SATISFACTION TOWARDS DOMICILIARY CARE SERVICES AND THE UNMET NEEDS AMONG STROKE PATIENTS IN KOTA BHARU DISTRICT

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LIST OF ABBREVIATIONS

ADL	Activity daily living
AOR	Adjusted odds ratio
BI	Barthel index
CBR	Community Based Rehabilitation
COPD	Chronic obstructive pulmonary disease
CT	Computed tomography
CBD	Continuous bladder drainage
CVDs	Cardiovascular diseases
DALYs	Disability-adjusted Life Years
EFA	Exploratory Factor Analysis
HRPZ II	Hospital Raja Perempuan Zainab II
ICC	Intra-class correlation coefficient
IIR	Investigator-Initiated Research
IQR	Interquartile range
JePEM	*Jawatankuasa Etika Penyelidikan (Manusia)*
MBI	Modified Barthel Index
M-CSI	Malay Caregiver Strain Index
MOH	Malaysia Ministry of Health
MLR	Multiple Linear Regression
mRS	Modified Rankin Scale
NHS	the National Health Service
NICE	the National Institute for Health and Clinical Excellence
NMRR	National Medical Research Register
PPD	*Program Perawatan Domisiliari*
RM	Ringgit Malaysia
SD	Standard deviation
USM	Universiti Sains Malaysia
WHO	World Health Organisation

ABSTRAK

KEPUASAN TERHADAP PERKHIDMATAN PERAWATAN DOMISILIARI DAN KEPERLUAN YANG TIDAK DIPENUHI DI KALANGAN PESAKIT STROK DI DAERAH KOTA BHARU

Penjagaan domisiliari adalah penjagaan pemulihan pelbagai disiplin yang menyediakan kesinambungan penjagaan di peringkat komuniti. Penglibatan penjaga diperlukan dalam menyediakan penjagaan berterusan di rumah dengan bimbingan daripada kakitangan kesihatan. Kajian ini mengenalpasti faktor-faktor yang berkaitan dengan kepuasan penjaga terhadap perkhidmatan perawatan domisiliari dan keperluan yang tidak dipenuhi kalangan pesakit yang tidak layak mendapat perkhidmatan perawatan domisiliari dari perspektif penjaga di daerah Kota Bharu. Kajian ini dibahagikan kepada tiga bahagian iaitu kajian rekod pesakit strok secara retrospektif di HRPZ II dan Hospital USM, kajian kepuasan penjaga terhadap perkhidmatan perawatan domisiliari, dan kajian keperluan yang tidak dipenuhi di kalangan pesakit yang tidak memenuhi kriteria kelayakan perkhidmatan perawatan domisiliari. Tahap kepuasan penjaga diukur menggunakan borang kajian FAMCARE. Keperluan yang tidak dipenuhi dari perspektif penjaga diukur menggunakan borang kajian UN-CARE. Regresi linear berganda digunakan untuk mengenal pasti faktor yang berkaitan dengan kepuasan dan keperluan yang tidak dipenuhi. Seramai 79 (23.9%) daripada 330 pesakit strok yang dipilih secara rawak menerima perkhidmatan penjagaan domisiliari, sementara yang lain menerima sama ada lawatan perawatan di rumah 121 (36.7%) atau perkhidmatan pesakit luar 130 (39%). Hanya 79 (36.1%) daripada 219 pesakit yang dirujuk untuk penilaian penerimaan perkhidmatan memenuhi kriteria kelayakan.

