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Concept Paper on Cost Analysis and Quality of Life for Caregivers and Stroke Patients Managed in Community: *The Development of Conceptual Framework*

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ABSTRACT

Stroke is a prevalent public health issue whereby stroke requires long-term care either at a primary care centre or home. Long-term care may jeopardize the Quality of Life (QoL) and financial aspect of the patient and caregiver as they need to visit the outpatient clinic and rehabilitation centre regularly. In recent year, home-based care is more favourable among the patient. However, in Malaysia study comparing the outcome of the primary care centre and home-based care specifically from the perspective of QoL and cost is still lacking. This is especially involving the patient and caregiver. Hence this study attempts to develop the conceptual framework in analysing the cost and QoL quality of life for caregivers and post-stroke patients receiving home care and primary care.

Keywords: Stroke, Long-term care, Primary Care, Home-based Care, QoL, CEA, EQ5D, Cost Analysis

INTRODUCTION

Prevalence of Stroke

Stroke is a neurological deficit attribute by the focal injury of the cerebral function that can cause death and permanent disability. Globally, 15 million of the populations were diagnosed with stroke yearly and, in 2016, stroke was the third leading cause of death after Ischemic Heart Disease which causes 5 millions of death and the number of patients with permanent disability amounting to 5 million(Feigin et al. 2017; World Health Organization 2018). The incidence of stroke is among the major contributor to the disability-adjusted life years (DALYs) in which it was estimated that DALYs due to stroke problem would rise to 61 million in 2020 (Feigin et al. 2017).In the past 20 years, the extended longevity and increment of the ageing population are the common factors influencing the diagnosis of stroke and, these factors also increase the stroke-related healthcare cost and expenditure, specifically in developed countries(Gioldasis et al. 2008; Ortman et al. 2014).

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Similar to the global pattern of stroke, Malaysia also is dealing with the increment of stroke's cases. In 2006, the prevalence of stroke was 0.3% and had gradually increased to 0.7% in 2011(Amal et al. 2011). The National Health Morbidity Survey (NHMS) in 2011 revealed a more prevalent incidence of stroke among the population of the age of 75 years and above and among divorcees. Although a study in the United Kingdom reported a distinguish distribution of stroke across ethnicity, there was no predominance of ethnic reported in a study conducted in Malaysia(Gulli et al. 2016). In Malaysia, the mortality rate of cerebrovascular disease (CVD) was 15.1 per 100,000 people (Organization 2012). Statistic by Department of Statistic (DOS) Malaysia also highlights CVD as the third leading cause of death after Ischaemic Heart Disease and Pneumonia and, it contributes for approximately 7% of the total disease burden in persons aged 30–59 years and 12% of the total disease burden in persons aged 60 years old and above (Department of Statistics 2019).

The disability caused by stroke especially among the elderly has led to the needs for long-term care which may jeopardize the Quality of Life (QoL) and the financial perspective of the patient as well as the caregiver. The management of stroke continues even after a hospital discharge where it still requires long-term care either in the long-term care institutions or at home(Simon et al. 2009). In Malaysia for instance, after the hospital discharged, the patient is required to attend the outpatient stroke clinic in three month's duration and also outpatient rehabilitation(Aznida et al. 2012).A study assessing the utilization and demand for long-term care in Taiwan have demonstrated that patients with stroke are the major users of long-term care(Wu et al. 2014). However, observation of the recent study reveals that in recent years, the number of patients who continues their care at the care centre is declining in which, patients prefer to continue their care at home that attributes to the tremendous financial, social and emotional burdens among the caregiver(Clery et al. 2020; Wu et al. 2014).

Management of Stroke

The management of stroke begins even pre-hospital admission. The effectiveness of stroke management is time dependent whereby a rapid transportation to Emergency Department is crucial.The pre-hospital delays may attribute to poor clinical prognosis of patient. For instance, in managing the Acute Ischemic Stroke (AIS), the intravenous thrombolytic therapy is among the most effective treatment but, to ensure the effectiveness of this treatment, it needs to be performed within 4 and half hours from onset (Lou et al. 2020). Therefore, it's crucial for the caregiver and patient to recognise the early symptom of the stroke.

