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# A Qualitative Study Exploring Understanding and Perceptions of Stroke Survivors Regarding Healthy Lifestyle Changes for Secondary Prevention

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## ABSTRACT

**Introduction:** This study explored stroke survivors' understanding regarding stroke, the perceived facilitators and barriers of healthy lifestyle changes, and provision of secondary prevention education. **Methods:** Semi-structured interviews were conducted with 22 stroke patients (13 males and nine females; aged 34-80 years) who were attending rehabilitation clinics in three Malaysian hospitals. Each interview was audiotaped, transcribed, and analysed using the framework approach. **Results:** Six themes were reported: understanding of stroke; facilitators of healthy lifestyle changes; barriers of healthy lifestyle changes; food taboos; recovery; and provision of secondary stroke prevention. A third of them were uncertain about the cause of stroke and the perception towards risk of recurrent stroke varied widely. The lack of secondary prevention education was obvious although many had received general verbal advices. Several personal, social, and environmental factors were identified as the facilitators or barriers in healthy lifestyle participation. Food taboos were common and had become one of the barriers in practising healthy eating practices. Families had a strong influence on the patient's belief and behaviour changes, both in positive and negative ways. Besides, patients tended to have a problem in information recall, while some faced confusion during the early stages of stroke recovery. **Conclusion:** More efforts to improve knowledge regarding cause of stroke and secondary prevention strategies are needed. Use of appropriate behavioural changes strategies, family-centred approach and continuous health education are necessary to facilitate patients' efforts at making successful lifestyle modification after stroke event.

**Keywords:** Stroke, Secondary prevention, Perception, Health behaviour

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## INTRODUCTION

Despite advances in reperfusion and pharmacological therapies for stroke patients, recurrent stroke continues to account for 25–30% of all strokes (1). The actual national incidence and prevalence rates for recurrent stroke are not available in Malaysia although there are hospital registries that reported recurrent stroke is common with prevalence of about 20% among stroke survivors (2,3). Despite higher risk of recurrent stroke, many stroke survivors continue to have poor risk factors control and unhealthy pre-stroke lifestyle behaviours (4–6). A recent cross-sectional study conducted in East-Coast region of Peninsular Malaysia among 398 stroke survivors attending outpatient clinics in hospital supported the findings (7). It was found that 52% of them had elevated blood pressure, 7% of them were active smoker, 65% were overweight and obese, and 65% had low physical activity levels. Besides, poor dietary adherence among stroke patients were also observed with regards to sodium, saturated fatty acids and fibre intake.

Studies designed to change multiple health behaviours and reduce cardiovascular risk among stroke survivors appears to be promising yet their effectiveness have been largely ineffective or inconclusive (8–11). The limited success of secondary prevention interventions might be explained by difficulty and challenges in initiation and maintenance of health behaviours among stroke patients. In addition, stroke patients were found to have poorer risk factors control after discharge as compared to those with cardiovascular diseases although both often shared the common risk factors (4,12). The reasons

behind this phenomenon are not clear but it may be linked to patient's different perception regarding risk of future illness (13–15). Moreover, very poor knowledge regarding risk factors is consistently reported among inpatient stroke survivors from different countries including Malaysia (16–19). Although it would be expected that patients would have more knowledge of risk factors some months after stroke, however studies have showed contradicted findings (20,21).

Participants usually make healthy lifestyle choices based on their understanding or as a matter of common sense (22), although poor knowledge and erroneous perceptions have been reported in some studies (23,24). Besides this, stroke-related impairments (physical, cognitive, and emotional conditions) have further restricted a patient's ability to conduct lifestyle modifications (25–27). Most of these studies however have been conducted in Western countries. Therefore, more research is needed to find out why some stroke patients change their health behaviours while others do not and their current understanding and educational needs regarding future stroke prevention in Asian context. These will be better captured by using a qualitative study than quantitative study to help to improve the healthcare services in secondary prevention management.

Therefore, we conducted a qualitative study, which aimed to explore: a) understanding of stroke; b) perceived facilitators and barriers of healthy lifestyle changes; and c) provision of secondary prevention education. The novelty of this study is its finding will assist us to develop a lifestyle interventional study which will be implemented in the next phase of our study targeted to improve knowledge and adherence of patients towards secondary prevention strategies.

