

**EXPLORING THE BURDENS, EXPERIENCES, AND COPING STRATEGIES
OF MALAYSIAN FAMILY CAREGIVERS ATTENDING PUBLIC
REHABILITATION CENTRES DURING THE COVID-19 PANDEMIC**

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UNIVERSITI SAINS MALAYSIA

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By

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DECLARATION

I, Muhammad Iqbal, hereby declare that this is the result of my determined and independent hard work originality-based research project, unless where due to reference is made. All information that is required in this study obtained from appropriate reported and acknowledged sources, and that this document previously is not addressed entirely or partly, or concurrently submitted to any university for academic qualification.



Muhammad Iqbal Bin Haji Mukhti

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LIST OF ABBREVIATIONS

COVID-19	Coronavirus disease 2019
HRPZ II	Hospital Raja Perempuan Zainab II
MCO	Movement Control Order
nCOV	Novel coronavirus
PdPR	Pengajaran dan Pembelajaran di Rumah
SARS-CoV-2	Severe acute respiratory syndrome coronavirus 2
S.O.P	Standard Operating Procedure
USM	Universiti Sains Malaysia
WHO	World Health Organization

ABSTRAK

MENEROKA BEBANAN, PENGALAMAN DAN STRATEGI MENGATASI OLEH KELUARGA PENJAGA PESAKIT STROK DI MALAYSIA YANG HADIR KE PUSAT REHABILITASI AWAM KETIKA PANDEMIK COVID-19

Pengenalan: Pesakit strok bergantung kepada penjaga, sama ada secara keseluruhan atau separa dalam melakukan aktiviti seharian mereka. Tugas menjaga pesakit kronik yang sedia ada dikendalikan sepenuhnya oleh ahli keluarga pesakit yang diakui lebih mencabar dalam dimensi yang berbeza. Sementara ahli keluarga penjaga bergelut untuk mengatasi situasi tersebut, kehadiran pandemik COVID-19 yang bermula di Bandar Wuhan, Wilayah Hubei, China pada akhir Disember 2019 dan seterusnya merebak ke pelbagai negara yang akhirnya pada 25 Januari 2020 kes pertama di Malaysia telah dilaporkan membabitkan tiga warganegara China masuk ke Malaysia melalui Johor dari Singapura. Hal ini telah membawa kepada impak negatif atau mungkin sesetengahnya adalah impak positif terhadap ahli keluarga penjaga pesakit strok. Sebagai kesannya, tindakan daripada ahli keluarga penjaga untuk menghadapi keadaan krisis yang tidak pernah terjadi seperti ini adalah penting sebagai penanda aras terhadap peranan penjagaan pesakit yang mampan untuk jangka masa yang panjang dan dapat menentukan kesan kesihatan kepada pesakit strok pada masa depan. Sehingga kini, terdapat hanya sedikit penyelidikan yang diterbitkan di peringkat antarabangsa dan dalam negara terutamanya kajian di dalam bentuk kualitatif mengenai keluarga yang menjaga pesakit strok sewaktu tempoh pandemik COVID-19.

Tujuan: Kajian ini bertujuan meneroka impak pandemik COVID-19 terhadap keluarga penjaga pesakit strok di bawah kendalian pusat rehabilitasi awam di Kota Bharu, Kelantan dengan tujuan-tujuan tertentu iaitu; i) untuk meneroka bebanan dan pengalaman yang dilalui oleh ahli keluarga penjaga pesakit strok di Kota Bharu, Kelantan dalam menjaga pesakit strok semasa tempoh pandemik COVID-19, dan ii) meneroka strategi untuk mengatasi yang diambil oleh keluarga penjaga pesakit strok di Kota Bharu, Kelantan dalam menghadapi kesukaran sewaktu menjaga pesakit strok di dalam tempoh pandemik COVID-19.

