



**PSYCHOSOCIAL ADJUSTMENT, SPIRITUAL WELL-BEING AND  
ASSOCIATED FACTORS AMONG PATIENTS WITH SPINAL CORD INJURY  
IN MALAYSIA**

**By**

**DANIAL ASYRAF BIN SAHARUDDIN**

**Thesis Submitted to the School of Graduate Studies, Universiti Putra  
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Science**

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Abstract of thesis presented to the Senate of Universiti Putra Malaysia in  
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**November 2022**

**Chair : Chew Boon How, PhD**  
**Faculty : Medicine and Health Sciences**

Psychosocial adjustment is a required transition process from disabled to functioning states. People with spinal cord injury (SCI) stand facing a great challenge in psychosocial adjustment after the illness. However, this is less known among people with SCI in Malaysia. This study aims to examine the level of psychosocial adjustment and its associated factors in people with SCI who are receiving follow-up care at eight public hospitals one year after disability onset. This cross-sectional survey was conducted from December 2019 to November 2020 in University Malaya Medical Centre (UMMC), Sungai Buloh Hospital, Cheras Rehabilitation Hospital, Raja Permaisuri Bainun Hospital, Penang General Hospital, Sultan Ismail Hospital, Queen Elizabeth Hospital, and Sarawak General Hospital. Eligible respondents were 18 years old and above, sustained SCI and under active follow-up at least once in the past year at the participating centres. The questionnaire package, either in paper or online form, consisted of an information sheet, a consent form, and included the following measures. The psychosocial adjustment is represented primarily as the quality of life (QoL) measured by World Health Organisation Quality of Life (WHOQOL-BREF), secondarily as the functional independence level by Spinal Cord Independence Measure – Self-rated (SCIM-SR), coping strategies by Brief Coping Orientation Problem Experienced (Brief COPE) comprises problem-focused, emotion-focused and dysfunctional-focused, quality of social support by Medical Outcome Study – Social Support Scale (MOS-SSS), and spiritual well-being which was by Functional Assessment of Chronic Illness Therapy - Spiritual (FACIT-Sp-12). Follow-up method were implemented to maximize the response rate. Data were cleaned, and missing data was replaced with multiple imputations, and analysed with multivariable analyses. The response rate was 61.3%, and after cleaning, imputation of missing data and exclusion of extreme outliers, 144 were included in the final analyses. Majority were males (68.8%), young adults (51.0%), Malay (59.7%), living with family (93.7%), completed basic education only (59.7%), unemployed (59.7%) and were on disability benefits

(57.4%). Three-quarters had SCI of traumatic origins, mainly from motor vehicle accidents (56.1%) with 75.9% have paraplegia. The median duration after SCI are 7.0 years. The mean (SD) for the total WHOQOL-BREF was 52.9 (9.26), SCIM-SR 36.8 (17.23), Brief COPE: problem-focused 15.1 (3.70), emotion-focused 26.0 (5.30) and dysfunctional-focused 20.3 (5.05), Overall Support Index of MOS-SSS 58.1 (21.44) and FACIT-Sp-12 29.1 (8.24). It is observed that older age at diagnosis with SCI reported lower QoL (adjusted B -2.9, 95% CI -5.45, -0.44). Dysfunctional-focused coping strategies had negative impact on QoL (adjusted B -0.48, 95% CI -0.80, -0.16). Oppositely, respondents with strong positive interaction support (adjusted B 0.07, 95% CI 0.00, 0.14), and higher sense of meaning and peace (adjusted B 0.57, 95% CI 0.28, 0.86) had higher health-related QoL. Psychosocial adjustment was observed to be relatively good in the current representative sample of SCI people in Malaysia, as represented by the QoL, moderate functional independence, quality social support, and spiritual well-being. The commonest coping method involves an emotional-focus coping strategy. Respondents who sustained SCI at a younger age, had more positive social interaction support, and had a strong sense of peace and purpose in life had a higher post-injury quality of life.

