

**DEPRESSION AMONG CAREGIVERS OF CHILDREN
FOLLOWING TRAUMATIC BRAIN INJURY IN
HOSPITAL UNIVERSITI SAINS MALAYSIA**

**DR FARIDAH BINTI MOHD ZIN
MBBChBAO(Ireland)**

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*For my beloved husband, Badriyah Idris,
my dear parents, Mohd Zin and Maimunah,
and the little ones, Syahir Iskandar and Mislaiha Sofea,
who had been and will always be my sweethearts.*

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ABBREVIATIONS

BDI	Beck Depression Inventory
DASS 21	Depression, Anxiety and Stress Scale 21
GCS	Glasgow Coma Scale
GOS	Glasgow Outcome Scale
HADS	Hospital Anxiety Depression Scale
HDRS	Hamilton Depression Rating Scale
HUSM	Hospital Universiti Sains Malaysia
PHQ-9	Patient Health Questionnaire
RM	Ringgit Malaysia
SPSS	Statistical Package for Social Science
TBI	Traumatic Brain Injury
WHO	World Health Organisation

ABSTRACT

English

Depression among caregivers of children following traumatic brain injury in Hospital
Universiti Sains Malaysia

Introduction Although it is generally accepted that traumatic brain injury leads to significant degree of depression among the caregivers, little is known about such impact on the population of North East Coast of Peninsular Malaysia. Hospital Universiti Sains Malaysia, being the only referral centre for traumatic brain injury in this region, it provides a suitable place to investigate the degree of depression and the possible risk factors.

Objective To determine the prevalence of depression and the associated factors among caregivers following traumatic brain injury in Hospital Sains Malaysia.

Methodology This is a cross sectional study involving 208 caregivers of children following traumatic brain injury. They were recruited during follow up at the Neurosurgical Outpatient, Hospital Universiti Sains Malaysia from April 2010 until March 2011. Duration since injury ranged from 1 week to 75 months. The caregivers were requested to answer a set of guided questionnaires on socio demographic and a self administered Beck Depression Inventory as the instrument to screen for depression. Those who had scored more than 10 were considered depressed. The medical records of the TBI patients were reviewed for the injury factors.

Results The prevalence of depression was 38.5% (95%CI: 31.89, 45.11). Depression among caregivers was significantly associated with income per capita ($p=0.035$). Depression among caregivers was not associated with severity of injury, outcome of injury, duration since injury or mode of injury. Socio demographic factors of the caregivers and the TBI patients, were also not associated with depression following traumatic brain injury, both by simple and multiple logistic regression.

Conclusion Prevalence of depression among caregivers of children following traumatic brain injury in Hospital Sains Malaysia was very much higher than the general population. Household income per capita was found to have significant association with depression. Other associated factors tested were found to have no association with depression among caregivers. Thus, depression has to be expected and assessed accordingly among the caregivers especially those with low household income per capita.

ABSTRAK

Malay

Kemurungan dalam kalangan penjaga kanak-kanak yang mengalami kecederaan otak akibat trauma di Hospital Universiti Sains Malaysia

Pendahuluan Kecederaan otak akibat trauma telah dibuktikan membawa kepada kemurungan dikalangan penjaga namun kesannya terhadap populasi di Pantai Timur Malaysia adalah tidak diketahui. Oleh kerana Hospital Universiti Sains Malaysia adalah pusat rujukan tunggal di daerah ini, ia memberikan sumber yang sesuai untuk menyiasat mengenai kemurungan dikalangan penjaga ini dan mengenalpasti factor yang berkaitan dengannya.

Kaedah Ini adalah kajian hirisan lintang melibatkan 208 penjaga kanak-kanak yang mengalami kecederaan otak akibat trauma. Penjaga telah disoal selidik ketika temujanji di Klinik Neurosurgeri, Hospital Universiti Sains Malaysia dari April 2010 hingga Mac 2011. Tempoh semenjak kecederaan adalah dari 1 hingga 75 bulan. Penjaga telah diminta untuk menjawab satu set borang yang terdiri daripada maklumat demografi sosio dan borang soal selidik "Beck Depression Inventory Malay version". Mereka yang memperoleh lebih dari 10 adalah di anggap sebagai murung. Faktor kecederaan pula diperolehi dari rekod perubatan pesakit.

Keputusan Prevalen kemurungan adalah 38.5% (95%CI: 31.89, 45.11).