## MATERIALS AND METHODS

All stroke patients who attended the rehabilitation department in three public hospitals were approached between 1 August 2019 and 30 November 2019. These hospitals were Hospital Tengku Ampuan Afzan Kuantan Pahang, Hospital Sultan Haji Ahmad Shah Temerloh Pahang, and Hospital Sultanah Nur Zahirah Kuala Terengganu. The patients were purposively chosen according to these criteria: if they were diagnosed with stroke, aged more than 18 years, and able to understand and speak Malay. Meanwhile, adults with severe language or cognitive impairment, on long-term tube feeding, suffering from contracture deformity or having severe psychological issues (severe anxiety or depression) were excluded. The cognitive (assessed using Mini-Mental State Examination) and psychological status of the patient was obtained from the latest medical notes. Estimated duration of the interview session and the scope of topic were explained to patient before the survey. Patients who were unwilling to share their thoughts or in a rush were also excluded. Ethics approval had obtained from the Medical Research and Ethics Committee [NMRR-19-1415-47421] and University Human Research Ethics Committee ([UniSZA/UHREC/2019/102). Written informed consent had obtained from all patients.

A semi-structured interview was developed and was piloted with two patients who met the inclusion criteria to enhance the main researcher's qualitative interviewing skills and refine the questions if deemed necessary. The content of the interview protocol was validated by expert panels from nutrition and nursing fields. The interview protocol was amended following the pilot testing. Questions that were unclear or difficult to understand by the patient were identified and refinement of the interview guide was done. Thereafter, in-depth interviews of approximately 30 to 70 minutes in duration were conducted in the Malay language and in a private room in the selected rehabilitation clinic. Twenty-two interviews were conducted by the main research assistant. Most of the patients were accompanied by their caregivers during the interview sessions as they were more comfortable with their caregivers around. Patient was the main respondent who involved in the interview process. The presence of caregiver however was helpful in facilitating patient's recall of the past events accurately particularly pertaining to the experiences in the acute phase as well as giving cues on the reliability of the self-reported lifestyle practices at home.

Important points and observation of non-verbal expression were written down as field notes after each interview process. Data collection and data analysis were concurrent, and data collection was continued until data saturation was reached. Data saturation was said to be reached when no new code occurred in the data and any additional data did not lead to any new emergent theme. All data were audio-taped and transcribed verbatim. Based on findings from previous studies, the sample size required was between 20-40 participants (25,26). The initial target of sample size of this study was set at 20 patients.

The internal validity of this study was established by patient validation on the transcripts by allowing the patient to check the transcript and made sure that the information was correctly interpreted during the interviews. The conduct of all interviews by only the main researcher based on the semi-structured interview protocol confirmed the reliability of this study. Strategies for trustworthiness and credibility included triangulation (interviews and field notes), team peer debriefing, and the use of verbatim quotations. Then, the framework approach was used during data analysis to identify key issues and themes (28). It involved "familiarisation, identifying a thematic framework, indexing, charting, mapping, and interpretation"(28). This framework approach allowed the inclusion of a priori and emergent concepts in coding. A prior concept in this study, related to healthy lifestyle categories of diet, exercise,

and smoking and was guided by some of the constructs in behavioural change theories (Health Belief Model and Social Cognitive Theory) as identified in previous research (26).

## RESULTS

Twenty-two patients participated in the interview, consisting of 13 men and nine women who ranged between 34 to 80 years of age. Seventeen participants were of Malay descent, while four were Chinese and one was Indian. Most of them were married, whereas two were widowed and two were single. Table I provides the socio-demographic and clinical characteristics of the participants. This study reported six main themes, namely: 1) understanding of stroke; 2) facilitators of healthy lifestyle changes; 3) barriers of healthy lifestyle changes; 4) food taboo; 5) recovery; and 6) provision of secondary stroke prevention.

### Understanding of stroke

i. Mechanism and risk factors of stroke

Many participants tended to relate stroke with the brain (n=15), blood vessel (n=16), and underlying diseases. A third of the participants, however, had difficulties to explain the cause of stroke (n=7):

"Stroke may have originated from our thoughts, we are too stressful and tend to overthink…The doctor never told and I'm also not sure." (P10, with underlying hypertension and hyperlipidaemia)

"I'm not sure the cause of stroke…My mother in law had stroke attack although she doesn't have any underlying diseases. Probably the blood vessels in the heart area or other places were clogged." (P15, with underlying hypertension and diabetes mellitus)

