

Original article:

Burden of Stroke Caregivers: Evidence from a Qualitative Study in Sarawak, Malaysia

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Abstract

Background: Stroke survivors experience long-term physical, psychosocial and cognitive impairment that are formidable challenges to caregivers because caring for stroke survivors needs explicit knowledge and caregivers have to endure the stressfulness as a result of caring. In addition, little is known about perceived benefits of the stroke care giving experience.

Objectives: This study was aimed to determine the caregivers' burden and challenges as reported by caregivers of stroke survivors. **Materials and Methods:** This was a cross-sectional study involving 18 stroke caregivers. The data were collected from November 2015 to June 2016 at a conveniently selected community rehabilitation centre in Kuching, Sarawak. **Results:** The qualitative data analysis revealed that the burden was aggravated by financial problems, multiple responsibilities hold by the caregivers, behavioural changes of the stroke survivors and lack of social support during care giving. **Conclusion:** This study highlighted the experiences by the caregivers in caring for the stroke survivors that focused on the different needs of the caregivers. Understanding these experiences may help the service providers to provide better support and resources for caregivers in caring for stroke survivors.

Keywords: Burden; Caregivers; Qualitative; Stroke; Sarawak; Malaysia

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Introduction

The operational definition of stroke was a rapidly developing sign of focal disturbance of cerebral function lasting more than 24 hours with no apparent non-vascular cause¹. Stroke is the third most common cause of death in developed countries, after coronary heart diseases and cancers. Three million women and 2.5 million men die from stroke every year worldwide². Annually, each 15 million people

worldwide suffer from stroke. Out of 15 million people, 5 million die and another 5 million are left permanently disabled causing a burden on family and community². The incidence and prevalence rates of stroke are decreasing in developed countries, but an opposite trend is taking place in the Asia Pacific, where an increasing number of patients are being diagnosed with acute stroke³. Some of the reasons that the incidence of stroke is declining in many

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