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Adherence to Home-Based Exercise among Stroke Patients: A Survey of Family Caregivers Perspectives in Central Region of Malaysia

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ABSTRACT

Background: Home-based exercise is important to improve and urge stroke survivors to keep an ideal degree of physical activity post-hospitalization. This study aimed to assess the adherence to home-based exercise among stroke survivors in the central region of Malaysia from the perspective of family caregivers. **Methods:** Cross-sectional survey was conducted among 54 the family caregivers of stroke patients from general hospitals in central region of Malaysia using convenience sampling technique. The respondents received a survey consisting of questions on demography, level of stroke disability and adherence to home-based exercises. **Results:** 74.1% of the respondents reported that the stroke patients in their care were adherent to the prescribed home-based exercises. The Pearson's Chi-Square analysis showed significant correlation between the level of adherence to home-based exercises with the timing of prescription given by the physiotherapists whereas no correlation with the stroke patients' degree of disability. **Conclusion:** From the perspective of family caregivers, most of the stroke patients in central region of Malaysia received and adhered to the prescribed home-based exercises.

Keywords: Family Caregivers; Home Care; Patient Adherence; Stroke

INTRODUCTION

In 2019, the Institute for Health Metrics and Evaluation (IHME) reported that stroke, or cerebrovascular disease, is among the five major causes of mortality in Malaysia. Stroke can be classified as ischemic or hemorrhagic, accounting for 80% and 20% of the total stroke cases, respectively (Alrabghi *et al.*, 2018). The rate of stroke in the last two decades has risen significantly as the number of elderly people with unhealthy lifestyle conditions has been increasing (Feigin, Norrving, & Mensah, 2017). On the other hand, the death rate for strokes has declined mostly due to the progress in acute healthcare; therefore, a larger number of stroke patients as well as the demand for post-stroke treatment are now seen in the world (Daly & Hale Collaborators, 2018). As a rapidly developing country, Malaysia is in need of strategizing a long-term care plan for stroke survivors with the aim of adequately regaining their functional recovery and good quality of life (Azlin *et al.*, 2016).

Lack of exercise can eventually lead to secondary complications in stroke survivors, such as decreased cardiorespiratory efficacy, muscle fatigue, loss of bone density, and thrombus formation caused by inadequate lower-arm blood circulation (Chin *et al.*, 2018). Low involvement in exercise, along with bad eating habits, has also been shown to be linked to stroke recurrence and additional morbidities (Chin *et al.*, 2018). Regular exercises, on the other hand, prove to be beneficial for physiological and cognitive improvements such as increased agility, coordination, cardiovascular health, and improvements in quality of life (Han *et al.*, 2017). As such, it is vital that stroke survivors take part in post-stroke exercise, particularly after returning from their hospitalization (Mohd, Yusoff & Singh, 2019).

Home-based exercise appeared to improve and urge stroke survivors to maintain an ideal degree of physical

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activity; a study has found that longer walking time is strongly associated with lower fatigue symptoms after stroke (Braaten *et al.*, 2020). It was also reported that over 45% of the stroke patients had inconsistent involvement in physical activities after being discharged from hospital care, leading to persistent post-stroke muscle weakness (Azlin *et al.*, 2016). A study from Teng *et al.*, (2020) stated that group exercise in a home program resulted in better functionality and prevented falls as compared to a non-exercise control group. A family caregiver or primary caregiver is an individual who plays a major role and spends time assisting with most of the activities of daily living (ADL) and caring for the stroke patient. Stroke is a long-term disability that limits the cognitive and functional abilities of stroke patients. Hence, they are highly dependent upon the family caregivers to perform the basic daily living activities as well as rehabilitation activities at home. Patients with a chronic disease may have an increased risk of non-adherence to prescribed home-based exercise therapy (Ricke, Dijkstra, & Bakker, 2023). There is a lack of studies done to elucidate the Malaysian stroke patients' adherence level to the prescribed home-based exercise. For this reason, this study conducted a survey to evaluate the adherence level of stroke patients to home-based exercise from the perspective of family caregivers.

Ethical Consideration

Ethical approval for this study was obtained from the Medical Research and Ethics Committee (MREC), Ministry of Health Malaysia on 21st April 2021 with reference number KKM/NIHSEC/ P20-2598.