**Table I: Socio-demographic and clinical characteristics of stroke survivors (n=22)**

| | n |
|---|---|
| **Sex** | |
| Female | 9 |
| Male | 13 |
| **Ethnicity** | |
| Malay | 17 |
| Chinese | 4 |
| Indian | 1 |
| **Age** | |
| 30-39 | 2 |
| 40-49 | 2 |
| 50-59 | 9 |
| 60-69 | 7 |
| ≥70 | 2 |
| **Marital status** | |
| Married | 18 |
| Single/widowed | 4 |
| **Stoke event** | |
| First | 18 |
| Recurrent | 4 |
| **Underlying diseases** | |
| Hypertension | 22 |
| Diabetes Mellitus | 11 |
| Hyperlipidemia | 16 |
| **Stoke event** | |
| Ischaemic | 20 |
| Haemorrhagic | 2 |

Several participants had doubts and disagreement regarding the relevance of underlying diseases with the incident of stroke (n=4):

"The doctor told me that my stroke was due to high blood pressure and uncontrolled diabetes… But my blood pressure at that time was not extremely high (only at 150)… My blood glucose level was also not very high… at 17 only. You will get stroke no matter what readings you have." (P7)

"I'm not sure regarding the cause of stroke. We had tried to ask the doctor regarding the cause of stroke during admission. At that time, my blood cholesterol level was only 5.8. When we discussed with my friends, 5.8 was not considered high." (P3)

Without this knowledge, it is uncertain that stroke survivors will realize the importance of making lifestyle changes to modify the underlying risk factors. These patients were less likely to make successful lifestyle changes as they were uncertain regarding what changes to be made. Besides, participants tended to reflect on their past bad lifestyle habits, neglect of medical care, and overworking issues when discussing the risk factors of stroke:

"Maybe due to diet, previously I loved to eat meat and high cholesterol foods." (P22)

"Stroke is caused by stress… I had a stroke attack when I was selling stuff in a night market, I didn't get enough rest and sleep at that time." (P7)

ii. Perceptions regarding the risk of recurrent stroke

A majority of the participants were aware of the risk of recurrent stroke. Their feeling of vulnerability to recurrent stroke, however, varied widely and these affected their decision to make behavioural changes:

"I don't know. If it happens again, just let it be. It feels like fate. I can't do anything…" (P9, who continued to smoke soon after stroke event)

"If you have stroke at your left side, the weaknesses are usually permanent, and you are less likely to get repeated stroke. My families were shocked when they found out that I had repeated stroke this time." (P13, who practiced unhealthy eating habits and sedentary lifestyle after the first episode)

### Facilitators of healthy lifestyle changes

A majority of the participants reported having made changes in either single or multiple health behaviours following their stroke event. A third of them, however, continued undesirable health behaviours. Using the social cognitive theory (29), perceived facilitators and barriers for each subcategory (diet, exercise, and smoking) were presented under the following thematic areas: i) personal factors; ii) social factors; and iii) environmental factors.

i. Personal factors:
a. Diet
Personal factors such as fear of uncontrolled risk factors (diseases) or new stroke, wish to become healthier, self-discipline, and usual dietary habits were driving forces in practicing healthy eating:
"I had cut down fat intake because afraid of high cholesterol level (near 6.0). I'm scared of having repeated stroke, that's why must control diet. (P7)
"The main driving force is yourself and you want to be healthier and live longer, so you must follow other people's advice (on eating)." (P21)

b. Exercise
Being keen to recover (such as achieving independence and to walk again) positively contributed towards a more active lifestyle (n=10):
"During a stroke attack, I asked the doctor regarding my chance of recovery or getting healthy again. He said the chance was about 50 per cent. So, you need to exercise a lot. Since then, I am determined to do exercises. The main motivation is I want recovery." (P9)
"I often come to exercise in hospital because I want to have faster recovery. I want to be independent and able to wash own clothes." (P1)

c. Smoking
Desire for better health and self-determination were personal factors which motivates participants to quit smoking after stroke event:
"For me, it is dependent on your self-determination and desire to change. If we wish to change (to quit smoking), we shall be able to do it." (P10)
"Smoking can lead to many diseases. I'm not sure regarding the association between smoking and stroke but I think those who smoke will have higher risk of stroke. The main factor which motivates me to quit smoking is thinking about health." (P18)