Metodologi: Kajian kualitatif ini dijalankan bermula pada November 2020 sehingga Jun 2021 menggunakan pendekatan fenomenologi dan dibentuk daripada temubual yang mendalam berdasarkan panduan soalan penyelidikan dan melibatkan pengambilan responden sehingga tiada data baru yang dihasilkan. Jumlah keseluruhan responden yang dipilih adalah seramai 13 orang ahli keluarga penjaga pesakit strok yang menjaga pesakit strok di mana pesakit strok adalah yang telah didaftarkan di bawah dua pusat rehabilitasi awam di Kota Bharu, Kelantan iaitu Hospital Raja Perempuan Zainab II (HRPZ II) dan Hospital Universiti Sains Malaysia (Hospital USM). Pensampelan bertujuan dengan teknik variasi maksimum telah digunakan untuk mengenalpasti responden yang berpotensi mewakili perbezaan umur, jantina, etnik, tahap pengajian, status pekerjaan, dan hubungan di antara responden dengan pesakit strok melalui senarai nama yang telah disediakan dalam populasi kajian. Sesi temubual diadakan semasa responden menghadiri temujanji susulan, berlangsung dalam dialek Melayu *Kelantan* dan dirakam menggunakan pita rakaman suara. Enam langkah analisis tema digunakan untuk menganalisa data yang telah dikumpulkan di dalam kajian ini.

Keputusan: Tiga tema berkaitan bebanan dan pengalaman yang dihadapi oleh ahli keluarga penjaga pesakit strok semasa tempoh pandemik COVID-19 telah dikenalpasti iaitu; i) isu-isu sedia ada yang semakin memburuk, ii) kemunculan isu-isu baru, dan iii) kurangnya bebanan dan cabaran. Sementara itu, sub-tema untuk isu-isu sedia ada yang semakin memburuk adalah; i) kekurangan kehidupan untuk bersosial, ii) bebanan kerja rasmi, dan iii) kepadatan jadual temujanji. Manakala sub-tema untuk kemunculan isu-isu baru adalah; i) kekangan pergerakan harian, ii) perubahan dalam perkhidmatan kesihatan, iii) kekangan pelaksanaan Prosedur Operasi Standard (S.O.P), iv) peranan tambahan untuk menjaga pesakit strok, v) kekangan sokongan individu dan vi) kekangan kewangan. Selain daripada itu, sub-tema untuk kurangnya bebanan dan cabaran adalah seperti yang telah disenaraikan; i) penambahbaikan dalam isu logistik hospital dan ii) pengukuhan hubungan kekeluargaan. Sementara itu, dua tema dikenalpasti sebagai strategi untuk mengatasi telah diambil oleh ahli keluarga penjaga pesakit strok dalam menghadapi kesukaran menjaga pesakit strok sewaktu pandemik COVID-19 adalah; i) penglibatan yang berfokus pada masalah dan ii) penglibatan yang berfokus pada emosi. Tiga sub-tema di bawah tema penglibatan yang berfokus pada masalah adalah; i) mengadaptasi sokongan yang sedia ada, ii) mengadaptasi perubahan dalam perkhidmatan kesihatan dan iii) kebenaran untuk bergerak semasa tempoh pandemik. Berbeza dengan hal demikian, tema penglibatan yang berfokus pada emosi menyenaraikan dua sub-tema iaitu; i) kepatuhan kepada S.O.P norma baru yang ketat, dan ii) respon pasif terhadap bebanan dan cabaran menjaga pesakit.

Penutup: Berdasarkan penemuan melalui kajian ini, kita dapat memiliki kefahaman yang lebih baik mengenai kesan pandemik terhadap bebanan dan cabaran yang dihadapi oleh

ahli keluarga penjaga pesakit strok melalui pembuktian dan apakah strategi untuk mengatasi yang diambil oleh mereka untuk menghadapi kesulitan. Ianya dapat disimpulkan dalam beberapa cara; i) isu-isu yang telah pun sedia ada semakin memburuk dengan kehadiran pandemik, ii) kemunculan isu-isu baru yang dialami dengan pelaksanaan langkah-langkah pencegahan yang diambil oleh kerajaan termasuklah perintah kawalan perjalanan, pelaksanaan S.O.P, pengadaptasian dalam sektor kesihatan, dan kesan berantai oleh pandemik terhadap penentu luaran yang akhirnya memberi kesan kepada ahli keluarga penjaga pesakit strok dan sebaliknya iii) impak positif yang diperoleh secara tidak langsung daripada tindakan kawalan yang diambil. Sementara itu, bagi strategi untuk mengatasi, kedua-duanya iaitu penglibatan yang berfokus pada masalah dan penglibatan yang berfokus pada emosi lebih banyak tertumpu pada isu-isu baru yang muncul berbanding menyelesaikan isu-isu sedia ada yang semakin memburuk. Beberapa usaha telah diambil dibawah strategi masalah berfokus tetapi hanya perasaan penerimaan yang dikaitkan dengan emosi berfokus dalam menghadapi bebanan dan kesukaran sepanjang tempoh pandemik.

