



MONASH University

The Experience of stroke in Malaysia

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(MD, MPH)

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Abstract

Stroke is the second leading cause of death worldwide and the third most common cause of disability globally. A third of people who have experienced stroke are left with a permanent disability. The impact of stroke is not felt uniformly across countries; in 2010, there were approximately 16.9 million strokes worldwide, of which 70% occurred in low and middle-income countries (LMIC). Presently, 87% of worldwide mortality from stroke occurs in LMIC. In Malaysia, the National Stroke Association reports that approximately 40,000 individuals suffer a stroke annually.

A robust public health strategy is therefore required for the prevention, treatment and management of stroke in LMIC. Cost-effective interventions aimed at reducing risk factors; aiding in the assessment and management of acute stroke; ensuring comprehensive health education for healthcare providers, the public and stroke patients; providing access to stroke; and supporting family and societal engagement with stroke survivors are needed. To inform such interventions, it is imperative to investigate and understand the lived experiences of stroke from the perspective of the survivor. Consequently, this study aims to expand on the experience of being a stroke survivor.

This study employs an ethnographic approach to investigate the experiences and concerns of survivors following a stroke within their social context in rural Peninsular Malaysia. Data for the study was obtained primarily through semi-structured interviews and participant observation documented through extensive field notes. The interviews were transcribed and translated. Data obtained from both the transcripts and field notes were analysed using thematic analysis.

This study established that the occurrence of a stroke presented with psychological, physical and social consequences which affected all facets of a survivor's life, forcing them to appraise and rebuild their lives and identity. Descriptions of the

impact of the stroke are demonstrated within the broader context of abilities, including in dressing, feeding, and religious practices. The impacts of stroke were also felt within a broader social context, notably in visiting friends and attending religious services. Roles within the family frequently changed, from being equal and undertaking the role of housemaker or breadwinner to being dependent on others. Recovery was seen not as a restoration of a pre-stroke life; instead, as a lessening of the impact of the stroke.

The study highlighted several factors that shaped the stroke survivors' recovery path, including hope, self-efficacy, coping strategies, coexisting medical conditions, family support, information from health professionals, and treatment management. Participants often used multiple strategies to cope with the effects of the stroke. The strategies most often used were turning to religion, acceptance, active coping, and seeking social support.

Living with stroke challenges the survivor and posits questions about how healthcare professionals provide information, treatment, practical and psychosocial support. This study thus highlights the contextual complexity of life with stroke and offers a robust and effective public health strategy for the management of stroke.

Publications during enrolment

1. Documenting the impact of stroke in a middle-income country- A Malaysian case study. Fatima Fanna Mairami, Narelle Warren, Pascale A. Allotey, Jun Shin Mak & Daniel D. Reidpath (2018) Disability and Rehabilitation, DOI: [10.1080/09638288.2018.1493544](https://doi.org/10.1080/09638288.2018.1493544))
2. Recovery after stroke in rural Malaysia (Under review, submitted to Rural and Remote Health, September 2018)
3. Contextual factors that shape recovery after stroke in Malaysia (Returned for revision, submitted to Disability and Rehabilitation, June 2018)
4. Stroke recovery in rural Malaysia: coping strategies employed by survivors (Under review, submitted to Neuropsychological Rehabilitation, August 2018)
5. Stroke recovery in rural Malaysia: the role of the Islamic faith (Under review, submitted to Religion and Health, July 2018)
6. Adaptive Inventions: independence and mobility through modifications Fatima Fanna Mairami, Pascale Allotey, Narelle Warren, Jun Shin Mak & Daniel Diamond Reidpath (2017): Disability and Rehabilitation: Assistive Technology, DOI: [10.1080/17483107.2017.1369586](https://doi.org/10.1080/17483107.2017.1369586)
7. Employment of patients with multiple sclerosis: the influence of psychosocial-structural coping and context. Vijayasingham L, Mairami FF. Degenerative Neurological and Neuromuscular Disease. 2018; 8:15-24. DOI: [10.2147/DNND.S131729](https://doi.org/10.2147/DNND.S131729).

Thesis including published works declaration

I hereby declare that this thesis contains no material which has been accepted for the award of any other degree or diploma at any university or equivalent institution and that, to the best of my knowledge and belief, this thesis contains no material previously published or written by another person, except where due reference is made in the text of the thesis.

This thesis includes two original papers published in peer-reviewed journals, and four submitted publications. The core theme of the thesis is recovery and well-being following a stroke. The ideas, development and writing up of all the papers in the thesis were the principal responsibility of myself, the student, working within the Department of Global Public Health, Monash University Malaysia under the supervision of Professor Daniel Reidpath and Dr Narelle Warren.

In the case of chapters five, six, seven and eight my contribution to the work involved the following:

Thesis Chapter	Publication Title	Status (published, in the press, accepted or returned for revision, submitted)	Nature and % of student contribution	Co-author name(s) Nature and % of Co-author's contribution*	Co-author(s), Monash student Y/N*
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In 6	Recovery after stroke in rural Malaysia	Submitted	70%. The concept, collecting data and writing the first draft	Study design & input into the manuscript- 1. Narelle Warren, 15%, 2. Pascale Allotey, 10%. 3. Daniel Reidpath, 5%.	No
In 6	Contextual factors that shape recovery after stroke in Malaysia	Returned for revision	70%. The concept, collecting data and	Study design & input into the manuscript- 1. Narelle Warren, 15%,	No

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			writing the first draft	2. Pascale Allotey, 10%. 3. Daniel Reidpath, 5%.	
In 6	Adaptive Inventions: Independence and mobility through modifications	Published	60%. The concept, collecting data and writing the first draft	Study design & input into the manuscript- 1. Narelle Warren, 15%, 2. Pascale Allotey, 10%. 3. Daniel Reidpath, 5%. Data collection- Jun Shin Mak , 10%	No
7	Stroke recovery in rural Malaysia: coping strategies employed by survivors	Submitted	70%. The concept, collecting data and writing the first draft	Study design & input into the manuscript- 1. Narelle Warren, 15%, 2. Pascale Allotey, 10%. 3. Daniel Reidpath, 5%.	No
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I have renumbered sections of submitted papers in order to generate a consistent presentation within the thesis.

Student signature:



Date: 17/12/2018

The undersigned hereby certify that the above declaration correctly reflects the nature and extent of the student's and co-authors' contributions to this work. In instances where I am not the responsible author, I have consulted with the responsible author to agree on the respective contributions of the authors.

Main Supervisor signature:



Date: 18/12/2018

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Abbreviations/Acronyms

ASEAN: Association of Southeast Asian Nations

CAM: Complementary and Alternative Medicine

CITF: Chronic illness trajectory framework

COPE: Coping with Problems Experienced

CT: Computed Tomography

DHSS: Demographic and Health Surveillance Sites

EHSD: Early Home Supported Discharge

FAST: Facial drooping, Arm weakness, Slurred speech, Time

FELCRA: Federal Land Consolidation and Rehabilitation Authority

FELDA: Federal Land Development Authority

GBD: Global Burden of Disease

HDSS: Health and demographic surveillance system

HIC: High-income countries

ICF: International Classification of Functioning, Disability and Health

LMIC: Low and middle-income countries

SEACO: South East Asia Community Observatory

WHO: World Health Organization

Glossary of terms

Local

Bahasa: language

Bumiputra: a Malaysian of indigenous Malay origin

Doa: supplications

Klinik: clinic

Klinik Desa: village clinic

Lah: slang used mainly to complement almost any sentence in a social conversation

Mukim: sub-district; the smallest administrative district, usually consisting of or spanning some villages

Surau: an Islamic assembly building used for worship and religious instruction

Arabic/Islamic

Alhamdulillah: praise be to Allah

Assalam Alaikum: Arabic/Islamic greeting that means, 'peace be upon you.'

Bismillah: in the name of Allah

Eid-al-Fitr: day of celebration that marks the end of Ramadan

Fidya: compensation paid for missing the fast of Ramadan

Hajj: annual Islamic pilgrimage to Mecca

Iftar: a post-sunset meal with which Muslims end their fast

Imam: an Islamic leadership position, commonly used for a community or mosque leader

In Sha Allah: if God wills

Ramadan: ninth month of the Islamic calendar whereby Muslims observe the fast

Sahur: a pre-dawn meal with which Muslims commence the fast

Salah: a physical, mental, and spiritual act of worship Muslims perform five times daily

Tarawih: extra prayers performed by Muslims during the nights of Ramadan

Tayammum: dry ablution using clean sand or dust, performed in place of ritual washing with water

Wudhu: Islamic ritual purification using clean water

Zikr: Islamic mantras to praise and remember God

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Chapter 1.

Introduction and overview of the thesis

Introduction

This thesis provides insight into the lived experience of stroke recovery. As most research discuss the clinical aspects of recovery from stroke, this research emphasises the understanding of recovery from stroke survivors' perspectives in a low and middle-income country. Survivors were given the opportunity to reveal their experience of living with a stroke to enhance our understanding of the illness. The thesis comprises one part of a larger project funded by the Australian Research Council's Discovery Project.

Context

Ayub was working at his farm when he felt his hands go numb and had needles and pins sensation. His speech became slurred, and his facial features became deviated. He tried to drive his car but could not. Two friends noticed his struggles with the car and came to his aid. They drove him to a hospital immediately. After waiting in the emergency room for quite a while, he was diagnosed with a stroke. Although he spent just two days at the hospital, he was quite unhappy with the stay. His wife was not allowed to spend the night with him, and he had to depend on the nursing staff for whatever he needed. He was particularly embarrassed when he had to request the nurse's help for toileting, even though it was a male nurse. After his discharge from the hospital, he went home; he recalls not being able to do much in the initial weeks following the stroke:

I didn't have much to do; I had to get used to it [stroke]. My wife would organise everything for me. I had to learn to sit, walk, bath. It's like one day we are normal, and suddenly the next we are not. It takes getting used to; it takes time to get back to before. At first, I didn't tell anyone, I told my wife not to tell anyone. It's shameful. Long time I didn't go to the mosque when I wanted to go, I felt ashamed.

Ayub, who was aged 48, lived with his wife and kids. After the stroke, he was unable to work, and his wife had to leave her job as a chef to take care of him at home.

Financially, they were stretched. He applied for the disability card and put in a request for welfare. The state Islamic religious council gave them some aid. To stay afloat, the wife began to take care of young children at home, earning some monthly income. As time went by he regained some motor function. By the time Ayub participated in this study, he could drive and would run errands for neighbours to make money and at times offer taxi services.

Ayub's story demonstrates that the effects of stroke go beyond physical functioning to affect the psychological lives of individuals and their interaction with the environment. A physical change may prevent the survivor from undertaking their daily living activities, participating in the everyday life of their family, and in returning to work, hobbies and sports (Clarke & Black, 2005; Lord, McPherson, McNaughton, Rochester, & Weatherall, 2008; McKevitt, Redfern, Mold, & Wolfe, 2004). The road to recovery for stroke survivors can be tumultuous; it is a challenge to recover from the bodily injury and an even greater challenge to recover from the psychosocial loss. It is often lonely and requires diligence, motivation, and the ability of the survivor to triumph (Peoples, Satink, & Steultjens, 2011).

Reintegrating into society, into a routine of tasks and responsibilities, gives the survivor a sense of purpose in a family and community. Recovering from physical and social trauma depends not just on the efforts of the survivor but also on the efforts of those around the survivor (Miller et al., 2010). The way family, friends and healthcare

professionals respond to the resultant changes plays a vital role in the recovery of the survivor (Miller et al., 2010). Social networks help the survivor through the process of rehabilitation by giving them something to look forward to as they strive to return to their pre-stroke lives (Egbert, Koch, Coeling, & Ayers, 2006).

Individuals who live with an illness or a disability are more equipped to convey their experiences and what recovery means to them as they live with its consequences and bear its burdens (Barnes & Mercer, 2010; Couser, 1997; Ware, 1992). This is particularly significant in understanding the milieu of illness and social relationships. Motor improvements are necessary for optimising treatment and setting standards for treatment courses; however, individuals tend to be objectified when this is used as the only measure utilised (Peoples et al., 2011). It is therefore essential that research into the lived experiences of individuals be carried out. Such research may auger the empathic understanding of the context of illness for healthcare providers (Van Manen, 2016).

A practical approach to recovery following stroke lies in the understanding of the experiences, and expectations of the stroke survivors (Sadler, Wolfe, Jones, & McKevitt, 2017; Sarre et al., 2014). A robust model of rehabilitation that supports stroke survivors in reclaiming the capacity to carry out day-to-day activities related to family life, work, and societal reintegration may address the psychosocial impact of the stroke, work towards minimalising the burden felt by both stroke survivors and their caregivers and restore well-being (Miller et al., 2010).

Researchers have provided extensive information and explored the prevention and treatment of stroke; however, limited research has examined how individuals who suffered a stroke respond to the condition and how they can manage and reconstruct their everyday lives particularly in low and middle-income countries (LMIC). For this reason, my thesis presents an ethnographic inquiry into the community experience of living with and recovery from stroke. This study aims to contribute towards an optimum pattern of care and rehabilitation of stroke survivors in the community.

The significance of the study

As the world population ages, there is evidence that many individuals live with chronic disease. Stroke, a chronic illness, is the third most significant contributor to the burden of disease worldwide. Research has shown that stroke is a leading cause of mortality and morbidity as well as hospitalisations (C. J. Murray et al., 2013). In LMIC, stroke is a major public health challenge (Abegunde, Mathers, Adam, Ortegon, & Strong, 2007). In Malaysia, the National Stroke Association reports that approximately 40,000 individuals suffer a stroke annually (National Stroke Association of Malaysia).

Stroke influences different populations in diverse ways. Understandings of the aetiology and risk factors, the pathways to help/care seeking, the informal systems of care, the meaning of recovery, and the resources to aid recovery are all culturally defined (Harwood, McNaughton, McPherson, & Weatherall, 2000). Religion, ethnicity, and health services all play a role in the context of health and well-being. Therefore, knowledge of the existential meaning of recovery from stroke for survivors is essential for healthcare workers involved in the rehabilitation of individuals living with stroke. Exploration of lived experiences may consequently enhance healthcare providers' empathic understanding and help improve the quality of support provided for the survivors. Understanding lived experiences provides a potent incentive for change by offering insights that are embedded within the story and resonate within the listener's awareness of the situation.

Development and delivery of stroke services are usually tailored to health professionals' understandings of recovery. This may have limited bearing to the experiences of the stroke survivor. Service provision requires a holistic understanding

of stroke from onset into the long-term and should take cognisance of the experiences of stroke survivors. Coping and adaptation skills for stroke survivors and their families at home and in the community, need to be taking into consideration (Miller et al., 2010; Peoples et al., 2011).

Most healthcare services in LMIC are fragmented, urban-located, and focus heavily on providing care for acute and infectious diseases rather than chronic conditions (Atun, 2015). Similarly, the reliance on healthcare facilities and over-burden of specialists in tertiary care make health systems in LMIC un-prepared to manage chronic conditions (Atun, 2015). To rely on treatment models designed for high-income countries (HIC) where specialists provide stroke care services within specialised units is not only impractical but also unsustainable.

Treatment and management models for stroke are based almost exclusively in the context of high-income countries with western concepts of social and cultural identity. In an overview of stroke management, Brainin and colleagues (2007) suggest that considerations of certain factors must be made when extrapolating stroke management approaches developed for HIC to LMIC. These factors include the cultural and social context of the countries as well as the availability of resources within the states. Research on such factors and how they fit in with international recommendations have been limited.

Taking Malaysia as an example, this research provides a rich understanding of the lived experience of stroke from survivors, exploring the contextual underpinnings of the recovery experience. The knowledge obtained will illuminate the lived experience of stroke survivors thereby providing a fulcrum for policy-making and public health interventions tailored to the needs of individuals in LMIC.

Aims and Objectives

This study aims to explore the lived experience of stroke from the stroke survivors' perspective and explore what recovery means to them.

To achieve this aim, I identified the following objectives.

- Provide an assessment of the trajectory of stroke experience for survivors
- Describe the impact of stroke on the lives of survivors
- Explore the meaning of recovery for survivors
- Explore the coping strategies employed by survivors to overcome challenges
- Explore the effects of stroke on religious practices and the use of religion as a coping strategy

Using ethnographic methods, I explored the objectives within a qualitative paradigm.

The research findings are made up of data from different data collection methods which include in-depth interviews, participant observations, and ©Talking Mats.

Thesis structure

This thesis adopts the format of a 'thesis including published works'. Chapters five, six, seven and eight contain published and submitted papers. **Chapter 1** provides a comprehensive picture of the thesis and describes how it is structured. It sets the context for the thesis, discusses the significance of the study, the aim and objectives of the research and the thesis outline. In **Chapter 2**, pertinent literature, including a brief overview of stroke, the trajectory of the stroke illness, consequences of stroke, the coping strategies used by stroke survivors and the association of stroke recovery with religion, are discussed. **Chapter 3** details the methodology used for the study. The research methodology, data collection techniques, fieldwork experience and data analysis, are described. The chapter starts with an overview of ethnography.

Subsequently, I report on my role as a researcher, the setting of the study, the methods

used in the research, participant recruitment, issues with confidentiality and translation and the process of analysis undertaken.

The subsequent five chapters outline the findings from the study. **Chapter 4** discusses the trajectory of stroke as a chronic illness in Malaysia. **Chapter 5** documents the effects of stroke on the participants' lives. **Chapter 6** discusses the meaning of recovery for the participants and the factors that facilitate or hinder their recovery. **Chapter 7** explains the coping strategies used by stroke survivors. **Chapter 8** describes how religion affects recovery from stroke and the impact of the stroke on religious practices.

Chapter 9 discusses the findings of the study within context. The stroke illness path and the impact on the lives of the survivors are drawn together to weave a pattern of recovery within the community and its implication for public health practice. Finally, **Chapter 10**, summarises the study and highlights areas for future research.

Summary

This chapter presented an overview of the study. It introduced the study, the justification for undertaking it and its significance to public health practice. The chapter outlined the aims and objectives of the research and described the structure of the thesis. Chapter two presents literature pertinent to the study.

Chapter 2.

Evidence from the literature

Introduction

This chapter encompasses a review of the literature relevant to the thesis. The section provides background information on stroke as well as an evaluation of recovery from stroke. Specifically, the literature review aimed to provide evidence on past and present modalities of recovery from a stroke; the impact on lives, the strategies used to overcome challenges and salient mediating factors in stroke recovery.

The questions addressed in the study are:

1. What is the course of stroke recovery for stroke survivors?
2. How has the stroke impacted the lives of survivors and what does recovery mean for them?
3. What coping strategies are employed by survivors to overcome challenges and availability/impact of social support
4. What are the effects of stroke on religious practices and the use of religion as a coping strategy?

The scope of the review thus covered four main areas:

1. An overview of stroke to identify the risk factors, diagnosis and treatment of stroke, and health services depiction of stroke recovery.
2. The physical, psychological and social impact of stroke.
3. Coping strategies used by stroke survivors to overcome daily challenges
4. Role of religion in recovery and within a Malaysian context.

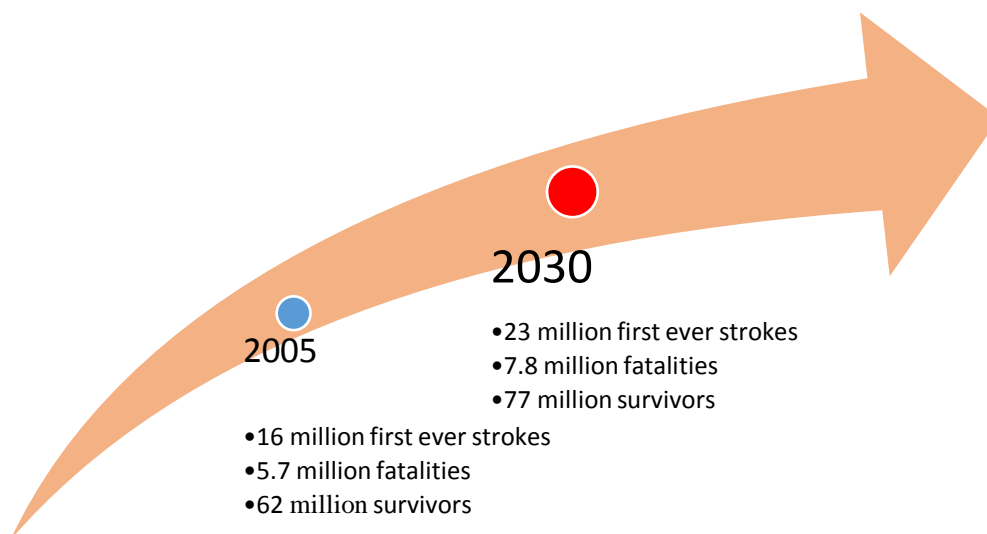
Several databases, including SCOPUS, Web of Science, Medline, EBSCOhost, PsycINFO, and Google scholar were accessed for the review.

Stroke

Incidence and prevalence of stroke

Stroke is a leading cause of morbidity and mortality globally and is projected by the Global Burden of Disease (GBD) study to increase between 2005 and 2030 significantly (see Figure 1., below) (Strong, Mathers, & Bonita, 2007). The Global Burden of Diseases, Injuries and Risk Factors Study (2010) recorded stroke as the second-leading cause of mortality (Feigin et al., 2014). The study also ranked it the third most common cause of disability-adjusted life years globally (C. J. Murray et al., 2013). However, despite this global ranking, the impact of stroke is not felt uniformly across countries: stroke is a leading cause of death in LMIC, with 87% of worldwide mortality occurring in these countries (Strong et al., 2007).

Figure 1: Global increase in stroke burden



Specific country data on the incidence and prevalence of stroke in LMIC is limited and quite small in ASEAN (Association of South East Asian Countries) countries (Health Technology Assessment Unit Medical Development Division Ministry of Health Malaysia, 2002). The Malaysian Ministry of Health reports an increasing trend in total admissions for cerebrovascular diseases; however, data on incidence and prevalence of

stroke is limited (Health Technology Assessment Unit Medical Development Division Ministry of Health Malaysia, 2002).

Stroke as an Illness

Stroke or cerebrovascular accident is a sudden neurological deficit attributable to an injury to brain tissue in a confined area of the brain due to inadequate blood flow (Hankey & Blacker, 2015). The reduced blood supply decreases the amount of oxygen and nutrients needed by the brain cells, leading to their death. A stroke may result in paralysis, speech impairment, visual impairment, memory loss, diminished reasoning skills, coma, and death (Party, 2012; Turkington & Harris, 2010). The level of debility experienced by the individual reflects the degree of injury to the brain.

Two forms of stroke exist; ischemic and haemorrhagic. Ischemic strokes account for 80- 85% of all strokes (Schweizer & Macdonald, 2014). These strokes result from a blockage or narrowing of cerebral arteries, often caused by blood clots formed within the cerebral arteries or further away in other arteries and being swept through the bloodstream to the cerebral arteries (Andersen, Olsen, Dehlendorff, & Kammersgaard, 2009; Burkman, 2010). Plaque (fatty deposits within the arteries) can cause these clots. Haemorrhagic strokes are less frequent and occur when arteries leak or break open, resulting in a bleed in the brain (Andersen et al., 2009). Haemorrhagic strokes are attributable to conditions such as hypertension, vascular malformations, amyloid angiopathy, an infarct, aneurysm rupture, coagulation, or platelet dysfunctions (Broderick et al., 2007). A small number of haemorrhagic strokes remain idiopathic (Andersen et al., 2009). Transient ischemic attacks (TIA) are episodes in which blood flow is disrupted temporarily with no lingering damage to the brain cells (Ralph L. Sacco et al., 2013). They are however precursors to major stroke with about 1 in 20 suffering a stroke within the following 36-48 hours (Schweizer & Macdonald, 2014).

The major risk factors for stroke which are modifiable are hypertension and heart disease (O'Donnell et al., 2016; Yusuf et al., 2004). Additional risk factors include elevated serum cholesterol, physical inactivity, diabetes, tobacco use, oral contraceptive use, and post-menopausal hormone replacement therapy (O'Donnell et al., 2016). The non-modifiable risk factors include age, gender, and race (Deoke, Deoke, Saoji, & Hajare, 2012; Håheim, Holme, Hjermann, & Leren, 1993). Others are a family history of stroke, previous stroke, structural heart defects, pregnancy, and postpartum (Grau et al., 2001; Petty et al., 1999; Ralph L Sacco, 2001).

Diagnosis and treatment of stroke

A history of sudden onset of focal dysfunction (problem with brain function), especially in aged patients with vascular risk factors; augmented by neurological imaging, makes a diagnosis of stroke typically unproblematic (Adams et al., 2003). Neuroimaging (CT scan) is important in obtaining a definitive diagnosis of the type of stroke and the location of the injury (Ralph L. Sacco et al., 2013). However, access to such technology is problematic in LMIC where CT scanners are expensive and only available in large hospitals (Brainin, Teuschl, & Kalra, 2007; Joubert et al., 2008). In HIC, the availability of neurological imaging equipment makes diagnosis easier. In LMIC, however, where neurological imaging is not readily available, some differential diagnosis must be entertained. These could include cerebral malaria, cryptococcal or tuberculous meningitis, encephalitis, head trauma, parasitic infections, or brain abscesses or tumours. Diagnosis of stroke can be made clinically using scores such as the Siriraj Score (Allen, 1983; N. Pongvarin, Viriyavejakul, & Komontri, 1991), which can distinguish with 90% accuracy a haemorrhagic stroke from an ischemic stroke. The Siriraj score uses five different clinical variables: atheroma marker, headache, diastolic blood pressure, vomiting and level of consciousness.

Hospital admission rates in HIC seemingly reflect the resources available for stroke care, with the attending physician taking cognisance of the closeness of a hospital with specialised stroke units, the severity of the stroke, availability of domiciliary nursing care, and expectations of those involved (patient and family) (Niphon Pongvarin, 1998). This contrasts with LMIC, where hospital admission hinges mainly on the severity of the signs and symptoms present and the availability of resources. The preservation of cardiovascular and pulmonary function, electrolyte, fluid and nutritional balance, avoidance of complications and competent nursing care are the backbone of acute stroke care (Brandstater & Shutter, 2002; Niphon Pongvarin, 1998). These parameters are rarely achieved in LMIC due to the tendency to admit only severe stroke cases, and specialised stroke teams are seldom available in LMIC where there is a critical shortage of neurologists (Asemota, 2016; Wissel, Olver, & Sunnerhagen, 2013). Stroke patients are more likely than not to be treated by general practitioners where generally, symptomatic treatment is the norm. More commonly, traditional therapies and home-based care are widely used in LMIC for acute stroke care (Thorogood et al., 2004). Such treatments include mind-body medicine (meditation, prayers, exorcisms, and energy therapies), herbs, acupuncture, massage, cupping, and traditional Chinese medicine (Akinyemi et al., 2009; Ali et al., 2015; Hamzat, Arulogun, & Akindele, 2010; Pandian et al., 2005). Thrombolysis, proven to be effective in Ischemic stroke when administered within three hours of stroke onset, is rarely employed as the high cost proves to be a significant barrier in LMIC (Brainin et al., 2007; Joubert et al., 2008). In circumstances where thrombolytic treatment is available, most patients in LMIC are unlikely to benefit from it due to delays in seeking or accessing care, and because its use is limited to selected patients presenting early to specialist centres (Brainin et al., 2007).

Stroke in LMIC as compared to HIC

Compared to HIC, stroke poses significantly more significant public health challenges in LMIC due to a higher mortality burden and higher rates of subsequent disability (Lee, Nam, & Lee, 2015). Feigin and colleagues (2009) in a meta-analysis of 56 population-based studies disclosed that in ten LMIC, the incidence of stroke more than doubled within four decades, while the rate in 18 HIC decreased by almost 42% during the same period. The same study showed that between 2000 and 2008, the incidence of stroke in LMIC exceeded that in HIC by 20%. More studies have demonstrated that the incidence of stroke in LMIC exceeds that in HIC mainly because of variations in risk-factor distribution, accessibility and availability of primary-prevention programs, the socioeconomic status of individuals within these countries, and provision of acute care (Brainin et al., 2007; Chin, 2012; Joubert et al., 2008). These studies also show a higher case fatality of stroke in LMIC as compared to HIC and younger age of first-ever stroke (Brainin et al., 2007; Joubert et al., 2008).

Another study on global surveillance for stroke fatalities showed that rates varied between countries but LMIC bear the most significant burden (Johnston, Mendis, & Mathers, 2009). Stroke fatalities had a ten-fold difference between the most affected and least affected nations with rates highest in Central Africa, Eastern Europe, North Asia, and South Pacific (Johnston et al., 2009). The researchers suggested that this could be due to the low National per capita income in the affected countries (Johnston et al., 2009). In Africa, stroke is a major contributor to the burden of disease (Kengne & Anderson, 2006; Mensah, 2008). Adeboye (2014) suggested that the burden of stroke in Africa is on the rise despite the unreliability of data on stroke from most African countries. Some studies have also shown an increasing trend of stroke affecting younger individuals in Sub-Saharan Africa than in HIC (Kengne & Anderson, 2006).

Consequences of stroke

The clinical consequences depend on the underlying causative process, the location of the haemorrhage or infarct, the extent of damage, and emergency management received (Caplan, 2009). Most individuals who have suffered a stroke have lingering neurological deficits that affect physical functioning. Others suffer permanent disabilities that result in dependence on others for basic daily activities.

The types of impairment are heterogeneous and vary by the area of the brain that suffered the lesion. The most common impairments are limb weakness, impaired consciousness, urinary incontinence, dysphagia, and cognitive impairment (E. S. Lawrence et al., 2001). The ability to walk and use the arm and have been reported to be the most frequent physical dysfunctions (E. S. Lawrence et al., 2001). Some stroke patients suffer aphasia, a cognitive language impairment that causes functional incapacity and high psychological distress (Berthier, 2005; Hilari, 2011; Starkstein & Robinson, 1988). Some studies have shown that 21-24% of patients become aphasic shortly after their stroke and about 33% of survivors may have aphasia (Brust, Shafer, Richter, & Bruun, 1976; D. Wade, Hewer, David, & Enderby, 1986).

Post-stroke depression, seen in about 33% of survivors is the most common affective impairment (Hackett, Yapa, Parag, & Anderson, 2005). A study conducted in Malaysia demonstrated that depression was common amongst survivors of stroke (Glamcevski & Pierson, 2005), attributing the reasons to old age, poor performance in essential living activities, and an inability to regain pre-stroke activities. The anticipation of death in the elderly may also play a role as it tends to reduce the motivation to survive (Valenstein, 2000). The study also suggests that depression was more common in persons of Malay and Chinese ethnicity (Glamcevski & Pierson, 2005). The authors, however, could not explain the high rates of depression amongst these two

ethnicities as compared to Indian ethnicity. They suggest further studies to investigate the findings.

For LMIC where infectious diseases are still widespread in susceptible populations, the burden of stroke poses significant threats to an already overstrained healthcare service (Lee et al., 2015). Similarly, healthcare infrastructure is poorly managed and services inadequately delivered because of limited resources and expertise in these countries (Lee et al., 2015) making stroke outcome worse. Similarly, access and availability of health information and resources for the management of risk factors are limited, resulting in a lack of identification of such risks and subsequent poor management (Lee et al., 2015).

Most illness can lead to economic and social effects on individuals and their broader networks (Berkman, Kawachi, & Glymour, 2014; Stoddart & Evans, 2017; Wilkinson & Marmot, 2003). Stroke is no exception. The economic impact of stroke is not limited to treatment and medication costs but go further to include costs of informal care within the home and opportunity costs from loss of employment. Stroke often results in catastrophic health spending (Heeley et al., 2009; Mendis, 2010) which ensues when out-of-pocket payments for health services consume a considerable portion of a family's available income thus pushing them into poverty (K. Xu, 2005). The loss of employment after some cases of stroke compounds the situation further. A country-wide study conducted in China demonstrates this, where 71% of the participants had catastrophic spending after a family member had a stroke (Heeley et al., 2009). The authors credited this to the high costs of stroke treatments and the likely reduction of earning capacity due to disability which in turns leads to long-term care (Heeley et al., 2009). This is particularly worrisome in LMIC where healthcare is expensive, and the majority of persons do not have health insurance (Escobar, Griffin, & Shaw, 2010).

Recovery from stroke

The threat to life posed by a stroke leads to varying degrees of psychological and physical trauma that may have a bearing on the life of an individual, their caregiver and the society at large. Although these features are most likely to cause significant distress to the stroke survivor, they have been given limited research attention. Recovery from stroke often occurs within a family, and broader social context (Thomas A. Glass et al., 2000; Thomas A. Glass & Maddox, 1992) and social support/networks/capital have been demonstrated as ensuring a successful reintegration into society (Wood, Connelly, & Maly, 2010).

Research into the experience of recovery and well-being from the perspective of the stroke survivor has highlighted the need to better understand the emotional and social consequences of stroke (Strong et al., 2007). Clinicians and healthcare providers have focused primarily on diagnosis, treatment and short-term support (Miller et al., 2010) while ignoring the long-term support for stroke survivors. The strategies which stroke survivors have developed to cope with everyday life post stroke has received limited attention, especially in LMIC. However, the projected increases in stroke incidence in these settings highlights the need for critical public health attention.

Recovery from stroke presents a multifaceted entity which aims at restoration to the physical, mental, and psychosocial abilities of the individual before the stroke. Rehabilitation in stroke recovery helps survivors regain functions lost due to the injury in the brain, enabling independence and achieving a higher quality of life. Recovery is thus governed by the extent of insult to the brain, the capabilities of the rehabilitation team, the time before the commencement of therapy and support from caregivers (Jamison et al., 2006). Availability of and access to rehabilitation services is limited in LMIC. In the Gambia, less than half of stroke survivors were seen by therapists (Garbusinski et al., 2005). In a hospital in Southern China, professional physiotherapy was not part of routine stroke care (Fang, Chen, Li, Lin, & Huang, 2003); equally, in

South Africa, a study highlighted that only 39% of adult stroke survivors attended physiotherapy after discharge (Hale & Eales, 1998). In Thailand, it took an average of 53 days from stroke onset to admission in a rehabilitation facility (Suputtitada, Aksaranugraha, Granger, & Sankaew, 2003).

The physical or biomedical pathway of recovery centres on the medical prognosis and the reinstatement of motor function. The psychosocial pathway focuses on ways stroke survivors perceive their circumstances and the relationship with others and the society (Kendall et al., 2007). Watson and Quinn (1998) postulate a model for recovery following a stroke. They describe that, at onset, stroke survivors were more likely to be overwhelmed by the condition and incapable of fully understanding the situation (Watson & Quinn, 1998). The functional disability brought about by the stroke as well as the series of complex tests undergone by the patient puts enormous strain on the individual. Within this initial period, family and social support are more likely to be available and intense, helping the individual cope with the situation. However, with time, the support networks decline, leaving the stroke survivor vulnerable and isolated. This severely hinders the recovery process (Godfrey, Partridge, Knight, & Bishara, 1993). In the beginning, the stroke survivor is dependent on healthcare providers for daily needs, and later, he is dependent on family members if available.

Doolittle (1991), highlighted that due to the uncertainty of the future posed by the stroke, there was an urge for the survivors to regain control of their lives and achieve independence. The dependence on others makes stroke survivors vulnerable to feelings of hopelessness, humiliation, anxiety, and frustration which ultimately could lead to severe depression (N. D. Doolittle, 1991). Personal factors such as a person's approach to life also shape the extent to which this is the case (Pritchard, Warren, Barker, Brown, & Haines, 2015). Pritchard and colleagues (2015), in a study on participation in activities after hospitalisation, demonstrated that persons with an

optimistic approach to life tackled barriers and obstacles pro-actively while those with a more pessimistic nature tend to get trapped in the situation they find themselves.

Previous research on stroke-related recovery to improvements in the biomedical domain; neuronal and functional improvements, (Salter et al., 2005; D. T. Wade, Wood, & Hewer, 1985; Wagenaar et al., 1990); however, recovery cannot be isolated to the biomedical domain alone (Eng, Brauer, Kuys, Lord, & Hayward, 2014). Recovery takes into consideration demographics and psychosocial factors for example how do religion, and treatment modalities affect recovery? Or why do individuals with a support network do better than those without?

Implications of stroke

From the current literature, a stroke is a significant life event that redefines an individual's perspective on life. Advances in clinical medicine and neuroimaging can diagnose a stroke, but healthcare providers are still unable to provide an accurate prognosis of the recovery phase. This could be attributable to a wide variety of factors that influence the phase which includes age, severity, and location of the stroke, comorbid conditions, and associated complications. Furthermore, interventions such as thrombolysis, care in a stroke unit and rehabilitation all influence the outcome of stroke (Edwardson, Dromerick, Kasner, & Dashe, 2016). These factors are particularly crucial in LMIC where associated complications due to the widespread prevalence of infectious diseases could be seen (Lloyd-Sherlock, 2010) and availability of thrombolysis, stroke units, and rehabilitation centres are limited.

In studying stroke recovery, researchers have found that stroke survivors quantified recovery against their pre-stroke lives (N. D. Doolittle, 1991; Dowswell et al., 2000; Gubrium, Rittman, Williams, Young, & Boylstein, 2003). They had to acknowledge the possibility of never being the same as before. This acknowledgement of permanent

impairment drastically changed the lives of the survivors (Dowswell et al., 2000). Pound and colleagues (1995) further discovered a divergence in goal setting for recovery after stroke between healthcare providers and stroke survivors. Stroke survivors tend to set goals for themselves with which to measure recovery based on a return to past activities (Dowswell et al., 2000; Kelley & Borazanci, 2009; Lawler, Dowswell, Hearn, Forster, & Young, 1999).

Healthcare providers focus mainly on goals related to physical function; this may differ from the stroke survivors' goals of simply returning to basic activities (Gubrium et al., 2003). For stroke survivors, these activities could refer to the everyday evaluation of being debilitated or of achieving improvements in their functioning (Gubrium et al., 2003). Stroke survivors are more concerned with how improved physical function enables them to achieve social activities thus improving their sense of independence and self-esteem. Involving the stroke survivor in setting goals and treatment plans can assist the survivor's participation in the management process. Achievement of these goals is largely determined by the survivor's motivation and the value he places on accomplishing the goal. In LMIC where the availability of long-term rehabilitation services is limited, setting goals related to improved physical function and how these translate to social functioning would prove beneficial. Survivors may not want to work at purposes if the goals are not realistic or match their interests.

Some stroke survivors find ways of readapting to the new situation, redefining their identities and reintegrating into society. Studies in HIC have shown that adopting positive coping strategies have a positive influence on well-being and recovery post stroke providing an enabling environment for reintegration into society (Ostwald, Godwin, & Cron, 2009). In the majority of cases, a stroke occurs suddenly without warning, forcing the individuals to develop strategies enabling them to adjust to the situation rapidly. The individuals often find themselves ensnared in a case where abilities, boundaries, and goals suddenly have to be re-evaluated (Ostwald et al., 2009).

Fraas and Calvert (2009) in their study on survivors of Acquired Brain Injury and Stroke, identified several themes that contributed to the recovery. Amongst these themes was the need to develop effective coping strategies, which ultimately was the most effective long-term strategy for improved quality of life. Positive coping strategies are vital for stroke survivors and their caregivers in conserving or re-establishing continuity after the disruption presented by the stroke (Clarke & Black, 2005). The coping strategies could influence recovery and lessen the adverse effects brought about by the stroke. There is a scarcity of documented information on coping strategies used by stroke survivors in LMIC. Few studies have reiterated the importance of positive coping strategies. Dalvandi and colleagues (2009) explored post-stroke life amongst survivors in Iran, and found that having adaptive strategies was essential for stroke survivors and their families in accomplishing activities of daily living and improving their lives post-stroke.

Health systems depiction of rehabilitation following stroke

Rehabilitation in a multi-disciplinary stroke unit decreases rates of mortality, disability and the need for long-term care (Trialists' Collaboration, 2007). Due to limited healthcare resources, however, such services – and the provision of rehabilitation – is problematic in LMIC. Healthcare policies in these countries focus on acute care services rather than recuperative services, mainly on account of inadequate funding (Docteur & Oxley, 2003). The scarcity of trained rehabilitation healthcare staff, as well as lack of dedicated stroke units, also impede rehabilitation for stroke survivors.

In HIC, community rehabilitation centres and or services exist, giving a case to the benefits of early supportive discharge post-stroke (Fisher et al., 2011; Indredavik, Fjærtøft, Ekeberg, Løge, & Mørch, 2000; Teasell, Foley, Bhogal, & Speechley, 2003). In LMIC however, early discharge with nominal or no support is usually the case (A. F. A.

Aziz et al., 2014). This has been documented in the Malaysian context: Aziz and colleagues (2010) reported that over a third of stroke survivors do not receive rehabilitation services during in-hospital stay. Those who do receive rehabilitation services receive it late in the stroke recovery pathway; further, a substantial number had only one session a day (Nordin, Aziz, Alkaff, et al., 2012). This inadequacy reflects the limited human resources for chronic healthcare, particularly the shortage of rehabilitation professionals, in Malaysia. Just over 800 registered physiotherapists work in Malaysian public hospitals, servicing a range of patient care needs (Nordin, Aziz, Alkaff, et al., 2012). In Malaysia, most specialist stroke centres are in tertiary hospitals, located in urban areas. After initial rehabilitation in hospital, lasting about five-seven days (Hamidon & Raymond, 2003; Nordin, Aziz, Alkaff, et al., 2012), patients are discharged home to be cared by family (A. F. A. Aziz et al., 2014). Rehabilitation, if available, is thus continued on an out-patient basis. A high number of individuals, however, are inclined not to attend the rehabilitation sessions, due to the financial and time limitations and a lack of cognisance of the benefits of stroke rehabilitation (A. F. A. Aziz et al., 2014).

Murray and colleagues (2003), in a systematic review, identifying the most common longer-term problems experienced by stroke patients and their informal caregivers showed that dissatisfaction with the health and social care services was the second most reported issue by stroke survivors. This is preceded only by the social and emotional consequences of stroke (J. Murray, Ashworth, Forster, & Young, 2003). Consistent with the findings of Murray and colleagues, other studies have found that stroke survivors were dissatisfied with rehabilitation services post-stroke (Langhorne, Pollock, & Collaboration, 2002; Mayo, Wood-Dauphinee, Cote, Durcan, & Carlton, 2002; Pang, Eng, & Miller, 2007). Stroke survivors described that goals setting was done by healthcare providers, physically driven and lacked psychosocial contributions from the patients themselves (Bendz, 2003; J. Murray et al., 2003; Peoples et al., 2011).

Stroke survivors similarly reported a lack of awareness about support services and inadequate follow-up by rehabilitation teams (J. Murray et al., 2003). Pound and colleagues (1994) studied patients' satisfaction with stroke services and found that 28% of their study population was not satisfied with the amount of information health providers offered them about their stroke; in addition, 31% were dissatisfied with the degree of recovery they had made since their stroke and 54% were dissatisfied with the quantity of therapy they received. Similarly, in a study by Mohamed (2010) in Malaysia, stroke survivors and their families reported receiving inadequate information about the nature and impacts of stroke, prevention of future strokes, complications and how to promote recovery. These findings highlight the need to identify the needs of stroke survivors as well as the resources available to them by health services about the provision of stroke information.

What does it mean to 'recover'?

Over the years, different disciplines and different health conditions have generated various definitions and understandings of what it means to recover. Anthony (1993: pg. 11) defined recovery as *'a deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills, and roles. It is a way of living a satisfying, hopeful, and contributing life even with limitations caused by illness.'* Recovery thus encompasses finding a new purpose in life while overcoming a biographical disruption. It is a personal journey lived that suggests fluidity and growth where change is inevitable for the individual.

This understanding of recovery as a form of growth contrasts historical and reductionist definitions of recovery which consider it as the absence of symptoms (Diamond, 2006) measured through an objective lens and expressed as 'cure.' In recent years, more holistic understandings of recovery have evolved, shifting its conceptualisation from such a biomedical-based approach. In doing so, the personal

discourse that emerges from lived experiences has been emphasised. Within this, recovery no longer focuses on cure or symptoms but is instead concerned with how an individual accepts the limitations imposed on them by a condition and endeavours to live life as best as possible. With this conceptualisation, recovery emphasises health and well-being rather than illness.

Recovery from a stroke typically includes treatment, rehabilitation, and the return to community living and involves making physical, emotional and social changes. It is a complex journey that is different for every survivor. The aphorism *“There are no diseases, but sick people”* reflects on the fact that individuals react differently in the face of the same condition and to treat an individual, it is imperative to understand their testimonies and the experiences which are just as important as the knowledge of the condition itself. For each stroke survivor, recovery is different and personal. For stroke survivors, recovery is a personal victory, which can range from using the toilet unassisted to climbing stairs, from getting back on the tennis court to being able to cook. Therefore, pertinent to the recovery process is the voice of the individual as it is the individual who navigates the path to recovery and therefore needs to be heard.

A more robust understanding of recovery has developed from the lived experiences of individuals as identified in mental health (Ralph & Corrigan, 2005). In considering post-stroke recovery, Dowswell and colleagues (2000), highlight that individuals relied on their former life as reference points for their recovery. This assertion suggests that recovery was conceptualised as an individual sphere and thus independent of professional criteria of recovery. The process of recovery was not measured by their adjustment to the impairments of the stroke, and rather it was weighed against their pre-stroke lives. Dowswell and colleagues (2000) further reiterate the need to understand the many facets of recovery in understanding what meets the requirements of the stroke survivor.

Jones and colleagues (2008) identified factors that influenced progress following a stroke, finding that internal factors, such as optimism, fears of dependency, personal control, and external factors, such as therapeutic interactions, hindered or facilitated recovery. While narrative accounts have played a role in describing pathways to well-being and the mediating factors that augment or undermine the process of recovery for individuals with stroke internationally, the mechanisms that influence recovery from stroke for people located in middle-income countries to require greater elucidation.

Questions now lie in the dimensions of recovery following stroke: what it means to the individual, the various positions it can be viewed from, and the contextual factors that mediate the process in low and middle-income countries.

Stroke illness trajectory

Chronic Illness Trajectory Framework

Illness trajectories can provide insights into disease onset, progression, and resolutions (White et al., 2012). In the case of stroke, the illness trajectory can help conceptualise the pattern of recovery and the use of established coping strategies. This can, therefore, aid in planning and delivery of appropriate services.

