UNIVERSITY OF SOUTHAMPTON

FACULTY OF HEALTH SCIENCES

Thesis Title

IMPROVING THE PROVISION OF HOME-BASED STROKE REHABILITATION AND SUPPORT IN BRUNEI DARUSSALAM: THE POTENTIAL ROLES AND EDUCATIONAL NEEDS OF NURSES IN THE COMMUNITY

by

Mursidi Haji Ali

Thesis for the degree of Doctor of Philosophy

February 2020

UNIVERSITY OF SOUTHAMPTON

ABSTRACT

FACULTY OF HEALTH SCIENCES

Doctor of Philosophy

IMPROVING THE PROVISION OF HOME-BASED STROKE REHABILITATION AND SUPPORT IN BRUNEI DARUSSALAM: THE POTENTIAL ROLES AND EDUCATIONAL NEEDS OF NURSES IN THE COMMUNITY

By Mursidi Haji Ali

Background: Stroke is the second most common cause of morbidity and mortality worldwide. In Brunei, the establishment of the first National Stroke Centre has improved patients' survival rates. A multidisciplinary stroke rehabilitation provision, to support patients and caregivers at home, is therefore increasingly crucial. The research aims to explore different aspects of home-based, stroke rehabilitation service provision in order to identify areas for improvement. **Method:** A two phase, convergent, extended mixed-methods design was employed. The first phase, using new and piloted methods of inquiry, involved a set of data which was simultaneously collected through interviews with stroke survivors (*n*=21) and their carers (*n*=18), and a survey questionnaire for community nurses (*n*=101), to explore areas needed for service improvement. Key findings from the first phase were discussed with six expert healthcare professionals (*n*=6) at the second phase of study. The NVivo^{TM} 10 and IBM SPSS version 22 facilitated analysis of data following Thematic Analysis and descriptive statistical tests. **Results:** Six key findings, identified from mixing of the interview and questionnaire data, were presented to the expert healthcare participants. Majority agreed that the stroke education for the patients, carers and nurses are lacking. It also revealed that the Malay culture and the changing family unit may impede recovery of the stroke patients. There were differing views with regard to roles of nurses in stroke rehabilitation. All participants indicated that involvement of non-government organisation for stroke care is essential. **Conclusion:** This study highlighted considerable gaps in the existing rehabilitation service provision for stroke in one specific country. The implications of cultural practices and religious belief of the stroke patients and their carer for improvement of the rehabilitation service delivery need consideration. Establishment of a multi-sector stroke team is needed. Future study is requires to expand findings of this research.

Table of Contents

List of Tables

List of Diagrams

List of Flowcharts

Academic Thesis: Declaration Of Authorship

I, Mursidi Haji Ali declare that this thesis titled, ***'Improving the provision of the home-based stroke rehabilitation and support in Brunei Darussalam: The potential roles and educational needs of nurses in the community'***, and the work presented in it are my own and has been generated by me as the result of my own original research.

I confirm that:

- This work was done wholly or mainly while in candidature for a research degree at this University;
- Where any part of this thesis has previously been submitted for a degree or any other qualification at this University or any other institution, this has been clearly stated;
- Where I have consulted the published work of others, this is always clearly attributed;
- Where I have quoted from the work of others, the source is always given. With the exception of such quotations, this thesis is entirely my own work;
- I have acknowledged all main sources of help;
- Where the thesis is based on work done by myself jointly with others, I have made clear exactly what was done by others and what I have contributed myself;
- Either none of this work has been published before submission, or parts of this work have been published as:
    - Community stroke rehabilitation nursing and its relevance to Brunei: a review of literature. Haji Ali, M., Koh, D., Collier, L. and Gobbi, M. Brunei Darussalam Journal of Health, 2014, 5: 80 – 87.

Signed: ……………………………………………………………………………

Date: …………………20/04/2020……..……………………………………

Acknowledgment

The undertaking of this research was not a solitary effort. I appreciate my supervisors, colleagues, family and friends who has helped me in so many ways. Without them, compiling this piece of work would not be possible. I wish to gratefully acknowledge the support and helpfulness of the following individuals and organisations.

Alhamdulilah – Praised to Allah the Almighty. A special appreciation to the Government of His Majesty Sultan Haji Hassanal Bolkiah Mui'izzaddin Waddaulah, the Sultan and Yang Di-Pertuan of Brunei Darussalam, for awarding the in-service overseas training sponsorship. Equally to the relevant staff of the Ministry of Education Brunei, PAPRSB Institute of Health Sciences, Universiti Brunei Darussalam, the Public Civil Services, Public Civil Commission and High Commissioner of Brunei in UK, thank you for all of the supports.

I would like to express my deepest and sincere acknowledgement to supervisors, Dr Lesley Collier, Professor Marry Gobbi and Dr Ruth Turk of University of Southampton, and Co-supervisor from UBD Brunei, Professor Dr David Koh and Senior Assistant Professor Dr Khadizah Haji Abdul Mumin, who have devoted their extensive time to guide, support and gave critical comments throughout completion of this thesis. Thank you so much for being meticulous, patience, tolerance and never-ending support. Your times were very much appreciated.

I am indebted to the following 'intermediary persons' who were so instrumental in helping identified potential sample and hence facilitated participants' recruitment. In particular to Mrs Vivian Tee, Ms Aisya Amirah Binti Abdul Rahman and other relevant therapists of the Rehabilitation Centre, JPMC; Principal Nursing Officer (PNO) Mrs Hajah Saniwati Binti Haji Mohd Noor, Nursing Officer (NO) Mrs Hajah Ramlah Binti Haji Kisut from Department of Community Nursing Services, and all Nursing Officers/Nurse In-Charge of the nine Health Centre/Clinics. In addition, many thanks to officers from RIPAS Hospital, especially for Mrs Tsara Nawwarah Binti Abdullah @ Chen and Mrs Tai Mei Lan of the Occupational Therapy Department; Mrs Hajah Wardah Binti POKSRDSS Haji Suhaili and Mr Jong Seng Khiong of Physiotherapy Department; and Dr Dk Nur'Ashikin Binti Pg Haji Tengah of Neurology Clinic. Not forgetting to revelant 'gate keepers' for permission to access targeted sample population, notably to Professor Dr Datin Uta Meyding-Lamade of BNSRC. Appreciation also goes to 'resource persons', Dr Dk Hajah Norazeida Binti Pg Haji Yassin, Consultant Neurolgist BNSRC and retired PNO Mrs Lim Poh Chuan for sharing their views about status of stroke and nursing service in Brunei.

Special thanks to Dr Hajah Maslina Haji Mohsin, former Dean of PAPRSB, IHS, UBD and Dato Seri Setia Dr Haji Zulkarnain Bin Haji Hanafi, former Vice Chancellor of UBD and Ministry of Health, for their recommendation in pursuing PhD programme. In addition to Mr Haji Julaini Bin Haji Latip, Haji Abd. Rahim Bin Haji Damit, Haji Hazilan Bin Haji Ramli and Ahmad Faisal Bin Haji Zainal Abidin, former lecturers of PAPRSB, Institute of Health Sciences, UBD, Dr Haji Md. Asyafie Hanif Abd Rahman, Assistant Professor Dr Deeni Rudita Idris, Dr Hjh Asmah Hj Hussein, IHS colleagues, and Dato Dr Isham Bin Jafar, Executive Director and Medical Director of JPMC, for their continuous support, advices and encouragements throughout development of this thesis. Not forgetting to Mrs Hjh Ardinah Haji Osman, former secondary teacher who provide proofreading of this thesis.

To my beloved wife; Dayang Jumarhani Binti Awang Haji Jumarali and our four children; Erra, Erza, Hassef and Hazim. Thank you for your patience and compromising time with me over completing of this PhD journey. To my parent, Haji Ali Bin Munap and Dayang Hjh Tengeh Binti Ahmed, for their countless prayers for our safety and health. Your endless love, faith and inspiration always motivates me. Special acknowledgement to my late brother; Haji Mayadi Bin Haji Ali and father in-law; Awang Haji Jumarali Bin Omar who sadly departed while we were away in UK. Your companionship and attendance were greatly missed.

Finally, to all participants involved in this study and whom that has contributed in completion of this thesis but was not mention unintentionally here, thank you so much for your valuable contributions.

“MAY ALLAH BLESSED YOU ALL”

Editorial Acknowledgment

With the oversight of my main supervisor, editorial advice for proof reading has been sought. No changes of intellectual content were made as a result of this advice.

Abbreviations

ADL	Activity of Daily Living
AHP	Allied Health Professionals
AMED	Allied and Complementary Medicine Database
BNSRC	Brunei Neuroscience Stroke Rehabilitation Centre
CAM	Complementary and Alternative Medicine
CINAHL	Cumulative Index of Nursing and Allied Health Literature
CSI	Caregiver Strain Index
COPM	Canadian Occupational Performance Measurement
CVA	Cerebrovascular Accident
CVMM	Convergent Validated Mixed Methods
DNE	Diabetes Nurse Educator
EADL	Extended Activity of Daily Living
EMBASE	Excerpta Medica Database
ESD	Early Support Discharge
HBN	Home-Based Nursing
IADL	Instrumental Activity of Daily Living
IAM	Instrumental Activity Measure
IBM SPSS	IBM Statistical Package for Social Sciences
ICF	International Classification of Functioning, Disability and Health
IHS	Institute of Health Sciences
JPMC	Jerudong Park Medical Centre
KNH	Krankenhaus Nordwest Hospital
MEDLINE	Medical Literature Analysis and Retrieval System Online
MeSH	Medical Subject Heading
MHREC	Medical Health Research Ethic Committee
MIB	Melayu Islam Beraja
MMSE	Mini Mental State Examination
NGO	Non-Government Organisation
NICE	National Institute of Clinical Exellence
PADL	Personal Activity of Daily Living
PJSC	Pantai Jerudong Specialist Centre
RCN	Royal College of Nursing
RCT	Randomised Control Trial
RIPAS Hospital	Raja Isteri Pengiran Anak Saleha Hospital
RMI	Rivermead Mobility Index
RSS	Relatives' Stress Index
SIGN	Scottish Intercollegiate Guidelines Network
SSEF	Stroke Specific Education Framework
UBD	Universiti Brunei Darussalam
UKFST	UK Stroke Forum for Stroke Training
UoS	University of Southampton
WHO	World Health Organization