Kata kunci: COVID-19, ahli keluarga penjaga, strok/angin ahmar, bebanan, cabaran, pengalaman, strategi untuk mengatasi, pusat rehabilitasi awam.

ABSTRACT

EXPLORING THE BURDENS, EXPERIENCES, AND COPING STRATEGIES OF MALAYSIAN FAMILY CAREGIVERS ATTENDING PUBLIC REHABILITATION CENTRES DURING THE COVID-19 PANDEMIC

Introduction: Stroke survivors are completely or partially reliant on their caretakers for routine daily activities. The existing chronic disease patient caregiving tasks are solely carried out by family carers, which were acknowledged to be more challenging in different dimensions. Whilst family caregivers are struggling to cope with the situation, the presence of the COVID-19 pandemic, which was started from Wuhan City, Hubei Province, China at the end of December 2019 and subsequently, spread to the various countries which eventually lead to the first case of COVID-19 reported in Malaysia at 25th January 2020 involving three Chinese peoples from Singapore that was entered to Malaysia via Johor. This situation certainly brought negative impacts or probably some positive impacts to the family caregivers. As the consequences, the reactions from family caregivers to compensate during the unprecedented crisis do matter as the benchmark of the caregiving role to sustain in the long-term run, hence establishing the health outcome of the stroke survivors in the future. To date, there has been deficient research published, particularly in qualitative design, on stroke family caregiving during the COVID-19 pandemic either internationally, or locally, Malaysia.

Objectives: This study was aimed to explore the impact of the COVID-19 pandemic on stroke family caregivers attended the public rehabilitation centres in Kota Bharu, Kelantan

with specific objectives derived; i) to explore the burdens and experiences faced by family caregivers in Kota Bharu, Kelantan during the COVID-19 pandemic while caregiving for the stroke patients and ii) to explore the coping strategies taken by family caregivers in Kota Bharu, Kelantan in dealing with the difficulties of stroke caregiving during the COVID-19 pandemic.

Methodology: This qualitative study was used a phenomenological approach, conducted from November 2020 until June 2021, and designated from the in-depth interview guide research questions involving the recruitment of respondents until no new data generated. The total respondents of 13 family caregivers who cared for the stroke patients were selected whereby the stroke patients were registered under two public rehabilitation centres in Kota Bharu, Kelantan namely Hospital Raja Perempuan Zainab II (HRPZ II) and Hospital Universiti Sains Malaysia (Hospital USM). Purposive sampling with maximum variation technique was applied to identify the potential respondents representing different ages, sex, ethnicity, educational level, employment status, and relationships to the stroke patient through the list name of the study population. The interviews were set up during respondent's follow-up appointments, established in the *Kelantanese* Malay dialect, and recorded via digital voice recorders. The six steps of thematic analysis were used to analyze the collected data in this study.

Results: Three themes were identified with regards to the burdens and experiences faced by the family caregivers during the COVID-19 pandemic; i) worsening pre-existing issues, ii) emerging of new issues, and iii) less burdens and challenges. Whereas the subthemes for worsening pre-existing issues were; i) defect social life, ii) burdens of formal duty, and iii) tight appointment schedule. As for emerging of new issues were; i)

defect in daily mobility, ii) changes in healthcare services, iii) limitation in strict Standard Operating Procedure (S.O.P), iv) extra role of cares on patient, v) constraints of supportive persons, and vi) financial constraints. On the other hand, the subthemes for less burdens and challenges as listed; i) improvement in hospital logistic issues and ii) strengthening the family bonding. Meanwhile, two themes were recognized as the coping strategies taken by the family caregivers in dealing with difficulties of caregiving during the COVID-19 pandemic; i) problem-focused engagement and ii) emotion-focused engagement. There were three subthemes beneath the problem-focused engagement theme; i) adapting the available support, ii) adaptation to the changes of healthcare services, and iii) permission to mobilize during the pandemic. In contrast, the emotion-focused engagement theme was listed the two subthemes that were; i) the obedience to the strict S.O.P of new norms and ii) passive response to the burdens and challenges of caregiving.