Kebanyakan kriteria dapat dipenuhi oleh pesakit kecuali kriteria keberadaan penjaga semasa lawatan terapi. Kepuasan penjaga secara umum, terhadap perkhidmatan perawatan domisiliari dikaitkan dengan perbincangan bersama keluarga sebelum discaj (larasan *b*= 0.51, 95%CI 0.31,0.69, p<0.001). Kepuasan dari segi pemberian maklumat dan penjagaan fizikal ditentukan oleh perbincangan bersama keluarga sebelum discaj. Selain daripada perbincangan bersama keluarga, kepuasan terhadap subskala penjagaan psikososial dikaitkan dengan tempoh penyakit. Kepuasan dari segi ketersediaan penjagaan ditentukan oleh penjaga yang berpendapatan dan indeks tekanan penjaga. Keperluan yang tidak dipenuhi pada umumnya, di kalangan mereka yang tidak menerima perkhidmatan perawatan domisiliari dikaitkan dengan umur penjaga (larasan *b*= -0.002, 95%CI -0.004,-5.34×10^{-5}, p=0.044), penjaga berpendapatan sendiri (larasan *b*= 0.11, 95% CI 0.03,0.19, p=0.008), tekanan penjaga tinggi (larasan *b*= -0.13, 95%CI -0.18,-0.07, p<0.001), dan perbincangan keluarga sebelum discaj (larasan *b*= -0.19, 95% CI -0.25,-0.14, p<0.001). Keperluan yang tidak dipenuhi dalam sokongan dikaitkan dengan ketidakupayaan, keterbatasan aktiviti, dan pesakit yang tinggal bersama penjaga. Keperluan yang tidak dipenuhi dalam penglibatan penjagaan dikaitkan dengan umur penjaga, penjaga berpendapatan sendiri, tekanan penjaga yang tinggi, dan perbincangan bersama keluarga sebelum discaj. Keperluan yang tidak dipenuhi dalam manfaat penjagaan dikaitkan dengan keterbatasan aktiviti, bebanan penjaga yang tinggi, dan persidangan keluarga sebelum discaj. Kajian ini mendapati bahawa perkhidmatan perawatan domisiliari di Kota Bharu umumnya memenuhi matlamat di kalangan mereka yang menerimanya. Perbincangan bersama keluarga adalah penting bagi mereka yang tidak layak menerima perkhidmatan tersebut.

Kata kunci: Strok, penjaga strok, pemulihan, kepuasan penjaga, keperluan yang tidak dipenuhi

ABSTRACT

SATISFACTION TOWARDS DOMICILIARY CARE SERVICES AND THE UNMET NEEDS AMONG STROKE PATIENTS IN KOTA BHARU DISTRICT

Domiciliary care is a multidisciplinary rehabilitation care which provides the continuity of care at the community setting. It requires the involvement of caregivers in providing continuous care at home with guidance by the health professionals. This study examined the factors associated with caregivers' satisfaction towards provided domiciliary care services and the unmet needs for care among patients who are not eligible to receive domiciliary care in Kota Bharu district as perceived by the caregiver. This study was divided into three parts, the retrospective record review of stroke patients from HRPZ II and Hospital USM, a caregiver satisfaction survey for patients who received domiciliary care, and an unmet needs survey as perceived by the caregiver of stroke patients who were not eligible to receive domiciliary care services. Caregiver satisfaction was measured using the validated FAMCARE questionnaire. The unmet need was measured using the UN CARE questionnaire. Multiple linear regression was used to identify the determinants of satisfaction and the unmet needs. Seventy nine (23.9%) of the randomly selected 330 stroke patients received domiciliary care services, whereas others received either nursing care visit 121 (36.7%) or outpatient service 130 (39%). Out of those 219 (66.4%) who were referred to be assessed for eligibility to receive domiciliary care services, only 79 (36.1%) fulfil the eligibility criteria. Most eligibility criteria were fulfilled by most of the patients except availability of caregiver during therapy visit. Caregiver's satisfaction in

