TRANSLATION AND VALIDATION OF ADULT CARER QUALITY OF LIFE (AC-QoL) QUESTIONNAIRE AND MEDIATION ANALYSIS OF DEPRESSION, ANXIETY AND STRESS ON QUALITY OF LIFE OF INFORMAL CAREGIVERS OF STROKE SURVIVORS IN KELANTAN

By

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List of Symbols

n - Sample size

p - Probability of success in a binomial trial

r - Pearson correlation coefficient

R^2 - Coefficient of determination

α - Cronbach's alpha (reliability coefficient)

β - Standardized beta coefficient in regression

$\leq$ - Less than or equal to

$\geq$ - Greater than or equal to

χ^2 - Chi-square statistic

df - Degrees of freedom

List of Abbreviations

AC-QoL - Adult Carer Quality of Life Questionnaire

AGReMA – A Guideline for Reporting Mediation Analyses

BIBLIO - Bibliometric Analysis Guideline

CVI - Content Validity Index

CVA - Cerebrovascular Accident

FVI - Face Validity Index

HRQOL - Health-Related Quality of Life

ICC - Intraclass Correlation Coefficient

I-CVI - Item-level Content Validity Index

I-FVI - Item-level Face Validity Index

MBI - Modified Barthel Index

MeSH - Medical Subject Headings

mRS - Modified Rankin Scale

QoL - Quality of Life

R - R programming language

S-CVI/Ave - Scale Content Validity Index Averaging Calculation Method

S-FVI/Ave - Scale Face Validity Index Averaging Calculation Method

TIPPS - Tabung Insentif Pembangunan Pengajian Siswazah

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Abstrak

Pengenalan: Seiring dengan penuaan populasi global dan peningkatan kadar penyakit kronik, peranan penjaga telah menjadi semakin ketara dan hal ini mendorong minat yang semakin tinggi untuk memahami kualiti hidup (QoL) mereka. Penjaga pesakit strok menghadapi cabaran dan ganjaran yang unik, mempengaruhi QoL mereka.

Objektif: Untuk menentukan ciri-ciri penerbitan mengenai QoL penjaga melalui analisis bibliometrik, menterjemah dan mengesahkan Soal Selidik Kualiti Hidup Penjaga Dewasa (AC-QoL) dalam versi Bahasa Malayu, memodelkan hubungan antara faktor faktor penjaga tidak formal dan faktor faktor pesakit strok dengan QoL penjaga tidak formal dan menganggar kesan perantara kemurungan, kebimbangan, dan tekanan.

Bahan dan Kaedah: Data bibliografi diekstrak dari pangkalan data Scopus menggunakan kata kunci seperti “penjaga” dan “kualiti hidup”. Analisis termasuk artikel asal atau ulasan dalam bahasa Inggeris hingga Ogos 2023, menggunakan pakej 'bibliometrix' dalam RStudio. Kajian kedua adalah kajian keratan rentas yang menterjemah AC-QoL ke dalam Bahasa Melayu melalui sepuluh langkah. Pengesahan kandungan dan muka masing-masing dilakukan dengan enam pakar dan sepuluh subjek. Analisis faktor pengesahan (CFA) dilakukan pada data dari 222 penjaga tidak formal. 60 penjaga tidak formal diuji semula untuk kestabilan soal selidik. Kajian ketiga, satu lagi kajian keratan rentas, menganalisis data dari 250 penjaga tidak formal. Model regresi linear digunakan untuk memodelkan hubungan antara faktor faktor pesakit strok dan faktor faktor penjaga tidak formal dengan QoL penjaga tidak formal. Model 4 dalam Hayes PROCESS makro untuk pengambilan sampel berulang dengan kesan tidak langsung digunakan bagi menganggar kesan perantara kemurungan, kebimbangan, dan tekanan.

Keputusan: Sejak 1989, 1859 artikel penyelidikan asal dan ulasan telah diterbitkan, dengan kadar pertumbuhan tahunan sebanyak 15.52%. Amerika Syarikat mendahului dengan penerbitan terbanyak (327), petikan (9993), dan aktiviti kolaborasi. Kata kunci utama termasuk “kemurungan”, “kebimbangan”, “strok”, “dementia”, “kanser”, dan “beban”. Kluster untuk “kemurungan”, “kebimbangan”, “kanser”, dan “penjaga keluarga” mendominasi penyelidikan semasa, manakala “dementia” dan “penyakit Alzheimer” adalah topik yang sedang meningkat naik. Dalam kajian kedua, kesahihan kandungan menunjukkan keperluan untuk menyusun semula dua item. Kesahan muka adalah tinggi untuk semua item. CFA mencadangkan penyingkiran empat item kerana beban faktor yang rendah, dan ini menghasilkan model dengan indeks yang memuaskan: CFI (0.889), TLI (0.877), RMSEA (0.066), dan SRMR (0.064). Kebolehpercayaan komposit berkisar antara 0.77 hingga 0.91. Perbezaan signifikan diperhatikan dalam skor QoL dalam kalangan penjaga tidak formal dengan pelbagai tahap kemurungan, kebimbangan, dan tekanan. Soal selidik menunjukkan kestabilan yang baik (ICC = 0.86). Dalam kajian ketiga, kebergantungan pesakit strok (b = 0.14), kemurungan penjaga tidak formal (b = -0.81), dan kebimbangan (b = -0.73) secara signifikan berkait dengan QoL penjaga tidak formal. Kemurungan (kesan = 0.02) dan kebimbangan (kesan = 0.01) menjadi perantara separa di dalam hubungan antara kebergantungan pesakit strok dan QoL penjaga tidak formal.

