A QUALITATIVE STUDY OF 4-6 MONTHS POST-STROKE SURVIVORS' PERCEIVED BARRIERS TO HOME EXERCISE PROGRAM

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ABSTRACT

Post-stroke disability rate in Malaysia has subsequently increased throughout the year. However, despite knowing optimal motor recovery occurs within the first six months of stroke, Home exercise program (HEP) engagement in stroke survivors was found low. Therefore, to reduce the economic burden of the nation, a study was conducted to find out the barriers to HEP in four to six months post-stroke survivors concerning the bio-psychosocial factors. Phenomenology qualitative approach with snowball sampling method was used, and a semi-structured one-to-one interview was conducted until the fifth when content saturation was achieved. Barriers contributed by biological factors (physically tiring, fear of fall, and other medical conditions); Psychological factors (mental tiring, not motivated, impatient, forgetful, fear of relapse, anger, disappointment and stress); sociological factors (support, daily routine, and lack of stroke knowledge). Psychological and sociological factors were found to have a great impact on HEP engagement. Hence, physiotherapists play a huge role in educating stroke survivors on the importance and difference of HEP compared to normal physical activities like walking.

Keywords: *Home Exercise Program; Motor Recovery; Physiotherapists; Stroke Survivors*

INTRODUCTION

Cerebrovascular accident (CVA) is the sudden loss of neurological function caused by interrupted blood flow to the brain and is commonly known as stroke. It happens to people of all ages and results from a blood clot that impaired blood flow which causes deprivation of essential oxygen and nutrients to the brain or ruptured blood vessels causing leakage in the brain and it is known as ischemic stroke and haemorrhagic stroke respectively (Sullivan, Schmiz and Fulk, 2014). There are various kinds of risk factors for stroke which included

health conditions such as hypertension, cardiovascular diseases, and diabetes, besides, lifestyle factors like smoking, alcohol consumption, and obesity were found to contribute to stroke risk as well (Teh et al, 2018).

Each year, there were roughly 79, 5000 people experienced a new or recurrent stroke (Benjamin et al, 2018). It is the third leading cause of mortality in Malaysia since 2005 with an increase in premature death of 5.9%. Therefore, it remains one of the major public health problems in the world (Lee et al, 2017). Besides, stroke patients that do not go through proper rehabilitation will lead to long-term disability. Data from the National Stroke Register provided evidence that only about 20% of patients surviving stroke can return to their former work (Ekushera and Damulin, 2015).

In 2014, Ng reported that in Malaysia, the prevalence of depression in post-stroke patients is higher compared to those facing other medical issues. Stroke affects not just the physical part but as well as the mental part of a person as it might result in a disrupted sense of self by affecting one's age-normative roles and self-image. Being physically disabled will be a challenge for stroke survivors as they will need to adapt to restrictions in daily activities in terms of eating, bathing, self-managing, traveling, etc. However, rehabilitation after stroke was found to bring significant gains in physical ability and decreased dependency (Connor et al, 2011).

Plastic reorganization occurs immediately after the stroke and it provides a foundation for the recovery of motor function. Studies have shown that regardless of the therapeutic intervention, the process of spontaneous motor recovery happens in the first four weeks and tapers off over six months. However, motor improvement is still seen in chronic stroke (>1 year) through mass practice (Li, 2017). Therefore, repetitive and task-specific practice at a high intensity should be done within six months for optimal motor recovery. However, a few studies found that physical activity among early post-stroke survivors was low and post-stroke fatigue has eventually resulted in a sedentary lifestyle (Bernhardt et al, 2004; Tseng et al, 2010).

In Malaysia, the number of stroke patients has subsequently increased throughout the year and the ratio of patients to physical therapists has therefore increased. Hence, the outpatient rehabilitation appointment in the Malaysian government hospital is only available once a month or mostly twice, depending on the nature and severity of the stroke. Therefore,

dependency on physiotherapy sessions alone is not enough to promote motor relearning. Thus, for spontaneous motor recovery, a customized home exercise program (HEP) needed to be conducted at home multiple times throughout the day as moderate-intensity exercises were usually prescribed to prevent fatigue (Smith et al, 2011).

