeling lonely, bored, anxious, sad or depressed, and angry or aggressive). The subjects also reported high levels of QoL.

Another finding was related to the age of subjects in this study. Most of the subjects in this study were young adults with the median age of 31 years. It is shown that age has a negative relationship with QoL (Table 11) which mean that younger subjects reported higher QoL. This finding is similar to the previous studies (Hu et al., 2012; Nestvold & Stavem, 2009; Truelle et al., 2010).

An increase from 12% before injury to 21% after injury was found in the percentage of unemployed subjects in this study. Among the unemployed subjects, it was shown that 77% had current symptoms and more than half had some form of disability. In addition, the subjects who were unemployed reported lower QoL than subjects who were employed (Appendix I). This finding may be partly due to (1) disability and (2) no policy to support unemployed persons. Only health insurance from the social insurance ("*jamkesmas*") mechanisms was available for poor people. However, there was no significant difference of QoL among those who were unemployed and those who were employed (t = -1.96, p = .05). This findings contrast with a previous study by Corrigan (2001), which showed that the employment status is one of the factors related to QoL of TBI patients. Subjects who have gained employment in 1 and 2 years after their injury would have higher life satisfaction.

Regarding the time after injury, it was found to have a positive relationship with QoL (Table 11). This may be because the recovery from TBI had been progressing over time, although more than half of the subjects who had injuries for more than 12 months continued to have symptoms. In addition, more than half were diagnosed with mild TBI and a lesser amount required access to rehabilitation. It was noted that only a small number of subjects joined a rehabilitation program in this study (n = 19). This reflects the situation of Indonesia, where access to rehabilitation units is limited. Rehabilitation is provided by tertiary or central referral hospitals in each province. Moreover, after discharge from hospital, people are less likely to follow up in a hospital. More commonly they prefer traditional treatments such as herbs or massages or visiting a spiritual healer. It was also found that, among those who were enrolled in rehabilitation, 74% were experiencing symptoms. Therefore, this confirms that the majority of those who had access to rehabilitation also had symptoms. Meanwhile, there was a significant mean difference between those who had symptoms and those who had no symptoms (U = -2.11, p = .04) (Appendix I), whereas subjects who had symptoms reported a lower QoL.

#### Factors Predicting QoL of Patients with TBI

Based on the study framework, there were physical factors and psychosocial factors, also demographics as confounding factors, which are discussed together.

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In the last step of multiple regression analysis, both of the physical factors (severity of injury and functioning and disability) and the psychosocial factors (social support, anxiety, and depression) explained the variation of QoL with the adjusted  $R^2 = 32\%$ . It was found that depression was the only variable which made a significant contribution to the variance of QoL (B = -2.12, t = -5.33, p = .000). As seen in Table 11, there was only one physical factors variable which had a correlation with QoL, while all of the psychosocial factors variables showed a correlation with QoL. It was also found that, among the study variables, depression yielded the highest correlation with QoL (Table 11). This finding reflects that psychosocial factors had a stronger influence on TBI patients than physical factors. People can cope with their physical limitation through their environment, such as social support. People emphasize what they consider most important and they expect to contribute to maintaining or increasing their life satisfaction. When reality does not match the needs and wishes, this can evoke certain reactions. This was consistent with the findings of previous studies (Lin et al., 2010; Steadman-Pare et al., 2001; Underhill et al., 2003; Vickery et al., 2005) which revealed depression's strong impact on QoL. It is evident that the inclusion of psychological variables in prediction models has been shown to increase the predictive value (Table 12). This is similar to certain previous studies (Kalpakjian et al., 2004; Nestvold & Stavem, 2009; Steadman-Pare et al., 2001) which found an increasing variance of 33 to 49% with the inclusion of psychological variables, while the physical factors variable had only 17% of the predicted value (Pierce & Hanks, 2006). Moreover, there was a recommendation from the WHO collaborating task for mild TBI to explore psychological distress as one of the important topics for research (Caroll et al., 2004).