METHODOLOGY

Participants

A convenience sample of 54 family caregivers of stroke patients participated in this cross-sectional survey after obtaining their informed consent. Participants were considered eligible if they were over 18 years old, fluent in English or Malay, and giving care to a stroke patient at home after their hospitalization. The participants were given the survey at the physiotherapy and stroke rehabilitation departments of three general hospitals in the central region of Malaysia.

Instrument

The survey questionnaire was divided into three sections: the first section requested demographic information concerning age, gender, and level of education; the second section assessed the perspective of the respondents on the degree of disability or dependence in the daily activities of the stroke patients who were in their care by using the modified Rankin Scale (mRS); and the third section assessed the perspective of the respondents on the adherence of the stroke patients to home-based exercise using the Stroke-Specific Measure of Adherence to Home-Based Exercises (SS-MAHE) which has been validated and showed good internal consistency (Cronbach = 0.89) in a previous study (Mahmood *et al.*, 2020). The participants received a one-time self-administered online survey questionnaire, and no follow-up was required for this study.

Data Analysis

The raw data was processed and entered for analysis using SPSS version 23. Categorical variables were expressed as numbers and percentages. Pearson's Chi-Square analysis was used to determine the association between adherence to home-based exercise and the following variables: stroke severity or timing of home-based exercise prescription. The statistical significance level was achieved at p 0.05.

RESULTS

Socio-Demography

From the 54 family caregivers who participated in the survey, 46.3% (n = 25) of the respondents were male and 53.7% (n = 29) were female. The family caregivers of stroke patients were mostly aged between 40-59 years old (38.9%), followed by 30-39 years old (22.2%), 60-69 years old (18.5%), 18-23 years old (3.7%) and above 70 years old (1.9%). As for the level of education, the family caregivers mostly graduated from secondary school (40.7%) followed by a diploma (24.1%) and bachelor's degree (14.8%). There were few who graduated from primary school (11.1%) while there were only three respondents with postgraduate degrees (5.6%) and another two (3.7%) described having other professional certificates. Table 1 provides an overview of the respondents' characteristics.

Table 1: Respondents Socio-Demography Characteristic

Sample characteristic		*n*	*%*
Gender	Male	25	46.3%
	Female	29	53.7%
Age	18- 23 years old	2	3.7%
	24- 29 years old	8	14.8%
	30- 39 years old	12	22.2%
	40- 59 years old	21	38.9%
	60- 69 years old	10	18.5%
	70 years old and above	1	1.9%
Education	Primary education	6	11.1%
	Secondary education	22	40.7%
	Diploma	13	24.1%
	Bachelor's degree	8	14.8%
	Master	3	5.6%
	Others professional	2	3.7%

Stroke Severity

The mRS is a 7-level scaling system for stroke disability that covers the complete range of functional outcomes from having no symptoms (scale 1) to death (scale 7). The mean (± SD) for mRS of the stroke patients was 4.1 (± 1.3) as rated by the respondents when they were asked to rate the degree of disability of the stroke patients in their care. As shown in Figure 1, there were five (9.3%) stroke patients with a scale 3 indicating slight disability, 16 (29.6%) with a scale 4 indicating moderate disability, 19 (35.2%) with a scale 5 indicating moderate to severe disability, and five (9.3%) with a scale 6 indicating severe disability in their functional outcomes. Meanwhile, nine patients had good functional outcomes with mRS scale 1 (5.6%) and scale 2 (11.1%) which indicate no symptoms and slight disability, respectively.

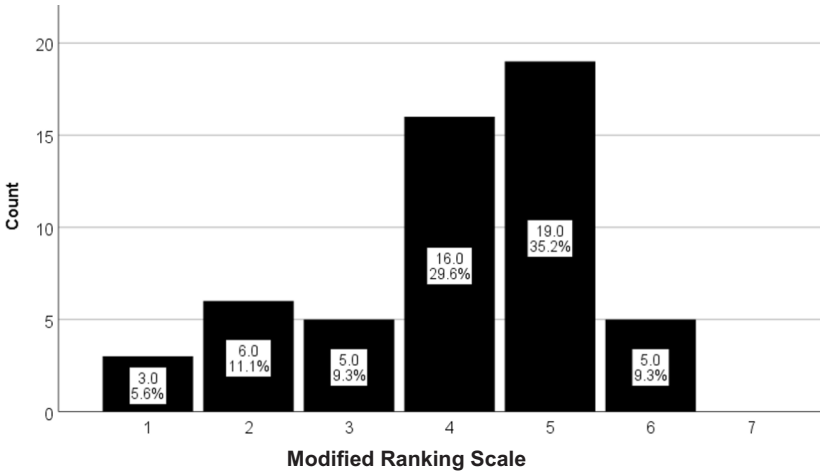

Figure 1: Distribution of Level of Disability among Stroke Patients from the Perspective of Respondents

Timing of exercises prescribed by physiotherapists.

