

Communication

Communication: The Need for Inclusive Algorithm and Multi-Disciplinary Approach in Managing Long-Term Stroke Care Patients the Community, Focusing on Primary Care

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Abstract: Post stroke care is ever evolving from the acute in-hospital stroke unit approach to the long-term stroke rehabilitation process that extends beyond the hospital settings. This is in accordance with the recent development in the neuroplasticity process which now believed to continue beyond the six months sub-acute recovery phase. A long-term comprehensive stroke care beyond in-hospital treatment through a multidisciplinary approach has been practiced in developed nations and proven to have favorable outcome for post stroke patients. This has lessened the stress in the medical system which has become increasingly exhausted due to the increasing prevalence of stroke cases and the overburden in handling the COVID-19 pandemic. The lockdowns during the COVID-19 pandemic have disrupted the usual stroke care in countries with an already scarce resource like Malaysia. Therefore, a more practical approach in utilizing resources available in the community can be a solution to optimize stroke care in the community. In this review, we shared our experience in managing post stroke patients using a comprehensive primary care team approach in providing a holistic multi-component post stroke management in the community settings. The model integrates various disciplines that combine preventive and rehabilitation treatment for post stroke patients in a coordinated systematic approach.

Keywords: Stroke, Primary Care, Long Term Stroke Care, Multidisciplinary Approach, Malaysia

1. Introduction

Stroke is defined as ‘rapidly developing clinical signs of focal (or global) disturbance of cerebral function, lasting more than 24 hours or leading to death, with no apparent cause other than that of vascular origin’ [1]. The advances in imaging techniques and better insight of the nature of stroke resulted in newer and varied interpretation in stroke definitions as described by the AHA/ASA Cerebrovascular Disease Categories and Definitions based in ICD 11 [2] (Table 1). These newer definitions of stroke incorporate the

understanding of infarction, hemorrhage and most importantly, it also includes the redefinition of transient ischemic attack (TIA). Although these definitions are mostly used in acute and research settings, it provides an understanding of the broad definition of stroke which is beneficial to all stroke providers, including in primary care, rehabilitation, and community.

Until the new millennium, the stroke recovery process was divided into three phases, namely acute, sub-acute and chronic phase. Figure 1 [3] shows the natural stroke care algorithm, with onset of repair starting within hours after stroke and reaching optimum recovery during subacute phase. At this

stage, active re-organization of neural networks around the tissue's injury site occurs, creating new tissue penumbra thus initiating endogenous plasticity process. Nonetheless, many believed that the re-organization process plateaued after six months of stroke, rendering it no benefit to have further rehabilitation or care beyond the subacute phase. Newer evidence in the last two decades have started to contradict this

theory with evidence pointed towards the roles of internal and external stimuluses in influencing the rate and process of neuroplasticity [4, 5]. The presence of repetitive stimuli coming from rehabilitation activities and task-specific activities might increase the existing neuroplasticity process, thus prolonging the re-organization process and providing window for long-term rehabilitation in overall stroke recovery period.

Table 1. Definition of stroke as proposed by the AHA/ASA Cerebrovascular Disease Categories and Definitions [2].

Category	Definition
Stroke	Cerebral ischemic stroke: Acute neurological dysfunction caused by focal infarction at single or multiple sites of the brain or retina. Evidence of acute infarction may come either from, (1) symptom duration lasting more than 24 hours, or (2) neuroimaging or other technique in the clinically relevant area of the brain. Intracerebral haemorrhage: Acute neurological dysfunction caused by haemorrhage within the brain parenchyma or in the ventricular system. Subarachnoid haemorrhage: Acute neurological dysfunction caused by subarachnoid haemorrhage.
Transient ischemic attack**	Stroke not known if ischemic or haemorrhage: Acute focal neurological dysfunction lasting more than 24 hours (or lead to death in less than 24 hours), but subtype of stroke (ischemic or haemorrhagic) has not been determined by neuroimaging or other techniques. A transient episode of focal neurological dysfunction caused by focal brain or retinal ischemia without acute infarction in the clinically relevant area of the brain or retina. Symptoms should resolve completely within 24 hours.
Cerebrovascular disease without acute cerebral symptom**	Silent cerebral infarct, demonstrated on neuroimaging or at autopsy that has not caused acute dysfunction of the brain. Silent cerebral micro bleed or macro bleed. Silent white matter abnormalities associated with vascular disease, i.e. abnormalities in the cerebral white matter of proven or assumed vascular origin.

