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Understandings of stroke in rural Malaysia: ethnographic insights

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ABSTRACT

Background: Stroke is a public health concern in Malaysia but local beliefs and lay understandings of stroke have not been examined before. Explanatory models provide a way for people to make sense of their illness and influence health seeking behaviors, in a locally relevant way.

Methods: Drawing on ethnographic research from rural Malaysia, this descriptive article explores ethnic Malaysian-Chinese stroke survivors' lay understandings of stroke. Eighteen community-dwelling stroke survivors aged 50–83 took part in the study.

Results: Causation of stroke was derived from cultural, biomedical and social sources. Participants also drew simultaneously from both biomedical and traditional explanations of stroke to develop their own understanding of etiology. Similarities with biomedical causation and other studies from different cultures were found. Participants' typically focused on the more immediate effects of stroke and often do not attribute causation and association with their comorbid conditions which are also risk factors of stroke.

Conclusion: Lack of knowledge about stroke and its symptoms was evident in participants' account. Findings emphasize the importance of knowledge based health interventions, especially in health education strategies for stroke survivors to reduce delays to diagnosis and potentially improve health outcomes post-stroke.

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Stroke; ethnography; lay models; explanatory models; older adults

► IMPLICATIONS FOR REHABILITATION

- Stroke survivors often form explanatory models of stroke that draw from both biomedical and traditional explanations of stroke.
- Understanding how people derive lay understandings of stroke can contribute towards developing the goals and activities that facilitate recovery and rehabilitation in similar settings.
- Health practitioners in the community should strengthen communication regarding the identification, etiology and risk factors of stroke with stroke survivors and their carers to improve compliance to medication, exercise and diet for better recovery. Sustained health education which is culturally relevant is recommended.
- Communication should also include non-physical impact of stroke (such as cognitive deficits and emotional difficulties) as the stroke survivors were unlikely to relate such symptoms to stroke.



Introduction

Stroke is a major cause of mortality and morbidity worldwide. It was ranked as the second most common cause of death globally [1], after ischemic heart disease, and as the third most significant cause of disability-adjusted life years (DALYs) lost [2]. In the elderly, stroke is the most common cause of disability and ranked third in the top causes for reducing quality of life [3]. Stroke poses a particular challenge for low and middle income countries (LMICs), which have reported increases in stroke burden [4], because health services may be limited, especially in rural areas [5]. Even in areas where biomedical treatments are available, modern medicine may not be the first choice for health care, people in LMICs report seeking traditional, spiritual or alternative medicine as their first resolve [6,7].

Stroke, as biomedically understood, occurs when blood flow to the brain is disrupted. This deprives the affected area of oxygen

and results in an injury to the area. In consequence, the abilities controlled by the affected area in the brain – such as cognition or muscle control – are then lost or compromised [8]. Biomedical explanations attribute stroke to the presence of risk factors such as diabetes, high cholesterol levels and hypertension [9]. These risk factors are highly correlated: diabetics are more likely to have hypertension, and having both conditions exacerbates their effects [10]. This can cause damage to blood vessel functioning, eventually resulting in stroke [11,12]. Treatment for stroke and prevention of first stroke involves medication to control the risk factors. In the cases of ischemic strokes (which is more common than hemorrhagic strokes [13,14]), blood thinners such as anti-platelets are usually prescribed to prevent blood clots [15].

Cultural beliefs and perceptions of disease play a role in shaping individuals' health-seeking behavior. Kleinman postulated that when people become ill, their emerging concerns regarding their

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symptoms, their cause(s), and understandings of any remedial actions can be answered with locally-relevant “explanatory models” [16,17]. These models, which are socially and culturally constructed understandings of illness, help people to manage and make sense of their bodily signs and symptoms. Indeed, perception of illness causation is a main influence on how people seek treatments for their conditions and what treatment they seek [18]. In South Africa, stroke was conceived as both a physical and social condition, resulting in pluralistic health-seeking behavior, with the type of treatment determined by the prescribing symptoms [19]. For stroke symptoms (e.g., numbness) that were perceived to be physical in nature, biomedical treatment would be sought [19]. However, when that same numbness symptom was also perceived as socially caused (e.g., when numbness is attributed to supernatural caused maladies due to someone’s jealousy), spiritual healers, prophets and churches would be sought for treatment. In Tanzania, differences in health-seeking existed between individuals who experienced stroke in rural and urban areas due to different beliefs about causation [6]. In urban areas, causation was understood to be of biomedical in nature; therefore the first choice for treatment would be the hospital. In contrast, in the rural areas causation was thought to be of supernatural in nature, thus necessitating treatment from traditional healers to be sought. Some interpretations of stroke causation lay beyond biomedical explanations, (e.g., when causation is believed to be socially caused or supernatural in nature). These interpretations in part explained some of their treatment choices. Such explanatory models have been described globally, including in the LMIC countries of Southeast Asia. Norris et al. [7] for example found that people attributed their stroke to local blockages (on affected limbs) or agitated blood, which was seen as reflective of personal troubles or socio-political factors.