From the survey, 17 (31.5%) of the respondents reported that the physiotherapists prescribed the exercises within the first week of stroke, and 15 (27.8%) respondents reported receiving the exercise prescription within one-month post-stroke. Twenty-two respondents reported either being unable to recall receiving an exercise prescription (25.9%) or being prescribed exercises within six months after a stroke (14.8%). Figure 2 summarizes the timing of home-based exercises prescribed by physiotherapists.

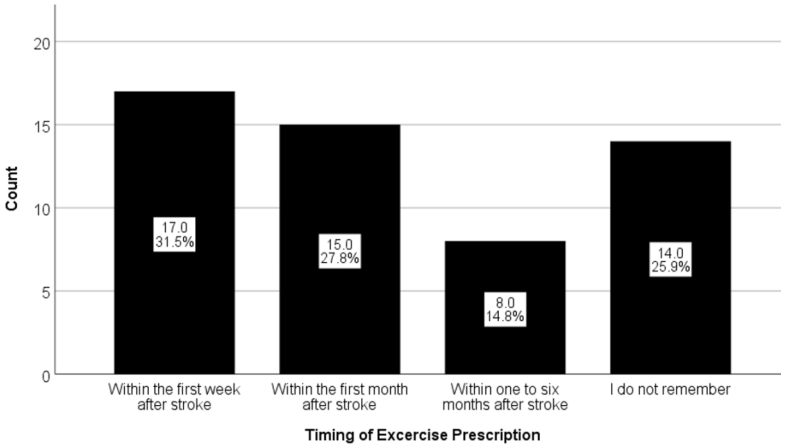

Figure 2: Timing of Exercise Prescription by Physiotherapists

Home-based exercises prescribed by physiotherapists.

The most common prescriptions received by the stroke patients from physiotherapists included 5–10 exercises (n = 26, 48.1%) to be performed once a day (n = 14, 25.9%), for 15–30 minutes (n = 21, 38.9%), and for less than 10 repetitions for each type of exercise (n = 23, 42.6%). All the respondents reported receiving specific intensities of exercises based on the Borg Rating of Perceived Exertion (RPE), whether less than or equal to scale 5 (n = 25, 46.3%) or more than scale 5 (n = 29, 53.7%). There were 30 respondents (55.6%) who reported receiving written prescriptions for exercises. Figure 3 summarizes the dosage of post-stroke exercises prescribed by physiotherapists.

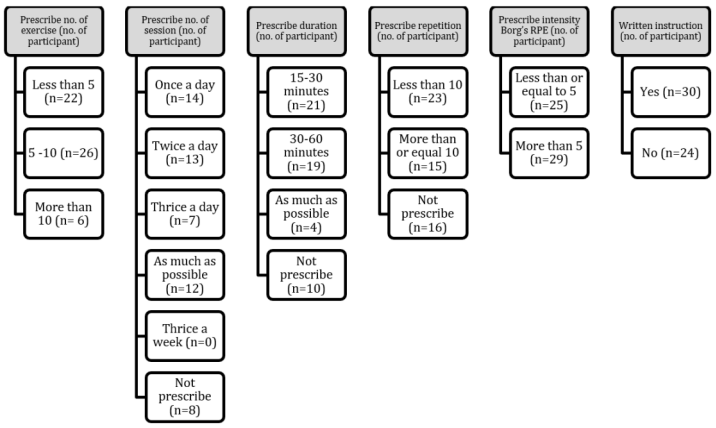

Figure 3: Dosage of Home-Based Exercise Prescribed by Physiotherapists

Adherence of stroke patients to home-based exercise

Fourteen respondents (25.9%) reported that stroke patients in their care abandon doing exercises at home. The remaining 40 respondents reported that the stroke patients in their care remembered the prescribed exercise and followed more than 70% of the prescriptions, which indicates that adherence to home-based exercises was achieved by 74.1% of the stroke patients. Figure 4 summarizes the distribution of adherence to home-based exercise among stroke patients from the perspective of family caregivers.