Definitions/terminology

Alhamdulillah	Praise and thanks to Allah Almighty: in Islam anything in existence is only able to achieve due to Allah's infinite mercy and grace. This often denote feeling of content and relieved
Allah Ta'ala	God for every Muslim
Amah	The malay terms for a house maid. Often hire from neighbouring countries such as Indonesia or Phillipines
Angin Ahmar	A Malay term commonly used by Bruneian to denote a stroke
Bruneian	Denote the local people of Brunei
Exercise	A common term used by participants to denote "rehabilitation therapy'
Doa	An Arabic term which mean to 'call out' or to 'summon' Allah. It involves an act of supplication and worship.
Expert healthcare professional	Individual who is very experience and knowledgeable in relation to the research topic. This person has been at the current post for over three years
Gate keepers	A leader of an organisation or the head of department who have direct authority on targeted sample population
Hikmah	Reap the benefits out of the difficult situation, such as stroke.
Islam	A religion for every Muslim
Ketua Kampung	Translate literally as village head. A person who was elected by the villagers and has responsibilities to maintain, as well as oversee the interest and security of the village under his care.
Malay	The term 'Malay' carries two meanings. Firstly, Malay as a language. Malay subjects contains such as on grammar, verbs, nouns, idioms, and construction of sentences. Secondly, Malay as a race. This is the largest race in Brunei. Malay make up of seven indigenous group including, Brunei, Kedayan, Tutong, Belait, Bisaya, Dusun and Murut. Unless stated, the term 'Malay' denotes to the Malay language
MIB	A Malay phrase which is formally translated into English as 'Malay Islamic Monarchy'. The MIB incorporates Brunei Malay Culture, Islamic principles and the application of the monarchy system as a way of life of the Bruneian people
Mudarat	A Malay term to denote potential detrimental effects as a result of actions
Muslim	People who practice Islam
Old-age pensioner allowance	An allowance provided by the government once the resident have reach 60 years old. The cost of the allowance is $250 per month and obtained from respective village head.

Paid carer (*amah*)	This carer commonly designated to a house maid who was hired privately from the neighbouring countries. The carer lives with the patient at the same house.
Pasrah	Feeling of surrender and sure to Allah that He will help.
Quran	Holy book for Muslim
Rahmat	Belief with high degree of faith that good thins will come because of the difficulty or experiencing disease.
Ramadhan	One of the Five Pillars in Islam. Also known as fasting month for the Muslim. All Muslim are required to refrain from eat and drink beginning from early dawn until the sun set.
Redha	A Malay term to denote a feeling to approve something. This often involves a degree of fondness for the act.
Rezeki	A divine provisions granted by Allah the Almighty
Ritual prayer (*Salat)*	One of the central elements of Islamic practice and worship that was performed five times each day. This consist recitation of specific verses from the Holy Quran and a sequence of movements; standing, bowing, prostrating and sitting. For every Muslim, their views towards health and illness incorporates belief of receiving illness and death with patience, mediation and prayers. Practicing Muslim accepts that illness, suffering or dying are part of life and a test from Allah
Ruku	Bowing 90 degree forward flexion with both hands on knees as part of the standard body positioning/movements during performing prayer.
Sujud	Flexion with the hands and forehead flat on the floor part of the standard body positioning/movements during performing prayer.
Urut	Traditional massage that usually performed by religious person. The practise of *urut* often associated with several benefits such as relieving pain, ease emotional disturbance, improve physical and psychological functions
Ustaz	A Muslim men who has a practice and maintain religious obligation stongly.
Wudu	A ritual washing of specific parts of the body such as face, hands, arm up to elbow, before performing the five time per day prayers

Chapter 1: Introduction and Background Study

1.1 Introduction

This thesis describes the process and findings of research that explored the different aspects of the home-based stroke rehabilitation service delivery in Brunei Darussalam (henceforth, Brunei). The purpose of this research was to identify areas needed for improvement and understand the reasons why those services were not meeting the international recommended standard. To bridge this gaps, any potential roles and educational needs of nurses in the community in stroke rehabilitation were critically explored. The introductory chapter presents the development and background of the research comprising the best practice and care of stroke rehabilitation globally and within the context of Brunei. Chapter two provides a critical review of the literature which explored existing evidence regarding rehabilitation support provision for patients with stroke and their carer following hospital discharge, the nursing intervention in stroke rehabilitation and the current clinical guidelines for community stroke rehabilitation service provision. Chapter three presents the overall design and methodology for the phase one and phase two of the study, outlining the research design employed, ethical approval, sample recruitment process, data collection methods and strategies for analysing the data. Findings from the phase one study are presented in chapter four, chapter five and chapter six. Next, chapter seven presents the key findings of phase one study, identified through the integration process of the qualitative and quantitative results from the first phase of the research. Chapter eight presents findings for the phase two study. Chapter nine discusses the overall findings of the research and the implications for future planning on improving the home-based rehabilitation service provision. Finally, the direction and plans for future work are presented in chapter ten.

This chapter provides the background of the study, highlighting personal interest in this research, the prevalence and impact of stroke, the disparities in provision of stroke rehabilitation services and the role of nurses, the current context of Brunei and an overview of the study setting. This discussion concluded with a summary of chapter.

1.2 How was Interest in this Topic developed?

The interest in this area originated from my clinical experiences as a registered nurse. I have completed my three and the half years of nurse training at our local college of nursing in 1998. Afterwards, I work at one of our main public hospital. Being a registered nurse, my nursing practices were bound to the Brunei Nurses' Standard of Practice and Code of Ethics (Nursing Board for Brunei, 2010). Throughout my working experiences, I had opportunities to provide nursing care for patients with various medical and surgical conditions. In this aspect, nursing care is define as nurse activities or interventions pertaining to patient care which follow specific steps of nursing process; assessing patient’s problems, formulate nursing diagnosis, plan the interventions, implement the care and evaluate the prescribed nursing interventions (Hemingway. 2013). From my ongoing working experiences, the impact of stroke on a patient’s daily living activities, such as impaired mobility, concerned me most. I have learnt and gained experiences to help these patients optimise their functions in meeting basic daily needs, such as dressing, mobility or self-care. However at that stage, I was not aware regarding the complementary role of nurses in stroke rehabilitation. The possible reasons to explain for my lack of understanding regarding this role is due to the absence of rehabilitation component in our nursing curriculum, and every so often I observed that rehabilitation therapy was performed by the therapists. Thus, rehabilitation was not considered as part of my prescribed nursing care duty. In defining rehabilitation, it is defined as "a set of measures that assist individuals, who experience or are likely to experience disability, to achieve and maintain optimum functioning in interaction with their environments" (WHO, 2011). Whereas, rehabilitation nursing is described as specialist trained nurses who provide preventative care at the beginning of the illness, that continue through the restorative stage of care, and helps patients adapt to the whole new living. Rehabilitation nurse provides care coordination, education and support for the patient and family (Koc, 2012). This definition, thus, described nature of nursing rehabilitation which widely used in this thesis.

I have worked as a registered nurse at the main government hospital for over 12 years before being promoted to nurse lecturer at the Institute of Health Sciences (IHS), Universiti Brunei Darussalam (UBD) in 2010. Because of this background, I have explored the potential area of research for my doctoral study. International nursing literature showed nurses, complement the allied-health therapists, can embrace roles in stroke rehabilitation. To illustrate, a study by Wang and Yang (2016) suggested that nurse interventions in relation to positioning and moving of patients with stroke in sub-acute stroke setting helps prevent pressure ulcer formation. Further, McGinnes et al. (2010) found community nurses who provides continue long-term mobility support for home-based patients with stroke improved patients’ quality of life. However, a study to investigate this complementary role for nurses in Brunei is presently absent. Moreover, their role in supporting patients with stroke and their carers has not been explored. With stroke care is increasingly performed in the patient’s home (Marcheschi et al., 2018), thus I became interested to learn and understand how nurses in the community can contribute in improving post-stroke rehabilitation service provision. The subsequent sections that outline problems of stroke, the existing stroke provision and nursing services in Brunei further provide justification for conducting this research.

1.3 The Problems of Stroke Worldwide and in Brunei

Stroke, locally known as *‘angin ahmar’* in Brunei, can be classified either as ischaemic or haemorrhagic (details of stroke provided in Chapter Two). The WHO estimated that 15 million people have a stroke annually and of these, 5 million die and another 5 million are left permanently disabled (World Health Organization, 2012). Worldwide, the incidence of ischaemic stroke is more prevalent; however, most stroke burden (deaths and disability-adjusted life years lost) were due to haemorrhagic stroke (Krishnamurthi et al., 2013). Feigin et al. (2014) reported that, in 2010, stroke affects about 5·2 million (31%) children aged <20 years old and young and middle-aged adults between 20–64 years. In terms of gender distribution, Appelros et al. (2009) suggested that 30% of strokes occur more often in men, but women are more severely ill. In the UK, the Stroke Association reported that stroke is the fourth biggest killer and estimated over 100,000 people experience strokes each year. In addition, it was anticipated that the rate of first time strokes in people aged 45 and more is increase by 59% by 2035 (Stroke Association, 2018).

In Brunei, the prevalence of stroke is comparable with this international data. Over the past decade, stroke remains one of the top four, leading causes of death after cancer, heart disease and diabetes. The number of death from stroke is increasing from 82 cases in 2013 to 143 deaths in 2017. During this five years period, the total death due to stroke is 453, with an average mortality rate is 90 patients per year (Ministry of Health, 2017). Complete data pertaining to stroke in Brunei is not yet available. However, the first private Brunei stroke centre; the Brunei Neuroscience and Stroke Rehabilitation Centre that was established in 2010, has recorded a total of 876 out and in-patient visits from 2011 to 2014, with about 23 new admissions each month (Medical Record Unit, 2015). Meyding-Lamadé et al. (2015) reported that 85% of strokes in Brunei are ischaemic and 15% are haemorrhagic. Meanwhile, Chan et al. (2013) found that stroke occurs more predominantly between the ages of 31 to 50 years and was more common in men than women. Recent admission data for stroke and TIA (transient ischemic attacks) showed a total of 233 admissions, with the youngest patient is at the aged of 39 years (Colacion, Naing & Yassin, 2019). In their early review, Nainar and Venketasubramanian (2009) postulated that the incidence of stroke in Brunei would be likely to escalate due to increasing risk factors such as hypertension and an aging population: in 2017, life expectancy was recorded at 77.3 years. Evidently, the first Brunei epidemiological research which investigated the risks associated with stroke among public showed that nearly half from five thousand and sixty-three respondents were hypertensive and over eighty percent were either overweight or obese (Lupat et al., 2016). Furthermore, this survey found positive correlation between hypertension and level of education, where participants who completed their secondary and lower level of education were frequently identified as hypertensive. This study indicates the urgent need for information campaigns and preventative programmes regarding the risks of stroke. Consequently, nurses in the community may have potential roles to help address this concern.