Malaysia is a multi-ethnic middle income country located in South East Asia. The ethnic composition of Malaysian citizens include Malays (54.5%), Chinese (24.5%), Indians (7.3%), other indigenous groups other than the Malays (12.8%) and other ethnic groups (0.9%) [20]. While there exists limited information estimating the burden of stroke in Malaysia, stroke is a considerable public health concern [21], and is the second leading cause of death in the country [22]. The considerable impact of stroke in the lives of rural stroke survivors were documented in an ethnographic analysis of Malaysian stroke survivors [23]. However, the way stroke is understood across different ethnic groups has not been documented to date and, to our knowledge, limited (if any) research has been conducted on local beliefs and lay understandings of stroke in Malaysia. Ethnic and cultural influences on pluralistic health-seeking behavior persist [24], whereby people simultaneously seek care in tertiary care centers alongside traditional and alternative treatments [24–26]. It was therefore unsurprising that stroke patients from one Malaysian rehabilitation center reported that traditional and complementary medicine use was common [27]. This paper, starts addressing this gap, and aims to examine how ethnic Malaysian-Chinese stroke survivors and their caregivers in Malaysia understood stroke, and explores how their beliefs can be used to develop strategies for responding with the aftermath of stroke.

Methods and settings

Participants were drawn from a larger ethnographic study on stroke recovery recruited through the South East Asian Community Observatory (SEACO) [28], a health and demographic surveillance system (DHSS) located in Segamat district, Johor state

in West Malaysia. Malaysian-Chinese participants all resided in a single rural village and were recruited in two ways. First, stroke survivors residing in the surveillance district were identified in the 2015 health data collection rounds conducted by SEACO; these individuals were then visited by the first author [KHY] to assess their suitability and willingness to participate in the study. In Malaysian community settings, individuals may not be able to provide complete records of any previous hospitalization pertaining to their stroke event. However, the villagers were clear about their stroke status and so those individuals (or their carers) who verified that their stroke status had been determined by doctors in hospitals were invited to participate in the study. Fifteen potential participants were identified as having had stroke in the health round. Two participants had passed away prior study commencement, one declined to participate and one had not had stroke upon verification. The remaining eleven participants were recruited into the study. An additional ten stroke survivors who were not identified during the health round were referred by a key informant community member. Three of these stroke survivors did not provide consent and thus seven stroke survivors were further recruited into the study. This gave a total of 18 participants.

All participants and their carers provided written or audio-recorded informed consent, and our process included strategies outlined by Hubbard et al. [29]. First, the study was explained to potential participants and their carers. Those who understand the nature of the study and the implications of agreeing to participation were assumed capable of providing consent. When in doubt, consent was also obtained from the identified carer of the stroke survivor. In instances where an individual could not provide informed consent, their carer instead took part in the study. This process of consent often took place over multiple encounters, which was facilitated by the ethnographic study design. Consent for participation in the study was negotiated and renegotiated throughout the duration of the study, in recognition of the fluctuating nature of capacity [30]. This process was important as no participant had ever been medically diagnosed with cognitive impairment, and so we were unable to draw upon this in establishing capacity to consent. The conduct of this study was approved by the Monash University Human Research Ethics Committee (CF14/315 – 2014000105).

Data collection was conducted from July 2015 to June 2016. In order to gain an in-depth understanding of experiences and culture of the participants, KHY lived intermittently in the village for data collection. Living alongside participants, observing how they lived, carry out daily routines and what is meaningful in their lives allowed the additional insights into participants’ experiences of stroke. Data were also obtained through in-depth interviews (IDIs) and participant observations; these were documented through transcripts and field notes which were supplemented by the participatory data collection methods, including photovoice [31]. Photovoice utilized images taken by participants as representations on their stroke-related life experiences (particularly the things, places and activities important to them) were used to guide some of the IDIs and participant observations. Interviews initially focused on participants’ experience of stroke; including their initial responses at stroke onset, subsequent actions, understandings of stroke causation and their health maintenance after stroke. Probing questions further directed the interviews based on participants’ responses to questions about their stroke experiences. Multiple interviews were conducted with each participant, ranging from a minimum of two to a maximum of six audio recorded IDIs. All were audio recorded and ranged from a