The Chronic Illness Trajectory Framework (CITF) developed by Corbin and Strauss (1998) was proposed as a grounded theory from research on chronic diseases and nursing practice. Over the years, the framework has evolved through research and observations in describing the experience of chronic illness and applied in several chronic disease states which include stroke (Christopher R Burton, 2000), cardiac disease (Hawthorne, 1991) and traumatic injury (Halcomb & Davidson, 2005). Central to the framework is an illness pathway that represents the effects of the illness and efforts to manage the illness. It mirrors the diversity, complexity, and ever-changing

dynamics of chronic conditions. Although individuals experience diseases in different and unique ways, the framework identifies common phases based on the assumption that changes in health status and healthcare have the likelihood of shaping the illness path (Corbin, 1998; Corbin & Strauss, 1991). The CITF (see Table 1. below) identifies 8 phases; Pre-trajectory, Trajectory onset, Crisis, Acute, Stable, Unstable, Downward, and Dying. To my knowledge, this framework has not been explored on stroke survivors in Malaysia, an upper middle-income country.

Table 1: The Corbin and Strauss Chronic Illness Trajectory Model

	Phase	Characteristics
I	Pre-trajectory	Before the illness course begins, the preventive phase, no signs or symptoms present
II	Trajectory onset	Signs and symptoms are present, includes diagnostic period
III	Crisis	A life-threatening situation requiring emergency/critical care
IV	Acute	Active illness or complications that require hospitalisation for management
V	Stable	Illness course/symptoms controlled by a regimen
VI	Unstable	Illness course/symptoms not controlled by regimen but not requiring hospitalisation
VII	Downward	Progressive deterioration in physical/mental status characterised by increasing disability/symptoms
VIII	Dying	Immediate weeks, days, hours preceding death

Source: Corbin and Strauss (1991)

Kirkevold (2002) presents a slightly different view of the phases from Corbin and Strauss. Generally, once an individual survives a stroke, it is no longer considered a life-threatening illness (Rolland, 1994). As such, Kirkevold (2002) suggests that the last three

phases; unstable, downward and dying are thus not typically concomitant with stroke. Both conceptual frameworks, however, draw on research conducted in HIC and consequently, their applicability to an LMIC context is not certain. The CITF offers a realistic structure for the development and evaluation of management in stroke recovery. The framework takes cognisance of the stroke survivors' experiences with stroke, their pre-stroke lives and underscores the role of contextual limitations that may affect recovery. The subsequent paragraphs will provide a brief review of the literature on stroke illness and recovery to adapt it to the trajectory framework.

Pre-Stroke (Pre-Trajectory Phase)

In the case of stroke, the pre-trajectory phase corresponds to the risk factors for stroke. High blood pressure and heart disease have been identified as the significant risk factors for stroke (Grau et al., 2001; Petty et al., 1999). The Framingham study established a general cerebrovascular risk profile that consists of five risk factors, namely: raised systolic blood pressure, elevated serum cholesterol, tobacco use, glucose intolerance, and left ventricular hypertrophy (Wolf, Kannel, & Verter, 1983). In contrast, a 12-year longitudinal study in Oslo on the risk factors for stroke incidence and mortality identified raised blood pressure and daily cigarette smoking as the major risk factors (Håheim et al., 1993). The study failed to find elevated serum cholesterol as an important risk factor. Other risk factors include physical inactivity, previous stroke or transient ischemic attack, family history of stroke, oral contraceptive use and post-menopausal hormone replacement therapy. Advancing age, male gender, and black race have also been identified as stroke risk factors (Panel et al., 1997).

Stroke onset (Trajectory-Onset Phase)

The appearance of stroke signs and symptoms characterise the onset phase. Signs and symptoms vary based on the location and severity of the stroke. In general, the most

common symptoms are facial drooping, arm weakness, and slurred speech. Other signs and symptoms which may occur are a headache, imbalance, visual disturbances, dizziness, confusion, memory loss, disorientation and lack of coordination. Although the impairments, from stroke, could be temporary or permanent, most stroke survivors experience a certain amount of recovery, albeit, slow (Becker & Kaufman, 1995). An individual suffering a mild stroke may present with weakness that is temporary and may ultimately recede, while one experiencing a severe stroke may experience paralysis on the affected side or limb that may or may not improve over time.

Emergency event (Crisis Phase)

The onset of stroke symptoms signals a life-threatening event, and independent of the pathway of help-seeking the patient adopts, this phase marks an emergency, requiring in-hospital care (Woog, 1992). The health-seeking behaviours undertaken following the onset of stroke symptoms depends on the awareness of stroke of the patient, their knowledge about stroke and available treatment, and their financial situation (Miah et al., 2012). Research by Miah and colleagues (2012) demonstrated that behaviours were influenced by the perception of the gravity of the symptoms. Moderate symptoms such as dizziness or headaches were not perceived as severe, whereas facial droop or limb numbness were regarded as serious (Mellor et al., 2015). Individuals who believed the symptoms were severe sought help by calling family members, emergency services, or made their way to the hospital/traditional healer/religious organisation (Mellor et al., 2015). However, in Doolittle's research (1992), stroke patients adopted one of two paths: self-diagnosis, whereby the stroke patient consciously reported to emergency care themselves or delayed treatment based on the severity of the symptoms. The other pathway was the diagnosis by emergency care providers or a physician after symptoms presented (Nancy D Doolittle, 1992).

In LMIC, seeking help for stroke from traditional healers and religious organisations was not uncommon (Thorogood et al., 2004). Culture influences a person's health beliefs, behaviours, and medical treatment and as such, in some cultures, illness is considered as of natural or unnatural forms (Blue, 2000). Natural illness occurs when there is a failure to preserve congruence in the natural world. Alimentary or lifestyle overindulgences, cold weather and filth are the most frequent causes of natural illnesses (Blue, 2000; Snow, 1983). On the other hand, unnatural illness ensues as a result of bad omens or sorcery (Blue, 2000; Snow, 1983) and echoes conflict in the social environment. Some healers perpetuate theories that stroke is as a result of witchcraft, requiring appraisal and management through supernatural means (Mshana, Hampshire, Panter-Brick, & Walker, 2008). Lack of money, transportation, and family-support also factor as obstacles at the time of seeking treatment (Miah et al., 2012; Morgenstern, Steffen-Batey, Smith, & Moyé, 2001).

Stroke acute phase (Trajectory acute phase)

Throughout this phase, the emphasis is on stabilising the individual and reducing comorbidities and complications. The stroke survivor usually has no input, leaving all decisions to healthcare professionals and family (Kirkevold, 2002; Lutz, Ellen Young, Cox, Martz, & Rae Creasy, 2011). The participants in Doolittle's (1992) study described the acute phase as lonely and found seeking assistance for basic activities such as toileting very demeaning. In this phase, there is concern about survival by both the patient and his family as well as fear of what disability the stroke might produce (Brandstater & Shutter, 2002). The uncertainty of the future, of receiving assistance and perception of not having control over the body lasts throughout the acute rehabilitation phase (Brandstater & Shutter, 2002).

Initial rehabilitation (Stable phase)

After the acute event, survivors focus on recovery (Lutz et al., 2011). The initial rehabilitation phase commences within a few days or weeks after the stroke. Recovery for the survivors in this phase usually focuses on motor recovery, the performance of activities of daily living and speech therapy. Stroke survivors and health professionals in this phase are most often optimistic, as the patient experiences improvements regarding physical strength, mobility, speech and the capacity to carry out basic tasks. Corbin and Strauss (1991) consider this phase as stable because the planned package of interventions. A structure is proposed in which the stroke survivor continues the training program initiated by healthcare professionals.

Goals setting were based on the return of functional abilities and, in most instances, were set by professionals (Christopher R. Burton, 2000; Christopher R Burton, 2000; N. D. Doolittle, 1991). This view, however, differs from the recovery goals of stroke survivors, who tend to set their goals of recovery as a return to their pre-stroke lives; the principal challenge of this phase is the need to accept that they may never be the same as before (Nancy D Doolittle, 1992; Dowswell et al., 2000; Pandora Pound, Patrick Gompertz, & Shah Ebrahim, 1998; P. Pound, P. Gompertz, & S. Ebrahim, 1998). In a study on stroke patients' perception of hospital nursing-care, Macduff's (1998) patients reported that 'hope' was fundamental to ensuring progress and in their descriptions of the recovery process.

Some studies postulated that the transition to home from the hospital was regarded as a satisfying milestone as it signalled the restoration of control in familiar settings. However, it was also marred with frustration on account of withdrawal of professional services, health provider support (N. D. Doolittle, 1991; Lutz et al., 2011), as well as the uncertainty of how to adapt on return to the home. Stroke survivors become tormented by feelings that range from frustration to sadness, anger, and even depression as they realised they needed to depend on others for the performance of daily living activities,

which they previously took for granted (Lutz et al., 2011). During this phase, the focus is on adjusting to a familiar structure of daily living as the stroke is integrated into the survivor's life (Kirkevold, 2002).

As time progresses, the stroke survivor realises that the stroke is not a short-term event and has to come to accept that he or she may never be the same again (Nancy D Doolittle, 1992; Kirkevold, 2002). Most stroke survivors began to reflect on their lives and tried to minimise its impact (Becker, 1993; Kirkevold, 2002). The stroke event stimulated the development of coping strategies targeted at dynamically altering the situation with an aim to continue life as it was before the illness or adjust to the consequences of the stroke (Darlington et al., 2007) al., 2007). Stroke survivors tend to develop the coping strategies to achieve a sense of continuity with their lives.

Unstable/Downward/Dying phases

Corbin and Strauss (1991) characterised the unstable period as a time when the recovery is not on course but not requiring hospitalisation. For stroke, this could be related to the appraisal of circumstances, re-evaluation, and adaptation of coping strategies by stroke survivors. The ever-changing dynamics of chronic illnesses such as stroke imply that stroke survivors can have fluctuations as the illness path progresses. The framework suggests that unsuccessful adaptation to the challenges of the illness could lead to progressive deterioration in both physical and mental status which could eventually lead to death. The individual will chart his course of life as a stroke survivor, until the final stage of life.

Coping

The Concept of coping

Understanding the recovery course involved in stroke requires a robust appraisal of the physical, emotional and cognitive process involved. Emphasis on coping has been of crucial interest in research for several years (Taylor, 1990). Coping refers to as an alleviating element that enables adaptation to a stressful situation (Billings & Moos, 1981; Lazarus & Folkman, 1984). The coping process is dynamic and responds to changing demands and appraisals of stressful situations. Lazarus and Folkman (1984), leading theorists in the study of coping, defined coping strategies as on-going efforts made at psychological and behavioural levels that enable people faced with a crisis to tolerate and reduce their adverse effects. There are three significant aspects to this definition of coping. First, it is dynamic; meaning that coping changes as the stressor unfolds. Second, the coping process need not be completely effective, but an effort is needed. Third, the individual's evaluation of and resources to manage the situation influence coping (Lazarus & Folkman, 1984).

Coping following a serious, long-lasting ailment such as stroke is a fundamental issue (Meng, Zdrahal-Urbaneck, Frank, Holderied, & Vogel, 2006) which may predict rehabilitation success. To effectively manage the consequences of stroke, and achieve goals of recovery and well-being, it becomes essential to reinforce the stroke survivors' coping resources. It is, therefore, necessary, as part of rehabilitative stroke interventions, to identify the coping strategies of stroke survivors. Understanding the coping strategies that stroke survivors use to reinstate themselves back into their lives and society may inform how professionals plan healthcare management and rehabilitation with the aim of recovery and well-being.

Coping strategies: major theories

Research is increasingly focusing on the psychosocial determinants of recovery from chronic illness with attention to the role of coping strategies. The nature of coping efforts focused on alleviating the strain caused by the illness or disability bears further consideration. Myriad studies have investigated the role of coping in cancer, heart disease, chronic pain, amputations and traumatic brain injury (Desmond, 2007; H. Livneh, 2000; Hanoch Livneh & Antonak, 2005). These studies suggest that, in dealing with their conditions, individuals utilise a wide range of coping efforts which assume different roles to regulate the stressful condition. Researchers have made several attempts to establish the dimensions of coping. A well-known dimension is a classification into problem-focused and emotion-focused coping (Folkman, Lazarus, Dunkel-Schetter, DeLongis, & Gruen, 1986).

Folkman and colleagues (1986) describe problem-focused coping as efforts aimed at defining the problem and creating solutions or actions to modify the problem. Taking direct action and seeking information are forms of problem-focused coping. Emotion-focused coping, on the other hand, aims to diminish the emotional distress that accompanies the problem. Tactics utilised include avoidance, distancing, blaming, venting emotions, positive thinking, and seeking help. Problem-focused coping is used when the problem or stressor is modifiable. Emotion-focused coping is often employed when the problem is not modifiable. Table 2. below gives a brief description of the two dimensions.

Table 2. Problem and Emotion-focused Coping

Problem-focused coping	Emotion-focused coping
Active coping: a process that involves active efforts to eliminate, diminish or avoid the effects of the stressor	Seeking of emotional support: seeking emotional support, obtaining sympathy and understanding from family, friends and social networks
Planning: a process of discerning how to manage the stressor. It involves coming up with approaches and steps of controlling the stressor	Positive reinterpretation: this process is targeted at emotionally dealing with the stressful situation rather than managing the stressor. It aims at reframing the stressor in a positive aspect
Suppression of competing activities: in this, the individual attempts to subdue his immersion in competing activities or networks of information and avoiding distraction to enable him to focus primarily on the stressful situation	Acceptance: accepting the reality of the situation
Restraint coping: a process that involves controlling oneself and not acting prematurely until the right situation arises	Denial: a method of refusing to acknowledge the situation as real. Although denial can minimise the distress, it is sometimes argued that it could confound the problem by allowing the problem to persist and eventually become more serious
Seeking of instrumental social support: is seeking advice, assistance, or information	Turning to religion: seeking support and solace from faith

Another classification is into assimilative and accommodative coping (Brandtstadter & Renner, 1990). These two tendencies are distinctive yet interrelated in achieving actual and desired perspectives on individual improvements (Brandtstadter & Renner, 1990). Assimilative coping strategies predominate in the early phases of a stressful encounter while accommodative coping gradually sets in with time.

Darlington and colleagues (2007) report that both approaches are positively related to the quality of life. Assimilative coping strategies (tenacious goal pursuit) aim at modifying the environment. It reflects determined efforts to actively adjust situations to one's preferences to continue life as it was before the stressful event. Accommodative coping strategies (flexible goal adjustment) on the other hand aim at modifying oneself. A process of streamlining and reassessing one's goals and priorities and accepting the consequences of the stressful event.

The Pro-active coping theory is an alternative theory which takes into account time perspective and the subjective inevitability of events (Schwarzer & Taubert, 2002). It involves four main strategies; reactive, anticipatory, preventive and proactive strategies. *Reactive-type coping* encompasses efforts aimed at managing harm or a loss that has undoubtedly occurred such as seen in, job loss, lack of accomplishment of a goal and work-related accidents. The individual compensates and alleviates the situation by redefining his life and adjusting his goals. Reactive coping utilises problem focused and support-seeking strategies. Of significance is the role of self-belief, the optimism to overcome the challenge. *Anticipatory-type coping* deals with events in the near future, imminent to occur such as retirement, parenthood, commencing higher education, where the individual appraises the situation as threatening or benefitting. In this instance, the individual adopts problem-focused strategies such as investing resources to combat the issue and support-seeking strategies that may offer reassurance. Avoidance strategies such as distraction may also be employed.

Preventive-type coping is influenced more by personality traits than stressful events in that the individual has an innate concern about dangers and acts to prevent the uncertain risks that may arise. Preventive coping deals with events that are unspecific and uncertain to occur in the long term thus the individual builds and draws upon personal strengths, characteristics, skills and wealth should in case the event occurs. Self-efficacy strategies are drawn upon in preventive coping.

In contrast, unlike the previous themes, negative assessment of a stressor does not precede *Proactive-type coping*. In this, the focus is on building up resources that enable adaptation to stressful situations and fosters personal growth. It is governed by a vision of risks and opportunities in the far future. The individual rather than appraise these visions as negative, sees them as challenging and begins to construct a positive path of action (Schwarzer & Taubert, 2002).

Social Support

The Concept of social support

Social support is the awareness and actuality that an individual is loved, valued, cared for and part of a caring and sympathetic network (Cobb, 1976). Social support can take the form of emotional (e.g., motivation from a spouse), practical (e.g., financial assistance) and informational (e.g., health advice). Social support comes from a variety of sources including family, friends, neighbours, medical personnel and religious organisations.

Social support is a coping resource which can be drawn upon when faced with a stressor (Thoits, 1986). Seeking of the support is considered a coping strategy (Schreurs & de Ridder, 1997) that individuals use in times of stress to alleviate difficulties by actively influencing their social settings. Seeking social support provides the individual with understanding, compassion, advice, information and lessens the individual's feelings of loneliness (Prati & Pietrantonio, 2009).

There is considerable evidence suggesting social support has an impact on physical and psychological well-being, playing a vital role throughout the process of recovery from ill health. Studies have demonstrated that individuals with social networks and support groups are healthier than those with fewer or no support networks (Broadhead et al., 1983; Mitchell, Billings, & Moos, 1982). Another study also suggests that social support is a significant predictive factor in recovery from a stroke; associating it to functional recovery (T. A. Glass, Matchar, Belyea, & Feussner, 1993), whereby individuals who received greater support showed more significant improvement than those with less. The same study highlighted social support as an influencing factor in the speed of recovery (T. A. Glass et al., 1993). Other studies have also highlighted an improvement in the emotional well-being of patients because of

social support (Billings & Moos, 1981; Holt-Lunstad, Smith, & Layton, 2010; Uchino, 2009). In a study of quality of life in patients with human immunodeficiency virus infection, the authors suggest that the quality of social support obtained directly influences the emotional and physical well-being of patients (Swindells et al., 1999).

The absence of or inadequate social support may lead to undesirable psychological circumstances such as anxiety or depression which can in due course affect physical well-being (Cohen & Wills, 1985). Critically examining the role of social support on health and well-being, a meta-analysis, determined that perceived support was linked to lower risk for all causes of mortality (Holt-Lunstad et al., 2010). In breast cancer patients, social support has been shown to alleviate the stress linked to the disease (Dunkel-Schetter, 1984) (Holland & Holahan, 2003).

A literature review of the predictors of disability after stroke demonstrated that social support was amongst the most constant and vigorous predictors of functional recovery following stroke (Kwakkel, Wagenaar, Kollen, & Lankhorst, 1996). Stroke survivors with families that provide excellent communication, right problem-solving strategies and a strong emotional connection do better regarding health outcomes than survivors without (Evans et al., 1987). In their study of quality of life following a stroke in Nigeria, Hamza and colleagues (2014) found that having the stroke survivor's spouse as caregiver considerably improved their emotional and physical status. This is attributed to the fact that the spouse can provide emotional and moral support to the stroke survivor as well as home-based physiotherapy. The spouse, being near the stroke survivor can help with daily living tasks, such as taking a bath, getting dressed, feeding and administration of appropriate medication. The study also demonstrated that the lack of financial and social support affected the emotional status of the stroke survivors (Hamza, Al-Sadat, Loh, & Jahan, 2014).

Stroke and religion

Disruption of devotional activities

As previously outlined, stroke affects activities of daily living. Included in these activities are the devotional practices of religious people. World religions teach myriad ways to practice devotion, prayer; where a variety of body postures may be assumed, chanting, singing, dancing, fasting and many more (Bowker & Bowker, 1997). For example, Catholics pray with a rosary while Hindus recite a *mantra* (sacred utterances) with their palms joined together while bowing or bending forward. Muslims perform the *Salah* (a prayer which involves a series of positions while reciting the Quran), Protestants sing hymns and Buddhists chant (Bowker & Bowker, 1997). These activities include physical movements, language, and communication which can all be affected by a stroke.

A recent study conducted in Malaysia revealed that there was awareness amongst family caregivers and health professionals on their responsibility to assist Muslim stroke survivors in fulfilling their *salah* (Mohamed, Nelson, Wood, & Moss, 2015). The study, however, failed to detail how the stroke disrupted the devotional practice of the *salah* or how religious practices such as the *salah* aided or not their recovery.

Spirituality and religion as a coping strategy

Spirituality, defined as a way individuals seek purpose and meaning, and how they understand their connectivity to themselves and others expressed through attitudes, habits, and practices (HG Koenig, McCullough, & Larson, 2001; H. G. Koenig, 2012). Religion is a type of expression of spirituality established in structured, organised beliefs about a supernatural being that shared within a community of people (H. G. Koenig, 2012).

Anxiety, fear, and constant oscillations between stability and instability often mark the trajectory of chronic illness (Corbin, 1998). Studies that have focused on the role of religion and spirituality in chronic illness suggest it is important especially concerning adaption to life with ill-health (Harvey & Cook, 2010; Rozario, 1997). Turning to religion has been identified as a coping strategy that has been utilised by individuals suffering from chronic conditions. The significance of religious coping is echoed in its enclosure in coping questionnaires, for example, the COPE, the Brief COPE and the Ways of Coping Checklist.

People who are spiritual may make use of their beliefs to cope with illnesses and hassles of life. Studies have highlighted the role spirituality and religion play in providing better health outcomes during illness, anxiety, and depression (Balboni et al., 2007; Contrada et al., 2004; Holt et al., 2009; Johnstone, Glass, & Oliver, 2007). Although religious and non-religious people experience stress and illness, religion could aid individuals in dealing better with problems. A significant association has been found between religious practices and positive self-management behaviours amongst individuals with Type-2 diabetes (Newlin, Melkus, & Chyun, 2007; Polzer & Miles, 2007). Similarly, patients with advanced cancer were found to be happier, had less pain and were more satisfied with their lives when they turned to their religious and spiritual beliefs (Yates, Chalmer, James, Follansbee, & McKegney, 1981).

Unantenne and colleagues (2013) described different ways in which individuals living with chronic illness draw on their spirituality to manage their everyday lives and conditions. The authors found that the individuals relied on spirituality to cope with pressure by being dependent on devotional practices such as meditation and prayer to attain serenity and regain control over their body and condition. Religiosity enabled the individuals to accept their situation and fit it in with their daily lives. The participants had hopes of recovery and feelings of enhanced self-worth which they believed was

through practices such as meditation and prayer (Unantenne, Warren, Canaway, & Manderson, 2013).

In individuals with myocardial infarction, religiosity positively influenced recovery. Similarly, women with breast cancer had improved survival rates. The authors related this achievement to spirituality providing the participants with strength, peace and a sense of well-being (Walton, 1999). Giaquinto and colleagues (2007) explored the role of religious beliefs in protecting from emotional distress after stroke and found that by turning to religion, their participants were connecting to God, considering others, becoming more attentive to their daily activities, finding strength and being unburdened and finding comfort. Because the life-changing experience brought about by a stroke, religious practices may offer support to survivors in finding meaning and completeness through the confidence it provides.

Koenig (2012) summarises the impact of religion and spirituality on better health outcomes in three domains. The psychosocial domain which enables coping and permeates undesirable events with purpose and meaning. The social realm where beliefs and guiding principles inspire the growth of virtues such as self-discipline, patience, selflessness, honesty, courage, and compassion that encourage social relationships, provide opportunities for altruism and increases the flow of health information. The health behaviour domain which promotes health by discouraging drug, alcohol and tobacco use, better diet and more physical activity (Harold Koenig, King, & Carson, 2012; H. G. Koenig, 2012).

Salah for Muslims is said to encourage good health and well-being and act as a coping strategy in stressful situations (Achour, Bensaid, & Nor, 2016). A study that reviewed the effects of yoga in health and disease revealed that there are significant health benefits to its practice, including reduced cardiovascular risk, blood pressure, and diabetes as well as improved cognition and respiration (Balaji, Varne, & Ali, 2012). Yoga was also found to improve immunity and joint disorders (Balaji et al., 2012).

Many individuals have spiritual and religious beliefs that can affect their health. For public health practice, learning about the stroke survivors spiritual and religious beliefs; their role in coping with the illness, how they could influence medical decisions and the individual's participation in a religious community could assist the survivor in coping better with the illness and increase compliance with treatment and rehabilitation models.

Religion in Malaysia

Malaysia is a multi-confessional country with 61.3% of the population who are predominantly of Malay origin professing the religion of Islam, 19.8% Buddhism, 9.2% Christianity, 6.3% Hinduism, 1.3% traditional Chinese religion and 2.1% professing none or unknown faiths (DoS Malaysia, 2010). Religion plays a vital role in Malaysian society with Islam being the official religion and subsequently dictates many social and economic conventions and therefore unpins the nuances of everyday life (Haque & Masuan, 2002).

Haque and Masuan (2002) estimate that 90% or more of the Malay population practice Islam and do not question the doctrines stipulated in the Islamic holy book, The Qur'an. Religion influences virtually every facet of the Malay life, and healthcare is no exception. The sizeable Islamic population of Malaysia means that religious and spiritual beliefs of the Malays concerning stroke recovery must be considered.

Implications for healthcare and policy

Disability has significant consequences for the individual and their family and impacts on all aspects of life. In LMIC, inadequate resources impede rehabilitation following stroke. To compound this situation, Governments and health policymakers in LMIC tend to undervalue the consequences of stroke (Niphon Pongvarin, 1998). Health policy is fundamental to the clinical environment and is driven by scientific evidence. The decisions of health policymakers determine the type of medical services to be made available and promoted. It involves two aspects, clinical policy; in the form of guidelines or practice improvements, and public policy in the way of training programs, insurance structures, and legal requirements. Traditional models of recovery from chronic illnesses are restricted in the sense that they are underpinned by clinical principles of treatment (Eubanks, 1990; Pawlson, 1994).

Designing and implementing interventions that focus holistically on the biopsychosocial dimensions of recovery are needed. Such interventions, therefore must take into cognisance the lived experience of stroke from the survivor's perspective and not focus entirely on health professional views. Cost effective and high-quality rehabilitation interventions are critical in enabling the individual to maintain optimal participation in society and reduce the need for expensive medical treatments. Interventions should aim at providing information to patients through educational brochures, videos, counselling sessions, group support and targeted strategies that will increase self-confidence, reduce isolation, and encourage stroke survivors to take up active roles in their rehabilitation.

Chapter 3.

Methodology

Introduction

This chapter elucidates the conceptual basis that supports the methodological approach used. It describes the research site, setting, participant recruitment as well as data collection techniques and analysis. An integral part of my methodology is how I positioned myself as a researcher, the ethical considerations I had to consider and to work with a translator. My research being ethnographic, I describe how my methodology evolved as my research progressed.

Study Design

The choice of a research design commences with a nexus of beliefs, values, and methods of a topic and a paradigm. For this study, an ethnographic approach was chosen based on the nature of the research objectives. Ethnography obtains its root from anthropology and is a methodological approach that explores meanings and actions within a socio-cultural context (P. Atkinson, 2017; Wolcott, 1999). It places great emphasis on patterns of beliefs, values, and behaviours of a group of people.

Researchers conducting ethnographic studies study a group or phenomenon in their natural settings using data gathered over a period (P. Atkinson, 2017; Madison, 2011) described ethnography as a process of encountering a world that is alien and trying to make sense of it. This process requires intensive involvement and the ability to learn. Cornwell (1984) suggests that ethnography pays attention to the details of an individual's life and the differences between individuals in a particular setting. Hammersley and Atkinson (2007) posit that the aim in an ethnographic study is to

describe what transpires in a setting, how individuals view their actions and those of others around them about the socio-cultural world around them.

Traditionally, ethnographic studies concentrate on culture and how people involved making sense of living in that culture (P. Atkinson, 2017; Hammersley & Atkinson, 2007). This is achieved through active involvement in the world of the participants. Ethnographic research over time has been impacted by theoretical ideas that shape fieldwork such as participating over time, adopting a covert or overt position and using several sources to obtain information (Hammersley & Atkinson, 2007) .

Gibbs (2002) describes ethnography as an approach to explore the meanings and actions within a sociocultural context of a community. Ethnography illuminates and describes the beliefs, actions, relationships, and contextual issues that define communities (Wolcott, 1999). As my research aimed to explore the social and human context of the lived experience of stroke within a culture, an ethnographic approach was deemed appropriate. Secondly, I was committed to using a method that would permit me to gain a connection with the community under study with the hope of being a voice for them.

The ethnographic process pays attention to the respondents' position as an expert insider to the concepts under study. As such, the methods of ethnographic inquiry as utilised in this study such as in-depth interviews, and observations were designed to draw insider concepts and explanations on their world (Bernard).

Furthermore, ethnography highlights the researcher's influence in data collection and analysis resulting in an interpretive account of the experiences studied (Hammersley & Atkinson, 2007) as it exploits the ability of the researcher to review and interpret participants' experiences objectively as an outsider. Lastly, research has also shown that ethnography is appropriate in exploring new environments where similar research has not been undertaken previously as it helps in ascertaining what is conceived as relevant

to that environment (Henderson, 2005). This study is the first to explore recovery and well-being following a stroke in Segamat.

Research Setting

SEACO: The South-East Asia Community Observatory (SEACO) is a Health and Demographic Surveillance Site (HDSS) in Segamat district of the state of Johor, Peninsular Malaysia.

Figure 2: Map of Malaysia



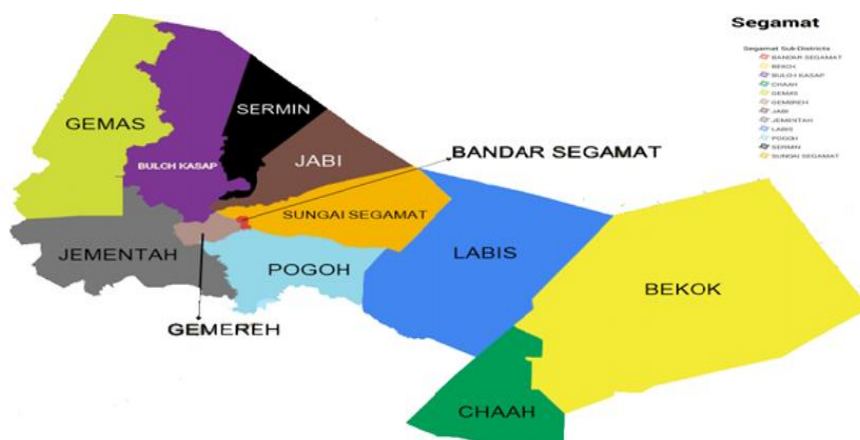
(Source: http://malaysia.mol.go.th/map_countries)

SEACO was launched in 2011 with the primary purpose of collecting relevant and high-quality data to gain a better understanding of the factors that affect health in a holistic life context. The SEACO platform is a multi-purpose research platform that allows complex interventions and research projects to be conducted in both health- and non-health-related areas (Allotey et al., 2014). The SEACO platform has a network of qualified community data collectors, key informants and a community reference group that facilitate working across the diverse ethnic and religious groups. SEACO's research covers 5 of 11 sub-districts (*mukim*) of Segamat district: Bekok, Chaah, Gemereh, Jabi, and Sungai Segamat. The five sub-districts covered by SEACO differ in population density, ethnic composition, and size (Partap et al., 2017). SEACO is a partnership with

the community of Segamat and several stakeholders at the state and federal levels. SEACO data was initially collected as a baseline census in which almost all the resident population of the five sub-districts were captured. Rounds are conducted to update the data regularly.

Segamat is predominantly semi-rural, though there are several remote rural communities (Figure 3). The 2010 census puts the population of Segamat at approximately 189,820 of which 50% are *Bumiputra* (a combination of the Malays and Indigenous people), 36% Chinese, 9% Indian, and 5% non-citizens (Allotey et al., 2014)). SEACO comprises five sub-districts: Sungai Segamat is the most populous mukim, with over 200 residents per square kilometre. The Segamat town centre is in this mukim. Gemereh is the smallest sub-district and Bekok, a remote town on the eastern border is the largest. It is famous for its waterfall known as Sungai Bantang and having an entrance to the Endau Rompin National Park. The southernmost sub-district in Segamat is Chaah and is surrounded by oil palm plantations. A major challenge I encountered before entering the field was the limited information and literature available about these five sub-districts.

Figure 3: Map of Segamat



Within the five sub-districts of SEACO, different types of communities exist, and these various forms of communities had implications for my research. In line with

ethnographic research, I studied and documented my research population and location (Ghodsee, 2016). Below, I describe the study area.

Like most districts in Johor, Segamat is an oil palm and rubber producing community. Most of the men in the study were retired farmers who had worked in their fields usually a few minutes away from their homes. The female participants and spouses often catered to housework and the children. However, a few women worked outside the homes as cooks, cleaners or managed food stalls. The size of the houses in the different sub-districts vary; houses in Jabi, Gemereh, and Chaah were considerably larger than the ones in Bekok and Sungai Segamat and are dependent on family size and financial status. The houses are usually one-story constructed from cement blocks and bricks. They include a living area and in some cases an entrance area where guests are entertained, bedrooms, washrooms with showers but no bathtubs, a kitchen area which is usually situated at the back of the house with a door leading to the outside. All the homes had running water and electricity. The apartments all had fans; wall mounted, ceiling or standing fans but none had air conditioning. Most houses had a working television, and a few had cable tv.

Participants who lived in the FELDA and FELCRA settlements (See below) had more spacious apartments and seemed to have more high-quality household items. In Gemereh, Jabi and Chaah, the houses were surrounded by a garden which grew flowers and fruits and in a few cases, potatoes. Access is through well-constructed roads maintained by the government. Public transportation within and beyond the districts was not common. Most families owned cars and motorbikes which are driven by men, women and teenage children. Food stalls and coffee shops are numerous and spread all over the district. There are several Chinese owned businesses such as auto-repair shops, groceries, building material and household supplies shops. Every sub-district has at least three elementary schools with the specific curriculum of Malay, Indian or Chinese.

Healthcare in Segamat is provided predominantly through a well-established system with a 300+ bed district hospital, 25 community clinics known as the *Klinik Desa* and ten government primary healthcare known as *Klinik* (Allotey et al., 2014). Private general practice (GP) clinics are found throughout the districts as well as several complementary and alternative medicine clinics.

FELDA and FELCRA communities within SEACO

Many communities within SEACO have been set up by the Federal Land Development Authority (FELDA, established 1956), a government agency to redress perceived ethnic inequalities by managing the relocation of rural poor Malaysians into developed areas and smallholder farms growing cash crops. Residents were given land to initially cultivate rubber; now the primary product is the palm oil fruit. They were required to reside at the settlement in a prearranged community. Settlers bear the cost of acquiring and developing the land through loans provided by the FELDA. The loans are then refunded through scheduled payments deducted from the residents' agricultural revenue over time.

FELCRA, The Federal Land Consolidation and Rehabilitation Authority, was set up in 1966 with the aim of improving the standard of living of the rural sector. This was achieved by developing privately owned idle land and encouraging the community to partake in state and national economic activities. FELCRA just as the FELDA developed plantations and settlements for landless rural Malays. Both settlements are numerous and are found across Segamat district. The settlements are divided into sections or blocks with each section displaying the names and house numbers of the occupants on a block wall at the entrance (Figure 4). Within the settlements are a primary and a secondary school, food stalls, coffee shops, a clinic, *surau* (Islamic prayer room) and a community centre (Figure 5).

Figure 4: Names and house numbers of Occupants at a FELDA



Figure 5: Clinic at a FELDA



My role as Researcher: Positioning myself

Ethnographic researchers argue that dilemmas emerge for the researcher before, during and after the research process (Madden, 2017; Roberts & Sanders, 2005). Researchers are faced with decisions that arise from these dilemmas and thus it was imperative for me to undertake constant reflexivity. In this section, I describe my role as a researcher and some of the dilemmas that arose during the research process.

Undertaking ethnographic research in public health brought together my previous experience as a medical doctor with my research interest in community-based recovery. I hold a medical degree (MD) and a Master of Public Health (MPH) degree. My prior work was in primary healthcare and maternal/child health in Nigeria and Cuba. Before commencing this study, I had very little exposure to stroke survivors within a community setting and thus had little understanding of what I could expect, either regarding the broader Malaysian population or the participants recruited as part of my study sample. None of my participants has had any prior social connection with me. Thus, interactions were less likely to be influenced by previous relationships. My primary role was to collect data, conduct analysis on the data and disseminate the findings as a contribution to knowledge.

As I set out to commence this study, it was important that I set aside any pre-existing assumptions that I had regarding recovery and the overall experience following a stroke and focus on the accounts of my participants. At the same time, my training and work as a medical doctor gave me understanding and insights into the workings of the human body and the influence of Orthodox-based medicine on the nature of health and illnesses.

Cognizance of this probable influence was essential throughout this research. In managing my positionality and challenging myself to be open to change/responding to new ideas as they emerge with my research, I continuously discussed matters of bias with my colleagues. This reflexivity helped me to deconstruct how my own beliefs and

experiences crisscrossed with that of my participants. Most of my participants were curious about my own life. They asked questions about me and about the research I was conducting. I answered them honestly in an open manner. I told them I was working towards a higher degree. I also explained to them that I hoped my findings would act as a voice for them and that the government may use the research to understand them more and improve their lives. They asked specific questions about stroke, and the stroke patients I had worked with before, such as the curability of stroke, and what treatments or medications could cure stroke, did such drugs or treatments exist outside Malaysia.

It was indeed challenging at times to extricate the doctor in me from the researcher. One participant was in a poor state, possibly with depression. My recognition of this had a direct influence on our interview. I discussed her situation with her primary caregiver, her husband, who explained that she was refusing medical checks and intervention, and rejected all forms of physiotherapy at home. Indeed, it turned out to be a counselling session rather than a research interview session. I talked with her, encouraged her and demonstrated simple exercises she could do at home to aid in motor recovery. Although I was aware that counselling and showing exercises to her was interfering with my research, I decided to intervene because being a medical doctor; my priority was the well-being of the individual. She passed away a few weeks after that encounter. My inability to actively act as a doctor left me completely frustrated and heartbroken.

Stepping into the field

Stepping into the field was a daunting experience for me. I had to consider various aspects. Firstly, this was new terrain for me. I had no prior contact with the research location. Secondly, I am a foreigner, of a different race and did not know the languages spoken. My perception was that the respondents would feel uncomfortable discussing

details about their life due to my identity as a foreign female of colour. To overcome these challenges that were laid out in front of me, I devised a plan to 'sell myself' through my conviction in the work I was doing, and my skills as a qualified medical doctor. I likewise began to inquire about the research site, the people, the culture, and the religious practices.

My faith proved an important part of my interaction with the respondents as most of my participants were Muslim. Islam, being intricately woven into the everyday lives of the Malays, was the arsenal I used. In my time in Malaysia, I realised that the Malays saw me first as a 'Muslim'. My race and gender was not an issue as I was considered a part of them. My dressing and greeting of *Assalam Alaikum* (Peace be upon you), immediately signalled to them I was part of them. During the interviews, I would continuously make Islamic references and adopt Islamic behaviours such as saying *Bismillah* (In the name of Allah) before drinking or eating anything. However, I had no knowledge of Buddhism or Hinduism which were the second and third major religions in the research location. I did some reading about the basics of Buddhism and Hinduism, learned what to expect and what not to, what was acceptable and what was not. For example, I learned about the Hungry Ghost and that it wasn't unusual to see people praying and leaving food by the roadsides for the Hungry Ghosts and that it was not appropriate to touch the statuettes on the altar of a Hindu home.

I set out to learn some words in Malay using a phrase book and paying attention to signage in the environment. Learning from a phrase book indeed wasn't enough to provide me with the skill to conduct interviews and interact with people. I needed to work with an interpreter. Although not fluent, I have a fair understanding of the Arabic language. This greatly helped as several Malay words are derived or borrowed from Arabic. Words used in everyday conversation such as *Kerusi* (chair), *nasihat* (advice), and *waktu* (time) are derived from Arabic. This knowledge helped me understand ideas being discussed during the interview thereby easing the process as I would nod to my

interpreter, letting him know I understood the idea that was being discussed and he didn't have to interpret.

Accessing the community

Getting access to a community to conduct research is one of the challenges that most qualitative researchers must face especially foreign researchers. I relied on the SEACO platform to break that barrier for access to the communities. SEACO's initial engagement approach was led by key persons from within the community (Allotey et al., 2014). These individuals provided access to health and educational services and, access to the residents of the communities within the five sub-districts. The key individuals also trained SEACO field staff in working with communities. This engagement ensured that most residents well knew SEACO and the SEACO logo.

The sites I conducted my research were widespread, and so it was impossible to establish a full-time residence in any one of the districts. I resided in Sungai Segamat and made daily trips with my interpreter by car to the other sub-districts. Having a list of the potential participants as well as maps of their locations provided by SEACO, I stepped into the field. I wore the SEACO T-Shirt or Jacket and carried my university ID card. We would locate a house on the list and knock on their doors. My interpreter would introduce us as researchers under SEACO and explain my research as well as obtain their consent. The logo proved to be invaluable. Most people would readily welcome us into their homes on sighting the emblem. To access the FELDA and FELCRA, which were more like closed communities, we had a SEACO staff accompany us to make the initial introductions.

Locating the stroke participants' homes served as a windshield tour for me. We toured the community, and I would observe the setting, places of interest and certain peculiarities that I would later explore during interviews or informal conversations with community members. An example is a Chinese temple that was located close to a

Malay community. There were hardly any Chinese homes in the area. We stopped at the temple, sought permission to enter and asked several questions regarding its purpose and location. The temple was located near the Malay community due to the tranquillity of the area and as a symbol of Segamat's inclusivity, diversity and religious tolerance.

Throughout the study, I documented my observations and interview points in field notes. These notes contained a description of settings and accounts of what was observed as well as reported. I also noted down my impressions and initial interpretations and notes for future probing. I refrained from structuring my interview data and field notes during data collection. This was a deliberate attempt to safeguard the actual complexity of the data. However, I did create initial codes based on the information I obtained; this allowed me to familiarise myself better with the data and allowed me to start thinking analytically while the interviews were being transcribed and translated into English. This also enabled me to determine new questions to include in subsequent meetings iteratively.

Participant Selection

Participants were drawn from the South-East Asia Community Observatory (SEACO) data that met the criteria. The inclusion criteria for the study was that participants needed to:

- a. Be a stroke survivor;
- b. Be a resident of Segamat district;
- c. Could provide consent for the study; and
- d. Could communicate directly or through a caregiver

In 2014, SEACO collected data on stroke survivors based on the World Health Organization stroke screening criteria, FAST.: Facial drooping, Arm weakness, Speech difficulties, and Time. Those who reported two or more of these symptoms were deemed potential stroke survivors. From this, 64 potential participants were identified. Using a list provided by SEACO, I visited each person individually to determine whether they had experienced a stroke and to obtain their informed consent regarding participation. To ensure the participants' stroke, I asked them for a hospital-confirmed report of their diagnosis. Not all participants had that documentation, and so, in addition to their verbal self-reported diagnosis of stroke, I drew upon my clinical background to assess them and ensure that they had symptoms and a history that complied to the WHO STEPS Stroke Surveillance criteria (World Health Organization, 2005).

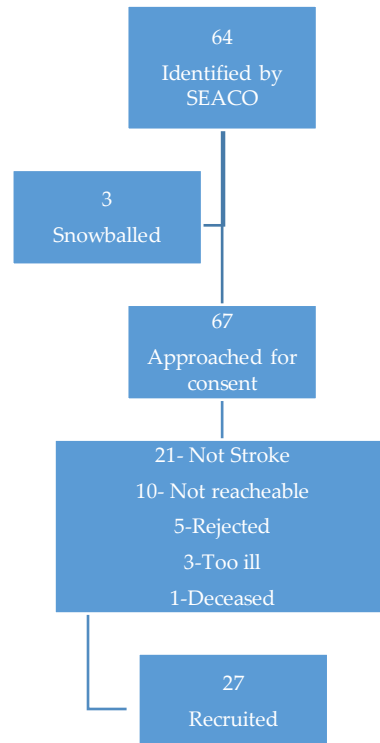
Of the 64 people initially identified through the SEACO data collection, twenty-one were identified as false positives (i.e. as having symptoms that were not due to stroke), and ten could not be contacted after several attempts at their homes or via telephone. Five refused consent for the study, one passed away, and three were too ill to participate. Twenty-four people thus consented to the study. A further three participants were identified by SEACO community liaison officers, who identified stroke survivors who had not been captured during the SEACO data collection. The liaison officer explained the nature of the study to the potential participants and asked if they were keen to partake in the study. I approached these people and gave them detailed information about the study and my role in it; consequently, I obtained consent and recruited three more, bringing the total to 27 participants. Figure 6 (below) outlines the study recruitment process.

Informed consent in Malay, Chinese or Tamil was sought from all participants for access, recruitment, observation, and interviews. I informed all individuals who consented to the nature of the study not only at initial contact but on subsequent

fieldwork contacts as well. For individuals with difficulty communicating, I obtained consent from the caregiver. Prior research shows that consent can be obtained from a surrogate or decision maker where consent from potential participants with dementia (who cannot consent) is not obtained, and assent reaffirmed from the participant (Beuscher & Grando, 2009).

Stroke survivors who were severely ill were excluded from the study, as they were unable to consent, communicate or actively participate in the study. My sample does include some participants with aphasia or other language problems, who could consent and communicate through a caregiver. The exclusion criteria meant that my study is not a representation of all individuals with stroke. This includes not only people with severe ill health (described above) but also individuals who had minor symptoms of stroke or whose symptoms had resolved. As such, individuals with the extremes of symptoms, both severe and mild, may not be given a voice in the study, an issue that has been documented in prior research: literature affirms that it is not uncommon for people severely affected by stroke to be excluded from research (Gillen, 2005; C. D. Murray & Harrison, 2004).

Figure 6: Flowchart of Participant recruitment



Ethical considerations and data management

The researcher-participant relationship in qualitative studies can bring about a range of ethical concerns, including dilemmas around whether to intervene or not (discussed above). Researchers must take into consideration issues such as confidentiality and privacy of participants, benefits and possible risks of the study to the participants and informed consent (Fritz, 2008). A full ethics clearance was obtained from the Monash University Human Research Ethics Committee (MUHREC: 2014000105) before this research commenced.

During fieldwork, it was essential to engage with participants in a constant discussion regarding my role in the research process and around consent to participate. Some participants expected that I would provide monetary aid or recommend them for assistance with the welfare department of the state. In some instances, I did provide clinical advice when requested or deemed appropriate. I also assisted some participants and their caregivers with information about stroke. Throughout the study, I had to

repeatedly make clear my primary role was that of interviewer and observer to avoid misunderstandings. I was mindful of the position I held as a clinician and a researcher, and the unequal balance of power the situation projected. Because of that, I continued to stress the voluntary nature of participation in this project, people's choice of withdrawing at any time with no prejudice, and their choice regarding how the interaction could proceed (to be audio recorded or not, etc.).