Kesimpulan: QoL penjaga tidak formal sangat dipengaruhi oleh tuntutan penjagaan, terutama bagi pesakit strok. Analisis bibliometrik menunjukkan landskap penyelidikan yang berkembang, manakala pengesahan AC-QoL menyediakan instrumen yang boleh dipercayai untuk menilai QoL penjaga tidak formal di Malaysia. Analisis mediasi menekankan peranan signifikan tekanan psikologi, khususnya kemurungan dan kebimbangan, dalam memodulasi kesan kebergantungan pesakit strok terhadap QoL penjaga tidak formal. Penemuan-penemuan ini menekankan keperluan untuk saringan dan intervensi yang bersasar untuk mengurangkan beban psikologi penjaga tidak formal, akhirnya meningkatkan kualiti hidup mereka.

Kata Kunci: Penjaga, Kualiti Hidup, Kemurungan, Kebimbangan, Tekanan, Strok

Abstract

Introduction: As the global population ages and the prevalence of chronic illnesses rises, the demand for caregivers has grown substantially, prompting increased interest in understanding caregivers' quality of life (QoL). Caring for stroke survivors presents unique challenges and rewards, impacting caregivers' QoL.

Objectives: To determine the characteristics of publications on caregivers' QoL through bibliometric analysis, to translate and validate the Malay version of the Adult Carer Quality of Life Questionnaire (AC-QoL), to model relationships between informal caregivers' and stroke survivors' factors with informal caregivers' QoL and to estimate the mediation effects of depression, anxiety, and stress.

Materials and Methods: Bibliographic data were extracted from the Scopus database using terms like “caregivers” and “quality of life”. The analysis included original articles or reviews in English up to August 2023, utilizing the 'bibliometrix' package in RStudio. The second study was a cross-sectional study that translated the AC-QoL into Malay through a ten-step process. Content and face validation were conducted with six experts and ten subjects, respectively. Confirmatory factor analysis (CFA) was performed on data from 222 informal caregivers. 60 informal caregivers were subjected for retesting for stability. The third study, another cross-sectional study, analysed data from 250 informal caregivers. Linear regression modelled relationships between stroke survivors' and informal caregivers' factors with informal caregivers' QoL. Hayes's PROCESS macro model 4 for bootstrapping indirect effects was used to estimate the mediation effects of depression, anxiety, and stress.

Results: Since 1989, 1859 original research articles and reviews were published, with a 15.52% annual growth rate. The USA led with the most publications (327), citations (9993), and collaboration activity. Key keywords included “depression”, “anxiety”, “stroke”, “dementia”, “cancer”, and “burden”. Clusters for “depression”, “anxiety”, “cancer”, and “family caregivers” dominated current research, while “dementia” and “Alzheimer's disease” are emerging topics. In the second study, content validity indicated rephrasing for two items. Face validity was high for all items. CFA suggested removing four items due to low factor loading, resulting in a model with satisfactory indices: CFI (0.889), TLI (0.877), RMSEA (0.066), and SRMR (0.064). Composite reliability ranged from 0.77 to 0.91. Significant differences were observed in QoL scores among informal caregivers with varying levels of depression, anxiety, and stress. The questionnaire showed good stability (ICC = 0.86). In the third study, stroke survivors’ dependency (b = 0.14), informal caregivers’ depression (b = -0.81), and anxiety (b = -0.73) were significantly associated with informal caregivers’ QoL. Depression (effect = 0.02) and anxiety (effect = 0.01) partially mediated the relationship between stroke survivors’ dependency and informal caregivers’ QoL.

Conclusion: Informal caregivers' QoL is profoundly influenced by the demands of caregiving, particularly for stroke survivors. The bibliometric analysis highlights the evolving research landscape, while the validation of the AC-QoL provides a reliable tool for assessing informal caregivers' QoL in Malaysia. The mediation analysis underscores the significant role of psychological distress, specifically depression and anxiety, in modulating the impact of stroke survivors’ dependency on informal caregivers' QoL. These insights emphasize the necessity for targeted screening and interventions to alleviate informal caregivers' psychological burdens, ultimately enhancing their quality of life.

Keywords: Caregivers, Quality of Life, Depression, Anxiety, Stress, Stroke

CHAPTER 1

Introduction

1.1 Background of Stroke

Stroke is defined as a focused (or, in some cases, global) neurological impairment that occurs suddenly, lasts longer than 24 hours (or results in death), and is thought to be of vascular origin (World Health Organization, 2006). Stroke is associated with a significant risk of mortality and disability. Survivors may endure visual and/or speech loss, paralysis, and bewilderment. Stroke incidence is decreasing in many developed countries, owing primarily to better treatment of high blood pressure and lower smoking rates. The mortality associated with stroke is also reducing in trend. Indirectly, this has led to more people with disabilities (Fang *et al.*, 2014). Every year, 15 million individuals worldwide suffer from a stroke. 5 million of these people die, and another 5 million are permanently crippled, putting a strain on families and society (World Health Organization, 2022).