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However, in transporting the patient to the hospital, it's also highly crucial for the caregiver to ensure the capacity of the hospital in managing stroke's cases(Collaboration 2013). The addmission to stroke unit compared to general neurology or general ward is more beneficial for the stroke patientswith regards of early rehabilitation and improved assessment procedures. A Cochrane review done by Aziz et al. have shown a significance of stroke rehabilitation in relation to patients' needs and healthcare(Abdul Aziz et al. 2014). A hospital consisted of stroke rehabilitation unit and multidiscplinary team is imperative to evaluate the patient's own learning style, ability and needs(Aznida et al. 2012). When a person is diagnosed with stroke, the disturbance of the brain could impacts the mental state or mood of the patient. Therefore, a multidiscplinary team consisting of the nursing staffs, doctors, physiotherapists and the family members is imperative to assess the patient's condition and identifying the appropriate procedure could reduce the incidence rate of stroke's complications.

After receiving treatment at the hospital, the long-term care of the stroke patient continues. The long-term care is the phase that starts soon after the patient was discharged home with the completion of necessary therapies or rehabilitation. During this phase, the management of a patient post-stroke, focused on improving their QoL involving their relationship with their families as well facilitate the patient to adapt with their new circle of life. The longer-term care for stroke patients was suggested to be between three to a year or more after stroke (Patel et al. 2006). Post the hospital discharged, the management of stroke relies heavily upon the caregiver which requires the caregiver to be equipped with patient's education content which consists of information on the monitoring of physical and psychological symptoms. In addition, in mainaining the safety of the long-term care by the caregiver knowledge on the activities, events or any other stimuli that could disturb the patient after they were dischargedis also imperative among the caregiver.

The diagnosis of stroke could change a person life as the person needs to depend on a third party in sustaining their life. Post diagnosis, majority of stroke patients were challenged with motor, cognitive and psycho-emotional limitations. In addition to the patient, the condition of stroke impacted the caregiver as well. The caregiver plays a crucial role in recognising the symptom of stroke and helping the patient to receive immediate treatment from a suitable care centre. In addition, the importance of caregiver's cooperation post-hospital discharged also has been highlighted by previous studies.

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HEALTH-RELATED QUALITY OF LIFE

The WHO defines Quality of life as

> *"Individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns."*(Power & Kuyken 1998)

In the health care sector, the concept of QoL has been broadened by measuring the impact of the specific condition of the patient's illness whereby it assesses the impact of particular disease towards the patient's physical, economic and social well-being in which this concept is named as Health-related quality of life (HRQoL) (Chappell & Colin Reid 2002; Shafie et al. 2013). In measuring the QoL and HRQoL, several instruments such as EuroQoL five-dimensional (EQ5D), EuroQoL visual analogue scale (EQ-VAS),Short Form 36 (SF-36), Short Form 12 (SF-12) have been developed and validated(Pequeno et al. 2020; Shafie et al. 2013). However compared to other instruments, EQ5D is commonly used to measure the QoL of stroke patient(Cramm et al. 2012; Hunger et al. 2012; P Lindgren et al. 2006; van der Gaag & Brooks 2008). The EQ5D is suitable for clinical and economic evaluation as it couldestimate QALYs in economic evaluation study.

The QoL of stroke patient relies on the outcome of the treatment rendered to the patient. Hence, in sustaining a good QoL among the stroke patient continuous care and support need to be rendered to the patient. Post-stroke diagnosis, the QoL of the stroke patient was significantly decreased, but it could be increased through the good outcome of stroke as the result of high quality of medical services and accurate medical intervention to the patient in mitigating the morbidity, mortality and stroke recurrence(Chen et al. 2019).Inefficient stroke management may lead to the stroke recurrence that could deteriorate the HRQoL of the patient(Garbusinski et al. 2005; Wang et al. 2014).A Malaysian study revealed that 66% of their stroke patients suffered from depression between 3 to 6 months post-stroke, with 51% of them were diagnosed with mild depression and remaining 15% suffered with moderate to severe depression(Glamcevski & Pierson 2005).In the same study, discontinuation of pre-morbid lifestyles and poor activities of daily living were the cause of depression among the patients. In another study conducted in Malaysia, the mean score of stroke patients for all eight health domains in the SF-36 was remarkably lower than the general population, except bodily pain(Mn et al. 2009)