I treated all data and interviews with the utmost confidentiality. Participants were assigned numbers and pseudonyms. Specific references to health institutions or health professionals were avoided. Before commencing my fieldwork, I envisioned presenting my work as journal articles and having my thesis published. As such, I informed them that the information they give might be used and photographs they provide consent to may be published. Interviews were digitally audio-recorded, and the transcripts kept in password-protected computer records; hard copies were kept in a protected drawer in a locked room. As this study was a component of a broader project, electronic copies of the transcripts and audio files were uploaded into a secure drive, accessible only to those directly involved in the study (my supervisors). Data were entered into a computer using a coding system to protect the identity of the participants and backed up on an external drive. A notebook containing field notes, observations, reflections and records of my interactions was also locked in the drawer with the transcripts.

The Participants

Twenty-seven participants, six women and 21 men, were recruited for this study (Table 3.). Participants were aged between 37 and 83 years, and most had several children and grandchildren. While my study did not specifically consider gender, more men than women were included in the sample because the SEACO data identified more men with stroke.

Table 3: Participant demographics

Variable	Frequency
Gender	F: 6 M: 21
Age	30-39: 1 40-49: 3 50-59: 8 60-69: 9 70+: 6
Ethnicity	Chinese:3 Indian: 4 Malay: 20
Religion	Islam: 20 Christianity: 1 Buddhism: 2 Hinduism:3 None declared: 1
Years of stroke	<1: 2 1-3: 10 4-6: 8 7-10: 1 10+: 6
Stroke type	Ischemic: 26 Haemorrhagic: 1
Number of strokes	1: 22 2: 3 3+: 2
Marital status	Single: 1 Married: 25 Widowed: 1
Primary caregiver	Spouse: 25 Daughter in law: 1 None: 1
Education	No formal: 2 Below tertiary: 24 Tertiary: 1

Data Collection

In line with my study design, ethnographic data were collected through personal immersion in the day-to-day activities of the individual or community under study and

based on interviews and observations (Schensul, Schensul, & LeCompte, 1999). In ethnographic research, interviews are an extensively used method of data collection, which aim to contribute knowledge that is not only theoretical but grounded in the meanings people attribute to life experiences (DiCicco-Bloom & Crabtree, 2006). Based on this reason, I used the 'interview' as the primary method of data collection. Schensul and colleagues (1999) describe in-depth interviews as a way of exploring a topic in detail while being open-ended meant the researcher is open to all responses.

I developed an interview schedule to guide the interaction between the participants and me. My questions were open-ended, to obtain descriptive and rich information about the respondents and their lives. I prodded the participants gently when they didn't respond to a line of questioning, or when I needed to clarify an issue. My interview schedule was a guide, to prompt participants into conversing about their experiences, and not all participants were asked the same questions as such, the direction of questioning changed depending on the flow of the conversations. This was so because the critical element is the individual expressing himself freely. As Hammersley and Atkinson (2007, pg. 117) explain: *"Ethnographers do not usually decide beforehand the exact questions they want to ask, and do not ask each interviewee the same questions, though they will usually enter the interviews with a list of issues to be covered. Nor do they seek to establish a fixed sequence in which topics are to be covered; they adopt a more flexible approach, allowing the discussion to flow in a way that seems natural... ethnographic interviews are closer in character to conversations than are survey interview."* I aimed to stimulate answers from the participants and attempt to unravel the context and meaning of the responses. The iterative nature of qualitative research in which data analysis is conducted simultaneously with data collection meant that my questions altered and evolved as I learned more about the topic investigated. Throughout the interviews, I acknowledged my participants as experts of their life post-stroke, for they had the experience and knowledge which I did not.

My discussions with the stroke survivors focused on how the stroke evolved, the impact on their lives, how they coped and reconstructed themselves. Furthermore, I explored how their views on the healthcare they received, are currently receiving and how professional interventions if any, facilitated their recovery. This comprised a discussion on family structure, education, religious beliefs, and practices. Interviews varied in length from thirty minutes to two hours, and most were audio-recorded, with each participant's consent to aid in textual analysis. In other cases, notes were taken as the presence of an audio-recorder seemed to make them uncomfortable and limited their participation.

Even though my initial contact with the participants was in their homes, I invited them to choose the place of our interviews. All participants preferred to remain in their homes. One reason for this was that mobility and transport would have been problematic as some were disabled and housebound due to their stroke. Another reason was that they felt more comfortable in their home setting, as it was a familiar location for which they had control over. As a researcher exploring lived experiences, the choice of home was particularly suited to my needs. The 'home' was a natural environment where multiple scales of social interactions occurred. The natural environment offered a rich source of data as I could observe first-hand the roles, identities, and activities of the participants within their sociocultural context that enabled me to understand and relate to the participants' experiences. Items such as mobility devices, therapy contraptions, photographs, posters, religious relics or the positioning of a bed within the home revealed certain priorities or commitments of the participants that were relevant to the study.

The context of the research shaped the pace of interviews. Frequently, I would have to pause or defer the interviews so the participants could perform their prayers. Similarly, I avoided going to the participants' home at the time of prayers. My interpreter and I would stop at a coffee shop or have lunch while we waited for the

prayer time to pass then approach the participant. During Ramadan, the Islamic month of fasting, we conducted interviews only with non-Muslim participants. Such consideration was imperative as it reflected our understanding and respect of religious norms that were central to the lives of the participants. At the end of the interviews, I thanked the participants for sharing their stroke stories and hospitality. Participants offered invitations for my interpreter and me to visit at any time, especially invitations to the *Eid-al-Fitr* (end of the Islamic Fasting period) festivities. Follow-up visits were arranged before departure.

During the interviews, I employed a semi-structured interview guide which gave a focus to the interview and gave me opportunities to ask follow-up questions, thereby expanding on the responses provided. The interview schedule was used to prompt participants into conversing about their experiences. I asked broad questions during the interviews which included:

- Can you tell me about the day the stroke occurred? What were you doing?
- What do you think caused the stroke?
- What happened after? Where did you go?
- Tell me what happened at the hospital/clinic
- What did the doctors say caused the stroke?
- Before you left the hospital, what did the doctor tell you?
- Did you go to any other place for treatment?
- How has life changed since the stroke? Did the stroke affect your religious practices?
- Can you tell me about your daily routine?
- Is there anything else you would like to tell or ask me?

Informal conversations with the participants also took place. They usually occurred when I would drop in to see a participant because I was in the neighbourhood. They would offer us tea or lunch with them while a conversation took place. Although these informal conversations did not start out with a conscious structure, aspects of my research were never far from my mind. I was aware of when something related to the study emerged from the conversation and would steer the conversation in that direction exploring in detail the information presented. As these conversations were informal and mostly unplanned, I continuously reaffirmed consent. Before probing on issues relating to the research, I would ask if it was alright to talk about the issue.

Observation of the participants' activities was undertaken to get a sense of the daily lives of the individuals in my study to understand the culture and social dynamics that influence their experience. Participant observation, therefore, provided me with additional contextual information that was not only data but also gave a lens through which additional meaning could be found in the data. During some interviews, other family members were present; children, grandchildren, neighbours, and friends would come and go. These individuals, although not the central focus of the stroke narrative, influenced the story-telling. The way tones, moods, and body languages changed with these interactions added depth to the stories. In line with ethical considerations, I verbally sought consent from these individuals to include their interaction with the participant in the research. At other times, it was not possible as pausing to seek consent would have interrupted the natural flow of information as reported in previous literature (Shefner & McKenney, 2018; Stevenson, Gibson, Pelletier, Chrysikou, & Park, 2015). However, the individuals' stance and continued participation were accepted as consent. Shefner and McKenney (2018) highlight that the physical action of participating in the conversation when it was clear to the individual a research was on-going implied consent.

As mentioned above, the home itself was data that was invaluable to my study. I observed the home dynamics and the environs such as who received us, where we were asked to sit, who sat with us, who gave instructions around the house, photos, and decorations on the walls and shelves. I interacted with their grandchildren, played with their cats, or helped take crockery back to the kitchen. Mobility assistive devices, such as wheelchairs and walking sticks, medication and supplements were regularly observable in the room, prompting me to question their usage. I documented these interactions and observations and went periodically over the notes with my interpreter to ensure the accuracy of details.

Most stroke survivors spent their time at home. However, a few would venture outside to food stalls, coffee shops, or their places of work. I would accompany them on these outings to generally observe how they went about their activities, researching their behaviours and the conversations they had with others. I noticed the curious looks of people around as to who I was and what I was writing down in my notebook. Most would smile at me, say hello and carry on with their business, especially when they noticed the SEACO logo on my t-shirt.

Additionally, we had walk-throughs which involved having the participant take the researcher on a walk around their household, property or local vicinity, an approach which aligned with Kusenbach's (2003) 'go-along' method. As we would walk through an area, participants would discuss everything encountered or noticed while I asked for explanations of things we saw. Afterwards, I made notes of the discussions held. Walk-throughs helped collect information on the geographic features, household features, and activities that occurred within the environs of the home, neighbourhood, and community. The purpose of this method was to collect and visualise spatial information about participants' perception of space, items, and activities carried out in a focused and systematic manner (Kusenbach, 2003). I used a camera to photograph my observations during the walks. Care was taken not to photograph individuals other

than the participant and their family who gave consent. Similarly, I refrained from taking photographs of materials such as architectural relics, commercial prints and dramatic works as they could be protected by copyright laws. I recorded my observations and reflections in a notebook. I tried to record the notes during fieldwork quickly, making short jottings which I would then expand on in the evenings. These notes contained descriptive bits of information that enhanced my thinking about my research topic, as well as my written work. The field notes provided me with a means to assist and prod my memory on events that occurred. At the same time, I used them to document points of reference for my observations and reflections about my participants.

The interviews and field notes were supplemented using photo-voice and ©talking mats. This combination of methods was useful to optimize data generation in the research (Teachman & Gibson, 2018). Photo-voice is a method in which community members are given cameras and asked to photograph their everyday lives. As part of this process, they are asked to suggest aspects they would like to see improved (Baker & Wang, 2006). Photo-voice aligns with other visual methods, including auto-driven photo-elicitation (Samuels, 2004) and photo-elicitation interview methods (Clark-Ibáñez, 2004), but was chosen for use in this study to gain a more comprehensive understanding of the ways common factors shape and impact the stroke recovery path.

I issued cameras to the participants at the end of the first encounter, and they were asked to take photographs of what they felt was important to them, what made them happy or sad, what they could do, or what they would like to do. I explained to them that their photographs could be of anything ranging from their mobility within the house, their chores, their interactions with friends and community members, or even of their prayer sessions. I gave them the flexibility of choosing their priorities of the photographs. I further gave instructions on how to use the cameras to them or a family member. However, most participants were reluctant to accept the cameras,

mainly because they were not used to handling a digital camera. This was understandable: most of the participants did not even own a smartphone, and thus the use of a digital camera was alien to them. Therefore, only 2 participants agreed to complete this stage.

Once these participants had taken their photographs, they partook in another round of interviews in which they were invited to discuss the pictures and what they represented about their lives. They were asked to explain the photographs, why it was taken, and what it meant to them. This led to discussions about significant aspects of their lives and facilitated further discussions and clarification of information they had provided during the initial in-depth interviews.

©Talking Mats (www.talkingmats.com) supplemented the data collected through interviews, observations, and photo-voice. Because individuals experiencing difficulties in communicating are often left out of research because of the expressive challenges in obtaining their views, the ©Talking Mats tool was developed to enable researchers to communicate with these individuals (J. Murphy, Tester, Hubbard, Downs, & MacDonald, 2005). The tool uses picture symbols to assist individuals with or without communication difficulty to comprehend and respond better to questions (J. Murphy & Oliver, 2013) (see Figure 7). They may be useful beyond this: Murphy and colleagues (2005) suggest that weak, older individuals with reasonably good language and speech may benefit from the tool because the mat captures and sustains their attention and aids them to reflect on their views at their own pace. With ©Talking mats, the interaction emphasises the mat rather than the individual, which some people may struggle with (J. Murphy et al., 2005). The ©Talking mats were used where appropriate as a participatory elicitation tool. This was particularly effective with participants who had some degree of aphasia as they found it challenging to generate language. The ©Talking mats were a clear, easy and straightforward way for them to communicate

their thoughts as has been demonstrated in earlier studies (Allard et al., 2014; J. Murphy & Oliver, 2013; K. Murphy, Jordan, Hunter, Cooney, & Casey, 2015).



For this study, I used the ©Talking Mats *Health and Well-being* bundle which comprised a mat and a set of cards. The Health and Well-being bundle explores a wide range of 13 topics on everyday life based on the WHO International Classification of Functioning, Disability and Health (ICF) framework. The symbols on the cards were simple and colourful. Three cards representing emotions – happy, unhappy and not sure – were placed along the top of the textured mat. I presented one card at a time to the participant, asking open-ended questions and giving them adequate time to comprehend and reply. The participant would then place the card under one of the three emotion symbols on the top of the mat. A snapshot of the mat was taken to have a record for analysis.

Participants in my study spoke any of four (or more) different languages, including Bahasa Malaysia, Mandarin, Hokkien, Hakka, Tamil or English. Due to this complexity of language, combined with time constraints placed on my doctoral research, I conducted all my meetings and most of my interactions with participants with the support of one of two interpreters. My main interpreter, JSM, was a bicultural research assistant who was fluent in Bahasa Malaysia and other languages. He was briefed on the research by my supervisors (the chief investigators of the broader research project), including regarding the theoretical approach employed, the study design, the specific data collection methods used, and ethical issues specific to this research. This strategy outlined at the onset of the research process promotes a unified understanding of the process, strengthens and clarifies expectations of both the researcher and the interpreter (Bergen, 2018). Another colleague – also a PhD candidate – interpreted for the four Tamil-speaking participants, if they were more comfortable speaking in Tamil rather than Bahasa Malaysia.

Before I started working with JSM, I was worried that there would be less flexibility and spontaneity than direct interviewing. I also held concerns that my participants would feel uncomfortable having a three-way conversation, particularly given the presence of the audio-recorder. This did not turn out to be a problem, and the interviews mostly ran as smoothly as my interviewees realised that it was a conversation to understand their experiences. Another issue was the possibility that JSM would introduce his biases into the study. In translating what the participants said, I assumed JSM might provide the responses that he believed I wanted to hear or would provide answers that he thought were appropriate. To minimise these biases, before entering the field, I emphasised to him the importance of translating everything the participant says.

I usually greeted the interviewees in their language (*Selamat Pagi, nama saya Fatima. Kami dari SEACO*; Good morning, my name is Fatima. We are from SEACO). I

did my best to maintain eye contact with the interviewees and gave non-verbal cues (including nodding and smiling) to make it clear that I understood what was said (Freed, 1988). Between interviews, JSM and I would discuss how things were going. I would give him feedback, and we would work together to evaluate the quality of the work. I felt that doing this built some trust with my participants. I also paid attention to the body language, and expressions of the interviewees' while I posed questions to them.

The relationship between a researcher and interpreter takes time and effort to build and can lead to disruptions and inconsistencies in the interviews (Bragason, 1997). As such, there were some obvious challenges in conducting the interviews. I was not skilled in working with an interpreter; I needed to learn how to do this best – a process that took time. Often, especially during the initial stages of my research, my questions were directed to the interpreter rather than the participant. At the same time, the speed with which the participants spoke did not always allow for complete interpretation on the part of the interpreter. We found ways of overcoming the challenges; after each interview, we discussed the flow of the conversation, and developed systems of signalling between us, allowing us to develop non-verbal forms of communication which has been documented in prior literature (Kapborg & Berterö, 2002; Raval & Maltby, 2018). Debriefing sessions aim to clarify issues and strengthen the interview process (Raval & Maltby, 2018). During these debriefing sessions, JSM expanded on issues which he couldn't translate fully during the interview. Over time, both JSM and I became more skilled and more comfortable in conducting the interviews.

As time went by, JSM's position evolved; he went beyond interpreting to rephrasing my questions in a such a way as the interviewee would understand better, pursuing issues he felt were relevant that I might have missed, and issuing cues to let me know when to slow down or pause. For me, JSM was not just an interpreter; he had multiple roles: as an interpreter, a key informant, and a researcher. In the evenings, he

would take me to buy dinner and played with my toddler son. He became my friend, which ultimately facilitated our working together.

Data Analysis

My fieldwork produced extensive qualitative data that responded to the research aim. Analysis began in the field with my scribbles, diagrams, interview notes, and observations summarised to start a list of initial codes. As I collected the data, I identified initial patterns and themes. More questions emerged as the research progressed, as such, to refine my data, I relied on the flexibility of the ethnographic process to improve my questions by following up on identified themes and pursuing new ones.

Transcription and Translation

Audio-recorded interviews were transcribed verbatim and I documented demographic variables such as gender, age, and time post-stroke for each interviewee. Themes were identified and manually recorded in a separate worksheet that was later used to provide linkages. General ideas first guided the analysis and then modified as the study advanced. The process was subjective and reflective, consistent with ethnographic research (LeCompte & Schensul, 1999). Essential themes were identified and reported. Gaps and missing data were identified during the analysis and followed up as fieldwork progressed.

Although most interviews were conducted in Bahasa Malaysia, a few were conducted in English, Mandarin, and Tamil. This blend of languages and use of interpreters added other voices to the narratives as well as a further layer of examination. The audio-recordings of the interviews were transcribed verbatim by my main interpreter who was fluent in Bahasa Malaysian and Mandarin. Interviews

conducted in Tamil were transcribed and translated into English by a local Tamil speaker as mentioned above.

Thematic Analysis

A thematic analysis approach was used to analyse the data, drawing on the work of Braun and Clarke (2006). In thematic analysis, themes are often anticipated through a review of pertinent literature and themes that emerge during fieldwork (Pope et al., 2006). Braun and Clarke (2006) proposed six phases of analysis: familiarisation with the data, generation of initial codes, sorting codes into themes, refinement of themes, defining and naming themes, and writing up results.

Thematic analysis was suitable because of its theoretical flexibility; it allowed for use within different theoretical contexts (Braun & Clarke, 2006). Thematic analysis recognised both: *“the ways individuals make meaning of their experience, and, in turn, the ways the broader social context impinges on those meanings”* (Braun and Clarke, 2006: pg. 9).

My analysis was data-driven. However, Braun and Clarke (2006) argue that themes do not merely ‘emerge’ from the data, emphasising that data is not coded from a vacuum; instead, the researcher actively identifies the themes. They further contend that researchers may not be able to extricate themselves from their preconceived epistemological and theoretical philosophies (Braun & Clarke, 2006). Although I attempted to draw out themes from the data itself, it is likely that my coding and themes were influenced to a certain degree by my preconceptions about the research topic.

My analysis commenced early in the research process. As I gathered the data, I began to identify patterns. Reading through my notes and transcripts numerous times allowed me to familiarise myself more with the content. As I became more familiar with the data, I started to extract semantic content that became my initial codes (see Table 4.

below). I highlighted sections of the data and ascribed codes to them. Subsequently, with an extensive list of codes, I organised them into possible themes, identifying similarities in the codes and grouping them into themes. I further grouped the themes into main themes and sub-themes.

I reviewed my themes, regrouping some and collapsing some into the same theme guided by my research questions. At this stage, I began to see a 'story' come out of the data. The pieces of information that were once random became more coherent. Finally, with the themes identified, I named them and matched them to my research questions and accompanying excerpts from my transcripts. With the themes and narrative excerpts in place, I began to write up the 'story' in a coherent way that would resonate with the reader.

Table 4: Example of codes and themes

Transcript excerpt	Coded for	Theme
It's like ants, and numbing. Then I felt like sweat coming out from one side of the body (laugh) sweat, on one side. Then my friend [asked] me to walk, but [I] couldn't. [I] held on to that pole, held on, then went into the car. After I got into the car and [tried] to start the car, the keys dropped. Then I felt saliva come out. I looked into the mirror, [my mouth] was deformed.	Nature of stroke onset	Stroke event
I couldn't do anything. Just kept quiet. They ask us to take the medication, I took. Change clothes? How? I have stroke? Can't do it. They (the nurses) help with changing clothes or other things... My recommendation, [is that] the wife or husband should stay and take care of the person. It was 7 pm. My wife had already gone home. I wanted to go to the toilet, and I couldn't. I called out to the nurses for help, but I was ashamed. Shameful... Let the wife take care of me.	Feelings of dependence, shame	Hospital experience

Rigour

Ensuring rigour is a key component of any qualitative research, and includes a range of strategies including confirmability, credibility, dependability, reflexivity, and transferability (Lincoln & Guba, 1985). To ensure my findings were rigorous, I

employed the following strategies: triangulation and reflexivity; at the same time, I attended to ideas of transferability. I discuss these below.

Triangulation is an important way of obtaining rigour in qualitative research studies and is situated in the heart of ethnography (Fetterman, 2010). Triangulation is a process using two or more methods of data collection to answer a research question (Denzin & Lincoln, 1998). In this study, data were collected through a range of techniques (interviews, talking mats, observations, and field notes. These multiple data collection methods extended beyond the interviews and included extensive field notes, participant observation, and reflective journaling. Taken together, this provided a depth of information gathering which made sure that the narratives of my participants' experiences and social context were not viewed lightly. Furthermore, my use of participants' direct quotes added depth and trustworthiness to the narrative.

I adopted an analytical and descriptive reflexive approach in all stages of this research. Brewer (2010) explained analytical reflexivity as a process that allowed for the elucidation of the way data is understood and interpreted. He also explained reflexivity as a method that involved pondering on all possible scenarios and issues that could influence research – including the research site, the participants, preconceived beliefs of the researcher, power relations and interactions in the field, how data is managed and analysed (Brewer, 2000). In this study, I regularly reflected on how I managed data and reflected on my positionality about issues that arose in the field. Earlier in this chapter, I discussed the process of participant recruitment and described participants providing information on the gender, age, ethnicity, duration since the stroke. The frequent supervisory sessions with multiple supervisors and opportunities for progress reviews during the doctoral study period permitted a more profound understanding of the research course, clarification of epistemologies and allowed for a variety of perspectives on the research evolution.

The results presented in this thesis are not an omniscient finding, as people's lives are in a state of continuous change. As such, my thesis does not propose finding one reality; instead, it provides one interpretation of the experience of recovery and well-being following a stroke. Similarly, the results do not aim at generalizability; however, they can apply to similar situations and contexts. By providing a detailed, rich account of my research methodology, my readers can relate to the findings and transfer them to other settings.

Summary

In this chapter, I have laid out the aim and objectives of the research, the rationale behind my methodological approach, and how I collected data. I have also explained my fieldwork experience and how it has shaped the research. The chapter also provided an overview of the research site and setting and how I achieved accessibility to the research site. I also discussed the participant selection, ethical issues and my role as a researcher. Similarly, I provided an outline of how data was managed and analysed.

Chapter 4.

The trajectory of stroke in rural Malaysia

Introduction

Stroke recovery often involves a long and staged process of regaining function and, ideally, independence. In industrialised settings, robust models of rehabilitation exist within healthcare settings and the community to support stroke survivors' recovery (L. Smith, 2010). These models aid in reclaiming the ability to carry out daily activities related to family life, work, and societal reintegration. These can also address the psychosocial consequences of the stroke, restore wellness, and work towards minimising the burden felt by both stroke survivors and their caregivers. However, such services are limited in low and middle-income countries; as discussed in chapter 2, these are scant in Malaysia, largely offered through private clinics or in a considerably truncated form.

In operationalising rehabilitation for stroke, it is useful to outline its illness course, such that factors which may hinder or aid an individual's adjustment to disability within the wider socio-economic environment are highlighted. The term 'trajectory' is used where this focus on illness course extends to consider recovery and is the focus of this chapter.

Illness trajectories provide insights into disease onset, progression, and resolutions (White et al., 2012) as discussed in chapter 2. In the case of stroke, the illness trajectory can help conceptualise the pattern of recovery and the use of established coping strategies. The trajectory phases act as windows to identify needs and address the management of those living with stroke. This can, therefore, aid in planning and delivery of appropriate services; at the same time, the concept of trajectories offers stroke survivors and their caregivers a better understanding of stroke and its

consequences. This may, in turn, equip them to understand their prognosis and empower them to cope with its impact on their lives. Using stroke illness trajectories also allows a consideration of the relationships between stroke survivor, family members (including family caregivers), and health professional to focus on the provision and acceptance of a realistic prognosis, symptom control, and supportive care from stroke onset. In this way, health professionals can obtain the best possible quality of life for the stroke survivor.

In this chapter, I apply Corbin and Strauss's (1991) CITF to understand the experiences of stroke recovery of men and women living in rural Malaysia. In so doing, I highlight the relevance of such frameworks for use in low and middle-income countries and thus emphasise their utility for informing health service planning in rural Malaysia.

Corbin and Strauss' (1991) Chronic Illness Trajectory Framework

Corbin and Strauss conceptualise 'trajectory' as a sequence of events in an illness course with phases defined within specific turning points. The timing and shift from one stage of the trajectory to the next can be understood regarding 'trajectory phasing,' a term which refers to the changes in status that a chronic condition undergoes throughout its course. Table 5 (below) highlights the key stages of the chronic illness trajectory identified by Corbin and Strauss.

Table 5: The Corbin and Strauss CITF (Corbin and Strauss, 1991)

Phase	Description	Plan of action (trajectory scheme)
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Pre-Trajectory	The absence of signs or symptoms, but the presence of genetic factors or lifestyle behaviours that place an individual or community at risk for the development of a chronic condition.	Prevent the onset of chronic illness, address risk factors
Trajectory Onset	The appearance of noticeable symptoms includes periods of the diagnostic workup.	Expert help is sought.
Crisis	A critical or life-threatening situation requiring emergency treatment or care. Everyday life activities suspended until the crisis passes.	Removal of threat, minimising complications
Acute	Severe and unrelieved symptoms or development of illness complications necessitating hospitalisation to bring course under control. Everyday life activities temporarily placed on hold or drastically cut back.	Bring illness under control and resume everyday life.
Stable	Illness course and symptoms are under control. Everyday life activities are being managed within limitations of illness. Illness management at the home	Maintain stability of illness and everyday activity.
Unstable	Trajectory not maintained by existing care packages, but not requiring hospitalisation. Periods of inability to keep symptoms under control or reactivation of illness. Difficulty in carrying out everyday life activities. Adjustments being made in the regimen, with care usually taking place at home.	Return to stability.
Downward	Illness course characterised by rapid or gradual physical decline accompanied by increasing disability or difficulty in controlling symptoms. Requires biographical readjustment and alterations in everyday life with each significant downward step.	Adapt to increasing disability, with each significant downward turn.
Dying	Final days before death. Characterized by gradual or rapid shutting down of bodily processes, biographical disengagement, and relinquishment of everyday life and activities.	To bring closure, let go and die peacefully.

Two concepts are central to explaining the dynamics of the chronic illness pathway (Strauss, 1984): trajectory projection and trajectory scheme. The *trajectory projection* gives an overall image of the illness path, including its meaning(s), prognosis, symptom

experiences, and the time course of the illness (Strauss, 1984). In contrast, *trajectory scheme* refers to the strategy (or strategies) considered by the individual, their family, and the health practitioner when shaping the illness pathway, including how symptoms are controlled or how disability is managed (Strauss, 1984). The trajectory scheme thus represents the plan of action undertaken to manage the illness. The trajectory scheme may include both medical and alternative treatments and is responsive to what treatments people use at what points in their post-stroke experience.

These concepts of trajectory projection and trajectory scheme assume particular types of healthcare systems and rely on highly industrialized settings – where chronic conditions health management is highly prescribed and where recovery is influenced by accessible and well-developed rehabilitation systems which employ benchmarking to clearly indicate the recovery process (Gubrium et al., 2003; Manderson, Warren, & Markovic, 2008). These recovery contexts are often not available in LMIC, as I previously discussed in my consideration of the Malaysian setting (Chapter 2). The CITF is valuable in understanding the illness course of stroke in an organised manner, by highlighting trajectory phasing. In the following sections, I examine the relevance of the CITF in stroke recovery in an LMIC.

The trajectory phases

The pre-trajectory phase

The pre-trajectory phase represents the time before the illness course commences (Corbin & Strauss, 1991; Woog, 1992) when no bodily signs or symptoms of the impending illness are evident but when risk factors are present. All the participants in my study lived with risk factors for stroke, although they were not always aware that they experienced these. They were not concerned about the potential for stroke: as it was a time lived before the disruption of life events by stroke, participants instead

focused on the prevention of a (potentially unspecified and unanticipated) illness. Any preventive health behaviours were therefore not specific to stroke but rather were about general health issues.

Importantly, the pre-trajectory phase characterised by the presence of risk factors was often left unnoticed or ignored. For many study participants, this often related to low levels awareness about stroke. Amit (59-year old man, two-years post-stroke), was a lorry driver, spending his day loading and off-loading cement for a construction company, which kept him feeling strong and healthy. Despite having been diagnosed with diabetes and high blood pressure several years earlier, he had no idea that these were risk factors for stroke:

But I don't even know how I would get a stroke. How can I get it? I was not fat. I worked heavy you know. I thought by carrying heavy bags of cement, 50kg, one bag per person, [I was taking] exercise! How can I get it? Oh, God!! Although I gained a little weight now, I was slim.

Amit was not alone in being unaware of stroke and its risk factors; all my participants had elevated blood pressure when they attended the hospital for the stroke, and two had a family history of stroke. In addition to high blood pressure, many also knew that they had diabetes and high blood cholesterol.

It was only in hindsight that (some) participants could see a link between these risk factors and their stroke. More commonly was the association between generalised 'lifestyle' factors, such as sedentarism and unhealthy food choices. Although they never anticipated that they would have a stroke, these factors led them to feel some sense of guilt and responsibility for their stroke. This was primarily the case for those participants who were young at the time of stroke: Ayub (now aged 48), for example, was 43 and overweight when he had his stroke five years earlier. He recognised that he didn't take care of his health well enough, which he mainly attributed to his poor diet, which was high in fat and carbohydrates, and his lack of physical exercises. Similarly,

David, a 44-year-old manager, also felt that his (unintentional) disregard for his health resulted in the stroke two years earlier: being very busy and stressed at work, he used to drink a lot of alcohol, ate fat-laden foods and did not exercise.

Participants did not always interpret lifestyle factors in the same way as they are understood in public health, and as Ayub and David described them. Instead, some participants attributed their stroke to previous actions which they perceived as morally transgressive. Dram (aged 43 at time of stroke), for example, was sure that his stroke occurred due to karma, or as a form of karmic punishment, because he had been an avid hunter, *“Indians, we believe that if you hunt, you will get an illness. We should not kill animals”*.

Accordingly, he felt God was punishing him for taking the lives of innocent animals for leisure. These moralised explanations also drew, to some extent, on public health understandings, yet these also had a moral dimension: Dram also felt his excessive alcohol consumption contributed to the stroke. By reflecting on these moral ‘transgressions’, Dram was left with a sense that he could have prevented the stroke. In the context of alcohol consumption, while Dram was aware of the adverse health and social effects of drinking, he was unaware of the medical evidence that underpins such effects and its categorisation as a risk factor for several health conditions including stroke. It was only in retrospect that he felt his alcohol consumption was morally transgressive. The guilt, however, motivated him to attempt to repair the damage done. He gave up drinking after the stroke and encouraged youngsters within the community to avoid drinking alcohol. His experience and feelings of guilt serve as a form of health promotion for the prevention of stroke risk factors.

As demonstrated by the data, evidence from the literature support the findings that high blood pressure, diabetes, high cholesterol are major risk factors for stroke (Grau et al., 2001; Ralph L Sacco, 2001). Other risk factors identified in the study include excessive alcohol consumption, previous stroke or transient ischemic attack and family

history of stroke. Corbin and Strauss emphasise the importance of health promotion activities at this point as a feature of nursing care for the prevention of chronic and disabling illnesses (Corbin & Strauss, 1991; Woog, 1992).

The participants seemingly limited knowledge of risk factor links to stroke reflect a significant public health gap that needs to address. In a Malaysian context, despite the abundant media campaigns on healthy lifestyle, the limited number of qualified health workers such as educator nurses and dieticians (Muhamad, Yahya, & Yusoff, 2012) to emphasise the importance of lifestyle changes is a significant challenge in health promotion.

The onset

The commencement of bodily signs and symptoms characterise the trajectory onset phase. In a stroke, these are wide-ranging due to different stroke pathologies and the location of the lesion. There are some general signs of stroke, with the most common symptoms including facial drooping, arm weakness and slurred speech (E. S. Lawrence et al., 2001) which correspond to the signs and symptoms highlighted in the World Health Organization stroke screening criteria, F.A.S.T.: Facial drooping, Arm weakness, Speech difficulties, and Time. However, not all people have these three symptoms and instead report one or two, in combination with other symptoms including a headache, imbalance, visual disturbances, dizziness, confusion, memory loss, disorientation, and lack of coordination.

In contrast to the pre-trajectory phase, the onset phase was recognisable for people who have a stroke. Most participants could recall the onset of the stroke, and described it as a sudden feeling of weakness and numbness on one side of the body, with a sense of their face deviating to one side:

It's like ants and numbing. Then I felt sweat... come out from one side of the body. Then my friend invites me to go around, I tried to walk but couldn't. Held on to a pole...and went into the car and wanted to start the car and the keys dropped. Then I felt saliva come out. I looked into the mirror, the mouth already deformed. (Ayub)

It was around 2 am; I wanted to go to the toilet. I couldn't get up. I called out. I thought I was speaking loudly, but no one could hear me. I felt myself yelling, but no sounds came out. My mouth was deformed, deviated to the side. (Ma'aruf, 72-year-old man; 16-years post stroke)

I was sweeping the rubbish [in the compound]. It was early in the morning. Then I felt weak; I laid down. I didn't have energy. I was so weak...I could speak a little, but my mouth was deformed. (Zainab, 58-year-old woman; 1-year post stroke)

Although participants commonly reported facial impacts, this was not always the case. Umar (aged 56; at five-years post stroke), for example, initially had symptoms in his legs:

It was time for prayers, so I woke up, about 5-5.30am. I tried to stand up then I felt my right leg pull me right away. I was awake, but I couldn't feel it [the leg]. I just sat down, rub the leg. After 10 minutes, still cannot move it. Another 10 minutes later, still cannot, it was jammed.

Most of the participants were immediately overwhelmed by their symptoms: the numbness, the affected mobility and communication abilities. The descriptions provided by the participants highlight the shock, fear, distress, and sense of helplessness they experienced at the time of the stroke. These embodied emotional responses highlighted the trauma of the stroke event itself.

What actions people take in response to their symptoms – and which occur during the onset stage – are mediated by the type and severity of symptoms presented

(Miah et al., 2012) as well as prior knowledge of stroke. This was evident through cases in my study, which presented varied responses. Maryam, a 63-year-old woman, was working in the kitchen preparing for her granddaughter's wedding when she collapsed and became unconscious. She was rushed to the hospital by her husband and children. In contrast, Amit's symptoms started while he was out driving his lorry. He drove himself home and rested, thinking the symptoms would pass. After a few hours with no resolution of his symptoms, his wife took him to the hospital.

Shuaib, whose symptoms included mild facial deviation, slurred speech, and right arm weakness, believed his condition could be cured by traditional means, such as Islamic prayers and massage and only attended to the hospital a week after his signs and symptoms didn't resolve. Ayub, who felt his arm go numb and saliva dripping from his mouth, looked into his car mirror and saw his mouth had deviated to the side. He recognised he was having a stroke from the symptomatology as his mother had experienced a stroke several years back. He immediately asked his friend to take him to a hospital.

For participants in my study, the severity of the symptoms, beliefs about causation, and availability of appropriate services – which is at least partly influenced by geographic location and health system-related factors – usually determined the course of action taken by the stroke patient and their family, as well as by the health professional. Prompt attendance at a hospital was commonly associated with certain symptoms. Moderate or generalised symptoms, such as dizziness or headaches, were not perceived as serious and thus did not lead to attendance at a healthcare facility. In contrast, facial droop, limb numbness and loss of consciousness were regarded as serious and thus led to help-seeking through calling family members, emergency services, or attendance at the hospital/traditional healer/religious organisation. Similar findings have been reported from a study in the United Kingdom indicating that mild symptoms did not warrant attendance at a health facility (Mellor et al., 2015).

Most of the participants in my study sought hospital care with the occurrence of stroke signs and symptoms which heralded entry into the crisis phases. The onset is a period that spans the time from the appearance of the first signs and symptoms to the full conceptualisation of a diagnosis of stroke. A period of shock and fear that leads to the crisis phase characterises the onset phase.

The Crisis phase

Corbin and Strauss defined this Crisis phase as requiring emergency in-patient care (Corbin & Strauss, 1991; Woog, 1992), and characterised the crisis as a life-threatening situation requiring emergency or critical care. In this, the patient's condition is uncertain. The focus of this phase, therefore, has its location in biomedical activities and interventions: namely, the goals are to stabilise the patient, to limit the motor damage, and to prevent complications. During this phase, the family and those around the patient decide as to what happens next. The stroke survivor usually has no input, leaving all decisions to healthcare professionals and family (Kirkevold, 2002; Lutz et al., 2011). In this phase, there is concern about survival by both the patient and his family as well as fear of what disability the stroke might produce (Brandstater & Shutter, 2002).

The crisis phase of my study was distinct from that described by Corbin and Strauss (1991). Only one participant, David, would be considered to have had a 'crisis' that necessitated critical care. His wife turned over in bed about 3 am to find him unresponsive. He was rushed to the hospital by the wife and other family members. David's symptoms and presenting history pointed towards a haemorrhagic stroke and, after his wife drove him to three hospitals over a five-hour period, he was finally operated on as an emergency. David stayed in the hospital for two weeks, receiving biomedical interventions to stabilise him and prevent further complications from the stroke. He vaguely recalled this phase, relying on the accounts of family members.

When asked, what had happened, he replied, *“I cannot remember, you have to ask my wife”*.

While my other study participants did not discuss the life-threatening crisis that is characterised by Corbin and Strauss (1991) as part of the crisis phase, they did describe their early actions – centred on biomedical or health professional engagement – in response to the onset of symptoms. Most participants reported delays in receiving care. Ayub, who had cognisance of having a stroke, lamented the wait he had to endure, *“We waited and waited for the doctor to arrive [which] took a long time”*.

I argue that this constituted an alternative form of crisis phase. The aspect of emergency stroke service provision as characterised by Corbin and Strauss (1991) is variable and depends on the severity of the stroke, availability of specialised stroke and rehabilitation units. Malaysia does not have the highly technological interventions available in the highly-industrialized settings – for example, MRI machines are few and specialist stroke and rehabilitation centres are limited and overwhelmed (A. F. A. Aziz et al., 2014) often only available in tertiary hospitals, located in urban areas (Hamidon & Raymond, 2003; Nordin, Aziz, Alkaff, et al., 2012)- and mean that stroke patients do not always receive emergency care. Most patients with ischemic stroke are attended to by a general physician or an internist, before being admitted to a regular hospital ward for a very brief stay. In the event of a haemorrhagic stroke, patients are admitted to an intensive care unit before being transferred to a general ward as in the case of David, mentioned above. The occurrence of the stroke was not immediately interpreted as a ‘crisis.’

In this section, I have documented how the crisis phase in stroke in Malaysia appears distinctly different from the framework proposed by Corbin and Strauss (1991) and other researchers who have used the CITF. These variances arise because of differences in the availability of technologies – including diagnostic technologies, first-line time-sensitive interventions, and neurological specialists – for stroke care in rural

areas. They also have their foundations in the healthcare system. Some aspects of the CITF's Crisis phase resonate in the Malaysian setting, particularly the engagement of family members and the (albeit brief) period of hospitalisation in which symptoms are made stable.

The Acute phase

The acute phase follows the crisis phase and refers to the period when the patient's symptoms can be controlled within a hospital setting. The acute phase covers the duration of active medical intervention and initial rehabilitation. Participants in my study were dissatisfied with the care they received at the hospital. They related considerable confusion and an inability to comprehend what had happened, which was also related to the effects of stroke itself. Most credited their dissatisfaction to the short hospital stay, insufficient information from medical personnel about the cause of their stroke, and overall management of their condition, *"They gave me a drip, that's all, after that, they gave tablets... That's all, [my stay was] just one day"*! (Amit)

Participants described brief stays at the hospital (average three days) before being discharged home: Amit, described above, only stayed one day. David, who had private hospital insurance and who had haemorrhagic stroke, had the longest stay, of two weeks due to having a surgical intervention for the stroke. Most expressed concern over the in-hospital stay and found seeking assistance for basic activities, such as dressing and toileting, very demeaning (which is not limited to this study; see (Doolittle, 1992), leading to feelings of frustration, uncertainty, and distress. Especially disturbing for some was the limited control and privacy they had over personal care such as toileting, *"I want to urinate also suffer, defecate also suffer... If we call for help, I feel ashamed. Shameful! I need to take off the trousers right, shame"*! (Ayub). Dram also felt that as a grown man, he had lost privacy, *"If I have to pass urine, I am shy; I am an adult"*. (Dram)

The short hospital stay for my participants corroborates other studies in Malaysia documenting short (5 to 7 day) in-hospital stays following stroke (Hamidon & Raymond, 2003; Nordin, Aziz, Alkaff, et al., 2012; Nordin, Aziz, Sulong, & Aljunid, 2012), and contrasts what high-income countries report (Becker & Kaufman, 1995; Meyer, Britt, McHale, & Teasell, 2012). This inadequacy reflects the limited resources for chronic illness care, particularly the shortage of rehabilitation professionals, in Malaysia: over one-third of stroke survivors do not receive rehabilitation services during their in-hospital stay (N. Aziz, 2010).

Short hospital stays and the lack of structured physiotherapy and other rehabilitation services such as speech therapy was of concern to some. (See Chapter 5 for more information). At the time while they were still trying to make sense of what had occurred to them, most survivors were discharged home with minimal information about their stroke, the possible cause, treatment options, and the future. Razak, aged 76, had lived with stroke for 15 years. He recalled staying in the hospital for just three days and received limited information on rehabilitation, *"I was in [hospital] for three days only. They discharged us, and we tried traditional medication. The doctor only said to do exercises"*.

Yusuf, was 51 years old when he suffered his stroke eight years ago, he also recalled the minimal information he received about his condition, *"They didn't give any information about caregiving. They just said there is no cure for stroke, that's all. There's nothing the doctor can do about it"*.

He lamented the fact that the medical personnel did not offer his spouse any information on how to care for him at home.

My participants were not exceptional in their early discharge from hospital with no support, with other Malaysian research reporting similar findings (A. F. A. Aziz et al., 2014; Mohamed, 2010). The stroke survivors and their carers all expressed concern about the limited information received at the hospital and the unavailability of support services both in the hospital and in the community. These findings highlight the need to

identify the needs of stroke survivors as well as the resources available to them by health services about the provision of information and education on stroke.

Participants described the crisis phase as a frightening and uncertain time. However, they also recognised it as a time when they did not feel the seriousness of the impact of the stroke. Although the stroke caused abrupt bodily changes for the majority, it was not initially perceived to be a long-term condition. Most participants approached the situation with optimism believing they will return to normal within a few weeks or months. This was clear when I spoke with Luqman (37-year-old man, government employee, at three-weeks post stroke) who had suffered a transient ischemic attack (TIA) two months before his stroke. Because the symptoms resolved almost immediately following his (TIA), he was optimistic that this time around he would recover quickly as well. He felt no financial burden because he was still on medical leave and was receiving his full monthly salary, and so was not cognizant of the reality that his impairments may prevent him from ever returning to work and may lead him to lose his income.

The uncertainty of the future, the challenges participants, reported in receiving assistance, and their perceptions of not having control over the body commenced in the onset phase and continued throughout their stroke journey aligns with work by Brandstater and Shutter (2002). The crisis phase progress into the stable phase where the 'recovery process' unfolds. The process of the stable phase and the fluctuations discussed briefly in the next subsection form the basis of the following chapters.

The Stable phase

Corbin and Strauss (1991) define stability as a time when recovery is on course because of a planned package of interventions. As with the crisis phase, such an understanding relies on particular features of the healthcare system or the broader socio-political

context. This definition of the stable phase was problematic for the current study: most participants received little or no planned interventions. Instead, they were discharged home with minimal information about the recovery course. All participants were told to undertake exercise or physiotherapy, yet only two received a scheduled course of physiotherapy at the hospital.

What is salient about the stable phase, as Corbin and Strauss (1991) describe it, is the management of activities of daily living at home, within limitations of the condition, and the sense that the illness path is under control. Throughout this phase, the focus is on adjusting to a familiar structure of daily living as the survivor integrates the stroke into their life (Kirkevold, 2002) also resonates with the current study findings. As I describe in Chapter five, the stroke survivors in my study faced the disruption to their physical bodies and then had to find ways to cope with this in their everyday life. Following the initial phase of acknowledgement of the disability, there was a time of acceptance and adjustment. Most began to seek ways of overcoming the limitations presented by their physical self, which took time, money and effort. Yet, it was a necessary process to regain the independence their former lives offered. The survivors often came to terms with their stroke and resultant disability and attempted to live life despite the restrictions and limitations of the stroke. They did this in various ways, including traditional massage therapy and continuous exercises, “[You] *have to do exercise.... Indeed, you have to do it, even if it’s a little, you have to do it...otherwise you would be finished*”. (Ayub)

The participants began to hope for a return to normality, such as returning to work, driving a car, walking to coffee shops with friends or sweeping the house. As time moved on, however, they often had to revise their goal of full recovery: for most, recovery was slower and less complete than they had anticipated. Importantly, almost all the participants needed to redefine what recovery itself meant (as I discuss in Chapter six). Some became tormented by feelings that range from frustration to

sadness, anger, and even depression as they realise they needed to depend on others for the performance of their activities of daily living, which they previously took for granted (Lutz et al., 2011).

It was during this Stable phase that the trajectory stability of the stroke and achieving well-being became the focus of the stroke survivors' lives. They took ownership and control of their recovery as discussed in chapter six; probing for treatment options. The treatment options they sought were not limited to orthodox - based treatment. Traditional or religion-based healers have a particular place in stroke care in most LMIC (Thorogood et al., 2004), either because symptoms were not perceived as serious or because stroke units were either non-existent or inaccessible (discussed above). Shuaib, for example, went to a traditional healer for massage and stayed home; it was only when his signs and symptoms hadn't resolved that he sought hospital care a week later. He travelled to different states seeking therapies to help him recover. He took several herbal medications and had various massage and acupuncture sessions. Once, he travelled all the way to the northern part of the country where he was told to bury himself from the neck down on the beach from morning to midday. The therapist assured him the heat from the sand would make his blood flow better and resolve the weakness he had. Even where they had attended a hospital or doctor, seeking healthcare from traditional healers – usually for massage, acupuncture or herbal medications– was commonly described by participants. Traditional healers offered the benefit of a longer consultation, empathy and were often located locally to participants' homes, despite having a higher cost than the public clinic (Klinik Desa, Klinik Kesihatan or hospital) doctors. Ayub was constantly reading and asking for information about stroke recovery. He showed me a book about stroke from an Islamic perspective; this is interesting as it speaks to the centrality of religion in the participants lives as discussed in chapter eight. While many knew the possibility of complete

recovery was limited, they were aware that improved physical functioning could not be achieved by doing nothing.