A review of International literature found that the consequences of stroke adversely affects individuals' as well as carers' health and wellbeing. These individuals may experience long-term health problems which affect their health-related quality of life. De Wit et al. (2017) reported that stroke patients continued to experience poor quality of life five years post-stroke which is associated with depression, anxiety and disability. A longitudinal study that investigated quality of life, anxiety, depression and burden of stroke caregivers (Pucciarelli et al. 2018) concluded that the extent of problems for the carer due to caregiving roles is more significant during the first nine months after stroke. With the continuing shift of health provision towards community care, providing appropriate support for stroke survivors and their carer at home appears to be a substantial task. Subsequent sections provide a brief overview regarding the provision of stroke care in Brunei

1.4 Overview of Healthcare Service Provision for Stroke – Gap Analysis

Over the years, there has been a major shift in care provision and management for patients with stroke in Brunei. In the early stages, care of patients with stroke was primarily managed at the Government hospital; Raja Isteri Pengiran Anak Saleha Hospital (RIPAS) Ministry of Health. In 2010, the first private national stroke centre; the Brunei Neuroscience Stroke Rehabilitation Centre (BNSRC), Pantai Jerudong Specialist Centre was established. Since 2010, individuals who experience stroke or a suspected stroke attack may go to either of these two healthcare settings.

1.4.1 Provision of care and rehabilitation at the RIPAS Hospital

RIPAS Hospital is the largest hospital in Brunei which predominantly acts as the main referral health centre in the country. It offers a wide range of services and facilities such as diagnostic imaging, clinical laboratory, allied health professionals' services as well as medical and surgical services covering almost 30 different specialities and subspecialties (Ministry of Health, 2015). However, available medical, surgical and rehabilitative facilities for stroke are limited. For this reason, eligible individuals such as local residents with minor complications due to stroke, will be sponsored by the Government to get treatment at the BNSRC. Meanwhile, non-eligible patients such as non-Bruneians will resume treatment at RIPAS hospital

Diagram 1 illustrates the provision of stroke rehabilitation services starting from the hospital to a community-based setting. In RIPAS hospital, rehabilitation services are provided by a team of allied health professionals, including occupational therapists, physiotherapists, speech-language therapists, psychologists or neuro-medical specialists. The inpatient rehabilitation therapy often begins in the intensive care unit after a patient survives an acute episode of stroke. Then therapy will be continued in the ward or the patient will be sent to adjacent rehabilitation departments. When the patient is discharged home, therapy usually continues as weekly outpatient rehabilitation visits to the hospital and may last up to 6 months. However, home-based rehabilitation is only offered to those patients who are likely to recover but unable to attend the outpatient therapy due to transportation constraints. Thus, most daily care for these patients are undertaken by the family members or a paid carer. On the other hand, if a stroke patient is discharged home with chronic disability or if recovery has reached a ‘plateau’ (Karla & Langhorne, 2007), the these patients are usually referred to the Home-Based Nursing Unit to continue long-term care, such as changing a wound dressing or providing urinary catheter care (Abdullah Chen, T.N., Haji Suhaili, W. & Seng Khiong, J., Personal Communication, February 24, 2015). Presently, home visits by rehabilitation nurse specialists in RIPAS hospital is absent.

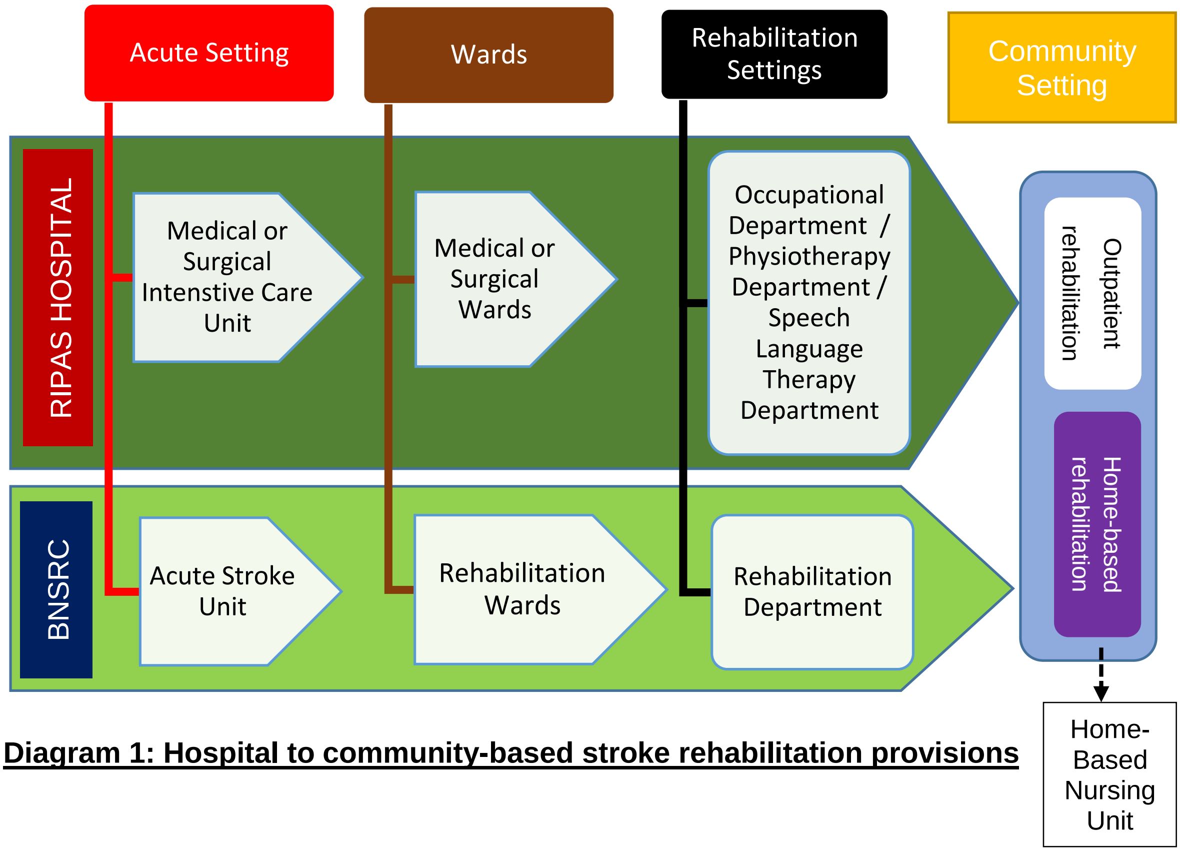


Diagram 1: Hospital to community-based stroke rehabilitation provisions

1.4.2 Provision of care and rehabilitation at the BNSRC

The BNSRC is run through a partnership between Brunei and the Krankenhaus Nordwest Hospital (KNH) and Heidelberg University of Germany. The centre has modern facilities including the rehabilitation wards, an acute stroke unit, a neurology intensive care unit, inpatient and outpatient rehabilitation services and a stroke check-up. This centre offers comprehensive treatment for stroke and other neurological diseases and is equipped with telemedical facilities for remote communication between BNSRC and KHWN hospital. Patients referred by doctors from RIPAS hospital or patients who attend privately receive care from a multidisciplinary stroke health team, consisting of stroke consultants, neuro-surgeons, therapists and therapist assistants. However, the involvement of rehabilitation nurses and neuro-psychologists is currently absent. The National Institute for Health and Care Excellence (NICE) (2016) emphasises the importance of providing a clinical psychologist for stroke patients who can help the latter with psychological difficulties such as low mood and anxiety.

With reference to Diagram 1, initial therapy usually commences in the acute stroke unit and continues to a rehabilitation ward in the rehabilitation department. Once a patient is discharged home, therapy will be provided in the form of an outpatient visit, typically lasting from 30-45 minutes delivered once a week. The therapy will be discontinued if the patient’s goal is accomplished, or if a patient feels satisfied with their functional and physical performance or after such time when therapy is no longer beneficial to the patient's recovery. Similarly to RIPAS hospital, a home-based rehabilitation service is only offered to certain patients, in particular those who are bed-bound, have a history of recurrent falls and those who require context specific therapy at their home due to cognitive or psychosocial problems. This visit undertaken by the physiotherapist is usually provided once a week and for a period of three months, followed by reviews at six and nine months. Finally, a telephone call is made 12 months from the initial home-visit (Tie, V., Personal Communication, February 02, 2014). Patients who require long-term care support are referred to the Home-based Nursing Services.

1.4.3 The provision of stroke nursing care in the community

In Brunei, residential home care such as Care Home service or Nursing Home is not practice. Therefore, it is common for stroke survivors continue to live with their extended family upon discharged from the hospital. The provision of stroke nursing care and support in the community presently provided by two public services, namely the Home-Based Nursing Unit and the Community Healthcare Centres. The different roles provides by these two groups of nurses are distinguish below.

The home-based nursing unit was first introduced in 1998. The primary function of this unit is to provide a long-term nursing care and support to various range of patients with chronic conditions, such as patients with cognitive or physical disabilities caused by stroke, spinal injuries, cancer or renal diseases through scheduled home visits. These patients often discharged home with complex co-morbidities (such as diabetes), bedridden and poor recovery prognosis (Idris, 2012). Currently, there is one home-based nursing unit within each of the four districts of Brunei, with altogether the total number of staff is 23 nurses. The care activities of these nurses mainly involves monitoring patients' general health status, performing pressure ulcer dressing, inspecting urinary catheter or naso-gastric tubing or providing health-related advises. In relation to stroke, most stroke survivors attended by the home-based nurses often reached rehabilitation plateau, described as failure for patient to respond positively to rehabilitation therapy (Karla & Langhorne, 2007), and have severe functional disabilities due to the stroke. The role of the nurses therefore centred upon providing continue health maintenance and optimising patients' level of comfort.

Whereas, the community healthcare centres encompasses primary health care services (out-patient services, maternal and child services and flying doctors), school health services, psychology services, community nutrition unit, health promotion and education unit, district health services and community nursing services (Ministry of Health, 2014). The staffing consist healthcare centre nurses, community-based nurses, school health nurses and midwifes. The healthcare centre, through the out-patient services, can be a focal point for patients with stroke. Normally, if these patients experience problems with health and well-being, they may seek treatment at a nearby health centre. Therefore, nurses in the community centre may form the first point of contact for stroke patients upon discharge home. However, these nurses presently don't have explicit roles in provision of stroke rehabilitation and may have limited knowledge of stroke care. Thus, this research explored the potential roles of these nurses in this aspect in order to provide continue support for recovery to patients with stroke.