minimum of 20 min to two hours. All IDIs were later translated and transcribed. At the time of the study, KHY (who undertook the field research) had more than nine years' experience in coordinating clinical research (observational studies and clinical trials), mainly in the field of aging and stroke. She is of Malaysian-Chinese descent and was able to converse in the Chinese dialects used within the village. KHY had also accompanied participants and their family members during some of their visits to health facilities, of which observations were documented through fieldnotes. All observations and fieldnotes were later written up in full. All written material were integrated and then analyzed using Braun and Clarke's [32] thematic analysis approach. The collated data were first reviewed through multiple readings. Initial open codes were generated at sentence level and then grouped according to their similarities. These were then organized into themes. Inter-relationships between codes were then grouped into sub-themes under the overarching themes. The themes were then organized and reported in a coherent pattern. Data from each individual participant were extracted as quotes corresponding to themes and are reported in this paper. Repeated encounters with participants and their family units; and the triangulation of data collected through different methods in this study served to establish credibility and trustworthiness of the results, as per recommendations (see Lincoln and Guba [33]) for assessing quality in qualitative research. All participants and carer names were replaced with pseudonyms and specific references to healthcare facilities were omitted.

The analysis presented in this paper is focused on the experiences of 18 stroke survivors, aged 50–83 and who ranged from three months to 30 years post-stroke at the time of recruitment into the study (Table 1).

Results

For the purposes of this study, health practitioners were defined as qualified and certified practitioners who underwent formal education in tertiary institutions and were registered with the Ministry of Health in Malaysia. Two types of health practitioners were mentioned by participants. Biomedical health practitioners were based in public and private clinics and hospitals, practicing conventional modern medicine. Traditional Chinese Medicine (TCM) practitioners whose medical practice included various forms of herbal medicine, acupuncture, massage and even exercise were also important in participants' health-seeking. All study participants were on active or intermittent follow-up with biomedical health practitioners at one point or other, and many of them also sought acupuncture treatment with the TCM practitioner during the initial stages after acute stroke.

Two main themes were evident from participants' accounts and these are presented in the data section: "identifying stroke

and interpreting its symptoms at onset" and "lay explanations of stroke." A further four sub-themes are presented under the "lay explanations of stroke" theme: unknown, "wind," hypertension and blood flow (see Figure 1).

Main theme 1: identifying stroke and interpreting its symptoms

Participants reported symptoms of stroke including limb and body weakness, which resulted in paralysis on one side or both sides of their bodies, numbness, facial droop, and speech impairment. For most, the stroke started with sudden physical deficits: they were doing the usual activities in their lives when they were interrupted by stroke symptoms. These initial symptoms of stroke were met with puzzlement and confusion over what could be happening to them, as Mr Shui (aged 70, 6 years post-stroke, no carer) recounted:

I was sitting on the floor, you know, my left hand had no strength, totally no strength and I could not move already. [I] thought it could be some bone disease, if it's that then, [it] should not be anything major... then my speech was [affected]... then even when I needed to go to the toilet, I could not go [walk].

Participants then tried to stabilize their symptoms by resting, to see if normality resumed. It was only when they experienced a worsening of their symptoms after this period of rest and observation that they realized their condition was not transient and thus they sought help from people around them, usually their family members.

One of the challenges faced by participants was determining what was happening to their body in the first instance, and then making decisions about what to do. This was often difficult given the subtlety of their stroke symptoms which were sometimes obscured by the effects and symptoms from their other comorbid conditions. Madam Lan (aged 69, lives with adult-child carer), for example, was a chronic diabetic and had some wounds on her leg around the time of her stroke three years ago. She had stayed at home from work because she wanted the wounds to heal, but then experienced stroke symptoms when she got up from her nap:

That month, I was resting because my leg had some 'rot' [infection], so I did not go and tap rubber... When I woke up, my leg was a little off when I was walking... I still had [strength], I could still [walk]... I was holding on [to the wall] for support, but I could still you know [walk].

She first thought that she was probably still drowsy following her sleep, then attributed the unsteadiness to her recovering from her wounds. She finally realized something was not right when a rest did not resolve her limb weakness and after her wounds healed over subsequent days. Even then she was not sure what was happening. It was only when discussing her symptoms over the telephone with her sister that she decided – at her sister's urging – to make her way to the hospital for a checkup, because persistent leg weakness even when following light duties was not usual. Madam Lan's stroke symptoms were thus obscured by symptoms from her other comorbidities that she was experiencing at the same time. Thus, the stroke symptoms were not noticeable immediately and did not overly interfere with her usual activities. Her initial interpretation was that those symptoms were not severe and should resolve on their own.