The stroke event stimulated the development of coping strategies targeted at dynamically altering the situation with an aim to maintain life as it was before the stroke or adjust to the consequences of the stroke (Darlington et al., 2007), which I discuss in detail in Chapter six. The stroke survivors developed these coping strategies to achieve a sense of continuity with their lives. Most participants emphasised the importance of accepting their stroke and associated consequences with the realisation that they may never get back to their pre-stroke lives. Having a positive outlook on recovery, turning to religion, persistent exercises and increased patience were described by most. They reported helpful, active coping approaches including engagement in activities, participation in rehabilitation exercises, ensuring healthy eating behaviours, and seeking information. Not all participants used these active strategies, and a few others had negative coping strategies, such as: giving up trying to deal with the consequences of the stroke (as in the case of Aisha discussed in the subsequent section), expressing negative feelings, and venting their emotions on the family.

Though the survivors hailed progress in well-being, they had to accommodate changes. Their improving motor function, albeit minimal, provided an upward trend in physical functioning which heightened their expectations of reintegration into society and their lives before its disruption. They wanted others to see and treat them as they had done before the stroke. The stable phase which is the post-discharge stage (from conventional or alternative care) is directed towards the regaining of lost or impaired physical and psychological functioning as well as the realisation of the impact of stroke on life. It is a period of rehabilitation and adjustment to the effects of the stroke. Challenges will unavoidably occur along the recovery path as stroke survivors may have oscillations between stability and instability which will require a reassessment and adaptation of strategies to promote coping as discussed in the next section.

The Unstable phase

In contrast to the relative control of the stable phase, the unstable phase reflects periods where symptoms of the condition are not under control or the reactivation of illness (Corbin & Strauss, 1991). The CITF describes the unstable phase as a period where the course of illness is not controlled but can be managed in an out-patient setting.

Participants went through these fluctuations, maintaining their family and social network. Participants in this study chartered through the unstable phase through experimentation and coping mechanisms that they had adopted over the course of the illness demonstrating the long-term nature of stroke. The unstable phase, as Burton (2000) suggests, presents when challenges either directly or indirectly associated with the stroke occurred. This period required a reappraisal of goals, limitations, and adaptation of interventions and strategies that promote a return to stability (Christopher R Burton, 2000). While several responses to these challenges are successful and a return to stability achieved, recovery may occur at some point decline.

The downward and dying phases

The trajectory framework outlines a downward trend, a time when physical decline characterises the illness course and accompanied by increasing disability. It is characterised by the occurrence of conditions of growing frequency often because of motor deterioration, infections and worsening risk factors such as high blood pressure and high blood glucose. The motor dysfunction caused by a stroke can worsen with persistent immobility or another stroke. Atrophy of muscle could occur from disuse which could lead to further difficulty in carrying out everyday life activities. Saif, a 66-year-old pensioner, had lived with stroke for 13 years. He depended entirely on the family for activities of daily living since the stroke. It had put a strain on the family as he gave up hope and refused to do any form of physiotherapy or even seek help

through prayers. His condition continued to decline. His lack of mobility gave rise to bed sores, pneumonia and atrophied stiff limbs. Eventually, he became bedridden due to atrophy of his lower limbs.

Participants could experience a period of depression or difficulty with coping with the impact of the stroke as is reflected in Saif's case. Aisha, a 55-year-old homemaker, lost the capacity to care for her home after her stroke five years back. This made her sad and frustrated. She would sit for hours on end in her wheelchair by a door overlooking the street, oblivious to the happenings around her. Her husband had to retire from his job to take on the responsibilities of the home. A former serviceman who believed in an active regimen, he was frustrated at her lack of will to live and to perform strengthening exercises. He was unable to motivate her. She refused medical care, would not have checks and would not take her blood pressure medications.

Now I don't eat any medicine. Lazy to take it. I am bored of taking medicine... Tired of taking medicine. Massage, I massaged for long, I stopped that too.... No effect. It's been a long time. I stopped that as well. Kept on massaging, but no effect or anything.

The deterioration in functioning for the survivors may be so severe that they become critically ill. Aisha's condition worsened over time. Her muscles became atrophied and stiff, and she suffered from constant headaches. She passed away a few weeks after my third visit to her. Saif died at home after a bout of a severe chest infection. Both Aisha and Saif had lost hope in recovery and in being functional to society. While it was clear that Saif's health was failing, it was unclear that he was approaching death. His wife recounted that he lost all zeal to live, he had stopped taking his medications and was not responsive to all suggestions to strive. Aisha felt she was a burden to her family and gave up trying to recover. This created a wedge between her and the family especially her husband. They fell into a vicious cycle of constant guilt and blame. This demonstrates the unavailability of support services to enable them weather through the recovery process.

At some point in time, a life trajectory will ultimately end in death. For some, decreasing physical functioning alluded to the end of life. Their deaths can be attributed to complications that may have risen from the stroke. Undeniably, for most participants, good health was maintained along the illness course. However, the impact of the stroke may remain with a person for life. This is relevant in that, having survived a life-threatening situation, the course of life of an individual alters and may persevere into subsequent illness patterns.

Trajectory projection and trajectory scheme

The trajectory projection identifies the illness course vision and is founded on knowledge, experience, and beliefs of those involved: the patient, family and healthcare professionals. The visualisation of the illness course fosters support, dispels uncertainty and identifies a decisive course of action to be taken, i.e. the trajectory scheme. Corbin and Strauss view the scheme as a plan *“designed to shape the overall illness course, control any immediate symptoms, and handle disability”* (Corbin and Strauss 1991: 163).

The conceptualisation of the trajectory projection and scheme is particularly important in the different phases. The projections of their condition determined the course of action they took to deal with the situation. The assumption and visualisation of stroke as a short-term illness led participants to seek and explore various treatment options with the expectation of full recovery. Over time, their conceptualisation of the illness as long-term led them to development of coping strategies and readjustment of goals to enable them to live life as best as possible within the limitations of the stroke.

The pragmatic application of Corbin and Strauss CITF can provide insight into the illness course of stroke taking into consideration factors that aid or hinder recovery, as well as the contextual elements of LMIC such as availability of diagnostic equipment and specialist professionals. The CITF can provide healthcare professionals with a

foundation to manage the circumstances of the illness as it unfolds, using individual, family, and community resources while fostering support to the individual.

Summary

I have endeavoured to apply the characteristics of stroke illness and recovery in an LMIC to an existing model of care in this chapter. The CITF offers a logical structure for the establishment of stroke recovery strategies as it takes into consideration an extensive array of contextual issues that affect the recovery path for stroke. This requires an understanding of the interdependence of the client and professional views of the illness that is grounded in the stroke survivors' pre-stroke lives, worldviews and health services. In the following chapters, I discuss the process that unfolds in the stable, unstable, and downward phases of the trajectory.

Chapter 5.

The impact of stroke

Overview

Most stroke survivors have some degree of impairment that affects motor function, language, social roles and cognition. These effects often exert a negative effect on the patient's quality of life. The occurrence of a stroke restricts the ability to perform basic everyday life activities, causes role changes and financial strains on households. Given the extensive impact of stroke on the everyday lives of survivors, coupled with current demographic and risk factor trends, stroke is predicted to pose a public health challenge in low and middle-income countries in the future, emphasising the need for a robust, cost-effective intervention.

This chapter, presented as an article, published (September 2018) in the journal *Disability and Rehabilitation*, offers insights into the adjustment process post-stroke, management of roles within families and identity over time. The participants report on their hospital experience following the stroke, the myriad feelings they experienced, their physical limitations and the impact on self-identity and life roles. The chapter provides evidence on how stroke affects survivors' lives and provide an understanding of the health services and community-level factors that affect stroke recovery in Malaysia.

Documenting the impact of stroke in a middle-income country



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Documenting the impact of stroke in a middle-income country: a Malaysian case study

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ABSTRACT

Purpose: Stroke is an abrupt event that often leaves survivors with long term disabilities, causing role changes, and financial strains on households. The profound impact of stroke on survivors may lead to a decline in quality of life due to the physical, psychological, and social difficulties they experience. Taking Malaysia as an example, this study aimed to explore the impact of stroke on survivors and how health services influence their recovery in low and middle-income countries (LMIC).

Method: An ethnographic approach with data obtained primarily through in-depth interviews was used. Twenty-seven participants identified as having suffered a stroke were drawn from a health and demographic surveillance system in Malaysia.

Results: The physical and social disruption of the lives of stroke survivors was intensified by the resultant financial constraints placed upon individuals, families and households, compounded by inadequate support from the health, and welfare systems. Despite the disruption to their lives, most participants were, at least in part, able to reestablish their lives through various factors that include a strong family support and active coping strategies.

Conclusion: In LMIC, recovery can be shaped by the family unit and through active coping strategies especially those in relation to spirituality.

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KEYWORDS

Stroke; low and middle-income countries; recovery; coping strategies; family support; health services

► IMPLICATIONS FOR REHABILITATION

- The impact of stroke on survivors and lack of specialized stroke care compromise the recovery process and quality of life for stroke survivors in low and middle-income countries.
- Support from the family and reinforcement of religious coping were judged to successfully aid recovery.
- Physical and emotional impairments as well as psychosocial wellbeing of survivors in the context of environmental factors need to be addressed.



Introduction

Stroke is an abrupt and life-changing event. Those who survive a stroke are often left with incapacities; some acquiring long term disabilities [1]. The wide range of physical, emotional, cognitive, communication, and social difficulties that often follow a stroke may prove overwhelming for some. The survivors are often left grieving for their lost lives and identities, frustration, and anger at being unable to carry out the activities they used to do and had once taken for granted [2–4].

Most stroke survivors have lingering neurological deficits that impair physical and social functioning in varying degrees [5,6], and which may make them dependent on others for basic daily activities [6–9]. The most common impairments include weakness of the limbs, cognitive impairment, aphasia, and urinary incontinence [10]. The ability to use the affected arm and difficulties with walking have been reported to be the most frequent physical dysfunction [10,11]. Aphasia has been reported to cause functional incapacity and high psychological distress [12–14] due to the difficulties in communication, the physical dependency on others, loss

of autonomy, negative feelings of irritation and anxiety. Depression and anxiety are two of the most common affective impairments seen in stroke patients, affecting about a third of stroke survivors [15–17]. Several studies have highlighted cognitive impairment as a long-term consequence of stroke, with prevalence remaining high over time [18–20].

The occurrence of a stroke has been shown to restrict the ability to perform basic everyday life activities, from walking to toiletting or performing prayers to carrying out house chores [21]. Stroke has been reported to cause role changes and financial strains on households. Prior studies conducted in high income countries (HIC) have described stroke as a traumatic event that disrupts life [22,23]. Bury (1982) characterizes the associated personal and social impacts following stroke as a biographical disruption that affects all aspects of one's life [24]. However, other researchers have suggested that it may not necessarily be a disruption and that the context in which the stroke occurs must be taken into consideration in defining the extent of loss and impact it has on survivors [25]. As such, it should not be assumed that

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the impact of stroke and any resultant disruption on the lives of individuals is universal. The influence of the broader sociocultural context of communities must come into play in understanding the impact of stroke and the recovery process [26,27]. Cultural and religious beliefs influence how people perceive traumatic life events such as a stroke. How the illness is perceived and beliefs about causation, diagnosis, and treatment are culturally defined and are crucial to how individuals experience a stroke [28,29].

The World Health Organization (WHO) projects that the Disability-Adjusted Life Years for stroke will increase to 61 million in 2020 from 38 million in 1990 [30]. This increase is due, at least in part, to increased rates of stroke in Low and Middle-Income Countries (LMIC) [31]. Yet specific country data on the incidence and prevalence of stroke in LMIC is limited and quite small in South East Asian countries [32]. The Malaysian Ministry of Health reports an increasing trend in total hospital admissions for cerebrovascular diseases [32], however data on incidence and prevalence of stroke is lacking.

Although research into the impact of stroke has been conducted, most of the evidence has been based on the context of HIC where health services and socioeconomic factors are different from those in LMIC. Lack of specialized stroke care, inadequate rehabilitation services, and lack of social support systems compromise the recovery process and quality of life for stroke survivors. There is a paucity of information regarding how stroke affects the lives of individuals and the specific needs of the stroke survivors in LMIC.

Given the considerable impact of stroke on the everyday lives of survivors, coupled with current demographic and risk factor trends, stroke is predicted to pose a public health challenge in LMIC in the future [33], thus emphasizing the need for a robust cost-effective intervention. To inform such interventions, an understanding of the lived experiences of stroke in a LMIC is necessary. Taking Malaysia, an upper middle-income country [34], as an example, this study aimed to explore the impact of stroke on the lives of survivors and how health services influence their recovery in LMIC. In doing so, it will provide evidence on how stroke affects survivors' lives and provide an understanding of the health services and community level factors that affect stroke recovery in Malaysia with the goal of informing health practitioners and health services in the design of appropriate interventions tailored to the needs of stroke survivors. Specifically, in this study, the recovery experience following stroke is explored from the survivor's perspective.

Methods

This ethnographic study was conducted at a health and demographic surveillance system (HDSS), the South-East Asia Community Observatory (SEACO), situated in rural peninsular Malaysia. SEACO is a multipurpose research platform that allows complex interventions and research projects to be undertaken in both health- and nonhealth-related areas [35]. The HDSS, works across a population of approximately 40,000 across five sub-districts in Segamat district (the detailed SEACO methodology can be found in a case study documenting the establishment of a HDSS in Malaysia [35]). Approximately 25,000 individuals that spanned all ages, took part in the survey. Participants were drawn from a population that were identified as having suffered a stroke or stroke-like symptoms through a question asking if they had had stroke or not. Sixty-four people who responded "yes" were then visited by the researcher. Twenty-one of these were identified as false positives (not stroke), 10 could not be contacted after

several in-person visits to their homes or via telephone, 5 refused consent for the study, 3 were too physically too ill to partake in the research, and 1 passed away before they could be approached for consent. Overall, 24 participants consented to the study. A further three potential participants were identified by key informants (HDSS community liaisons); all consented to participate. This resulted in a final sample size of 27 participants who took part in this study. The inclusion criteria for this study were that the respondents must have suffered a stroke, be living in one of the districts covered by SEACO and able to communicate; whether personally or through a caregiver.

Given our interest in the lived experiences of individuals following stroke and the influence of their broader social and cultural context on this, ethnography was deemed the most appropriate methodology as it is an effective way of obtaining comprehensive data. Data were obtained from in-depth interviews as well as through observation captured in field notes recorded by the first author. In addition, *talking mats* were used where appropriate as a participatory elicitation tool. This was particularly effective with two participants who had some degree of aphasia as they found it difficult to generate language. The *talking mats* were a clear, easy and straightforward way for them to communicate their thoughts. All interviews took place at the homes of the participants and lasted between 30 and 90 min per session; each participant took part in 2–3 sessions. Participants were invited to speak without restrictions about their lives with stroke and the transitions they experienced over time. A semi-structured interview guide was employed which gave a focus to the interview but gave the researcher opportunities to ask follow-up questions, thereby expanding on the responses provided. The interview schedule was a guide, to prompt participants into conversing about their experiences, and not all participants were asked the same questions as such, the direction of questioning changed depending on the flow of the conversations. Broad questions were asked during the interviews which included:

- Can you tell me about the day the stroke occurred? What were you doing?
- What do you think caused the stroke?
- What happened after? Where did you go?
- Tell me what happened at the hospital/clinic
- What did the doctors say caused the stroke?
- Before you left the hospital, what did the doctor tell you?
- Did you go to any other place for treatment?
- How has life changed since the stroke? Did the stroke affect your religious practices?
- Can you tell me about your daily routine?
- Is there anything else you would like to tell or ask me?

In cases where participants had memory lapses, family members (spouses, siblings, and children), who were present during the interviews, provided and augmented information. Caregivers, especially spouses, although not the central focus of the stroke narrative, had an influence on the story-telling as they provided spontaneous information on the overall stroke experience and were prodded further to provide clarity to their contribution.

Demographic data of all participants were obtained from the baseline data collected by SEACO and confirmed during fieldwork. The interviews were audio-recorded, translated and transcribed. Using Braun and Clarke's (2006) approach to thematic analysis, the information was sorted, coded, and grouped [36]. Transcripts and field notes were read repeatedly to obtain an overall sense of the data in respect to the research questions and codes assigned to salient aspects. A second level of coding formed categories

which were then organized into themes. Initial themes that echoed significant meanings across the respondents' stroke experience were identified and grouped into subthemes. These were then condensed to form main themes. The data in each transcript was explored in relation to themes across different interviews for individual participants and against the cohort of all 27 participants. Finally, the identified themes were organized and reported as a chronological narrative based on the order of events, i.e., events surrounding the occurrence of the stroke, immediately after the stroke, and weeks/months/years after the stroke. The interpretation of data presented was conceptually derived from the themes identified. The quotes highlighted in the paper reflect the true experiences and insights of the participants, however, as with all qualitative research they are not representative of a larger population and thus cannot be generalized to other populations.

Monash University Human Research Ethics Committee provided ethical approval for the study (CF14/315– 2014000105). The study purpose and nature was explained to the participants and consent to participate was obtained verbally from each participant prior to commencing the study. Caregivers provided consent for participants with communication difficulties or memory problems. Privacy and anonymity of participants was upheld using pseudonyms in reporting the results of the study.

Results

The sample population comprised 27 individuals; 21 males; and 6 females and were aged between 37 and 83 years. Time since first stroke ranged widely 2 months to 32 years. Spouses were the principal caregivers. See Table 1 below.

Three core themes emerged from the data; all were related to aspects of time (1) The trauma, (2) Altered life, and (3) A new life. See Table 2 below. In reporting the results, "all" referred to all 27 participants, "many or most" referred to 70% and above of the participants, whilst "few" referred to 30% and below. In some instances, exact figures are given.

The trauma

The stroke event

A stroke is an unexpected event for most individuals and their families, and left them in shock and disbelief. For many, this disbelief was compounded because it did not seem to make sense given the previous messages they had received from health professionals. Shuaib, a 68-year-old man who is 11 years poststroke, described his shock at the stroke despite his attendance at clinics. He had described he regularly sought health care:

I was healthy, then suddenly I became like this [had stroke]. Ah, they said it's about diet, but I didn't simply eat anything, I watched my diet. I took all sorts of medications and went to all sorts of hospitals. Every year, I go for check-ups at the hospital.

His comments were especially illuminating given his lifestyle risk factors; he had been diagnosed with high blood pressure and smoked regularly.

Similarly, Yusuf, a 59-year old man (8 years poststroke) who was sturdy, lived an active life but suffered from high blood pressure and high cholesterol laments: "I was a building constructor. I sweat every day! People say I shouldn't have had stroke. I sweated a lot, worked hard; running, walking, carrying heavy things. But I still got the stroke". For Yusuf, the occurrence of stroke made little sense in the broader context of his active lifestyle – which he equated to healthy living.

Table 1. Demographic characteristics of study participants.

Variable	Frequency (%)
Gender	F: 6 (22.2) M: 21 (77.8)
Age (years)	30–39: 1 (3.7) 40–49: 3 (11.1) 50–59: 8 (29.6) 60–69: 9 (33.3) 70+: 6 (22.2)
Ethnicity	Chinese: 3 (11.1) Indian: 4 (14.8) Malay: 20 (74.1)
Religion	Islam: 20 (74.1) Christianity: 1 (3.7) Buddhism: 2 (7.4) Hinduism: 3 (11.1) None declared: 1 (3.7)
Years of stroke	≤3: 12 (44.4) 4–10: 9 (33.3) 10+: 6 (22.2)
Stroke type	Ischemic: 26 (96.3) Hemorrhagic: 1 (3.7)
Number of strokes	1: 22 (81.5) 2: 3 (11.1) 3+: 2 (7.4)
Marital status	Single: 1 (3.7) Married: 25 (92.6) Widowed: 1 (3.7)
Primary caregiver	Spouse: 25 (92.6) Daughter in law: 1 (3.7) None: 1 (3.7)
Education	No formal: 2 (7.4) Below tertiary: 24 (88.9) Tertiary: 1 (3.7)

Table 2. Core themes and associated sub-themes.

Core theme	Sub theme	Contents
The trauma	The stroke event Hospital experience	Suddenness, nature Short stay, lack of information, feelings of dependence and shame
Altered life	Impairments Emotional reactions Financial burden	Physical and practical difficulties, lost identity Anger, frustration
A new life	Coping strategies Progress Support	Accepting, adapting, turning to religion, venting Self-initiative Family, friends, community

Most participants could recall in detail how the stroke occurred, largely because it presented a starting point to the interruption of their lives. In all cases, the stroke event was associated with a physical symptom; weakness or paralysis of a limb, facial deviation, or slurred speech. Ma'aruf, a 72-year-old man, at 16 years poststroke, described his stroke: "It was around 2am, I wanted to go to the toilet. I couldn't get up. I called out. I thought I was speaking loudly, but no one could hear me. I felt myself yelling, but no sounds came out. My mouth was deformed, deviated to the side". His account highlighted the trauma of the stroke event itself. The sense of helplessness he described speaks to the fear and distress he experienced at the moment of the stroke.

Hospital experience

Many participants were hospitalized after the stroke event. This served as a point of reference to recount their hospital

experiences. The hospital experience was different and personal to each survivor, although they all shared a common perspective: it was frustrating, uncertain, and emotionally upsetting. Delays in receiving care were common. Abdullah's caregiver, Kamila, described the experience after his stroke:

It was in the evening, he wanted to get up for prayers but couldn't.... We took him to the hospital. The doctor was slow, slow, yea, very slow until 2 o'clock in the afternoon. Only then did the doctor admit him to the ward. He could speak, could still speak, just that he couldn't move. Doctor was slow in attending to him because they thought it wasn't critical.

Key to this account was the idea that the bodily signs associated with stroke for Abdullah (aged 79, 2 years poststroke) were not indicative of a serious illness. Such delays in receiving formal care were traumatic for both the person with stroke and their caregivers because of the heightened level of worry they felt.

The survivors reported a feeling of uncertainty, which they attributed to insufficient information about the cause and circumstances of their stroke. They felt their stay in hospital was very short and no adequate recovery plan was put in place. Thus, many sought traditional medicine:

We spent 4 days in hospital, did X-ray and all. They said nothing is wrong.... They checked whether there are any blood clots, none. They sent us home. So, we went for traditional medicine. (Ma'aruf, aged 72, 16 years post-stroke)

[I was in hospital] for 3 days only. They discharged us and we tried traditional medication. The doctor only said to do exercises. (Razak, aged 76, 15 years post-stroke)

Although exercises are an integral part of stroke rehabilitation, this was not clearly explained to the participants. There was clearly limited information provided to most of the respondents on the impact, type, and frequency of exercises to perform, yet all expressed a desire for recovery – traditional healers offered an option to meet their needs.

At the same time, participants' hospital experiences were characterized by dependence. For some, such as Ayub aged 48 at 5 years post stroke, the sense of shame he felt when he needed help with toileting further added to his distress:

I couldn't do anything. Just kept quiet. They ask us to take the medication, I took. Change clothes? How? I have stroke? Can't do it. They (the nurses) help with changing of clothes or other things.... My recommendation, [is that] the wife or husband should stay and take care of the person. It was 7pm. My wife had already gone home. I wanted to go to the toilet, I couldn't. I called out to the nurses for help but I was ashamed. Shameful.... Let the wife take care of me.

This loss of privacy was of concern to the stroke survivors due to the personal nature of toileting and their particular location in a cultural environment where religious norms restrict personal contact between males and females. In addition to the loss of privacy, many participants discussed the burden they felt they placed on others when requiring assistance with toileting as it was physical and difficult. This burden with assistance extended beyond the hospital environment, as most respondents needed help with mobility in the home.

Altered life

Impairments

Recovering from stroke greatly impacted on the survivors' lives at an existential level. The physical and practical aspects of having to live with an altered body was a challenge for most. All respondents described the impairments and limitations that

resulted from the stroke. The impairments varied between respondents; they included problems with mobility, weakness of affected limbs, problems with gait, audition, memory, speech, and concentration. For many survivors, the complex mix of issues compounded their distress as in the case of Hanif, a 74-year-old man (4 years poststroke) who was unable to walk, experienced weakness in his right arm, fatigue, and hearing loss. He, like other respondents, discussed the initial changes that resulted from the stroke and how his life has been altered:

[It is] hard to move this leg (patting the left leg). Stiff. When I got it, I went to the hospital. They said it was minor stroke. They said it's nothing much but this is tough. The pain is all over. It is difficult for me to even speak. It is even difficult for me to lift this (left) hand. I cannot walk at all. I cannot even hear you clearly. Now it's the eyes. I sit down for prayers. I cannot walk. I sit down to bath. I do everything sitting.

His spouse further explained that he used to read the Qur'an to alleviate his worries, but with declining eyesight, he was no longer able to. This created further distress for him, making him lose hope in recovery.

Mobility

All survivors conveyed mobility difficulties. Losing control over a leg was incapacitating as it restricted movement leaving some survivors confined to a room or only able to move with the aid of a wheelchair or when carried by family members. Others resorted to using a cane or walked with a limp. Participants who were no longer independently mobile felt a sense of being trapped as Husna, a 65-year-old woman (5 years poststroke) reported: *"I just sit here until I am bored."* At the same time as this boredom was derived from Husna's poststroke immobility, it also impacted upon her capacity to engage socially, and thus impeded her recovery.

Such implications of the difficulties in mobility did not impact on the stroke survivor alone, but affected the family as a whole, as changes to the physical environment often had to be made. This could clearly be seen in terms of toileting, especially where people lived in older homes and had external toilets. For example, Chuanli's (aged 83 years, 2 years poststroke) home had a toilet in the backyard but his son, Andy, worried that he might fall when going to use the toilet outside, improvised with a bucket in the nearby kitchen where Chuanli could relieve himself. Although Andy emptied the bucket often, he complained that it was not hygienically suitable yet recognized that it was a compromise they needed to live with to ensure Chuanli's safety. For other participants, difficulties around toileting due to immobility led to further challenges in terms of continence management: Saif (aged 66 years, 13 years poststroke) was rendered bed-bound and uncooperative after the stroke. He was often left soiled for long periods which, left a terrible stench in his bedroom and surroundings. Similarly, the loss of functionality of a limb, albeit partly, meant that everyday taken-for-granted activities had become cumbersome for the survivors. They had to rely on their caregivers for activities such as feeding, toileting and dressing, emphasizing the feelings of dependency in some.

Family members made considerable efforts to accommodate the stroke-related impacts. Kamila reported that they had to reorganize their living arrangements to make it easy for her to move Abdullah about. Husna's spouse explained how he had to construct a new bed and adjusted the bedroom to assist his wife. He raised her bed with concrete supports and moved it to an opening he had made in one wall of the bathroom. He placed

a bench inside that she could slide onto with less difficulty and have access to the facilities with ease:

We custom made this bed [gesturing towards the raised bed his wife was on]. That [other bed in the room] over there, was too low, she couldn't get up. Difficult for her to get up. This one is directly accessible to the toilet. I made this for her... if she wants to go to the toilet, she can just hold onto the handle and get into the bathroom on her own. You don't have to carry her. She can hold onto the metal grip and move. The bed has to be high.

Using an assistive device such as a wheelchair or cane, by some disrupted their daily activities as there was a lack of spontaneity and a lot of planning was needed [37]. Husna, Saif, and Abdullah depended on family members to move them about creating a sense of helplessness and of being a burden to the family.

Social activities and identity

Study participants all found that they were unable to perform some of the activities they used to, especially in the early weeks and months poststroke due to their physical impairments. Participants who used to drive a car or ride a motor bike could no longer do so, limiting their freedom and ability to partake in social activities outside the home. The six women in the study all discussed how they were unable to perform their usual household chores such as cleaning and cooking. This sense of loss extended to identity. Husna felt she had lost her identity as a homemaker as she was no longer able to perform any activities for the home. She found it difficult to accept her inability to fulfill the responsibilities of a wife and mother, principally because she had raised nine children and never relied on anyone for help. Participants who were employed lost their jobs. Hanif, aged 74 (4 years poststroke), who was an *Imam* (Islamic leader), at the community mosque for close to 20 years felt resentful. He recounted that the stroke has stripped him of his calling as an Islamic leader. In some instances, it was the prospect of being seen with a changed body by the outside world that created a sense of lost identity, shame and feelings of inadequacy. Ayub (aged 48, 5 years poststroke) felt so ashamed of being seen with his impairment that it took him 2 years to attend prayers at the mosque close to his home: "At first, I didn't tell anyone, I told my wife not to tell anyone. It's shameful... Long time I didn't go to the mosque, when I wanted to go, I felt ashamed."

The sense of shame was exacerbated by accompanying changes in social participation. The participants elaborated on their social network, with most admitting it had waned over time. Many attributed it to the difficulty in getting out due to their physical impairments. They could no longer visit friends or attend functions as they used to. Razak (aged 76, 15 years poststroke), for example, felt his impairments limited his social interaction: "When people have weddings or funerals, I couldn't attend. The body cannot take it". He spent most of his time at home as he found it difficult to climb stairs whenever he had to go out. Ibrahim (aged 60, 32 years poststroke), wheelchair-bound since the stroke, described his isolation: "[After the stroke] I can't work, can't even walk. I just stay home. Once I went to my village, to visit. Stayed for a day and returned". His caregiver added: "[He is] disabled, cannot travel for long. Difficult to use the toilet. Needs this and that". Ibrahim wasn't alone in this. Musa's caregiver related: "He used to go out a lot. Now he just stays home. If he didn't get the stroke, he can visit his farm, can go to his stall, to his other house. His [other] house isn't far from here". Transportation was a major issue as most were unable to walk long distances, drive, or ride a motorcycle. They felt they would be imposing on others by

asking for help or their time, and so preferred to stay home than create a burden on others.

Communication issues

Communication, concentration and memory are often disrupted, especially in the early phase [38]. Participants with communication difficulties reported the frustration they felt when trying to communicate and all respondents reported varying degrees of aphasia. When asked if his family members could understand his speech, Yusuf explained the challenges he faced in learning to communicate after his stroke:

Sometimes they understand, sometimes they don't. I know what I am saying, but they don't understand me. 'What is he saying', they keep asking? Speak slowly, little by little. It took me one and a half years to speak comfortably, for people to understand me.

Three participants also presented with receptive aphasia, which is concerned with understanding, as confirmed by their caregivers. Two participants also had dysarthria, which affects the speech mechanism making it difficult to comprehend. Many of the stroke survivors were left with perceptual difficulties in varying degrees. These included an inability to sustain concentration, recall information, and mental sluggishness. Fatigue and pain also affected the ability to take information in and stay focused. Apart from the five participants who had communication difficulties, two participants displayed poor word finding and slow thinking. David (aged 44, 3 years poststroke), for example, had several pauses during the interview. It took him a while to comprehend what was asked, much longer to respond, and he found it difficult to find the right word. Abdullah presented with severe short-term memory loss. During the interview, he would repeatedly ask the same questions, even though they had been answered before. His wife confirmed that since the stroke, his memory had been affected. He could recall events and people from before the stroke but found it difficult to take in new information since the stroke. Despite this, none of the participants obtained cognitive or neuropsychiatric assessments, and no family members recognized their cognition poststroke as problematic.

Impaired family relationships

Relationships within the family were also often transformed both directly following a stroke and as a result of its emotional affective impacts. Spouses and children had to assume the role of caregivers and in most cases, survivors alluded to the fact that roles within the household had reversed, with spouses, and at times with their children. Several had been the support providers for their families but now received such support. Chuanli was the caregiver for his wife who suffers from dementia. Due to his stroke, he was unable to care for her and his son had to take over the caregiving responsibilities of both parents. Spouses and children had to give up work or other activities and, in some cases, relocated in order to provide care to the stroke survivor. Chuanli's son, who was living in another city, resigned from his work and relocated to care for both parents when his father had stroke. Family members took on the new role as breadwinner or homemaker. Maryam's spouse summarized these shifts in social roles when he said: "I didn't used to cook. Now I've become the 'mother, wife'... I do all sorts of things now, boil water, cook the rice". His caregiving was of questionable success as the physical environment of the home was in total disarray; dirty dishes that had been left for several days were visible in the kitchen, carpets were stained with food residue and livestock feces, and flies were everywhere. Maryam kept a deodorant spray nearby, which she used to mask the stench in the house. When asked why the

home was in a such a state, Ihsan, lamented that he couldn't cope with the role changes. He relied on the children to clean the home whenever they came to visit.

In most instances, the daily activities of the home seemed unaffected by the stroke. Rather than being created, roles were adjusted. In Yaqub's home, his daughter would cook breakfast and lunch early in the morning before setting out for school. His spouse, having more time as she didn't have to cook lunch, concentrated on doing other household chores, and looking after him and their granddaughter. Shuaib, a widower, had his children take turns bringing lunch and dinner for him which they had cooked in their homes. For Shuaib's children, this activity was not out of the ordinary, as they used to cook for him when they lived with him. Abdullah, a father of 10 children, who was retired at the time of his stroke had been supported financially by all his children since his retirement. Following his stroke, his caregiver reported that each child contributed more financially than they did before the stroke.

Changed religious activities

Religious practices were often affected by the stroke due to motor weakness. All of the Malay participants reported that the way they performed their *salah* (prayers) had changed following the stroke. Rather than stand and sit during the prayers, they performed the entire *salah* in a sitting position. Others had stopped going to the mosque for prayers because of their difficulties in getting there and in keeping up with the prayers. Yusuf, (aged 59, 8 years poststroke), whose children were all living elsewhere, explained:

I cannot go for Friday prayers at the mosque. I do it at home. No one to take me, it's far. Furthermore, I have to climb the stairs. His caregiver, Nazifa, added: At the mosque, you have to keep up, you have to be very fast. It requires you to sit and stand, sit and stand. Difficult. With prayers, you have to go down quickly, cannot be slow.

Despite the effect of the stroke on their religious activities, the participants continued with their obligations at their homes. Family members provided opportunities for the stroke survivors and aided them in performing their *salah* at home.

Emotional reactions

Many participants reported negative changes in emotional states, which they acknowledged as unanticipated and undesirable. Feelings of frustration ultimately led to anger when they were incapable of expressing themselves or carrying out activities they wanted to. The feelings of anger and frustration are often directed towards family members. Maryam's spouse explained that she had turned out angrier, impatient and more frustrated since the stroke. When asked about the changes he saw in her, Ihsan, responded: *"Yes, big changes. Different from before the stroke. She is short-tempered now. If she wants something, she wants it fast. She wants it instantly"*.

In a few cases, depression often set in over time, especially when progress in their condition was not visible, slow to come, or when they had unmet needs. Four participants who saw no progress in their recovery described feelings of loneliness in their lives. They had lost all hope in recovery and appeared incapable of communicating the psychological impact of the stroke to others. For example, Safiya (aged 59, 4 years poststroke) stated that she was awaiting death. Her arthritis and asthma had impeded her ability to perform exercises, and she spent most of the day sitting on the floor. Similarly, Saif no longer prayed for recovery, as he didn't believe he would recover. Despite being relatively young at 55 years, Aisha who is 5 years poststroke,

would sit on her wheelchair all day staring at the street through the sliding doors, talking to no one. Although her husband and youngest daughter were there to provide her with practical support, especially in terms of mobility, she seemed completely devoid of emotions. She refused medications, checkups, and would not perform exercises. She had become completely detached from the family and the outside world. Her spouse's responses to questions asked were expressionless, devoid of empathy. The atmosphere within the home seemed to reflect that of emotional neglect. The emotional effects of Aisha's stroke not only affected her, but also profoundly impacted on her spouse, causing distress and affecting the family dynamics.

Financial burden

As these role changes suggest, stroke can impact heavily on a family's income. In cases where stroke affected the breadwinner, the family experienced sudden changes in income level that they were not prepared for. A few survivors returned to work; however, this was often not to the same jobs as they had before. In many cases, the stroke also necessitated changed roles for the caregiver, leading to impacts on income that were also felt. Some caregivers had to give up work, change jobs or reduce their working hours due to caregiving responsibilities. Similarly, the costs of caring for a stroke survivor sometimes exhausted family resources; subsequently, the family would run out of resources for postdischarge management. For example, Chuanli stopped going for traditional acupuncture and massage because it was too expensive even though it gave him *noticeable improvements*: *"At first I used to go, now we can't afford it, can't go. Very expensive. Couple of tens each time"*. This meant that he had to give up an effective rehabilitation intervention, and necessitated the development of strategic ways to take charge of his recovery, as discussed below.

The connection between lost income and family responsibility was reiterated by Umar (aged 56, 5 years poststroke). He lamented his inability to fully care for his two children, who had mental disabilities. Although they received free health care from the state, he had to pay for the son's education at a special school which he found difficult:

I am waiting for my EPF (employee provident fund; a social security fund), [it will take] another two years before its ready. When I obtain the money, I will set up a business. I used my wife's EPF now to settle debts, a little for food. Now I can work and earn a little, I use the money to pay rent, clinic. I am waiting for the money to be available, for my son's education. He is also OKU (disabled), a slow learner... he goes to a special school.

Many of the participants were receiving welfare from the government and other organizations. However, they all complained that it was meager and not enough to sustain them. Yusuf felt his financial situation had improved after the stroke which he attributed to having to do less:

Before I had stroke, my financial situation was much more difficult. Now I can do whatever [I want] and have no debt. No debt now, [I] have some savings. Our children give us money... I can save... Just two of us (pointing to wife), we don't need much for living. We don't do much, don't go out much.

The stroke had forced him to stay home and therefore spend less on moving about. Such an experience was however uncommon.

A new life

Coping strategies

Following stroke, participants were compelled to discover a new self. This included finding ways to adapt and discovering

strategies with which to cope. The stroke survivors talked about accepting the stroke as a part of a new life for them, the progress they made and the support they received to help them on their journey to recovery. Over time, survivors learnt more about their bodies and limitations. This led to an understanding that an optimistic attitude was essential in overcoming their challenges and enhancing recovery and wellbeing. In doing so, they developed coping strategies to enable them adapt to the stroke and carry on with everyday life. Several strategies were used by the participants, including acceptance, emotional support, and comparison with other. In particular, some felt that turning to religion helped in ameliorating the difficulties: *"Pray, after salah, ask for blessings. Each of the five daily salah, ask for blessings, ask Allah to heal the sickness. [I] recite the Quran after magrib prayers... In Sha Allah, (by God's will) it really can help. It can help remove, forget all the negative thoughts"* (Yaqub). For most of the participants, spirituality had a significant impact on their recovery. They discussed making supplications as a way of accepting their condition through surrendering to the will of Allah. They also discussed reading the Quran, supplications, and praising Allah as a way of warding off negative feelings. Performing the *salah* was of paramount importance to them despite having to perform it lying down or sitting, as they considered it a crucial pillar in their religion. Without *salah*, they would not benefit from Allah's mercy; accordingly, it gave them hope for recovery.

Comparison with other stroke victims was another strategy used by some of the participants. Razak, who had stroke three times, drew strength from knowing he was better off than others: *"Our fate is different from others, although we are all human beings. There are others who are far worse than me. There are people who cannot walk at all, eating is difficult, but I can"*.

Progress

Moving on from the initial shock of the stroke, participants spoke about the progress they had made. All except three participants believed they had achieved significant progress in physical function since the stroke and initial impairments. For example, Anika (aged 51, 6 months poststroke) talked about how she could now walk with the aid of a tripod cane despite being immobile following the stroke: *"I couldn't walk at all initially, now I can walk with this (the tripod cane) I can move about the house even when my husband is not around"*.

In contrast, Aisha was adamant that she made no progress in the 5 years since the stroke: *"Now I don't eat any medicine. Lazy to take it. I am bored of taking the medicine... Tired of taking medicine. Massage, I massaged for long, I stopped that too.... No effect. It's been a long time. I stopped that as well. Kept on massaging, but no effect or anything"*. Aisha, observing limited functional progress, perceived her condition as beyond her control. This led her to abandon hope and active coping strategies. Husna, who also perceived limited progress, explained that there was no progress and in fact, had gotten worse: *"No changes at all, getting weaker. [my body] is getting weaker"*. Abdullah's caregiver, Kamila, related his lack of progress to the severity of his stroke, his frail composition, and old age. His caregiver had no expectations of him achieving much motor functionality:

He is already 80 years old, what else does he want? He just needs to rest. He doesn't have to earn money, he can do his salah whilst sitting, he can pass feces in the diaper. If he can walk, it means we have to monitor him constantly. If he falls in the toilet, someone like him, his bones will break, because he is weak. Its better he just lies down and we take care of him.

Self-initiative was mentioned by most of the participants [37]. They took charge of their own recovery and rehabilitation by performing physical tasks within and around their homes. These included activities such as walking around the compounds of their homes or on the street, and sweeping the patios. Ma'aruf's spouse, Bilkis, explained how she made him perform household chores: *"I gave him work to do, like sweeping the rubbish, watering the plant. To move his hands. Otherwise the hands will just sleep. He sweeps the floor indoors and waters the plants. That's his job. Outdoors, he weeds the plants too"*. Through doing such tasks, participants kept active and engaged in life, if only at the household level.

Others devised ways to exercise their limbs using household equipment. Chuanli had a contraption hanging from the ceiling which his son had made to help him exercise his arm: *"We did treatment, this one (pointing to the contraption). Do it yourself. If you have to go for professional treatment, need money, this one, free of charge, made it ourselves"*. Maaruf converted an old baby hammock used by his grandchildren into an arm exercise devise. Similarly, Ibrahim, who was wheelchair-bound, ingeniously converted a sofa in his home into a wheeled chair, as his initial regular wheelchair was too light and not suitable for his needs [37].

Support

In realizing this new life after stroke, family support was highlighted by all the participants. They all felt the support they received from family was vital to their recovery and most emphasized that it would have been difficult without the support of their spouses. David mentioned how he appreciated his spouse more after the stroke because of how she took care of him. His in-laws were also of great assistance as they provided David and his family with shelter when he lost his home due to loss of employment following the stroke. Ayub had tears in his eyes and smiled when he related how his wife would scold him when he refused to perform his exercises: *"She was my strength, my motivation"*. For Ayub, his wife was a locus for love and encouragement, the person who provided him with personal care, helped with and, reminded him about exercises. She made him feel valued. Abdullah, who had severe aphasia, didn't speak when he was asked who gave him the most support, but he turned his head towards his spouse and smiled. The family proved to be the bedrock of the recovery process for most.

Discussion

Our findings demonstrated that the journey to recovery is different for everyone; however, there were common overarching themes that resonated between our participants. Stroke significantly impacted on a survivor's way of life, encompassing the onset of the stroke, the altered life, and an attempt to embrace a new life. This impact enabled a change in lifestyle and a discovery of a new way of life which facilitated embracing the changes and limitations brought on by the stroke. This corresponds to existing research by Doolittle (1991) and Burton (2000) who ascertained that recovery from stroke involves adapting and restructuring most aspects of one's life [39,40]. The impact that stroke had on the lives of survivors were widespread and included physical, practical, psychological, and financial difficulties. For most of the survivors, recovery was an ongoing learning curve. In this study, while we categorized the impact of stroke into themes, these themes did not exist in isolation, and were often interrelated.

The occurrence of the stroke was significant for most survivors as it represented a break from a familiar world as a functional

and independent individual, a notion that mirrors Bury's (1982) concept of a biographical disruption [24]. The physical and social disruption of the lives of the stroke survivors was intensified by the resultant financial constraints placed upon individuals, families and households, and was made harder by the inadequate support from the health and welfare systems. Despite the disruption to their lives, most of the participants in this study were, at least in part, able to reestablish their lives through various factors that include a strong family support and active coping strategies. Most could recall in detail how their stroke had occurred and felt a need to have their story heard, as few had told their stories, except to some family and friends. They felt relieved to talk about their stroke experience and the impact it had on their lives. This point is particularly significant as it highlights the importance of listening to experiences of patients, which Koch (1998) describes as therapeutic [41].

The unexpected nature of the stroke had most participants surprised at the diagnosis. This was compounded by a limited awareness of stroke, which included stroke prevention strategies, knowledge of risk factors and stroke warning signs and symptoms. This finding has been reported in prior research conducted in both HIC and LMIC where knowledge of stroke risk factors is generally low among the general population and in those that have had stroke [42–44]. This low level of knowledge creates a health risk, as it likely hinders efforts aimed at preventing stroke, reducing mortality, and morbidity from stroke. With preexisting knowledge about stroke, individuals may change to healthier lifestyles as several stroke risk factors are modifiable [45]. Likewise, knowledge about the warning signs and symptoms will lead to earlier presentation at a health facility that may in turn result in better outcomes for the individual [42,46]. Kernan and colleagues (2014) report that delayed arrival at hospital poststroke is a major factor in the failure to administer thrombolytic treatment within the appropriate time frame of 3 to 4.5 h [47] which negatively affects outcome. The extent to which this can be realistically achieved in LMIC settings requires interrogation, especially given the accounts of the present study's participants.

In addition to delayed admission, participants felt that the care they received at the hospital was lacking. This is consistent with the findings of prior research where participants identified difficulties with inpatient stroke care and a lack of longer term contact [16,48]. Research conducted in HIC highlight that often, stroke patients are admitted as emergency cases and receive a multidisciplinary approach to care during in-patient rehabilitation. Also, research in HIC prove that rehabilitation services, both in-patient and out-patient improve functioning in stroke survivors (Walker, 2007). This contrasts to the findings in this study and studies conducted in other LMIC where stroke patients receive minimal emergency response and even less rehabilitation services [49]. It is important to note that there is limited information about the quality and availability of rehabilitation services in LMIC and can be attributed to inadequate resources and management of stroke in these countries [49,50]. Participants' dissatisfaction with services were primarily due to unmet needs. In particular, the survivors were dissatisfied with the minimal information they received about stroke, including its causes, consequences, and prognosis. Similarly, they were dissatisfied with the lack of a rehabilitation plan and consequently felt that the health system left them to navigate through their recovery alone. This finding has been documented by a study conducted in South Africa revealed that on discharge, stroke survivors had limited functional independence and were sent home with inadequate support [51].

The same study also highlighted that community based rehabilitation services were lacking [51].