** Not classified as stroke

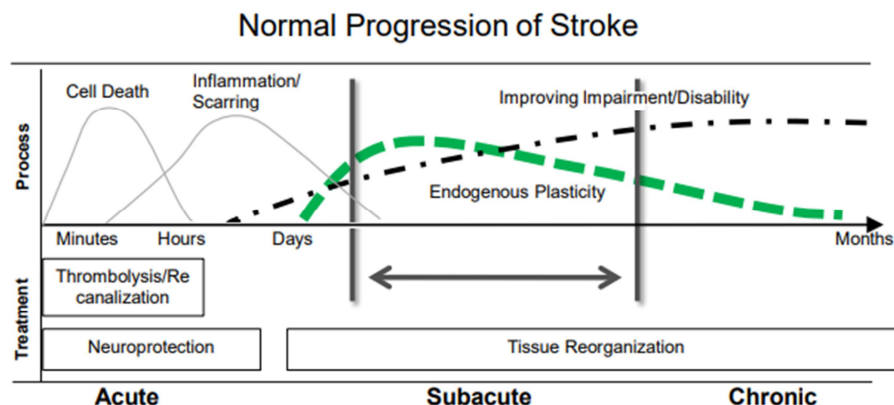


Figure 1. Care algorithm of the natural stroke care and recovery, starting within hours after stroke and reaching optimum recovery during subacute phase [3].

The further (or long-term stroke care) which is one of the components in comprehensive stroke care was introduced in early 2000, involving components of transfer of care, follow-up care, leisure intervention and community re-integration. The stroke providers now in consensus that this phase of long-term stroke care should begin as soon as the patient is being discharged from hospital to the community, utilizing shared care approach involving multi-disciplinary team management in looking into the various needs of the patient and the family. In Malaysia, the concept of long-term stroke care in primary care is new compared to the established stroke care in hospital settings. The shared care approach involving multi-disciplinary team is viewed as the most suitable approach for long term stroke care, as survivors at this stage require various care approaches to fulfil the multiple needs and issues of patient and the family. This article describes the review of stroke care, focusing on the long-term stroke care in Malaysia's community context, and narrates the

need for re-look into the management of stroke after hospital discharge.

2. Current Stroke Situation in Malaysia

Stroke in Malaysia has become a major public health issue, with newly diagnosed cases and the number of stroke survivors showing a persistent increasing trend in this millennium. The nationwide Third Morbidity Survey (NHMS III) in 2006 had reported that stroke contributed to 0.3% of the prevalence of chronic disease in Malaysia [6], by which in 2011, the concurrent Fourth National Health Morbidity Survey (NHMS IV) had reported an increase in stroke cases to 0.7% of chronic disease, with cases parallel to the increasing age groups [7]. The analytical review of stroke risk factors among Malaysian population showed a worrying but expected findings with three major risk factors to stroke reported as hypertension, diabetes, and dyslipidemia; with contributory

factors of smoking, having history of previous stroke or transient ischemic attack and chronic kidney disease increased the risks of having strokes [8].

The COVID-19 pandemic that seen countries including Malaysia, imposing strict lockdowns and movement restrictions during earlier phase of the pandemic resulted in the disruption in health care services [9]. Stroke, especially the ischemic types have been reported both as COVID-19 presentation and complications [10]. Through post-mortem findings, there were similarities between stroke and COVID-19, in which the pathogenesis of both conditions showed inflammation of the vessel walls and hypercoagulability condition. As the consequence, those with risk factors of stroke faced higher risks of having embolic phenomenon leading to vessel occlusion should they simultaneously have COVID-19 infection. On the other hand, COVID-19 has also interrupted the healthcare services, consequently affecting stroke care management in this country. Firstly, the long lockdowns together with lack of exercise and high consumption of high caloric foods saw an increasing trend of non-communicable diseases (NCD) namely hypertension, diabetes, and dyslipidemia that in turn increased risks of having stroke. The risks were heightened during the pandemic, as the already diagnosed NCD cases suffered setbacks in missing regular appointments due to fear that the clinics might be the epicenters for COVID-19 infection [11]. Secondly, the pandemic has seen the hesitancy and public aversion towards hospital visits that lead to potential delay in receiving diagnosis and acute treatment, thus resulting in more severe stroke, higher mortality, and morbidity [12]. This in turn increased the burden in long-term stroke care in terms of needs for more rehabilitation, medical care, and social support. Lastly, the pandemic has shifted the resources in many government primary care clinics and hospitals, hence many of stroke patients are having interrupted management of their stroke recovery and rehabilitation that affected the long-term recovery and the re-integration back into the community. The years ahead will pose challenge to all stroke care providers in all components from primary prevention, in-hospital management, rehabilitation, and post-discharge care as the trend of new and stroke survivors will continue to increase and the co-existing of COVID-19 will see some of the stroke services to change and adapt to the new norms.