There was a positive correlation between functioning and disability (DRS) as well as depression and anxiety, whereas negative correlations were shown between QoL and DRS, QoL and depression, and QoL and anxiety (Table 11). Among subjects who reported symptoms of depression, from cross tabulation, it was found that 59% had current symptoms such as headaches, memory problems, fatigue, and vision problems. It was also found that 68% of subjects were experiencing disability. The increased reported functional limitations were followed by increased depressive and anxiety symptomatology. This finding is similar to an observation from a study by Pagulayan et al. (2006), which concluded that perceived changes in daily functioning influence emotional well-being over time after TBI. Moreover, another report revealed that depression among persons with TBI may also result from inadequate medical treatment and low treatment compliance (Underhill et al., 2003). However, this study did not explore this data.

There was a negative correlation between depression and QoL (Table 11). In additional analysis of the mean difference in the domain of self (subdomain of QoL) among those with depression and those with no depression, a significant difference was found (t = 4.84, p = .000). The subjects who had depression had lower levels of self-domain (M = 62.83, SD = 10.67) than those who did not have depression (M = 72.53, SD = 7.60) (Appendix I). It is suggested that a poorer view of self was associated with higher levels of depressive symptoms. It also suggests that those with the lower levels of depressive symptoms reported higher perceptions of QoL. This finding concurs with a previous study which explored the relationships between depression, self concepts and perceived QoL (Vickery et al., 2005).

Even though there was a positive relationship with QoL, it was found that social support cannot make a significant contribution to the variance of QoL. This may be because the majority of subjects in this study had no disability and less need of support. Another explanation of this non significant finding is because the social support variable is a suppressor variable, which enhances the effects of other variables in the set of independent variables. It showed that social support has the opposite sign of the bivariate correlation and beta weight in the regression analysis. This result contrasts with the findings of a study by Kalpakjian et al. (2004) which found that social support makes a significant contribution to the QoL variance (B = .37, t = 2.11, p < .05). The correlation between social support and QoL is also confirmed in other studies (Kalpakjian et al., 2004; Petchprapai, 2007; Steadman-Pare et al., 2001; Tomberg et al., 2007), in which subjects who had more social support reported higher levels of QoL. However, in this study, it was found that there was a negative correlation between depression and social support (Table 11). This reflects that low social support was associated with higher levels of depressive symptoms and lower QoL. This finding corresponds with the theory of the buffering model of social support by Cohen and Wills (1985). Social support buffers the adverse impact of illness.

The number of subjects who reported depression symptoms in this study were 21.4% (n = 22), which was divided into mild symptoms (n = 18) and moderate symptoms (n = 4) of depression. The incidence of depression in the present study was lower when compared to other studies (Draper et al., 2007; Underhill et al., 2003: Vickery et al, 2005; Whelan-Goodinson et al., 2009), which ranged from 28-46%. For example, in a study of mild to severe TBI at the 10-year follow up stage, 46% had depression (Draper et al., 2007), while other reports revealed that depression was found in 38% (Vickery et al., 2005) and 28% (Underhill et al., 2003) depending on time of measurement and subject's severity of injury. However, anxiety did not make a significant contribution to the QoL variance, although it showed a negative relationship between anxiety and QoL (r = -.50, p = .01). Similar results showed that high levels of anxiety had an impact on QoL (Hawthorne et al., 2009).

None of the physical factors could predict QoL. This result contrasts with the findings of a study by Pierce and Hanks (2006), which found that the WHO model of functioning and disability significantly predicted life satisfaction. However, in the present study, the functioning and disability as measured by DRS had a negative relationship with QoL (Table 11). Subjects who had a disability reported lower levels of QoL than subjects who did not. This finding is consistent with previous studies which found a relationship between disability and QoL (Huebner et al., 2003; Lin et al., 2010; Resch et al., 2009). Moreover, it showed that the functioning and disability variable has a high standard error in regression coefficients (Table 12). It may contribute to the non significant finding in the regression analysis. Another reason may be due to the selection bias. It found that the majority of the subjects in this study (78%) has no disability.

It also found that the severity of injury had not made a contribution to the variance of QoL in the regression analysis. Severity of injury using GCS was collected only on admission, which is retrospective data assessed from a patient's medical records. This may cause a bias which contributes to the result. It was also found that the data distribution had negative skewness; therefore, the transformation was used. The majority of subjects were initially reported as having mild TBI, while only a small number had severe TBI (n = 3). The finding was similar to a study by Nesvold and Stavem (2009), who found that there was no association between the severity of TBI and QoL. Similar to a meta analysis of the relationship between injury severity and outcome following TBI, it was also found that injury severity was most poorly associated with QoL (Cappa, Conger, & Conger, 2011).