In Malaysia, stroke incidence has been increasing over recent years with a reduction in mortality as well (Hwong *et al.*, 2021). Malaysia has implemented stroke rehabilitation programmes that are hospital-based and staffed by medical professionals such as doctors, nurses, physiotherapists, counsellors, and occupational therapists, as well as home-based programmes operated primarily by caregivers and supplemented by domiciliary care (Abdul Aziz *et al.*, 2014). This is significant because, to improve the post-stroke condition of stroke survivors, a combination of appropriate acute medical treatment, prolonged medical attention, and rehabilitation is warranted (McCurley *et al.*, 2019).

The Modified Rankin Scale (mRS) and the Modified Barthel Index (MBI) are essential tools for assessing stroke severity and the subsequent impact on patient care dynamics. The mRS is a global disability scale that ranges from 0 (no symptoms) to 6 (death), providing a comprehensive measure of overall disability. It is widely used to evaluate recovery and outcomes in clinical trials and stroke rehabilitation (Lee *et al.*, 2020).

The MBI, on the other hand, focuses specifically on a patient's ability to perform basic activities of daily living (ADL), such as feeding, bathing, and mobility. It scores these activities on a scale from 0 (complete dependence) to 100 (complete independence), thus offering a detailed assessment of a patient's functional independence (Lee *et al.*, 2020). These scales are crucial in shaping the care dynamics for stroke patients. High mRS scores, indicating severe disability, often necessitate extensive caregiving resources, including full-time care and specialized medical attention. Conversely, higher MBI scores, reflecting greater independence, can reduce the caregiving burden and allow patients to engage more actively in their daily lives (Pan *et al.*, 2021). Understanding and utilizing both the mRS and MBI helps healthcare providers to tailor rehabilitation programs effectively, predict long-term outcomes, and allocate resources efficiently to improve the quality of life for stroke survivors (Lee *et al.*, 2020; Pan *et al.*, 2021).

1.2 Stroke caregivers

Because of their significant disability as a result of the stroke, some stroke survivors require caregiver assistance to help them function physically and cognitively. This involves assistance with everyday tasks such as personal hygiene, toileting, feeding, and ambulation. Because the period of impairment for stroke patients is generally longer, many carers are prone to depression, anxiety, and stress, which will subsequently impact their quality of life. The burden of care, not just due to physical assistance, but also financial, emotional, and spiritual support, as well as adjusting to a new lifestyle, may all have an impact on their quality of life (McCurley *et al.*, 2019; Ostwald *et al.*, 2009; Wan-Fei *et al.*, 2017). The nature of stroke that usually spontaneous will also be a big issue for unprepared, first-time caregivers (Bierhals *et al.*, 2019). Moreover, when it comes to stroke, all the focus has always been on the patients, leaving the caregivers often neglected (Bierhals *et al.*, 2019).

Caregivers of stroke patients are particularly prone to depression, anxiety and stress due to the demanding nature of their role, which often includes extensive physical and emotional support for their loved ones. This is especially true for caregivers of patients with severe stroke, categorized as having a mRS score of 4 or higher. These patients are typically bedridden, incontinent, and require constant assistance, significantly increasing the caregiving burden. In Malaysia, the prevalence of severe stroke (mRS 4 and above) is substantial, with studies indicating that a significant portion of around 40% of stroke survivors fall into this category (Abdul Hadi *et al.*, 2018; Ministry of Health Malaysia, 2019).

This high burden not only impacts the mental health of caregivers but also has broader public health implications. The prevalence of depression among caregivers can lead to decreased quality of life, increased healthcare costs, and reduced productivity. Approximately 63.8% of caregivers in a

Malaysian study reported experiencing depression, highlighting the need for targeted mental health support and interventions (Abdul Hadi *et al.,* 2018).

From a public health perspective, the high incidence of severe stroke necessitates comprehensive policies that support both stroke survivors and their caregivers. This includes the development of respite care programs, caregiver training, mental health services, and financial assistance. These measures are critical to alleviating the psychological burden on caregivers and ensuring sustainable caregiving practices (Abdul Aziz *et al.*, 2014). Implementing such policies can improve the overall health outcomes of stroke survivors and the well-being of their caregivers, ultimately benefiting the national healthcare system.

1.3 Problem Statement

As discussed earlier, due to improvements in the acute treatment of stroke, there is an increment in the number of stroke survivors. However, they are at the dispense of significant residual disability that increases dependence towards caregivers, hence, with the increasing number of stroke survivors, the number of caregivers is expected to increase as well (Caro *et al.*, 2018). As the spotlight is primarily focused on the patients, research on caregivers' quality of life is still limited, leaving a big gap in knowledge on related issues. Globally, based on a search on Scopus and Web of Science, only around 1700 articles and reviews were ever published in this area. In Malaysia, the numbers of research on caregivers' quality of life are even more scarce. One reason for the paucity of studies is the traditional focus of healthcare research on patients rather than caregivers, which has led to a significant knowledge gap in understanding the impacts on caregivers (Lutz *et al.*, 2011). Furthermore, caregivers often operate in informal settings, making it difficult for researchers to identify and access this population for study (Koopmanschap *et al.*, 2008) In Malaysia, cultural factors and societal norms may also play a role; caregiving is often viewed as a familial duty rather than an area requiring formal study, resulting in less academic and clinical attention (Abdul Aziz *et al.*, 2014). Additionally, limited funding and resources for caregiver-focused research further contribute to the scarcity of studies in both global and Malaysian contexts (Abdul Wahab *et al.*, 2024). Consequently, the limited body of research fails to fully capture the complex and multifaceted experiences of caregivers, underscoring the need for more targeted studies in this area.