For other participants, the stroke symptoms were more profound, impacting mobility and even communication. Madam Qin (aged 64, one year post-stroke, no carer) was sitting on her bed when she was suddenly unable to verbally respond to her daughter's call for help putting her (Madam Qin's) grandchildren to sleep. She was not able to command her body to move, so she

Table 1. Participant characteristics.

Characteristics	N	Characteristics	N
Participant age		Time since stroke	
50–59 years	1	Less than 1 year	2
60–69 years	6	1–2 years	7
70–79 years	6	3–6 years	7
80–89 years	5	More than 10 years	2
Participant sex		Carer	
Male	10	Spouse	4
Female	8	Adult-child	6
		None	8
Religion		Education level	
Buddhist/Chinese religion	17	6 years and below	17
Christian	1	Above 6 years	1

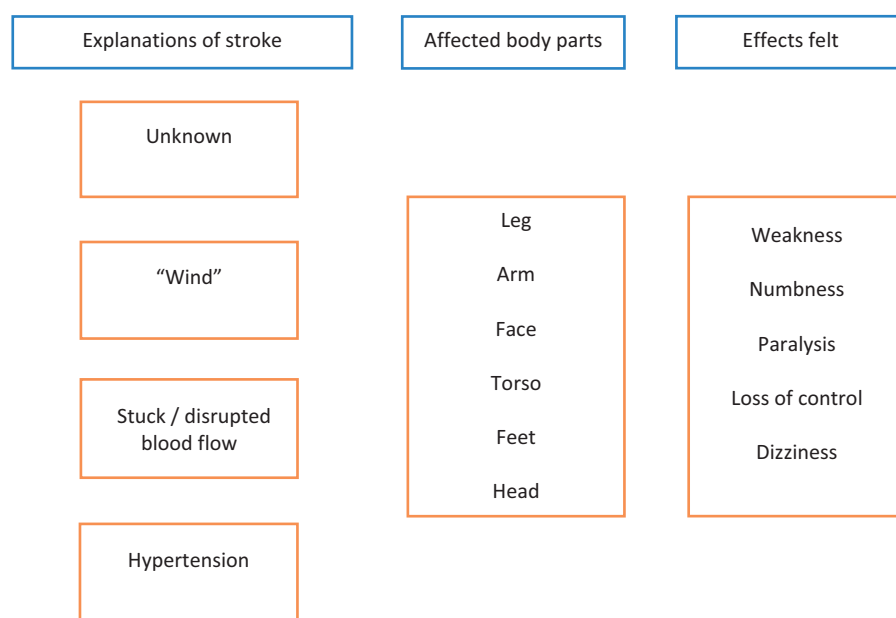


Figure 1. A diagrammatic representation of how stroke survivors perceived stroke (their lay understandings of stroke). The explanatory sub-themes (unknown, hypertension, disrupted blood flow and "wind") were thought to directly affect their body parts that were left with the lingering symptoms of stroke.

pushed herself to the floor, and dragged her body onto the floor over to where her grandchildren lay and patted the children to sleep. She then went to sleep herself. When she woke up, she still could not stand due to paralysis she experienced on her left side. Her daughter and husband tried to pull her up to standing position but were not able to handle the weight of her body. At that point, her daughter realized that Madam Qin might have suffered a stroke and started making calls to ask for help from relatives:

Wanted to stand but I couldn't [laughs], and I had to drag on my buttocks from there to the washroom, and Ah Lei (daughter) wanted to pull me up but not able to [too heavy] as she is only one person so this one (husband) wanted to help but also unable ... She [daughter] started calling my younger brother ..."

The stark difference in bodily abilities before the stroke and immediately after stroke alarmed Madam Qin's family members and they took immediate action to seek for help from relatives to help send her to the hospital.

Main theme 2: lay explanations of stroke

Participants held diverse understandings sometimes holding multiple contradictory explanations regarding what the stroke was, and what factors caused it. Few participants knew what a stroke was prior to their own experience of stroke, and thus they remained unable to clearly explain what a stroke was. Where they had some sense of stroke etiology, participants' understandings of stroke were informed by their encounters with different health care systems. In this respect, Chinese medical understandings of the body were much more influential than biomedical perspectives. These are described below.

Sub-theme 1: I don't know why

More than half of the participants and their families did not know the cause of stroke. Madam Qin, for instance, responded with a bland "I do not know" when asked. When she was discharged from the hospital after her stroke a year ago, she returned home with medications for hypertension and cholesterol, however she never discussed these two conditions when explaining the cause of stroke. She was instead occupied with searching for cures to

help her walk better, often trying out new suggestions of different medical facilities and going for regular injections from a health practitioner in the next town, as she claimed these made her legs feel less stiff.