It is interesting that the confounding variables of demographic factors could explain 11% of QoL with age and time after injury as the significant variable in the first step of regression analysis, even though none of the demographic variables reached a level of significance in the final model. This finding is consistent with a study conducted by Nestvold and Stavem (2009), which found that age explained 35% of the variability of the physical component summary score of QoL. A negative relationship between age and QoL in the present study showed that younger subjects reported higher QoL than older subjects. This finding is consistent with previous studies (Hu et al., 2012; Nestvold & Stavem, 2009; Truelle et al., 2010). There was evidence that older subjects with TBI had worse functional outcomes, longer hospitalization, and greater disability and mortality (Flanagan, Hibbard, & Gordon, 2005: Sendroy-Terrill, Whiteneck, & Brooks, 2010).

A correlation between time after injury and QoL in this present study was consistent with previous studies (Hu et al., 2012; Lin et al., 2010; Pagulayan et al., 2006). In the present study, it was found that time after injury positively related with QoL (Table 11), which subjects with less time has passed since their injury reported lower QoL. This may reflect that recovery from TBI progresses with the passage of time. This supports the findings of a study by Hu et al. (2012), which found that there was statistically significant improvement of QoL among TBI subjects
from discharge to 6 months, to 1 year, and to 2 years. However, different patterns of recovery were reported by Pagulayan et al. (2006), who found that significant improvements over 6 months were only evident in the physical domain of QoL, while the improvement of psychosocial domains of QoL was minimal and still nonsignificant up to 3 to 5 years post injury.

No relationship between gender and QoL was found, which is consistent with previous studies (Resch et al., 2009; Teasdale & Engberg, 2005). Gender was also not a significant factor in predicting QoL, which is in contrast to the findings of a study by Steadman-Pare (2001), who found that gender can predict QoL. Gender contributes 3% of the unique variance of QoL and women tended to report higher QoL than men (Steadman-Pare et al., 2001). Although there was a report in a meta analysis of gender differences in the outcome after TBI, women had worse outcomes than men (Farace & Alves, 2000). The finding regarding gender differences needs to be considered because the number of females in the TBI population was small. In this study, the proportion of females was only 23%.

As shown in Table 11, most of the variables were associated with QoL and some of them can predict QoL at different levels of coefficients. These were: (1) depression, (2) age, and (3) time after injury. Moreover, depression was found to have the highest influence on QoL with a coefficient of the total effect of -2.11. The findings of this study indicate that TBI patients can achieve QoL through many factors. Psychosocial factors, particularly depressive moods, seem to directly affect patient QoL the most.

#### **CHAPTER 5**

#### CONCLUSION AND RECOMMENDATIONS

This chapter presents a summary of the research findings, the strengths and limitations of this study, and the implications and recommendations for future knowledge development.

#### Conclusion

This study was a cross sectional survey to describe the level of QoL and determine the predictive factors of QoL in patients with TBI in Indonesia. The samples in this study consisted of 103 adults ranging in age from 18-59 years old with mild, moderate and severe TBI, all of whom had been discharged from hospital at least 1 month previously and were available for follow ups. Subjects were recruited from the medical record data of patients who were admitted to the neurosurgeon unit at Dr. Kariadi Hospital, Central Java, Indonesia from 2011 until 2012. Subjects who met the sampling criteria were contacted by telephone or by a home visit and were asked for a convenient time and place for an appointment in order to conduct an interview.

The instruments used for data collection were a questionnaire, which was composed of four parts: (1) demographic and health related data questionnaire, (2) physical factors questionnaire (GCS and DRS), (3) psychosocial factors questionnaire (MOS SSS and HADS), and (4) QoL questionnaire (QOLIBRI). Data were analyzed by using descriptive statistics to describe the demographic data and clinical characteristics as well as the inferential statistics to examine the correlations between the identified factors and QoL. Hierarchical multiple regression was used to determine the strongest predictors of QoL. The confounding variables (demographic variable) were entered as the first step of hierarchical multiple regression. The second step, physical and psychosocial variables, was entered into regression analysis.