In addition, research in this area, including those done in Malaysia, was primarily conducted using general quality of life questionnaires such as SF-36 or WHO-QOL which did not address specific issues related to caregivers such as carer satisfaction, appreciation by patients or whether they receive specific training before that lead to impairment of quality of life. Realizing these problems, a team of psychologists and sociologists specifically designed a questionnaire that can address these issues related to adult caregiver's quality of life (Joseph *et al.*, 2012). There is no Malay version of this questionnaire available at the time.

Some of the studies highlighted the relationship between caregivers' depression, anxiety and stress with their quality of life (Ostwald *et al.*, 2009; Wan-Fei *et al.*, 2017). However, there is limited research that discussed the mediation effect of depression, anxiety and stress in the relationship between caregivers' factors as well as patients' factors with caregivers' quality of life. This has led to the underestimation of the effect of depression, anxiety and stress on caregivers, making in often neglected by health care practitioners as the mechanisms of these effects are poorly understood. Caregivers are not regularly screened for these problems. Depression, anxiety and stress of caregivers that led to impairment of their quality of life, could also affect the quality of caregiving received by patients, hence will subsequently affect their recovery and rehabilitation (Wan-Fei *et al.*, 2017).

1.4 Justification

This study aims to contribute new knowledge to the understanding of caregivers' quality of life and its determinants. By conducting a bibliometric analysis, we will explore the characteristics of publications on caregivers' research in terms of the number of publications, citations, countries, collaborations, authors' productivity, trending keywords, and emerging or declining themes. This information will be valuable for discussing the findings of this study and comparing them with other relevant studies.

One of the novel aspects of this research is the translation of a Malay version of a quality-of-life questionnaire specifically tailored for caregivers of stroke survivors. This questionnaire addresses the unique quality-of-life issues faced by stroke caregivers in Malaysia and can also be adapted for caregivers of other diseases with disabilities. The original English version was developed from participants recruited from 12 caregiver centres across the United Kingdom. The Chinese version was validated among caregivers of stroke survivors, while the Italian version was validated among caregivers of persons with disabilities (Joseph *et al.*, 2012; Mei *et al.*, 2017; Negri *et al.*, 2019). Our study will be the first to validate a Malay version, thus providing a culturally relevant tool for assessing caregivers' quality of life in Malaysia.

Furthermore, this study will quantify the magnitude of the mediation effects of depression, anxiety, and stress in the relationship between caregivers’ factors and stroke survivors’ factors with the caregivers’ quality of life. This aspect of the research is particularly novel, as there is currently a lack of studies examining these mediation effects. The findings will provide valuable insights into the psychological factors influencing caregivers' quality of life, informing policymakers to incorporate the assessment of caregivers’ depression, anxiety, and stress as part of stroke survivors’ rehabilitation programs. By addressing these psychological factors early, proper interventions can be implemented, helping caregivers to function better and improving the quality of care they provide to stroke survivors, ultimately resulting in better outcomes for the stroke survivors' rehabilitation program.

1.5 Research Questions

1. What are the characteristics of the publications on caregivers' research on Quality of Life in terms of the number of publications, citations, countries, collaboration, authors’ productivity, trending keywords and emerging or declining themes?
2. Is the Malay version Adult Carer Quality of Life Questionnaire (ACQoL) valid and a reliable tool to measure the Quality of Life among Family Caregivers of Stroke Survivors in Kelantan?
3. What are the relationships between caregivers’ factors and stroke survivors’ factors with caregivers’ quality of life?
4. What are the mediation effects of caregivers’ depression, anxiety and stress in the relationships between caregivers’ factors and stroke survivors’ factors with caregivers’ quality of life?

1.6 Objectives

1.6.1 General objective

To comprehensively examine and understand the dynamics affecting caregivers' quality of life in Kelantan, Malaysia, through a bibliometric analysis of existing literature, the translation and validation of assessment tools, and the application of statistical modelling to identify key factors and mediating effects.

1.6.2 Specific objectives

1. To determine the characteristics of the publications on caregivers' research on Quality of Life in terms of the number of publications, citations, countries, collaboration, and the author's productivity and to further identify the trending keyword and emerging or declining themes by bibliometric analysis.
2. To translate and validate the Malay version of the Adult Carer Quality of Life Questionnaire (AC-QoL) among caregivers of stroke survivors in Kelantan.
3. To model relationships between caregivers’ factors and stroke survivors’ factors with caregivers’ quality of life among caregivers of stroke survivors in Kelantan using linear regression.
4. To estimate the mediation effects of caregivers’ depression, anxiety and stress in the relationships between caregivers’ factors and stroke survivors’ factors with caregivers’ quality of life in Kelantan using the bootstrapping method for indirect effects.

1.7 Hypotheses

1. There will be an uptrend in the research on caregivers’ quality of life in terms of the number of publications, citations, countries involved, collaboration, and the author's productivity. Additionally, trending keywords and emerging or declining themes will be identified through bibliometric analysis.
2. The Malay version Adult Carer Quality of Life Questionnaire (AC-QoL) is a valid and reliable tool to measure the quality of life among informal caregivers of stroke survivors in Kelantan.
3. There are significant relationships between caregivers’ factors and stroke survivors’ factors with caregivers’ quality of life.
4. There are significant mediation effects of caregivers’ depression, anxiety and stress in the relationships between caregivers’ factors and stroke survivors’ factors with caregivers’ quality of life.