Kemurungan dikalangan penjaga mempunyai kaitan dengan pendapatan isi rumah per kapita ($p = 0.035$). Kemurungan dikalangan penjaga adalah tidak berkaitan dengan tahap kecederaan, hasil kecederaan, tempoh sejak kecederaan atau cara kecederaan. Faktor demografi sosio penjaga, termasuk umur, jantina, taraf pendidikan, pekerjaan dan bilangan ahli tinggal bersama; dan demografi sosio kanak-kanak TBI tidak berkaitan dengan kemurungan dikalangan penjaga kanak-kanak setelah mengalami kecederaan otak.

Kesimpulan Prevelen kemurungan dalam kalangan penjaga kanak-kanak setelah mengalami kecederaan otak di Hospital Universiti Sains Malaysia adalah lebih tinggi dari populasi umum. Secara amnya, kemurungan kerap berlaku dikalangan penjaga terutamanya dalam kalangan kumpulan berpendapatan rendah.

CHAPTER 1

INTRODUCTION

The World Health Organization (WHO) defined depression as a common mental disorder that presents with depressed mood, loss of interest or pleasure, feelings of guilt or low self-worth, disturbed sleep or appetite, low energy, and poor concentration ¹. They claimed that this debilitating illness affects about 121 million people worldwide ¹. Depression that has become chronic or recurrent may lead to significant impairment in an individual's self care ability and at its worst, leading to suicide which has been estimated to claim about 850 000 thousand lives every year ¹. On top of that, depression has been rated as a major cause of disability and the forth leading contributor to the global burden of disease in 2000¹. Although primary care setting is the most convenient point of entry into the health care system, fewer than 25% of those affected have access to the effective treatment¹. Thus, an effective screening among the public and awareness among the health care providers for this treatable condition are desperately needed.

On top of that, depression has been proven to have negative effects on the caregivers physically including nonfatal coronary heart disease in women and; mortality and nonfatal coronary heart disease in men ². Care giving itself has been shown to increase levels of metabolic syndrome and depressed immune system function ².

Depression among caregivers posed significant impact on the caregivers themselves as well as those under their care especially the children. In Malaysia, the Child Protection Act 1991 defines a “child” as anyone less than 18 years old³. A “child”

who is also considered as a minor, belongs to one of the most vulnerable groups of human being making them bound to their legal guardians not only by law but also with a very strong bond created by nature known as responsibility and love. Literature has shown that maternal depression jeopardises main parental functions in nurturing healthy relationships among the family members as well as in carrying out parenting role, leading to demonstrable impairment in young children's behavioural, cognitive, social and emotional functioning ^{4, 5}. Paternal depression has also been shown to have a strong relation to maternal depression and in families where both parents are depressed, the effects on children are compounded ⁵.

Due to the inseparable bond created by nature between the children and their caregivers, should anything happen to this group of human being, the burden would be suffered not only by the person but also by those attached to them. Malaysia has been built from the uniqueness of family bonding which has managed to stand since the beginning of time. A profound psychological impact is bound to happen should any of the family members falls into mishap especially if it involves the most vulnerable group namely the children.

1.1 Justification of study

Literatures have proven that, depression is common among caregivers of adult following traumatic brain injury (>16 years old). None of the previous studies tested the impact of such mishap on the caregivers of the younger age group. Furthermore, following TBI of the loved ones, caregivers have to make adjustments in their daily lives. These adjustments may lead to depression among them depending upon the individual's coping mechanism. Screening and active interventions may facilitate caregivers' adjustment. Literatures have also shown that a good rehabilitation program should involve the caregivers and programs which include the caregivers had produced better outcome among the TBI patients together with the caregivers themselves. Hence, caregivers emotional being needs to be address in order to produce a good rehabilitation program. The results obtained from this study may increase awareness among the health care providers and facilitate screening among the caregivers particularly following TBI among their children. This study could also provide epidemiological data on depression among caregivers following TBI in Kelantan and Terengganu.

CHAPTER 2

LITERATURE REVIEW

2.1 Traumatic brain injury (TBI)

The American Brain Injury Association defined TBI as an insult to the brain, not of a degenerative or congenital nature but caused by an external physical force, that may produce a diminished or altered state of consciousness, which results in an impairment of cognitive abilities or physical together with behavioural or emotional functioning^{6, 7}. These impairments may be either temporary or permanent and cause partial or total functional disability or psychosocial maladjustment^{6, 7}. The Centre for Disease Control however defined TBI as an occurrence of injury to the head that is documented in a medical record, with one or more of the following conditions attributed to head injury: observed or self reported decreased level of consciousness; amnesia; skull fracture; objective neurological or neuropsychological abnormality; and diagnosed intracranial lesion⁸.