METHODOLOGY

This study aims to find out the barriers to HEP in four to six months post-stroke survivors concerning the bio-psychosocial factors. Qualitative research serves to explore the thoughts and feelings of a participant's experiences and attempt to interpret the phenomena through different empirical materials like observational, visual texts, interviews, etc (Denzim and Lincoln, 2005).

Sampling serves as a process of population searching from a part to represent the whole. However, the circumstances might not be theoretical or practically sensible in applied social research. Therefore, the non-probability sampling method meets the appropriateness as an alternative.

In a qualitative study, the number of participants in particular to the different methodology is not determined or standardized. Hence, decision-making by the researchers is required to find a balance in the number of participants to prevent superficial data findings but to produce highly relevant information for analysis from a small group of well-selected participants. Information gathering stops when the redundancy of information appears (Cleary et al, 2014).

Ethical approval for the study was first gained from the university, while components taken into consideration include voluntary participation, written informed consent on the study and permission for voice recording, transparency on aims and objectives so as to prevent any possible misleading information while informing participants on the right to withdraw at any stage. In addition, the language and words used were extra careful to not cause any harm or any feeling of inferiority especially when it is about personal life stories and experiences (Yip, Han and Sng, 2016).

Qualitative data are different from quantitative as they are non-numerical. There are different categories like content analysis, narrative, discourse, framework, and grounded theory. While for this study framework analysis was found suitable to identify a thematic framework that is

flexible and involves six common steps which are familiarization, coding, themes generation, themes review, defining and naming themes, and lastly write up (Braun and Clarke, 2006; Maguire and Delahunt, 2017).

Manual transcription of verbal data from interviews was done. Verbal and non-verbal utterances like coughs were included in the transcript. Auto transcription is available and saves time, however, the chances for early-stage analysis were lost and the accuracy is not guaranteed. Therefore, the transcript needs to be rechecked against the original audio recording. Although manual audio transcription is time-consuming, however, it was recognized as an interpretative act rather than simple text conversion as it is an active act that has contributed to easier pattern identification later on as the contents are well understood and known. Transcripts were then printed out for easier reading and main points highlighting. Repeated reading was done to make sure that the depth and breadth of the content were familiarized. And throughout the process of reading, notes were done and ideas were marked down in the blank spaces around the printed transcript before proceeding to formal coding. Therefore, writing runs along with data analysis by jotting down potential coding schemes and ideas.

All the raw data extracted were coded, and collated together with similar code into meaningful groups. It was found that some were fitted into many different themes while some doesn't fit into any. Therefore, some extracts were coded once, while some many times or even not coded. The relationship between the codes was determined and codes were then sorted into different potential themes and subthemes. Extra extracts that don't fit into any theme were not discarded as they might be able to combine with other themes or subthemes. For a better visual and easier organization process, a thematic table was created. Code and themes were further reviewed to refine and to make sure that themes created adequately capture the contours of coded data. Besides, the thematic map was further investigated as a whole to review the validity of individual themes. Themes were then named concisely and defined. Subthemes were identified as it is important in providing a hierarchical meaning by structuring a complex theme. And for the last step which is writing up was done by narrative analysis with sufficient evidence to support the themes while providing concise yet logical content to be read.

RESULTS AND DISCUSSION

A total of 5 participants were open to being interviewed and at the 5th interview, redundancy of information occurs. The characteristics information of the participants is shown in table 1.

Through analysing, extracts were coded and grouped into three main themes which are barriers to HEP contributed by biological, psychological, and sociological factors.