CHAPTER 2

Literature Review

2.1 Conducting Bibliometric Analysis on Caregivers' Quality of Life

Understanding the characteristics of publications on caregivers' QoL through bibliometric analysis is essential for several reasons. Bibliometric analysis provides a quantitative assessment of research trends and patterns, helping to identify the growth and development of research fields. This approach has been increasingly utilized in various disciplines, including medical and social sciences, to map scientific productivity, collaboration networks, and emerging research themes (Donthu *et al.*, 2021).

Examining the number of publications and citations over time reveals the growth trajectory of the caregiver QoL research field. Understanding these trends helps researchers and policymakers recognize the increasing importance and focus areas within the field. For instance, Zhao *et al.*, (2022) highlighted how tracking publication trends in healthcare research can reveal shifts in focus towards emerging health issues and inform future research directions. Moreover, analysing the countries contributing to caregiver QoL research and their collaboration networks provides insights into the global reach and interconnectedness of research efforts. This information can help identify leading countries and institutions, facilitating international collaboration and knowledge exchange. Fu *et al.*, (2022) demonstrated the importance of international collaboration in advancing healthcare research and improving its global impact.

Identifying prolific authors and their contributions can help recognize key researchers and thought leaders in the field. This recognition can foster mentorship and collaboration opportunities, promoting further advancements in caregiver QoL research. Cheng *et al.*, (2024) emphasized the significance of understanding author productivity to enhance research collaborations and academic mentorship programs.

Trending keywords analysis helps in identifying which topics are gaining or losing research interest over time. This information is crucial for researchers to stay updated with current trends and focus on emerging areas that require further investigation. Yang, (2020) highlighted that tracking research trends can guide funding agencies and researchers in allocating resources to areas with high potential impact. By mapping the thematic evolution of caregiver QoL research, bibliometric analysis helps in identifying well-studied areas and those that are underexplored. This understanding can guide future research efforts to address existing gaps and foster a more comprehensive understanding of caregiver QoL. Cheng *et al.*, (2024) noted that identifying research gaps through bibliometric analysis can lead to more targeted and impactful studies.

Insights from bibliometric analysis can inform policymakers and practitioners about the critical areas of caregiver QoL that need attention. This knowledge can lead to the development of better support systems, interventions, and policies aimed at improving the well-being of caregivers. Manoj *et al.*, (2023) demonstrated how bibliometric insights could influence policy decisions and enhance the practical applications of research findings.

Conducting a bibliometric analysis on caregivers' QoL research is vital for understanding the development and direction of the field. It helps identify key trends, influential authors, collaboration networks, and emerging themes, thereby guiding future research, policymaking, and practice improvements. The growing interest and evolving focus in caregiver QoL research underscore the need for comprehensive and systematic analysis to better support caregivers and enhance their quality of life.

2.2 Stroke

A stroke, also known as a cerebrovascular accident (CVA), is an abrupt disruption in brain perfusion or vasculature. Approximately 85% of strokes are ischemic, with the remainder being haemorrhagic (Mozaffarian *et al.*, 2016). Although the incidence of stroke is reducing worldwide, it is still the leading cause of adult disability (Fang *et al.*, 2014). In contrast to other countries, stroke incidence in Malaysia is increasing, although there is a reduction in mortality (Hwong *et al.*, 2021).

Stroke can be caused by a variety of factors. Ischemic aetiologies are further classified as embolic, thrombotic, or lacunar. Hypertension, diabetes, smoking, obesity, atrial fibrillation, and drug abuse are all common risk factors for stroke. Hypertension is the most prevalent modifiable risk factor for stroke among all risk factors. Haemorrhagic aetiologies include hypertension, aneurysm rupture, arteriovenous malformations, venous angiomas, drug-related bleeding, haemorrhagic metastases, amyloid angiopathy and other obscure causes (Mozaffarian *et al.*, 2016). Both types will result in ischaemia in an area of the brain. The Na+/K+ ATPase pumps fail mostly due to insufficient adenosine triphosphate generation and failure of the aerobic process. Ischemia causes cell depolarization, which results in calcium influx, increased lactic acid, acidosis, and free radicals. Cell death raises glutamate levels, triggering a chemical cascade known as excitotoxicity (Xing *et al.*, 2012).

Acute manifestations of stroke include hemiparesis, sensory impairments, diplopia, dysarthria, and facial droop. Strokes in the posterior circulation cause ataxia and vertigo to appear suddenly. Symptoms associated with increased intracranial pressure, such as nausea, vomiting, headache, and blurred or double vision, may also potentially support a stroke (Tadi and Lui, 2022). Following the acute attack, stroke survivors may completely recover or suffer a residual disability that increases dependence towards caregivers. They will require assistance with everyday tasks such as personal hygiene, toileting, feeding, and ambulation (McCurley *et al.*, 2019).