2.2 Epidemiology of Traumatic Brain Injury

Published epidemiology data of traumatic brain injury in Malaysia is very limited. Rohana *et al* published their prospective observational study on head injury among children below 14 years old who presented to the Emergency Department from November 1993 to January 1994, which showed accidental head injury made up 4.75% of all cases seen with the ratio of boys to girls at 2:1, and the mean age of 5.2 years old⁹. The main cause of head injury was fall (63%) followed by road traffic accidents (30.7%) while the rest were due to 'impact' (injury caused by flying objects or

missiles). More than half 54.4% of those injured in RTA were pedestrians. Pedestrian injury was particularly important in the 5 to 14 years old ⁹.

Kareem *et al* reported road traffic accidents registered in Hospital Universiti Sains Malaysia whereby a total of 522 cases of head injury in the year 1997 and 570 in the year 1999 which showed that the accidents were more common among the motor vehicles¹⁰. The injuries included fractured skull, fractured base of skull, subarachnoid, subdural and extradural haemorrhage, cerebral laceration and contusion¹⁰.

More recently, Chan *et al* compared the characteristics of patients with mild head injury (GCS 13 to 15) presenting to accident and emergency departments of Ipoh General Hospital in Perak and Hospital Universiti Sains Malaysia in Kelantan, from 1st January 1998 to 31st December 2001, and determined clinical predictors that affect children who were admitted with mild head injury¹¹. In the Ipoh study, there were 54(35.3%) boys and 99(64.7%) girls among the paediatric head injury patients with the majority of patients were Malays (54.9%), followed by Indians (26.1%), and Chinese (18.3%)¹¹. The patients in HUSM hospital consisted of more Malays ($p<0.001$) with older mean age of patients [mean(SD)=15.7(1.7)] compared to Ipoh [mean(SD)=6.1(3.4)] years old¹¹.

In 2008 alone, 262 cases of brain injury involving children less than 18 years old have been hospitalized at HUSM with 6 % mortality ¹². This level has been more or less static for the past three years where 252 were admitted in 2007 and 254 in 2006 ¹². The number of cases hospitalized was higher in 2005 (291) and 2004 (342) ¹². Motor vehicle accident has been the most common mode of injury at 72% of all injuries, followed by

falls at 15%¹². The remaining 13% includes assault and accidental injuries with hard objects¹². 34% of falls occur in children less than 4 years old, and this percentage decreases with the increment of age whereby only 18% involves the 13 to 17 years old¹². However, for motor vehicle accident, older children, subgroup of 13 to 17 years old, is dominant comprising of 83% of cases compared to those less than 4 years old at 5%¹².

A recently updated epidemiology on traumatic brain injury (TBI) in the United States showed that TBI remains a public health problem even though the rates has been decreasing from 1997-2007¹³. The rate of TBI deaths was three times higher among males (28.8 per 100,000 population) than among females (9.1 per 100,000 population)¹³. TBI was found to be the leading cause of death among Americans younger than 45 years old with the risk of TBI peaks between the age of 15 and 30 years and one fifth of cases occur in the paediatric age group (birth to 17 years)¹³. Firearm (34.8%), motor-vehicle (31.4%), and fall-related TBIs (16.7%) were the leading causes of TBI-related death¹³. Similar to us, motor vehicle-related death rates were highest among those aged 15–24 years (11.9 per 100,000 population)¹³. They also estimated that 2.5 to 6.5 million Americans live with TBI-related disabilities¹³.

2.3 Assessment of head injury

A Glasgow Coma Scale (GCS) with 14 points which was first published in 1974 produced a great impact on the assessment and management of head injured patients in both community and hospital settings¹⁴. Later in 1976, Teasdale and Jennett modified the scale by adding an extra element, abnormal flexion, to the assessment of motor response, to create the 15-point scale that is now in use¹⁵. A guideline produced by

Badjatia N *et al.*, published in 2007 recommended that pre-hospital measurement of the Glasgow Coma Scale (GCS) is a significant and reliable indicator of the severity of traumatic brain injury (TBI), and should be used repeatedly to identify improvement or deterioration over time for both adult and children¹⁶. For the paediatric group, the adult protocol for standard GCS measurement should be followed in children over 2 years of age. On the other hand, the P-GCS should be employed in those less than 2 years old¹⁶. Prior to determination of conscious level by means of GCS score, airway, breathing, and circulation must be assessed and acted upon accordingly including ventilator support if indicated¹⁶. However, the GCS should be measured prior to administering sedative or paralytic agents, or after the drugs has been metabolized if used¹⁶. The GCS divided the severity of the brain injury into mild impairment (scores of 13 and above), moderate impairment (scores of 8 to 12) and severe impairment (scores of 3 to 7)^{14, 15, 17}.