Abstrak tesis yang dikemukakan kepada Senat Universiti Putra Malaysia  
sebagai memenuhi keperluan untuk ijazah Master Sains

**PENYESUAIAN PSIKOSOSIAL, KESEJAHTERAAN ROHANI DAN  
FAKTOR-FAKTOR BERKAITAN DENGAN PESAKIT-PESAKIT YANG  
MENGELAMI KECEDERAAN SARAF TUNJANG DI MALAYSIA**

Oleh

**DANIAL ASYRAF BIN SAHARUDDIN**

**November 2022**

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Penyesuaian psikososial adalah sebuah proses peralihan dari keadaan kurang upaya ke keadaan berfungsi yang sangat penting. Orang yang mengalami kecederaan saraf tunjang (SCI) menghadapi cabaran besar dalam penyesuaian psikososial selepas kecederaan. Walau bagaimanapun, ini kurang dikenali kalangan orang yang mempunyai SCI Malaysia. Kajian ini bertujuan untuk mengkaji tahap penyesuaian psikososial dan faktor-faktor yang berkaitan dalam kalangan orang dengan SCI yang menerima rawatan susulan di luar hospital awam satu tahun selepas mendapat kecacatan. Kajian keratan lintang ini dilakukan dari Disember 2019 hingga November 2020 di Pusat Perubatan Universiti Malaya (UMMC), Hospital Sungai Buloh, Hospital Rehabilitasi Cheras, Hospital Raja Permaisuri Bainun Ipoh, Hospital Umum Pulau Pinang, Hospital Sultan Ismail Johor, Hospital Queen Elizabeth Sabah; dan Hospital Umum Sarawak. Peserta yang layak menyertai merupakan yang berumur 18 tahun dan ke atas, mempunyai SCI dan aktif menerima rawatan susulan sekurang-kurangnya sekali pada tahun lalu disalah satu pusat kajian yang mengambil bahagian. Pakej soal-selidik, sama ada kertas atau dalam talian, terdiri daripada lembaran maklumat, borang persetujuan, dan soal-selidik tersebut merangkumi soalan berikut: penyesuaian psikososial diwakili terutamanya sebagai kualiti hidup (QoL) yang diukur oleh Pertubuhan Kesihatan Dunia - Kualiti Hidup (WHOQOL-BREF), kedua sebagai tahap kebebasan fungsi oleh Pengukuran Tahap Kebebasan Saraf Tunjang – Perkadaran Diri (SCIM-SR), strategi mengatasi masalah oleh Brief Coping Orientation Problem Experienced (Brief COPE) merangkumi strategi berfokuskan masalah, strategi berfokuskan emosi dan strategi berfokuskan disfungsi, kualiti sokongan sosial oleh Kajian Hasil Perubatan - Skala Sokongan Sosial (MOS-SSS), dan kesejahteraan kerohanian menggunakan Penaksiran Kefungsian Terapi Penyakit Kronik – Kesejahteraan Spiritual (FACIT-Sp-12). Satu kaedah susulan telah dilaksanakan bagi memaksimumkan kadar tindak balas. Data dibersihkan, dan data yang hilang diganti dengan beberapa sangkaan dan dianalisis dengan analisis multivariabel.

Kadar tindak balas adalah sebanyak 61.3%, selepas pembersihan data, proses imputasi bagi data yang hilang dan pengeculian unsur luar yang ekstrem, data dari 144 peserta dimasukkan ke dalam analisis. Majoriti daripada peserta kajian adalah dalam kalangan lelaki (68.8%), dewasa muda (51.0%), Melayu (59.7%), tinggal bersama keluarga (93.7%), dan mempunyai pendidikan asas sahaja (59.7%); menganggur (59.7%), dan mendapat faedah hilang upaya (57.4%). Tiga perempat peserta kajian memperoleh SCI disebabkan oleh trauma, terutamanya dari kemalangan melibatkan kenderaan bermotor (56.1%) dengan 75.9% menjadi lumpuh separa. Tempoh median selepas SCI adalah 7.0 tahun. Purata (SD) untuk jumlah WHOQOL-BREF adalah 52.9 (9.26), SCIM-SR 36.8 (17.23), strategi mengatasi: berfokus kepada masalah 15.1 (3.70), berfokus kepada emosi 26.0 (5.30) dan berfokus kepada perkara tidak berfungsi 20.3 (5.05), Indeks Sokongan Kesuluruhan MOS-SSS 58.1 (21.44) dan FACIT-Sp-12 29.1 (8.24). Daripada pemerhatian, ia didapati bahawa usia yang lebih tua semasa diagnosis dengan SCI melaporkan QoL yang lebih rendah (disesuaikan B -2.9, 95% CI -5.45, -0.44). Strategi mengatasi berfokus kepada perkara tidak berfungsi mempunyai kesan negatif terhadap QoL (disesuaikan B -0.48, 95% CI -0.80, -0.16). Sebaliknya, peserta dengan sokongan interaksi positif yang kuat (disesuaikan B 0.07, 95% CI 0.00, 0.14), dan peserta yang mempunyai rasa makna dan aman yang tinggi (disesuaikan B 0.57, 95% CI 0.28, 0.86) mempunyai QoL yang lebih baik. Penyesuaian psikososial dilihat agak baik dalam sampel kajian orang SCI di Malaysia, seperti yang diwakili oleh QoL, tahap kebebasan untuk berfungsi yang sederhana, sokongan sosial yang berkualiti, dan kesejahteraan rohani. Kaedah mengatasi yang paling umum merupakan strategi yang berfokuskan emosi. Peserta yang mengalami SCI pada usia yang lebih muda, mempunyai sokongan interaksi sosial yang lebih positif, dan mempunyai rasa aman dan tujuan hidup yang kuat didapati mempunyai kualiti hidup selepas kecederaan yang lebih baik.