Conclusions: Based on the findings from this study, we can have a better understanding of the evidence-based pandemic impact on the burdens and challenges faced by family caregivers and what were the coping strategies taken in dealing with the difficulties. It is best concluded in several ways; i) the pre-existing issues were worsening with the existence of the pandemic, ii) the emerging of new issues experienced with the execution of control measures taken by the government including travel restriction order, the implementation of S.O.P, the adaptation made by health sectors, and the chain effects of the pandemic upon external determinants that eventually affected the caregivers, and in contrast iii) the positive impacts derived indirectly from the action of measures taken. Meanwhile, as for coping strategies, both problem and emotion-focused engagement were

rather focusing on the new issues that emerged as compared to solve the worsening pre-existing issues. Few attempts were taken under the problem-focused strategies but only a feeling of acceptance associated with the emotion-focused in facing the burden and difficulties during the pandemic.

Keywords: COVID-19, family caregivers, stroke, burdens, challenges, experiences, coping strategies, public rehabilitation centres.

CHAPTER ONE:

INTRODUCTION

1.1 Introduction

With such comprehensive and continuous care required throughout the individual's life-course encountered upon acute and chronic presentation of stroke, it is well understood that the burden of stroke is not limited and confined only to the stroke patient but extends far beyond specific local circles of people involving family institutions, communities, nationwide, and undeniably to the global across countries. Moreover, the presence of any situation that resulting in humanitarian crisis such as war, urbanization, migration, starvation, drought, climate change as well as what is the world currently faced with - the pandemic of infectious disease COVID-19 - would certainly bring a major impact to the burden of stroke locally and globally in a short period of time and last for the long-term run. In this chapter, the researcher attempted to view the burden of stroke in the global context, subsequently narrowing it down to more concerning on the local context in Malaysia and the relation of stroke burden with the pandemic of COVID-19.

1.1.1 Global burden of stroke

Globally, since the early 90s, stroke has been a significant and persistent leading cause of early death, ranked the third-most in 2017, and is expected at second-most after ischemic heart disease in 2040 (Institute for Health Metrics And Evaluation, 2018). World Health Organization (WHO) stated stroke as the second most global cause of death from 2000 to 2016, persistently ranked second most causes of death in 2016 among high-income

countries, lower and upper-middle-income countries, but yet significant fifth in low-income countries (World Health Organization, 2018). Stroke was declared the second-leading cause of mortality in the Global Burden of Diseases, Injuries, and Risk Factors Study (GBD) in 2016, with 5.5 million deaths and 116.4 million disability-adjusted life years (DALYs) reported globally. And in the same year, 13.7 million new stroke cases were reported, with an overall prevalence of 80.1 million cases. As for the global trend from 1990 to 2016, the age-standardised rate of deaths, DALYs, and incidence declined by 36.2%, 34.2%, and 8.1% respectively in all Socio-demographic Index (SDI) quintiles. However, in contrast to age-standardised incidence, the East-Asia has shown an increment by 4.9%, thus manifest the overall burden of stroke as relatively significant throughout the years (GBD 2016 Stroke Collaborators, 2019).

1.1.2 Burden of stroke in Malaysia

In Malaysia particularly, the trend of mortality rate was increasing throughout the years of 2010 till 2016 as stated in Annual Report of The Malaysian Stroke Registry 2009-2016 (Aziz *et al.*, 2016). Stroke was placed on the third most premature death in 2017 and ranked similarly on the common cause of death in 2019. Nevertheless, stroke reflects the second most as combining death (years of life lost) and disability (DALYs) after ischemic heart disease (Institute for Health Metrics And Evaluation, 2019). The prevalence of stroke in Malaysia was 0.7% (20,966 cases) as implies by National Health Morbidity Survey 2011 (Volume III). Meanwhile, Kelantan was positioning as the sixth state with most stroke cases reported across Malaysia; 1,338 cases or equivalent to 0.5% prevalence rate (Institute for Public Health, 2012).