2.4 Complications of traumatic brain injury in children

Traumatic brain injury has been known to cause a lot of complications to a child. Ong *et al* compared the neurobehavioral outcome of children aged 6 to 12 years with head injury, they found that although most of those children seemed to make good physical recovery, there were residual complications in the cognitive, motor, memory, learning and behaviour which led to deterioration in school performance, especially among those with severe head injury¹⁸. As a consequence, they highlighted the need for better integrated rehabilitation services to enable a gradual return to school¹⁸.

Apart from causing a significant neurobehavioral outcome, head trauma is also the most common cause of coma in children¹⁹. A Saudi Arabian study in 1999 on 91 children with coma (age range 28 days to 12 years), trauma (head trauma or poly-

trauma) was found to be the commonest cause of coma (52.8%), followed by infection (25.3%)¹⁹. Mortality was 47.2% and impaired outcome in 19.8% of patients¹⁹. They also concluded that the GCS in traumatic coma is one of the most important prognostic factors for the outcome of children who acquired brain injury¹⁹.

The recovery of a child after having brain injury would take some time to happen especially in those with severe outcome. Abdullah *et al* did a study in 2002 looking at the outcome of children with traumatic brain injury in rural Malaysia, they showed that improvement in outcome is seen only after a six month period after the injury²⁰. This long term recovery period among the children will definitely pose a significant emotional distressed among their caregivers.

2.5 Depression among caregivers following traumatic brain injury

Although there is no published data on depression among caregivers of children following traumatic brain injury in Malaysia, a few studies had been done elsewhere²¹⁻²⁶. A retrospective study done in Japan by Watanabe *et al* evaluated the levels of depression and anxiety among family members living with TBI patients, one to 3 years post injury using the Hospital Anxiety Depression scale, yielded a high prevalence of depression at 43 percent²⁶. Their results showed that family members with poor outcome and had difficulties in performing cognitive and behavioural tasks, were more likely to report higher levels of depression²⁶.

Kreutzer *et al* studied 273 caregivers of patients who were 1, 2 and 5 years post brain injury found that 17.6 percent of the caregivers exceeded the Brief Symptoms Inventory 18 (BSI-18) clinical cut offs level for depression²¹. Among the associated

factors tested, relationship with the TBI patients was not associated with depression among caregivers²¹. They also found no association with the duration since injury ²¹. However, depression among caregivers was associated with caring for TBI survivors who had poor functional outcome ²¹. More recently, Wade *et al* compared the emotional distress among the parents of children aged 6 to 12 years old who acquired severe and moderate brain injury versus orthopaedic injury up to one year post-injury, and they reported significantly higher levels of stress, and psychological symptoms among parents in the TBI groups²².

A study by Marsh *et al* on caregiver burden at 1 year following severe traumatic brain injury among adults, using the Beck Depression Inventory, revealed significant number of depression at 32% ²³. The same group of researcher found that the level of depression at 6 months post injury was 39% ²⁴. Harris *et al*, in a study on caregiver depression following traumatic brain injury (TBI) showed a prevalence of depression at 23 % ²⁵. Among the associated factors tested, age of patient and caregiver, sex of patient and caregiver, relationship of caregiver to patient, the socio-economic status of the family, time since injury and severity of injury have no significant relationship with caregiver depression ²⁵. The associated factors found to have significantly related with depression scores were behaviour and social problems among the TBI^{24,25}. Stancin *et al* found that family stress and maternal depression occur both shortly after brain injury reflecting response to the injury itself, and may develop over a longer period of time in response to changes in the child's cognition or behaviour due to the injury²⁷. Rivara *et al* further support the significant impact of TBI among children on their caregivers when they followed the families of children following TBI for three years post injury, and observed that family functioning deteriorated over time²⁸.

These levels of depression are significantly higher than the general population. The Malaysian Ministry of Health, in the 2011 National Health Morbidity survey , reported that 12% of the adult population has some form of psychiatric morbidity with depression made up 2% of the percentage ²⁹. Ruzanna *et al* in a study on the primary care attendees showed higher prevalence of depression at 14.4 percent which could be explained by the concurrent medical illness among the subjects³⁰. WHO reported the prevalence of major depression in the general population can go from an average of 3% up to 10%¹.