The loss of bodily functions and restrictions imposed by the stroke were strongly communicated by the participants. The lingering effects of the stroke, including the restrictions in mobility, did not only encompass the difficulty of moving from one place to another, but importantly, it affected their entire routine of daily living. For the participants, carrying out basic activities such as going to the mosque, visiting friends, or doing house chores was a challenge. This led to some becoming socially isolated from the outside world. Previous research has discussed social isolation after stroke [16,52] which could be further compounded by the perceived stigma of the stroke [52,53]. Our study revealed that although most of the survivors had some social interactions outside the home, they all experienced a decline in their social network due to feelings of shame, loss of interaction through recreational activities and employment. For most, this isolation and inability to carry out simple tasks they used to do, crushed the perception they held of themselves. The women in the study felt that, apart from the housework not getting done, they had lost control of their domain and what defined them as women. A study on the experience of stroke in low socioeconomic areas of South Africa revealed similar issues as identified in this study [54]. Stroke survivors had challenges that included loss of community mobility and social isolation [54]. Another study in The Gambia found that stroke survivors lived an isolated life with less than half attending social or religious gatherings [55].

This impact on social roles also led to participants questioning their contribution to the household, and speaks to broader literature on participation and wellbeing [56]. Several participants felt that they have become a burden as they are deeply cognizant of the impact the stroke has had on their families. Role changes often occurred with the family, from being an independent, equal partner to being dependent on a spouse, from being the caregiver and parent to being cared for by children, from being the breadwinner to being one who received support. Inability to meet the expectations of the home had a negative impact on self-worth. Similar findings have been reported in other LMIC where role reversal within the family impacted on their feelings of self-worth [54].

Owing to limitations in rehabilitation services, the family assumed an even greater role in providing care for the stroke survivor. This is especially notable in LMIC settings, where health resources may be constrained [57]. Despite the limited information about stroke, caregiving and what to expect, as well as lack of support provided by the health services and limited financial resources, the families embraced their caregiving role with acceptance and showed massive resilience. Care of the stroke survivor and maintenance of the family was considered a responsibility of the whole family, whereby members contribute by providing practical, financial and emotional support. This devotedness to the ailing individual and sense of cohesion of the family exemplifies the strong family unit in the Malaysian culture [58]. The family buffered the disruptions posed by role changes by assuming roles once held by the stroke survivor or other family members. As Kirkevold (2002) described, new roles were created within the family structure however in this study; rather than recreating roles, the family reinforced and adjusted to already established roles [59]. Spouses, daughters, sons and in-laws took up more active roles to maintain the family unit and establish a sense of cohesion by contributing more practically, financially and emotionally. However, this shifting of care into the home itself devolves the government of some responsibility in the delivery of

health care and related services [60], and creates considerable emotional and practical work at the household level [61].

The loss of employment, and accompanying loss of income, was shattering both for the survivor and for the rest of the family. Garbusinski and colleagues (2005) highlighted loss of employment in stroke survivors with less than half resuming a paid job a year after the stroke [55]. When individuals became ill, financial obligations did not stop. In most cases, the financial obligations were amplified due to increased medical bills, and were required to make tough decisions on how to economize and live. Maleka and colleagues reported that financial difficulties as a result of the stroke were a threat to livelihood of stroke survivors of low socioeconomic status in South Africa [54]. Similarly, this loss of income further enhanced the feelings of dependency. Because most of the respondents had low educational levels and were employed in low level, physically demanding jobs, they had limited prospects of alternative employment poststroke which may necessitate adjusted tasks and environments. The literature argues that stroke survivors in low level, physically demanding jobs were less likely to return to work poststroke due to several factors, including a need for modifications to accommodate them and transportation difficulties [62–66]. Stroke impacts substantially on the economic status of families [67]. A large-scale survey in China found that stroke led to catastrophic spending for most households [68]. In LMIC, although such large-scale surveys have not been conducted, it can be deduced that stroke would cause even more catastrophic expenditure. This can be attributed to the high cost of treatment for stroke [49,69] and the reduced earning capacity of survivors with disabilities. This is particularly worrisome in LMIC where health care in general is expensive and majority of persons do not have health insurance [70].

Participants in our study experienced emotional difficulties, particularly frustration due to a decline in abilities. This decline lead to a dependence on others for everyday functioning and a perceived sense of burden on the family. As Pound et al. (1998) highlighted, communication difficulties, which were commonly experienced especially in the early phase of the recovery path, proved to be time-consuming and a source of frustration to most [71]. The fear of not being understood and the physical effort it took to communicate caused some survivors to withdraw and exclude themselves from the larger network. The physical losses, negative emotions, social isolation, and overwhelming reality of the stroke led some participants to depression. This is not uncommon in stroke, as prior studies have highlighted that about a third of patients present with depressive symptoms at some point after its onset [15]. Murphy (1982) and Glamcevski and Pierson (2005) attributed depression after stroke to a loss of physical health and function and an inability to return to prestroke activities [72,73].

Despite these impacts, the stroke survivors in our study devised creative ways of performing rehabilitative activities at home and took up active roles within the house. Others adapted their assistive devices to suit their needs. These findings extend those of Pound and colleagues (1999) who suggested that survivors were ingenious in managing their activities of daily living [74]. This ingenuity was evident through the coping strategies employed. Motivating themselves by comparing their situation with other stroke survivors increased participants' empathic capacity, giving them a perspective of their own condition. Acceptance and optimism are considered assets for recovery.

Stroke-related impairments interfered with the recovery process and despite the efforts of the family (or lack of), some stroke survivors found it difficult to cope with the poststroke life and became depressed. The practical needs of Saif, who was often left

soiled, Aisha who received little emotional support from her husband, or Safiya whose comorbidities made it difficult for her to perform rehabilitation exercises are all examples of the harsh realities of life post stroke that could not be met or alleviated by the family. The vulnerability of these individuals who became depressed demonstrated the specificity of the circumstances and personal experience that shape the recovery such as practical and emotional support from family. It also emphasizes the lack of structured rehabilitative care and inadequate continual psychosocial support from the health services.

In Malaysia and other LMIC, the challenge of stroke care lies not in the resultant impairments from stroke, as these are not much different in HIC, but in the rates of disability and mortality [75]. This difference is due to inadequate primary care to screen for stroke and address risk factors, delayed emergency admission, and a lack of structured poststroke rehabilitation plan both in the hospital and in the community. These inadequate services as referenced by healthcare professionals [76] suggest that individuals who could achieved substantial recovery instead have high rates of disability, social isolation, and financial difficulties.

Implications for practice

Constrained economic resources in LMIC further compounded by poorly resourced health care services have led to inadequate investment in stroke prevention, treatment, and rehabilitation and to a greater extent, other noncommunicable diseases [77,78]. In LMIC, which account for the greater burden of worldwide stroke morbidity and disability adjusted life years, advocacy emphasizing the disabling nature of stroke whose risk factors comprise non-communicable diseases may catalyze an effective campaign to address not just the burden of stroke but the broader context of noncommunicable diseases. The study findings highlight the long-term physical, emotional and psychosocial needs of stroke survivors, which can directly affect their recovery process. An understanding of the consequences of stroke can equip healthcare professionals with the skills necessary to identify physical, emotional and psychological issues. The integration of a stroke clinical guideline into clinical practice to assess psychosocial functioning of the survivors after discharge may be warranted.

General knowledge about stroke and subsequent prevention may be addressed by the implementation of a stroke education program. Prior research has indicated that educational interventions to stroke survivors and their families may assist them in making effective decisions about their treatment [79]. Specifically, the results in this study suggest that the recovery process poststroke can be shaped by the family unit and through active coping strategies especially those in relation to spirituality. Support from the family and reinforcement of religious coping were shown to successfully aid the Malaysian stroke survivor in adapting to life poststroke. Thus, a community-based approach centered around specific patient and family needs may be more realistic in addressing the demands of LMIC regarding stroke management. A robust intervention plan is needed which includes protocols to address loss of social network and roles as well as lost activities and employment. A key aspect is guaranteeing adequate support is available to the survivor to either prevent them from becoming depressed or where they do become depressed, to support their recovery.

Health care providers can also facilitate access to community centers and stroke support groups such as the National Stroke Association of Malaysia to prevent the feelings of social exclusion and isolation amongst survivors. The narratives implied that there

is a sense of loss and change in lifestyle that can only be understood by those who have experienced stroke. This suggests the importance of interaction with others who have had stroke to foster a feeling of connectedness, such as through support networks. Bishop (2002) and Lamb et al. (2008) have highlighted engagement with stroke groups as beneficial in the stroke recovery path [80,81]. Increasing investment in the provision of a multidisciplinary stroke team which may include clinicians, psychologists, speech, and occupational therapists to manage stroke survivors both in hospital and in the community, is key. Adequate discharge strategies should include a therapy plan and information on managing physically, practically and emotionally. The participants' perceived lack of support from the health system warrants scheduled and regular reviews of survivors by health care providers which may in turn facilitate long-term recovery.

Strengths and limitations

This study is not without limitations. First, the reported findings are from a limited set of individuals whose stroke experience may not be reflective of the wider population. Nonetheless, it was conducted amongst a population that represented the ethnic and religious mix distribution of the country and as such the findings may be inferred for other stroke survivors across the country. Second, the study only investigated the perspective of the stroke survivor. Future studies should target a larger sample to also include health professionals and traditional/faith healers. Due to the qualitative nature of the study, data interpretation could be subjective, however, the authors attempted to minimize bias through the use of multiple data collection techniques, validation of the interview transcripts, and meticulous cross checking of codes.

The study also has several strengths. First, its focus on the perspective of the stroke survivor gives a voice to the individuals at the center of the issue and gives credence to the need for a patient-centered care. The use of qualitative, ethnographic methods provides contextually-rich information which could not have been obtained through quantitative methods. The study findings also provide new insights into the resilience and perseverance of the survivors; how they were able to navigate their own recovery process through the use of certain strategies.

Conclusions

This study has demonstrated that stroke changes the lives of individuals in profound ways. For most of the participants, although the stroke caused a disruption of their lives, it is an on-going process they have come to accept and adapt to. More people are surviving stroke with improved medical care. It is important that not only the physical impairments but the emotional and psychosocial wellbeing of the survivors in the context of environmental factors are addressed to provide them with quality of life.

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Summary

This chapter offered insights on the impact of stroke on the lives of individuals. The stroke for most of the participants was a state of life they had to adapt to and accept. This impact enabled a change in lifestyle and a discovery of a new way of life which facilitated embracing the changes and limitations posed by the stroke. As the recovery process was unique for each, the next chapter discusses what 'recovery' meant for the survivors and the factors that shaped the recovery process.

Chapter 6.

Recovery after stroke

Overview

The occurrence of a stroke offers challenges and adjustments for individuals. Prior studies highlight that recovery as subjective and unique about past roles and context (Dowswell et al., 2000) yet, there has been limited investigation into the resources and community-level factors that stroke survivors have used in their stroke recovery trajectory in LMIC. Considering this, it is important to research in-depth the responses and strategies used in adapting to the challenges encountered during the stroke recovery journey. In this chapter, I elucidate the meanings individuals ascribe to their stroke recovery and offer insight into the factors and personal resources which have mediated their recovery.

The chapter presents as three journal articles. The first, **Recovery after stroke in rural Malaysia** has been submitted for consideration in the journal *Rural and Remote Health*. The article discusses how the participants view recovery from stroke. As recovery is shaped by multiple factors operating within the individual and in interaction with the broader environment, the second article highlights the contextual factors that shape the recovery process. The article, **Contextual factors that shape recovery after stroke in Malaysia**, has been submitted for consideration in the journal *Disability and Rehabilitation*. The third article, **Adaptive Invention: Independence and mobility through modifications**, published in *Disability and Rehabilitation: Assistive Technology*, uses a case study to elucidate how assistive devices can shape recovery following a stroke. The paper also reports on how existing structures can be adapted to aid recovery and issues of affordability and accessibility of assistive devices for persons in LMIC.

Recovery after stroke in rural Malaysia

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Reidpath

Abstract: Introduction: Recovery from stroke is personalised, drawing on people's life experiences before the stroke, while cultural tensions between autonomy and dependence may also have an impact. Because stroke recovery is therefore understood in light of individual life histories, there is a need to consider many facets of recovery for health professionals to meet the needs of the stroke survivors. This article, therefore, conceptualises the meaning of post-stroke recovery from the perspectives of stroke survivors in a rural locale of a middle-income country; Malaysia. **Methods:** This article draws on data collected from people who self-reported stroke through a health and demographic surveillance system [name withheld for review], located in rural Peninsular Malaysia. Annual community-based census rounds collect information on a wide range of health problems among the enrolled population aged across the life course, including information on chronic conditions and their management. Twenty-seven participants were invited to take part in semi-structured interviews using an ethnographic approach. **Results:** Recovery was viewed as feeling better, as an impossibility, and as restitution. The prospect of feeling better or hopes of waning symptoms triggered an attempt to turn the ordeal caused by the stroke into an opportunity to grow into a new person; from being a victim to being a survivor. **Conclusions:** A community-based approach centred around the stroke survivor's understanding of recovery buffered by adequate fostering of optimism from health care providers and support from the family/community may be more realistic in addressing the demands of individuals living in rural Malaysia regarding stroke management. From a practical, community point of view, viewing recovery as 'feeling better' shifts the focus from a medical model to a more holistic model where stroke survivors can

explore the practical aspects of their changed bodies within the context of their everyday lives. In achieving this, cultural competence and social contexts must be incorporated into the design and implementation of services.

Introduction

Stroke, a leading cause of morbidity and mortality worldwide (Strong et al., 2007) is ranked as the third most common cause of disability-adjusted life years globally (C. J. Murray et al., 2013). However, despite this global ranking, the impact of stroke is not felt uniformly across countries, with 87% of worldwide mortality occurring in Low and middle-income countries (Strong et al., 2007) where almost 80% of the populace live in rural areas (Strong et al., 2007).

Stroke recovery in rural areas has often been described as suboptimal due to several factors that include a lack of specialized stroke services and personnel as well as financial constraints amongst the population (Feigin et al., 2014). Understanding the concept of recovery for survivors in rural regions is important for the development of interventions that are tailored to reflect the economic and sociocultural factors specific to the areas (Hartley, 2004).

Conceptualizing Recovery

The definition of recovery is vague, with different disciplines and different health conditions generating their conceptualisations of what it means to recover. The literature highlights conceptualizations such as clinical recovery that defines recovery from the perspective of disease and elimination of symptoms (Le Boutillier et al., 2015; Slade, 2009) and the consumer-oriented understanding of recovery aimed to influence policies and service provision that considers the reclamation of personal identity, social inclusion, and dignity (Bellack, 2006; Slade, 2009).

Drawing on the mental health literature to capture the fluidity in definitions of recovery that are used outside of Western / highly industrialised settings, we follow Anthony's description of recovery as *'a deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills, and roles. It is a way of living a satisfying, hopeful, and*

contributing life even with limitations caused by illness' (Anthony, 1993). Important in this definition is the notion that recovery is a personal process that encompasses finding a new purpose in life while overcoming, adapting to or living with a traumatic event. Recovery is, therefore, a personal journey characterised by fluidity and growth, and in which change is inevitable for the individual. Anthony's conceptualisations of recovery emphasise the complexity of the process and places ownership of that process on the individual undergoing it.

This understanding of recovery as a form of growth contrasts reductionist definitions of recovery, which considered it solely about the absence of symptoms (Diamond, 2006), which are measured through an objective lens, and expressed in terms of whether the person is 'cured' or not. This understanding relies heavily on the concept of restitution (Frank, 2013), in which recovery is both a point that can be reached and reflects a return to 'normal' pre-morbid functioning. While this is the case for some health conditions, it is not appropriate for many chronic diseases (Manderson & Smith-Morris, 2010)). A more holistic understanding of recovery has shifted its conceptualisation from a biomedical-based approach to a greater emphasis on the personal discourse that emerges from lived experiences. This approach to recovery moves its focus from cure or symptoms to a concern with how individuals accept the restrictions imposed on them by their health condition and endeavour to live life as best as possible. With this conceptualisation, recovery emphasises health and well-being.

'Living the best life possible' is significant in conceptualisations of recovery. Allott and colleagues (2003) described recovery as a turning point in the illness path where an individual begins to focus less on the illness and more on getting on with life. Here the focus is shifted away from the biomedical body and more to the psychosocial and emotional aspects of the disease. This shift also represents a change in identity: rather than the passive body which has been affected by the disease; the individual instead becomes an active agent who engages with the challenges of their condition in

the management process (Allott, Loganathan, & Fulford, 2009). Due to the subjective nature of recovery, how this manifests as intensely personal, and varies per sociocultural context.

Recovery from stroke is similarly complicated and personalised, drawing on people's life experiences before the stroke, while cultural tensions between autonomy and dependence may also have an impact. In considering post-stroke recovery, Dowswell and colleagues (2000) highlighted that individuals relied on their former life as reference points for their recovery. Their findings suggest that recovery was conceptualised as an individual domain and thus independent of professional criteria of recovery (Dowswell et al., 2000). The process of recovery was not measured by people's adjustment to their post-stroke impairments, instead was weighed against their pre-stroke lives. Because stroke recovery is therefore understood considering individual life histories, there is a need to consider many facets of recovery for health professionals to meet the needs of the stroke survivors (Dowswell et al., 2000).

Consequently, in this article, we aim to conceptualise the meaning of post-stroke recovery from the perspectives of stroke survivors in rural Malaysia. In examining individual narratives of recovery collected from 27 rural Malaysians, we seek to elucidate the understanding and experience of the recovery process and consider their implications for public health practice.

Methods

This article draws on data collected from people who self-reported stroke through a health and demographic surveillance system (HDSS), [name withheld for review], located in rural Peninsular Malaysia. The platform [name withheld] operates across five *mukim* (sub-districts), which range from peri-urban to rural. Annual community-based census rounds collect information on a wide range of health problems among the

enrolled population aged across the life course, including information on chronic conditions and their management.

Participants in the current study were identified during a health census round conducted in 2015. In response to questions about the appearance of facial drooping, arm weakness and speech difficulties, they self-identified as having suffered a stroke or stroke-like symptoms. From the initial census data, 64 people were identified as potential participants and were followed up through a face-to-face visit by the first author to determine their suitability for participation in the current study. Study participants (in contrast to those in the broader HDSS) were required to: have ever experienced a stroke, communicate personally or with the aid of a caregiver, and provide informed consent to study participation. Consent to participate was determined by the first author, who is a qualified medical doctor.

Twenty-seven participants met the study inclusion criteria (see Table 1 below for detailed demographic distribution). Of these, the majority (n=21) were men, and participants ranged in age from 37 to 83 years. Considerable variance was reported in the time since stroke, with the most recent being three weeks and the most extended duration 32 years. Most were Malay (n=20). All participants lived with one or more family members and all reported receiving informal support from family, friends, community members, or traditional therapists (including Malay healers or Chinese Medical Practitioners). Caregivers were most commonly spouses of the stroke survivors (n=25).

Table 1: Characteristics of Study Participants

Characteristics of participants	Number of participants (n=27)
Gender	
Male	21
Female	6
Ethnicity	
Chinese	3
Indian	4
Malay	20
Age range (at time of the first interview)	
30-39	1
40-49	3
50-59	8
60-69	9
70+	6
Years since stroke (at recruitment)	
<1	2
1-5	18
6-10	1
10+	6
Marital status	
Married	25
Widowed	1
Single	1
Main caregiver	
Spouse	25
Son	1
Daughter-in-law	1

Participants were invited to take part in semi-structured interviews with the first author and, where necessary, an interpreter, to provide a deeper understanding of issues that shaped participants' subjective experiences (R. Atkinson, 1998; Johnson, 2002). All interviews took place in the participants' homes and lasted from 30 minutes to 2 hours per session over two to three visits.

Where participants experienced aphasia, dyspraxia or dysarthria, interviews were augmented through the use of ©Talking Mats, a communication device that uses picture symbols to assist individuals with (or without) communication difficulty to

comprehend and respond to questions (J. Murphy & Oliver, 2013). The ©Talking Mats also assisted in sustaining participants' attention and allowing them to reflect on their views at their own pace (J. Murphy et al., 2005). Data from the interviews were supplemented by participant observation of their everyday activities, recorded through extensive field-notes. Interviews were audio-recorded, translated (where relevant), and transcribed verbatim.

Data analysis followed a six-stage thematic analysis (Braun & Clarke, 2006). Analysis commenced following the first interview and continued throughout data collection. Following transcription, transcripts and related field-notes were read various times to ensure familiarity with the content (stage 1) and extract semantic content that became the initial codes (stage 2). Once all data had been collected, and first coding occurred, the codes were subsequently sorted by identifying similarities between the codes and grouping them into potential themes (stage 3). Themes were further grouped into main themes and sub-themes (stage 4). Further reading of the transcripts was undertaken to ensure the fit of the themes with the research question, identifying consistencies and inconsistencies. Interpretations were developed as themes emerged (stage 5). Segments of the data from the interviews and field notes were also compared to add depth to the analysis. In-text verbatim statements of the participants are used throughout this paper to exemplify themes (stage 6).

Ethics

One University Human Research Ethics Committee approved the conduct of the study [details withheld for review]. Participants were informed of the study aims and objectives, what participation involved, and the voluntary nature of their involvement during the process of obtaining informed consent at the time of recruitment into the study and again before each interview. In addition, participants were informed that all information they shared would be kept confidential and that their identity would be

protected in study dissemination. Accordingly, all names used in this paper are pseudonyms. To quantify participants, 'all' referred to all 27 participants, 'many or most' referred to 70% and above of the participants, while 'few' referred to 30% and below.

Findings

Meaning of Recovery

Participants provided diverse understandings of recovery and attributed different meanings to their post-stroke recovery. These included: recovery as feeling better, evidenced by waning symptoms, recovery as an impossible feat, and recovery as a form of restitution. In many cases, these three understandings co-existed and created tensions or contradictions in participants' accounts, as explained below.

Recovery as feeling better: Many participants described changes in their conditions which indicated that they were better, thus signifying that their stroke and related bodily signs had achieved some form of resolution. For these participants, recovery meant feeling better and being supported by family, health professionals, and the community at large to move on with life. Recovery was therefore conceptualized as an improvement in the way they felt, a lessening of the impact of the stroke or improved motor functioning. These participants typically did not view their recovery as something that could be completed, in that, the idea of being recovered was seen as problematic. Rather, they saw post-stroke improvements as part of a process in which each functional improvement marked a form of 'recovery':

I haven't recovered, I can't walk properly with this leg, I will be fine if I can walk properly.... not really recovered, but I feel my body is lighter now. I can walk around easier. I no longer need help to go to the bathroom, or pray or eat. I can walk on my own.

(Razak, 76-year-old man)

Razak saw his gradual independence as a form of recovery. His improved mobility indicated that he was recovering. Safiya, a 59-year old woman was a homemaker before her stroke. Her daughters and two grandchildren moved back into her home to help with household chores since the stroke. She moves about by dragging herself on the floor, at other times, when she has more strength, she uses a tripod cane. Safiya had no expectations of going back to 'normal':

Sometimes I ask, why is this leg still affected and not recovering. If I am able to walk, then it's okay. I ask for recovery for the hands, it's numb. If I can get well a little, it's enough, even this is quite heavy you know (massaging her leg), the leg is heavy.

Safiya had resigned to the fact that complete restoration of the way she was before the stroke was impossible. For her, a lessening of her symptoms was a positive sign of recovery. Similarly, Musa, a 68-year-old man accepted the progress he has made as a sign of recovery. He was optimistic he would continue to get better, albeit gradually, "My heart wants me to recover.... I feel I will recover.... Slowly". His caregiver added that he based his recovery up to that point in this sense: "He can walk now, he feels he is stronger now, so he feels he is recovering".

As evident in these excerpts, recovery was understood by participants in various ways predominantly around physical and motor functioning. Importantly, recovery was not understood as synonymous to cure, nor was it considered a return to a former state. Instead, it was considered a fluid process that comprised incremental steps in several aspects such as a waning of symptoms, improved strength, and improved mobility.

Recovery as an impossibility: For a few participants, recovery was synonymous with cure. Paradoxically, those same individuals had reservations about whether stroke was an illness that could be cured. They considered recovery as being a point at which they would be freed from the stroke, but they also saw stroke, not as something they could

recover from – precisely because they didn't see stroke as a curable illness. This created a tension in their accounts and gave rise to confusion about how they were doing following the stroke. The rate of progress varied amongst participants, and some found it difficult to recognize their achievement when the changes were slow, leading them to lose hope in recovery. Hanif, for example, seemed depressed and was not doing so well. His caregiver (wife) reported that although he had improved slightly regarding motor functioning, he had lost the zeal for recovery:

Hope? There's no more. Usually, people who got this recovered by the 4th or 5th month. Me, three years but still the same. This is getting tougher, can't even get up, legs are stiff. (Hanif, aged 74 years)

Hanif measured recovery against the yardstick of his former self and perceived no progress. He had been an *Imam* (Islamic mosque leader) at the community for over twenty years, and stroke had stripped him of this role. For him, recovery was all or nothing. His lost hope in a return to his former self-meant he had accepted a passive stance as an impaired individual. Hanif's feelings of lost hope and helplessness brought about by his perceived lack of progress produced a motivational deficit to control outcomes: he seldom performed exercises, seeing no point in doing them, and alluded to awaiting death.

Chuanli, an 83-year-old man, was physically active and independent before his stroke. In contrast to Hanif, had tried to remain active, performing arm and leg strengthening exercises at home since the stroke to obtain a form of recovery:

Very tough, this kind of illness is tough... It won't recover, can't go anywhere. I hope it will recover (laugh). But what use is there for hope, there's no more hope (laugh). I got stroke, and it's really tough, the legs are useless, so it's really tough getting stroke, no joke.

Despite Chuanli's efforts, he perceived no improvement in his condition, and this led him to accept that there was nothing that could aid him to regain his mobility. In this way, recovery from stroke was an impossible feat - yet something that was still sought regardless: Chuanli continued to perform exercises and a few household chores. A rural, former plantation worker with limited resources, his workouts were what kept him going. He was unable to care for his ailing spouse due to his health and thus relied on his son for all almost all aspects of daily life. Holding onto his exercises was, therefore, his last connection to what was once normal life.

Recovery as restitution: For many participants, the notion of recovery was powerfully tied to a return to their pre-stroke life, both regarding being the person they used to be, as well as in having the same motor function as they had before their stroke. Zainab, for example, explained this: *"I hope to recover quickly, back to before the stroke"*. For Zainab and other participants, the importance of reclaiming who they were before the occurrence of the stroke was evidenced through their active participation in processes of recovery, which occurred through following lifestyle prescriptions, participating in formal or informal rehabilitation, or taking their medication:

I don't know if I will recover. I have taken many medicines, but still, I have not recovered. I want to recover. I want to be able to walk again. (Husna)

Husna, just like Zainab, sought for her former life, in which she was an active, independent woman who cared for others. This aligns with the restitution narrative, where the illness is viewed as transitory and recovery seen as a return of the body to a time before the disease (Frank, 2013). For both Husna and Zainab, their current life, which they saw as characterised by dependency, limited mobility, and other impairments was contrary to what they saw a normal life as, where they had roles as active homemakers. For Husna, Zainab and the other women in this study, this sense of

'rolelessness' affected their identity, and thus recovery for them was conceived as a return to that role. Importantly, in contrast to Chuanli and others' who spoke of cure, those participants who saw recovery in terms of restitution highlighted their social participation/engagement.

Ideas of 'normality' pervaded these participants' accounts. Indeed, Umar (aged 56 years) simply wished to overcome the visible signs of the stroke sufficiently that he could be seen as normal by others:

I feel my body is half-half. I feel I have the strength to work, I ask for work too, but the way I walk is slanted, they [potential employers] ask me why? I say I have stroke. They are afraid to give me work.

Umar, a father of two young children, needed a job so that he would have an income to keep his family afloat. He felt he was in a physical situation to work yet, during job interviews, potential employers saw his disability and declined to hire him. This social categorisation of Umar as perception and new identity of the disabled affected him both emotionally and financially. The label of 'disabled' was a blow to his self-esteem and made him feel less than normal, precisely because it denied him the opportunity of meaningful employment and thus the possibility of fulfilling the role of father and husband.

Discussion

This study explored the concept of recovery from the perspective of stroke survivors. Participants discussed the unravelling of their condition, adapting to the disease, and living their lives as best they could. Recovery was a personal journey that involved motivation, commitment, hard work, and time, and was therefore individually defined and experienced (Slade, Amering, & Oades, 2008). Recovery was viewed in three

distinct ways – as feeling better, as an impossibility, and as restitution – although some participants drew upon multiple understandings of recovery.

Recovery was conceptualised as 'feeling better' when changes in health states were observed. This suggested resolution in the impairment as evidenced by continued improvement over time. Emphasis on physical resolution of symptoms and achieving mobility seemed to represent recovery. However, central to these participants' narratives was the view that recovery did not simply relate to the absence of symptoms and functional impairment, rather to an improvement of functioning and a lessening of the impact of the stroke. This aligns with Anthony's (1993) definition where recovery is viewed as a resolution of the psychological catastrophe of the illness and an establishment of a meaningful and satisfying life. The prospect of feeling better or hopes of waning symptoms triggered an attempt to turn the ordeal caused by the stroke into an opportunity to grow into a new person, from being a victim of an unexpected and unwelcome event to being a survivor despite (or perhaps because of) adversity. This transformation in locating oneself was, for some, a central part of the coping process. What mattered for these participants was not a return to a previous life, instead a return to a meaningful life (N. D. Doolittle, 1991).

Recovery viewed as restitution follows Frank's (2013) narrative where the participants tell about recovery from the perspective of illness and treatment. Recovery for these participants stems from the hope of a return to pre-morbid state; a time before the stroke as reported by Dowswell and colleagues (2000) in their study with stroke participants. Participants who viewed their recovery as restitution, having expectations of a return to their former selves, emphasised the importance of personal agency as evidenced by their active participation in processes of recovery. This participation was associated with feelings of hope for recovery (Becker, 1993; Pilkington, 1999). A significant milestone for these participants was the resumption of previously valued

activities, especially activities within the home as has been reported in the literature (Robison et al., 2009).

Recovery was viewed as an impossibility due to a lack of perceived progress over time. Hope in regaining full physical functioning reduced as time progressed when improvements reached a plateau. This finding has been reported by prior studies where initial optimism about recovery tended to diminish over time, mainly as recovery slowed or became stagnated (Christopher R. Burton, 2000; O'Connell et al., 2001). The reality for these stroke survivors was that their impairments would not resolve.

Implications for practice

Although recovery primarily lies with the patient, the understanding of what recovery means to patients by health practitioners can have a significant influence in promoting recovery-based approaches. As Anthony (1993) suggests, support systems that are grounded in cultural competence and appropriate treatment modalities aid the individual in the recovery process. This study emphasises the need for understanding the many facets of recovery and the demand for services that respond accordingly. Consideration of the meanings of recovery by health professionals in rural Malaysia could result in greater understanding and higher quality of care for the stroke survivor. The importance of interventions that are valuable and meaningful to the individual and tailored to their needs have been highlighted in prior literature (Brown, Brown, Sharma, & Association, 2005) where evidence-based medicine is moving towards value-based medicine.

Traditionally, delivery of rehabilitation stroke services is based on the restitution model where recovery is defined in a 'return to normal' terms. This poses significant challenges for the stroke survivor given the limited availability and accessibility of stroke units and neurologists in rural Malaysia (Abdul Aziz, Aziz, Sulong, & Aljunid, 2012). The absence of such services impacts on the stroke survivors hopes of recovery in

that resources to aid their active participation in the recovery process are limited. From a practical, community point of view, viewing recovery as 'feeling better' shifts the focus from a medical model to a more holistic model where stroke survivors can explore the practical aspects of their changed bodies within the context of their everyday lives. In achieving this, cultural competence and social contexts must be incorporated into the design and implementation of services.

Given the pervasive belief, acceptance, and use of complementary and alternative medicine in Malaysia (Anuar, Fadzil, Ahmad, & Abd Ghani, 2012; Z. Aziz & Tey, 2009) there might be a need to integrate its use into primary health care. Similarly, owing to limitations in rehabilitation services, notably in low and middle-income countries (Feigin et al., 2014) including in Malaysia (Abdul Aziz et al., 2012), the family assumed an even more significant role in providing care for the stroke survivor. As such, it provides an avenue to incorporate home-based therapy into practice. Integrating these mechanisms may help the stroke survivors take ownership of their recovery at their own pace in a familiar environment; the home or community.

As reported in prior literature, hope, aided individuals navigate through the recovery process (Cross & Schneider, 2010; Hopper, 2001). Hopper, in his study of the nature of hope in psychoanalysis, proposed that hope could aid individuals to achieve a goal or enable them to wait patiently for things to be better. Hope provides positivity, strength and actively supports the stroke survivor in achieving a meaningful life (Bays, 2001). Hope, therefore, may be an enabling element that takes away the 'impossibility' of recovery. Having hope in recovery could foster the need to work towards and participate in processes of recovery despite limited progress in improved functionality. As the health professional plays a role in supporting the stroke survivor attain an adequate level of functioning, encouraging the survivor and ensuring that their illness narratives are not narratives of 'impossibilities' may be of benefit to the survivor.

A community-based approach centred around the stroke survivor's understanding of recovery buffered by adequate fostering of optimism from health care providers and support from family/community may be more realistic in addressing the demands of a low-and middle-income country such as Malaysia regarding stroke management.

Strengths and Limitations

This study reflects the viewpoint of the stroke survivor, provided in a familiar, unconstrained environment and thus reflects issues that are pertinent to the survivor. As the study was based on findings from a limited sample size, the results cannot be generalizable to the broader population. However, qualitative research does not seek to produce findings that are generalizable; rather the value is in presenting the understandings of a group of individuals and how it impacts on their health. This allows consideration of ways to improve the delivery of healthcare services to them. Participants with severe communication difficulties were excluded from the study; therefore, our sample may not have captured the full perspective of what recovery means for individuals following stroke. In this study, the meaning of recovery was explored from a subjective viewpoint of the stroke survivor. The results, although being of great value, may be supported by quantitative measures.

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The authors declare no conflict of interest.

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Contextual factors that shape recovery after stroke in Malaysia

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Reidpath

Abstract: Purpose: A stroke is a sudden event which may leave individuals and their families ill-prepared to deal with the resultant disability. Several contextual factors can influence the recovery process. These factors, internal and external, exist interactively in the lived experiences of the survivors. The limited availability of rehabilitation centres that are located in urban centres meant that recovery predominately occurred outside of the biomedical health and instead relied upon the resources available to individuals and their families. **Methods:** A qualitative approach with data from in-depth interviews and observations were used to identify contextual factors that shaped recovery following stroke in a community. Twenty-seven individuals with stroke were drawn from a health and demographic surveillance system in Malaysia. **Results:** Hope and optimism, coping strategies, motivation and support from family and friends, and the use of alternative and complementary medicine shaped the process of recovery within a context where infrastructure is extremely limited. **Conclusion:** The identification of factors that facilitate the recovery process provides a background in which healthcare providers can utilise to improve their understanding of the stroke experience. Such understanding could be instrumental in aiding health professionals to offer the most effective help to their clients.

Introduction

A stroke is a sudden event which may leave individuals and their families ill-prepared to deal with the resultant impairments (Anderson, Linto, & Stewart-Wynne, 1995; Billinger et al., 2014). Stroke is associated with physical, emotional and social consequences that affect an individual's quality of life (Carod-Artal, Egido, González, & Varela de Seijas, 2000; Raju, Sarma, & Pandian, 2010; Tyedin, Cumming, & Bernhardt, 2010). Individuals with stroke aim to return to active living and reintegrate into society (Brookfield & Mead, 2016).

The conventional approach to stroke recovery is the delivery of rehabilitation services based on the medical principles of cure (Christopher R. Burton, 2000; Langhorne, Bernhardt, & Kwakkel, 2011; Pawlson, 1994). Clinical measures of recovery following stroke alone fail to offer a complete picture of what constitutes a successful recovery (Dowswell et al., 2000; Jones, Mandy, & Partridge, 2008). Accordingly, some studies have suggested that stroke survivors measured the impact of the condition in relation to the emotional and social domains of their lives (Dowswell et al., 2000).

Although stroke recovery may be individualised, multiple factors influence a person's progress – recovery – following a stroke. These may include internal factors (such as optimism, fears of dependency, or personal control), external factors (such as therapeutic interactions), or a combination of these, and which can hinder or facilitate recovery (Jones et al., 2008). Prior studies have highlighted the despair and disappointment felt by stroke survivors after discharge from the hospital due to limited information given and encouragement by health professionals (Eames, Hoffmann, Worrall, & Read, 2010; Ellis-Hill et al., 2009; Ing, Linton, Vento, & Nakagawa, 2015; Martinsen, Kirkevold, & Sveen, 2015). Other studies have found that individuals developed and used a range of coping strategies to adjust to life with stroke (Lo Buono, Corallo, Bramanti, & Marino, 2017; Pound, Gompertz, & Ebrahim, 1999).

While these findings have investigated the factors that augment or undermine the process of recovery for individuals with stroke internationally, few studies have discussed the contextual factors involved in stroke recovery in Malaysia (Mohamed, 2010). An understanding of these elements that influence recovery following a stroke could be instrumental in aiding health professionals to offer the most effective help to their clients.

A rehabilitative approach to post-stroke care may pose challenges to Malaysian stroke survivors given the limited availability and accessibility of specialised stroke care in Malaysia (Abdul Aziz et al., 2012). The inadequacy of such services could impact on recovery, making evident a need to focus on contextual dimensions of recovery. Of course, one of the challenges in Malaysia is that such recovery needs to be self-directed or using local health services, given the lack of rehabilitation facilities in the country, and particularly in rural areas. The development of such services, however, must consider the experience of recovery from the perspective of the stroke survivor (Christopher R. Burton, 2000; Wyller, Sveen, Sødning, Pettersen, & Bautz-Holter, 1997) as the views of people with disabilities is required to fully understand what is of value to them and develop interventions that are tailored to their needs (Peters, 1996).

In this paper, we aim to explore the contextual factors that mediate recovery following stroke in Malaysia, a middle-income country, from the perspective of stroke survivors. In examining individual narratives of recovery collected from 27 rural Malaysians, we seek to elucidate the personal, social and community-level elements influencing the recovery process.

Methods

Participants

This study was part of a larger ethnographic study that explored the experience of stroke in Malaysia at a health and demographic surveillance system (HDSS), [name withheld for review], located in rural Peninsular Malaysia. The platform [name withheld] operates across five sub-districts, and yearly census rounds are conducted to collect information on an extensive range of health conditions among the enrolled population (Allotey et al., 2014).

People were included in the study if they had ever experienced a stroke, could communicate personally or with the aid of a caregiver, and could, therefore, provide informed consent for participation. Through a household survey, sixty-four participants with stroke or stroke-like symptoms were identified using the FAST criteria. These participants were then visited by the researcher. The presence of stroke was self-reported by the participants. It was further confirmed at the first interview by the first author who is a medical doctor through the patients' medical records, history and presence of signs/symptoms. Of the 64 participants, ten could not be contacted despite several visits to their homes, 21 individuals did not suffer a stroke, five refused consent, three were too ill to partake in the study while one passed away before consent was obtained. Twenty-four individuals consented to participate. Key informants (HDSS community liaisons) identified three more individuals; which were confirmed to have suffered a stroke and consented to participate. The final study sample consisted of 27 participants.

Though the recruitment comprised no gender preference, more men were enlisted into the study as the HDSS data recorded more men with stroke within the specified population. A description of the demographic characteristics of the participants is outlined in table 1 below. The majority of the 27 participants (n=21) were

men. The participants ranged in age from 37 to 83 years. Twenty participants were of Malay ethnicity, four were Indian, and three were Chinese. The stroke occurred recently for some participants, while for others, the stroke occurred decades ago. Time since stroke ranged from 3 weeks to 32 years. All participants lived with one or more family members, and all reported receiving informal support from family, friends, community members, or traditional therapists (including traditional Malay healers or Chinese Medical Practitioners). Caregivers were most commonly spouses of the stroke survivors (n=25).

All participants experienced some residual impairment from the stroke, including weakness or paralysis on one side of the body and slurred speech. Five participants had communication difficulties, and two others had trouble with attention. For these participants, interviews were augmented through the use of ©Talking Mats, a communication device that uses picture symbols to assist individuals with (or without) communication difficulty to comprehend and respond to questions (J. Murphy & Oliver, 2013). The ©Talking Mats also helped in sustaining their attention by giving them time to reflect on the questions asked and respond at their own pace (J. Murphy et al., 2005). A few used assistive devices, such as a cane, tripod or a wheelchair. One participant moved about permanently on a wheelchair, and another was completely immobile and confined to a bed. The participants often had other health problems, including diabetes, hypertension, asthma, and gout. Certainly, time since stroke and number of strokes will affect the recovery experiences of the survivors. While there were different narratives among participants, there was no clear pattern in how these variables affected the construct of the recovery experience.

Table 1: Characteristics of Study Participants

Variable	Frequency (%)
Gender	F: 6 (22.2) M: 21 (77.8)
Age (years, at time of first interview)	30-39: 1 (3.7) 40-49: 3 (11.1) 50-59: 8 (29.6) 60-69: 9 (33.3) 70+: 6 (22.2)
Ethnicity	Chinese: 3 (11.1) Indian: 4 (14.8) Malay: 20 (74.1)
Religion	Islam: 20 (74.1) Christianity: 1 (3.7) Buddhism: 2 (7.4) Hinduism: 3 (11.1) None declared: 1 (3.7)
Years of stroke (at time of recruitment)	≤ 3: 12 (44.4) 4-10: 9 (33.3) 10+: 6 (22.2)
Marital status	Single: 1 (3.7) Married: 25 (92.6) Widowed: 1 (3.7)
Primary caregiver	Spouse: 25 (92.6) Daughter in law: 1 (3.7) None: 1 (3.7)

Procedure

Semi-structured interviews with the first author and an interpreter were conducted to explore the barriers and facilitators to stroke recovery. All interviews took place in the participants' homes and lasted from 30 minutes to 2 hours per session over 2-3 interview visits. Data from the interviews were supplemented by extensive field-notes taken to document participants' non-verbal responses and the surrounding environment.

To reduce recall bias, specific questions about the stroke event were asked. We also explored details about mentioned events in subsequent interviews to corroborate

the information provided. Caregivers (spouses, children, and siblings) were present during the interviews. The caregivers participated by augmenting and clarifying information provided by the stroke survivor. All interviews were audio-recorded with permission from participants, translated, and then transcribed verbatim. Discussions with the stroke survivors focused on how their experience of stroke evolved, how they coped and reconstructed themselves. Furthermore, we explored their views about the healthcare they received, are currently receiving and how conventional and traditional interventions if any, facilitated or hindered their recovery. Broad questions were asked during the interviews. Table 2. provides a synopsis of the interview guide.

Table 2: Interview guide

Can you tell me about the day the stroke occurred? What were you doing?
What do you think caused the stroke?
What happened after? Where did you go?
Tell me what happened at the hospital/clinic
What did the doctors say caused the stroke?
Before you left the hospital, what did the doctor tell you?
Did you go to any other place for treatment? What other treatment did you seek? Who else treated you?
Can you tell me about your daily routine?
How has life changed since the stroke?
How did you manage your life after the stroke?
Did you seek any help? Who helped you?
How did your faith help? Did the stroke affect your religious practices?
Is there anything else you would like to tell or ask me?

Data analysis

As transcription commenced, relevant themes were identified and recorded in a separate worksheet that was later used to provide linkages. It was first guided by initial

general ideas and then modified as the study advanced. The process was subjective and reflective, consistent with ethnographic research. Essential themes were identified and reported. Gaps and missing data were identified during the analysis and followed up as fieldwork progressed. Analysis commenced following the first encounter with participants and continued throughout the study.

A six-stage thematic analysis technique was used (Braun & Clarke, 2006). The data set, interview transcripts and field-notes were compared against each other to ensure validity and reliability. The transcripts and field-notes were read in their entirety the first time to provide familiarity with the content. The second reading resulted in a line-by-line analysis to extract initial codes. Following initial coding, the codes were categorised into potential themes. The themes were then sorted into groups and cross-checked against the transcripts and field-notes to ensure consistency with the research question. The themes were then modified accordingly, and quotes from the participants used to exemplify them.

Ethics

The study was approved by one University Human Research Ethics Committee [details withheld for review]. Participants were briefed thoroughly on the nature of the study regarding what participation involved before providing consent. Informed consent was obtained verbally at the time of recruitment into the study and again before each encounter. Verbal informed consent was sought due to the reluctance of the populace to sign documents. For participants with communication difficulties or memory problems, caregivers, who were mostly spouses, provided consent. All names used in this paper are pseudonyms.

Findings

The participants' narratives identified several factors that facilitated or hindered their recovery experience and included internal or external mediators. Internal mediators included hope and optimism, self-efficacy and self-motivation, coping strategies, and comorbidities. External mediators included family and social support, access to or the presence of empowered health professionals, and treatment management strategies.

Internal mediators

Hope and optimism: The recovery path was often paved with frustrations and challenges and, as such, hope allowed individuals to have a positive mindset towards recovery. Whether hope originated from within the individual or from those around them, it fostered optimism for a functional and meaningful life. Ayub, aged 48 years (five-years post-stroke), pointed out that learning about the positive outcomes of other stroke survivors provided him with hope:

I once went for massage [and] I could sit on the chair. Another person came. His family carried him. He was just lying down. He had it, I had it, [we] both had stroke. In two months, he recovered, just like a normal person. No imbalanced gait. But I am still imbalanced. I asked him, "Uncle what did you do?" He said once he recovered a bit, he exercised. I can't even grip... no strength right, that's why I can't. But I think we use this (points to the head), every day we use the mind. As time goes by, if we try harder ...we can recover.

Ayub's statement offered insights into the relationship between hope and recovery. Observing the progress an individual with severe stroke made had him realise that if he worked towards recovery, he would recover. Seeing others' positive outcomes reinforced participants' beliefs that recovery could happen.

However, not all participants had hope in recovery. As the rate of improvement was wide-ranging among participants, some lost hope in recovery when their progress

was slow. Hanif, aged 74 years (four-years post-stroke), viewed his recovery as an impossibility:

Hope? There's no more. Usually, people who got this [stroke] recovered by the 4th or 5th month. Me, three years but still the same. This is getting tougher, can't even get up, legs are stiff.

Hanif, who had previously attended massage sessions and practised standing and walking by supporting himself against the wall now hardly performed any exercises. He spent much of his time sitting on the floor in his home, with most of his social contact occurring when visitors would come. Hanif was no longer able to attend mosque or community events. His lack of optimism about recovery meant he rarely partook in processes of recovery. He seemed depressed and mentioned a complete absence of happiness in his life – which impacted his capacity to participate in recovery-directed activities actively.