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This thesis was submitted to the Senate of Universiti Putra Malaysia and has been accepted as fulfilment of the requirement for the degree of Master of Science. The members of the Supervisory Committee were as follows:

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## LIST OF ABBREVIATIONS

ADL	Activities of daily living
AIS	ASIA Impairment Score
ANOVA	Analysis of variance
ASIA	American Spinal Injury Association
B40	The bottom 40% of socioeconomic ladder
CI	Confidence interval
COPE	Coping Orientation to Problems Experienced
COVID-19	Coronavirus Disease 2019
FACIT	Functional Assessment of Chronic Illness Therapy
FACIT-Sp-12	Functional Assessment of Chronic Illness Therapy - Spiritual
IBM	International Business Machines Corporation
ID	Identifier
M40	The middle 40% of socioeconomic ladder
MCO	Movement Control Order
<i>MD</i>	Mean Difference
MOS-SSS	Medical Outcome Study - Social Support Survey
MVA	Motor vehicle accidents
MYR	Malaysian Ringgit
NGOs	Non-governmental organisations
PIS	Participant information sheet
QoL	Quality of Life
REDCap SCI	Research Electronic Data Capture Spinal Cord Injury
SCIM-SR SD	Spinal Cord Independence Measure - Self-rated Standard Deviation



T20	The top 20% of socioeconomic ladder
UMMC	University of Malaya Medical Centre
UPM	Universiti Putra Malaysia
URL	Uniform Resource Locator
VIF	Variance inflation factors
WHO	World Health Organisation
WHOQOL Group	World Health Organisation Quality of Life Group
WHOQOL- BREF	World Health Organisation Quality of Life Instruments

## CHAPTER 1

### INTRODUCTION

#### 1.1 Background of the study

Adapting to a new condition may be a daunting experience for people with disability, especially if it involves significant alteration to their day-to-day life functioning and requires a tremendous amount of support from people surrounding them. This is especially apparent among people with spinal cord injury (SCI). Spinal cord injury is a complex condition resulted from either trauma or disease, or degeneration.

Each year, around 400,000 people suffer from SCI, and a considerable proportion of it is due to traumatic causes and preventable causes, i.e., motor vehicle accidents (MVA), falls or violence (Spinal cord injury, n.d.). The incidence rate of spinal cord injuries in proportion to the general population may seem to be low, but because of the nature of the condition, which is very costly and a high burden of illnesses to the person and family members make, the subject is more concerning and requires much attention from the healthcare providers.

Apart from life-changing experiences such as traumatic falls and sports injuries, people with SCI also must face challenges from many aspects of life post-injury, including health complications secondary to the injury. Past studies have noted that spinal cord injury increases the likelihood of experiencing secondary health complications such as pressure ulcers, bladder and bowel complications and musculoskeletal pain (Adriaansen et al., 2016; Craig et al., 2015). These health complications may have effects on the psychosocial functioning of people with spinal cord injury (Braaf et al., 2017; Kennedy et al., 2006). For example, a person with SCI may have a sense of diminished self-values and autonomy whenever they receive special care for the problems they are experiencing such as dressing changes for the management of pressure ulcers. This would affect the process of their psychosocial adjustment to the SCI.

Psychosocial adjustment is a process by which a person with a disability transition from a state of disablement to a state of enablement. At the final stage of the process, maximum congruence between an individual's internal experience and external environment is achieved (Chan et al., 2013). It is a dynamic process involving the psychological, social, environment and personal factors. There are three main components to psychosocial adjustment: a) background and triggering events, b) presently influencing processes and life context and c) a set of outcome indicators which mainly focuses on quality of life (intrapersonal, interpersonal and extrapersonal life domains).