2.6 The importance of screening for depression among caregivers

Along with the high prevalence of depression as described above, the implication of depression among caregivers on the off springs should also be considered as a justification of screening for depression among the caregivers. Maternal depression jeopardised main parental functions in nurturing healthy relationships and carrying out parenting role, leading to demonstrable impairment in young children's behavioural, cognitive, social and emotional functioning ^{4, 5}. In a 13 years prospective longitudinal study by Halligan *et al*, on mothers who had post natal depression, higher rates of affective disorders in adolescent offspring were shown only if there had also been later episodes of depression among the mothers beyond the post natal period ³¹. Moreover, maternal depression was found to be a significant risk factor for impaired functioning in offspring ³², specifically more towards depressive disorder ³³. The impact of depression varies by its timing with maternal depression during infancy having a bigger impact on a child's development compared to later exposure, its severity, and the length of time suffered ³⁴.

Depression in other caregivers can also give significant impact on the children. There are very few studies done on paternal depression especially on the impact of the disease on children. Sherr *et al* showed that it is possible to recruit fathers to mental health studies among the fathers of children aged 6 years and under who were approached during the attendance at the family doctor ³⁵. Some studies show that depression in fathers is strongly related to maternal depression and in families where both parents are depressed, the effects on children are compounded ⁵. On the other hand, non-depressed fathers offer a protective effect on children of depressed mothers ³⁶.

Furthermore, the role of parents in improving outcome following illnesses among children has been proven to be an essential component, making their health mentally and physically should be addressed appropriately. Alliance between health care providers and parents in the treatment of children has been viewed as a facilitative condition, which both enhances application of interventions and is therapeutic in its own right³⁷. It has been called the "quintessential integrative variable" in psychotherapy which has been considered to be one of the most important therapeutic factors across different therapies³⁷. Furthermore, as proved by Sherer *et al* in 2007, following TBI, stronger therapeutic alliance obtained at rehabilitation program were predictive of a greater likelihood of a productive outcome³⁸.

2.7 Screening for depression

Many tools have been developed for the assessment of depression worldwide and used in many previous studies on impact of TBI among caregivers, including the Beck Depression Inventory, Hospital Anxiety Depression Scale, Brief symptoms Inventory and the Centre of Epidemiologic Studies Depression Scale. Mukhtar and Oei

recently reviewed the assessment for depression in Malaysia, they found two reliable assessment tools which can be used comfortably in the research setting namely the Malay version of Beck Depression Inventory (BDI) and the Malay version of Depression, Anxiety and Stress Scale (DASS-21), with internal reliability (Cronbach's α) of more than 0.75 in primary care setting³⁹. Although BDI Malay and DASS-21 have similar strength in terms of internal reliability, BDI Malay was chosen as the tool for the current study because we were interested in assessing depression alone which could not be assessed by DASS-21. The questionnaire for the later composed of a mixture of questions assessing all three components including depression, anxiety and stress making it impossible to rate depression *per se*. Hence, using DASS 21 in this study will lead to the unnecessary need to answer questions not related to depression.

2.7.1 Beck Depression Inventory (BDI)

The BDI has been one of the leading instruments for measuring level of depression in clinical and research domains for the past 40 years, and validated for depressed patients (Cronbach- α =0.86) along with the non-clinical samples including the general population (Cronbach- α =0.87)⁴⁰. This instrument bears 21 items that provide an indication of the level of depressed mood, whereby participants respond to questions in relation to how they have felt over the past week.

The BDI-Malay is a translated version of the original BDI which has strong psychometric properties, with mean alpha coefficient exceeding 0.90 and test-retest reliability of 0.80⁴¹. Mukhtar and Oei validated the BDI Malay Questionnaire among a collection of Malay subjects including students, general community, primary care and depressed patients⁴¹. Item 21 was discarded in the translation process as it did not load

onto the two main factors of cognitive/affective and somatic/vegetative, resulting in 20 items included in the BDI-Malay⁴². Different scores are given for each item answered by the participants, the cumulative score will then be classified into five groups as below (Table 1);

Table 1: The Beck Depression Inventory Score

Scores	Level of depression
0-10	Normal
11-20	Mild depression
21-30	Moderate depression
31-40	Severe depression
41-63	Very severe depression

2.7.2 Depression, anxiety and stress scale (DASS)

The DASS-21 is a short form of Lovibond and Lovibond's (1995) 42-item self-report measure of depression, anxiety, and stress (DASS)⁴³. DASS 21 is a self report questionnaire designed to measure the severity of symptoms related to depression, anxiety and stress, which has been proven to have good reliability and validity with the cronbach α value of 0.88 for depression, 0.82 for anxiety and 0.90 for stress, and overall reliability of 0.93⁴⁴. In 2007, a validated Malay version of DASS21 has been published to be used as a screening instrument for depression, anxiety and stress in Malaysia⁴⁵. The validation study was done on the general population of Klang Valey with high overall Cronbach's α at 0.90, making it a good tool to screen for depression, anxiety and stress in Malaysian population⁴⁵. As discussed earlier, DASS 21 was not chosen as the screening tool for this study as we were interested in depression alone which cannot be assessed by this tool.