Table 1: Characteristics

CHARACTERISTICS	PERCENTAGE (%)
Age range	
30-40	40
41-50	20
51-60	20
61-70	20
Gender	
Male	40
Female	60
Education level	
Primary	0
Secondary	20
Tertiary	80
Race	
Chinese	80
Indian	20
Malay	0
Religious	100
Non-religious	0
Relationship status	
Single	40
Married	60
Occupation	
Employed	60
Retired	40
Other medical problems	
Present	60
Absent	40

Biological factors are anything that has affected the function and behavior of a living organism. It includes genetic, physiological, physical, and others. The barriers determined concerning biological factors include physical issues and other medical conditions.

Post-stroke exertion fatigue was found to be common and is related to musculoskeletal and cardio-respiratory fitness. One participant claimed that he is physically tired and fatigued after an hour of physiotherapy sessions. ‘Usually, after I do the physio sessions ah, I get very tired.

I'm just fatigued already la, so usually after that one-hour session, I will just rest already.' Other participants seemed to agree that even if they would like to push more, their physical capability was limited, for example: 'Sometimes it's tired, that's why you stop. Depends on your tiredness, sometimes I walked two to three rounds also very tired already.'

On the other hand, stroke impairment serves as one of the factors as well. 'I have numbness over my Left body all of the time.' And 'the shoulder is painful.' And thereby impairments lead to a barrier commonly found among stroke survivors which is the fear of falling especially when no one is around. While some are because of other medical conditions like high blood pressure, diabetes, and arthritis. One of the participants was asked about her daily routine and she answered: 'sit down and play games over the phone. Because I have arthritis over all the joints.'

However, two claimed that physical barriers are nothing compared to mental barriers. 'I feel the mental state is much more important. 'Or else you will feel like you are doing it for the sake of doing it, but not for yourself.'

Psychological factors were further classified into mental and emotional. Barriers reported contributing to the mental state include being mentally tired, lack of motivation, and different priorities. Although some claimed physical tiring to be one of the reasons HEP was not done but also commented 'I think it's mentally tiring. I think it's not physically tiring, but because I've been doing it for months.'

Hence, the level of stroke knowledge was found to be the greatest contributor to fear as four out of five participants expressed not understanding how stroke happens and the consequences of it as illustrated in the statement: 'The biggest part is the not knowing, not understanding, because not knowing triggers a lot of over-thinking. Not understanding triggers, a lot of fears.'

A stroke is a life-threatening event and results in a drastic change in lifestyle and self-perception which might disrupt one's identity. According to the Kubler-Ross Grief Cycle, after the first stage of denial and isolation, individuals will enter into the second stage where anger starts to build up.

'I remember telling my girlfriend I am so angry but I have nowhere to release my anger.' [J] and 'the emotions and the feelings they fluctuate you see. Some days are good and some days you are more hopeful. Some days you are really very hopeless. And some days you're really angry. I was getting very moody and getting very angry easily. So, when I had most of the days, I have suicidal thoughts, you know like crying for no reason.'

However, as much as emotional fluctuations are normal, a major behavioural change might indicate a sign of depression. Two participants rejected the referral to visit a psychiatrist in the early stage of stroke and one of the participants admitted the decision was a mistake as he was diagnosed with depression after three months.

Although it is important and was preferred by most stroke survivors to conduct the exercises in a group, some expressed a feeling of disappointment and frustration. 'Whenever I see someone improve but I'm not improving, I am really disappointed [Sobbing].' And when negative emotions like disappointment and frustrations hindered one's mental state, competence to engage in HEP will get affected.

Interestingly, one participant claimed that the more you force yourself to exercise, the more stressful you will be. 'So, I will just do, if I feel good, then I will just continue doing la, if I don't, I will just stop and rest and called it a day.'