The findings of the present study are summarized as follows:

The majority of subjects in this study were male (78%) with ages ranging from 18-59 years (M = 32.48, SD = 12.27) and with an average length of time after injury of 13.76 (SD = 6.79) months, ranging from 2-24 months. More than half of the subjects reported having current symptoms such as headache (57%), problems with memory (12%), fatigue (5%), and problems with seeing (1%). Based on the DRS scores, 78% of the subjects had no disability, while 6% had a mild disability, and 17% had a partial disability.

It was found that 58% of subjects were classified as mild TBI, while 39% and 3% of the subjects were classified as moderate and severe TBI respectively, based on their GCS score at the time of admission. Social support was at a moderate level, and the majority of TBI subjects reported a normal level of anxiety (n = 80), while the remainder were reported as mild (n = 17), moderate (n = 5), and severe (n =1). In addition, the majority of the subjects had normal levels of depression (n = 81), while the remainder had mild (n = 18) and moderate (n = 4) levels of depression.

Regarding QoL, it was found that the total mean score of QoL was 69.00 with SD = 10.96. More than half of the subjects (65%) had a moderate level of QoL, followed by those with a high level of QoL (18%) and low level of QoL (17%).

Hierarchical multiple regression showed that the first step was supported (adj.  $R^2 = .11$ , F = 5.07, p = .003). Age, gender, and time after injury

explained the variation of QoL for 11% (p = .003) with age and time after injury significantly explaining QoL (p < .05). In the second step, the proposed variable including physical factors and psychosocial factors was supported (adj.  $R^2 = .43$ , F =10.44, p = .000). The contribution of the severity of injury, functioning and disability, social support, anxiety, and depression explained the variation of QoL for 32% (p =.000) with depression as the powerful variable that could explain QoL significantly (B = -2.11,  $\beta = -.63$ , t = -5.33, p = .000).

#### **Strengths and Limitations**

The strengths of this study are related to theoretical and methodological issues. The QoL conception used in the present study was the specific HRQoL assessment model for TBI patients which included the specific issues of TBI patients. For the methodological aspects, the instruments used in this study were existing tools which had been validated. In this study, the instruments were tested for validity and reliability. The reliability of instruments ranged from .89 to .99 and the validity ranged from .90 to 1. In addition, this study used power analysis to determine the sample size.

Despite the strengths, there were several limitations in this study. The theoretical model proposed in the present study was derived from the conceptual assessment model of HRQoL specific for TBI patients with modified variables based on the literature review on factors associated with QoL in patients with TBI. There may be other factors which have not yet been included as predicting factors as in this study only 43% variance of QoL was found. Another limitation was due to methodological issues. The GCS data for classifying the severity of injury used

retrospective data which may contribute to bias. The other factor that needs to be considered was the Likerts scale that was used in the instruments. There may be a tendency that people will choose a middle point when asked to rate their condition. In addition, the subjects were obtained from only one referral center in Indonesia and method of approaching the subjects may not reach those with high severity of injury or those living a long distance from the center. As this was only a cross sectional survey, the findings may be limited.

#### **Implications and Recommendations**

#### **Nursing education**

The findings in this study provide information about the importance of preventing the incidence of depression for enhancing QoL after TBI. Perhaps teaching assessments for preventing depression should be incorporated into the curriculum. Also, because there was a relation between depression and disability and also with the persistent symptoms, teaching recognition of disability and persisting symptoms in patients with TBI should be one of the assignments for students who are training in surgical or neurological departments so that intervention is not delayed.

#### **Nursing practice**

The findings from the present study can serve as baseline data for monitoring and improving some dimensions of QoL. In addition, the development of nursing interventions to prevent the incidence of depression in patients with TBI is imperative. Nurses should be aware if patients have a disability before discharge. An appropriate information with involving the family should be given priority. Nurses also need to inform the family that their support of the patients is important as social support can buffer the effect of illness and enhance the QoL of patients. Patients and family should be advised that if their symptoms or disabilities persist beyond 3 months, they should re-contact the health care facility or health care provider.

#### Nursing research

It was found that the variables of demographic factors, physical factors, and psychosocial factors which was used in this study can predict only 43% of QoL variance. It means that there will be other variables which require further exploration. Further research should examine the longitudinal design and follow up the outcomes and extend the study to include subjects from different settings or geographical areas.