3. Long-Term Stroke Care in Malaysia

The new paradigm shifts of managing stroke in Malaysia had been discussed by stroke providers over the last two decades [13, 14]. N. A. Aziz had highlighted the needs for rehabilitation for patients beyond one year of stroke, as this phase of stroke should focused more on gaining of independence and re-integration into community rather than focusing only on regaining physical activities. Abdul Aziz A. F et al. had further elaborated this concept, in which rehabilitation in the community should be provided in a multi-disciplinary approach, involving not only rehabilitation

but integrating the primary care services as well. This is in line with the current guideline in stroke care [15] that outlines the need for a more holistic, goal-directed, and patient-centered primary care management for adult patients with stroke. Nonetheless, the components of stroke care outside hospital remain fragmented and piece-meals, with many of the stroke providers are working in silos, with lack of communication and planning between the disciplines [16, 17]. The management of long-term stroke care in Malaysia lacks the comprehensive care compared to the structured acute stroke management in the hospital. This is expected as the current shift of neuroplasticity theory was only established only this millennium, hence resulting in lack of exposure and knowledge regarding the needs for providing stroke care beyond hospital discharge, focusing only on secondary prevention in preventing stroke recurrence. Additionally, the provision of care has been also limited by the inadequate understanding about long-term stroke care among health professionals, availability of resources at the community level and accessibility of support service [17].

The stroke care at the community level may be in the form of special stroke units in primary clinics, rehabilitation services in the community, advanced nursing care, or regular joint care of primary services and hospitals. A comprehensive post-stroke care led by a primary care physician is warranted as they provide a continuity of care towards long-term coordinated care in the community. Through the medical reference received from the acute care settings, primary care physicians can coordinate further care and stroke rehabilitation services for their patients in the community where they reside. These may include attending to the patients' medical needs and coordinate care together with the patients' support network. They will also conduct the secondary and tertiary preventive measures intensively through well-coordinated manner involving a structured multidisciplinary approach. They also provide comprehensive stroke care in the community which involves components of physical examination, motor, co-morbid conditions, emotions, family support, and social integration. This is to enable stroke patients and their families to receive a comprehensive management covering complications, advanced care, emotional assistance, return to work assistance, and community support systems. The role of nursing in supporting primary care physicians is also important, from providing stroke-based education, training the stroke patient and their families in improving functional outcome and as facilitators in navigating the complex process of medical appointments, seeking social support and getting back to the community, Langhorne [18] and Page et al. [19] agreed that comprehensive stroke care is essential to address advanced stroke patients who vary in terms of recovery and response to recovery. Additionally, the care given may help to address the lack of support and stroke-related information which renders them from optimum recovery, thus resulting in unnecessary stress to the stroke sufferers and their caregivers [20, 21].

4. Combining the Algorithm of Multidisciplinary Long Term Stroke Care: The Way Forward

The complex management of stroke beyond hospital care involves multiple disciplines managing not only the stroke survivors, but involving the family members, caregivers, employers, and community. The main components of long-term stroke care are primary care, rehabilitation, and nursing supported by medical social workers, hospital-based disciplines such as neurology, nephrology, and other stroke support groups. Thus, there is a risk of overlapping of activities, poor organization, and patchy management between disciplines, as the disciplines work as independent providers without any formal link. Fisher *et al.* in Delphi consensus study in finding an ideal model for community-based rehabilitation suggested that stroke services in the community should be structured, provided in multi-disciplinary approach, and should be based on the local resources and patients' needs after stroke [22]. Nonetheless, the panels were also aware of the differences in geographical locations, resources, and expertise in adhering to one standard model, thus advocating that the care pathway need to be flexible in addressing the differences, but at the same time should include the main care components namely rehabilitation, primary care and family and community support.