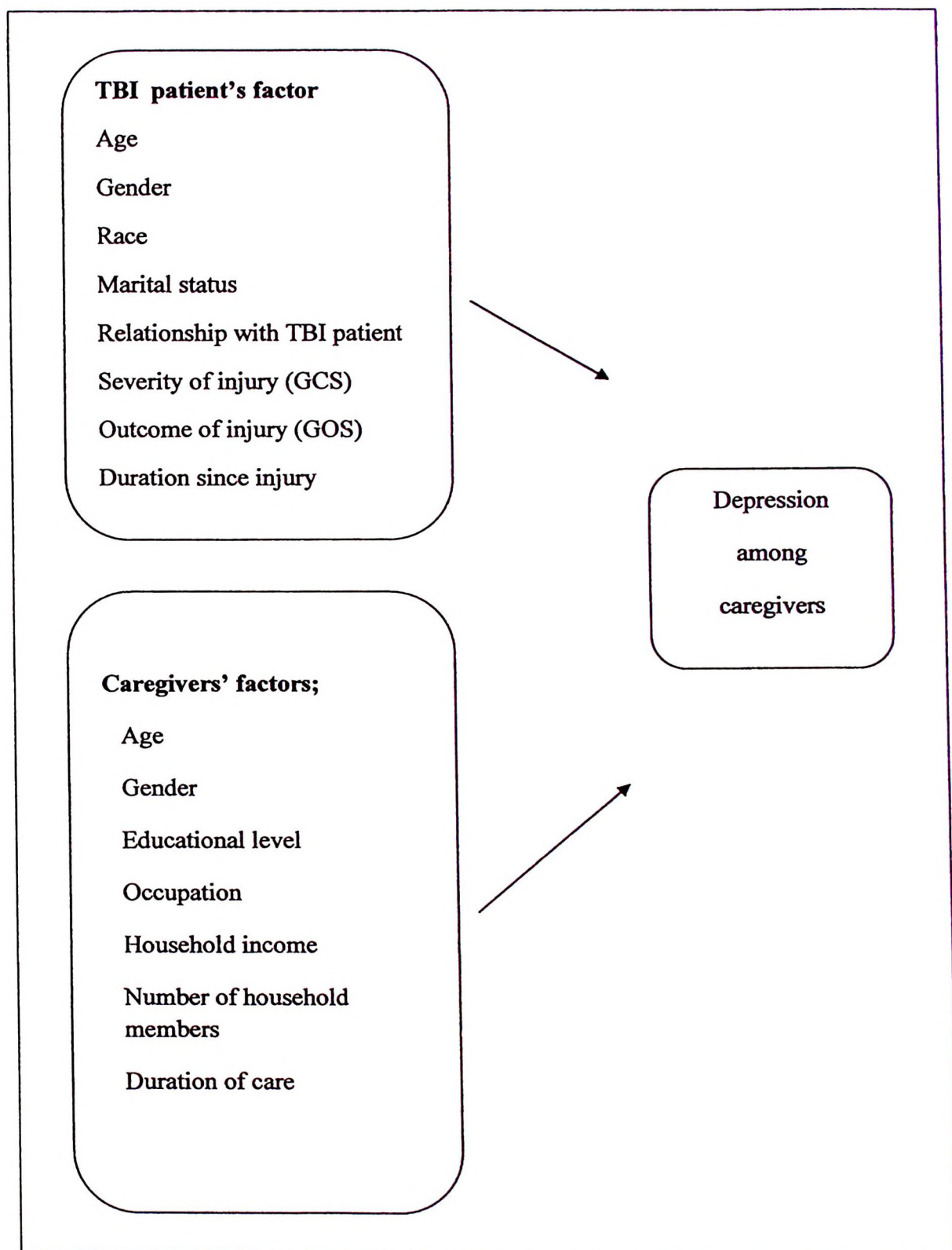


Figure 1 The conceptual frame work of depression among caregivers of children following traumatic brain injury

CHAPTER 3

OBJECTIVES AND HYPOTHESIS

3.1 General objective

To determine the prevalence of depression and its associated factors among caregivers of children following traumatic brain injury in HUSM

3.2 Specific objectives

1. To determine the prevalence of depression among the caregivers of children following traumatic brain injury attending the Neurosurgical Outpatient, HUSM
2. To determine the associated factors (caregiver and TBI patient factors) for depression among caregivers of children following traumatic brain injury attending the Neurosurgical Outpatient, HUSM

3.3 Research hypothesis

Caregivers' (age, sex, ethnicity, educational level, occupation, household income per capita and number of household members) and TBI children's (age and sex, severity of injury, outcome of injury, duration since injury and mode of injury) are significant associated factors for depression among caregivers of children following traumatic brain injury.