The determinant of caregiver QoL is the QoL of the patient. Majority of the stroke patient is being managed by their family member at home(Dorsey & Vaca 1998; Ski & O'Connell 2007). Managing stroke patient would challenge the physical and mental state of

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the caregiver which may relate to the situation whereby the caregiver would compromise their physical health, social life, and emotional well-being. When the caregivers suppressed their physical and mental needs, it would cause mental and physical exhaustion such as burn out and sleep deprivation which would hinder the best delivery of care for stroke patient(Clery et al. 2020). A study using Zarit Burden Interview short version revealed that 33% of the caregivers perceived to feel the burden in managing the patients as the patients required caring in a long duration daily (van Heugten et al. 2006).In a situation of sudden onset of stroke, majority of the caregivers need to adapt with the situation within a limited time which may also impact their QoL as they are not mentally and physically prepared(Bakas et al. 2002; Craig et al. 2017; Tooth et al. 2005). In other situations where the severity level of the patient is increasing, it would also relate to the poor QoL of the caregiver as more critical patients require more attention and care(Kong & Yang 2006). Past research has also highlighted the QoL of the caregiver could also be influenced by the age and educational level of the caregiver(Cramm et al. 2012).

COST ANALYSIS ON STROKE

The diagnosis of stroke would provide an extensive impact on the socio-economic of the patient and the caregiver. In addition to the direct cost such as cost of medication and supplement, the indirect cost such as cost of transportation also needs to be considered as stroke patient requires a significant number of visit to outpatient clinic and rehabilitation centre. Data from 2012 shows that the cost of treating a patient with acute major stroke in a teaching hospital in Malaysia per admission was MYR 9000 and MYR 3353 for minor stroke(Aznida et al. 2012). The same data also reported that the patient cost for the outpatient clinic was RM103 per visit and cost of rehabilitation was RM43 per patient per session disregard of the severity level.

Table 1 below summarised the finding on the cost of treatment in managing stroke among five multicenter hospitals in Asian countries. The sample size of these five studies was between 189 to 5255. Pakistan's study indicates the highest mean cost of stroke amounting to US$5230, and the Malaysian study shows the lowest cost of stroke amounting to US$2050. Besides these 5 studies, a study that was conducted in Sweeden in 2008 indicates stroke relates to18.5 work weeks loss, which translates to approximately 120 000 Swedish Kronor (SEK) among patients in the working ages(Peter Lindgren et al. 2008).

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Table 1 The characteristics of cost of stroke treatment studies in Asian countries

Study	Country	Study period	Design of cost analysis	Estimation procedure	Number of patient	Average cost stroke treatment in (USD)
(Khealani et al. 2003)	Pakistan	1998-2001	Retrospective	Bottom up	443	5230
(Nordin et al. 2012)	Malaysia	2005-2008	Retrospective	Top down	813	2050
(Kwatra et al. 2013)	India	2009-2011	Prospective	Bottom up	189	2711
Wei et al. (2010)	China	2006-2007	Prospective	Top down	5255	3626
(O. et al. 2012)	Thailand	2008-2009	Prospective	Bottom up	407	2115

RESEARCH GAP

Stroke is a significant public health issue. The diagnosis of stroke would impact the QoL and financial aspect of the patient as well as the caregiver. Rehabilitation is crucial in stroke management but, recently home-based therapies is one of the alternatives with regards to the increasing number of a stroke patient. However, currently, the data on the cost analysis and QoL of stroke patient and caregiver in Malaysia is still limited. In addition, the study on the comparison of the outcome of home-based care and primary care is also limited in Malaysia. Therefore to encounter this limitation, this study aims to assess the cost and quality of life for caregivers and post-stroke patients receiving home care and primary care managed in the community in a teaching hospital.

Attempt to Encounter the Limitation

In an attempt to encounter the limitation, this study will focus on analyzing the cost of managing stroke and the QoL of a stroke patient and caregiver treated at the primary care centre and home. Hence the specific objectives of this study were developed as below.