general, towards provided domiciliary care services was found to have association with the family conference prior to discharge (adjusted *b*= 0.51, 95%CI 0.31,0.69, p<0.001). Satisfaction in term of information giving and physical care were associated with only family conference prior to discharge. Besides family conference prior to discharge, satisfaction subscale on psychosocial care was also determined by duration of illness. Satisfaction in term of availability of care was also associated with care giver income and strain index. The unmet needs in general, among non-recipient of domiciliary care services was found to be associated with age of caregivers (adjusted *b*= -0.002, 95%CI -0.004,-5.34×10^{-5}, p = 0.044), caregivers with own income (adjusted *b*= 0.11, 95%CI 0.03,0.19, p = 0.008), high caregiver's burden (adjusted *b*= -0.13, 95%CI -0.18,-0.07, p<0.001), and family conference prior to discharge (adjusted *b*= -0.19, 95%CI -0.25,-0.14, p<0.001). Unmet needs on support was associated with impairments, activity limitations, and patient-caregiver who stayed together. Unmet needs on engagement of care was associated with age of caregivers, caregivers with own income, high caregiver's burden, and family conference prior to discharge. Unmet needs on benefit of care was associated with activity limitations, high caregiver's burden, and family conference prior to discharge. The study found that the domiciliary care services in Kota Bharu generally met the purpose to those who received. The family conferences were important for those who were not eligible to receive the services.

Keywords : Stroke, stroke caregivers, rehabilitation, caregiver satisfaction, unmet needs

CHAPTER ONE

INTRODUCTION

1.1 Introduction

Stroke is a clinical syndrome characterised by rapid development of clinical symptoms and/or signs of cerebral function loss. The signs and symptoms may be focal or at times global. The symptoms may last more than 24 hours and may even lead to death, with no apparent cause other than that of vascular origin (Ministry of Health Malaysia, 2012) . The stroke prevalence rate has increased in Malaysia for both ischaemic and haemorrhagic type (Aziz *et al.*, 2015). Stroke has also become one of the major contributors of disease burden with its complex short-term or long-term disabilities which lead to significant socioeconomic loss especially among young stroke patients.

The young stroke patients frequently live longer with several disabilities and experience a greater loss in salary earnings over a longer period. The effects and complications of strokes differs individually. Certain stroke patients may experience disability or impairment which are minor and short-termed, while others may be left with serious long-term incapacitation. The immediate or long-standing effects generally involve the same part of the body or the same cognitive function. It is important to become aware of the common effects of stroke and the way to improve the affected person's physical and emotional well-being and their caregiver not only during hospitalisation but also at the community level. Questions often arise about those life changes to expect and how to gain control and independence in everyday life situations. Those disability or activity limitations that developed after a stroke may improve with further management and care such as attending or receiving intensified stroke rehabilitation services. Stroke survivors who are left with some degree of

physical or cognitive impairment need a proper post-stroke management called rehabilitation. The goal of stroke rehabilitation is to help them relearn movements or skills that have been lost. Stroke rehabilitation help the patient regain independence and improve their quality of life. The severity of stroke complications and each person's ability to recover varies. Early recovery and rehabilitation can improve functions and sometimes remarkable recoveries for stroke patients.

The World Health Organization (WHO) has introduced domiciliary care, a community-based approach of rehabilitation care and support. Domiciliary care provides care at home to assist someone with disability in their daily life activities. Malaysia officially started their domiciliary care service in 2014. It aims to provide a holistic treatment services to stable bedridden cases who requires continuity of care including treatment after being discharged from hospital or referred from a health clinic (Ministry of Health Malaysia, 2014). All patients should receive similar services including neurorehabilitation care regardless of their disability after being discharged from hospital. However in view of several technical constraints, assessment on patient’s needs prior to discharge is essential to determine the type of services than can be offered to them for further management at the community level. The community level services provided by the primary healthcare team consist of standard nursing care visits or the caregiver will be equipped with caregiving skills when receiving domiciliary care services (Ministry of Health Malaysia, 2014).

The domiciliary team is a multidisciplinary service which consists of family medicine specialist, medical officer, pharmacist, physiotherapist, occupational therapist, dietitian, speech therapist, social worker, counsellor, medical assistant and staff nurse.

