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RESEARCH ARTICLE

The Bandung neurosurgery patient outcomes project, Indonesia (Part I): Methods, participant characteristics, and pre-discharge outcomes

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Summary

Introduction Little is known about neurosurgery patient outcomes in Indonesia. Our study sought to describe patient characteristics, health care pathways, health-related quality of life, and health/rehabilitation care needs of patients admitted to, and discharged from, a major neurosurgery department.

Methods Eligible patients were aged ≥18 years admitted to the Neurosurgery Department in a regional referral hospital in Bandung, Indonesia. Baseline data was collected on admission. An in-person interview (in the Indonesian language) was held 1 to 2 days pre-discharge. Sociodemographic along with clinical characteristics, Glasgow Coma Scale (GCS), and EQ-5D-5L data were collected.

Results A total of 217 patients were admitted, 37 died before discharge, and a pre-discharge interview was undertaken by 178 (82%). Almost half (48%) were admitted because of injury, 38% brain tumour, 10% acute illness, and 4% other conditions. The mean age was 41 years. On admission, 63% had a mild Glasgow Coma Scale, 31% moderate, and 3% severe. The average hospital stay was 8 days for injury and 24 days for illness patients. Prior to discharge, one-third, or less, of the 178 patients interviewed reported "no problems" in the EQ-5D dimensions of mobility (32%), self-care (27%), usual activities (16%), and pain/discomfort (32%), whereas 70% reported "no problems" with anxiety/depression.

Conclusion A large proportion of patients are being discharged with considerable levels of difficulty in four of the five EQ-5D dimensions. This stresses the importance of providing good follow-up and support of patients and their families.

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KEYWORDS

EQ-5D-5L, Indonesia, neurosurgery, quality of life

1 | INTRODUCTION

Internationally, there is an increasing incidence in traumatic brain injury particularly in low-income and middle-income countries (LMIC).¹ Also, while specific estimates for the burden of brain tumours in LMIC are scarce, the overall global burden of cancer continues to increase, in a large part because of ageing populations and cancer-causing behaviours.² Indonesia is one such country that is seeing an increase in the number of people with brain injury. With a population of 250 million people and recent marked economic growth, the number of people using cars and motorbikes has increased considerably contributing to an increase in road traffic injuries,^{3,4} similar to that experienced in many other Asian countries.^{5,6}

The disruption in patients' lives that occurs following some kind of brain injury or illness can be significant—potentially affecting their physical, emotional, psychological, social, and economic well-being and overall quality of life, all of which can continue for some time after the event. Various support mechanisms and services can alleviate this disruption, improve their quality of life, and hasten their return to normal everyday life and work. Knowledge about health care pathways and post-discharge outcomes are vital for effective service planning but are rarely reported in LMIC.

Dr. Hasan Sadikin Hospital (RSHS), in Bandung City, is a large 900-bed, state-funded referral hospital for the densely populated West Java Region of Indonesia. While there are a number of neurosurgeons working in general hospitals throughout the region, a key Neurosurgery Department, and accompanying intensive care unit, is located at RSHS. Patients are admitted not only for trauma resulting from road traffic crashes but also for a variety of neurovascular events such as stroke, brain tumour, or infection. A greater understanding of the characteristics of these patients and of support mechanisms that can be, or are being, effectively and efficiently undertaken is important for planning health care services. Therefore, the overall aims of our Bandung Neurosurgery Patient Outcomes Project are to describe patient characteristics, health care pathways, health-related quality of life (HRQoL), and health/rehabilitation care needs of patients admitted to, and discharged from, the RSHS Neurosurgery Department. This Part I paper aims to: (1) provide an overview of the study design, (2) describe the characteristics of patients admitted to RSHS, and (3) describe HRQoL and other characteristics of patients prior to discharge from RSHS. The companion Part II paper describes: (1) patients' pathways into RSHS, (2) pathways following discharge, and (3) the feasibility of following up this patient population by telecommunication.

2 | METHODS

2.1 | Study design

This was a prospective study with interviews undertaken with patients at discharge and again at 1, 2 and 3 months post-discharge from RSHS.

2.2 | Patient eligibility, recruitment, and study procedure

Eligible patients were aged 18 years and over and admitted to the Neurosurgery Department at RSHS from October 19, 2015, to February 17, 2016. Baseline data was collected at, or around, the time of admission from the clinical notes for all patients. After the patient had stabilised, one of the two senior neurosurgery research nurses employed in this study approached the patient to explain the study and seek their consent to participate. The interview