Nevertheless, with regard to the recent local study conducted, there were 14,396 stroke cases reported across 11 states in Malaysia from 2012 till March 2019. The geo-spatial distribution of most stroke cases was disclosed over East Coast Peninsular (Kelantan and Terengganu), Northern Region (Pulau Pinang, Kedah, and Perlis) and Southern Region (Negeri Sembilan). Terengganu rated as “*red alert*” as it has the highest stroke count in Malaysia with 6,744 cases were noted whilst Kelantan ranked in the top four states with 1,620 cases after Sarawak (2,340 cases) and Pulau Pinang (1,754 cases) (Ganasegeran *et al.*, 2020).

1.1.3 The COVID-19 pandemic and stroke

Coronavirus disease 2019 (COVID-19) or currently called severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2; formerly called 2019-nCoV) is an illness caused by a novel pathogen that was first identified from an outbreak of respiratory illness in Wuhan City, Hubei Province, China, and reported to WHO on December 31, 2019 (David J Cennimo, Scott J Bergman, 2020; World Health Organization, 2020b). Sooner, the virus outbreak was declared as a public health emergency of international concern (PHEIC) on January 30, 2020 (World Health Organization, 2020c). Shortly afterward, a global pandemic concerning COVID-19 was announced by WHO on March 11, 2020 (World Health Organization, 2020e). The number of new cases and deaths has continued to grow, with roughly 4 million new cases and 60,000 new fatalities recorded in the most recent epidemiological week (9 to 15 November 2020). Cumulatively throughout worldwide, as of 18th June 2021, 177 million confirmed cases and 3.8 million deaths involving more than

220 countries, areas, or territories have been reported to WHO (World Health Organization, 2021).

As stroke carries high burden via the inclining trend of mortality, and morbidity rate globally, specifically in Malaysia and Kelantan particularly, hence it brings together the significant challenges upon stroke healthcare systems, healthcare providers, government, stroke survivors, family caregivers, and other stakeholders. Most of the daily living activities of stroke survivors highly depend on family caregivers thus contributing to the high burden among this group. In fact, the presence of COVID-19 pandemic leading to a crucial impact on stroke caregiving management including treatment, and rehabilitation processes of stroke survivors especially in relation with Movement Control Order (MCO). Malaysia's countrywide Restriction of Movement Order was first imposed on March 18, 2020, as a means to effectively manage disease transmission under the Control and Prevention of Infectious Diseases Act 1988 and the Police Act 1967 (Gill *et al.*, 2020; Prime Minister's Office of Malaysia, 2020). The management of stroke patients required a patient to go through regular and constant follow up at the rehabilitation centre, thus by the implementation of MCO; limits the patient's movement to seek appropriate and effective medical attention, the necessity of continuation therapy to be rescheduled back, and the attendance visit at rehabilitation centre to be restricted in order to control the exposure, contact, and crowd in confined space. By improving the psychosocial well-being of family caregivers, leading to the seeking treatment in a timely manner during acute presentation and sustain rehabilitation care even with the current and future pandemic crisis, thus the quality of stroke survivor's life enhanced by the augmentation of the stroke healthcare services quality during the pandemic.

Therefore, this study is mainly conducted with the general aim to explore the impact of COVID-19 pandemic on caregiving of stroke patients in Kelantan's rehabilitation centre with specific objectives derived; *i) exploring the possible barriers faced by family caregivers of the stroke patient, and ii) exploring the coping strategies that were taken to overcome the difficulties experienced during the pandemic.* Retrospectively, the abundance of research has been conducted abroad to dismantle the direct and indirect chain effects of stroke burden on stroke survivors, stroke healthcare system, and healthcare providers in general condition and particularly in relation to COVID-19 pandemic. However, with regards to the burden of stroke on family caregivers, researchers had been discussing mostly in the accustomed situation. As for the local studies that have been conducted previously only confined to the ordinary scene as references. Despite several studies proved the significant decline of stroke admissions during period of the COVID-19 pandemic, yet the findings are not depicted on the behind's reason. Thus, there are very limited resources that published, discussing on stroke burden of family caregivers during the period of the COVID-19 pandemic especially in Malaysia and the peninsular east coast, Kelantan specifically.

1.2 Problem statement

The countrywide implementation of the MCO is an effective approach for breaking the COVID-19 transmission chain. To present, the Malaysian government has indicated three key phases of MCO: MCO 1.0 on March 18, 2020, MCO 2.0 on January 13, 2021, and MCO 3.0 on June 1, 2021. The approach purposely limits the public movement, shuts down many industries, offices, and schools, thus establish the physical distancing and