

# Quality of Life and its associated factors among caregivers of patients with dementia – A cross-sectional study in Kuching, Sarawak, Malaysia

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## Abstract

**Background:** This study aimed to determine the quality of life and its associated factors among caregivers of patients with dementia in Kuching, Sarawak, Malaysia. **Methods:** This cross-sectional study was carried out among caregivers for dementia patients who visited three main hospitals in Kuching, Sarawak. Using a validated questionnaire, data was obtained based on socio-demographic profile, patient and caregiving characteristics, supports needs by caregivers, and quality of life (QoL) of caregivers modified from Zarit Burden Interview (ZBI), Hospital Anxiety and Depression Scale (HADS) and Evaluation's Scale of the Caregiver's QoL. **Results:** A total of 217 caregivers participated with response rate of 99.6%, with 67.3% female and 63.1% Chinese. Most respondent provide care for their parents (62.7%), and stay with patients (67.3%). Average duration of care was 4.2 years (SD±3.72). Resource referral (M=3.52, SD±1.334) and education support (M=3.67, SD±1.054) was highest need. Majority respondents experienced little to no burden (59%). Most respondents were not depressed (98.1%). The QoL of respondents was satisfactory (M=41.36, SD±25.840). Gender of caregivers, patients with behavioural and psychological symptoms of dementia, duration of caregiving, respite care need, caregiver disability or illness, belonging support need, education support need were significantly associated with QoL of caregivers ( $p < 0.05$ ). **Conclusion:** This study on QoL of caregivers of dementia patients in Sarawak, Malaysia shows that it can be influenced by many factors, both at the caregivers' level as well as the patients themselves. Therefore, intervention should aim at patients and their caregivers, and within community and healthcare settings.

**Keywords:** quality of life, dementia, caregiving, support needs, Sarawak, Malaysia

## INTRODUCTION

Dementia is a collective symptom or a syndrome of neurodegenerative diseases, in which there is a deterioration in cognitive function.<sup>1</sup> It is usually chronic and progressive in nature, and often disrupts a person's Activity of Daily Livings (ADLs).<sup>1</sup> There are many causes of dementia - infective and reversible type or non-infective and irreversible in nature.<sup>2</sup> The risk of getting dementia is still under rigorous study, but experts generally advised to counter risk of vascular disease such as in many other Non-Communicable Diseases (NCDs).<sup>3</sup> The clinical presentation of dementia may differ depending on its type especially in the early stage. However, memory loss and increasing dependency on caregivers are almost exclusive features at later stage.<sup>1</sup> According to Ministry of Health Malaysia<sup>4</sup>, 15% of people with

dementia have a potentially treatable cause, but the prevalence of reversible dementia is only 1%. Therefore, the non-infective cause of dementia is a more concerned issue as it is the major cause of increasing in Disability-Adjusted Life-Years (DALYs) and contributes to the burden in medical care or even the society.<sup>5</sup>

Like in many other countries, Malaysia has deinstitutionalized its mental health care since the 1970s, focusing on community based healthcare.<sup>6</sup> Apart from empowering the people with the knowledge regarding the diseases, patients were slowly reintroduced into the society provided they were stable enough. The care of patient then falls partly into the hand of the informal caregivers who are closest to the patients. However, these caregivers may not be ready or well-trained to cope with the task as professional health care providers.

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