Mr Yun (aged 83, two years post-stroke, lives with adult-child carer) was blind in one eye and also had high blood pressure – which, according to his son, was the cause of his blindness: "blood pressure went up to his eye" (presumably hypertensive retinopathy) about 10 years previously. He had been on blood pressure medications since then. He had also been on cholesterol medications since the stroke, which was diagnosed in the hospital during his hospitalization four years before and did not relate this condition to stroke as well. He was also not concerned about the cause of his stroke, because he was occupied with recovering his physical abilities so that he could walk without the help of his walking frame. As he was told by the biomedical and traditional Chinese medical (TCM) health practitioners he visited that stroke has no cure, and that his only hope was to "train" his legs with exercise, he exercised religiously every morning on his exercise bike.

Another participant, Madam Nu (aged 78, one year post-stroke, lives with adult-child carer), claimed she did not know the cause of stroke. However, further conversations with her revealed that she unconsciously linked stroke to poor dietary habits: "I am not like other people, greedy and eating everything – I do eat but not like others who just eat and eat ... [I eat] just a little, not too much." Since she thought she was doing fine and did not have the poor dietary habit of "eating too much," she was puzzled that she had stroke. However, her general health status suggested that she had many risk factors for stroke; it was just that she was unaware of many of these. She was diagnosed with diabetes, hypertension and hypercholesterolemia when she had her stroke two years ago. Post-discharge, her hypertension was often uncontrolled and she was hospitalized on several occasions when her blood pressure was found to be very high. During one of these hospitalizations, she was found to have atrial fibrillation (AF), a heart-related condition which increases the risk of stroke [34,35]. Despite the presence of these biomedical risk factors of stroke, she, like Madam Qin and Mr Yun, did not relate these risk factors

with stroke. She was also not particularly concerned with her dietary intake nor did she engage in any particular activities to recover further, partly because she was only left with facial numbness, which did not bother her.

The participants were likely not aware that they had risk factors before stroke as their comorbid conditions were diagnosed only after their hospitalization for stroke. Even where the risk factors were diagnosed before stroke (e.g., the hypertension in Mr Yun's case), the participants did not realize that these were linked to stroke in any way. Some participants who claimed that they do not know the cause of stroke unconsciously relied on socially and culturally drawn causes of stroke, as illustrated in the next two sections.

Sub-theme 2: the wind

Two participants directly related their stroke to the presence of "wind" in the body. The term stroke in the Chinese language is 中風 (*zhòngfēng* in Pinyin¹), which means "hit by the wind," and was taken literally by these study participants. Both Mr Ge (aged 68, lives with spouse-carer) and his wife felt that his left body was still weak (although improved tremendously from when he first had stroke 30 years ago) because the "wind" remained inside the left side of his body:

Yes there is improvement, but his work (speed) is very slow ... the 'wind' is still inside.

According to Mrs Ge, they had no idea what happened to Mr Ge when the left side of his body suddenly became weak. It was some elderly neighbors who visited them at that time who mentioned that it could probably be *zhòngfēng*:

When we were younger, we did not know what this *zhòngfēng* was all about, what is *zhòngfēng*, we do not even understand ... and then with this situation, some elderly [person] said this looks like *zhòngfēng*. Because you know, the elderly will know what is going on, and we were young then, we did not know, so we heard from them that it is *zhòngfēng*.

However, there was no clear indication on what this 'wind' was. Mrs Ge had taken Mr Ge to a hospital in neighboring Singapore, where he had a brain scan. It was there that the doctor said that there was a broken nerve in his brain.

That's why the hand is not natural, he works a little slower. He can do work, but just a bit slower ... the 'wind' is still inside ... we went for treatment/consultation in Singapore, and he [the doctor] said that the nerve in his brain broke, and this condition there are no medications for it, like that ... they [at the hospital] scanned his brain and told me there is a broken nerve in his brain ...

Mrs Ge believed that the "wind" caused the broken nerve, and as a result of this broken nerve, the connections in his body were not complete, rendering him "slower" when he did things. He was also diagnosed with hypertension after the stroke event and continued to take medicines for it, yet this was not mentioned in relation to stroke. Mrs Ge had likely integrated the information from the various biomedical practitioners she consulted in the initial year of Mr Ge's stroke.

Even where participants had no understanding of stroke etiology, they spoke about the impact of "wind." Mr Ying (aged 80, four years post-stroke, no carer) was unclear about the initial stages of his stroke treatment, yet described the medications given to him by the biomedical health practitioner as preventing the "wind." He then further explained that the doctor at the hospital who treated him mentioned that he had *zhòngfēng*, and he did not further ask what that meant as he was thankful to receive treatment: "There was no need, they already saved me, so I did not ask ... they gave me medicine, for those ... to avoid the

wind." He too directly and indirectly referred to his condition as caused by the "wind," although he did not further explain what the "wind" was. Like Mr Ying, the "wind" was interpreted by participants as something of unknown origin that blocks and disrupted the functions or flow that occur within the body. This knowledge of still having the "wind" explained the deficits experienced by their bodies even many years post-stroke, but as the origins were unknown, participants carried on with their lives with no specific targeted treatment to combat the "wind."