ii. Social factors
a. Diet
Participants were more successful in dietary changes if other family members or health professionals provided encouragement in making dietary changes:
"I think my family takes good care of me regarding eating…They help me to prepare food. They have changed the recipe for the whole family." (P20)
"My wife plays an important role in helping me making dietary changes. Initially I always argue with my wife regarding food choices. She helps me a lot in cooking and I have become more conscious in what I eat now. Discipline is also important." (P13)

b. Exercise
Having assistance to exercise was regarded as necessary and important to establish and achieve their exercise regimen at home:
"My sister assists me to do exercises every night. She helps me a lot and support me to do exercise." (P20)
"I wake up early in the morning, and my husband always ask me to go for a walk first… Family members keep me accompany and bring chair for me to sit whenever I practise walking. Previously I was afraid to fall down but now I'm getting better at walking." (P16)

c. Smoking
Some participants were advised by doctor or friends to stop smoking after stroke:
"To be honest, the doctor told me that cigarette smoking is associated with many diseases and advised me to quit. I took the advice and quit smoking immediately." (P18)
"I heard people (friends) said that we must quit smoking and alcohol. I had quit smoking ever since." (P1)

iii. Environmental factors
a. Diet
Some participants expressed that it was much easier to sustain healthy eating by staying at home:
"Since I'm eating at home most of the time, I still can limit what to eat. The main motivation of making dietary changes (stop taking teh tarik) is that I couldn't find the sweet condensed milk at home (his wife has stopped purchasing after the stroke event)". (P6)
"My wife helps me a lot in controlling my food intake since I'm eating at home now. I am able to limit foods such as red meat." (P22)

b. Exercise
Having exercising equipment at home was considered helpful, although some of them felt that it might not be necessary (n=7):
"There is a bicycle at home, which I borrowed from my friend, and it is helpful. I use it every day." (P20)
"I don't have any exercise equipment at home. I don't think it is necessary to use exercise equipment, it can be replaced with something else." (P16)

c. Smoking
Some participants informed that they quit smoking because of lacking access to cigarettes:
"I had quit smoking for the past two years. The motivation to change is because I'm not feeling well. I can't walk and thus unable to purchase new cigarettes." (P3)
"Initially I was able to quit smoking because doctor and family had prevented me from spending time around the mamak stall (afraid offering of cigarettes from other friends). I stay at home most of the time." (P22)

**Barriers of healthy lifestyle changes**
i. Personal factors
a. Diet
Difficulty to change old habits and lacking knowledge of dietary recommendations were among most cited personal barriers in adopting healthy eating (n=9):
"It takes time to change as we are used to our old food habits… I feel bad after being advised on slight dietary changes. For example, taking vegetables in soup without stir-fried, or having fried foods once or twice per week

(instead of every meal). It is hard to accept that …"(P13)
"I'm not sure about the dietary recommendations for stroke patient. Just now the physiotherapist told me that I can eat all kinds of foods but in moderation. But I'm still wonder what kind of foods are allowed…I know about food pyramid, have seen the picture in clinic… but it is hard to practise. I've never heard about the Malaysian Health Plate recommendations." (P6)

Furthermore, personal physical difficulties such as chewing difficulties (n=4) and poor appetite (n=6) were considered as barriers in sustaining healthy dietary changes:
"Previously I weighed more than 70kg, but it dropped drastically to 56kg… I don't have any appetite to eat and my food tastes have changed. My family is still offering my favourite food (sugary drinks and fatty foods) since they are more worried about my decreasing appetite… Besides I'm toothless and my artificial denture didn't suit me well. I can't eat vegetables with bare gum." (P3)
"I have poor appetite issue… I can't smell beef or durian, I will feel dizzy. Previously these are my favourite foods. So, if I wish to eat something, my wife will prepare for me. Like for today, I wish to eat only instant noodles." (P22)

b. Exercise
Laziness emerged as the strongest barrier for not doing or achieving the recommended activity levels at home (n=13):
"But currently I still haven't reached my exercise goal. I have the knowledge. The main obstacle is laziness." (P6)
"At times, we become lazy and tend to fall asleep when repeating the same exercise regimen. Unlike doing massage, people will do it for us. But for exercise, we need to put in effort ourselves". (P2)