1.4.4 Summary for healthcare service provision

The provision of healthcare services for stoke patients is presently made up of the following; RIPAS hospital, BNSRC, the Home-Based Nursing Unit, the Tamada Nursing Service and Healthcare Centres. However, the involvement of nurses in rehabilitation support, particularly outside the hospital setting, seemed to be absent. Published international nursing studies sugges that nurses in collaboration with multidisciplinary stroke professionals, may have potential roles in community-based stroke rehabilitation. Many studies have explored the role of nurses: in stroke rehabilitation units (Burton, 2000; Clarke, 2014; Kirkevold, 1997; O'Cornor, 1993); in community stroke rehabilitation

(Gibbon, 1994; McGinnes et al., 2010; Murray et al., 2008) or as part of a multidisciplinary rehabilitation team (Long et al., 2000).

The different service offered by RIPAS hospital and BNSRC, meanwhile, suggested that stroke patients may likely received difference service quality and health outcome. The usual out-patient therapy provision appeared not meeting the international standard. Whereby evidence from the Cochrane Review revealed that patients required 30 to 60 minutes therapy per day, delivered at five to seven days per week, in order to show considerable improvement with their activities of daily living independence and motor functions (Pollock et al., 2014).

This subsection illustrates service deficit along the stroke recovery pathway and in particular, support available outside of the hospital setting. A discussion of how nurses in the community can bridge this gap ensues and informs the direction of this research. Finally, the existing global best practice model for outpatient stroke care that incorporate nurses as part of the team is briefly presented.

1.5 Outpatient Stroke Rehabilitation Model

The importance of providing appropriate support for stroke patients who have been discharged home has been well documented. For example, the UK’s National Stroke Strategy emphasised the provision of inpatient specialist stroke care should be transferred and delivered within the patients’ normal environment at home (Department of Health, 2007). Arguments with regard to existing best practice model of outpatient stroke care between hospital visit, community or home-based interventions have been reported (Teasell, 2018). However, cumulative evidence for effective continue care and cost-saving services, in comparison with the conventional inpatient care, is the Early Supported Discharged (ESD) service.

Early Supported Discharge consists of a multidisciplinary stroke rehabilitation team who provide intensive rehabilitation and care of patients in the home (Fisher et al., 2011). This support service model constitutes the best stroke practice guidelines (Hebert, 2016; NICE, 2013), and has been widely implemented across several countries such as in the UK, Canada, Australia and Thailand. In a meta-analysis of 17 research trials consisting of 2422 participants, Langhorne and Baylan (2017) found that patients with acute stroke who were supported by a coordinated multidisciplinary ESD team were more likely to become independent in their daily activities, avoid admission to institutional care and reduce the length of hospital stay by approximately five days. The ESD team thus should include diverse stroke specialist professionals such as nurses who are competent and knowledgeable in stroke cases (Fisher et al., 2011). A detailed discussion regarding ESD and clinical guidance for stroke rehabilitation service following discharge from the hospital forms the basis of Chapter Two. What follows next is an overview of nurses' education and training of stroke in Brunei.

1.6 Nurse Education and Training Related to Stroke Rehabilitation

In Brunei, the training and education of nurses is provided by several education organisations, comprising the Institute of Brunei Technical Education, the Politeknik Brunei and the Pengiran Anak Puteri Rashidah Sa'adatul Bolkiah Institute of Health Sciences, Universiti Brunei Darussalam. Courses offered range from certificate to doctorate level in Nursing and Midwifery programmes. Specific courses regarding stroke and rehabilitation nursing are not presently available. However, topics related to stroke that concern pathophysiology, the impact of stroke on patients and families, the complications of stroke and the nursing care of patients in the hospital are incorporated as part of the Surgical Nursing Module. More importantly, practices related to rehabilitation techniques were not explicit. Students commonly learn about assisting patients in activities of daily living such as personal cleansing and dressing, manual handling, assistance with elimination, moving and transferring of the patient and assistance with ambulation during the first and second year of their programme (PAPRSB IHS UBD, 2009). During clinical practice, students are usually allocated to the General Medical or Surgical Wards, or to community health centres. Furthermore, nurses who work at the stroke centre undertake educational training in the form of in-house training or short clinical placements abroad (Zainal, 2010).

To summarise, the above description regarding nurse education and training in stroke indicates that the present programme lacks emphasis on stroke rehabilitation nursing. Related studies concerning nurse education (Booth et al., 2005; Catangui & Stark, 2012; Mauk, 2013), nurses' preparation for roles in rehabilitation (Long et al., 2002) and educational needs in stroke education (Smith et al., 2008a; Smith et al., 2008b), collectively showed a deficit of stroke knowledge. Therefore, this study seeks to address the educational needs of nurses in stroke rehabilitation and proposes specific roles with respect to a stroke multidisciplinary team. Findings could inform rehabilitation therapists, researchers and other stakeholders so as to improve and plan future, post-stroke services and education in Brunei.

1.7 Policy Context

In Brunei, several published government's policy documents and national initiatives such as the Brunei 'Vision 2035 and Health Strategy' (Ministry of Health, 2009), the 'National Multisectoral Action Plan for the Prevention and Control of Non-communicable Diseases' (Ministry of Health, 2013) and the 'Health System and Infrastructure Master Plan for Brunei Darussalam' (Haji Md. Hashim, 2015) have included rehabilitation as part of the ongoing and future service improvements. For example, one of the 5 themes from the Ministry of Health Vision 2035: “Together Towards A Healthy Nation”, emphasised service excellence through holistic approach in the provision of healthcare which focuses on promotive, curative and rehabilitative services. However, the scope of this rehabilitation service and what the policy entails, particularly for involvement of nurses in rehabilitation, are not explicitly outlined. Therefore, the UK’s policies and initiatives are used to support the context of this study. This is because Brunei and the UK have a longstanding, bilateral relationship with the result that many Bruneians continue their training and studies in the UK. Consequently, these practices may influence the delivery of healthcare and education in Brunei.

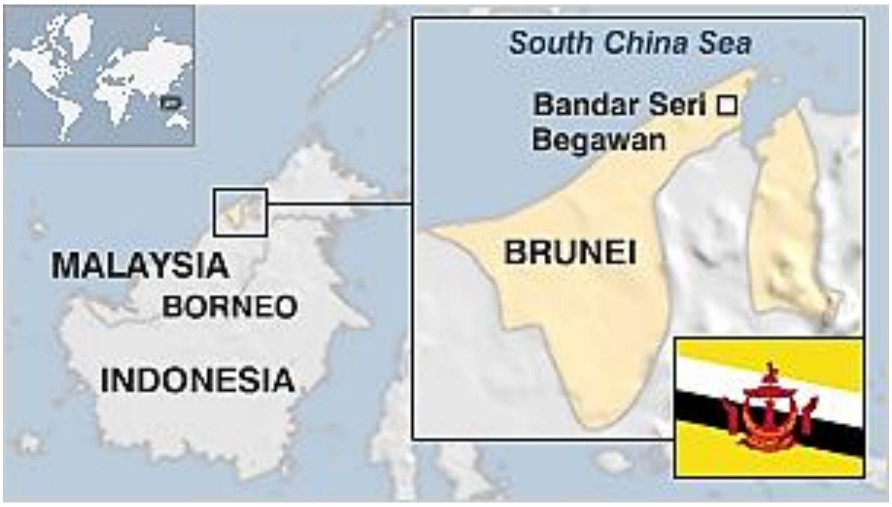
In the UK, several government organisations have highlighted the importance of community stroke rehabilitation support as part of stroke care pathways (Department of Health, 2007; House of Common, 2006; National Institute for Health and Clinical Excellence, 2010; Royal College of Nursing, 2007; Royal College of Physicians, 2008; Stroke Unit Trialists’ Collaboration, 2009). Referring to the National Stroke Strategy as an example, this initiative recommended that rehabilitation and support services are offered to patients with stroke and their carers beginning at the hospital, immediately after going home and for as long as they are needed (Department of Health, 2007). The National Audit Office (2010) highlighted that these multidisciplinary stroke services can be central in delivering high quality care and effective rehabilitation post-stroke. The subsequent sections outlines study setting which further justifies the relevance of this research within the local context of Brunei.

1.8 Study Setting

This study was undertaken in Brunei. This section provides a brief overview of Brunei, its geographical location, the culture and healthcare delivery system.

1.8.1 Geographical Location of Brunei

‘Brunei Darussalam’ denotes ‘the Abode of Peace’; its capital city is Bandar Seri Begawan. It enjoys an equatorial climate with an average of 28° Celsius, high humidity and heavy rainfall. The area of Brunei is 5,765 square kilometres, situated on the northwest coast of the Island of Borneo in the Southeast Asia region. Brunei’s neighbouring countries include the state of Sarawak, Malaysia and Indonesia. Thus, findings of stroke research from these countries may be transferable to the context of Brunei. (See diagram 2 for location of Brunei.)

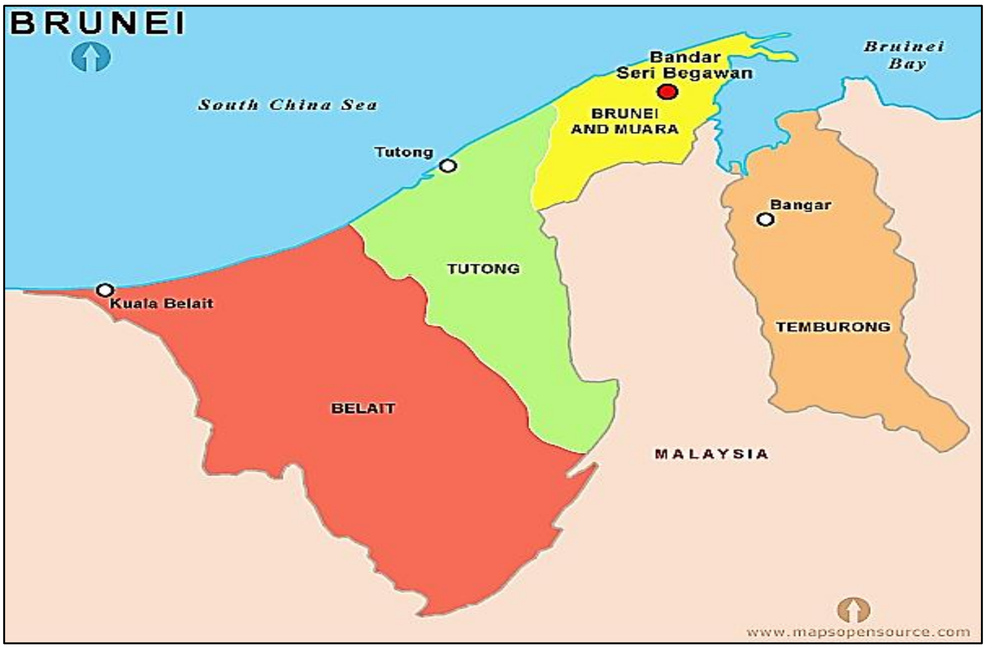


Map source: (BBC, 2015)

Diagram 2: Geographical location of Brunei

1.8.2 Districts of Brunei

About 58% of the population live in Brunei's Muara District. This area is where participants in the present study were recruited. Other districts include Tutong, Belait and Temburong. In 2015, Brunei had an estimated population of 417,000 (Ministry of Health, 2015). (See diagram 3 for map of Brunei.)