Sub-theme 3: hypertension

Only one participant, Mr Duo (aged 69, four years post-stroke, no carer), stated that he thought his stroke was caused by hypertension. This was informed by his biomedical healthcare provider, who had informed him that "Stroke is related to high blood pressure ... because you do not feel it, then you get dizziness." His understanding of stroke was unclear, however. He did not know how hypertension or even stroke related to his brain function (which he recognized in his mention of "dizziness," above). This confusion related, at least in part, to the limited explanation that he received when he attended the hospital following his stroke: after undergoing scans, he was told that things were okay. All Mr Duo recalled was that stroke was caused by hypertension and that he needed to "take care" of the blood pressure. He monitors his blood pressure with a home machine, and was compliant to his antihypertensive medications.

Sub-theme 4: blood flow

Perhaps the most common cause of stroke, described by a third of the participants – where they were able to articulate ideas of causation – related to "clogged" or "stuck" blood vessels that prohibited blood flow to the different parts of their bodies, resulting in numbness, paralysis or weakness in the specific parts of their bodies. These participants related the different experiences in their lives that may have resulted in the blood clot, including life-style-related factors. Mr Song (aged 64, no carer), for example, felt that his stroke was caused by clogged blood vessels as a result of eating oily food: "[The] blood did not reach, blood vessel stuck, it is because you eat too much oil and clog it up ... The doctor told me that I should not eat too full ... so I should not eat [too much]." When he was receiving treatment in the hospital during the acute stage immediately after his stroke two years ago, Mr Song was diagnosed with hypertension and diabetes. It was therefore possible that, when asked, Mr Song repeated the explanation given to him in hospital. It was common for biomedical practitioners, when explaining stroke to participants in lay terms, to use the phrase of having a "blocked blood vessel," and this was perceived literally by the participants. They would try to reconcile the new information from life experiences that may have caused the blood vessel blockage, as was the case for Mr Song.

In contrast, Mr Xiu (aged 81, no carer) felt that his stroke two years ago was caused by lack of water and sleep, which then disrupted the blood flow to his affected leg. He had lingering numbness on his affected leg and thought that improving the blood flow in his leg by soaking in hot water would help his condition. He felt better after soaking his leg because, according to him, it became more comfortable and felt less numb but he had to do it regularly or the numbness would "come back." He was a chronic smoker, and although he had high blood pressure even before his stroke, he did not attribute his stroke to these risk factors. While he was still compliant with his antihypertensive medications, he consumed other traditional remedies thought to

improve blood flow including herbal medicines purchased from China and some “red flower” ointment for topical application. Part of the belief with blood flow may have stemmed from TCM understandings and explanations of stroke to participants. The TCM practitioner had described the definition and cause of stroke as per in the biomedical explanation. This was linked closely to the education of the particular TCM practitioner who treated some of the participants, which was described as “30% Western, 70% Chinese (traditional)” in one of the medical colleges in China. That said, the methods of treatment differed, of which for stroke, it mainly involved acupuncture to “trigger recovery and to get the blood flowing,” which is in congruence with explanations pertaining to the biomedical treatment of stroke, further strengthening the definition of stroke as a problem with blood flow.

Not all participants associated ischemic stroke with lifestyle practices, instead focusing on other life experiences. Madam Ke (aged 71, lives with adult-child carer) felt that a childhood traumatic experience, in which she was physically abused by her then employer, was the main cause. This, according to her, resulted in a blood clot that was never resolved, which in turn caused her stroke one year ago. She connected this childhood trauma with what the treating physician had explained to her about her condition:

I was a child, and she [her employer] hit my head against the wall ... I lost my teeth, hit my head, here [gestured to her head] it is stuck and there [head] it is stuck ... The doctor told me that my blood vessel here is stuck, the small blood vessel here is stuck.