Furthermore, fear of falling, fatigue, and pain appeared to contribute towards personal difficulties in maintaining exercise after stroke (n=9):
"I'm still not confident to start walking. I'm scared whenever I start walking and fear that my condition becomes worse after falling" (P3)
"It is difficult to initiate exercise after stroke. I easily get fatigue… I am unable to jog now. I only can walk slowly." (P8)
"The main obstacle of initiating exercise is having knee pain. I have knee pain problem long before stroke, yet I still can go for gardening at that time. But now my knee pain is getting worse." (P19)

c. Smoking
Smoking was challenging to overcome, particularly when an addiction issue was apparent (n=2).
"I know the disadvantages of cigarette smoking. However, it is hard to change when dealing with cigarette addiction." (P9)
"Initially my wife never allowed me to resume smoking, but she gradually gave in when she saw me anxiously and aimlessly walking in and out of the house (having withdrawal symptoms)." (P22)

Perceived benefits of adopting healthy lifestyle behaviours were constantly challenged by individual experiences. One participant resumed alcoholic drinking as she perceived that the behaviour failed to meet her outcome expectation:
"After the first stroke incident, I stopped smoking and drinking alcoholic drinks… yet I still have the second attack. I think better not to stop smoking and alcoholic drinks since they are useless. Now I've started drinking back alcoholic drinks (samsu) to make my body stronger…. need to take some samsu for a healthier body. " (P1)

ii. Social factors
a. Diet
Although family members are helpful in making healthy food choices, yet some participants expressed their concern regarding negative influences from family members:
"Family members often buy delicious and unhealthy foods that triggers my urge to eat together. They are acting like "double-edged sword". (P12)
"Foods prepared by my wife are delicious and it is a waste if I'm not taking it… By having children around at home, it is difficult to ask them to follow me to take soup-based foods (low fat) every day." (P11)

b. Exercise
Lacking supervision and companionship from family while doing exercise came across as strong social barrier for not participating in exercise by some participants (n=9):
"I fall asleep most of the time when at home. Motivation to do exercise at home is less. When I'm at home…if I exercise, my wife never comes to watch, she has a lot of work to do (in the kitchen), so I have to exercise alone." (P4)
"My wife is busy and unable to monitor me. Without supervision, I will just fall asleep… I think I need some assistance while doing exercise." (P22)

c. Smoking
Some participants were having difficulty to overcome smoking addiction due to constant stimulation from other people who smoked around:
"I have resume smoking within these two months, just take a few cigarettes in a day. When other people smoke, I can't stand the smell… I had tried to withhold the urge to smoke initially…. but eventually gave in since I smell the cigarette smoke too often (son smokes at home every day)." (P22)
"I'm afraid that I will resume smoking in future since I'm a hardcore smoker…. I can't give promise (to quit smoking)…. I haven't mix around with friends who smoke." (P18 who previously had experience of resumed

smoking after quitting for one month).

iii. Environmental factors

a. Diet

Affordability and accessibility to healthy eating were also a concern for some participants (n=5). Some families did not have the extra resources to buy healthy food choices exclusively for the stroke participants:

"My wife is working…With limited time, and current busy lifestyle, we are eating out most of the time. We need to choose properly when eating out." (P21)

"We cook whatever foods that we have at home. They are not putting extra resources on me as a stroke patient to have this and that… We need to think of our children who need to eat as well." (P2)

b. Exercise

Some participants relied on caregivers to bring them to the hospital for exercise therapy (n=5):

"There are transportation and parking issues whenever I come for exercise therapy in the hospital. This is because my son is working in Kuala Lumpur. I need to rely on others to bring me to the hospital." (P6)

"I have financial and time constraints. My son sends me to the hospital (for exercise therapy) but I need to go back by taxi. The taxi fare is 20 Ringgit Malaysia per trip." (P11)

c. Smoking

Two of the persistent smokers in this study mentioned that they have never been referred to smoking cessation clinic before. They have mixed opinion regarding the usefulness of the referral:

"I've never been referred to smoking cessation clinic. But I don't think it is necessary as I'm not ready to quit smoking." (P9)

"I've never heard about the smoking cessation clinic before. It might be helpful in facilitating me to quit smoking." (P22)

**Food taboos**

One-third of the participants practised food taboos following a stroke event. They believed that people with stroke would have "cold" nerves:

"I went to see traditional Chinese medicine practitioner… he checked my pulse and said my nerves were cold, that's why I was having a stroke. I could eat vegetables, but I need to avoid ice, soybean curd, potato, sweet potato, and cabbage. Currently, I only take vegetables in a minimal amount." (P7)

"I heard the food taboos from others. I avoided watermelon…. Watermelon is high in sugar and is considered "cold" food. I'm afraid of having cold nerves." (P6)