Acute stroke management aims to restore vascular circulation to the affected area through a combination of multidisciplinary medical approaches (Tadi and Lui, 2022). This is followed by long-term stroke care via rehabilitation that aims to improve residual weakness and prevent recurrence. Along with multiple NCD comorbidities, many stroke survivors face a lifetime burden of physical, emotional, cognitive, and economic consequences. Physical impairment necessitates that stroke survivors alter their daily life activities; yet, adjusting to new norms may result in stress, anxiety, and depression for both survivors and their caregivers. As a result, numerous measures must be implemented to avoid repeated episodes, regulate existing symptoms, and enhance the quality of life and function via rehabilitation (McCurley *et al.*, 2019; Wan-Fei *et al.*, 2017).

Stroke severity outcome measures are critical in assessing the initial impact of a stroke and predicting patient recovery trajectories. The National Institutes of Health Stroke Scale (NIHSS) is widely utilized for its reliability and ease of use in clinical settings. Recent study affirm its predictive validity for long-term outcomes, particularly in acute ischemic stroke patients (Chalos *et al.*, 2020). The Modified Rankin Scale (mRS) is another prevalent tool, primarily used to evaluate the degree of disability or dependence in daily activities. Recent findings highlight its robustness in predicting long-term functional outcomes and its sensitivity to changes over time (Broderick *et al.*, 2017).

Additionally, the Modified Barthel Index (MBI) remains a staple for assessing performance in activities of daily living (ADLs). Contemporary research underscores its effectiveness in chronic stroke populations, offering valuable insights into rehabilitation needs (Lee *et al.*, 2020). Meanwhile, the Glasgow Coma Scale (GCS) is frequently employed to evaluate consciousness levels, particularly in cases involving intracerebral haemorrhage. Its utility in predicting mortality and functional outcomes in haemorrhagic stroke has been reaffirmed in recent studies (Bodien *et al.*, 2021).

Emerging measures, such as the Stroke Impact Scale (SIS), are gaining traction for their comprehensive approach, evaluating physical, emotional, and social domains affected by stroke. This multidimensional assessment aligns well with the current holistic approach to stroke recovery, addressing the broader impacts on quality of life (Richardson *et al.*, 2016). Collectively, these outcome measures provide a robust framework for clinicians and researchers to evaluate stroke severity and tailor interventions to improve patient outcomes effectively. We chose the mRS and the MBI for assessing stroke severity in this study due to their established reliability and validity in evaluating functional outcomes and daily living activities post-stroke. The mRS is widely recognized for its simplicity and robustness in measuring disability levels, making it a standard tool in stroke research and clinical practice. The MBI, on the other hand, offers a comprehensive assessment of a patient's independence in activities of daily living, crucial for planning rehabilitation strategies. Importantly, both scales are available in the Malay language, ensuring that assessments are culturally and linguistically appropriate for our Malaysian population (Chen *et al.*, 2019; Ministry of Health Malaysia, 2014). This availability enhances the accuracy and relevance of our evaluations, ensuring that language barriers do not impede the assessment process. Consequently, the mRS and MBI provide a holistic and practical approach to understanding stroke impact and guiding patient care in our study context

2.3 Post-Stroke Care

As suggested by the International Classification of Functioning, Disability and Health (ICF) model proposed by the World Health Organization (WHO) in 2001, stroke rehabilitation can be characterised as a health procedure that "aims to facilitate people with health state experiencing or likely to experience disability to attain optimal functioning in interaction with the environment" (Silva *et al.*, 2015). In general, it is a catch-all term for a variety of therapies aimed at assisting stroke patients in increasing their physical, psychological, and vocational potential while taking physiologic and environmental limits into account. Numerous advancements in stroke prevention, treatment, and rehabilitation have lately been accomplished globally. Over the last decade, these advancements have resulted in a considerable fall in the population-based mortality rate. Stroke rehabilitation programmes, in general, continue to be the most important recommended therapy option for post-stroke functional impairments and disability (Morreale *et al.*, 2016).

The stroke rehabilitation team is a multidisciplinary team formed by patients and their families, rehabilitation nurse, rehabilitation social worker, physician, occupational therapist, physical therapist, orthotics/prosthetics technologist, speech and language therapist, psychologist, dietitian, recreation therapist and optometrist with every team member has their specific role. Caregivers are responsible for physically, emotionally, financially, and spiritually caring for patients and are encouraged to attend sessions with other stroke rehabilitation team members so that they can be trained to carry out the proposed programme, ensuring the program's success and sustainability (Bindawas and Vennu, 2016).

When a patient is discharged from the hospital in Malaysia, their medical treatment and rehabilitation are maintained in a variety of settings, including primary care (both public and private health care), hospital-based rehabilitation, out-patient rehabilitation services, or nursing home (Abdul Aziz *et al.*, 2014). Malaysia had introduced a domiciliary care program for patients with disability including stroke. This program aims to assist patients in continuing treatment and care at home as a continuation of treatment after discharge from the hospital, to guide patients and families on how to improve self-care, and to encourage family and community participation in the management of patients with disabilities to reduce readmission to the hospital (Ministry of Health Malaysia, 2014).

In Malaysia, stroke rehabilitation is also supported by other government agencies and organizations, including the Department of Social Welfare (JKM), SOCSO (Social Security Organisation), and the National Stroke Association of Malaysia (NASAM). The JKM provides rehabilitation services through its Community-Based Rehabilitation (CBR) program, which aims to help stroke survivors regain independence and improve their quality of life by offering tailored rehabilitation programs and support services. SOCSO offers financial assistance and rehabilitation to employees affected by work-related injuries or illnesses, including stroke, through comprehensive programs at their rehabilitation centres. NASAM, a non-profit organization, provides affordable rehabilitation services through its multiple centres across Malaysia, offering group therapy, one-on-one therapy, and support programs for stroke survivors and their families. NASAM's mission is to promote early rehabilitation to reduce long-term dependency and to inform the public about the possibilities of recovery after a stroke (Teoh *et al.*, 2023).