She concluded that the blood clot explained to her by the doctor was left behind when she was injured. She would occasionally ask if there were medicines to dissolve the blood clot in her brain so that she would recover from the numbness that unnerved her. To encourage blood flow, she would also tap the limb and other bodily parts affected by stroke. She was a chronic diabetic even before her stroke and was further diagnosed with hypercholesterolemia and hypertension while she was hospitalized for stroke. Like other participants described in this section, she never thought that her comorbid health conditions contributed to stroke. One year after her stroke, she still felt the remnants of stroke in the form of numbness and slight weakness in her hand. She then sought treatments with a spiritual healer to disperse the clot in her brain because that was the way she thought she could be cured completely:

I went to look for the master [spiritual healer], so the master performed some therapy on me. He said my blood vessels are unblocked now, that my blood vessel here [gestured to her head] is unblocked. So I replied yes, I know when I am sleeping the nerve was flowing/moving, like something was moving ... My blood is flowing. My hand with the stroke is not as good as before, no matter how it is still a bit worse off, not as good as the other hand. This one is a bit worse off. But need to work at it ... He [the healer] used his hands to knead my arms and my back ... He said, ‘you owe something that is not good. And that “thing” wanted to pester you. And that “thing” is not good. If not, you would have recovered earlier.’ I said that, ‘if it were so, it would be good.’ He asked if I believe that he can heal me, and now you see, it’s gone, I am healed.

A reference to supernatural entity as the cause of her perceived slow recovery (but not the cause of stroke) was described by the healer. However, her faith in the healer’s assurance that the therapy worked meant that, despite still feeling hand weakness, Madam Ke believed that she was healed and stopped monitoring her health with the general practitioner. Madam Ke is one example where spiritual healing was considered the answer to curing stroke by removing the clot blocking her blood flow. She

drew on both traditional beliefs and biomedically explained causation of stroke to make sense of stroke.

Spiritual healing was not commonly sought for stroke among the participants in this study. Only one other participant (in addition to Madam Ke) described treatment seeking with spiritual healers: Madam Di (aged 81, three months post-stroke, no carer) explained that spiritual healing was important in improving her “sticky” or “thick” blood that would not flow properly, and which had thus caused the stroke. Although the reason for the sticky blood was not described very clearly, she had faith that her “master” would be able to heal her:

I actually wanted to look for my master to make a magical pill for me to consume to heal me ... He said need to move around, so that the blood can flow.

Madam Di’s “master” was not a physical person, unlike Madam Ke’s master. According to Madam Di, her “master” came to her in dreams and communicated with her in her mind:

My master wanted to give [the pill] ... his pupil did not give me the medicine ... I used to go to him ... the master won’t die you know, but the pupil died ... The miracle pill will be produced by the golden body [of the master].

She was a fervent believer of spiritual mediums, where the medium acted as a vessel for the spirit of a god or deity to possess and perform healing. It was this god or deity that she called her “master.” Unfortunately, the particular medium (referred to as the pupil by Madam Di) possessed by her “master” passed away shortly after her stroke, so the miracle pill was not produced. Despite this, she continued to religiously light josssticks and pray to Chinese gods in her home, and felt that her good progress after stroke was due to blessings from her prayers. She also followed the advice given to her by her “master” by going for morning walks to improve her blood flow. At the same time, she visited TCM practitioners for acupuncture, and also visited other alternative (unlicensed) practitioners for blood-letting, also for blood flow purposes. While Madam Ke and Madam Di did not attribute spiritual factors as contributing to the cause of stroke, their personal beliefs instilled hope that spiritual healers can remove the cause of stroke and therefore cure them completely.

Discussion

This study aimed to understand how Malaysian-Chinese stroke survivors and their family members from one rural village in West Malaysia perceived stroke. The initial stages of stroke were usually met with confusion, especially where the symptoms were not immediately apparent or whether they could be attributed to multiple causes. Most participants had other co-morbidities and conditions that obscured the initial signs of stroke. Stroke that resulted in marked experiential differences, especially in terms of physical performance, were given attention more rapidly. For our study participants, the presence of stroke was felt in their bodies: in the lack of strength, the lack of control over movement, and the lingering numbness (Figure 1).

These symptoms were commonly encountered at the onset of stroke, and resolving to some extent over time. When recovering in the community, the stroke survivors targeted treatments on the parts of their bodies that they felt were affected by stroke with various methods, ranging from acupuncture to home remedies, such as soaking the affected limb in hot water, tapping affected parts of the body, or applying topical ointments.

In this study, participants derived and integrated the understandings of the causation of stroke from cultural, biomedical and

social sources. Strangely, even though all of them had attended consultations in biomedical facilities for stroke at some point during their recovery journey, the biomedical causation of stroke (hypertension) was only explicitly reported by one participant. Almost all study participants were on active follow-up with either hospitals or primary care for their chronic conditions of hypertension, hypercholesterolemia or diabetes. However, the majority still claimed that they did not know the cause of their stroke and did not attribute their stroke to the contribution of their co-morbid conditions of hypertension, high cholesterol or diabetes. Participants who did not form any explanatory reasons for stroke were inconsistent about how to target the consequences of stroke.