3.4 Operational definitions

1. Primary caregiver

The primary caregiver was defined as the person who provide the essential care in looking after the TBI patient, appointed by the TBI patient or the family members^{21, 25}.

2. Traumatic brain injury (TBI)

Traumatic brain injury was defined as an occurrence of injury to the head that was documented in the medical record²⁵.

3. Depression

Depressed was defined as BDI scores in the mild, moderate, severe and extremely severe categories for depression (scores of > 10). Non depressed is defined as BDI scores in the normal category (scores ≤ 10)^{23, 41, 46, 47}

CHAPTER 4

METHODOLOGY

4.1 Study area and background

This study was conducted at the Neurosurgical Outpatient, Hospital Universiti Sains Malaysia (HUSM), Kubang Kerian, Kelantan. The Department of Neurosains, HUSM, provides care for all the neurological cases in the North East Coast of Malaysia, mainly the two states of Kelantan and Terengganu, owing to the fact that it is the only neurosurgical centre in this region. Thus, all neurological cases in this area including traumatic brain injury among adults and paediatric age group are being followed up at the Neurosurgical Outpatient, HUSM. This clinic is currently being run by the neurosurgeons and neurosurgeons in training. There are two clinic days per week with the daily attendance of around 70 cases. However, only 10 percent of the attendees are in paediatric age. Moreover, the defaulter rate is also high, around 40 percent, due to large area of coverage which makes significant numbers of patients are living far from the facility. There are also paramedic staffs supporting the clinic session including the head nurses, medical attendants, and medical assistants.

4.2 Study design

This is a cross sectional study.

4.3 Reference population

All caregivers of children following traumatic brain injury in Kelantan and Terengganu.

4.4 Source Population

All caregivers of children following traumatic brain injury attending Neurosurgical Outpatient, HUSM from April 2010 until March 2011.

4.5 Inclusion Criteria

1. Primary caregivers of children following traumatic brain injury
2. Children aged less than 18 years old who acquired brain injury as documented in the medical record

4.6 Exclusion criteria

1. Known psychiatric illness
2. Illiterate

4.7 Sampling Method

Non-probability sampling was applied where all caregivers of children following traumatic brain injury attended the Neurosurgical OPD and fulfilled the inclusion and exclusion criteria were included in the study.

4.8 Sample size calculation

Objective 1 was to determine the prevalence of depression among the caregivers of children following traumatic brain injury. The sample size calculation was done with single proportion formula.

$$n = (z / \Delta)^2 p (1 - p)$$

n = minimum required sample size

z = value of standard normal distribution = 1.96

Δ = precision = 0.06

p = percentage of caregivers after traumatic brain injury found to be depressed
= 23 %²⁵

Thus, the sample size calculated was 189. However, after considering the non respond rate of 10%, the number of caregivers needed for this study was 208.

For objective 2, the sample size calculation to identify the associated factors of depression among caregivers of children following TBI in HUSM was done using Power and Sample Size Calculation software⁴⁸. The sample size for comparing two proportions using the Power and Sample size calculation (PS) was used for categorical variables. The calculation of sample size is as follows;

α	= 0.05
Power	= 0.8
P_0	= 0.74 (proportion of married caregivers among non-depressed) ⁴⁹ .
P_1	= 0.90 (proportion of married caregivers among depressed).
M	= 1:1
n	= 71 x 2 = 142

Thus, the sample size calculated was 142. However, after considering the non respond rate of 10%, the number of caregivers needed for this study was 156. Summary of the sample size calculation for objective 2 is tabulated in Appendix 4. Since the largest sample calculated was from objective 1, 208 was taken as the sample size for this study.

4.9 Research tool

The research tools composed of (Appendix 3);

4.9.1 Medical record

The data regarding the TBI children namely age and sex; and the data concerning the injury which include the mode of injury, duration since injury, GCS on admission and the GOS were obtained from the medical record.

4.9.2 A guided self administered questionnaire

Questionnaire on the socio demographic factors required responses on age, sex, race, marital status, relationship with TBI patients, educational level, occupation, household income per capita and number of household members.

4.9.3 Self administered Beck Depression Inventory Malay version

The Beck Depression Inventory(BDI) has been one of the leading instruments for measuring level of depression in clinical and research domains for the past 40 years, and validated for depressed patients (cronbach- α =0.86) along with the non-clinical samples including the general population (cronbach- α =0.87)⁴⁰. The BDI Malay is the translated version which bears 20 items that provide an indication of the level of

depressed mood, whereby participants respond to questions in relation to how they have felt over the past week⁴⁷. Different scores are given for each item answered by the participants, the cumulative score will then be classified into five groups as in Table 1. In this study, those who score more than 10 were considered depressed. Permission to use the questionnaire was obtained.