Besides, food associated with pain and bad illness experience was also avoided by some participants:

"I will have a fever if I take a banana or catfish. My hands are extremely painful if I take cassava leaves or sardine. I can't even sleep at night. Now I choose only foods that are not causing me any pain…These symptoms are very similar to those when I have a stroke attack."(P16)

"We need to prevent "poisonous foods". For example, fish that have horn. Catfish is not good for stroke patient. I can't eat patin as well because it can cause knee pain… Many vegetables also can cause "wind" inside body such as jackfruit and pumpkin. " (P19)

**Recovery**

Hope for recovery was obvious among participants (n=6) and emotional changes were observed during the conversation:

"I want to know when this disease will be recovered. Why I'm still not healthy while others have recovered a lot? When I was young, I've never been to other places because always busy with work. I want to go travel. I've never been to Kuala Lumpur." (P1)

"Initially doctor told me that the paralysis is permanent. Other doctor however mentioned that some patients can recover almost 90% while others only reach 50% and below, it is dependent on the patient's own recovery progress. I'm still wondering about this. I don't think I can recover by 100%. If you ask me, I want a medication that can cure instantly. So far, the medication does not exist, right? (patient was sad when telling this)." (P12)

The extent of recovery influenced their expectation to be recover and their determination to sustain the specific health behaviour. Patients had tried different therapies which they believed will aid in the recovery process:

"I had tried all sorts of things when I had a stroke that day. I went to hot spring, massage and spa centre… The massage therapy never stops. I believed massage is helpful as it affects the nerves. Until now, I practised massage nerves monthly. … After the massage, you will feel fresh. The nerves are "softer" and we don't feel pain. " (P4)

"When I had a stroke, I heard from my friends said taking the food supplements is good for fast recovery…. However, it's all a lie… We are no longer taking it now…. We had spent more than ten thousand of Malaysian Ringgit on these supplements." (P8)

**Provision of secondary stroke prevention**

i. Lacking information

A majority of the participants (n=15) recalled that no education on future stroke prevention was given although half of them did receive general verbal advice regarding healthy eating, exercise, and smoking:

"So far there is no advice given regarding healthy lifestyle practices either in the ward or outpatient clinic… When I met doctor in a health clinic… he only checked my medication." (P17)

"The doctor just told me that I need to quit smoking and eat healthy food. He didn't elaborate more on the nutrition information." (P9)

ii. Sources of information

It was apparent that the participants mostly acquired health information from health professionals (n=14) and friends and families (n=11). A majority of them did not actively search for information regarding secondary prevention (n=12). Only three of them mentioned that they had encountered a dietitian or nutritionist. Some participants, particularly the younger ones, used the internet as sources in obtaining more information on stroke (n=4).

"Most of the information was obtained from doctors or friends only. I never go to search for information by myself." (P1)

"I tired search internet 6 months after I had a stroke. When you had a stroke in the early phase, you will not feel like to read anything (felt down and sad). We never actively go and search the information by ourselves." (P21)

iii. Difficulty in information recall

Difficulties to recall information given were evident among some participants (n=8). Only six of them received information in the written format, although many of them perceived it as necessary:

"When I went to the hospital, they told me I need to control diet and don't overeat. They also mentioned other things, but I could not remember now. No written education materials were given." (P10, aged 55 with 132 months post stroke)

"Doctor advised to take care of diet and eat more vegetables… Different kind of information was given. But I could not remember many of them… They gave pamphlets and we keep it… After discharged from ward, there are no continuous education." (P2, aged of 60 with 3 months post stroke)

Although many would have appreciated in-depth advices from the healthcare providers about the cause of stroke and lifestyle modifications, a few participants (n=4) pointed out that they faced confusion during the early stages of stroke recovery and had difficulties in reading and understanding:

"During early phase of stroke, our mind was still in confuse state and had slurred speech. We tend to behave like baby, drink milk and wear pampers." (P15)

"During hospital stay, I was partially conscious and alert… I felt much better only after two to three weeks. I think it would be better to provide education after discharge…If education is given at that time (during early phase), I may have been confused and could not understand what you have said. Family or caregiver must be around during the session." (P20)