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APPENDICES

#### **APPENDIX A**

#### **INFORMED CONSENT FORM**

My name is Nury Sukraeny. I am a master's student of the Master of Nursing Science (International Program) at Faculty of Nursing, Prince of Songkla University, Thailand. I am conducting a research study with the title "Determinants of quality of life (QoL) of patients with traumatic brain injury (TBI) in Indonesia".

The purpose of this study is to find factors that can explain the quality of life of patients, like you. Although the study will not benefit you directly, it will provide information that might enable nurses to determine factors influencing QoL among adults living with TBI after discharge and can be used for the development of nursing intervention to improve patient's QoL after discharge.

The study and its procedures have been approved by both the Research Ethics Committee of Faculty of Nursing, Prince of Songkla University, Thailand and the Health Research Ethics Committee of Dr. Kariadi Hospital, Central Java, Indonesia. The study procedures might cause fatigue to you. If you decide to participate in this study, you will be asked about your personal information in demography questionnaire and health-related data. Then you will be asked to fill some questionnaires to reflect how you satisfy your life and perhaps some factors that may contribute to it. The whole process will take approximately 30 minutes.

Your participation in this study is entirely voluntary and you may refuse to complete the study. You have the right to withdraw at any time and the care of you and your relationship with the health care team will not be affected. You are free to ask the researcher any questions you may have about the study or about being a subject and you may contact the researcher: Nury Sukraeny, mobile phone 081325248178 or email: <u>nury\_sukreny@yahoo.com</u> if you have further questions.

All records of participation will be kept strictly confidential. Your name will never be connected to your result or to your responses on the questionnaires; instead, a number will be used for identification purpose. The data will be accessible only to those working on the project. The result of this study will be reported in a written research report and presented as an oral report. Information about the study will be presented in an overview without exploring individual data. I have read the above information and voluntarily consent to participate in this study.

Date	Date
Signature of	Signature of
participant	researcher
Name of	Name of
participant	researcher

# **APPENDIX B**

# DEMOGRAPHIC AND HEALTH STATUS QUESTIONNAIRE

Code :						
Date :						
Age	: years					
Gender	:  Male /  Female					
Religion	$: \Box$ Moslem / $\Box$ Chris	tian / 🗆	Budd	ha / 🗆 H	Hindu	
Marital status	: $\Box$ Single / $\Box$ Married	l / 🗆 Di	vorced	/ 🗆 Wi	dowed	or Widower
Educational level	: $\Box$ No schooling		🗆 Di	ploma		
	□ Elementary School	l	🗆 Ba	chelor		
	□ Junior High School		🗆 Gr	aduate S	School	
	□ Senior High School	l				
Previous occupation	: 🗆 Student			ivate em	ployee	
	□ Government emplo	yee	🗆 Re	tired		
	□ Farmer/gardener		$\Box$ Ho	ousewife		
	$\square$ No occupation		□ Ot	her		
Present occupation	: 🗆 Student			ivate em	ployee	
	□ Government emplo	yee	🗆 Re	tired		
	□ Farmer/gardener		□ Ho	ousewife		
	$\square$ No occupation		$\Box$ Ot	her		
Family members wh	o live in the same place	: 🗆 1	$\Box 2$	□ 3	□ 4	$\square > 5$
Average income	: $\Box > Rp.1.000.000$		$\Box < \mathbf{R}$	kp.1.000	.000	
Time after injury	: months					
Access to rehabilitat	ion after discharge	: 🗆 Ye	s		$\square$ No	
Home visit by health	n care provider	: 🗆 Ye	S		$\square$ No	
If yes, who a	nd how frequently	:	•••••	••••••	•••••	
Use complementary	therapy	: 🗆 Ye	S		🗆 No	
If yes, what a	and how frequently	:	•••••	••••••	•••••	
Current symptoms	: 1)		•••••			
	2)					