Self-efficacy and self-motivation: Self-efficacy is the ability to organise and execute the courses of action that are required for attaining certain goals and was defined as a person's confidence in their ability to perform a task (Bandura, 1977). In shaping the course of action to take, the amount of effort to put in, and a person's determination to carry on despite obstacles, self-efficacy beliefs played a central role in stroke recovery. Participants had confidence in their ability to steer their recovery. When Ayub's stroke affected his right hand and arm, he learned to write with the left, *"This hand, (shows left hand) writes. I used to write with the right. Now I use this hand to write. Learn, learn until I could write...but all in large letters"*.

Ayub's successful performance of writing boosted his confidence and encouraged him to perform more complex tasks such as driving. Similarly, the participants reflected on feelings of helplessness and dependency on others that triggered a change in attitude

and led to their progress toward independent functioning. This desire to be independent motivated them to work towards achieving recovery:

I laid here...for nearly three months. I couldn't walk. My wife massaged me, took care of me, fed me. I couldn't get up. After that I thought to myself, you can't be like this. I must fight back. Then I got up and started moving. I walked to the mosque. Early in the morning, I started going around, walk, and walk! (Shuaib, aged 68 years, 11-years post-stroke)

Shuaib, like most other stroke survivors and in contrast to Hanif, refused to passively accept the changes caused by his stroke and sought to find self-management activities which enhanced functionality and independence. These participants had higher levels of self-efficacy and focused on exercising and relearning skills to overcome the challenges of their disability. Umar, aged 56, (five-years post-stroke) for example, believed exercises would aid in his recovery. Despite not having access to planned health professional rehabilitation (like most of the participants in our study), he performed strengthening exercises, *"I do exercises on my own. I just walk around, ride the bicycle. Then when I do prayers [salah], that is also some exercise"*. These participants recognised that their attitudes of determination, self-motivation and pushing limits were a significant facilitator to their recovery.

Coping Strategies: The participants were compelled to find ways to cope with the challenges brought about by the stroke. As they learned more about their body and its limitations, participants developed a wide range of strategies, which included turning to religion, active coping, and performing activities at a slower pace.

In this study, most the participants *turned to religion* to help them cope effectively with their condition. They used their faith to seek strength and deal with the challenges posed by the stroke. For the Muslim participants, the stroke was viewed as a test from God. Accepting the stroke and its consequences, therefore, meant believing in

God's supremacy. Razak, aged 76 years, said during the interview, *"If God wants us to have stroke until death, then so be it. We accept it"*. Shuaib, a deeply religious man, emphasised, *"If Allah wants us to recover, we definitely will recover"*. This acceptance of the infinite power of God reduced their psychological distress as they surrendered their recovery to God. Reciting the Holy Qur'an was also vital for these participants. Yaqub's caregiver – his wife – talked about how her husband would read the Quran in the evenings since the stroke. Yaqub, a 66-year-old man at two-years post-stroke, added: *"In Sha Allah, (by God's will) it can help remove, forget all the negative thoughts"*.

Religion for the Muslim participants supported recovery in two ways. It provided a psychological coping strategy, enabling them to accept the condition and alleviated their fears about recovery as they believed recovery would only come from God. It also provided physical ways of coping for the participants. The physical aspect of the *salah*, which is a fundamental requirement for all Muslims, was considered a form of exercise as Umar mentioned above.

Dram, a 47-year-old, who was not very religious before his stroke discussed how turning to his faith provided him with solace and hope in recovery. A Buddhist, he had his family take him to the temple regularly where he would pray and make sacrifices. He prayed for strength and patience and believed his sacrifices would leverage the provision of recovery from God.

'Active coping' refers to the process of taking steps to eliminate or avoid a stressor or to ameliorate its effects (Carver, Scheier, & Weintraub, 1989). Our participants tried to lessen the effects of the stroke by focusing their efforts on activities that would aid their recovery. Most participants took up or continued with past household chores at home to assist with functional motor recovery. Musa, aged 68 years (4-years post-stroke), described his daily activity this way, *"I exercise; I sweep the veranda, pick up the leaves that fall from the trees. It is like killing two birds with one stone, cleaning and exercise. Helps me a lot"*.

For Musa and others, their household chores were a form of exercise that was performed persistently as they believed it would help with recovery. This belief stemmed from advice given to them by health professionals, traditional therapists, and other individuals who have suffered a stroke. Household chores, although not a structured rehabilitation approach, helped the participants with muscular flexibility, strength and endurance.

Pacing activities and relaxation were other strategies employed for engaging in everyday tasks. The participants had come to accept that it was difficult to compensate for lost functions and that energy and strength were needed to keep up with living. Because of this, some of the participants chose to limit their daily activities and take regular breaks. Yaqub, for example, cut down his hours working at his rubber farm so he could have more time at home to rest. Similarly, pacing meant that they had not given up on activities they used to perform. Instead, they adjusted how they performed those activities. For the participants, this was a vital element, and it gave them a sense of normality in the face of their disability. Relaxation offered the participants relief from the stress brought about by their disabilities. Musa, who lived in a house atop a hill, would sit out in the compound overlooking the beautiful landscape, *"I love to sit outside. Every morning when they [children and grandchildren] leave, I will sit there. It is quiet and nice, and the air is fresh. It makes me calm"*.

Relaxation has been documented in past literature as a way of providing improved concentration, confidence, motivation and improved functioning in individuals with stroke (Carin-Levy, Kendall, Young, & Mead, 2009). Similarly, relaxation helped to reduce stress and anxiety (Carin-Levy et al., 2009; Kneebone, Walker-Samuel, Swanston, & Otto, 2014). By working in pauses and scheduling in time for breaks and relaxation, participants had the vigour and strength to complete household chores, move about and generally feel good about themselves. The use of these strategies assisted the participants in accommodating their impairments and

limitations by constructing new meanings to their situation, prioritising certain activities and revising values that would aid in their recovery.

Comorbidities: Many participants had pre-existing medical conditions which affected their stroke recovery. High blood pressure, diabetes, and high blood cholesterol were most common, although several participants reported other medical conditions such as asthma, gout, and complications that included kidney failure, limb amputation, vision impairment, and diminished sensitivity in the limbs. For these participants, the presence of these conditions slowed their progress.

Some participants were more disabled by the associated medical conditions than the stroke itself, as was seen in the case of Safiya, a 59-year-old housewife who was four-years post-stroke. She suffered from asthma and found it challenging to perform rehabilitation exercises as she was always breathless, *“I can’t exercise, [its] very difficult, I want to recover, but this asthma won’t let me exercise. I become like a dog [panting]”*. Her example demonstrated how other medical conditions could slow or hamper individuals from pursuing recovery goals. The existence of comorbidities could undermine the benefits of rehabilitation. Some medications taken for the comorbidities such as anti-hypertensive drugs could cause headaches and fatigue which would, in turn, detract from rehabilitation activities. Similarly, conditions such as gout and arthritis could hinder rehabilitation efforts due to the exacerbated pain produced by physical exercises.

External mediators

Support from family and friends: Family support appeared to have a significant impact on participants’ recovery. It provided them with emotional and financial aid, supporting them in fulfilling (or taking over) their previous roles, and assisting in therapeutic exercises. Yaqub, for example, described the support from his daughters and their husbands:

We have daughters; they look after us. Wherever I want to go, they take me. Even for prayers, before I regained the strength to ride the motorcycle, my sons-in-law would take me.

Because of the stroke survivors' disability, most families experienced changes in income level they were unprepared for. For the most part, participants had limited access to personal funds but were reliant on remittances from family members and government pensions to support them. Friends and religious organisations would also provide financial aid to the stroke survivor. Safiya regarded her spouse as her physical therapist. He assisted her in rehabilitation exercises at home, encouraging and motivating her:

When I had to learn to walk, he [husband] asked me to lean against the wall, asked me to do it every day. Then as time went by, I began to use the walker with four legs. He would wait behind, scared I might fall.

Safiya's spouse provided her with a safe and caring environment where she could manage her disability. Narratives from the participants demonstrated that the help and support from family were of enormous importance in the recovery path. Participants regularly made statements such as: *"I couldn't have done it without them"*. The encouragement received helped the survivors achieve self-confidence and independence. Family boosted the survivor's will to recover.

Family, however, was not the only source of such socio-emotional support. Some participants mentioned the support they obtained from friends and neighbours. Yaqub said, *"People came to visit, gave advice, to recover quickly, prayers from friends. Friends came, just to chat, to give spirit. The neighbours helped out [too]"*. Yaqub had an extensive network of friends and lauded their efforts in helping him and his family through the recovery process. Similarly, Arjun, aged 77 (five-years post-stroke), a still-active church member, was never short of friends to keep him company and attend to his needs, *"I wake up around 7.30am... if I need to get anything from the store I call my friend, he comes and takes me...when I go out, my friends help me"*.

These support networks were essential for participants' well-being through the provision of instrumental and emotional support, which helped encourage them to keep actively working on their recovery. Additionally, having maintained their network of friends helped to preserve salient aspects of the stroke survivor's identity, of who they were before the stroke such as churchgoers and sports enthusiasts. Amit, on the other hand, mentioned friends with bitterness in his tone when asked about his social network:

Few people came. Even when I had my leg amputated, my best friend didn't turn up.

Sad! We used to work together...we would have tea and eat at the food stalls. It was a good time. All gone now.

Amit felt rejected and abandoned by friends. The rejection created bitterness within him accompanied by a lack of comprehension as to why he was rejected. An avid footballer before the stroke, he was also saddened by the loss of friends with whom he discussed and celebrated football with. The lack of social contact intensified the feelings of depression where life seemed bleak, full of despair and loneliness.

Healthcare provider information and treatment management strategies: Information provided by health professionals was mentioned as an essential aspect of recovery. Most participants were dissatisfied with the care they received at the hospital and the inadequacy of information about stroke. Yusuf, aged 59 (eight-years post-stroke), complained about the lack of information given to his spouse on how to take care of him after leaving the hospital, *"They didn't give any information about caregiving. They just said there is no cure for stroke, that's all"*.

The limited information obtained from healthcare professionals at the hospitals created further anxiety and uncertainty for both participants and their caregivers on how to cope. Vague information on what was a stroke, its causes, prognosis and management left participants feeling neglected by the health system. However, some

participants did admit that the limited information they did obtain proved to be valuable in their recovery:

The doctor said don't get used to the walking stick. The doctor [also] said this type of sickness can recover; you have to take supplements, have to take care of our health...look after the diet, fewer fats, and sugar. (Sulaiman, aged 69, at 12-years post-stroke)

While health professionals asked participants to adhere to medications and perform exercises to improve physical functioning, clear and adequate recovery intervention plans were not instituted. The participants were discharged home after a very brief hospital stay (average of 3 days) with limited information about their condition, limited rehabilitation and follow up plans. This brief hospital-stay supports other studies in Malaysia detailing short (5 to 7 day) in-hospital stays following stroke (Hamidon & Raymond, 2003; Nordin, Aziz, Alkaff, et al., 2012).

Treatment management strategies were described in two dimensions: management as prescribed by health professionals, and culturally-specific management, which comprised consultations with religious healers and the use of complementary and alternative medicine (CAM). These therapies comprised traditional Chinese, Malay and Islamic medicine that include massage, herbal medication, reflexology, homoeopathy and the use of special ceremonies and spells (Kadir, Hamid, & Mohammad, 2015). Most stroke survivors believed in a combination of both orthodox and CAM management, especially for their pre-existing medical conditions. Traditional therapies were seen to have an essential role in the restoration of muscle tone, improved blood circulation, and movement (Kadir et al., 2015). For most, treatment management of the condition was vital. They would take any medication or therapy recommended by anyone to recover, as Shuaib explained:

Hospital medication, traditional medicines advertised on TV, I bought all sorts of medicine. Even bird's nest, all. Whenever I hear about a particular medicine being effective, I bought it.

Shuaib's desire to recover meant he was ready to try anything and everything. He felt he needed to take control of his recovery by whatever means. It did not matter whether it was conventional treatment or CAM. The source of therapy was not important, all that mattered was the result. Ayub's desire to regain the capacity to care for his wife and young children led him to seek CAM treatments and endure the negative consequences of the treatment:

The massage, it's painful, but I endure it. People gave me all sorts of medications, the taste [is] sour, bitter [but] I take it. I have even tried drinking some liquid like that of a drain...urgh the smell, but I just drank. I want to recover.

Like Ayub, many participants used CAM. This occurred because there are pervasive acceptance and beliefs in the benefits of traditional medicine in Malaysian cultures (Anuar et al., 2012; Z. Aziz & Tey, 2009). Yusuf suffered from hypertension and, although he was compliant in taking his antihypertensive medications, he lauded CAM and credited part of his recovery to the massage he received:

Traditional massage every day for three months. No medication, just massage. They used water from white soil...After massaging with the white soil, I could walk, and my deformed mouth was back to normal.

This assertion of the benefits of CAM by participants highlighted the demand for the utilisation and or integration of CAM in the treatment management of stroke for survivors in Malaysia. The CAM masseurs and therapists were also a source of information and encouragement to the stroke survivors. They provided information about stroke; such as the possible causes, what exercises to perform, how to perform them and dietary advice. Umar, who had a history of hypertension and high blood cholesterol explained the dietary information provided by his masseur, "*The masseur said don't simply take other medications, don't apply oil for massage. However, he said to take vegetables, soup, no fried food, mutton or beef*". For these participants, CAM practitioners worked with the individual to help them heal. David's masseur, for example, not only

provided him with massage but ensured that he performed physical exercises and moved about. He (masseur) explained:

Those that I massage, I teach them how to walk, squat and go up and down the stairs. If I only massage them, and they can't manage on their own, then it's useless.... what's the use of massage then? Have to teach them to manage themselves, else they have to rely on others.

It is an integrative approach that seeks to go beyond mere offering of treatment to provide a holistic approach to recovery.

The contextual factors affecting stroke recovery, although presented as internal and external mediators, are not mutually exclusive. The impairments brought about by the stroke limited the social interactions of the participants, thereby pulling them out of their familiar and supportive environment. This withdrawal and limitation in support networks, which is an external mediator, as described in the case of Amit, resulted in feelings of despair that affected the stroke survivors' optimism about recovery, an internal mediator. In comparison, information about stroke from healthcare providers, an external mediator, boosted morale, motivated and provided the survivors with resources to actively drive their recovery. Similarly, the use of religion as a coping mechanism, an internal mediator, governed some participants' stroke management approaches. Sulaiman, aged 69, said, *"This sickness, it is as if there is something in our body... however, if we recite the Yaseen (a chapter in the Qur'an), it will stop. This is the Islamic medication"*.

The use of and belief in the effectiveness of Islamic medicine for some of these survivors also reinforced their religious conviction, as they believed they were surrendering to the will of God. This external mediator of recovery aligned with their coping strategy of turning to religion.

Discussion

This study has emphasised the fact that although a stroke is a difficult and challenging event, survivors can adapt to the condition and resulting impairment. Several contextual factors can influence the recovery process. These factors, internal and external, exist interactively in the lived experiences of the survivors. This study explored the internal and external factors that mediated recovery from the perspective of stroke survivors. Recovery was a personal journey that involved motivation, commitment, hard work, and time, and was therefore individually defined and experienced (Slade et al., 2008). Consistent with findings from prior research, our results suggest that the dynamics of the recovery process in stroke involves factors operating both within the individual and in interaction with the broader environment which should be considered (Albrecht & Devlieger, 1999). The factors identified in this paper could be perceived as barriers or facilitators to recovery by different individuals. The factors may have different effects that are dependent on the individual and their subjective interpretation (Algurén, Lundgren-Nilsson, & Sunnerhagen, 2009).

It is essential to recognise the limited health service environment that exists in relation to stroke recovery in Malaysia: there are few rehabilitation centres in the country. They all are privately run and located in urban centres, a considerable distance from our study site. The confluence of these factors meant that recovery predominately occurred outside of the biomedical health system – with the exception of comorbidity management – and instead relied upon the resources available to individuals and their families. The current paper examines the internal and external factors that shape the process of recovery within a context where infrastructure is minimal.

Internal mediators

Most of our participants expressed hope and optimism about recovery. Prior research has demonstrated that individuals with hope and optimism were likely to recover faster

than those with lost hope (Cross & Schneider, 2010; Jones et al., 2008; Räikkönen, Matthews, Flory, Owens, & Gump, 1999). Some of our participants alluded to motivation from other stroke survivors who have demonstrated resilience in dealing with the challenges of the stroke. Perceiving the success of others boosted their hope and optimism for recovery. Mostly, the participants showed self-efficacy, having confidence in their ability to manage the condition. This aspect corroborates work by prior authors who highlighted that self-efficacy was important for improving functional independence during rehabilitation (Cott, 2004; Robinson-Smith & Pizzi, 2003). High self-efficacy may help patients reclaim their ability to perform daily tasks, resulting in less dependence on others (Hellstrom, Lindmark, Wahlberg, & Fugl-Meyer, 2003). Self-efficacy, as underscored by Bandura (1977), provides resilience, pushing the individuals to remain strong regardless of minimal improvements as demonstrated by our participants.

The participants actively employed a variety of strategies to enable them to maintain their day-to-day activities in the face of impairment. Similar findings were reported by previous research where individuals dealing with chronic illness employed a variety of active coping strategies in response to their condition (Bury, 1982; Pound et al., 1999; Smout, Koudstaal, Ribbers, Janssen, & Passchier, 2001). Religiosity, as a coping strategy, has been shown to protect stroke survivors from emotional distress, which may in turn aid recovery (Giaquinto, Spiridigliozzi, & Caracciolo, 2007). Other research also suggests some positive influence of faith on chronic disabling conditions (Harris & Koenig, 2016; HG Koenig et al., 2001; H. G. Koenig, 2012; Unantenne et al., 2013).

Bodily states are also influential in supporting or impeding stroke recovery. Albrecht (1998) in his study on the paradox of disabilities showed that pain, fatigue and other medical conditions negatively affect the quality of life of individuals with disabilities. Our study showed that comorbid medical conditions adversely affected functional recovery in stroke. Similar findings have been reported in previous research

where comorbidities had a negative correlation with functional outcomes and gains in individuals following a stroke (Karatepe, Gunaydin, Kaya, & Turkmen, 2008). Earlier studies have associated the presence of diabetes and heart disease amongst stroke survivors with poorer quality of life, affecting the recovery process (Lai, Studenski, Duncan, & Perera, 2002; Mackenzie & Chang, 2002).

External mediators

Our results highlight that support and resources within the environment are essential for stroke survivors to engage in adaptive strategies with an aim to regain their lives. Health professional services and support, both orthodox and traditional as well as support from family members, friends, and the community, were necessary for the provision of emotional and instrumental supports that assisted the stroke survivors in their recovery process.

Support from family members was emphasised as significant in the recovery path. Pound and colleagues (1999), in their study of people living at home with stroke, highlight the family unit as a substantial resource in supporting stroke survivors. The support provided by the family became embedded in everyday life. The family assisted the stroke survivor in activities of daily living, such as feeding, toileting, and exercising. Similarly, the family acted as informal therapists by aiding with rehabilitation exercises, ensuring medications are adhered to and preventing further complications. The families in this study holistically provided support by not only supporting the stroke survivors in their personal needs but also by supporting the entire family unit. This is consistent with prior studies that found that family strength improved stroke outcomes (Cecil, Thompson, Parahoo, & McCaughan, 2013; Niyomthai, Tonmukayakul, Wonghongkul, Panya, & Chanprasit, 2010).

Our participants highlighted the need for better information about stroke and a clear recovery plan for health professionals. Our participants echoed other studies that

suggest a general dissatisfaction with the limited information provided by health professionals (Eames et al., 2010; Ing et al., 2015) and a lack of intervention plan post-discharge (L. N. Smith, Lawrence, Kerr, Langhorne, & Lees, 2004; Tholin & Forsberg, 2014). This dissatisfaction with services and a view that it hindered recovery has been reported in the Malaysian context (A. F. A. Aziz et al., 2014; Eng et al., 2014; Mohamed, 2010).

Stroke survivors highlighted that limited information about stroke from healthcare providers hindered recovery and expressed a need for encouragement and feedback on progress. Resource constraints and the fragmented services within the Malaysian health services meant that specialised stroke services are often unavailable; leading to a shortage of skilled staff to provide adequate and timely information on stroke to survivors and their families as well a structured rehabilitation plan (Kooi, Peng, Aziz, & Looi, 2016). It was essential to the stroke survivors that they acquired information about the cause and nature of their stroke. They needed information and structured rehabilitation plans that would aid in their recovery. The literature emphasised that uncertainty and limited knowledge of the condition could reduce motivation for rehabilitation and hinder recovery (Barker & Brauer, 2005; Laskiwski & Morse, 1993).

Participants credited the use of medication for helping them attain stable functioning of their pre-existing medical conditions and the use of traditional medical therapies for their stroke. It has long been part of the Malaysian culture to seek services of traditional healers when unwell. There is a deep-rooted belief in the benefits of traditional medicine for the treatment of chronic conditions and stroke in particular (Anuar et al., 2012; Z. Aziz & Tey, 2009; Siti et al., 2009). Most participants believe that stroke cannot be cured by orthodox medicine and rely heavily on the use of complementary and alternative medicine such as offered by traditional Chinese medicine; acupuncture, massage, herbs, and Islamic medicine.

All the participants had tried one or a combination of the traditional therapies. Most reported improvements in their condition and believed it had aided significantly in their recovery. A few, however, claim no benefit came from the treatments. Studies in CAM for stroke recovery have highlighted the benefits of acupuncture, massage, exercises and herbal or vitamin supplements (Chen, 1992; Han, Hong, Xie, Zhao, & Xu, 2017; Tseng, Hsu, Chiu, & Wu, 2017; Van Puymbroeck, Allsop, Miller, & Schmid, 2017; Winsor, Tsang, Krishnamurthy, & Kannan, 2018; H. Xu, 2000). These studies argue that CAM aids with symptom relief, increased mobility and improved mood in stroke survivors. The use of non-biomedical practitioners in stroke management in South-East Asia has been documented in a study conducted in Indonesia (Norris, Allotey, & Barrett, 2011). The study emphasised the acceptance and reliance of CAM in the management of stroke and calls for further exploration of its possible incorporation within international stroke management.

CAM practitioners undergo higher education programs that are accredited by the Malaysian Qualifications Agency (MQA) (Ministry of Health Malaysia). However, some practitioners are not certified by professional bodies and claim to inherit their skills through mystical powers or past traditional practitioners (Anuar et al., 2012; Ikram & Ghani, 2015). In 2007, the Malaysian Ministry of Health recognising the importance and need for CAM integrated CAM units within three hospitals. These units offer acupuncture, herbal medicine for patients with cancer, and the traditional Malay massage to help in the rehabilitation of post-stroke patients (Anuar et al., 2012). As of 2015, nine public hospitals in Malaysia integrated CAM units within their structure (Ikram & Ghani, 2015).

Implications for practice

The identification of factors that facilitate the recovery process provides a background with which healthcare providers can utilise to improve their understanding of the stroke experience, the strengths, and weaknesses of their patients. The practitioner's role in this is to support the stroke survivor by eliciting individual attributes which characterise their recovery and prepares the individual for successful self-management. Peer-provided services or support groups where some stroke survivors serve as role models for other survivors may help to foster hope for those struggling to accept their condition and recovery process. Practitioners should further promote hope and manage the expectations of their patients, conveying the message that a pre-stroke life might not be achievable but it is possible to live a fulfilling and purposeful life (Salyers & Macy, 2005).

Furthermore, boosting confidence in task performance may aid in averting deterioration and improve recovery. Individuals who are self-efficacious, feel confident in their ability to manage activities of daily living and thus will continue to perform necessary activities (Robinson-Smith & Pizzi, 2003). The progress made by individuals, albeit minimal may be vital in reinforcing an optimistic view that further improvements may occur.

Religion plays a central role for Malaysians, due to the spiritual, psychological and physiological comfort it provides. The results of the study show that improved healthcare provider's understanding and recognition of the importance of religious coping in stroke survivors may aid in their recovery. The literature highlights that some healthcare professionals may be reluctant to incorporate religion into rehabilitation as it is not a scientifically validated method of coping with disability (Johnstone et al., 2007; R. J. Lawrence, 2002; Sloan et al., 2000). However, given the context of this study, incorporation of religion into rehabilitation could support and maintain hope in recovery for the survivors and aid acceptance. This aspect, although not generalizable globally, may be an important point of consideration for individuals in locales where

religion plays a significant role in the day-to-day lives of the population. Strengthening stroke survivors' religious beliefs may aid them in coping with their disability by providing new meaning to their lives and lessening their emotional distress (Cigrang, Hryshko-Mullen, & Peterson, 2003; Johnstone et al., 2007).

As most strokes occur in the context of other medical conditions (Nelson et al., 2017), the recognition and management of comorbidities are essential for the achievement of successful recovery. The burden of comorbidities may slow rehabilitation progress. Health professionals, therefore, need to provide a holistic management approach where the individual is assessed and managed not just as a stroke survivor but as an individual considering other medical conditions he may have.

Complementary and alternative medicine therapy is a universal healthcare choice adopted by most individuals with stroke in Malaysia. In a Malaysian context, a more robust collaboration of healthcare professionals with traditional medicine therapists may prove beneficial for the rehabilitation of stroke survivors. The incorporation of CAM into conventional clinical practice may provide the stroke survivors with psychological relief, improved emotional regulation, increased mobility, improvements in activity and participation in activities of daily living.

It is essential to balance rehabilitation with adequate information and emotional support throughout the inpatient rehabilitation phase. The provision of information by health professionals, which should go beyond didactic information to include a well laid out rehabilitation plan for the stroke survivors and their caregivers is imperative.

Strengths and limitations

This study was conducted as part of broader research that investigated the experience of recovery from stroke, as such, the amount of data on the factors that mediated recovery was limited. The findings are from a small sample of stroke survivors whose

experience may not be reflective of the broader populace. However, the sample recruited fairly represented the ethnic and religious mix distribution of Malaysia. As this is a qualitative study, data interpretation could be subjective. However, the authors attempted to lessen bias using robust data collection and analysis techniques. This study contributes to the literature on recovery by offering insights into the contextual factors that guide recovery from stroke in Malaysia. The study, can, therefore, be considered a valuable contribution to the field of stroke care at the community level.

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Adaptive Invention: Independence and mobility through modifications



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ORIGINAL RESEARCH



Adaptive invention: independence and mobility through modifications

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ABSTRACT

Background: Stroke is a leading cause of disability that limits everyday activities and reduces social participation. Provision of assistive devices helps to achieve independence and social inclusion. However, due to limited resources or a lack of suited objects for their needs, individuals with disabilities in low and middle income countries (LMIC) often do not have access to assistive devices. This has resulted in the creation of purpose built innovative solutions.

Methodology and case content: This paper uses a single case derived from a larger ethnographic study of stroke survivors in rural Malaysia to demonstrate the role of assistive devices in shaping stroke recovery and how existing structures can be modified. Second, the concept of affordances in relation to structures within the environment, issues of affordability and accessibility of assistive devices for individuals in LMIC are discussed.

Findings and conclusions: Stroke recovery involves adapting to new limitations and discovering the support necessary to live life. These changes are influenced by a range of environmental factors. Healthcare professionals need to support stroke patients in identifying challenges and work to find innovative ways to address them. Stroke survivors may benefit from the use of an assistive device beyond its clinical function to participate purposefully in activities of daily living.

► IMPLICATIONS FOR REHABILITATION

- Stroke is a cause of disability that limits everyday activities and reduces social participation.
- Assistive devices help achieve independence, social inclusion and shape stroke recovery.
- Individuals with disabilities in low and middle income countries often do not have access to assistive devices and resort to innovative solutions that are purpose built.
- Stroke recovery involves adapting to new limitations and discovering the support necessary to live life as best as possible.

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Stroke; disability; assistive devices; affordances; low and middle income countries



Introduction

Stroke is a foremost cause of disability [1,2] and a common global health problem. A third of people have a fatal outcome following stroke [1]. A third make a full recovery or suffer only minor complications; others are left with a permanent disability [1,2] that limits everyday activities and reduces social participation. These limitations are mostly due to reduced motor functioning which is greatly affected in stroke and one of the most common impairments.

Research has revealed that, for stroke survivors, the most important goals have to do with independence, social inclusion and activity [3–5]. Ideally, the provision of assistive devices to help achieve these goals should be an integral part of rehabilitation care of a functioning health system. However, due to limited resources or a lack of suited objects for their needs [6], individuals with disabilities in low and middle income countries (LMIC) often do not have access to assistive devices. This has resulted in the creation of ingenious and innovative solutions that are purpose built [7]. These inventions usually spring from an urgency to fulfil unmet needs, lack of financial resources to obtain what is already

in the market, and lack of time, ability or resources to obtain professional services. Such inventions can provide positive contributions to sustainability as they are tailor-made to suit the user. Similarly, they respond to the constraints of the environment within which the individual resides.

Following stroke, many survivors live with acquired disabilities. In comparison to those with disabilities from birth, they tend to react differently to assistive devices [8] as they have to adapt to a whole new way of living and carrying out activities. The physical environment, particularly in LMIC settings is often not disability friendly [9]. As such, individuals with disabilities must recognize and respond to the affordances of their local settings/environments to devise ways to manage their daily life and to overcome obstacles. The International Classification of Functioning, Disability and Health (ICF) is a framework for describing and organizing information on functioning and disability, and identifies how impairments in body structure and functions activities can be influenced by environmental factors [10]. These factors – “affordances” – include technological products, as well as man-made changes to the environment, which can mediate or hinder

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functioning. Specifically, the ICF emphasizes that modifications to the environment, through accommodating the needs of individuals with disabilities, have the potential to lessen their impairment [10].

The concept of "affordances" was theorized by Gibson [11] as an opportunity for action offered by the environment: they are features of the environment that enable an individual to act upon, or within, that environment. In showcasing the interdependence of an individual's capabilities and their environment, affordances are perceived in an instantaneous unswerving way, such as handles for holding, knobs for rotating and buttons for pushing, as well as in the enduring features of the environment, such as in dirt tracks (rather than sealed roads) out of a village, the presence or absence of footpaths around a community, or in waterways that regularly flood, covering roads [9]. Gibson does not refer to any visible property, rather refers to all properties, perceivable or not that enable the user influence the realm. Therefore, affordances are not there to be perceived, rather they just exist. It is up to the user to unravel the utility presented by the affordance.

Gaver, in his paper entitled *Technology Affordances*, supports Gibson's notion that affordances exist irrespective of them being perceived or not [12]. He went further to suggest that the design of an item suggests its affordance [12]. Design in this sense is the information that specifies the affordance the item offers. Gaver separates affordances into four categories based upon the perceptual information available about them. "Perceptible affordances" are those that have information available such that one can perceive and act upon it. For example, the "PUSH" sign on a door panel provides information that for the door to open, it should be pushed. "False affordance" is an apparent affordance that provides no possibility for action. One example is a ramp with steps at either end, which does not offer the possibility of being used as a slope for wheelchair users. "Hidden affordance" suggests that possibilities for action exist, but the person involved may not perceive them. A door, whilst serving a primary purpose of separating spaces, could also serve as a stretcher to carry an injured person. "Correct rejection" happens when there is no affordance and no perceptual information to indicate it. The handle of a door that does not afford pulling nor does it have any information that might suggest it could be pulled [13].

A consideration of affordances is of importance in disability research and management, because it adds an integrated dimension of functional, sensory, visual and cognitive needs of individuals. The current research considers how the concept of affordances extends to how environmental factors and structures can impact acquired disabilities, such as stroke. Stroke survivors experience several motor losses due to damage to the brain, which often leads to the loss of independence and mobility. Such losses – and finding a way to minimize the impact of these – is vital to the stroke survivor [14]. The use of assistive devices for mobility provides the stroke survivor with some sense of normality, bodily control and inclusion [15]. A mobility device for a stroke survivor can reduce social and physical challenges [16].

Assistive devices are those items which aid individuals with disabilities by increasing, improving or maintaining their practical abilities in activities of daily living. Assistive devices can offer the user a chance to reintegrate into society and feel appreciated [17]. Various types of assistive devices exist which include: devices for mobility impairments such as wheelchairs, walkers and prostheses; braille embossers, screen magnifiers and readers for visual impairments; and hearing aids and listening devices for hearing impairment. Prior research has suggested that use of assistive devices augments and increases independence and improves the quality of life of its users [18–20]. Furthermore, other studies have

revealed that use of assistive devices such as mobility aids reduces the need for support services and the burden on caregivers [21,22]. Assistive devices can thus reduce disability and possibly supplement support services, thereby reducing costs.

On the other hand, several studies report high rates of assistive device rejection and abandonment due to lack of device functionality [8,23,24]. Inadequate functionality of the device could be attributed to the fact that assistive devices are designed for the impairment rather than the individual [25], and not all devices are suitable for all environments as demonstrated by Reidpath et al. [26]. Researchers within healthcare have proposed that users must be taken into consideration when designing assistive devices [11–13]. Anderson et al. demonstrated that individuals were often interested in understanding the therapeutic and functional benefits devices offered as well as their impact on their lives [27]. Several variables such as weight, range of movement, living arrangements and environment have to be accounted for.

Purpose

This paper aims to demonstrate the role of assistive devices in shaping stroke recovery and how existing structures can be modified to aid recovery. Second, the concept of affordances will be elaborated in relation to structures within the physical environment. Lastly, the paper will analyse the issue of affordability and accessibility of assistive devices for individuals in LMIC.

Methods

The participant, Ibrahim (not real name), in the single case study was interviewed as part of a larger ethnographic research that seeks to produce a rich understanding of the experience of stroke survivors in rural Malaysia. Drawing on Gibson's theory of affordances [11], the research centres on discovering the different ways affordances shape recovery and wellbeing following stroke. Participants for the broader study were drawn from the South-East Asia Community Observatory (SEACO) data. The observatory collected data on stroke survivors by using the F.A.S.T. criteria (Facial drooping, Arm weakness, Speech difficulties and Time) over two update rounds.

This study was conducted in a rural district of the state of Johor and consisted of detailed ethnographic studies of 27 individuals, conducted within and around the person's home to chart the complex individual, social and cultural needs of the participants. The single case study presented in this paper was chosen due to the unique context it provides in discussing adaptations to assistive devices, the independence they provide. Yin reveals that single case studies allow for a comprehensive exploration of a phenomenon within real-life context [28].

Two in-depth interviews were conducted with Ibrahim at his home. The first interview was semi-structured to enable free expression whilst capturing crucial aspects of the research [29]. The second interview was informal and unstructured to enable maximum free expression [29]. The interviews were translated and transcribed verbatim. A field-journal was kept during the study to guarantee the original context of data was maintained.

Results: Ibrahim's case study

Ibrahim, a 60-year-old obese man had his first stroke at the age of 28 in 1984. He was employed on a rubber plantation at the time. Discussions about his life before the stroke highlighted that he smoked heavily, consumed foods rich in fat, and was unaware of stroke or stroke risk factors. The occurrence of the stroke was a



Figure 1. Ibrahim's bespoke wheeled chair.

shock for him and his wife partly due to his young age at the time. Following his stroke, it was discovered that he had been hypertensive, had diabetes type 2 and high cholesterol. The stroke left him with impaired functioning on his left-hand side. He could no longer walk and became house bound. Simple activities of daily living were very difficult or impossible for him to accomplish by himself, so Ibrahim was forced to depend on others for feeding, toileting, and getting to bed. As his dependence on others grew further, his family requested for a wheelchair from the department of social welfare. To obtain the wheelchair, Ibrahim had to obtain supporting documents from the hospital and register as a disabled person. Initially he rejected the wheelchair, as it put a label of disablement on him. He felt ashamed to be seen in the wheelchair and would rather remain indoors.

Reluctantly, to provide mobility, participation and some sense of independence, he began to use the device. Having limited mobility without the wheelchair, Ibrahim became completely dependent on his assistive device, to the point that he spends all day in it and showers in it, only leaving the wheelchair when he needed to relieve himself and to get into bed. Using the wheelchair involved postural changes; from lowering himself into the chair, to shifting positions whilst sitting to getting out of the chair. These tasks all required adaptations. Ibrahim experienced a change of balance, whilst sitting in the wheelchair, especially when he had to change directions or make a turn. Due to the unavailability of a physiotherapy centre close by, he had to learn to use the wheelchair and adapt to it on his own without the help of health care providers. Ibrahim's lightweight manual wheelchair was not appropriate for his weight, postural and functional needs. He reported back and shoulder pain during its use, blisters had begun to form on his backside. During the early stages after stroke, he sat directly on the wheelchair seat, but with prolonged sitting, he developed pressure sores. He was unaware of the existence of pressure-relieving manoeuvres or cushions. In undertaking his modifications, he had the seat cushions replaced with a firmer orthopaedic foam to alleviate some of the distress caused by prolonged sitting. He had difficulty with independent propulsion and transferring out of the wheelchair. Due to his



Figure 2. Ibrahim's bespoke wheeled chair.

weight, the wheelchair did not provide stability and the mobile rear wheels did not enable propulsion. Ibrahim requested a custom-made power wheelchair from the state but was unable to get it and he could not afford one. Consequently, he was forced to innovate to gain mobility that would enable him accomplish activities and achieve participation.

Adaptive invention

To make up for his postural and mobility difficulties, Ibrahim converted a chair in his home into a wheelchair. The modifications took time, with adjustments and readjustments made to cater for his needs. The chair was a wide-frame armchair made of wood and had two cushions. Reinforced with steel and with wheels fitted to the chair legs, the rear wheels were fixed as in a two-wheel drive vehicle to give him adequate support during propulsion. The wheels positioned the chair to a height that would enable him transfer in and out of bed. The seat cushions had been replaced with firmer foam to alleviate pressure sores. When asked where he obtained his wheeled chair, Ibrahim responded:

It's the single chair of a sofa set in the house.... I had a welder make it.

The chair was made around 1988. The changes to the wheelchair were thought of by Ibrahim but without the skills and physical ability to make the changes, he had a welder within the community to make the changes. Due to Ibrahim's innovation in personalizing a mobility device to suit his own needs, he has been able to spend long hours in the chair, affording him independence and mobility (Figures 1 and 2).

In 2003, Ibrahim suffered another stroke, this time affecting the right side of his body. Not as severe as the first stroke, it still compounded his situation as both sides of his body now had diminished functionality. He became even more dependent on mobility assistance; when asked why he continued to use the modified wheeled chair and not a normal wheelchair, he explained:

The normal wheelchair with the big wheels was difficult to use on my own... and it was not stable enough... I used to sit in it (the sofa chair) comfortably... so when the wheelchair wasn't helping me... I got the idea of adding wheels to this chair.

Nevertheless, he had to learn to navigate the wheelchair around the house and its environs. Living in a single story large house, he was not required to make any changes to the living

environment. The doors were wide enough for access and there were no stairs; the slight differences in levels between rooms were simple to navigate. His lightweight wheelchair was not manoeuvrable in confined spaces, i.e., the home, nor did it provide stability or power to negotiate obstacles outside the home. Over the years, with wear and tear, he has had the wheels and cushions changed. He also had the steel frame replaced and reinforced several times.

Having and using the wheelchair did not negate total dependence for Ibrahim, indeed he still needed help from others for activities of daily living but it provided him with a certain degree of freedom to navigate the environment as well as improved ease of access to facilities.

Discussion

Individuals with neurological conditions, such as a stroke, may experience negative effects on their body structure and functions, as well as disability. These impairments are associated with decreased mobility, increased dependence on others, and a decrease in their ability to carry out activities of daily living. Immobility, in particular, affects one's participation in family life and the wider society, which negatively impacts health and quality of life [30].

For many individuals living with a disability, a wheelchair serves as an assistive mobility device. However, the wheelchair is more than that, it is also a means by which they can attain independence and experience social inclusion. Independent mobility allows individuals partake in activities of daily living, both at the household and the community level. Without it, one might be unable to live an inclusive life. The wheelchair is thus a facilitator of both physical and social functioning. In this way, it can afford greater engagement with the immediate environment.

A wheelchair is a seating assistive device that should stabilize, support and enhance functionality for the user. Certain factors must be considered in the functionality and hence prescription of a wheelchair, such as body weight and the amount of time spent in the wheelchair. Individuals above 100 kg are usually over the weight limit for most wheelchairs [31], and require reinforcement of the wheelchair to accommodate the body weight. Global increases in obesity rates [32] present new challenges in terms of assistive mobility technologies. With disability, physical ability tends to decrease which could lead to atrophy and diminished muscle strength [33]. Thus, overweight individuals may require more energy to propel a manual lightweight wheelchair [34].

Individuals with dependent mobility would require a wheelchair that provides an all-day seated milieu. The wheelchair therefore must have the ability to accommodate different positions for pressure relief and comfort. Some manufactured wheelchairs attempt to accommodate these factors, and are fitted with such features as an add-on-rear wheel to aid propulsion for people who propel manual wheelchairs. In LMIC, local infrastructure and environments are not always suitable for devices such as wheelchairs [26,35], ditches, hills, untarred or muddy roads, absent or cracked pavements all contribute to make wheelchair propulsion difficult and may reduce the life span of the wheelchairs [26,35]. Due to these factors, some individuals rely on their own innovativeness and resourcefulness to enhance mobility. Ibrahim's wheeled chair offers one example.

Ibrahim's bespoke wheeled chair

Ibrahim's stroke brought on a sudden change in physical ability that required the use of an assistive device. Prior research has

demonstrated that stroke patients experience life course disruption that is amplified during the initial recovery process [36,37]. A number of individuals with disability undergo the initial reluctance to accept an assistive device [17]. Stenberg et al. also studied the acceptance of mobility devices and found that stroke patients had worries about self-identity and social acceptance regarding the use of mobility devices [38]. For Ibrahim, the wheelchair represented a public marker of physical impairment affecting his self-identity. He had to undertake a process of self-renegotiation to accept the wheelchair as an assistive device rather than a marker of impairment. The wheelchair afforded him mobility, independence and a means to rebuilding his self-identity.

The current case study highlights that assistive devices require adaptations. Ibrahim experienced a radical change, from fully functional to a person with impediments, from having unaided mobility to being dependent on a device. Having lived in his wheelchair for almost three decades, it was not possible to gain insights into its impact in isolation as the wheeled chair had become a part of his life.

These adaptations of the material (physical) device extend to its usage. Individuals who use wheelchairs are at a long-term risk of acquiring decubitus ulcers due to a combination of pressure and friction [39], and Ibrahim discussed having pain whilst using the wheelchair as well as pressure sores from prolonged sitting. In Ibrahim's case, he obtained a wheelchair but without the necessary support to aid him in its use. Health care practitioners such as occupational and physiotherapists can aid individuals in the proper use of assistive devices such as wheelchairs [40]. They help the individual modify and adapt them to their specific needs to enable optimal use [40].

Financial constraints are a significant barrier for acquiring assistive devices for many [41]. The World Health Organization (WHO) reports that in LMIC, only 5–15% of individuals who need assistive devices obtain them [42]. This clearly highlights the unmet needs of people with disabilities as regards assistive devices. Individuals with disabilities more often than not procure their assistive devices themselves [43], through out of pocket spending. In most LMIC, however, due to limited resources, assistive device provision is not an essential part of the healthcare system. The provision of these devices is more often absorbed by international aid agencies and other non-governmental organizations. In most instances, the devices are produced without considering the specific needs of people and the environment in which they live. As Reidpath et al. demonstrate, most wheelchairs are of limited use on dirt tracks or homes with elevated verandas [26]. A great number of wheelchairs in LMIC, contributed to the communities by international donors, are rejected or abandoned by the user because they are not suitable for use within the environment [44,45].

This was certainly the case for Ibrahim. He was provided with a wheelchair at no cost by the welfare department, however, the wheelchair did not serve his purpose. Although he requested for another, more suitable (powered) wheelchair, this request was denied because the State welfare department did not have sufficient resources. The cost of obtaining a power wheelchair privately was beyond his financial means.

Implications for LMIC

The WHO's *Guidelines on the Provision of Manual Wheelchairs in Less Resourced Settings* [46] seeks to inform the delivery of appropriate care for individuals with disabilities by addressing the challenges confronted in the provision and distribution of wheelchairs. By adapting the guidelines into practice, health providers can be better equipped to provide suitable wheelchairs that fit the individual's

needs. The guidelines outline eight steps to appropriate wheelchair provision: (1) referral and appointment; (2) assessment; (3) prescription; (4) funding and ordering; (5) product preparation; (6) fitting; (7) user training; and (8) maintenance, repairs and follow up.

Although Ibrahim's wheelchair was obtained before the guidelines came into play, his journey clearly demonstrates the valuable input such guidelines play in less resourced settings. A referral network that would allow health care providers to identify Ibrahim's need of a wheelchair was not in place at the time of his strokes, nor did his stroke management include an assessment and prescription for wheelchair use. In fact, despite considerable post-stroke disability, Ibrahim's wheelchair was only obtained from the social welfare department at his family's request. This drew upon a letter from the hospital, which did not include information prescribing his particular needs. Unsurprisingly, as the wheelchair obtained was not adjusted to support Ibrahim's functional and postural needs, it did not fit him. Ibrahim was not trained on how to use the wheelchair, either for mobility or in terms of how he (or a family member) could adjust it, nor was any follow up around this provided by health professionals. As a result, the health system was unaware of the unsuitability of Ibrahim's wheelchair, and his request for another wheelchair that would suit his needs was denied due to lack of funding. His case study highlights inadequacies in wheelchair provision and support around this at each of the eight steps outlined by the WHO. This is especially concerning given the comprehensiveness of the Malaysian Health Care System and relative wealth of Malaysia as an upper Middle Income Country [47,48].

In LMIC, where assistive devices such as wheelchairs are expensive and often not accessible, individuals are discovering innovative ways to address the issue. In Rwanda, for example, two designers, Josep Mora and Clara Romani, built low-cost wheelchairs from locally available materials [49], substituting a conventional wheelchair seat with a plastic chair. Using cheap and readily available plastic chairs and buying only the wheels dramatically reduced the cost of the wheelchairs. Costs were further reduced as a workshop was set up where users took part in making their wheelchairs, thus ensuring they could maintain and repair it if broken. Hospital staff were also trained in the manufacturing of the wheelchairs.

Similar efforts have been undertaken elsewhere: Des La Rance, a member of Rotary International, a global network of community volunteers, recognizing the need for affordable wheelchairs in LMIC, designed low-cost wheelchairs made from used bicycle frames and wheels [50]. Over 3000 wheelchairs have been distributed to Southeast Asia. These examples of wheelchairs made for LMIC, speak not just to the design and making of affordable wheelchairs but also to job creation. Ibrahim's modification of a chair to make a wheeled chair with the help of a local welder strengthens the argument. Workshops employing community artisans and technicians to build, repair and maintain wheelchairs may help create an economic opportunity for local communities.