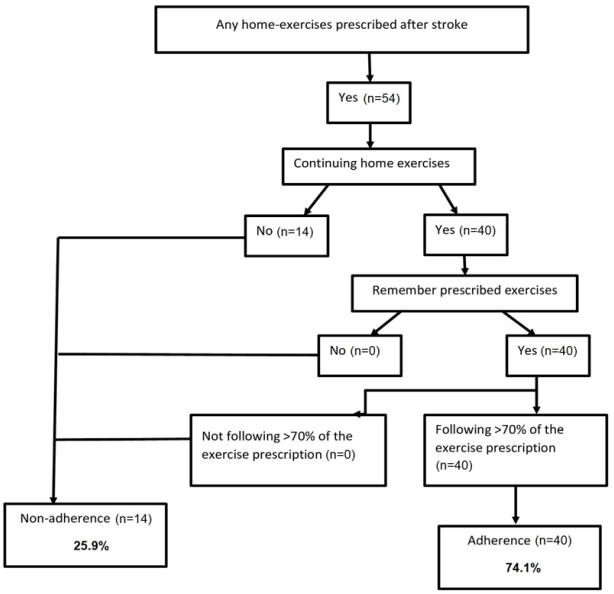

Figure 4: Adherence of Home-based Exercise among Stroke Patients

Correlation study

From Pearson's Chi-Square analysis, there was no association between the severity of stroke disability and adherence to home-based exercise among stroke patients from the perspective of family caregivers (p = 0.921). Meanwhile, there was a significant association between the timing of prescriptions given by the physiotherapists and adherence to home-based exercise among stroke patients from the perspective of the family caregivers (p = 0.001).

DISCUSSION

Family caregivers play a central role in assisting stroke patients in daily activities and self-care such as eating, bathing, grooming, dressing, continence, and mobility (Kong & Lee, 2014). According to the survey of this study, there were more women than men who took on the role of primary caregivers for stroke patients. It is a common Asian tradition that women are the family caretakers, where they are 'expected' to be in charge of nursing sick family members, partly due to the social role of gender identity, religious beliefs, and filial piety (Meira *et al.*, 2017). All respondents in this study have a certain level of formal education background that reflects the characteristics of the urban community in the central region of Malaysia. Previous studies reported that caregivers from urban areas have a relatively higher level of knowledge and greater access to media information and modern health services than those from rural communities (Genasan & Ramli, 2022; Molyneux *et al.*, 1999).

In this study, 74.1% of respondents reported that the stroke patients in their care adhered to the prescribed home exercises, while 25.9% were not following the prescribed dose. While most existing literature focuses on influencing factors and interventions for home-based exercise, there are few studies that report the adherence level to home-based exercise among stroke patients. A study conducted among stroke support groups in the Midwestern region of the United States reported that 98% of the respondents received a home exercise prescription, yet only 65.3% of those reported being adherent to at least part of the prescription (Miller *et al.*, 2017). Meanwhile, Ogwumike, Badaru & Adeniyi (2014) study in Kano, Nigeria, demonstrated that approximately 55.8% of stroke patients were adherent to home-based exercise, while 44.2% were not. In 2020, Mahmood *et al.*, conducted a study on 92 stroke survivors in coastal India and found that only 28% of the respondents were adherent to the prescribed home-based exercises, which was described as due to unclear instructions and an emphasis on exercises at home.

In this study there were 31.5% of the patients who received home exercise prescriptions within the first week after stroke. The dosages of home-based exercise prescribed by physiotherapists differ among the stroke patients due to the

different levels of stroke severity among them (Fujino *et al.*, 2021). Early intervention refers to initiating rehabilitation within 3 months after the onset of stroke, while initiation of rehabilitation after 3 months is considered late intervention (Winstein *et al.*, 2016). As stated in the current guidelines, exercising early after stroke provides maximum benefits to the patient's recovery (Lynch, Cox & Gall, 2014). Successively, this study further proves the benefit of early exercise, as the adherence to home-based exercises among stroke patients was significantly associated with the timing of exercises prescribed by the physiotherapists.

Approximately 55.6% of patients were given written exercise prescriptions. Receiving written instructions will help them remember the movements of the prescribed home exercises when they return home. According to Hillig, Ma & Dorsch, (2019), stroke patients increased their rate of repetitions of the exercise by 62% to 128% when given specific goal-oriented instructions as compared to non-specific instructions. Although written instructions are important, they should be complemented with verbal and written communications to ensure the patients' comprehension of the exercise's protocols (Falvo, 2010). Clear instructions and emphasizing the advantages of exercise by health professionals can greatly influence stroke patients to comply with the prescribed exercise. Kurtz (2002) reported that improved communication skills by the physician can improve a patient's performance and clinical outcomes.