As for private care for stroke patients in Malaysia, several institutions provide specialized services. For example, Sunway Medical Centre offers a comprehensive range of stroke care, including emergency response, acute treatment, and extensive rehabilitation by a team of specialists (Sunway Medical Centre, 2023). Genesis Life Care focuses on early intervention and intensive rehabilitation, providing services like physical therapy, nutrition management, cognitive training, and psychological support tailored to individual needs (Genesis Life Care, 2023). Other than that, Homage Malaysia provides in-home care services, including personal hygiene assistance, mobility support, and medical procedures, with flexible care packages from hourly to 24-hour care (Homage Malaysia, 2024). These options ensure that stroke patients receive high-quality, personalized care for their recovery.

2.4 Caring for Stroke Survivors

In general, caregivers can be classified into two types: professional formal caregivers and non-professional informal caregivers. Professional formal caregivers are medically trained individuals, such as nurses, medical assistants, or physiotherapists, who hold at least a professional diploma in their respective fields and provide paid care services. Non-professional informal caregivers, on the other hand, are often unpaid and lack medical training. This group includes family members, relatives, close friends, or could also include other paid services such as maids (orang gaji) that involved in patient care. Unlike formal caregivers, informal caregivers are typically not professionally trained (Cejalvo *et al.*, 2021). This study focuses on unpaid, non-professional informal caregivers and exclude the paid informal service, as the financial compensation for paid services, for example, maid, could serve as a motivating factor, potentially confounding their quality of life. Henceforth, in this thesis, we will refer the unpaid, non-professional informal caregivers as informal caregivers.

Due to the burden of caregiving that is usually longer for stroke survivors, as well as the complexity of the caregiving; having to support the patients physically, emotionally, as well as financially, as most stroke survivors were unable to work while they have residual weakness, an informal caregiver may experience depression, anxiety, and stress, which may affect the quality of life. Caregivers have experienced poorer self-esteem, a lack of confidence, and increased psychological discomfort. Caregivers of stroke patients may also experience fatigue and strain, which can have an impact on how they care for and cope with their patients (Pio *et al.*, 2022).

Moreover, caregivers are sometimes caught off guard and unprepared to carry out the obligations of caregiving as most stroke cases occur spontaneously (Bierhals *et al.*, 2019). In addition to caring for the patient, most adult carers, particularly the patient's spouse, may have to cope with their own health issues (Bierhals *et al.*, 2019). Poor physical and mental health can, in turn, impair a person's capacity to care, with most of these carers saying that their health issues harmed the person they were caring for (Carers UK, 2004).

However, the negative impact of caring does not represent the entire variety of experiences of carers (Koopmanschap *et al.*, 2008). Although they are not compensated, there are several reasons for one to serve as an informal caregiver. Along with the obligation to their loved ones, tenderness, a sense of belonging, and patient appreciation are key motivators for a caregiver to continue serving the patients. This will result in caregivers' own happiness and satisfaction, especially if the person they have been caring for has exhibited physical, mental, and emotional progress. Therefore, it is critical to broaden the scope of how caregivers are impacted to include both negative and positive elements because research has shown that a lack of positive influence on carers' quality of life might be indicative of issues in the caring position. (Joseph *et al.*, 2012).

2.5 Informal Caregivers' Quality of Life

Research has been conducted to assess informal caregivers' quality of life and its determinants. However, most of these studies utilized general quality of life questionnaires such as 36-Item Short Form Survey (SF-36) or World Health Organization Quality of Life (WHOQOL) that failed to recognize issues related to caregivers' quality of life such as support for caring, caring choice, ability to care and patients' satisfaction towards caregivers. Realizing these issues, a team of psychologists and sociologists from the United Kingdom with vast experience in dealing with caregivers developed a questionnaire (Adult Carer Quality of Life Questionnaire – AC-QoL) that specifically addresses issues related to adult carer quality of life. This questionnaire addressed both positive and negative quality of life issues that caregivers experienced from eight different domains namely: support for caring; caring choice; caring stress; money matters; personal growth; sense of value; ability to care; and carer satisfaction. The questionnaire can be applied on a single occasion to evaluate the quality of life at the time of administration. Furthermore, the questionnaire is expected to be beneficial in determining the effectiveness of interventions. It can be given before and after an intervention to determine whether or not the intervention was effective (Joseph *et al.*, 2012).

Previous research using this questionnaire discovered that the total quality of life mean score among adult informal caregivers of patients with all causes of disability recruited from 12 carer centres across the UK was 54.22 ± 19.71 for males and 58.76 ± 18.08 for females. This was graded as a mid-range reported quality of life (Joseph *et al.*, 2012). The same questionnaire was translated into Chinese version and the overall quality of life mean score among family caregivers of stroke survivors in China was 55.20 ± 15.88, also graded as mid-range reported quality of life (Mei *et al.*, 2017). The Italian version found that the total quality of life mean score among family caregivers of persons with disabilities was 85.94 ± 15.28 which indicates a high reported quality of life (Negri *et al.*, 2019). To the best of our knowledge, there is no local study in Malaysia that utilized AC-QoL to determine caregivers' quality of life. A study conducted using the Short Form-12 Health Survey (SF-12) on family caregivers of stroke survivors found that they had poor quality of life in the physical component score and moderate quality of life in the mental component score (Wan-Fei *et al.*, 2017).