Map source; (mapsopensource.com)

Diagram 3: Map showing Brunei Muara district where participants recruited

1.8.3 Kampung Ayer (Water Village)

Situated in Brunei's Muara district, *Kampung Ayer* ('Air' in standard Malay or translated into English as the 'Water Village'), is a residential area of stilt houses, linked together by foot-bridges that were built for several miles along the river banks of Brunei. More than 30,000 people live here and they rely on private water taxis to travel ashore. These resemble long, wooden, speed boats (Brunei Resources, 2012). For patients with stroke, this geographical area is often cited as a problem when attending out-patient rehabilitation therapy. Patients may find it difficult to travel because of physical restrictions or because they live far away from the hospital. Therefore, providing home-based services for these individuals can be crucial in order to sustain rehabilitation, post-stroke. (See diagram 4 for aerial view of *Kampung Ayer* and Inset picture for water taxi). However upon completion of this study, no participants from this village fulfilled sample inclusion criteria and eligible to take part in the study.

Source: (Welcome2Borneo, 2010)

Diagram 4: Aerial view of Kampung Ayer and private water taxi

1.8.4 The Brunei Monarchy System

On 1st of January 1984, Brunei achieved its independence and was declared by the present monarch as a sovereign, democratic and independent Malay Islamic Monarchy, or, in Malay, "*Melayu Islam Beraja"* (MIB), which would be administered according to the teaching of Islam. Since then, MIB has become the country's national ideology (Talib, 2002). MIB encompasses the teaching of Islamic laws and values, along with the monarchy system, which must be esteemed and practised by Bruneians. It encompass strong Malay cultural influences, stressing the importance of Islam in daily life and government and respect for the monarchy as represented by His Majesty, the Sultan (Tuah, 2002). Inevitably, MIB may be embedded in participants' lives, thus influencing their views and responses in the present study. Hence, participants were free to answer questions in Malay or English when asked, in order to encourage more detailed responses and meaningful data.

1.8.5 Culture, Ethnicities and Religion

Being an MIB country, most Bruneians are Muslims but other religions such as Buddhism and Christianity are openly practised. In 2014, Brunei implemented the Sharia law as ways of daily lives for every Muslims in the country. The official language spoken is Malay although English is widely used in the business and working environments. It is also the medium of instruction in the secondary and tertiary education systems (Borneo Bulletin, 2014). Brunei is a multi-ethnic and multi-racial society, consisting of many different nationalities. Three fifths of the population are Malay and other minority ethnic groups include Chinese, Indian, Iban, Dayak and Kelabit. Expatriates make up approximately 21% of the population. About 9% are from the European nations, Australia and the USA, and around 12% are from Indonesia and the Philippines (Government of Brunei, 2014).

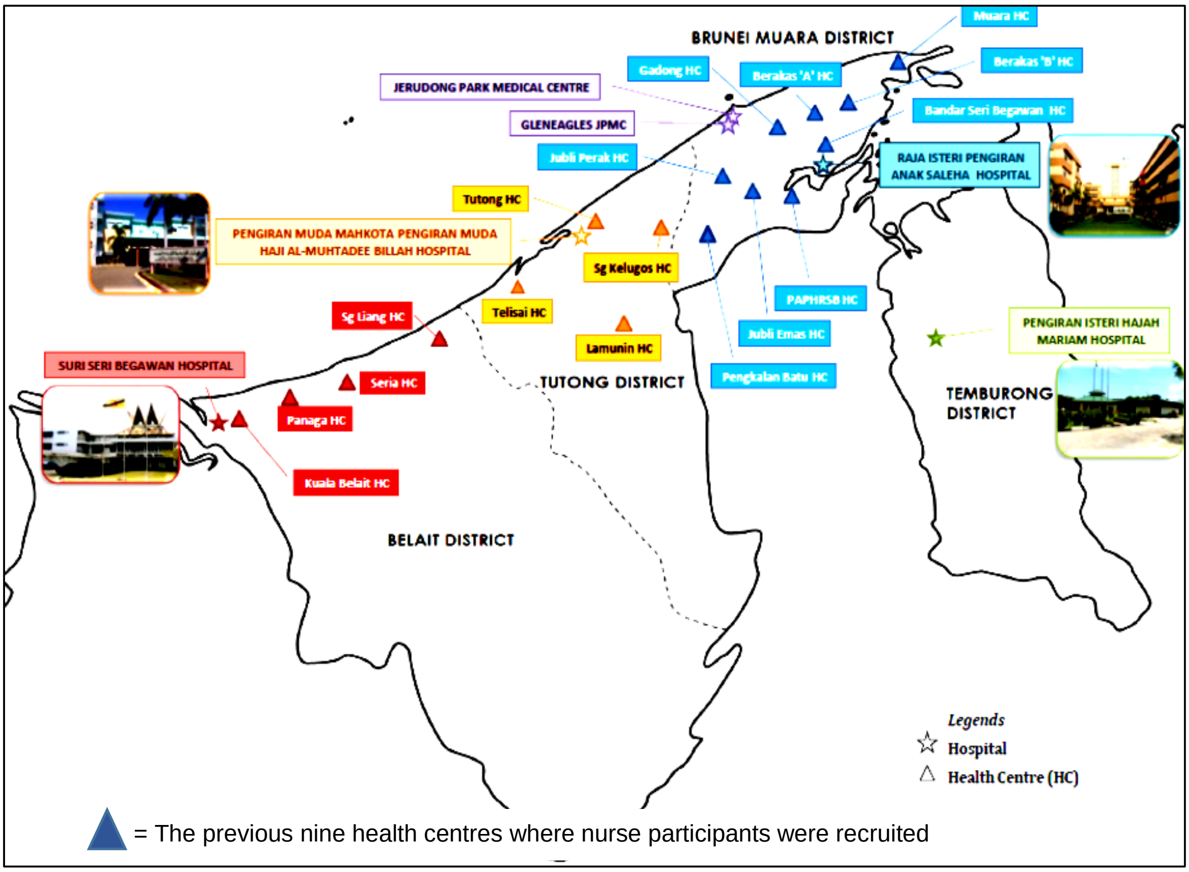
The use of complementary and alternative medicine (CAM) in Brunei is still widely practised. These traditional treatments are often inherited from older Malay generations and commonly used in health maintenance, prevention or to cure ailments (Rosli, 2012). It was found that the prevalence of CAM is high, particularly with older people (Nurolaini et al., 2014). Chong et al. (2008) noted that Bruneians generally used CAM to treat psychosomatic symptoms of depression, especially in chronic diseases.

Fundamentally, culture and religion are central to most Bruneians. This necessitates that the delivery of community stroke rehabilitation should be appropriate and sensitive to the different needs and backgrounds of these multi and inter-cultural people. Therefore, participants were recruited from heterogeneous backgrounds to assist transferability of future findings.

1.8.6 The Brunei Healthcare Delivery System

The Ministry of Health, Brunei, is responsible for the provision, management, delivery and regulatory functions of healthcare in Brunei. With the mission to provide excellent and quality health care for all, the Government has provided free medical and health care for its citizens through government hospitals, healthcare centres and health clinics. There are one Government hospital located in each district. During the study, there are total of 16 government's health centres throughout Brunei. Nine are situated in the Brunei-Muara district, are where nurse participants were recruited (Diagram 5 shows the location of health centres within each district). In 2015, three of these health centres ceased their operation and reallocated to one largest health centre.

The newly established stroke centre was situated in Brunei Muara district. This centre, along with the public hospital in this district, are where the stroke patients and carer participants from the first phase study, and the expert healthcare professional participants during the second phase study were identified and recruited.



▲ = The previous nine health centres where nurse participants were recruited

Map source: (Statistic Unit Brunei, 2013)

Diagram 5: The location of healthcare centres within each district

In 2017, there were 2,713 nurses (including midwives), with a population ratio of one nurse to 155 (Ministry of Health, 2017). The majority of these nurses were employed at the government hospitals and less than a quarter at the community health centres. Generally, the out-patient services at the health centres are staffed with various nursing levels: Nursing Officer, Staff Nurse and Assistant Nurse, commonly known as

Community Nurses. This is the group of nurses who were recruited in the first phase of the study.

1.9 Chapter Summary

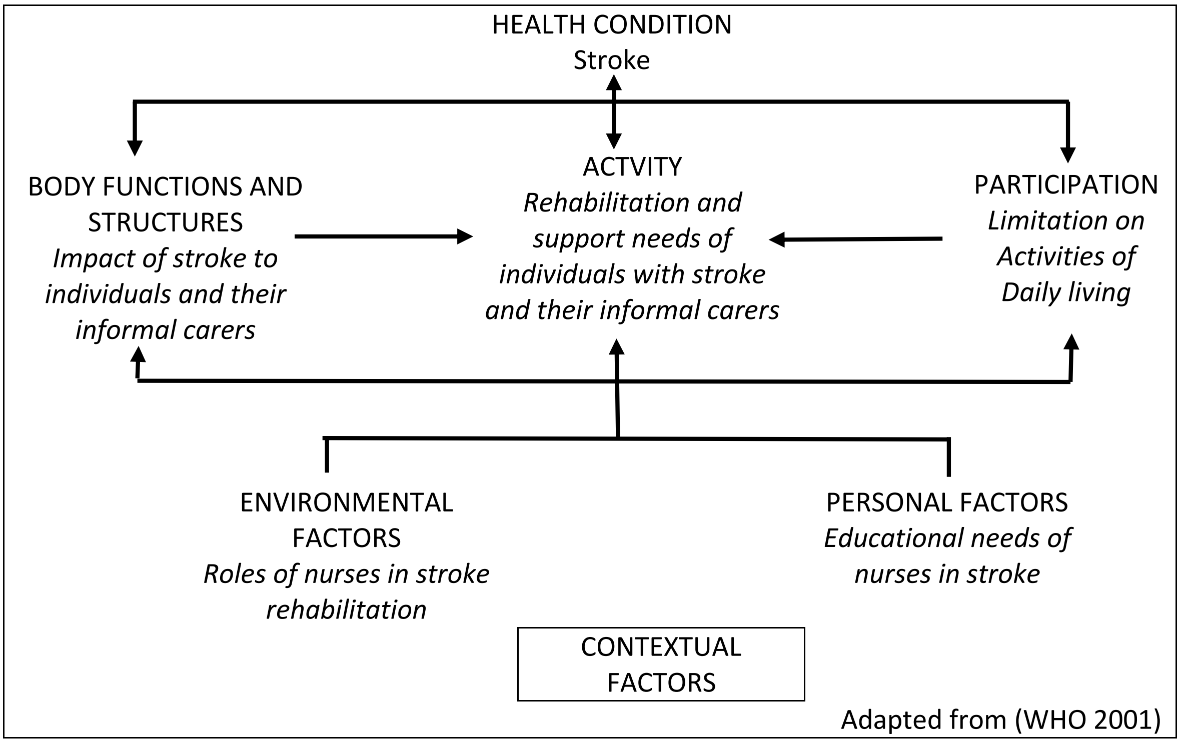
This chapter outlines my interest and the justification of conducting the study. The Government’s aim to enhance stroke healthcare services is apparent. However, provision of stroke rehabilitation and support for patients with stroke after leaving the hospital appeared not meeting the international standard or policy guidelines. Moreover, the role of nurses complements multi-professional stroke rehabilitation, and their training and education in stroke rehabilitation is still lacking. Therefore, recommendations that all patients were to receive care from competent and knowledgeable health professionals in stroke (Department of Health, 2007; Intercollegiate Stroke Working Party, 2012), was considered. Essentially, this goal aspires to achieve the Ministry of Health’s objectives which is to improve the health and wellbeing of the people through a high quality and comprehensive healthcare system (Ministry of Health, 2015).