This study also explored the family caregivers' perspective on the severity of stroke disability and assessed its association with the adherence to home-based exercises among the stroke patients in their care. It was reported that the mRS scale is feasible to use by both medical and family caregivers, and it has demonstrated a strong correlation with brain infarct volume, in agreement with other stroke assessment scales (Broderick, Adeoye & Elm, 2017). From the perspective of family caregivers, most of the patients that came to the rehabilitation hospitals had moderate to severe stroke symptoms. Smaller or moderate stroke severities were reported to have a greater capacity for a complete or near-complete recovery when compared to severe stroke (Teasell, Pereira, & Cotoi 2018). The smallest group of stroke patients to visit rehabilitation centers were patients with severe disabilities. This might be due to patients' severe immobility to travel to the hospital, and for that reason, severe stroke poses a significant challenge to the current healthcare and rehabilitation system in terms of post-stroke management (Teasell, Pereira, & Cotoi 2018). Interestingly, the degree of stroke disability did not reflect the adherence to home-based exercise among stroke patients, as no significant association was found between these two factors via Pearson Chi-Square analysis.

Apart from specific guidance or instructions for home-based exercise, there are several other factors associated with adherence to home-based exercise, which include self-confidence, self-motivation, previous adherence behavior, and social support (Essery *et al.*, 2017; Bachmann, Oesch, & Bachmann 2018). Since home-based exercise is to be conducted without professional supervision, the patients' self-motivation and self-confidence to complete the given tasks are strong predictors of their adherence. Patients with greater previous adherence behavior are also a strong factor that can predict their adherence level; this behavior could successively increase intrinsic motivation and the likelihood of persistence during home-based exercise activities. Nonetheless, social support from the family caregivers is very important to facilitate adherence by encouraging positivity and lessening stresses that arise from the illness while giving physical assistance.

Previous studies discussed some of the reasons for the non-adherence, which include worsening pain during the exercises, psychological factors such as stress and depression, a lack of supervision, and knowledge about exercises (Bachmann *et al.*, 2018; Mahmood *et al.*, 2020). The perception of giving late prescriptions can result in a lack of motivation for stroke patients, as constructive communication between the patients and healthcare professionals is a vital factor for patient compliance (Gabay, 2015). In addition, a lack of healthy physical activity from a previous lifestyle may disrupt self-motivation and discipline and therefore influence non-adherence to home-based exercise (Ogwumike, Badaru & Adeniyi 2014). It is estimated that 31% of the stroke patients developed post-stroke depression, which consequentially not only reduced the patients' confidence and affected the functional rehabilitation process but also deteriorated their conditions and increased the rate of mortality (Bartoli *et al.*, 2018). A reciprocal association of depressive symptoms was observed between the stroke patients and the family caregivers (Maholtra *et al.*, 2016); hence, this indicates the significant role of family caregivers' supports in the neuropsychological condition of the stroke patients. Evidently, the family caregivers played a crucial role in the stroke patients' social participation, which, therefore, decreased their level of depression during the chronic phases (Vadas & Kalichman, 2020).

Limitations

This study applied convenient cross-sectional sampling with a modest sample size of the participants, which therefore may present a lack of generalizability. However, it has captured a representative sample of family caregivers of stroke patients attending clinic sessions in tertiary rehabilitation centers. This is nevertheless the first study, to the best of our knowledge, to provide information on the adherence of stroke patients to home-based exercise prescribed by physiotherapists from the perspective of the family caregivers in the central region of Malaysia.

CONCLUSION

Seventy-four percent of the family caregivers in this study perceived that the stroke patients in their care were adhering to the prescribed home-based exercise. The adherence to home-based exercises was shown to be associated with the timing of prescriptions given by the physiotherapists but was not associated with the degree of stroke disability. This study may therefore further encourage stroke patients and their family caregivers that, regardless of the stroke disability, adherence to home-based exercise can be achieved successfully by receiving early and specific exercise prescriptions from the physiotherapists, aside from the constant support by the healthcare systems and the family caregivers.

Conflict of Interest

The authors declare that they have no conflict of interests.

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