4.10 Data collection

The TBI children were identified during the out-patient follow up at the neurosurgical outpatient, HUSM, from April 2010 until March 2011. The primary caregiver for each TBI child was appointed by the TBI children or the family members. The researcher explained regarding the nature of the study to the caregivers and written consent was taken. Only those who consented and fulfil the inclusion and exclusion criteria were given a set of research questionnaires. The caregivers were allowed to ask for clarification from the researcher should any problem arose upon completing the questionnaires. The medical record was reviewed for the TBI patients' factors. All the questionnaires were given identification numbers. The researcher reviewed each questionnaire to ensure completeness. For ethical purpose, those who scored more than 10 in the BDI questionnaire were advised to attend the nearest primary care clinic including HUSM for further assessment to confirm for possible depression and treatment on depression if indicated.

4.11 Statistical analysis

Data entry and analysis were done using the SPSS program for windows 18.0 version. Data were entered, reviewed for data entry error, explored and cleaned. Descriptive statistics including means and standard deviation were computed for the numerical variables. Frequencies and percentages were done for the categorical variables. Variables with small number were collapsed to form meaningful combination variable.

Objective 1 was to determine the prevalence of depression among caregivers of children following TBI. Descriptive analysis was done.

Objective 2 was to determine the associated factors for depression among caregivers. The simple and multiple logistic regressions were done. The dependent variable was depression, and the independent variables were a mixture of numerical and categorical variables as listed below;

- I. Socio-demographic factors of the caregivers
 - a. Age of caregiver
 - b. Household income
 - c. Number of household members
 - d. Sex of caregiver
 - e. Educational level
 - f. Occupation
- II. TBI patient socio-demographic and injury factors
 - a. Age of TBI patient
 - b. Duration since injury
 - c. Sex of TBI patient
 - d. Severity of injury
 - e. Outcome of injury
 - f. Mode of injury

The severity of injury was determined by the Glasgow Coma Score (GCS) on arrival to the accident and emergency department, and divided into severe and non-severe with GCS of less than 8 taken as severe and score of 8 to 15 as non severe^{25, 50}. The outcome of injury was determined by means of the Glasgow Outcome Scale which divided the outcome into five categories as summarised in Table 2⁵¹. In this study, the 5th category was taken as good outcome and 1 to 4 as poor outcome.

Table 2 The Glasgow Outcome Scale

Scale	Clinical condition
1	Death
2	Persistent vegetative state - patient exhibits no obvious cortical function
3	Severe disability - conscious but disabled
4	Moderate disability - disabled but independent
5	Resumption of normal life even though there may be minor neurological and psychological deficits.

Duration since injury was defined as the number of months from the injury sustained until the time of interview.

4.11.1 The procedure of logistic regression

The distribution and frequencies were examined. All continuous variables were expressed as mean and 95% CI. Frequency and percentage for categorical variables were calculated. Categories with small sample size and skewed distribution were noted. Meaningful combination of categories was done when indicated.

Simple Logistic Regression was used as a screening in selection of variables for further analysis. All variables with *P* value less than 0.3 and clinically significant

variables were included in Multiple Logistic Regression. This *P* value was set larger than the level of significance to allow for more important variables to be included in the model. The method that was used for variable selection was backward and forward procedure where the selection of variables were based on Wald's test. This process of deleting, refitting and verifying continued until it appeared that all the important variables were included in the model and those excluded were clinically and/or statistically unimportant. At this step, the preliminary main effect model was obtained.

All possible 2-way interactions were checked and those significant variables were included in the model. The independent variables were fitted into Multiple Logistic Regression and variance inflation factors were obtained to check for multicollinearity. Then, preliminary final model was obtained.

Fitness of the model was tested by Hosmer and Lemeshow goodness of fit test. The model was perfect fit if the *P* value approached to one. The classification table and receiver operating characteristic (ROC) curve were also used to determine the fitness of the model. The high overall percentage in the classification table and area under the curve towards one in the ROC curve showed that the model was fit. Findings were presented with crude and adjusted odds ratio (OR), 95% confidence interval (CI) and *P* value. Level of significance was set at 0.05 with two tailed fashion.

4.12 Ethical approval

The proposal of this study was presented to the ethical committee of University Sains Malaysia and received their approval on the 17th of March 2010 (Appendix 1).