Gibson's concept of affordances is relevant in the context of such adaptations. He states that at any given moment the environment affords a host of possibilities [11]; accordingly, items in the environment provide individuals with the ability to perform intentional actions in relation to themselves. This infers a shared liaison between awareness of the object and actions. Understanding this relationship – between the object and possible actions – allows for adaptive control of action and the existing structure. Events may also provide affordances or contribute to an affordance [9]. Ibrahim's resolution of mobility and independence dilemma relied on his ability to appraise his situation, understand his options, mobilize personal and social resources, and employ

adaptive, problem-solving actions. The sofa chair in his home was a hidden affordance; as a simple sofa chair, the possibility of it being used as a wheelchair was not initially perceived. In the case of such hidden affordances, the possibility for action is from other evidence [12], here, the use of the sofa chair for sitting generated Ibrahim's idea to adapt it for mobilization. This discovery of the assistive potential of an existing structure demonstrates how the environment can shape recovery: whilst, for an able-bodied person, the existing sofa chair served the purpose of "sitting", for Ibrahim, the sofa chair afforded him the ability to move around.

Ibrahim's wheeled chair, although able to serve his needs, could be significantly enhanced to afford greater independence and mobility if the eight steps of appropriate wheelchair provision are taken into consideration. Proper fitting, preparation and maintenance of the low-cost wheeled chair would ensure that quality is not compromised and hence that the physical and practical needs of Ibrahim addressed.

Implications for practice

This study highlights the interactions of the ICF components (body functions and structure-activities-participation-environmental factors) on individuals' lives: the occurrence of a stroke may change an individual's body structure and functioning due to decreased muscle tone and movement which in turn impact on the individual's participation in activities. These activities, particularly those regarding mobility, lead to dependence on others and social isolation – yet, as Ibrahim's case suggests, they can be mediated by environmental factors.

A consideration of affordances in resolving health issues enables identification of the role of environment as an integrated whole providing support during the recovery process. In Ibrahim's case, affordances were provided by the structures within his everyday living environment. Subsequently, as items seem to elicit potential actions, they should be viewed not as mere objects, but as objects with possibilities for actions to achieve specific goals. The challenge for healthcare providers is to recognize the potential for affordances within the lived environment and support innovations in actions.

Understanding stroke survivors' experiences of recovery provides important information to clinical practice about how contexts influence a person's actions, decisions and behaviours. In sharing his story, Ibrahim demonstrated how bespoke assistive devices can improve the quality of life of individuals with disabilities. Similarly, his story provided insights into the pros and cons of wheelchair use, and the adaptations he made to overcome the challenges presented. Through engaging with patients' stories, healthcare professionals can support individuals with disabilities to create positive futures.

Conclusion and recommendations

Stroke recovery requires changes in the physical, social and, emotional aspects of life [51,52]. It involves adapting to new limitations, learning new skills or relearning old ones, and discovering the support necessary to live life as best as possible. These changes are influenced by a range of environmental factors. Healthcare professionals need to support stroke patients in identifying their own challenges and work to find innovative ways to address these. Stroke survivors may benefit from the use of an assistive device beyond its clinical function. Devices such as wheelchairs may provide the ability to participate purposefully in activities of daily living, reconstructing their sense of self-worth and wellbeing.

In resource-poor settings, where the availability of assistive devices may be limited, the construction of low-cost bespoke

devices may improve the quality of life of people with disabilities. The pragmatic urgency for rebuilding a sense of self and independence allows for existing structures within the environment to shape recovery and improve functioning. The myriad material, social and emotional affordances within the community allows for the reconstruction of lives after a stroke. To ensure that assistive devices such as wheelchairs are appropriate, they should be made to suit the environment and the user. An empathic and participatory design approach that involves users, engineers and rehabilitation specialists could provide a means to resolve some assistive device-related issues. Such research could help engineers in the development of better solutions because it involves resonating with and gaining insights into the daily challenges of mobility and independence of the user. Such insights could result in the creation of low-cost, low-technology assistive devices, which have been identified as beneficial and useful for the majority of the population [53]. Additionally, the gap between functionality and aesthetics could be bridged as users would be able to recommend the appearance they would like their assistive devices to have. Optimal technical standards should be adhered to in the provision of assistive devices to ensure that they are of the appropriate and reliable quality for its users. Guidelines such as those developed by the WHO [46] should be taken into consideration.

Adequate information should be provided to individuals who use assistive devices. Healthcare professionals and technical personnel must ensure that the proper use of the device, possible challenges, and how to overcome them are made explicit to the user. Follow up by rehabilitation and technical personnel would also help ensure safe and efficient use as well as provide further training and support to the user. Equally, follow up appointments would serve as an opportunity to evaluate the assistive device; if deemed inappropriate or no longer appropriate, a new one may be prescribed.

More research in LMIC may aid the development of low-cost, effective approaches and policies that guarantee the availability, accessibility and affordability of assistive devices to all that need it. Such research may enable the development of a holistic, coordinated national healthcare plan to address the need for assistive devices. International organizations would also need to support national plans so parallel systems are not created. Similarly, adopting an approach to strengthen the capacity for provision of assistive devices by empowering technicians such as mechanics and welders with the skills to build the creates job avenues that may booster the economic development of communities.

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Summary

This chapter explored the meaning of recovery for stroke survivors and identified the factors that facilitated or hindered the recovery process. Participants conceptualised recovery as feeling better, as an impossibility and as restitution. The study highlighted several factors that shaped stroke survivors' recovery path which included hope and optimism, self-efficacy, coping strategies, coexisting medical conditions, family support, information from health professionals and treatment modalities. A key finding was that most participants identified coping strategies that strengthened internal traits of resilience and determination were helpful to their recovery. The participants emphasised that constant diligence was required to achieve recovery. In the next chapter, I discuss in further detail the coping strategies utilised by the stroke survivors.

Chapter 7.

Coping strategies of stroke survivors in rural Malaysia

Overview

The impact of the impairments brought upon by a stroke often has a profound effect on life, affecting daily routines, relationships and social integration. The relatively long duration of the impact of stroke may require certain lifestyle adjustments or changes while having to live with the physical, emotional, social and financial consequences of stroke. These impacts may be moderated using different coping strategies, which may in turn influence recovery.

A key finding in the previous chapter was that participants used a variety of coping strategies in the recovery process. In particular, participants highlighted the use of positive coping strategies as significant in their stroke illness trajectory. In this chapter, presented as a journal article submitted to *Neuropsychological Rehabilitation* I aimed to explore the variety of coping strategies employed by the stroke survivors.

Stroke recovery in rural Malaysia: coping strategies employed by survivors

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Reidpath

Abstract: Background: Understanding the course of recovery following stroke requires a consideration of the emotional, physical and cognitive processes involved. Individuals who have suffered a stroke may face life-long stressors such as the disability brought about by the stroke and social reintegration that prompt the development and adaptation of coping strategies. **Objective:** This study aims to provide an understanding of the coping strategies used by survivors of stroke. **Methods:** An ethnographic (qualitative) methodology was used for the research. Data were collected via semi-structured interviews conducted in participants' homes. **Results:** Three main themes emerged from the study; the first theme, *the centrality of religion* involved using faith to make sense of the condition and foster acceptance. The second theme, *proactive behaviours*, involved participants actively adopting new lifestyle behaviours and seeking solutions to enable them overcome challenges. The third theme, *the power of support* involved seeking emotional, instrumental and informational support. **Conclusion:** Our study cohort demonstrated considerable resilience regarding positive attitudinal changes, self-efficacy and continual seeking of recovery. It may be possible that strengthening positive coping strategies through interventions tailored to specific needs of individuals, post-stroke may enable them cope better with their condition.

Introduction

Understanding the course of recovery following stroke requires a holistic understanding of the emotional, physical and cognitive processes involved. Individuals who have suffered a stroke may be faced with life-long stressors such as the disability brought about by the stroke, fear of another stroke and social reintegration (Blomgren et al., 2018, Townend et al., 2006, Aguirre, 2018) that prompt the development and adaptation of various coping strategies. Emphasis on coping has been a key interest in research for several years (Taylor, 1990, Holahan et al., 1996, Lazarus and Folkman, 1984, Lazarus, 2000, Hobfoll, 1998), especially in health psychology. Coping is defined as an alleviating element that empowers an individual to adapt to a stressful situation (Lazarus and Folkman, 1984, Billings and Moos, 1981). Coping strategies are thus the on-going efforts made at the psychological and behavioural levels that enable them to tolerate and reduce the negative effects of a crisis (Lazarus and Folkman, 1984).

Coping efforts in the context of chronic conditions have focused on alleviating the strain caused by the illness or disability. Studies have examined the role of coping in heart disease, cancer, chronic pain, amputations, and traumatic brain injury (Livneh, 2000, Livneh and Antonak, 2005, Desmond, 2007), and have demonstrated that individuals utilise a wide range of coping efforts in dealing with their conditions. In providing a holistic approach to recovery and rehabilitation for individuals living with stroke, it is essential to facilitate their accommodation to and acceptance of their conditions.

Coping following a serious, chronic illness such as stroke is a fundamental issue, predicting rehabilitation success (Meng et al., 2006) as coping strategies may aid the individual in managing the consequences of stroke (Donnellan et al., 2006). In aiming at recovery and well-being following a stroke, it may be necessary to strengthen the stroke survivor's coping resource as they may offer improved psychosocial adaptation to

impairments brought on by the stroke (Livneh et al., 2004). When individuals become overwhelmed due to their impairments, they can become more vulnerable to subsequent psychological issues (Zimmer-Gembeck and Skinner, 2016). Consequently, it is essential, as part of rehabilitative stroke interventions to determine the coping strategies of stroke survivors. Understanding the coping strategies that stroke survivors use to manage everyday living can advise the development of rehabilitation methods with the aim of recovery and well-being. Healthcare professionals have a role to play in supporting their clients as they seek out and implement optimal strategies that will aid them.

Several researchers have sought to establish the dimensions of coping. Lazarus and Folkman (1984) classified coping into problem-focused and emotion-focused coping (Lazarus and Folkman, 1984), arguing that while both strategies may be used in stressful situations, problem-focused coping seeks to actively remove the stressor or make it more amenable, i.e. control the stressor. For example, engaging in physical exercises to improve motor function. Emotion-focused coping, for example, distraction and social withdrawal, seeks to regulate the effects of the stressor by managing the emotional reactions of the stressor such as despair, sadness and anger. Other researchers, however, argue that this categorisation is too broad in describing and differentiating the various coping strategies individuals use (Skinner et al., 2003).

To address these limitations, Carver and colleagues (1989) added two dimensions to those proposed by Lazarus and Folkman: seeking social support and avoidance coping (Carver et al., 1989). Social support was conceptualised a different dimension whereby individuals obtain advice or seek emotional support from others. Avoidance coping, which includes behavioural and cognitive responses, reflects attempts to avoid dealing with the stressor or its associated emotions (Zimmer-Gembeck and Skinner, 2016). For example, being in denial of the impact of the stressor and disengaging from activities that would alleviate the situation. The

conceptualisation of coping in this study includes the viewpoints of Lazarus and Folkman (1984) as well as Carver, Scheier and Weintraub (1989) to capture a broad range of responses to the life disruptions produced by a stroke.

The literature is replete with the importance of coping in healthcare. However, there are limited studies on coping by stroke survivors in Malaysia. Rehabilitation services for people with stroke in Malaysia are primarily hospital-based and for a limited period due to resource limitations (Nor et al., 2016). This constraint and limited access to post-stroke care in the community has resulted in stroke survivors being left to manage the impact of the stroke on their own (Nor et al., 2016, Kooi et al., 2016). The literature offers limited information about how individuals who have suffered a stroke cope with the consequences of stroke. The burden of post-stroke complications, such as depression poses threats to the already overwhelmed healthcare system and increase psychosocial strain on stroke survivors (Kooi et al., 2016). There remains a need to identify the coping strategies employed by Malaysian stroke survivors to support the design and development of appropriate and effective rehabilitative interventions.

Our study, therefore, aimed to provide an understanding of the coping strategies used by survivors of stroke within context. The present study focused on the variety of coping strategies used by individuals who have suffered a stroke to begin to address the paucity of research around coping within Malaysian stroke survivors. The study aims to develop a knowledge base around stroke recovery that can contribute to the discourse of recovery from chronic illness. For this study, coping strategies referred to the set of actions and behaviours utilised by the stroke survivors in their daily lives to overcome (or not) the challenges brought about by their condition.

Methods and design

The data on which this paper draws is part of a larger project that investigated people's experiences of stroke recovery in rural Malaysia. As part of the broader context of recovery, we sought to identify the coping strategies used by individuals in the aftermath of a traumatic event (stroke). An ethnographic (qualitative) methodology was used for the research, to gain an in-depth understanding of individuals' experiences in context, allowing them to reflect on social and cultural influences and their constructed experiences (Marshall and Rossman, 2014, Denzin and Lincoln, 2017). This approach is therefore suitable for understanding coping as a consequence of social interactions. Second, ethnographic methods provide subjective knowledge about phenomena and, as such, may lay the foundation for the development of culturally-appropriate interventions (Green and Thorogood, 2013).

Participants and Setting

The study was undertaken in a health and demographic surveillance system (HDSS); [name withheld for review] situated in [name withheld for review], Johor state, Peninsular Malaysia. The HDSS operates in 5 sub-districts of [name withheld for review]. Sixty-four potential individuals were identified through a household survey as having suffered a stroke or stroke-like symptoms. To be eligible for the study, participants were required to have a formal diagnosis of stroke from a medical doctor, be a resident of one of the five HDSS sub-districts, could communicate personally or through a caregiver, and could provide informed consent. Twenty-seven participants consented to be part of the present study. The descriptive data collected from participants is shown in Table 1 below. The twenty-seven participants comprised of 21 males and six females. Of these, 20 participants were of Malay origin, four were Indian,

and three were Chinese. Age ranged from 37 to 83. Duration since the stroke was from 3 weeks to 32 years.

Table 1: Participant demographics

Characteristics of participants	Number of participants (n=27)
Gender	
Male	21
Female	6
Ethnicity	
Chinese	3
Indian	4
Malay	20
Age range (at time of the first interview)	
30-39	1
40-49	3
50-59	8
60-69	9
70+	6
Years since stroke (at time of the first interview)	
<1	2
1-5	18
6-10	1
10+	6
Religion	
Buddhism	2
Christianity	1
Hinduism	3
Islam	20
None declared	1
Marital status	
Married	25
Widowed	1
Single	1
Main caregiver	
Spouse	25
Son	1
Daughter-in-law	1
Education	
No formal	2
Tertiary	1
Below tertiary	24

Data Collection and Analysis

Data were collected via semi-structured interviews conducted in participants' homes, which lasted in duration from 30 minutes to 2 hours per session. All participants took part in two or more interviews (between 2 and four visits). For all participants, at least one family member was present during the interviews and contributed to the conversation. Interviews commenced with a question about the participant's health and Well-being. Interview questions probed numerous aspects of the recovery process. These included questions around the evolution of the stroke, the services they received, and treatment management modalities. Also, participants were asked about how they coped with their stroke, the way they lived their daily lives, and how they felt about their condition.

©Talking mats and observations, captured through the use of field notes supplemented data from the interviews. For participants who experienced aphasia or dyspraxia, ©Talking mats were specifically used, as they are occupational therapy tools that use picture symbols to assist individuals with (or without) communication difficulty to comprehend and respond better to questions (Murphy and Oliver, 2013). The mats also served the purpose of sustaining participants' attention and allowing them to reflect on their views at their own pace (Murphy et al., 2005). Extensive field notes comprised of participant observations, the emotional condition of the stroke survivor and family member(s), summary and impressions of the interview, and points of interest to follow-up. Interviews were audio-recorded, and later transcribed and translated into English. The data were then coded and analysed by the first author, using the principles of thematic analysis (Braun and Clarke, 2006). First, familiarity with the content of transcripts and field notes was ensured through multiple readings of the data, before an initial open coding process was employed to identify initial descriptive

codes that captured the essence of the data. Subsequently, these codes were defined and, where relevant, grouped (by similarities) into salient sub-themes to ensure that there were no duplicate themes. These themes were then reviewed and checked against the initial codes before the final themes were refined, named and defined. Throughout the analysis process, the first author discussed the content of the codes, identified themes and text extracts with the other authors to ensure accurate representation of participants' experiences.

Ethical Considerations

The human research ethics committee of one university [name withheld for review] provided ethical approval for this study (Approval Number withheld for review). Prior to commencing the study, information was provided to participants and their caregivers about the research, including information on the study aims, the methods to be used, the voluntary nature of their participation (principles of informed consent), the option to be or not to be recorded or photographed, and the confidentiality of the information they provided. Consent to participate was then obtained verbally from all participants. Pseudonyms substitute the names of all the participants included in the results.

Results

Three main themes emerged from the study; the centrality of religion, proactive behaviours, and the power of support. The first theme, *the centrality of religion* involved using faith to make sense of the condition to foster acceptance, seeking help from God and interpreting the condition from a religious perspective. The second theme, *proactive behaviours*, involved participants actively adopting new lifestyle behaviours and seeking solutions to enable them to overcome the challenges associated with stroke. *The power of*

support involved seeking emotional, instrumental and informational support from various sources. Less frequently utilised strategies were also reported by participants; these are discussed later, under *Other strategies*, which are also presented at the end.

The Centrality of Religion

All but one participant in this study professed religious affiliations and described how religion played a role in coping with their changed body after a stroke. Participants found meaning, accepted their condition and found the strength to cope with religious beliefs embedded in their lives.

Turning to religion: Putting their trust in God meant performing their religious obligations and praying to God for recovery. For the Muslim participants, their religious practices involved performing the *salah* (the obligatory Muslim prayers, performed five times daily), supplications (humble petitions to God), *zikr* (mantras to praise and thank God), and recitation of the Qur'an. Yaqub (aged 66-years) designated a room in his home for religious activities. He would perform his *salah* and read the Quran daily in the room. His caregiver mentioned how his Quranic recitation had increased since the stroke:

He went for massage, but also, after Maghrib prayers [just after sunset], he will recite the Quran. Before the stroke, he did that; after stroke, he did even more. Much more. Yaqub added, "In Sha Allah (by the will of God), it can really help. It can; it can help eradicate, forget those negative feelings".

This turning to religion for coping seemed to be unrelated to pre-stroke religiosity. Dram, a 47-year-old Buddhist, rarely attended temple or participated in activities of worship. After the stroke, he began to look more into his faith. He regularly visited the temple for prayers and invocations and made offerings in the form of food or money there, hoping his good deeds would leverage the provision of recovery from God, *"I feel*

better, going to the temple. I have more faith in recovery. I can stand now (he stands to support himself with the arms of his wheelchair). Before, I can't". Yaqub and Dram turned to religion to help cope with the impact of the stroke. Their experiences affirmed the potential value of maintaining and renewing a relationship with God. The stroke represented a spiritual awakening and an opportunity to make a new connection with God for Dram. He attributed his recovery, evident through his ability to stand, to this renewed relationship. For many study participants, their spirituality provided solace, peace, and strength during the recovery trajectory.

Acceptance: Several participants highlighted acceptance of their stroke and accompanying disabilities as a way of coping. In this study, participants' religious beliefs fostered acceptance of their condition. Yusuf talked about accepting the stroke as the decree of God, *"If you ask whether I am angry towards the sickness, no. It is given by Allah, so we just accept it"*. For participants, acceptance meant living with the impairments of the stroke, without despair or attempts to avoid it. Their religious beliefs absolved them of these feelings of control over their condition and recovery by believing that God, and not them, was in control. In doing so, participants accepted that the stroke and their recovery was beyond their mortal ability, and instead reflected the will of God. Recovery was thus attributed to the will of a higher power. Shuaib, a 68-year-old deeply religious man, reflected, *"This is Allah's power, [I] can't fight Allah's power. Ah, if Allah wants me to recover, I definitely will"*. For Shuaib, determination to recover and performance of regular exercises to aid with recovery reflected an Islamic perspective of accepting and coping with life issues. Islam places the individual at the centre of taking responsibility and working towards change and accommodation of life affairs while emphasising the individual's relationship with the God and complete reliance on God in all affairs of life. Thus, the respondents were inclined to express optimistic acceptance rather than pessimistic acceptance of their condition. They

accepted the fact that they may never fully recover from the effects of the stroke but that they may get better.

Religious social support: Religious social support, that which is received because of an individual's religious beliefs and participation in religious activities (Barrett, 2013), was mentioned by some participants. Several Muslim participants received financial and material aid from the state Islamic religious council and their community mosques. The state Islamic religious council aids the needy from monies collected as *zakat* (annual payments made under Islamic law, used for charitable and religious purposes). The council provided Muslim participants, on request, with aid in the form of monthly finances. The mosques, on the other hand, aided the stroke survivors who approached them for help with food and household items. Arjun, a 77-year-old Christian, was a voluntary worker at his church, his religious activities were central to his life. He received monthly material support regarding food and household supplies as well as emotional support from the members.

In addition to material support, religious networks provided the participants with emotional support. The members could empathise with their condition from a faith-based perspective offering solace and encouragement to them. Religion, being an inherently social phenomenon bring individuals who share a common perspective together in a group. Participants stressed the need for religious contacts as group prayer and discussions helped them maintain their faith and with that, coping with their daily challenges.

Proactive behaviours

Where participants adopted a problem-solving attitude despite their limitations and frustrations, they appeared less distressed and better able to adjust to the challenges

brought about by the stroke. The participants reported some active/ behavioural strategies as helpful throughout the stroke trajectory.

Self-efficacy and determination: Most participants in this study declined to accept their impairments passively. Instead, they sought resourceful, innovative ways of creating and finding self-management ways of aiding their recovery. Participants' reflected on feelings of helplessness and dependency on others that triggered a change in attitude and led to independent functioning, as Shuaib described:

I laid here, on top of the mattress for nearly three months, I couldn't walk. My wife massaged me, took care of me, fed me. I couldn't get up, couldn't get up. After that, I thought to myself; you can't be like this. I must fight back. Then I got up and started moving about... I walked to the mosque. Early in the morning, before sunrise, I started going around, walk, and walk. I wanted to fight back. This condition, you must fight back. We can't just sit, can't.

Because they lived in rural Malaysia with insufficient access (if any) to rehabilitation centres and equipment, little or no physiotherapy, and limited information on how to exercise, participants took it upon themselves to perform exercises at home with the aid of household equipment. Maaruf (72-years-old; stroke at 56), for example, converted an old baby hammock into an arm exercise device:

It's been a long time, this stroke. The [rehabilitation] centre is in the city, far, I couldn't go. But I needed to do exercises to strengthen my arm and leg. I used to hold the [window] bars and go up-down, up-down. Difficult, but I did it. This [hammock] was no longer of use; my grandchildren used it. So, we tied a cloth and rope, and I would pull it. It helped my arm become stronger.

Chuanli (aged 83) had his son make a contraption from the ceiling to aid him with arm exercises as well, "We did treatment, this one (pointing to the contraption). Do it yourself. If you have to go for professional treatment, [you] need money. This one [was] free of charge, made it ourselves".

Ibrahim, a 60-year-old man who had suffered two strokes affecting both his left and right sides, was wheelchair bound for close to 30 years (see (Mairami et al., 2017) for a detailed case study). His first wheelchair, obtained from the state, was a conventional wheelchair that did not suit his needs. It was uncomfortable, did not support his weight, and did not provide him with adequate mobility. To fulfil his needs for independence and mobility, he converted a sofa chair in his home into a bespoke wheeled chair (Mairami et al., 2017), which allowed him to move without the help of others.

Participants' beliefs in their capacity to reflect, organise and execute a course of action to bring about change and produce desired results exemplified their self-efficacy and assisted their coping. Such views were vital and influential factors in determining what actions they took, the type and amount of effort required, and their determination to recover despite the limited resources available.

Active coping: Participants were determined that the stroke would not control their life, and so they employed active coping strategies which involved implementing behavioural interventions to improve their health. They endeavoured to have an active, healthy life despite the limitations of the stroke, and so focused on exercising to improve their mobility and flexibility. While Umar (56-years-old) considered his *salah* as a form of exercise, he also did other activities, *'I do exercises on my own. I just walk around, ride the bicycle there, walk. Then when I do prayers, that is also some exercise'*. Others described engaging in gardening believing that the physical activity would improve their health.

Notwithstanding the type of activity, all performed it at a moderate pace and took regular rest periods to avoid exhaustion. They also slowed their walking stride to give them more stability and prevent pain. Participants who were still working cut down on their hours. Yaqub discussed how he went to his farm at dawn but now would return by mid-morning, in contrast with pre-stroke, when he would return just before

the afternoon prayers at about 1 pm, *“I feel I can work now lah. Can work but not as before. I come back from the farm at 10 am. No more long hours like before”*. Work not only offered physical activity but was important in shaping access to resources. Two participants, who lost employment following their stroke, sought alternative sources of income to cope with their financial losses. Ayub (48-years-old) became a private taxi driver, ferrying his neighbours’ kids to and from school or clients around the district. These participants found their role as breadwinner for the family to be an important motivator for recovery. They wanted to recover and to help and support their family members. Umar had two children with developmental disabilities and so needed to work to be able to pay for their treatment; to do this, he obtained employment at a nearby café, making Indian bread.

Participants conveyed their efforts to pay more attention to eating a healthy diet. Many had high blood pressure, high blood cholesterol, or diabetes, and had been told their diet might have contributed to the stroke – they thus endeavoured to modify it. Dram was advised by traditional masseurs on changing his diet, *“I don’t take coconut oil. No eggs. At massage, they told me to stop eating pork, eggs, and oily food, less salt”*.

This behavioural lifestyle change, reported by all but two participants, were highly valued as helpful in providing the participants with a sense of control over their recovery, managing their comorbid conditions and, eventually, their overall sense of well-being. By actively seeking ways to improve their condition, participants refused to be passive actors, instead finding self-enhancing activities to improve their functional independence. Engaging in meaningful activities not only represented a financial outlet or a source of physical activity, but it also improved their self-esteem, self-identity, and feelings of being productive. Furthermore, the social integration gave them a sense of belonging and enabled them to normalise their lives.

The Power of Support

Social support plays an important role in recovery and coping responses to acute and chronic illness (Graber and Beveridge, 2013), through the provision of basic human needs such as companionship, a sense of belonging, intimacy, and reassurance of one's worth (Berkman and Glass, 2000). Our participants turned to others – family, friends, traditional healthcare providers and orthodox health professionals – for social support to assist them in coping following a stroke.

Family support: Family provided emotional support for almost all participants through providing understanding, increased attention, motivation, relief from responsibilities, and kind treatment. Within Malaysian culture, family support is considered a valued tradition. Several participants discussed the support they received from their spouses, encouraging them throughout their recovery. Ayub, for example, described how his spouse would scold him when he refused to perform his exercises and console him when he felt down, “*She was my strength, my motivation*”, he emphasised. Bilkis, Maaruf’s wife and caregiver, entrusted him with household chores, believing they would aid with his mobility and flexibility:

I gave him work to do, like sweeping the rubbish, watering the plant. To move his hands. Otherwise, the hands will just sleep. He sweeps the floor indoors and waters the plants. That’s his job. Outdoors, he weeds the plants too. Maaruf added, “whatever I needed, she provided. When I first had the stroke, I asked her for everything, dressing, eating, going to the toilet. Now I can do them myself, but before she had to help me.”

Family support extended beyond spousal support, including from children and in-laws:

We have daughters; they look after us. Wherever I want to go, they take me, even my sons-in-law. Even for prayers, before I regained the strength to ride the motorcycle, my sons-in-law would take me. I just have to ask, and they would do it. (Yaqub)

Chuanli's son, Andy, left his home and job in another city to move in with his father to aid him after the stroke. Aisha's (55-years-old) daughter moved to a nearer university to be closer to provide the necessary assistance. Participants all alluded to their realisation that, with the onset of the stroke and its associated impairments, getting better was a journey they couldn't go on alone. They needed the help of their family in physical and emotional ways. Although family support was offered whether the participants sought it or not, they mostly felt they needed to ask for help.

Support from friends: Socializing with friends was an important form of emotional support. Friends were a source of practical support and company for participants, providing acceptance despite their impairments and motivation during trying times. Arjun spent a good part of the day with friends having tea, which enabled him to relax, reduced stress and made him happy. Andrew's (67-years-old) spouse would drive him long distances so he could have coffee and chat with his friends. Shuaib was rarely at home; when asked where he went most days, he laughed and replied, '*Friends. I am always with my friends*'. He found sharing experiences with friends was helpful: his best friend also had experienced a stroke; it gave them relief to talk about their challenges with each other. This aligns with Thoits's (1995) claim that effective support is more likely to stem from individuals who share similar experiences. Such friends – as in the case of Shuaib's friend – provided opportunities to normalise life for these participants where they could continue to discuss life issues and experiences (including the stroke experience) within a trusting and understanding environment.

Pets also provided emotional support to some participants. Most Malay participants had cats and gained both company and entertainment from these. Shuaib stated that his three cats; '*keep me company*'. The owners had a special bond with their

pets, and by watching, playing with and feeding them, could distract themselves (albeit temporarily) from their problems and feel happy. Cats especially were considered as part of the family.

Support from professionals and seeking information: Most participants sought support from either medical professionals or traditional healers, which was instrumental in their understanding of the cause of their stroke, treatment management, and progression as well as in preventing complications. Throughout their interviews, most participants reiterated that they sought support from professionals because not only did they have relevant knowledge but also had access to information and resources that may be beneficial in recovery. Advice from traditional healers was especially valued, as they were viewed as respected and trusted members of the community. David narrated that he obtained the most support from his masseur, *“Him [gesturing towards the masseur], he gave me the most [support]. Dietary advice, exercise, and he always encouraged me. He also scolds me (laughs), when I don’t do what he says”*. Traditional healers could provide informational support while maintaining their empathic relationship with the stroke survivors as community members.

Information seeking was identified as an enabling strategy in coping with their stroke, reflecting the suggestion that informational support may enhance an individual’s perception of being in control as it offers them ways of working through their condition and managing symptoms (Helgeson and Cohen, 1996). In this regard, most participants listened to television and radio programs about health and Well-being (particularly, stroke), read books and pamphlets that discussed stroke, and asked friends about stroke and its management. Ayub sourced booklets discussing stroke from an Islamic perspective. Similarly, Andrew would browse the internet for articles on stroke, hypertension, and high blood cholesterol, to better understand his condition. Such strategies exemplify Bury’s (1982) assertion that individuals mobilise new resources to provide them with support and aid in the course of their illness.

Other strategies

Not all participants described coping as a positive process. Two participants demonstrated social withdrawal, in which they did not participate in activities that could aid with recuperation and avoided addressing matters associated with their condition. These participants perceived their recovery as slow or unattainable, and this perception shaped their post-stroke management. These participants described ignoring dietary recommendations, physical therapy, and clinical follow-ups. Aisha (55-years-old), for example, explained:

I don't eat any medicine. Lazy to take it. I am bored of taking medicine... Tired of taking medicine. Massage, I massaged for long, I stopped that too... No effect. It's been a long time. I stopped that as well. Kept on massaging, but no effect or anything.

Saif (aged 66) who had his stroke thirteen years back, gave up on seeking a sense of recovery from the early stages post-stroke when he couldn't walk. He stopped physiotherapy and showed apathy to life; he was not interested in his family, friends, and activities around him, including his religious obligations. Over time, he developed severe muscular atrophy and lower limb stiffness, and became completely bedridden, worsening his condition. Aisha and Saif's realisation of the permanency of their impairments and perceived slow recovery led to their passive response to the stroke and subsequent poor adaptation to the recovery process. This was borne out in their mental health: both reported feelings of despair and hopelessness.

Other participants also continued to participate in stroke-risk behaviours even after the trauma of stroke. Two smoked at least ten cigarettes each day:

This cigarette, I smoke one pack a day. Without smoking, I can't do anything. This is my friend... I stopped smoking for a while, after the stroke, for around three years. The doctor

asked me to stop smoking. When I became better, I could move around, my friends came over to visit, they offered me cigarettes, and then I got addicted again. (Shuaib)

As he spent most of the day on his porch overlooking the street, Ibrahim explained that smoking kept him calm and gave him something to do. Shuaib and Ibrahim used cigarette smoking as an outlet to vent their frustrations, anger or anxiety.

Discussion

While participants used a variety of coping strategies, our study focused on the most prevalent strategies used daily; these were often used in combination and exemplified problem-focused and emotion-focused coping (Lazarus and Folkman, 1984) as well as seeking social support coping (Carver et al., 1989). There were four such strategies: turning to religion and acceptance coping (which are categorised as emotion-focused coping), active coping (categorised as problem-focused coping), and seeking social support. Avoidance coping strategies, including behavioural disengagement and substance abuse (Carver et al., 1989), which has been reported in other studies (Moos et al., 2006) were reported by only four (of 27) participants. These brought about higher levels of distress and increased participants' depressive moods.

Turning to religion was the primary coping strategy that enabled participants to manage their situation. Most participants believed their stroke was a decree or test from God. Their faith enabled them to accept the condition and alleviated their fears about recovery, as they believed recovery would only come from God. Research on patients with chronic conditions has noted similar trends (Mukwato et al., 2010, Taleghani et al., 2006, Sulmasy, 2009, Unantenne et al., 2013, Padela et al., 2012), and our findings are also consistent with another Malaysian study which found that turning to religion was a critical coping strategy used in times of stress (Khan and Achour, 2011). The high level of turning to religion as a coping strategy may explain the feelings of tranquillity and

contentment amongst the participants. In our study, participants believed God would assist them in prayer, and their belief in His power offered them comfort and strength; these are considered emotion-focused domains. However, through the belief in the continuous observance of their religious obligations – for example, through the salah - they achieved some form of physical exercise which they believed would aid in motor function.

Acceptance was the second most common strategy used by most of the participants, which echoes prior studies (Li and Shun, 2016). In this study, acceptance was mostly fostered by their religious faith. The associated belief in the personal lack of control over their recovery may have promoted acceptance as a coping strategy. This finding is supported by the previous research that found a link between acceptance and religiosity/spirituality (Pérez et al., 2009, Siegel and Schrimshaw, 2002). Siegel and Schrimshaw suggested that individuals found meaning in the experience of their conditions, believing that their illness was part of Gods divine plan thus fostering their acceptance of the condition (Siegel and Schrimshaw, 2002). Similarly, it has been suggested that the tranquillity provided by religion reduces depression by increasing acceptance of the situation (Spiegel et al., 2009). Our data indicated that participants who accepted their stroke and its associated impairments experienced less distress, frustration and displayed more positive adaptation.

Our participants used active coping as a strategy by focusing their efforts on activities that would aid them in better adjusting to their challenges. Most participants changed their lifestyle behaviours by adopting self-management and self-care strategies, healthier eating, constant exercises, the creation of DIY devices to enable mobility and exercises, continued information-seeking and securing alternative financial resources. They demonstrated a deep desire to obtain expert opinion and information about treatment options and management, which led them to seek information from healthcare professionals and traditional healers actively. This desire

for information corroborates prior studies that identified information-seeking as paramount (Lambert et al., 2009, van der Molen, 1999). Patients needed information from experts about diagnosis, symptoms and treatment options, yet this was often not available. This highlights the need for healthcare professionals to establish home-based rehabilitation activities for stroke survivors before discharge.

Seeking social support from family or friends (or both) was fundamental for the participants. Social support buffers the negative effects of a traumatic event (Lazarus and Folkman, 1984, Ruiz et al., 2013), and receiving support from family and friends was positively related to quality of life (Li and Shun, 2016, Nurullah, 2012, Ruiz et al., 2013). The importance of family in the care for individuals, particularly in the Malaysian context, is a cultural expectation (Namasivayam et al., 2014) which may underlie participants' emphasis on this form of coping. In Malaysia, the family setting is important and commonplace for people to seek and receive support – suggesting that professional education about stroke caregiving may be beneficial to families to aid with post-stroke home management. The study also revealed an important aspect of social support provided by traditional healers. Masseurs, spiritual healers or herbalist were sources of not only treatment management but information, support and reassurance. Our study highlights a need for improvements, particularly at the community level which may include a collaboration between traditional healers and healthcare providers.

Similarly, our study discovered the comfort some participants placed on having pets around them. For these participants, their pets provided them with contentment, served as a diversion from thinking about their condition and reduced feelings of loneliness and isolation. Hodgson and colleagues (2015) determined that pets enhance physical and emotional Well-being in patients (Hodgson et al., 2015), offering a non-threatening way to commence conversations and enhance the client-health provider rapport (Hodgson et al., 2015). Research has also identified a role for pets beyond the

provision of comfort to patients. Pets, especially dogs, have been incorporated into rehabilitation programs for patients to aid with mobility and gait (Burres et al., 2016). In individuals with aphasia, interaction with pets have also been incorporated into speech therapy with positive results (Burres et al., 2016).

For most of the participants, their social support extended beyond family and friends to incorporate support provided by religious organisations. As Barret (2013) highlighted, many religious communities encourage health-promoting behaviours (Barrett, 2013) and religious individuals rely heavily on the information and support they obtain from such organisations. Consequently, health professionals may collaborate with religious organisations in the design of interventions that could aid individuals in their recovery process.

The stroke survivors discussed the well appreciated practical and financial aid they obtained from family, friends and such community organisations as mosques, churches and the social welfare department of the state. However, despite the overwhelming support, the participants noted they received insufficient information from orthodox healthcare practitioners. This was also the case for peer support groups which was completely lacking. Participants believed that sharing experiences with other stroke survivors would foster more understanding of the condition, alleviate isolation and provide them with motivation for recovery. Prior studies (Tomberg et al., 2005, Kuluski et al., 2014) have suggested that both social and professional support is vital for effective coping as well as successful reintegration into society following traumatic events. This finding highlights a need for professional education, psychological counselling groups and peer support groups.

The coping strategies cited in this study provide a repertoire for healthcare professionals in the provision of holistic care to their patients. Similarly, the findings from this study may benefit healthcare professionals on effective coping strategies that have been used by stroke survivors. It may be possible that strengthening positive

coping strategies through interventions tailored to specific needs of individuals post-stroke may enable them to cope better with their condition. In cases of mal-adaptive strategies such as loss of hope or social withdrawal, healthcare professionals can suggest new adaptive behaviours. There is a need to comprehend stroke survivors' experiences to recognise what they value and need to strengthen the various coping strategies they may need to use. The present study contributes to our understanding of the diverse use of coping strategies and may improve the work of healthcare professionals, community workers, and family in working with stroke survivors. The results of this study can be used to test the effectiveness of strengthening coping strategies on the overall quality of life of stroke survivors. As most participants turned to religion in coping with the impact of the stroke, the role of religion in the stroke recovery pathway needs to be further explored.

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Summary

Participants' narratives highlight the diversity of coping strategies used in stroke recovery. Most participants felt that, despite their impairments and challenges, the coping strategies they used and the resources they drew upon helped them survive the illness trajectory. Through their religious beliefs, self-efficacy active coping and support seeking, they could lift themselves up from stroke victims to stroke survivors. Turning to religion as a coping strategy was the most salient strategy used. It is therefore of importance to explore the role that religion plays in stroke recovery. The chapter ends with a case that exemplifies the self-efficacy efforts adopted by a participant in a quest to improve his independence and mobility. In the subsequent chapter, I elucidate the role of the Islamic faith in stroke recovery.

Chapter 8.

Role of the Islamic faith in stroke recovery

Overview

Religious faith has for long provided peace and comfort to individuals (Whitford and Olver, 2012, Harris and Koenig, 2016, Siegel et al., 2001). Similarly, evidence suggests that religion significantly affects the recovery process as many individuals count on their religious beliefs to support them during negative life events (Koenig, 2009, Pargament et al., 2005, O. Harrison et al., 2001, Tix and Frazier, 1998). The uncertainty of the future brought about by the occurrence of a stroke may trigger an increased religious conviction. Kay and colleagues (2010) argue that beliefs about the existence of a transcendent being act as a mode of coping when life events are perilous and random, which in turn relieves the uncertainty. This is because individuals' religious beliefs foster a reliance on the external control of God.

Islam is central to life for Muslims in Malaysia and as such may influence recovery and Well-being following a stroke. The previous chapter highlighted that turning to religion was a significant coping strategy amongst stroke survivors in rural Malaysia. The role of the Islamic faith in recovery from stroke amongst Muslim stroke survivors is an area that remains understudied. In this chapter, presented as a journal article submitted in *Religion and Health*, I explore how stroke impacts religious obligations and discuss the role Islamic beliefs play in promoting recovery from stroke.

Stroke Recovery in rural Malaysia: the role of the Islamic faith

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Abstract: Clinical rehabilitation improves long-term functional outcomes and lessens hospitalisation following a stroke. However, there is a need to identify alternative mechanisms that could lead to improved function beyond clinical recovery. There exists a paucity of information highlighting the role of religion amongst Muslim stroke survivors during the stroke recovery process. This study addresses the lacuna by examining the role of Islam in stroke recovery for people living in rural Malaysia using an ethnographic approach. Healthcare providers need to recognise the value of religion when attending to the care of patients by offering a holistic approach that would include supporting coping strategies and adaptation based on religious beliefs.

Background

Worldwide, stroke causes severe, long-term disability (Thrift et al., 2014, Mackay, 2004). Clinical rehabilitation programs improve long-term functional outcomes and lessen hospitalisation following stroke (Clarke and Forster, 2015). However, there is a need to identify alternative mechanisms that could lead to improved function beyond clinical recovery. The relevance of the spiritual dimension of individuals is often prominent in chronic illnesses (Koenig, 2014). Religiosity impacts an individual's ability to adjust and adapt to changes during chronic diseases (Harris and Koenig, 2016). Religious beliefs have a positive influence in curbing the emotional distress produced by chronic illness and retrieving purpose in life (Ellison and Levin, 1998).

Religion is a systematised organisation of beliefs, behaviours, and practices intended to enable nearness to a supreme being and consideration of an individual's

relationship and responsibility to others (Koenig, 2012). Religions typically have theories about life and death as well as guidelines about social conduct obtained over time from established traditions (Koenig, 2012).

The five pillars of Islam

The Islamic faith is based on the principles outlined in the Holy Qur'an and the Hadith (the sayings and actions of the Prophet Muhammad). Islam embodies a lifestyle built on five pillars: the declaration of faith, *salah* (prayer, described below), fasting during Ramadan, *zakat* (wealth purification, through the giving of alms), and the *Hajj* (the religious pilgrimage to Makkah that all Muslims must undertake at least once in their lifetime). Three of these pillars – the *salah*, fasting during Ramadan, and the *Hajj* – go beyond the psychological realms and require physical activity and are therefore linked with physical health.

The *salah* refers to the act of praying, which is both a spiritual and physical activity. The *salah* is performed by the individual reciting verses from the Holy Qur'an while assuming different positions including standing upright, bending over at the waist, kneeling and prostrating with the forehead on the ground. Apart from its spiritual role, the *salah* is believed to have a role in promoting health, preventing illness, aiding recovery and is a coping strategy as the purification of the soul through prayer provides the servant with a strong spirit and soul (Mohamed et al., 2015, Al-Krenawi and Graham, 2000). There are five obligatory *salahs* in a day, which can be performed at any place, individually or in a group. Before *salah*, an individual is required to perform the *wudhu*, an ablution or ritual cleansing of parts of the body using clean water. During an illness, an individual unable to perform the *wudhu* with water may perform *tayammum* (Rispler-Chaim, 2007), in which they strike their hands on clean earth and then wiping the hands and face with the soil.

The fast, performed in the ninth month of the Islamic Calendar (Ramadan), is a practice that includes refraining from food, drink, and sexual activities from sunrise to sunset. Traditionally, individuals would commence the fast with the *sahur*, a pre-dawn meal, and end the fast with an *iftar*, a post-sunset meal. The Ramadan fast is mandatory for all adult Muslims. However, concessions are made for individuals who are unable to perform it due to reasons, such as having a medical condition, which may cause the fast to be a burden. The Ramadan fast can be described as a drastic change in lifestyle, as it affects both dietary and sleep habits for a full month, and thus might contribute to biochemical and physiological variations in individuals which might affect those with pre-existing medical conditions such as diabetes (Slim et al., 2013).

Hajj refers to a Muslim's spiritual pilgrimage to Makkah at least once in their life. The *Hajj*, performed over a five-day period in the 12th month of the Islamic calendar (Dhul-Hijja) is a physically demanding exercise where processions of hundreds of thousands of individuals congregate in Makkah and its surroundings, performing series of prayers, rituals, and asking forgiveness and blessings from God. The *Hajj* is obligatory for all Muslims, except those who are physically or financially incapable of performing it.

Religion and stroke

Religious faith has long been accepted as providing peace and comfort to individuals (Whitford and Olver, 2012, Harris and Koenig, 2016, Siegel et al., 2001). Similarly, evidence suggests that religion significantly affects the recovery process as many individuals count on their religious beliefs to support them during adverse life events (Tix and Frazier, 1998, Koenig, 2009, O. Harrison et al., 2001, Pargament et al., 2005). The uncertainty of the future brought about by the occurrence of a stroke may trigger an increased religious conviction. Kay and colleagues (2010) argue that beliefs in the existence of a transcendent being act as a mode of coping when life events are

perilous and random, which in turn relieves the uncertainty (Kay et al., 2010). This is because individuals' religious beliefs foster a reliance on the external control of God. In the face of serious illness, individuals have found the medicinal, emotional and practical assistance offered by religion as supportive of their situation (Siegel et al., 2001) and better life satisfaction (Rowe and Allen, 2004). Several studies have highlighted the positive influence of religion in health conditions such as cancer, HIV, sickle cell, diabetes and other chronic diseases by decreasing depression, anxiety, blood pressure and improving psychological well-being as well as promoting healthy behaviours (Ng et al., 2017, Shaheen Al Ahwal et al., 2016, Ironson et al., 2016, Clayton-Jones and Haglund, 2016, Harris et al., 2010, Unantenne et al., 2013).

For the Muslim stroke survivor, the ability to perform the *salah*, fasting, and *Hajj* can be disrupted by the impact of the stroke, both physically and mentally. However, there exists a paucity of information highlighting the role of religion amongst Muslim stroke survivors during the recovery process. The current study aims to address this lacuna by examining the role of religious beliefs in stroke recovery for people living in rural Malaysia. Islam plays an important role in Malaysia with over 54% of the population professing the Islamic faith, and the constitution declares Islam as the official religion of the country (Haque and Masuan, 2002). Importantly, as most insights on the relationship between religion and stroke have defined spirituality and religion in a non-Islamic context, the results from prior studies conducted in non-Islamic societies might not apply to the Islamic community. This highlights the necessity to explore how religion informs health outcomes in an Islamic context. Understanding the role that religion plays in an individual's worldview may aid health professionals to be more responsive in addressing their health needs following a stroke.