Realizing these complexities, it is timely that the management for long term stroke care in the community should be operated as one singular model, using a team-based approach working pathway between disciplines. Figure 2 suggested a long-term stroke care algorithm embodies the principles of long-term stroke care as described by earlier consensus [11, 13, 14, 22]. The algorithm describes long-term stroke care as a comprehensive care management, involving a seamless process from community to hospital and later back to

community again. The algorithm starts with a primary prevention component which involves providing health education about risk of stroke, early symptoms of stroke, and need for early intervention to the public with targeted risk factor assessments and management in those with high risk of stroke. The hospital management includes early intervention best provided in a dedicated stroke unit, early start of rehabilitation intervention and preparation for transfer of care from hospital back to community care. This component involves multidisciplinary management, from medical/surgical management, rehabilitation, nursing support, family support and medical social services in preparing patients to be discharged back to community. Evidence has also advocated for early supported discharge services with multidisciplinary intervention in resourced settings as to reduce length of hospital stay and long-term dependency [23]. The last component observes the stroke patient going back to the community, in-lieu with the consensus outlining the needs for long-term periodic stroke care after hospital discharge [11, 24]. Stroke survivors at this phase of stroke recovery often face multifaceted needs and issues from medical and stroke-specific complications, managing cardiovascular risk factors, psycho-social issues, and probability of either going back to work or living at home with disabilities, which needs multiple interventions over a long period of time [25]. These needs are best met by providing regular primary care follow-up with a stroke-specific approach and providing further rehabilitation either as out-patient, home-based rehabilitation programs or through community-based rehabilitation intervention. At the same time, stroke survivors and their families should have access to periodic information about stroke and stroke support and should have good communication with community nursing and stroke support groups in order to build up their confidence thus preparing them to re-integrate back into the community.

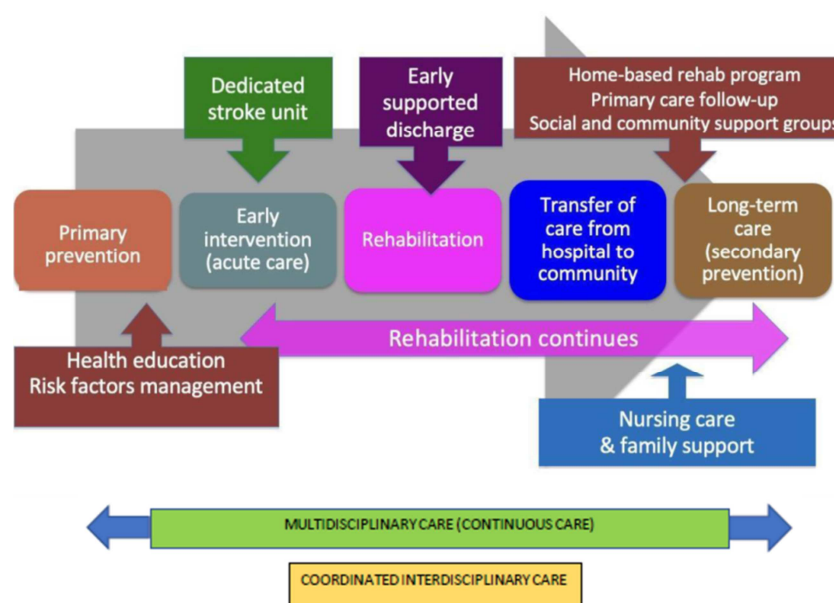


Figure 2. The algorithm of a comprehensive stroke care management. The process of care includes begins with a primary prevention, up to long term care. The care also involves a smooth transition from community to hospital and later back to community again.

The stroke care algorithm might not be ideal for all stroke care providers providing care in the community, but it might provide an insight on organizing the multi-faceted services and needs in caring for long-term stroke patients. It also highlights the roles of primary care providers and rehabilitation clinicians that provide services across phases intertwining with other disciplines. An on-going education may also be needed as the provision of long-term stroke care may be challenged by the limited knowledge of the care providers and rehabilitation clinicians [17].