Next, chapter two present critical review of the literature to gather existing evidence relating to research topic. The review will help identify any gaps in the knowledge and provide rationales to support the study purpose.

Chapter 2: Literature Review

2.1 Introduction

This chapter explores aspects of stroke rehabilitation for patients and their carers, as well as nurses' involvement in this process. The World Health Organization (2001) International Classification of Functioning, Disability and Health (ICF) framework was adapted in order to provide an outline of the review. The ICF is a core list that describes the interaction between individual health-related conditions and certain domains; body function and structure, activity and participation, and contextual factors. The ICF for stroke was developed by international specialists following a consensus process (Geyh et al., 2004). It has been validated by several health disciplines, including physicians (Emberg et al., 2010), occupational therapists (Glassel et al., 2010), and physical therapists (Glassel et al., 2011), and used to guide nursing interventions (Kearney & Pryor, 2004). Thus, the framework is considered appropriate for present study.



Adapted from (WHO 2001)

Diagram 6: The International Classification of Functioning, Disability and Health

Diagram 6 illustrates the ICF domains where the descriptions (shown in italics) indicate the main headings of the literature review. Briefly, the diagram can be interpreted as showing how a stroke affects an individual's body function, activities, and participation, and how the consequences of a stroke are influenced by contextual factors. In structuring the review, the health condition is identified as a stroke and briefly presented in section 2.3. Next, the impact of a stroke on the body functions and structures of individuals is discussed in section 2.4. Section 2.5 presents the impact of caring for individuals who have suffered a stroke on caregivers. Section 2.6 discusses the activity limitation and participation restriction, focusing on patient and carer rehabilitation needs and support at home. Section 2.7 explores the environmental factors, whereby the current state of evidence for stroke care after discharge is highlighted. Then, the personal factors referring to the educational needs of nurses with regard to stroke rehabilitation are discussed in section 2.8. Section 2.9 provides an overview of the existing model of community-based stroke rehabilitation. Finally, a summary of the literature findings is provided in section 2.10. This chapter begins by describing the literature strategy and results of the search in section 2.2.

2.2 Literature search strategy

Literature were identified through the University of Southampton (UoS) and Universiti Brunei Darussalam (UBD) library. Electronic databases; the Cumulative Index of Nursing and Allied Health Literature (CINAHL), Allied and Complementary Medicine Database (AMED), Cochrane Library, Excerpta Medica Database (EMBASE), MEDLINE (PubMed), Web of Knowledge and UBD Library database were used. The electronic searches were supplemented by manual searches of bibliographies of original articles, non-systematic review articles, organisational websites and reports, and relevant books.

Table 1 showed keywords applied to identify relevant articles. The initial search terms were “stroke”, “rehabilitation”, “home-based”, “nurse”, “roles”, and “education”. But, new main search terms: “Malay culture” and “traditional massage” were added following completion of analysis of the second phase study. Individual terms were searched using thesaurus terms; e.g. Medical Subject Heading (MeSH), or free text terms. The search terms were exploded or combined using Boolean search operator ‘AND’ and ‘OR’ and truncation (‘$” or ‘*”). For example, (stroke OR cerebrovascular accidents) AND (rehabilitation OR therapy) AND (home-based OR community-based) AND (nurs* OR community nurs*) AND (roles OR nursing care) AND (edu* OR knowledge). Inclusion criteria for search were studies that focused on patients with stroke who have been discharged home, and nurses roles in supporting these patients and their carer. Other inclusion included retrievable as full text, written in English and published from the period of 1990 to present 2017, to capture evolving evidences in stroke rehabilitation over the years.

1. stroke; post-stroke; cerebrovascular accident, CVA
2. stroke survivors; informal carer; caregiver; patients
3. rehabilitation; recovery; therapy; interventions
4. nurse; community nurse; care home nurse; district nurse
5. nursing role; management; care; support
6. education; knowledge; training; programme; educational needs
7. home-based; domiciliary; discharge; homecare: community
8. provision; services;
9. Malay culture; culture;
10. traditional massage; *urut*;
11. Islam; religious officer; mosque; prayer

Table 1: Key words used for searching literature

2.2.1 Literature search results

The process of the literature search began by applying and combining key words across the data bases. This resulted in 291 articles being identified; 29 from AMED, 85 from CINHAL, 86 from PsycINFO and 91 from MEDLINE. Table 2 shows the search results from each data base. Next, the screening of the titles and abstracts for relevance and duplication was undertaken. A total of 158 articles were deemed irrelevant, and a further 38 were duplicates and so excluded from the review. The remaining 95 articles were retrieved in full text format.

However, 13 articles proved inaccessible due to subscription requirements or unavailable as online articles. Therefore, 82 articles were accessed as full text. Upon reading these, a further 12 studies were excluded due to their focus on inpatient rehabilitation or interventions primarily performed by therapists. A manual search through the bibliographies yielded 4 related studies. To support the findings of the literature, 4 organisational websites (WHO, Royal College of Nursing UK, Department of Health UK and Ministry of Health, Brunei) and related books were used. No literature on the training and educational needs regarding strokes for nurses in Brunei was found. Overall, 82 literature sources were used to structure the review. A summary of the search strategy is illustrates in flowchart 1.

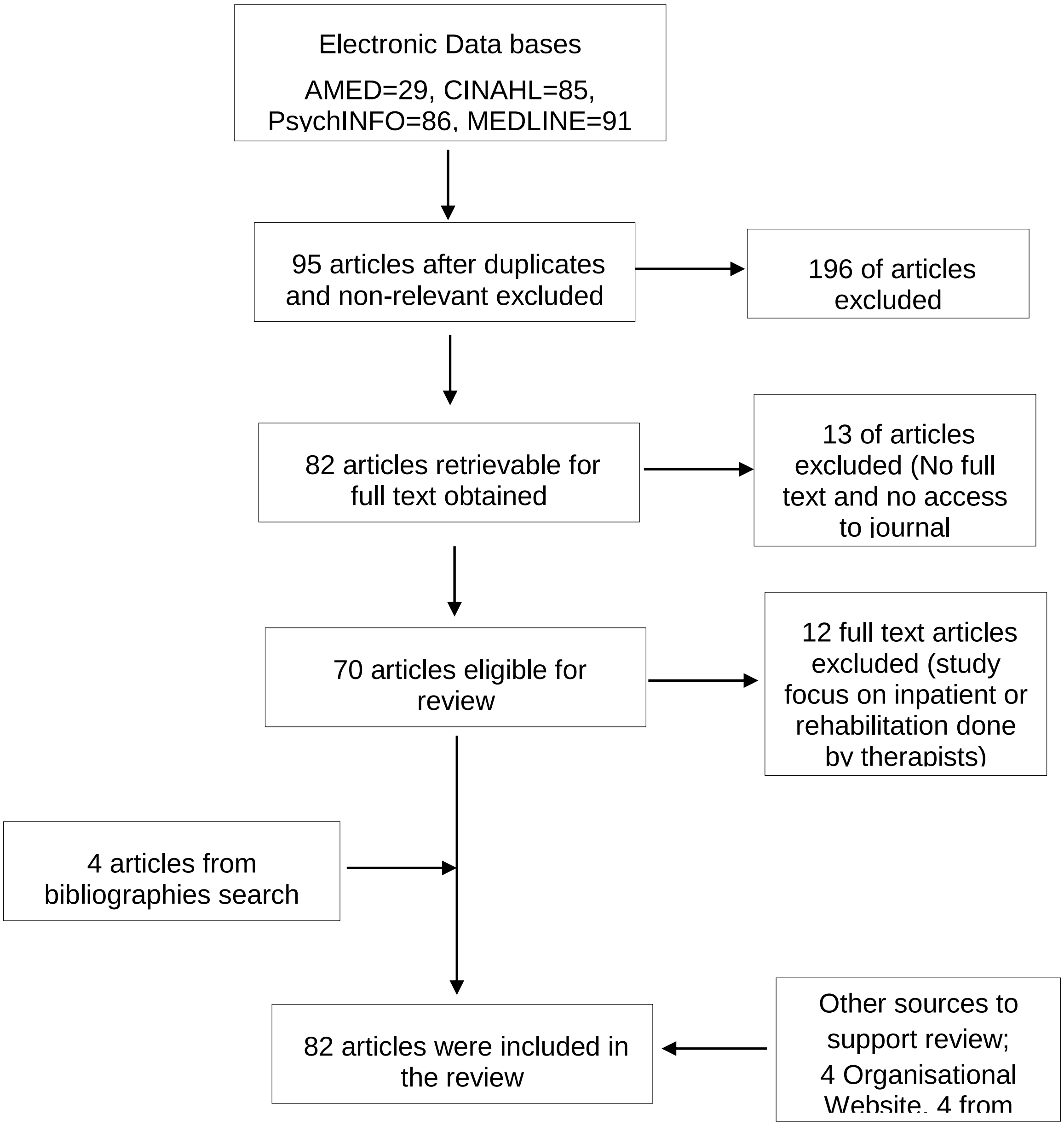
2.2.2 Appraising the quality of the reviewed literature

The strengths and weaknesses of the studies reviewed were critically appraised using relevant critical appraisal checklists (Critical Appraisal Skills Programme, 2013). Three key issues were considered in order to evaluate the quality of the study; the validity of the methodology, the interpretation of the findings and the inference of the results to different populations or contexts. Additionally, four criteria for assessing the trustworthiness of a qualitative study (credibility, dependability, confirmability and transferability (Guba & Lincoln, 1989)) were used. Descriptions about the strategy to ensure quality of quantitative and qualitative studies were provided in the methods chapter.