Sociological factors are problems raised by environmental or cultural rather than psychological or personal. Subthemes are lack of support from people around and lack of stroke knowledge. Family and friends play a huge role in a stroke patient's rehabilitation process as emotional support is essential. Therefore, factors like staying alone, and poor family support were found to be one of the barriers to HEP as it further affects an individual's emotional state. One participant expressed her anger, 'because they are lazy and don't want to help me so they say I do too many exercises. But personally, I think the exercises I do are not enough. So, I am actually very angry.' A few participants mentioned the importance of having a family as the greatest support in times of need as 'you need people around you, support, to tell you 'you don't do enough, you are doing too much and the importance of having someone around to journey with'. 'Wife was there with me most of the time or so and so she also pushed me on or spurred me on. So, although I feel unmotivated to go and do the physio, I still went la nonetheless.'

Hence, physiotherapy plays a major role in educating patients on the goal behind every home exercise given and its importance of it. Patients have to realize that HEP is not given just to promote physical activity but to train targeted muscle groups and a specific movement to resolve impairments so that daily performance can be optimized. Besides, HEP promotes a better quality of life and functions while reducing disability and depression (Chaiyawat et al, 2009).

The importance of HEP needs to be made known to not just the stroke patients but as well as their family members. Some stroke survivors were found to be more dependent on the career and rehabilitation team, therefore on days where no rehabilitation sessions were scheduled, HEP will not be done as it was claimed that supervision is important. A survey done in 2012 found that stroke survivors preferred exercises to be demonstrated or to be conducted in a group or with family members (Banks et al, 2012).

However, one's exercise preferences vary according to an individual's current activity levels, age, and psychological wellbeing just to name a few. The prevalence rate for post-stroke fatigue was found high and was up to 92% and comorbidities might contribute as one of the barriers to HEP. This happens as in some cases; the energy cost of walking in stroke survivors is doubled compared to a normal person as the debilitating motor effects reduce one's mechanical efficiency (Roth and Harvey, 2000). Therefore, family members and friends were worried and were not sure what extent of physical activities will be too much for a stroke survivor. Hence, to be on the safer side, family members will not allow house chores to be done or accept help from the stroke survivor. Therefore, healthcare providers play a role in educating and helping family caregivers as they prepare to take on a new role. And at the same time, it is an opportunity to build a closer relationship with the survivor's family to better understand the barriers faced by the patient. However, sadly most of the time as much as family caregivers want to engage with healthcare providers, they don't know how and what to ask (Creasy et al, 2013). Hence, healthcare providers should take the initiative.

Besides external factors, there are personal factors like unfavorable comparison with other stroke survivors' progress and struggling with the fear of relapse. Stroke survivors perceived that a lack of personalized information and understanding of the effects of stroke leads to substantial fear of relapse (Morris et al, 2007; Morris, 2011). Therefore, communication and patient education are important and a constant reminder of short-term goals and daily

achievements will be helpful. In addition, physical activity counseling intervention like follow-up calls can be made as it was found to result in a greater engagement in HEP for patients that are going through rehabilitation (Van Der Ploeg, 2007).

CONCLUSION

In summary, the effect of stroke affects the physical and mental state of stroke survivors while psychological and sociological factors were found to have a great impact on HEP engagement. Patient education is vital and the importance and difference of HEP from normal physical activities like walking need to be made known as a singular feature influenced adjustment. Also, the mental and emotional state of a stroke survivor should be looked after as optimal functional improvement will not be achieved if patients are reluctant to participate in exercises. Besides, medical professionals should ensure good communication and understand the needs of patient perceptions by providing emotional care.

The non-proportional quota sampling method was first taken into consideration to further determine the barriers to HEP faced by four to six months post-stroke survivors of different ages who are currently going through different life phases. However, access to hospitals and centers was denied due to the pandemic and with limited resources and the need for quick implementation, the snowball sampling method was applied instead. The Snowball sampling method might limit the size of the population covered as participants might share the same traits as the care received. Therefore, a larger study needs to be conducted to validate the results reported in this article. Future research should include stroke survivors of different backgrounds like income level and severity (National institutes of health stroke scale) should be taken into consideration as the functional improvement varies thereby perceptions and mental state might be different.

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