Methods

This ethnographic study sought to understand the role Islam played in stroke recovery and focused on how Muslims perceived their recovery experience. Questions of how they sought help, what they perceived as the cause of the stroke, how they used religion to deal with the effects of the stroke, and how they coped with their religious practices were of central concern. This study is part of broader research that explored the experience of stroke recovery in rural Malaysia.

Participants and Setting

The study was undertaken in a health and demographic surveillance system (HDSS) (withheld for review), situated in (withheld for review), Malaysia. The HDSS operates in five sub-districts (withheld for review). Study participants were identified through a household census as having suffered a stroke or stroke-like symptoms. Participants were required to have the capacity to communicate personally or through a caregiver (determined by Author A, a medical doctor) and to give consent to the study. Twenty-seven participants were recruited for the study, twenty of whom were Muslims, and their information forms the basis for this paper.

Data Collection and Analysis

Data was collected primarily through interviews at participants' homes. Interviews were audio-recorded and ranged from 30 minutes to 2 hours per session over 2 to 4 visits. With all but one participant, at least one family member was present during the interviews and contributed to the discussion. The interviewer asked participants to recall back to when the stroke occurred and discussed their recovery experience. Participants were then asked about various aspects of the recovery process, including

the impact of the stroke, health services and resources used in coping. Specific questions were asked about how the stroke affected their religious practices and how religion impacted on their recovery. Where participants experienced communication difficulties, a talking mat was used to aid the interview process. Talking mat is a tool that uses picture symbols to assist individuals with (or without) communication difficulties to comprehend and respond better to questions (Murphy and Oliver, 2013). The mats also served the purpose of sustaining their attention and allowing them to reflect on their views at their own pace (Murphy et al., 2005). Participant observation, recorded through extensive field-notes supplemented data from the interviews

The transcribed and translated data were analysed using thematic analysis technique (Braun and Clarke, 2006). Analysis commenced at the onset of data collection. The transcripts and notes were read and re-read various times. This process of repeated reading ensured familiarity and immersion into the data, which also resulted in the extraction of pertinent aspects that became the initial codes. The codes were subsequently sorted into potential themes, identifying similarities in the codes and grouping them into themes. The themes were further grouped into main themes and sub-themes.

Further reading of the transcripts checked to see the fit of the themes with the research question, identifying consistencies and inconsistencies. Interpretations developed as themes emerged. Segments of the data from the interviews and field notes were also compared to add depth to the analysis. Themes were then defined and named. Extracts from participants' narratives are included throughout the paper to exemplify the main themes.

Ethical Considerations

The study received ethical approval from one University [withheld for review]. Informed consent was obtained verbally at the time of inviting their study participation and immediately before each interview, during which participants were informed of the study aims and objectives, what participation involved, and the voluntary nature of their participation. Also, participants were informed that all information they shared would be kept confidential and that their identity/privacy would be protected in study dissemination. All names used in this paper are pseudonyms.

Results

Five women and fifteen men participated in the study (see Table 1 below). Given their Malay ethnicity, all participants were brought up in Islamic culture, and therefore their experiences of life and traditional concepts were based on Islamic teachings.

Table 1: Participant demographics

Gender	F: 5 M: 15
Age	30-39: 1 40-49: 1 50-59: 6 60-69: 8 70+: 4
Years of stroke	<1: 1 1-5: 12 6-10: 1 10+: 6
Marital status	Married: 19 Widowed: 1
Main Caregiver	Spouse: 18 Daughter in law: 1 None: 1
Education	No formal: 2 Below tertiary: 18 Tertiary: 0

Themes were grouped into two main categories: the impact of stroke on religious practices, which captures how the stroke affected the religious practices of the participants and the role of religion in stroke, which captures the interplay between religious beliefs and recovery from stroke. These themes were unsurprising, given our questions directly asked people about these two aspects of the experience. Within each theme, however, the data provide evocative insights into the relationship between stroke and individual's Islamic practice.

Impact of stroke on religious practices

The Salah: The stroke affected many people's ability to perform the *salah* as they had done before the stroke. Participants considered *salah* a vital activity that had to be maintained despite the physical limitations posed by the stroke, and they made adaptations to facilitate the *salah*. In cleansing themselves from impurities – performing *wudhu* – participants were aided by a family member. Husna, for example, was a 65-year-old woman who had limited mobility and spent most of her time in bed. As she wore diapers, her husband, Ashraf, would cleanse and change her diapers before each *salah* time. Other participants would perform their *salah* in any position they could; for some, this meant lying down or sitting rather than standing. Yusuf, a 59-year-old man, demonstrated how he performed the *salah* and explained:

I do salah at home. I cannot go to the mosque. [There's] no one to take me [and] you must climb the stairs. I can sit [on a chair] and stand straight; I can stand straight when needed. [But] if you want me to sit like healthy people, I really cannot. My hand is not strong to lift me up from the floor.

Another participant, Shuaib (aged 68) explained how stroke impacted on his *salah*, “My wife helps me do *wudhu*. I perform my *salah* while lying down”. Musa, a 68-year-old man who mostly communicated through his wife, pointed to a chair he sits on to perform his

salah. His wife, Khadeeja, commented, “He sits on a chair. If he sits on the floor, it is difficult for him to get up. He always sits on a chair. If he sits on the floor, he can get up, but it takes more effort”.

Being a physical activity, the *salah* was significantly impacted by the stroke, from the *wudhu* ritual cleansing before the act of *salah* to the physical act of the *salah*. Participants wanted to maintain their *salah* despite physical impairments as a fulfilment of their Islamic obligation. Notwithstanding being a personal practice, it is recommended that for men, the *salah* is performed in congregation at the mosque. The men regularly attended the mosque for *salah* and were involved in religious activities before their stroke. With the occurrence of the stroke, however, they were forced to perform their *salah* individually in their homes. This is also the case with the *tarawih salah* (long prayers performed in congregation during the month of Ramadan). Yusuf would perform his *tarawih salah* at his home as it was long and he could not keep up the pace with other worshippers, “I did not go for *tarawih*. Very difficult. It requires you to sit and stand, sit and stand. You have to be very fast”. His wife, Nazifa, added, “You have to go down quickly, you cannot be slow. I go [to the mosque]. He performs his at home”.

Although the stroke had affected the participants’ physical performance of religious activities, it did not affect the spiritual aspect of the activity. While neither Abdullah (aged 79) and Hanif (aged 74) could perform the *salah* in a standing position, they indicated (via a talking mat) that they could perform the *salah* optimally. Their inability to attend *salah* and religious activities at the mosque was not much of a concern to them because Islam did not oblige them to attend if they were ill. Such sentiments were shared by several study participants:

He does not need to trouble himself going to the mosque because he is ill. Unless its Friday salah, he will go. He cannot go to study religion anymore, there is a religious club there, he can no longer go, but it is not a problem. (Noor, Razak’s wife)

Being unable to attend the mosque was difficult for Hanif though, despite being excused due to the illness. Hanif's attendance at the mosque was more than a personal obligation as he had been an *Imam* (Islamic leader at the mosque). The loss of that role – which he had held for over 20 years – due to his stroke had significant consequences, and he felt stripped of his identity. Since his stroke four years previously, he had been unable to leave their home and was distressed by not having a purpose in life.

The Ramadan Fast: Fasting in the month of Ramadan was affected by the stroke for most participants, particularly during the initial stages post-stroke. Most were unable to fast during the first year of the stroke for myriad reasons: they were physically weak, took medications that had to be adhered to during the daytime, feared dehydration that would further weaken them, or were not in a psychological state to remember or understand the value of the fast. Kamila, Abdullah's wife, remarked:

He performed the fast. But not the first year when he had the stroke. I was worried [for his Well-being], so I did not allow him... Afterwards, he was able to complete the whole of Ramadan. After the sahur [pre-dawn meal], I gave him his medications.

Musa (68-years-old) had a stroke during Ramadan and was unable to continue the fast that year. His wife, Khadeeja, commented that his state of mind was affected during the first year, and therefore the fast was not obligatory on him. In the three years since then, he has been able to perform the Ramadan fast in its entirety. Husna was placed on medications for diabetes and hypertension immediately after her stroke, which meant she was unable to observe the fast in the first Ramadan after the stroke:

I was weak, very weak, couldn't do anything. I had to take medications three times a day. Now, [I] only [take them] twice, so I can fast now, but before, I could not. My husband paid fidya on my behalf. He paid for the whole month I could not fast. However, after that Ramadan, Alhamdulillah, I can fast.

When probed on how she felt for not being able to fast, she replied:

I was sad at first, I have been fasting since I was little. But this is Allah's will, I accept it. Allah told us to fast, but he also gave us this condition. I also paid the fidya, so no problem. It is not too expensive; we had grains in the house. My husband used it to feed people poorer than us.

Payment of the *fidya*, the expiation for missing the fast, substituted the fast for individuals like Husna. In this way, Husna felt that even though the stroke impeded her ability to fast, it did not impede her ability to worship.

The Hajj: None of the participants had performed the *Hajj* before the stroke and only one, 76-year-old Razak, had been able to perform it after his stroke. Noor, Razak's wife, explained:

At first, when he had the stroke, I was upset. But I think of it, it is a test for us. So, we had to be strong. It was only twelve days before we [were due to] go to Makkah for Hajj! Only twelve days away from going. He had stroke. We could not go anymore. We obtained a letter and sent it to the Hajj board.

The Hajj Board reasoned with them and slotted them in for the following year when Razak performed the Hajj with physical support from his family and friends he made in Makkah.

Sulaiman (aged 69) though, despite having saved enough money for the hajj was unable to perform it due to the physical limitations of the stroke. To perform it, he would need to pay for another individual that would aid him physically during the Hajj rituals:

My body cannot withstand it. I can go if I want, but I will need someone to accompany me... and it is expensive. I cannot pay for two people now. When my son can afford [it], we will go In Sha Allah [if God wills].

Just as Husna above, Sulaiman was saddened that he did not have the physical strength to perform a religious obligation, but like her, he accepted it and is hopeful he would be able to perform it someday. The 19 participants who were unable to perform the Hajj

have accepted the reality that they may never be able to perform it, due to their physical or financial limitations. Despite creating sadness in them, of not completing a pillar of Islam, they are not burdened as they know Allah will not hold them accountable.

Role of religion in recovery from stroke

While stroke affected participants' ability to meet their physical, religious obligations, religion remained central to both their understandings of stroke and conceptualisations of recovery. Study participants discussed the role of religion through four sub-themes: the centrality of religion, causation and help-seeking, the process of recovery, and family and communal support. These are discussed below.

The centrality of religion: Religion as central to participants' lives was evident in how they reflected on their lives and their recovery experience. Their speech often included the Islamic word *In Sha Allah*, meaning 'if God wills', and *Alhamdulillah* which means 'thanks and praise to Allah'. They referred to all aspects of their lives using these terms and recovery from stroke was not an exception. The strong presence of religion in their lives fostered acceptance, hope and a sense of peace.

Vital to the practice of Islam is the acceptance of God's decree that Allah decides all things and surrendering to His will while maintaining a relationship with Him is a test of that belief. Participants stated that their faith aided them in making sense of the condition, and many discussed their experience within the context of their faith. In explaining the principles and the belief systems, which impact their understanding of the stroke, they made references to scripts from the Qur'an and Hadith. They perceived their stroke as a test from Allah, to enhance their piety rather than as a punishment; accordingly, their recovery needed to be from Allah as well.

Participants believed that they could try to improve their condition even though they could not change fate – recovery was decreed by Allah. Shuaib saw the stroke as Allah's supremacy, *"This [stroke] is Allah's power. Can't fight it. If Allah wants us to recover, we definitely will recover"*. He laughed and added, *"If I do not have faith, I am finished"*!

Similarly, Razak commented:

God gives this illness, so when God decides to give me good health, it will happen. If God says you will get it for ten years, then you will have it for ten years. If God wants to reduce it, it will be reduced. This is God's will. If God wants us to have stroke until death, then so be it.

'It' in this context referred not only to the stroke itself but more importantly to the lasting effects of stroke. Central was the notion of acceptance, which Yusuf discussed regarding accepting the stroke as the decree of Allah and that no one was spared from Allah's decree, *"If you ask whether I am angry towards the sickness, no. It is given by Allah, so we just accept it. We're not the only ones that can get it"*. Nazifa, his wife added, *"Many people get it too. Many rich people. Poor people can get stroke, rich people like the chiefs can get stroke too"*. Yusuf believed Allah could test anyone despite their social standing or financial status. Having had the stroke was not due to his low financial status, rather a test from Allah.

The belief that Islam helps an individual with acceptance stems from several Quranic texts that affirm the power and decree of Allah over all things. Any illness or loss is considered a test from Allah and withstanding the pain with patience and trust in Allah helps to comfort the individual, as participants explained above. This belief, while encouraging acceptance, inspires the individual to remain hopeful as referenced in the Qur'an (12:87) (Al-Hilali and Khan, 2018). Participants could, therefore, free themselves from maladaptive thoughts and feelings of despair and rely on the mercy of Allah, knowing that Allah would aid them.

Patience was also important in participants' experiences and related to their interpretations of the Qur'an. Both patience and perseverance in the face of difficulties were highlighted in Islamic teachings (Qur'an 2: 153) (Al-Hilali and Khan, 2018). Noor (Razak's wife) explained, "*Allah wants to test us. We just have to be patient*". Islam offered participants a sense of connection to a greater power which, by being patient, leads to a sense of relief and peace. For study participants, accepting the stroke as a trial from Allah did not negate putting in effort to face the challenges. Accepting meant facing the trials patiently, but armed with resources given by Allah such as the *salah*, supplications, seeking help from others for example family and health professionals, and perseverance.

The need to worship was emphasised strongly by participants. Despite their physical limitations, there was an overwhelming need to continue with the acts of worship such as *salah*, supplications, *zikr* (mantras to praise Allah) and fasting. Shuaib explained, "*I am strong in faith, as always. The most important thing: don't leave the five daily salah. That is number one. Secondly, don't make enemies, don't steal or do bad things*". He went on to quote the Qur'an (Quran 47:35) (Al-Hilali and Khan, 2018), emphasising the need to do good.

Another participant, Yusuf, reiterated that the *salah* could be performed in any position, "*Salah can be done any way (lying down or sitting), all that matters is you do it*". For the participants, the importance of the *salah* and other obligations had additional significance directly related to their stroke. They viewed the performance of their obligations as a form of submission, accepting their mortality and Allah's divinity. Some discussed the discomfort they felt when these practices could not be continued. Kamila, Abdullah's wife, would draw the curtains and insist it was sundown so Abdullah would believe it was time to break the fast. She had, on several occasions, reiterated to him that the fast was no longer obligatory on him due to his condition; still, he insisted on fasting during Ramadan. Being 79 and frail, she worried that he would

become dehydrated from the fast and would feed him after a few hours of fasting. Caregivers, believing in the need for continuity of religious obligations and supplications to Allah, would constantly remind the stroke survivors to perform *salah* and to ask Allah for recovery:

The only time he did not fast was when he first got the stroke. It was during the Ramadan when he got the stroke. He could not remember things for a year after that. After the stroke, he forgets, he will not remember to do it. We must tell him; then he'll do. If we don't, he won't. After salah, we remind him to do doa (supplications) too; we have to remind him because he won't remember to do it. (Khadeeja, Musa's wife)

The belief that performing their religious obligations as a way of asking Allah for recovery provided emotional stability for the participants. Similarly, they believed Allah would heal them if they maintained a link with Him. Furthermore, the continuity of religious obligations offered participants a sense of normality.

The actions and way of life of the participants intertwine with their religious beliefs. Yaqub, who was deeply religious even before the stroke, had a room in the house designated as a quiet area for religious practices. He would perform his *salah*, recitation of the Qur'an, and supplications in the room. He attended religious activities and prayers outside the home. Others had religious relics hung on the walls of their homes. Some participants made mention of an Islamic medicinal diet consuming juices, teas, and other beverages that contained food substances highlighted in Islam to have medicinal properties such as *habbatus sauda* (black seed), honey, *sidr* (Indian plum or Chinese apple), dates, and *zam-zam* (water from the holy well in Makkah). These substances were believed to help lower blood sugar and blood cholesterol, regulate high blood pressure, and to help with indigestion, joint pains and overall well-being (Ahmad and Publishers, 1981). Religious beliefs also led participants to avoid alcohol and drugs, which are both positively correlated with health-enhancing behaviours (Oleckno and Blacconiere, 1991).

For most stroke survivors, the centrality of religion in their lives provided them with support and strength. Their beliefs enabled them to move from stroke victims to stroke survivors, allowing them to adjust and manage their daily lives. Religiosity allowed participants to seek help and actively pursue paths to recovery. They became resilient and persevered in their determination to live life as best as possible and to achieve a sense of enhanced well-being.

Causation and Help-Seeking: Participants' perceptions about the cause of their condition shaped their recovery path and assisted them in making sense of the stroke. Although they all believed their stroke was from Allah, most believed there was an organic connection between stroke and unhealthy lifestyle behaviours, including hypertension:

They only gave us medication [at the hospital]. There is no treatment; they don't have it.

They only ask us to go for massage. Traditional medication. He only has hypertension.

The cause of the stroke is hypertension, that's why they gave the medications (Noor, Razak's wife)

Irrespective of their perceptions of causation; in many instances, they sought conventional treatment first. After discharge from the hospital, or when they perceived no amelioration in their condition, participants sought help from traditional healers. However, a few rejected the notion that their stroke was 'medical' in nature and sought help from traditional healers in the first instance or exclusively, as Zahra (Ibrahim's wife) put it:

Stroke is quick to recover, right? In his case, he hasn't recovered... stays the same. We tried strong medication. The thing he's got is very strong. Jinn. That jinn [evil spirit] is very strong.

Others felt it was a combination of both: the stroke is of an organic nature, but evil spirits had a part to play in its occurrence. Sulaiman, who regularly attended the clinic for his hypertension and performed regular exercises, said:

This sickness, it is as if there is something in our body. It wouldn't allow us to think about good things... however, if we recite the Yaseen (a chapter in the Qur'an), it will stop, they [jinn] run away due to fear. This is the Islamic medication.

Some participants' religion had a direct effect on their treatment management strategies, and they viewed the disregard of the importance of their beliefs and practices by healthcare providers negatively. Maryam (aged 63), for example, refused all forms of conventional medicine as she believed her condition was not medical. She relied solely on fruit and herb-based juice, which she took daily, *"Doctors don't understand the value of this [juice]. No point going to the hospital. They don't understand"*. On further probing, Maryam revealed that doctors believed that they were the ones who could cure. For her, that meant, negating the divinity and power of Allah. Her thoughts stem from a misconception that belief in conventional medicine means acknowledging mortal beings have the power of healing. The correct Islamic perspective is that Allah provides healing through the knowledge he has given doctors. She also commented that they used products which were not *halal* (lawful in Islam). Maryam is sensitive to the fact that some medications or medical products like swabs may contain alcohol, pork or its derivatives which are considered unlawful in Islam. Avoiding conventional medical treatments, therefore, meant she could not be exposed to such products.

The process of recovery: Many participants were cognizant of the need to take responsibility for their recovery. Accepting their situation as a decree from Allah did not stop most from actively seeking improvements in health. Recovery for them was an active process, and most did not see themselves as passive individuals in living with the stroke. Instead, they felt they had a responsibility to cope with the effects of the stroke

and seek recovery through conventional means – attending clinics, massage, adhering to medications and exercises – as well as through religious means (as described above), as Sharifa, Yaqub’s wife, explained, *“He went for massage. Also after maghrib salah (fourth prayer), he will sit and recite the Qur’an”*. Ayub (aged 48) obtained a book that discussed stroke from the Islamic perspective and how to overcome its challenges, *“I got a book, written in there is the story of stroke. Everyone has to read it; all living person should read it, to avoid a stroke. I bought the book. I pray with it”*. The book described the proper diet for individuals with stroke, how to prevent a second stroke and also contained supplications for recovery. Ayub used the book to improve his understanding of the stroke and pray for recovery.

Most study participants perceived an overall sense of well-being as their recovery progressed. However, two participants believed their recovery had stagnated and reported limited or no changes in their condition. Both had very little hope of recovery and accepted their stroke as a test from Allah. Their acceptance, however, was different from other study participants, because it resulted in them becoming passive in their recovery. For example, Aisha (aged 55) was five-years post-stroke and spent most of her day in a wheelchair staring out the glass door. She had stopped taking her medications, stopped her massage sessions, and would not perform simple exercises:

Now I don’t eat any medicine. Lazy to... Tired of taking medicine. Massage, I massaged for long, I stopped that too... No effect. It’s been a long time. I stopped that as well. Kept on massaging, but no effect or anything.

Although Aisha claimed to still perform her *salah* and ask Allah for spontaneous recovery, her husband, Najib, shook his head and replied that, *“she would only do it when we tell her”*. Saif (66-years-old) had lived with stroke for thirteen years and was depressed, having given up hope on life and showing apathy in his religious practices. Saif’s wife, Nafisa, explained that he stopped supplications, *salah*, and other religious activities a few years after his stroke occurred. She requested that he ask Allah to relieve

him of his condition, either through death or recovery, but he dismissed her. He simply refused to ask Allah for anything she reiterated. Their fatalistic views towards their condition, acceptance of their stroke, and its attribution to the will of Allah may have led them to believe they could not change or improve their condition. Both Aisha and Saif passed away a few weeks after the interviews.

Family and communal support from a religious perspective: In the Islamic faith, the family operates as a unit with members socially and emotionally involved in all aspects of life. Parents are required to care for their offspring and, as parents age, this role is reversed, so children are expected to care for their parents. Similarly, spouses are required to care for each other. It is generally considered a personal sacrifice for the family to care for the ill, especially children caring for their parents (Qur'an 4:36) (Al-Hilali and Khan, 2018).

The family facilitated the stroke survivors' religious practices, reminding them about *salah* and supplications, helping them to perform *wudhu* and *salah*, taking them to the mosques, and motivating them to adopt healthy behaviours such as eating healthy and performing exercises (described above). They made efforts to ensure the stroke survivor fulfilled their religious obligations. The family also helped the stroke survivor in making sense of their condition, providing spiritual explanations, reinforcing coping strategies, and motivating the individual. The family also played a role in mediating management: they often decided on the course of treatment to be sought based on shared religious values and beliefs. In instances where the stroke survivor was unconscious or unable to communicate, the family would take on the responsibility of speaking for the individual. In this way, the family not only supported the stroke survivor but acted as a voice for them.

Participants also highlighted the support obtained from friends and neighbours, primarily through visiting and providing encouragement. Yaqub spoke about the

prayers and advice he obtained from friends as well as constant support from his daughters and their husbands:

People come to visit, give advice, to make my body healthy. Prayers from friends, to help recover quickly. We have daughters; they look after us. Wherever I want to go, they take me, even my sons-in-law. Even for prayers, before I regained the strength to ride the motorcycle, my sons-in-law would take me. I just have to ask, and they would do it.

By making supplications to Allah, family, friends, and neighbours interceded on behalf of the stroke survivor, asking Allah to grant them healing.

Discussion

This paper explores the role of Islam in recovery from stroke in rural Malaysia. Our study findings highlight that religion is central to developing positive dimensions to recovery. Understanding the role of religion in stroke recovery might enable the development of an informed treatment plan that encourages individuals to commit to treatment regimens, healthy-living practices and tap into resources that may contribute to improved coping and well-being.

Religion provided the stroke survivors with the strength and confidence to live with their chronic condition (aligning with work by Unantenne et al.). In rural Malaysia, religion – specifically Islam – was understood as embedded within participants' lives and impacted their understandings of recovery. This aligns with Rassool's (2015) claim that Islam is both a religion and a way of life, and thus has an impact on health behaviours as well as beliefs about life's purpose and goals (Rassool, 2015). For many of our participants, their faith forged a way of life where religious views played a central part in how they perceived, accepted and coped with life events. Many described various ways they relied on religion to navigate through their recovery, drawing on their spiritual capital; capacities generated through affirming and nurturing intrinsic

spiritual values, for understanding, support, and treatment management when limited information and intervention was provided to them by the health system. This finding supports Unantenne and colleagues' (2013) claim that participants drew on their spiritual capital for support in the face of frustrations with the healthcare service (Unantenne et al., 2013).

Recovery involved accepting the condition as a decree from Allah and actively seeking ways to cope effectively with it. By believing their condition was from Allah, they could deflect some of the responsibility of the condition onto the transcendent. Fatalism, the acknowledgement that the illness course lies beyond their control, fostered acceptance and hope within them. This assertion that belief in the power of the transcendent over illness and death nourished hope in individuals as they ascribed the outcome to a divine being, and was thus out of human control, has been captured in other studies (Sulmasy, 2009, Padela et al., 2012). Despite the very few participants whose fatalism inhibited active recovery-seeking behaviours, for most of our participants, fatalism promoted positive health-seeking conducts (as described by Unantenne et al. (Unantenne et al., 2013)).

The participants sought help from Allah through the performance of their religious obligations, recitation of the Qur'an, supplications, and asking others to pray for them. These activities empowered them and gave them hope in a recovery that would ensure a return to some form of normality – in doing so, glimmers of a bright future opened. For these stroke survivors, their convictions in hope for recovery defined a religious context in the stroke trajectory. Interestingly, there was also a general acceptance of Allah's 'indirect' role in healing, and most participants acknowledged that Allah could promote recovery through healthcare professionals, traditional healers, and family. This belief prompted their active participation in health-seeking: they sought medical treatment from health providers, adhered to medications, attended massage sessions, and accepted advice from family members.

While the participants were all aware of the religious concessions offered to individuals who were ill or unable to remember (in contrast with Rosli and colleagues' 2016 findings), and although the stroke affected their performance of religious practices, it did not negate their need to perform them. Religious practices, for our participants, offered social and emotional support and helped them find meaning in life. Importantly, Islam presented itself as a locus of control whereby observing these vital aspects of the religion in the face of disability represented a form of biographical continuity after the disruption presented by the stroke. This aligns with previous research that suggests social contingencies are integrated into the stroke narrative to construct a biographical flow (Faircloth et al., 2004). Participants' ability to return to pre-stroke activities such as performing the *salah*, attending the mosque and fasting were meaningful activities and gave them a sense that recovery was occurring. They were aware that they would continue to live with lingering effects of the stroke; therefore, their religious practices enabled them to understand that while a cure may not be possible, improvements may occur. Accordingly, religious practices positively impacted the adaptation process by helping them find stability and a sense of control.

This study also highlighted the vital role family plays in the recovery process. Islam considers the family as the foundation of Islamic society (Bloomer and Al-Mutair, 2013), and the maintenance of a family-centred approach to caregiving is thus vital for Muslims. In this study, the family provided physical care, spiritual and emotional support while facilitating treatment management for the stroke survivor. This finding is not new, and the importance of family support in facilitating recovery has been confirmed by prior studies (Boger et al., 2015, Cameron and Gignac, 2008, Harris et al., 2016). Similarly, friends and neighbours play a role by providing instrumental and emotional support. For the participants, there is a perception that caring for and supporting the ailing individual is a collective societal responsibility that conforms with religious practices.

Implications for practice

Our study findings support prior research that affirms an all-inclusive model of health which combines physical, social and spiritual realms. This validates the need to comprehend the associations between religious beliefs and practices about health and well-being. Healthcare professionals may benefit from learning about an individual's religious beliefs, ideals, and practices to better understand their recovery prognosis.

Research discussing spirituality in Parkinson's disease suggested clinical interventions may be improved when spirituality is incorporated into practice (Hermanns et al., 2012). Koenig also highlighted that the incorporation of religion into practice might aid individuals suffering from depression as some methods of religious cognitive behavioural therapy were shown to relieve depressive symptoms (Koenig, 2014). He emphasised that religious involvement often achieved the same goals as treatment in mental health settings (Koenig, 2014). These insights can be translated into stroke recovery for Muslim patients. The *salah*, for example, could be incorporated into stroke rehabilitation as it involves moderate physical and psychological efforts that may improve musculoskeletal and cerebral functioning (Reza et al., 2001). Such incorporation of an individual's sacred realms into practice may improve the client-provider relationship (Koopsen and Young, 2009, O'reilly, 2004). In instances where sacred realms cannot be incorporated, a respectful and conscious appreciation of the individual's spirituality may be of benefit. Understanding, supporting, and strengthening an individual's religious beliefs and practices which are significant to an individual's health that may affect acceptance, coping, treatment type, support networks, commitment to treatment regimens and general well-being should be an integral part of clinical care.

Healthcare providers need to recognise the value of religion when attending to the care of patients in offering a holistic approach to health provision that would

include supporting coping strategies and adaptation based on religious beliefs. Although the physical limitations of a stroke may prevent an individual from attending religious services, their spiritual needs can be addressed through other sources such as reading print and online materials, social media, television, radio, and health promotional talks at health centres.

Limitations and future research

This study was conducted as part of a broader project investigating the experience of recovery from stroke; as such, religion was initially not a research focus but emerged from participants' accounts. There remains need to examine the relationship between religion and quality of life, yet this is beyond the scope of the current study.

Additionally, most the participants were adult males, living in semi-rural areas. Despite these limitations, the study offered some novel insights into the role of religion in recovery following stroke. More studies are required to provide more insight into the role of religion in stroke recovery in other Islamic communities, for the general population, in different regions, and in different religions.

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Summary

This chapter highlighted the way the stroke survivors' faith forged a way of life for them where religious views played a central part in how they perceived, accepted and coped with traumatic events in life. They described how they relied on religion to navigate through their recovery. They drew on their spiritual capital for understanding, support, and treatment management. In this study, Islam presented itself as a locus of control whereby observing vital aspects of the religion in the face of disability represented a form of biographical continuity after the disruption presented by the stroke.

Chapter 9.

General discussion

Overview

This study set out to investigate the lived experience of stroke from the stroke survivors' perspective in a Malaysian context. Specifically, the research was designed to explore the stroke illness trajectory, the impact of stroke on the lives of survivors, what recovery meant for them, the ways they had coped post-stroke and the role of religion in their recovery. Participants made explicit statements in their narratives about their stroke experience and talked about how the stroke occurred, where they sought help and their hospital experience. They discussed coming to terms with the condition and the strategies they used to overcome the challenges of living life with a disability. They also spoke about the support they obtained from various groups, including family, traditional therapists, and friends. This chapter will discuss the key findings from the study and their implications for public health.

The stroke trajectory

This study drew on the Corbin and Strauss (1991) CITF to describe the stroke illness trajectory. The framework outlines the development and effects of the illness, with the core concept of an illness course that characterises the cumulative impact of a condition and is beneficial as it covers an extensive range of contextual factors. The CITF assists in ensuring that health professionals, family and the individual maintain a common ground in setting goals and expectations. The framework conceptualises the stroke experience as a process of creating a new whole by facilitating the growth of individuals and their family/caregivers. Healthcare professionals can use the CITF to enhance patient experiences by engaging in a dynamic relational process where specific

interventions in each phase are tailored based on the understanding, knowledge, and capabilities of the individual and their families, as well as the resources available to creatively guide the recovery path.

The stroke experience

Stroke has been recognised as a public health concern that causes serious and long-term disability. Stroke recovery has often focused on the physical realm with minimal consideration of the psychological, social, or environmental needs of the survivor (Burton, 2000). However, as this study demonstrates, successful recovery is not confined to the recuperation of physical functioning but is a multifaceted, interconnected process that encompasses recovery in the physical, emotional and social domains. For participants in the current study, the recovery process was a negotiation of understanding between the stroke survivor, their family, and social networks, and healthcare professionals both conventional and traditional. Recovery was conceptualised as an on-going process primarily determined by the stroke survivor and their reflection of the stroke experience.

This study established that the occurrence of a stroke affected all aspects of a survivor's life, forcing them to appraise and rebuild their lives and identity. The suddenness of the occurrence, the variety of lingering neurological deficits, the social consequences and the uncertainty and length of recovery time were surprising and difficult to comprehend for the survivors. This finding aligns with prior research that describes a stroke as an unexpected disruption to the lives of individuals (Bury, 1982; Norris, Allotey, & Barrett, 2012). Descriptions of the impact of the stroke have been shown within the broader context of abilities – dressing, feeding, or religious practices – and within a broader social context, including visiting friends and attending religious services. Roles within the family frequently changed, from being an equal, housemaker

or breadwinner to being dependent on others. Recovery was a process that challenged old ways of living, often requiring making informed decisions on how best to live life.

The study highlighted several factors that shaped the stroke survivors' recovery path which included hope, self-efficacy, coping strategies, coexisting medical conditions, family support, information from health professionals and treatment management. Several strategies were utilised by the participants to cope with the effects of the stroke. The strategies most often used were turning to religion, acceptance, active coping, and seeking social support. Turning to religion was important for the participants as it provided them with the strength and confidence to weather through the recovery process. Norris and colleagues (2012) highlight that the maintenance of religious activities aided stroke survivors in mediating and re-establishing their lives.

The participants credited the use of medication for helping them attain stable functioning of their pre-existing medical conditions and the use of traditional medical therapies for their stroke. It has long been part of the Malaysian culture to seek services of traditional healers when unwell. There is a pervasive deep-rooted belief in the benefits of traditional medicine for the treatment of stroke. Most participants believe that stroke cannot be cured by conventional medicine and rely heavily on the use of CAM such as offered by traditional Chinese medicine; acupuncture, massage, herbs, and Islamic medicine. All participants had tried one or a combination of traditional therapies. Most reported improvements in their condition and believed it had aided significantly in their recovery.

Implications for Public Health practice

This study described stroke illness recovery pathways, emphasising the process of recovery for the individuals: their adaptation, transitions, identity challenges and progress that go on in the community post-discharge. The participants stressed a significant gap in formal community health support for stroke survivors. Most stroke

survivors found themselves lost and forgotten post-discharge from the hospital, as virtually no formal support was provided. The recovery process following a stroke is an on-going one that needs continual assessment. In Malaysia, the National Stroke Association reports that approximately 40,000 individuals suffer a stroke annually.

The trajectory model (discussed in chapter four) offers a logical structure for clinical practice whereby management strategies for stroke recovery may be established and evaluated (Burton, 2000b). The model highlights the need for having a viewpoint on the illness recovery path of an individual. The phases of the model comprise psychological, physical and practical aspects for the survivor which would require comprehensive information, support and treatment management. A holistic stroke recovery plan involves teamwork across an array of skilled health and social care providers. Applying the trajectory framework provides a comprehensive and pragmatic problem-solving approach to care with the potential of providing an all-encompassing collaboration between inpatient and community settings by focusing on the lived experiences of individuals and their perspectives on their illness. The trajectory projection and trajectory scheme govern the management of the illness path. The overall goal of management is to achieve a recovery path that is stable, with less frequent oscillations between stability and instability. To accomplish this goal, however, contextual factors that include personal, interpersonal, cultural and religious domains come into play. The identification of factors that facilitate the recovery process provides a background with which healthcare providers can utilise to improve their understanding of the stroke experience, the strengths, and weaknesses of their patients. Corbin and Strauss (1991) identify these factors as demographic characteristics and personal, interpersonal, or social resources that are specific to individual stroke survivors (Woog, 1992).

The notion of the trajectory projection as providing a vision of the illness path requires collaboration between all parties involved: the stroke survivor,

family/caregiver, and the health management team. Health professionals should consider the physical, psychological, functional, social and economic situation of the stroke survivors in the recovery process. Goals must be realistic and most of all flexible to accommodate the oscillations that could arise during the illness course.

Rehabilitation lies in identifying the different phases of the stroke illness trajectory and setting achievable goals. With each phase, biographical and environmental factors can be assessed to determine the appropriate intervention to be administered.

The trajectory projection in stroke has two components. Initially, the vision addresses the issues involved at the onset, when the stroke occurs. With the initial disruption of having the stroke, clients often feel hopeful about recovery. Healthcare providers can promote this hopeful attitude by stressing the importance of physiotherapy and controlling risk factors. The vision changes when the client reaches a plateau where there may be no further improvement in motor functioning, and the impact of the disability from stroke seems long-term. There is a subtle shift as clients, and healthcare providers, admit that there may never be increased motor functioning and one must accept the reality of the situation.

For the effective management of the illness path, the first step involves determining where in the illness trajectory the stroke survivor falls. This can be achieved through effective communication with patients and their caregivers. Once determined, a plan of care should be set for implementation, i.e., the trajectory scheme. In achieving this, the health provider can carefully elicit the client's medical history, including risk factors, and should give them time to share their vision of the stroke. The health provider then proposes treatment options and sets goals. The next step involves assessing conditions influencing the management of the client. This includes the assessment of resources and settings of care, both in the present and into the future. A stroke survivor who is working may eventually be unable to work and might need

financial help. The health provider can attempt to manage the client's condition by identifying alternatives.

As demonstrated in this study, complementary and alternative medicine therapy is a universal healthcare choice adopted by most individuals with stroke in Malaysia. Our study highlights a need for improvements, particularly at the community level which may include a collaboration between providers of CAM and healthcare providers. Though it remains unclear how CAM practitioners manage stroke within a biomedical paradigm of care (Norris et al., 2011), a partnership between healthcare professionals and incorporation of CAM regimens into conventional clinical practice may prove beneficial for the acceptance and rehabilitation of stroke survivors. This assertion calls for international models of care for stroke, to examine best practices of care within individual contexts (Norris et al., 2011).

The health professional plays a central role in supporting the stroke survivors attain an adequate level of functioning. Practitioners should, therefore, foster hope and manage the expectations of their patients, conveying the message that a pre-stroke life might not be achievable but it is possible to live a fulfilling and purposeful life (Salyers and Macy, 2005). Although recovery primarily lies with the patient, the understanding of what recovery means to patients by health practitioners can have a significant influence in promoting recovery-based approaches. A discharge plan for the families should include information on working with the survivor through his physical, practical, financial and emotional needs. The survivors, whether they received care from the hospital or not, need follow-up at the community level to confirm adherence to medications and monitor their progress towards recovery. Housebound individuals and those who require assistive devices need adequate fitting of aids and proper education on their use and maintenance to enhance independence. The provision of information by health professionals, which should go beyond didactic information to include a well laid out rehabilitation plan for the stroke survivors and their caregivers is

imperative. The consideration of the beliefs, views, and abilities of the family may enhance health providers understanding of the different developmental experiences of the stroke survivor and facilitate the adoption of meaningful home-based therapy. Laskiwski and Morse (1993) pointed out that it was vital to listen to patients and understand what they view as crucial to understand what improvements were significant to them and how to tailor goals to their needs.

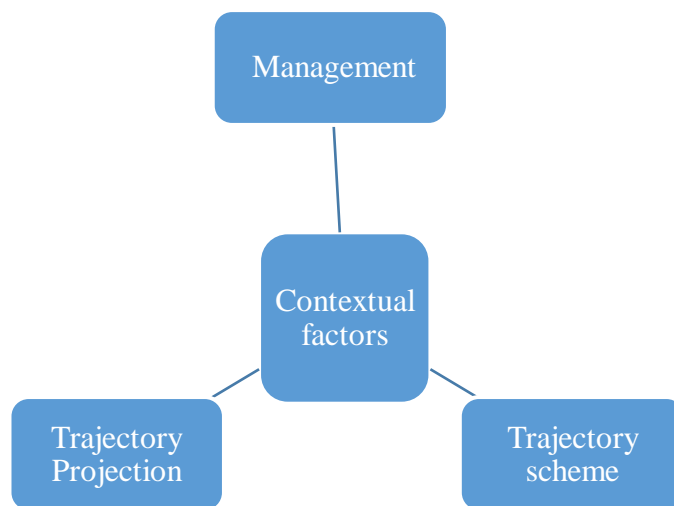
The trajectory scheme must take into consideration the needs of the survivors and their families beyond the hospital or clinic. However, community and home visits are an aspect of care that is lacking in most LMIC due to limited resources. Notwithstanding the difficulty, Burton and Gibbon stress that community/home visits post-discharge that focus on evaluation and continuous support to the survivors and their families have beneficial outcomes for recovery by improving physical independence and reducing caregiver burden (Burton and Gibbon, 2005). The factors, affecting the management of the trajectory scheme include the extent of motor damage, motivation, the setting of care and lifestyle. The practitioner's role in this is to support the stroke survivor by eliciting individual attributes which characterise their recovery and prepares the individual for successful self-management. The patient must want to recover and carry out rehabilitation therapies while maintaining a positive attitude (Becker and Kaufman, 1995). Some clients are motivated to adopt healthy behaviours and to feel optimistic about recovery. Others resume their unhealthy behaviours; sometimes to an even higher degree than before the stroke. The healthcare provider can assist clients to resume healthy behaviours and encourage them by maintaining a caring attitude. The setting of care is a significant factor in the stroke recovery pathway. Home physiotherapy is not a realistic option in clients who are not motivated to recover; often compliance with the medical regimen of set exercises can be difficult in clients who have no support network at home or in the community.

As the stroke event stimulated the development of coping strategies targeted at dynamically altering the situation with an aim towards recovery, there is a need to identify and strengthen the coping mechanisms of the survivors. Prior studies (Tomberg et al., 2005, Kuluski et al., 2014) recommended that both professional and social support is crucial for effective coping as well as successful reintegration into society following traumatic events. Core identity issues of the stroke survivors need to be explored to support its renegotiation. Health professionals in tandem with the family need to help the survivor re-establish past roles or engage in new ones to strengthen their self-worth. There may also be a need for professional education and psychological counselling groups and peer support groups. Studies have stressed the benefits of support networks in addition to the family support network (Bright et al., 2013, Barker and Brauer, 2005, Laskowski and Morse, 1993, Boger et al., 2015, Cameron and Gignac, 2008, Harris et al., 2016). Healthcare professionals may need to work more collaboratively with families of stroke survivors to foster physical, emotional and financial support and guarantee adherence to treatment schedules and medications as well as helping them recognise their strengths and effective coping strategies that may aid caregiving.

In a Malaysian context, an all-inclusive model of health that combines physical, social and spiritual realms would be of benefit to stroke survivors. This model validates the need to comprehend the associations between religious beliefs and practices about well-being. Healthcare professionals may benefit from learning about an individual's religious beliefs and practices to better understand their recovery prognosis and to offer a holistic approach that would include supporting coping strategies and adaptation based on religious beliefs. Although the physical limitations of a stroke may prevent an individual from attending religious services, their spiritual needs can be addressed through other sources such as reading print and online materials, social media, television, radio, and health promotional talks at health centres. Such understanding

and incorporation of an individual's sacred realms into practice may improve the client-provider relationship. In instances where sacred realms cannot be incorporated, a respectful and conscious appreciation of the individual's spirituality may be of benefit. Understanding and fostering religious activities through faith organisations could support and maintain hope in recovery for the survivors and aid acceptance.

Figure 8: Stroke management model



An intervention strategy such as the Early Home Supported Discharge (EHSD) approach might be beneficial for stroke survivors in rural communities (Fisher et al., 2011, Langhorne et al., 2011b). The EHDS emphasises the attainment of independence in the individual's own home. It incorporates specific individual needs and wishes into rehabilitation that impacts on the overall recovery process. The EHSD approach provides individuals and their caregivers, before discharge home and at home, with education on stroke, its consequences, healthy behaviours, how best to reintegrate into the community and how to find help within their communities.

The literature indicates that EHDS followed up with community rehabilitation (CR) is an effective rehabilitation strategy post stroke (Donnelly et al., 2004, Ann-Mari

Thorsén et al., 2005, Indredavik et al., 2000, Langhorne and Widen-Holmqvist, 2007). These studies highlighted that ESHD, through a multidisciplinary team coordinated discharge for stroke survivors. The CR team provided services through primary healthcare while being monitored by the ESHD team. Other studies also show that functional gains were achieved through CR with reduced incidence of functional decline (Kerr et al., 2016, Pang et al., 2005, Legg, 2004). In a Malaysian context, CR for stroke survivors may prove to be a low-cost approach that involves family members. As highlighted in the study, the family plays a significant role in the recovery trajectory of stroke, reinforcing the notion that family-assisted CR may be the best solution for the continued long-term care of stroke survivors. This model of care, delivered through trained family caregivers however needs to be implemented and evaluated.

Chapter 10.

Conclusions and future research

Conclusions

This study explored the overall stroke illness experience within a rural Malaysian community. Key findings from the study are:

Stroke as a significant life event

- A stroke occurs suddenly and is incapacitating with physical, psychological and social challenges that are interconnected and influence each other;
- In most cases, the short hospital stay, lack of adequate information on the stroke and a lack of post-discharge support service, all of which are specific to the Malaysian /LMIC context, caused frustration, anxiety, and uncertainty for the survivor and their caregivers;
- The physical effects of stroke such as those affecting mobility and speech often leave survivors disabled, resulting in a restricted lifestyle;
- The psychological effects of stroke include fear, frustration, loss of self-identity and depression;
- Social relationships within the family are altered. Role reversal often occurs with partners and children becoming caregivers; and
- Challenges in mobility and self-esteem make social relations and activities challenging to continue.

The recovery process

- Recovery is often a long-term process, forcing the survivors to adopt lifestyle changes and develop coping strategies;
- Inside the home, survivors took up chores as forms of exercise to improve physical function. Pacing activities and relaxation were essential to ensure sufficient energy to carry out tasks;
- The survivors became self-efficient and determined to regain former skills to reduce dependency and minimise disability;
- Return to work was necessary for some to reduce financial challenges but they often had to take up new jobs or cut work hours;
- Turning to religion was the most important coping strategy used by the survivors. They found solace and strength in their faith;
- Seeking emotional, instrumental and informational support from family, friends, and traditional healers was an important strategy that aided the recovery process; and
- Early supported home discharge and community rehabilitation of stroke survivors are recommended for long-term care.

Future research

This research has illuminated the experience of life post-stroke and the stroke recovery process for a rural Malaysian population. However, the study only provided a snapshot of a point in time of the recovery process, and presents a wide range of points within this. Although the narratives of the participants provided a story that spanned over time, longitudinal research is required to provide insights at every point of the recovery path, the adaptation process and the transitions over time. Qualitative longitudinal research is needed to understand the factors that contribute to successful role changes

and societal reintegration for stroke survivors. Similarly, there is a need for further qualitative studies on how healthcare services can help stroke survivors.

Much research has been conducted and documented on the needs and well-being of caregivers internationally. However, such research is limited in Malaysia and therefore, there is a need to explore this concept in a Malaysian context to improve support for stroke survivors. Likewise, a study on health professional views of stroke services and recovery will provide further insight into the overall stroke recovery process. Further qualitative research is also required to provide more insight into the role of religion in stroke recovery in other Islamic communities, for the general population, in different regions, and in different religions. The development, implementation and evaluation of a community based rehabilitation programme delivered through trained family caregivers needs to be considered.

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