Table 2: Search results from data bases

Electronic Data bases	Search key words										Search results
	(S1)	**(S2)**	**(S3)**	**(S9)**	**(S5)**	**(S6)**	**(S7)**	**(S8)**	**(S9)**	**(S10)**	**(S11)**
AMED (02/10/2015	27,895	502,337	622,461	29	775,865	928,760	272,763	354,147	1460	102	29
CINAHL (02/10/2015)	66,591	1,092,399	1,149,183	85	1,181,150	787,533	214,308	387,808	1901	876	85
PsychINFO (02/10/2015)	26,965	466,739	768,288	86	749,464	885,750	267,171	341,510	12	45	86
MEDLINE (02/10/2015)	27,895	476,559	38,791	91	775,865	928,760	272,763	356,147	201	320	91

Key descriptors:
(S1) stroke OR post-stroke OR cerebrovascular accident OR CVA
(S2) stroke survivors OR patients OR informal carer OR caregiver
(S3) rehabilitation OR recovery OR therapy OR interventions
(S4) nurs* OR community nurse OR care home nurse OR district nurse
(S5) nursing role OR management OR care OR support
(S6) edu* OR knowledge OR training OR programme OR educational needs
(S7) home-based OR domiciliary OR discharge OR homecare OR community
(S8) provision OR services;
(S9) Malay culture OR culture
(S10) traditional massage OR *urut*
(S11) S1 AND S2 AND S3 AND S4 AND S5 AND S6 AND S7 AND S8 AND S9 and S10



Flowchart 1: Literature review process

2.3 The ICF Health condition - The nature of strokes

A stroke is defined as a focal (or, at times, global) neurological impairment of sudden onset, lasting more than 24 hours (or leading to death), of presumed vascular origin (Hatano, 1976). Hickey (2009) described stroke as a heterogeneous, neurological syndrome characterised by the gradual or rapid, non-convulsive onset of neurological deficit that fits a known vascular territory and last for 24 hours or more. Essentially, a stroke is the consequence of an interruption to the flow of blood in the brain (Townsend et al., 2012).

An ischemic stroke refers to a blockage of the blood supply in the brain, due to either a thrombosis or embolus, that leads to a disruption of the blood flow resulting in tissue infarction (Pendlebury et al., 2009), while a haemorrhagic stroke occurs when one of the blood vessels in the brain is ruptured due to trauma or disease, such as hypertension. This results in the accumulation of haematoma that increases the pressure surrounding the affected area, leading to tissue death (Warlow et al., 2008). Ischemic stroke accounts for about 80% of all strokes and 20% of these are haemorrhagic in nature (Townsend et al., 2012). The impact of a stroke on an individual can vary but largely depends on the precipitating cerebral accident (Wolfe, 2000). Suffering a stroke may cause a wide range of problems, such as muscle weakness or paralysis, numbness and tingling, speech and language impairment, vision problems, fatigue, anxiety and depression (Walton, 2012).

2.4 The ICF Body functions and structure – The impact of strokes on individuals

The impact of strokes on individuals can be multifaceted. Strokes may cause physical disabilities, psychological problems, cognitive and emotional impairment, psychosocial difficulties and changes to individual spiritual/religious practices. However, the impacts of strokes often occur as overlapping consequences and are interrelated.

2.4.1 The physical impact of a stroke

The WHO (2001) described the impairment of body function as problems in the physiological and psychological functions of the body's system due to a significant deviation or loss. Langhorne et al. (2009) suggested that about 80% of patients developed physical impairments resulting from stroke. These impairments typically affects the face, arm, and leg on one side of the body (Warlow et al., 2008). Other physical impacts of strokes include dysphagia, aphasia, visual impairment, faecal or urinary incontinence, fatigue and sexual alteration.

In a quantitative study, Lee et al. (2010) investigated the impacts of stroke on 112 Taiwanese patients. They developed questionnaire interviews to measure three main factors of patients' concern; physical, psychosocial and cognitive/mental aspects. The impact and importance of these factors were rated using a 4 response scale (0=not at all, 1=mild, 2=moderate, 3=severe). The study showed that the participants noted a severe impact on their physical aspects of mobility (58.9%), self-care (57.7%) and hand/arm function (53.6%). They also rated physical aspects higher than psychosocial and cognitive/mental aspects. Lee et al. (2010) suggested that their findings are meaningful for assisting therapists to make decisions about therapy interventions. However, this study has limitations. The external validity of the new instrument was not discussed, hence generalisation to other populations was inappropriate. Equally, these findings may be influenced by gender bias, as the majority of the participants are male (*n*=75), so it is possible that more emphasis was placed on the individuals' physical aspect as a result (Connell, 2005).

Published studies show that problems with mobility can lead to a long-term physical impairment. Several outcome measurement tools were used to assess the functional mobility of stroke patients. For example, the Rivermead Mobility Index (RMI) has excellent reliability (test-retest, internal consistency and inter-observer), validity and responsiveness to change over time (Matthew Mosses & Teasell, 2013). In studies using this tool, Paolucci et al. (2001) followed up 141 stroke patients over a year after inpatient rehabilitation therapies. They evaluated the stability of the patients' mobility using the RMI scores and the odds ratios for improvement and decline in mobility. The study found that nearly 40% of the patients' mobility deteriorated, particularly those with global aphasia (speech problems), unilateral neglect (vision problems) and age over 75. On the contrary, van Wijk et al. (2006) evaluated 148 patients with stroke at two years after discharge using a similar tool, and found that only 12% of these experienced a decline in mobility. Arguably, the inconsistencies in both findings can be explained by the variation in functional impairment and the extent to which the participants received outpatient or community rehabilitation therapies. Nonetheless, these findings indicated considerable evidence of mobility decline after stroke, and imply that continued rehabilitation can be integral to preventing long-term mobility problems (Van de Port et al., 2006).

The effects of physical dysfunction due to stroke have caused significant problems related to survivors' Personal Activity of Daily Living (transfer, dressing, bathing, energy to eat, going to the toilet, faecal and urinary incontinence) and Instrumental Activities of Daily Living (washing clothes, cooking, cleaning, transport and shopping) (Pajalic et al., 2004). Moreover, physical support was reported as one of the common unmet needs following stroke (McKevitt et al., 2011). Therefore, continued rehabilitation to support the recovery of impaired movement and the associated functions is essential (Langhorne et al., 2009). Next, the impacts of a stroke on individual cognition, psychology and emotions will be discussed.

2.4.2 The cognitive, psychological and emotional impacts of strokes

The degree of physical impairment of stroke patients was associated with greater cognitive impairment. Tatemichi et al. (1994) suggested that people who had suffered a stroke may experience problems with their cognitive ability, such as memory, orientation, language and attention. Several follow-up studies have assessed the cognitive functions of stroke patients at multiple time intervals. Patel et al. (2003) assessed the rates of cognitive impairment among community-based stroke patients at three months, 1, 2 and 3 years. Using the Mini Mental State Examination (MMSE) as a psychometric screening tool, they concluded that cognitive impairment remained prevalent for up to three years following a stroke. Another longitudinal study which observed patients' cognitive status for up to 15 years following a stroke similarly identified that the impairments were persistently high (Douiri et al., 2013). These findings maintain that patients experience cognitive impairment after a stroke.

However in criticising these findings, it was unclear whether the participants were provided with specific interventions, such as in the form of information, which might affect their response to the screening test. Moreover, Jokinen et al. (2015) reported that MMSE was not sensitive in detecting cognitive recovery over time. Therefore, the findings were debatable and may misrepresent the actual prevalence of the population under study. Conversely, McKinney et al. (2002),who compared patients' cognitive function at 3 and 6 months after recruitment, found no significant difference between the control and assessment group. They concluded that routine care plus detailed cognitive assessment does not improve patients' functional outcomes. However, McKinney et al. (2002) did not describe the nature of 'routine care' in their study, and thus the interpretation of these findings proved difficult.

The psychological impacts of stroke are often more subtle and gradual compared with the physical impairments. These changes can be manifested in the way patients feel, think or behave. The most common psychological effect experienced by individuals following a stroke is depression. Warlow et al. (2008) noted that depression occurs in about one-third of patients in the first year after stroke. Although some patients recover, about 30-40% remained depressed regardless of the time since the onset of the stroke (Lincoln et al., 2012). In their updated review, Hackett and Pickles (2014) included data from 61 studies involving 25,488 participants. They found that a considerable number of patients experience depression as early as two days after a stroke, which then remains constant for up to five years. In another systematic review, Ayerbe et al. (2013) identified the extent of the disabilities, history of depression prior to the stroke, stroke severity, anxiety, cognitive impairment and lack of social or family support as the major predictors of depression. However, it has been argued that these reviews may be subject to publication bias, due to reporting selective studies based on the nature and direction of the review (Song et al., 2000), so these reviews were interpreted with caution.

The emotional changes in individuals following a stroke, however, can be exhibited in various ways. These problems include depression, anxiety, post-traumatic stress disorder, fear of falling, emotionalism, catastrophic reaction, mania, anger or aggression (Lincoln et al., 2012). Warlow et al. (2008) suggested that anxiety often co-exists with depression and commonly affects patients' emotional status. In a European multi-rehabilitation centre study, De Wit et al. (2008) found that approximately one-quarter of patients (n=532) experience anxiety for up to six months post-stroke. Lincoln et al. (2013) further followed up these patients (*n*=220) over 5 years and identified a significant increase in their level of anxiety from the initial study. These findings prove that anxiety can be a long-term problem for patients. Both depression and anxiety were a considerable concern as they can induce several negative outcomes, such as poor mobility function (van Wijk et al., 2006), lower quality of life (Milone et al., 2015) and less efficient use of rehabilitation services (Gillen et al., 2001), and are associated with higher mortality (House et al., 2001). Thus, assessing the patient's anxiety as part of the rehabilitation interventions post-stroke is vital.