## 1.2 Problem Statement

SCI can have a significant impact on multiple aspects of a person's psychosocial well-being, and the spectrum of responses a person may have can range from well-adjusted to poorly adjusted (Budd et al., 2022). People who have SCI often experience a number of psychosocial challenges as a result of the distress of recognising that a formerly active and healthy person is currently dealing with a disability (Mahooti et al., 2020). Mahooti et al. emphasised the importance of addressing and comprehending the psychosocial challenges of people with SCI in order to achieve comprehensive rehabilitation, which can be accomplished by integrating supports that may contribute to positive psychosocial adjustment into rehabilitation services (Mahooti et al., 2020). The degree to which an individual is able to psychosocially adjust to SCI influences a range of injury-related outcomes, including psychological well-being, social support and relationships, as well as overall well-being (Barone & Waters, 2012). It was concluded that secondary health difficulties, functional independence, social supports, vocation, a person's behaviours, the ways of coping post-injury, and financial and living conditions are psychosocial aspects that overlap and constantly interacting as a result of SCI (Budd et al., 2022).

In a recent study about the quality of life (QoL) and social support of people living with SCI in Switzerland, Carrard et al. established that SCI has a significant impact on the overall well-being and psychosocial resources, which highlights the need for more holistic care that emphasises the aspect of psychosocial management rather than just impatient rehabilitation (Carrard et al., 2021).

In addition, the study by Craig et al. revealed that QoL appraisal and coping strategies are important components of the adjustment process among people with SCI, and it was hypothesised that other categories of factors, such as social, environmental, and psychological factors may also influence the adjustment process (Craig et al., 2022). Strategies such as developing greater independence in self-management and adopting positive coping strategies can be utilised to promote positive appraisals of QoL; these strategies, in turn, emphasise the significance of personal responsibility and optimistic thinking (Craig et al., 2022).

A study conducted by Nizeyimana et al. observed the significant role that environmental factors—particularly employment and living situation—play in influencing the psychosocial adjustment following SCI among people with SCI in South Africa, which supports Craig et al. (2022)'s proposal that environmental factors may affect the adjustment process (Craig et al., 2022; Nizeyimana et al., 2022). Since the home is viewed as a base where people structure their sense of identity and establish ties with friends and the larger community, people with SCI who live in a more informal living situation are more likely to experience difficulties maintaining living and social skills after SCI (Nizeyimana et al., 2022).

In accordance with vocational outcomes such as employment correlated with adjustment process, a previous study among Taiwanese with SCI indicated vocational environment and social environment appeared to be problematic psychosocial adjustment aspects among the local people with SCI (Wu & Chan, 2007). However, the study discovered that employment was the only demographic characteristic that was significantly related to adjustment factors, indicating that employment alone may improve social relationships and assist people with SCI to adjust psychologically better (Wu & Chan, 2007).

In addition to the importance of QoL, social support, and environmental factors such as employment and the living situation on the adjustment process, researchers discovered that spirituality was positively associated with the well-being and facilitated in the adjustment process among people with SCI (Jones et al., 2016; Xue et al., 2016). In their study examining the relationship between spiritual well-being and resilience among people with SCI, Jones et al. discovered that spiritual well-being was positively associated with resilience, which was associated with increasing positive affect and life satisfaction (Jones et al., 2019). Jones et al. emphasised further that the incorporation of spiritual well-being support within spinal rehabilitation services could contribute to positive outcomes for the people with SCI (Jones et al., 2019).

The lack of clarity on the concept of psychosocial adjustment and guidance on managing the factors affecting it (Sandalic et al., 2022) compelled the present study to focus on psychosocial adjustment among people with SCI in the local community. Similarly, little is known about the association between spiritual well-being with the psychosocial adjustment of local people with SCI. Thus, the aim of the study was to assess the state of psychosocial adjustment of people with spinal cord injury in Malaysia as represented by QoL, functional independence, coping, quality of social support and spiritual well-being.

### **1.3 Significance of the Study**

The significance of this research is that it will provide an overall picture of the psychosocial adjustment and spiritual well-being of people with spinal cord injuries in the local setting, where there is currently a lack of evidence. It is expected that the outcomes of this study will serve as a foundation for future investigations involving people with SCI.

Knowing the psychosocial states examined in this study among people with spinal cord injury can assist healthcare providers in understanding and providing the appropriate supports and interventions to empower self-care and improve QoL of people with SCI.

The knowledge gained from this study enables for the reconstruction of a positive attitude of living with disability and the recognition that the majority of people adjust and successfully manage the related issues associated with SCI (Budd et al., 2022). Furthermore, the aim of this study is to make the rehabilitation process easier for people with SCI and to lessen the burden of SCI not only on the person but also on their family members. Ultimately, the purpose is to encourage in improving healthcare delivery for this community.