# **APPENDIX C**

# PHYSICAL FACTORS QUESTIONNAIRE

The	e GCS on admission	:		
	DI	SABILITY RA	TING SCALE	(DRS)
А.	EYE OPENING: (0) Spontaneous (1) To Speech (2) To Pain (3) None	<b>0-SPONTANEC</b> active arousal me <b>1-TO SPEECH</b> any verbal appro command to ope <b>2-TO PAIN</b> : test <b>3-NONE</b> : no eye	DUS: eyes open with echanisms, does not a AND/OR SENSOR ach, whether spoken n the eyes. Also, res ted by a painful stimu e opening even to pai	sleep/wake rhythms indicating assume awareness. Y STIMULATION: a response to or shouted, not necessarily the sponse to touch, mild pressure. ulus. inful stimulation.
B.	COMMUNICATIO	N ABILITY:		
C.	MOTOR RESPONS	5 <b>E</b> :		
D.				
E.				
F.				
G.				
H.	<b>"EMPLOYABILIT"</b> <b>STUDENT</b> )	Y''(AS A FULI	L TIME WORK	<b>ER, HOMEMAKER, OR</b> workshop, Non-competitive
	$\Box (1) \text{ Selected jobs,}$	competitive	(3)  Not Emp	loyable
	<b>0-NOT RESTRICTED</b> commensurate with exist associated with homem	): can compete in t sting skills; or can aking; or can under	he open market for a initiate, plan execute rstand and carry out n	relatively wide range of jobs and assume responsibilities most age relevant school assignmen

## **APPENDIX D**

# PSYCHOSOCIAL FACTORS QUESTIONNAIRE

# Medical Outcomes Study (MOS) Social Support Survey

People sometimes look to others for companionship, assistance, or other types of support. How often is each of the following kinds of support available to you if you need it? Mark the box with an " $\star$ " or " $\checkmark$ ".

	None of the time	A little of the time	Some of the time	Most of the time	All of the time
	1	2	3	4	5
Emotional/informational support					
Someone you can count on to listen to you when you need to talk					
Someone to give you information to help you understand a situation					
Tangible support					
Someone to help you if you were confined to bed					
Affectionate support					
Someone who shows you love and affection					
Positive social interaction					
Someone to have a good time with					
Additional item					
Someone to do things with to help you get your mind off things					

### The Hospital Anxiety and Depression Scale (HADS)

This questionnaire is designed to know how you feel. Ignore the numbers printed on the left of the questionnaire. Read each item and mark the box with an " $\mathbf{x}$ " or " $\mathbf{v}$ " the reply which comes closest to how you have been feeling in the past week.

Don't take too long over your replies; your immediate reaction to each item will probably be more accurate than a long thought out response.

	A 3 2 1 0	I feel tense or 'wound up': Most of the time A lot of the time From time to time, occasionally Not at all
D 0 1 2 3		I still enjoy the things I used to enjoy: Definitely as much Not quite so much Only a little Hardly at all
	A 3 2	I get a sort of frightened feeling as if something awful is about to happen:
D 0 1 2 3		I can enjoy a good book or radio or TV program: Often Sometimes Not often Very seldom

### **APPENDIX E**

## **QUALITY OF LIFE QUESTIONNAIRE**

# **QOLIBRI – QUALITY OF LIFE AFTER BRAIN INJURY**

For each question please choose the answer which is closest to how you feel now (including the past week) and mark the box with an "X". If you have problems filling out the questionnaire, please ask for help.

# PART 1

In the first part of this questionnaire we would like to know **how satisfied** you are with different aspects of your life since your brain injury.

A. These questions are about your thinking abilities now (including the past week).

		Not at all	Slightly	Moderately	Quite	Very
1.	How satisfied are you with your ability to concentrate, for example when reading or keeping track of a conversation?					
2.	How satisfied are you with your ability to express yourself and understand others in a conversation?					
B.	These questions are about your emotions and view of your the past week).	rself	now(	(inclu	Iding	
1. C. D.			•••••	•••••		
PA In	<b>RT 2</b> the second part we would like to know <b>how bothered</b> y blems	vou f	eel b	y dif	ferent	Ī
рю Е.		•••••	••••	•••••	•••••	
F.	These questions are about how bothered you are by phy (including the past week).	vsical	prol	blems	s now	7
1.	How bothered are you by slowness and/or clumsiness of movement?					
2. 3.						

#### **APPENDIX F**

#### SAMPLE SIZE EQUATION

The sample size was estimated by using the sample size

equation/formula of Cohen (Cohen, 1988: 445) as follows:

$$N = \frac{\lambda}{f^2}$$

N = sample size

 $f^2$  = effect size (this study fixed the medium effect size as 0.15)

 $\lambda$  = values from Cohen's table (table 9.4.2:  $\lambda$  values of the *F* test as a

function of power, u, and v) (Cohen, 1988: 452).

a = significance criterion = .05

v = degree of freedom of the denominator of the *F* ratio = 120

u = degree of freedom of the numerator of the F ratio = 4

Power (desired power) = .80

The value of  $\lambda$  according to Cohen's table is equal to 12.3. When calculating the above formula (N =  $\frac{12.3}{0.15}$ ), the minimum sample size is 82.