## DISCUSSION

Patient's lifestyle change following stroke is a complex and dynamic process and influenced by many factors. A few behavioural theories and models have been discussed in different studies and may shed further on the implications of the study findings (22,23,26,30). Readiness to change appears to be important when discussing smoking cessation and dietary changes among stroke survivors (22,23). Clauge-Baker and colleagues (2017), on the other hand, have suggested that discussing the benefits and barriers as per the Health Beliefs Model can be beneficial to support stroke survivors' attempt in practicing healthy lifestyle (26). Ultimately, these studies have suggested that programmes designed based on behavioural theories are more effective in modifying the behaviours among stroke survivors. Our study supported previous finding and believed that the Health Beliefs Model is important to be considered in this context, whereby its concepts include perceived susceptibility, perceived benefits, perceived barriers, and knowledge of stroke risk factors. Collectively, they can influence people's intention to prevent another stroke episode. Besides, some of the patient's health behaviours were based on the motive of achieving present improvements to compensate for the previous lifestyle, which echoed previous findings (25). The reflection and reflective practice theory may seem to be useful (31,32) in the curriculum development and delivery of stroke education programmes.

Even when patients perceived there is a need for behavioural modification, knowledge seldom translates into instant behaviour change because of existence of personal, social and environmental barriers. Laziness to exercise and difficulty to change old eating habits were evident, which explained why some participants continued undesirable health behaviours following the stroke event. However, this study also reported that physical and psychological barriers such as fear of fall, pain, and fatigue as strong barriers towards participating in a more active lifestyle. These difficulties have been previously identified in research assessing people with stroke (23,26,30). Additionally, the current study showed a significant number of participants complained of a poor appetite and undesirable weight loss, which made healthy eating more challenging. More studies are thus required to find better method to support stroke survivors in initiating and maintaining a healthy lifestyle despite these personal physical challenges. Nonetheless, food taboos were common practises among patients with stroke. This should be addressed adequately by a healthcare professional during health education as it appears to have further restricted the participant's food choices and prevents them from taking healthy food categories (i.e. vegetables, fruits, and fish). In addition, a strong influence of their families on each participant's beliefs and behaviours were seen in both positive and negative contexts, which echoed a previous study (22). Numerous studies have therefore advocated the use of a family-centred approach towards enhancing the effectiveness of secondary lifestyle interventions (22,30).

Nevertheless, this study showed that a third of the stroke survivors were uncertain about the cause of stroke and some were unable to identify any underlying

disease. These findings concur with the findings of other countries (26,30,33). The reason of poor understanding of cause of stroke is unknown but it might be related to the inadequate post-stroke information provision or reinforcement of information, which has been reported by this study and previous studies (22,26,30). Hence more effort to improve knowledge regarding cause of stroke and secondary prevention strategies are needed, particularly in the stroke patients where the risk of recurrent cardiovascular event is greater.

The patients' opinions regarding the content, timing, and mode of delivery of secondary prevention strategies following stroke are rather mixed (22,23,26). It may be inappropriate to introduce too much information during the acute stroke phase as confusion and difficulty in understanding are evident, which is in line with previous studies (22,34). The appropriate timing and duration of information delivery need to be further examined in order to cater for the needs of stroke patients and survivors. Besides, continuous education sessions (from inpatient to outpatient setting) are needed as a patient tends to have a problem in information recall (26,34). Geldens and colleagues (2017) have found that the patients are ready to education on risk factors control and healthy lifestyle about one week post transient ischaemic attack (33).

A few limitations are recognised in this study. First, the participants were recruited from the east-coast region of Peninsular Malaysia only, rendering the generalisation of results rather limited. Second, the average duration from the first episode of stroke varied widely from 1 month to 20 years and people's perception might vary over a different time period. This study, however, explored the insights of stroke participants from different socio-demographic backgrounds, including different genders (13 males and 9 females), ethnicities (i.e. Malay, Chinese, and Indian) and age groups (i.e. from 34 to 80 years old). Nonetheless, this is probably one of the limited numbers of qualitative studies conducted among stroke survivors in Malaysia, which explores the perceptions of healthy lifestyle participation for secondary stroke prevention.

## CONCLUSION

Despite recommendations regarding the importance of health education in clinical practices, poor understanding regarding cause of stroke and lacking secondary prevention information provision were commonly observed among stroke survivors. Initiation and maintenance of healthy lifestyle after stroke is challenging and is often influenced by many factors. Families had a strong influence on the participant's belief and behaviour changes, both in positive and negative ways. Use of appropriate behavioural changes strategies, family-centred approach and continuous health education are necessary to facilitate patients' efforts at making successful lifestyle modification after stroke event.

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