In some instances, participants melded biomedical and traditional explanations of stroke to develop their own understanding of etiology. The explanations of the “wind” blocking the flow, or of poor blood flow resulting from stroke may well be the result of how medical practitioners explained stroke to the stroke survivors and their family members. Participants referred to anti-platelets, in the form of aspirin, as blood thinners, and this may have further amplified, if only in part, the explanation of thick blood affecting the flow. The causes for the disruption of blood flow were woven with their life experiences of poor lifestyle choices or the exchanges with their social environment and their healthcare providers (be it biomedical or TCM). This was reflective of what was described by Norris et al. [7] in Aceh, Indonesia, where stroke was believed to be a disruption of blood flow stemming various causes which included the supernatural, food, previous life and health experiences. Beliefs on the causes of stroke were fluid and sometimes change as the stroke survivors interact with various medical practitioners and their own social environment.

Of interest in this study was the lack of attribution to supernatural sources which was found by Mshana et al. [6] in Tanzania. Only two participants in the current study subscribed to beliefs in the healing abilities of spiritual mediums and healers; none who talked about curses or occult forces. Instead, this study was more in line with Norris et al.’s study findings [7], even though the Muslim religion for the Norris and colleagues’ participants was completely different from the participants in this study (Buddhist and other Chinese folk religion). Madam Ke only sought the help of the spiritual healer after her condition stagnated and after she had tried both biomedical and TCM health facilities suggesting that she generally had no problems accepting biomedical health practices in the beginning.

This study also highlighted the need for better education on the prevention of stroke (both primary and secondary). Over four decades (1970 to 2008), stroke incidence in LMICs have experienced an increase of more than 100% compared to high income countries (HICs) which have experienced a 42% decrease in stroke incidence over the same time period [36]. Part of the success in the control of stroke in HICs has been attributed to better control of risk factors of stroke [37]. The majority of the participants in this study were unaware that some of their comorbid conditions (e.g., diabetes and hypertension) and lifestyle choices (smoking) were risk factors for stroke. The lack of awareness applied to those participants who only discovered their risk behaviors during their hospitalization for the stroke event. It was unlikely, though possible, that such risk factors were not communicated to the stroke survivors at all, as participants were able to articulate that their health practitioners had informed them to be compliant with their medication when it was prescribed on follow up visits. However, some participants integrated their cultural understandings of stroke with the information that they had received from

various health practitioners, leading to some dilution of messages emphasizing the importance of managing the risk factors of stroke. Participants also experimented with remedies to address the cause of their stroke, as can be seen in the case of improving blood flow. However, because the risk factors of stroke were not perceived as such, medical adherence and lifestyle changes were not in the top priority. Therefore, sustained and directed education on how the risk factors affect stroke during their post-stroke follow-up appointments combined with further efforts on regular community based health promotion programs should be encouraged. Health promotion must take into account the cultural context of this community and may be more useful in ensuring medication adherence and lifestyle changes. In this regard, sustained regular health promotion and education activities as part of a population based intervention trial may offer valuable insights: this trial had shown a reduction in the risk of incident stroke by more than 10% in an LMIC like China [38]. Other strategies like empowering caregivers of chronic stroke survivors with rehabilitation skills where therapy plans are executed at home may also improve functionality, and have proved to be feasible to deliver [39]. Sustained support and education in communities should be considered and assessed for future research.

Implications

Participants’ understandings of stroke – which represent locally-relevant explanatory models of stroke – were focused on the immediate bodily experiences they experienced, and did not typically include a consideration of their comorbid conditions, which were themselves risk factors of stroke. This suggests that participants held different explanatory models around stroke etiology in contrast to the biomedical understandings held by public hospital staff. Of concern too was the lack of awareness revolving around the risk factors of stroke. These findings emphasized the importance of communication between health practitioners, the stroke survivor, and their family members. This provides opportunities for intervention on behalf of health practitioners, who should continuously reinforce to their patients (and their family members) the explanations of stroke and the role of each type of medication prescribed in preventing recurrent stroke. Community health promotional activities and programs should also be considered in order to provide more sustained education and awareness. In doing so, this may improve compliance to medication, exercise, diet and lead to better recovery following stroke. Communication should also include a discussion of the non-motor and nonphysical consequences of stroke; significantly, none of the study participants directly discussed the cognitive and emotional difficulties following stroke, including memory problems, fatigue, and emotional instability. It is likely that these symptoms were simply not perceived as part of the effects of stroke and has implications for the reporting of worsening symptoms as the stroke survivors progress further along their stroke journey.

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No potential conflict of interest was reported by the authors.

Note

1. Official romanization system for Standard Chinese

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