The care responsibilities were carried out by patients' caregiver under the supervision and guidance of the team with the aim of reducing the caregivers' burden. The caregivers will be first equipped with knowledge and skills on proper care in order for them to care for the patient at home (Ministry of Health Malaysia, 2014). Currently, only patients who fulfil the set criteria will be included in the domiciliary care service. Patients who do not fulfilled the criteria will receive the regular nursing care visits from the primary healthcare team. Nursing care visit provides similar patient care depends on the patient's clinical condition as in domiciliary care service. In addition to patient care services, domiciliary care train and educate the caregiver on continuous patient care at home. The domiciliary care visits enable caregivers to discuss any issues on patient care with healthcare team. Patients with modified Rankin Scale score of less than 4 usually are more independent in their activity of daily living, thus will receive services from the outpatient clinic either at the hospital or health clinics. The full recovery is nearly impossible for patients with modified Rankin Scale score 4 and 5 (bedridden) as they need help in their activity of daily living (Figure 1).

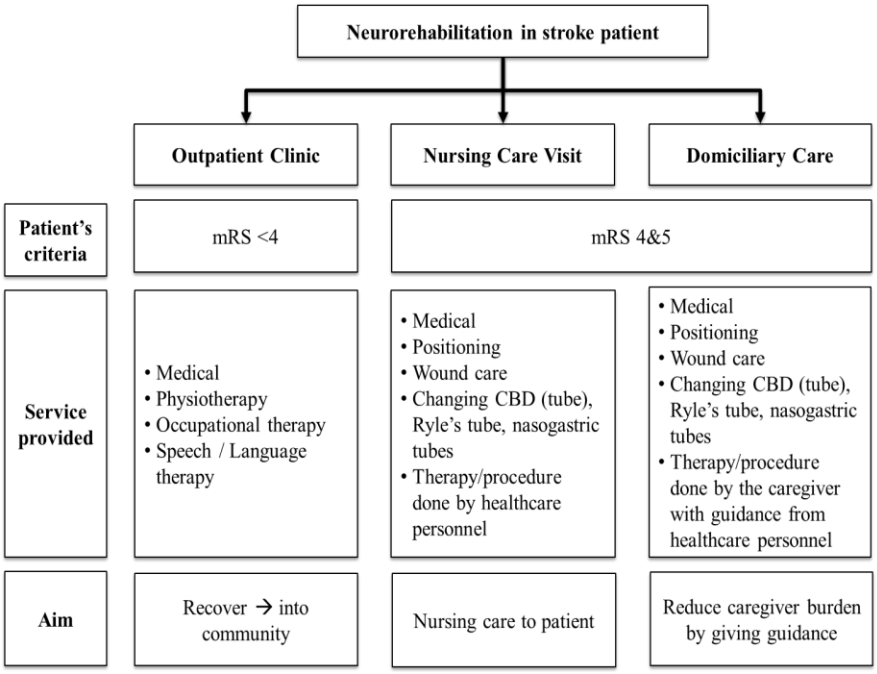

Figure 1.1: Neurorehabilitation services for stroke patients

1.2 Problem statement

The post stroke incessant rehabilitation and care at the community level only can be achieved with the help of skilful caregivers. Domiciliary care is a community-oriented rehabilitation healthcare service with the aim to equip caregiver with knowledge and proper skills. Family members often rely on the healthcare personnel in the aspect of rehabilitation of caregiving without realizing that they are the most important person in managing the patient. Caregivers need professional support for their tasks of providing the patient with proper care and if this does not happen the caregivers will become the 'fellow sufferers' or our 'silent patient'. Good professional support from domiciliary care team to caregivers, on the other hand, will only be efficient in helping post stroke patient if it is available and accessible to all patients.