2.6 Informal Caregiver Quality of Life Questionnaires and the Selection of the Adult Carer Quality of Life Questionnaire (AC-QoL) for Translation into Malay

Various instruments have been developed to measure the QoL of informal caregivers, each aiming to capture different aspects of the caregiving experience. Among the most commonly used questionnaires are the Caregiver Burden Inventory (CBI), the Zarit Burden Interview (ZBI), and the Caregiver Quality of Life Index-Revised (CQLI-R). The context of caring for stroke survivors, who often require extensive and long-term care, underscores the importance of selecting the most appropriate QoL assessment tool.

The Caregiver Burden Inventory (CBI) is a widely used tool that assesses the multidimensional burden experienced by caregivers. It includes domains such as time-dependence burden, developmental burden, physical burden, social burden, and emotional burden (Novak and Guest, 1989). While the CBI is comprehensive, it has certain limitations. It primarily focuses on the negative aspects of caregiving, potentially overlooking positive experiences and personal growth associated with caregiving. This focus on burden can be particularly limiting in the context of stroke caregiving, where the emotional and psychological impacts can be profound and varied (Valer *et al.*, 2015).

The Zarit Burden Interview (ZBI) is another extensively utilized instrument, specifically designed to evaluate the perceived burden of caregivers of older adults. It includes items that address the emotional, physical, and social impact of caregiving (Zarit *et al.*, 1980). However, the ZBI also predominantly focuses on the burden aspect, similar to the CBI. This narrow focus can lead to an incomplete understanding of the caregiving experience. Moreover, the ZBI's language and some items may not be culturally appropriate for all populations, necessitating careful adaptation for use in diverse settings (Kühnel *et al.*, 2020). For stroke caregivers, the ZBI may not capture the full spectrum of challenges and rewards, such as the significant emotional toll and the potential for personal growth and resilience.

The Caregiver Quality of Life Index-Revised (CQLI-R) focuses on the QoL of caregivers, incorporating domains such as physical functioning, emotional well-being, social functioning, and general health perceptions (Weitzner *et al.*, 1999). Although the CQLI-R provides a broader view of caregivers' QoL compared to CBI and ZBI, it still has limitations. The CQLI-R was initially developed for caregivers of cancer patients, which may limit its applicability to caregivers of individuals with other conditions, including stroke. Additionally, the CQLI-R does not specifically address the financial implications of caregiving, which can be a significant aspect of the caregiving experience (Weitzner *et al.*, 1999).

Despite the availability of these comprehensive instruments, the AC-QoL has emerged as a particularly valuable tool for measuring caregivers' QoL. The AC-QoL is specifically designed to capture the unique aspects of caregiving for adults, addressing domains such as support for caring, caring choice, caring stress, money matters, personal growth, sense of value, ability to care and carer satisfaction (Joseph *et al.*, 2012). Its development was grounded in extensive qualitative research, ensuring that it reflects the real-world experiences of caregivers.

In the context of stroke caregiving, the AC-QoL is especially relevant. Stroke survivors often require long-term and intensive care, encompassing physical assistance, emotional support, and coordination of healthcare services. The AC-QoL’s comprehensive coverage of various caregiving domains makes it well-suited to capture the complex and multifaceted experiences of stroke caregivers. Unlike the CBI and ZBI, the AC-QoL goes beyond the burden and includes positive aspects such as personal growth and sense of value, which are crucial for understanding the complete impact of caregiving for stroke survivors (Joseph *et al.*, 2012).

The decision to translate the AC-QoL into Malay is supported by several factors. First, the AC-QoL's comprehensive nature ensures that it captures the multifaceted impact of caregiving, making it suitable for diverse caregiving scenarios. Second, the AC-QoL has demonstrated robust psychometric properties, including high internal consistency and construct validity, which are critical for ensuring the accuracy and reliability of the translated version (Joseph *et al.*, 2012).

Cultural adaptation of QoL instruments involves not only linguistic translation but also ensuring that the content is culturally relevant. This process includes forward and backward translation, expert committee review, and pre-testing with the target population to ensure clarity and appropriateness of the items (Beaton *et al.*, 2000). By following these rigorous steps, the translated AC-QoL will maintain its validity and reliability in the Malay context, providing meaningful data for research and practice.

To sum up, while several QoL questionnaires for caregivers exist, the AC-QoL stands out due to its comprehensive coverage of caregiving experiences and strong psychometric properties. Its adaptation into Malay will provide a valuable tool for assessing and improving the QoL of caregivers in Malaysia, especially those caring for stroke survivors. This initiative is crucial for developing culturally appropriate interventions and policies to support caregivers, ultimately enhancing their well-being and the quality of care they provide.

2.7 Predictors of Informal Caregivers' Quality of Life

Both caregivers' factors and stroke survivors' factors can affect the caregivers' quality of life.

2.7.1 Informal Caregivers' Depression, Anxiety and Stress as Predictors of Their Quality of Life

It was found that around 46 to 72% of stroke survivors' informal caregivers were depressed (Ifeanyi *et al.*, 2018; Khalid and Kausar, 2008). Being