## **1.4 Research Questions**

- What is the quality of life of people with SCI in Malaysia?
- What are the factors associated with quality of life of people with SCI?
- Can people with SCI function independently post-injury?
- What are the coping strategies used by the people with SCI?
- What is the spiritual well-being of people with SCI in Malaysia?

## **1.5 Objective of the Study**

### **1.5.1 General Objective**

The general objective of the study is to determine the socio-demographic and clinical profiles of people with SCI in Malaysia and their state of psychosocial adjustment after SCI.

### **1.5.2 Specific Objectives**

This study aim to assess several components that made up the concept of psychosocial adjustment and to determine their association with socio-demographic and injury characteristics.

- To determine the quality of life of people with SCI and its independent effects by the sociodemographic and lesion profiles, and independence, coping, social support and spiritual well-being.
- To determine the functional status of people with SCI and its independent effects by the sociodemographic and lesion profiles, and quality of life, coping, social support and spiritual well-being.
- To examine the association of different coping styles of people with SCI in Malaysia and the independent effects by the sociodemographic and lesion profiles, and independence, quality of life, social support and spiritual well-being.
- To examine the association of different social support of people with SCI in Malaysia and the independent effects by the sociodemographic

and lesion profiles, and independence, quality of life, social support and spiritual well-being.

- To determine the spiritual well-being of people with SCI in Malaysia and its independent effects by the sociodemographic and lesion profiles and quality of life, independence, coping and social support.

## 1.6 Study Hypotheses

- H<sub>1</sub>*: People with SCI in Malaysia has good psychosocial adjustment, in particular has acceptable level of quality of life.
- H<sub>2</sub>*: The quality of life of people with SCI is influenced by the socio-demographic and lesion profiles; in particular influenced by the age at onset, education level, employment status, and level of injury.
- H<sub>3</sub>*: People with SCI who has high level of functional independence associated with better quality of life.
- H<sub>4</sub>*: People with SCI who employ dysfunctional-coping strategies have lower quality of life.
- H<sub>5</sub>*: Individuals with better quality of life tends to have higher level of social support and spiritual well-being.

## 1.7 Definitions of Variables

In this section, the terms are conceptually and operationally defined.

### 1.7.1 Psychosocial Adjustment

**Conceptual definition of Psychosocial Adjustment:** is the process of psychosocial response of person to significant life change (Mosby, 2017).

**Operational definition of Psychosocial Adjustment:** in the present study, psychosocial adjustment refers to the evaluation of QoL, functional independence, perceived social support, coping strategies and spiritual well-being.

### 1.7.2 Quality of Life

**Conceptual definition of Quality of Life:** is an individual's view of their situation in life in the context of the culture and value system they live in, taking into account all their goals, expectations, standards and concerns about the environment and system they live in (THE WHOQOL GROUP, 1998).



**Operational definition of Quality of Life:** in the present study, QoL refers to the sum score of 26-items from the WHO Quality of Life assessment (WHOQOL-BREF).

### 1.7.3 Functional Independence

**Conceptual definition of Functional Independence:** is an absence of necessity or dependence on another individual for one's own physical life (Mosby, 2017).

**Operational definition of Functional Independence:** in the present study, functional independence refers to sum score of 10-items from adaptation of Spinal Cord Independence Measure – Self-rated (SCIM-SR).

### 1.7.4 Coping Strategies

**Conceptual definition of Coping Strategies:** are actions or thinking processes used to deal with or change a stressful or unpleasant circumstance (American Psychological Association, 2015).

**Operational definition of Coping Strategies:** in the present study, coping strategies refers to the sum of scores for each of the three main categories of Coping Strategies, as well as the sum of scores for 14 individual coping strategies from the Brief Coping Orientation to Problem Experienced (Brief COPE).

### 1.7.5 Social Support

**Conceptual definition of Social Support:** is the providing of aid or comfort to others, often to assist them in coping with biological, psychological, and social stressors (American Psychological Association, 2015).

**Operational definition of Social Support:** in the present study, social support refers to the average scores of 18-items from the Medical Outcome Scale – Social Support Survey (MOS-SSS).

### 1.7.6 Spiritual Well-being

**Conceptual definition of Spiritual Well-being:** is described as the entirety of the theological and existential aspects of spirituality, both of which are distinct but interrelated components of spirituality (Ellison, 1983).

**Operational definition of Spiritual Well-being:** in the present study, spiritual well-being refers to the sum scores of the Functional Assessment of Chronic Illness Therapy-Spiritual Well-Being; The 12-items (FACIT-Sp-12).





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