5. Provision of a Comprehensive Long Term Stroke Care in the Community: An Example

A comprehensive post-stroke care that is led by a primary care physician is warranted to act as a continuity of care towards long-term coordinated care in the community. Realizing the need for such service, a Stroke Advanced Clinic was set up in UKM Medical Centre in Cheras Kuala Lumpur as a part of an extension services in the primary care discipline. The clinic provides a service space for stroke patients and families after being discharged from hospital treatment which incorporates other supportive medical services such as nursing, dietary, social work, and rehabilitation personnel (physiotherapy, occupational therapy, and speech therapy). The Stroke Advanced Clinic approach is based on the three main principles, namely:

1. Primary prevention that includes continuing health education to all patients, stroke patients, and families about stroke, risks, and risks of stroke recurrence.
2. Secondary prevention that includes aspects of identifying and treating risk factors such as diabetes, hypertension, dyslipidemia, smoking, and obesity together with established stroke etiologies such as carotid artery stenosis and atrial fibrillation.

Secondary prevention also includes active detection to detect complications due to stroke such as depression, prolonged fatigue, pressure sores, poor appetite, oral and dental care problems as well as kidney problems. Complications that have been identified are treated either through medications, specific therapies, or referral to relevant specialties. Often at this stage, joint stroke management involves collaboration from nursing, clinical rehabilitation, dietetics, dentistry, and clinical expertise in the hospital. This stage also requires long-term monitoring with periodic assessments as to ensure that the risk of recurrent stroke is reduced and minimized.

3. Tertiary prevention includes the process of optimizing the patient's physical functions through the process of recovery after stroke and reintegration into the community. Both processes are unique to advanced stroke care as it relates to the ability of stroke patients to achieve their best self-function in enabling them to return to work or at least to be able to be self-reliant in

self-care. The process of integration back into the community signifies the willingness of patients and families to return active in the community whether for work purposes or leisure activities. The Stroke Advanced Clinic constantly strives to design rehabilitation programs for patients and families to allow them to get out of the home and socialize with friends and the community.

A holistic assessment is vital during the earlier stage of stroke patients as patients in this phase often have various existing complications after stroke and at the same time are at risk of new medical complications and various psycho-social issues. Thus, it is suggested that a thorough systematic assessment that involves a post-stroke checklist developed specifically for long-term community care is practiced as to assure that all the complications and psycho-social problems are addressed and managed accordingly. The primary care physicians should work closely with the caregivers/family members in tailoring an individualized stroke care to their patients and at the same time channeling available community support services to the patients if indicated. This includes community peer support and respite care for the caregivers.

Realizing that peer support group able to create empowerment for stroke patients and their caregivers through engagement in social activities and sharing knowledge and resources, the Advanced Stroke Clinic had initiated the stroke support group to help with overall stroke recovery. The UKM Stroke Patient Support Club (KEKASIH) was initiated in 2014 just for this matter. The club, which is made up of stroke patients (and their families) receiving treatment at Stroke Advanced Clinic, is run entirely by the committee members appointed among patients and families. The committee is encouraged to meet and discuss on their own in planning their activities, with the support from the Stroke Advanced Clinic team members. Various activities have been carried out successfully fulfilling the aspirations of integration into the community, including social gatherings, sports meetings, and health talks. The support club also provided the space for stroke families to meet and share experiences, advice, and challenges in managing their daily lives. As for the Stroke Advanced Clinic team, the KEKASIH club provides a realistic learning curve to better understand the situation of stroke patients and their families thus providing a platform to plan better treatments and programs that meet their needs in longer-term stroke care.

6. Conclusion

Malaysia has made a considerable progress in supporting stroke survivors and their caregivers with their post-stroke care needs and living in the community optimally. The progress is remarkable with acute stroke care; however, the current provision of post-stroke care necessitates manifold improvements, namely with integration of care and communication between care providers. With long-term stroke care, further improvement is required with its

accessibility, availability, and provision of multidisciplinary services in meeting the needs of stroke survivors and their caregivers. The algorithm of longer-term stroke care that involves seamless management in the community and hospital might provide a platform for stroke providers in developing countries to plan similar programs. Nonetheless, there is no ideal algorithm that fits to every setting, as each country has its own needs, resources, and limitations in managing longer-term stroke patients in the community. Thus, further studies are required to inform further strategies in improving long term stroke care in the community settings, taking into accounts all these factors mentioned.

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