1. To compare sociodemographic data of post-stroke patients and their caregivers between home care and primary care.
2. To compare the clinical profile of post-stroke patients between home care and primary care.
3. To compare the cost (direct and indirect) of outpatient care between post-stroke patients receiving home care and primary care.
4. To compare the quality of life between post-stroke patients and their caregivers receiving home care and primary care.
5. To compare the satisfaction between caregiver of post-stroke patient receiving home care and primary care.
6. To compare the psychological well-being between post-stroke patients and their caregivers receiving home care and primary care.

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7. To compare the cost effectiveness of post-stroke services between post-stroke patients receiving home care and primary care.

METHOD TO CONDUCT RESEARCH

Research Design

To answer the objective of this study, a cross-sectional study will be conducted in tertiary hospital in Malaysia. Firstly, the cross-sectional study to determine the QoL of the targeted samples will be performed. Then the economic evaluation that entails cost analysis based on descriptive design to compare the cost-effectiveness of home care unit and primary care will be performed.

In conducting the cost analysis the Cost-Effectiveness Analysis (CEA) will be applied. In analysing the cost, CEA is recommended to compare the outcome of a minimum of two program alternatives (Figure 1)(M E et al. 2006). CEA will help the researcher to determine which program is more efficient and profitable.

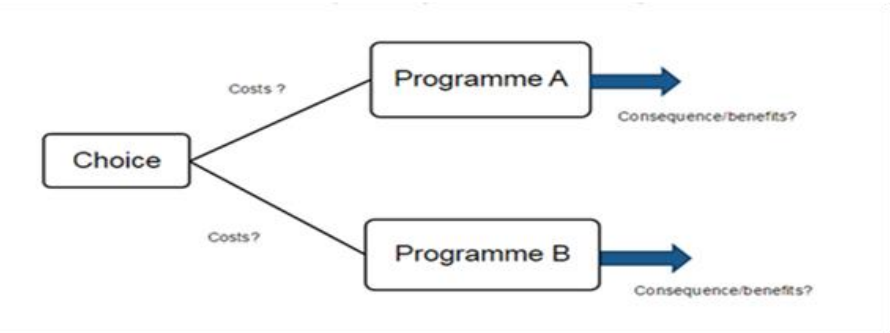

Figure 1Health Economic Model

Proposed CF

This study will focus on two essential components namely home care based and also primary care based. Long term care with increasing treatment cost that will subsequently increase the burden of managing stroke among families and caregivers and the government. Hence, it's crucial to assess the cost of post-stroke care managed in community especially in identifying which component of the treatment that contribute to the highest cost.

The diagnosis of stroke could be influenced by certain traits and conditions. Patient could be diagnosed with stroke duet o the hereditary factors such as ageing and family history. The existing conditions such as diabetic and patient's lifestyle could also become the risk factor of stroke. The literature review has shown the importance in having continuity of care after a patient is discharged from hospital or after acute stroke and the rising of patient being treated at home post-discharged. The continuation of long-care at home may inccur more cost to the patient and caregiver.To analyse these constructs and relationships, the

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Conceptual Framework has been developed as shown in Figure 2. These constructs may be further explained:

i. Impact to the caregiver and post-stroke patient: to estimate the outcome of satisfaction and quality of life.
ii. Post-stroke care: Treatment for a post-stroke patient who has been referred to Primary care based post-stroke service and home care unit.
iii. Treatment outcomes: Psychological well-being and cognitive status.
iv. Treatment cost: Societal cost for both settings.
v. Cost-effectiveness ratio: Measurement for both settings to indicate which setting is more cost-effective.

The cost-effectiveness of the management of post-stroke patient managed at the community level is a significant interest in this research. The researcher would like to study which setting is more efficient in stroke care.