# **APPENDIX G**

# SKEWNESS AND KURTOSIS OF STUDY VARIABLES

### Table 13

Skewness and Kurtosis of Study Variables

Items	Skewness/SE	Kurtosis/SE
Social support	172/.238	-1.211/.472
Emotional/ informational support	113/.238	.930/.472
Tangible support	.040/.238	895/.472
Affectionate support	364/.238	782/.472
Positive social interaction	028/.238	665/.472
Depressive mood		
Anxiety	.669/.238	.221/.472
Depression	.472/.238	539/.472
QOLIBRI	547/.238	009/.472
Cognitive	784/.238	.983/.472
Self	853/.238	1.626/.472
Daily life and autonomy	460/.238	.414/.472
Social relationships	400/.238	.733/.472
Emotions	056/.238	549/.472
Physical problems	695/.238	220/.472

# **APPENDIX H**

# SCATTERPLOT OF THE REGRESSION STANDARDIZED RESIDUAL AND REGRESSION STANDARDIZED PREDICTED VALUE





*Figure 3.* Scatterplot of the regression standardized residual and regression standardized predicted value

# **APPENDIX I**

# **ADDITIONAL ANALYSIS**

### Table 14

Comparison of QoL between Variable Group among TBI Subjects (N=103)

Variable group	п	Mean (SD)	t	р
Education status			.35	.73
Primary education and	39	69.49 (1.51)		
lower				
> Primary education	64	68.71 (1.49)		
Occupation status			- 1.96	.05
Unemployed	22	64.99 (2.65)		
Employed	81	70.10 (1.15)		
Symptom			-2.11#	.04
No symptom	33	72.46 (7.49)		
Having symptom	70	67.38 (11.98)		
# Manuel XVI: :				

# <sup>#</sup>= Mann Whitney U

### Table 15

Comparison of Self Domain between Group of Depression and No Depression (N=103)

Group	n	Mean (SD)	t	р
Depression			4.84	.000
Have depression (HADS_D score > 7)	22	62.83 (10.67)		
No depression (HADS_D score 0-7)	81	72.53 (7.60)		

## **APPENDIX J**

# LIST OF EXPERTS

The content validity of DRS, MOS SSS, HADS, and QOLIBRI was

performed by five experts:

1. Dr. Prapan Somporn

Neurosurgeon, Hat Yai Hospital, Thailand

2. Dr. Luppana Kitrungrote

Lecturer, Faculty of Nursing, Prince of Songkla University, Thailand

3. Phinwanan Nimitphan

Advance practice nurse in trauma, Songklanagarind Hospital, Prince of

Songkla University, Thailand

4. Dr. Muhammad Thohar, SpBS

Neurosurgeon, Dr. Kariadi Hospital, Central Java, Indonesia

5. Trimaningsih, S.Kep

Nurse in neurosurgical, Dr. Kariadi Hospital, Central Java, Indonesia

### VITAE

NameMrs. Nury SukraenyStudent ID5410420024

## **Educational Attainment**

Degree	Name of Institution	Year of Graduation
Diploma 3	University of	2000
	Muhammadiyah Semarang	
Bachelor of Nursing	University of Diponegoro	2005
	Semarang	

### **Scholarship Awards during Enrollment**

2011 – 2013	Directorate General of Higher Education Scholarship
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## Work - Position and Address

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### List of Publication and Proceeding

- Sukraeny, N., Songwathana, P., & Sae-Sia, W. (2013). Quality of life among traumatic brain injury survivors in Indonesia: A preliminary study.
  Proceedings of the 2013 International Conference on Health & Harmony, Nursing Values, Phuket Orchid Resort and Spa, Thailand, 1-3 May.
- Sukraeny, N., Songwathana, P., & Sae-Sia, W. (in press). Quality of life (QoL) in patients with traumatic brain injury (TBI): A literature review. *Nurse Media Journal of Nursing*.