Currently, only patients who fulfil the set criteria will be included in the domiciliary care service. Apart from modified Rankin Scale (mRS) score of 4 and 5 which is moderate and severe disabilities, patients will only be eligible to receive domiciliary care service if they had caregivers who agreed and willing to learn patient's care procedures and if they stay within the team coverage area. Those who do not have caregivers and stay far away from healthcare will only be receiving nursing care visit, thus missing the opportunity of a better post stroke care. These group of patients may be the one who need care the most to survive from stroke and regain better quality of life.

1.3 Study rationale

All stroke patients need multidisciplinary team approach of neurorehabilitation regardless of their disability. There are limitations in most of the healthcare service provided. Caregivers' satisfaction on the received care can be a proxy indicator for the efficiency of the provided service. As for the group who are not eligible to receive the domiciliary care, identifying their unmet needs despites the eligibility criteria can help service providers to understand the rights and needs of the patient as perceived by their caregiver. The information from this study may provide guidance to the local healthcare providers in improving the current service to an optimal level of rehabilitation services even though it do not evaluate thoroughly the effectiveness of neurorehabilitation care services. Continuous and accessible services to all patients and their caregivers on the supports and alternatives pertaining to the needs will further improve the patients' care. This will ultimately help to improve not only the quality of life of the patient but also their caregivers.

1.4 Research question(s)

1. What is the proportion of stroke patient utilising different types of rehabilitation services?
2. Which eligibility criteria of domiciliary care does the patients failed to fulfill?
3. What are the associated factors of caregivers' satisfactions towards the current provided domiciliary care services?
4. What are the unmet needs among those patients who are not eligible to receive domiciliary care?

1.5 Objective

1.5.1 General objective

To study the domiciliary care service satisfaction and unmet needs among stroke patients in Kota Bharu District.

1.5.2 Specific objectives

1. To describe the different types of rehabilitation services received by stroke patients in Kota Bharu District.
2. To describe the proportion of stroke patients who fulfil the eligibility criteria of domiciliary care services among those referred to primary healthcare team in Kota Bharu District.
3. To identify the factors associated with caregivers' satisfaction towards provided domiciliary care services in Kota Bharu District.
4. To identify the factors associated with the unmet needs among patients as perceived by the caregiver who are not eligible to receive domiciliary care in Kota Bharu District.

1.6 Research hypothesis

1. There is significant relationship between sociodemographic characteristics of patients and their caregiver, and clinical characteristics of patients with mean satisfaction score towards domiciliary services among caregivers of stroke patients in Kota Bharu District.
2. There are unmet needs among stroke patients as perceived by the caregivers who are not eligible to receive domiciliary care service in Kota Bharu district.

CHAPTER TWO

LITERATURE REVIEW

2.1 Introduction to stroke

Cardiovascular diseases (CVDs) are a group of disorders of the heart and blood vessels. They include coronary heart disease, cerebrovascular accident, rheumatic heart disease and other conditions (World Health Organization, 2017). Cerebrovascular accident or stroke was defined by the World Health Organization (WHO) as a rapidly developing clinical signs of focal or global disturbance of cerebral function, with symptoms lasting more than 24 hours or leading to death, with no apparent cause other than of vascular origin.

Stroke was broadly categorized as ischemic or haemorrhagic. It occurs when part of the brain does not receive enough blood flow for one of two reasons either the blood supply to part of the brain is suddenly interrupted (ischaemic), or because a blood vessel in the brain ruptures and invades the surrounding areas (haemorrhagic). Ischemic stroke can occur either due to atherothromboembolism, intracranial small vessel disease, or cardiogenic embolism (Ministry of Health Malaysia, 2012) . While haemorrhagic stroke can be caused by aneurysms or arteriovenous malformations (Gund *et al.*, 2013).

Patients who have had a stroke are susceptible to many complications either medical or neurological complications. Common medical complications are recurrent stroke, coronary heart disease, gastrointestinal bleed, and complications as the result of immobilisation such as aspiration pneumonia, systemic infection, deep vein