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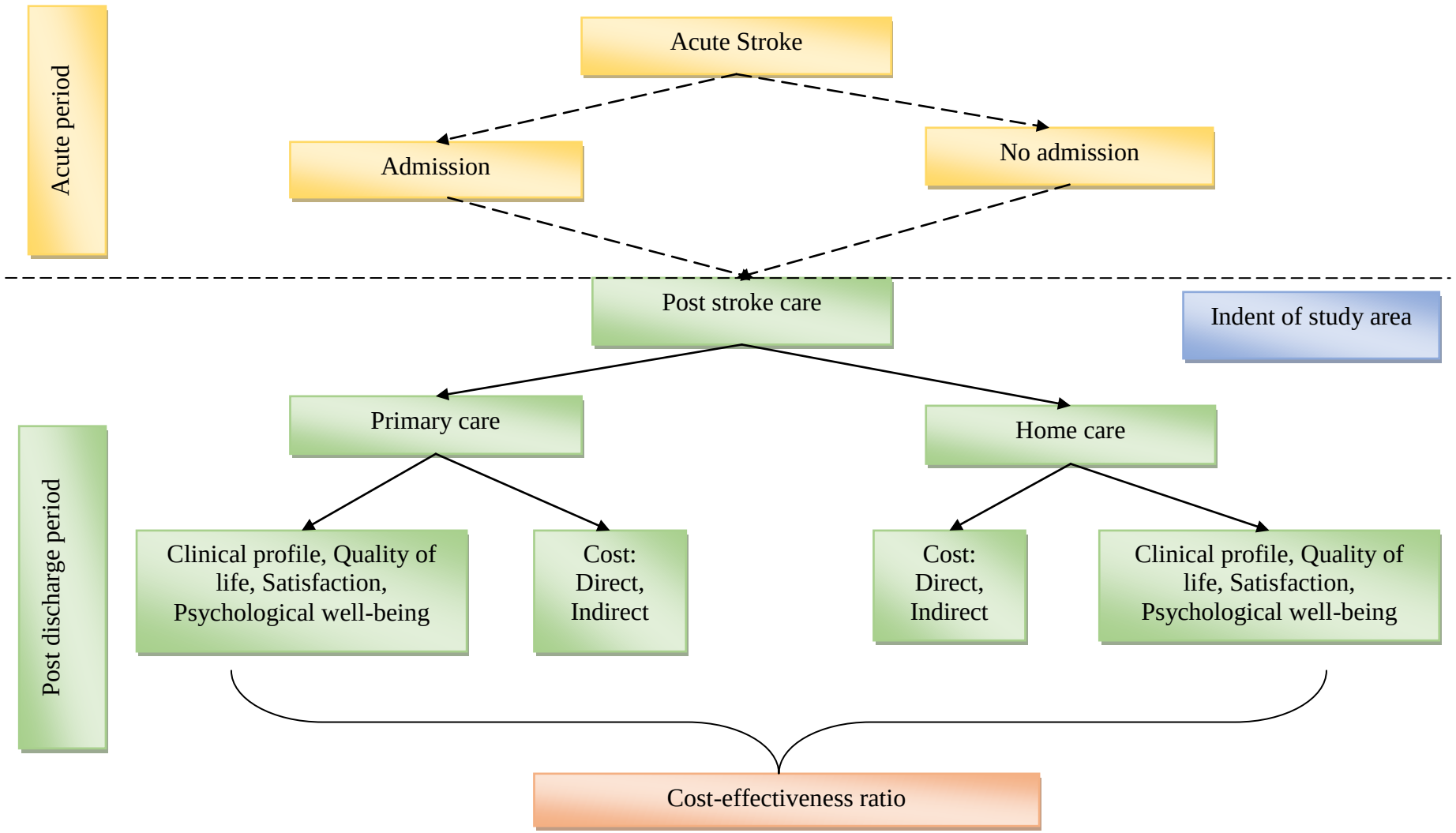

Figure 2 Proposed Conceptual Framework

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CONCLUSION

The incidence of stroke is a significant issue within the health care system in Malaysia. As the number of a stroke patient is increasing due to the extended longevity, the demand for stroke rehabilitation is also increasing. In recent years, home-based care is more favourable than the rehabilitation centre among patient. This is taking into consideration of the long-term care that needs to be undergone among the patient. The long-term care among stroke patient might impact the QoL of the patient as well as the caregiver. Besides, attending an appointment at the outpatient clinic and rehabilitation centre might also impact the financial aspect of the patient and caregiver. The financial burden could also increase if long-term care is performed at home. Therefore, it's imperative to assess the cost and quality of life for caregivers and post-stroke patients receiving home care and primary care centre.

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