Another common emotional impact of stroke is emotionalism. This has been described as an increased occurrence of crying (shedding tears, sobbing) or laughing compared to the patient's condition prior to suffering a stroke. Emotionalism usually arises without warning and is often more intense and excessive than simply a few tears or smiles (Carota & Calabrese, 2013). It was reported to affect about 20-25% of patients in the first six months following a stroke but gradually decreases after a year (Hackett et al., 2010). Choi-Kwon et al. (2012) found that patients with emotionalism tend to be associated with a severe stroke, worse cognitive function and poor social support. The effect of emotionalism can be distressing for both patients and carers. Therefore, Warlow et al. (2008) suggested offering psychological and emotional support such as spending time with patients and explaining that emotionalism is a common temporary episode.

Overall, those studies indicated substantive evidence of the existence of depression and emotionalism after individuals suffer a stroke. These findings suggests that the participants in my study may experience similar problems. Therefore, several strategies, as discussed in the methodology chapter, were undertaken during the collection of the data.

2.4.3 The psychosocial impacts of strokes

The residual impact of strokes on individuals’ physical, cognitive, psychological and emotional well-being is associated with reduced social and personal reintegration. For instance, Code and Herrmann (2003) suggested that the impairment of a patient’s speech may delay his/her recovery, reduce his/her response to rehabilitation and affect his/her psychosocial interactions. Several research trials have found that strokes substantially affect the psychosocial functions of patients (Knapp et al., 2000). These psychosocial consequences include effects on mood, social relationships, use of healthcare services, participation in leisure activities and returning to work. Although the findings of these trials were largely negative or modestly positive, Knapp et al. (2000) point out that the impact of a stroke on social isolation was prevalent. Psychosocial problems are considerable concern as they have negative implications for patients’ long-term functioning and health-related quality of life (Teoh et al., 2009). Therefore, support from healthcare professionals, family and the community are important in offering a sense of belonging and assisting patients to reengage successfully in valued activities and roles (Walsh et al., 2015). These studies provide meaningful evidence of psychosocial problems due to suffering a stroke. However, most studies are undertaken in western countries, and these findings may not necessarily be transferable elsewhere. Brunei has a different social and cultural orientation. For instance, the practice of MIB (See section 1.8.4) as ways of living may create a strong bond between patients and their family. Given this, psychosocial functions of stroke patients in current study was explored.

In a feasibility study aimed at facilitating patients’ psychosocial adjustment, Kirkevold and colleagues developed a dialogue-based nurse-patient interventions (Kirkevold et al., 2012; 2014). Scheduled dialogues were facilitated by community care nurses, either as individual or group dialogues, within 4-8 weeks and 6 months following a stroke. During each dialogue, the participants were encouraged to voice issues of particular importance to them, based on their needs. Two weeks after all of the interventions had been completed, the participants were interviewed in order to explore their experience and assess the content, structure and process of the intervention. The findings showed that the participants valued those psychosocial interventions and felt that they helped them through the initial adjustment process. Kirkevold et al. (2014) highlighted the importance of their study and suggested integrating this intervention as part of the community-based nursing role. However, this feasibility study not evaluated the effect of the intervention on the participants’ psychosocial wellbeing using a standard outcome measure, such as the Social Support Questionnaire (Sarason et al., 1983). Thus, there is weak evidence to support the reliability and external validity of these findings.

2.4.4 The impact of strokes on spiritual and religious practices

Giaquinto et al. (2010) described spirituality as a concept that generally means believing, valuing, or being devoted to some high power outside the corporeal world. In the context of Brunei, where Islam is widely practised as a religion, Muslims (the followers of Islam) are mandated to pray five times a day. A prayer is considered to be the chief act of worship for every Muslim. This consist recitation of specific verses from the Holy Quran is accompanied by a sequence of movements; standing, bowing, prostrating and sitting. For every Muslim, their view of health and illness incorporates a belief in accepting illness and death with patience, mediation and prayer. Practising Muslims accept that illness, suffering and dying are part of life and a test set by Allah (God under Islam) (Rassool, 2000).

Published literature on the impact of strokes on Muslim prayers is scarce. In a related study, Norris et al. (2012) explored the experiences of stroke patients from a devout Muslim community in central Aceh, Indonesia, and found that suffering a stroke can encourage spiritual growth to assist the participants’ coping strategies. While some participants believed that prayer promotes emotional stability, others felt that a stroke represents a test of faith. Thus, maintaining prayer, despite their physical limitations, was considered a source and motivator for their recovery (Norris et al., 2012). These findings were consistent with the themes found in a recent qualitative study undertaken in Kelantan Malaysia. Mohammed et al. (2015) explored the practices of maintaining prayer among Muslim stroke patients, and identified three key themes; prayer and the meaning of the stroke for the participants, difficulties related to praying, and prayer as part of rehabilitation therapy. This study showed that the preparatory rituals before praying and performing the five daily prayers were regarded as fundamental and a means of assisting the recovery from a stroke. The findings from both studies suggested that individual Muslims who practise spirituality and religious faith following a stroke achieved better health and rehabilitation outcomes. Thus, recognising the need of stroke patients to accomplish prayer can be essential as part of rehabilitation planning (Mohammed et al., 2015).

However, it was unclear to what extent the participants in both studies practised prayer prior to suffering a stroke. Arguably, this positive relationship between increased spirituality and coping strategies may be attributed to the individuals' past religious behaviour rather than religion itself. Moreover, Giaquinto et al. (2010) identified that religiousness as a coping strategy was not associated with improved functional recovery for stroke patients. The inherent limitation of qualitative studies is that their findings are not transferable to other populations. Nonetheless, the findings from the reviewed studies may be relevant to the present research. Geographically, both studies were undertaken in countries that border Brunei, where the religion and socio-cultural situation are comparable (See 1.10.1 for geographical location of Brunei). Moreover, the way in which prayer is performed by Muslims is similar across the world. These studies offer strong indications that Muslim stroke patients are likely to engage more often in religious practices as part of their daily activities. Therefore, the impact of strokes on spiritual practices was explored in the current study. It is hoped that future findings may complement the existing body of knowledge and contribute to the emergence of research in this area.

Conversely, Omu et al. (2014) undertook a two-phase mixed methods study and found no significant relationship between religiousness, self-efficacy and life satisfaction among patients (*n*=40) undergoing stroke rehabilitation (phase 1). The authors explained that, regardless of the strength of the individuals' religious faith, the stroke patients neither rated highly their level of confidence nor felt satisfied with their life situation. Omu et al. (2014) discussed these findings (phase 2) with a group of health professionals (*n*=12) who suggested that stroke patients may entertain fatalistic beliefs about their stroke and may not apply religious faith and practices to their recovery process. This study suggested that health professionals may have a role in utilising patients' degree of religious faith to motivate them to achieve their rehabilitation goals. However, this study suffers from methodological weaknesses, as using a different sample to interpret the findings from phase one of the study is debatable. Arguably, the findings from the second phase could be subjective and bias the health professionals' views. Moreover, the interview quotes presented were mainly extracted from seven health professionals, predominantly dominated by two therapists. Therefore, the external validity and confirmability of these findings are questionable.

2.4.5 Summary of the impact of strokes on individuals

The review highlighted the considerable functional problems experienced by patients after suffering a stroke. The reviewed studies showed compelling evidence that the consequences of stroke adversely affect individuals' health and wellbeing which can persist as long-term problems. However, the impacts of stroke on individuals are not necessarily detrimental. Emerging evidence from the reviewed literature affirmed that some individuals perceived stroke positively, particularly using religious and spiritual practices as coping strategies. Therefore, accurate assessment and rehabilitation interventions based on individuals' needs may be more appropriate and effective.

2.5. The ICF Body functions and structures – The impact of caring for stroke patients on caregivers

Typically, a caregiver can be a spouse, child, relative, friend or paid carer. In Brunei, for example, this role is commonly designated to a house-maid. The residual impact of strokes on individuals have caused the majority of these patients to rely heavily on informal caregivers in order to continue their daily activities (Pierce et al., 2006). Dewey et al. (2002) suggested that over 74% of the care for stroke patients was provided by family members or informal carers. The role of these carers often involves helping patients with their personal activities of daily living (PADL), such as washing, dressing, and eating, or Instrumental activity of daily living (I-ADL), such as leisure, domestic chores, and shopping (Walker M et al., 2013). The intensity and nature of these caregiving roles can be challenging and overwhelming (Cecil et al., 2010). Smith et al. (2004) argued that caregivers may feel they lack the required knowledge and skills to assume these caring roles. Additionally, support from health professionals for carers is frequently not readily available once patients have been discharged (Brereton & Nolan, 2000). Importantly, many studies have identified that the consequences of caring for stroke patients adversely affect the carer's health and well-being. These carers may experience strain, emotional stress, negative psychological impacts, poor physical health and difficulties with psychosocial adaptation, which can present as long-term difficulties.

2.5.1 The burden and strain on the carers of stroke patients

Studies have shown that the increasing burden or strain as a result of caregiving can have a negative impact on a carer's health and wellbeing, which subsequently impedes the recovery of the patient (Lui et al., 2005). In measuring this burden or strain associated with strokes, most quantitative studies have used standardised psychometric instruments. These tools, such as the Caregiver Strain Index (CSI), often incorporate the physical, social, psychological and emotional domains as outcome measures. Several international studies have investigated the prevalence of strain experienced by carers over time. In their study, Ilse et al. (2008) recruited 90 carers from the stroke rehabilitation unit at a university hospital in Belgium. They measured the level of the participants' strain at 2, 4 and 6 months post-stroke using the CSI. This study found the prevalence of the strain among carers to be fairly persistent: 28% at 2 months, 31% at 4 months and 29% at 6 months. The carers reported ‘feeling confined’, ‘feeling overwhelmed’, ‘changes to personal plans’ and ‘family adjustments’ as that factors commonly causing them to feel strained. Additionally, Hung et al. (2012) similarly identified that about 46% of the Taiwanese carers involved in their study suffered considerable strain at 3 months after discharge, which remained at 43% at 6 months. These findings indicate that carer strain is a long-term problem and prevalent, regardless of race, culture and the location of the studies. Therefore, the impact of the caregiver role on carers’ physical, psychological and emotional health were explored in the present study.

2.5.2 The impact of the caregiving role on the carer’s psychological health

The impact of the caregiving role on the carer’s psychological health was evident. In their review of 24 related studies, Saban et al. (2010) found that carers’ psychological problems were frequently characterised as stress (58% of the studies), altered mood (30%), depressive symptoms (16%), and poor coping (13%). For example, Louie et al. (2009) undertook a study to assess the level of stress among 33 carers from the Chinese population. They used the Relatives’ Stress Scale (RSS) to measure personal distress, life upset, and negative feelings, as a result of the caregiving role. Louie et al. (2009) reported that the level of stress was higher, particularly among older carers. This study suggested that age is the main predictor of stress among Chinese carers of stroke patients. However, it is difficult to determine the validity of these results. The authors did not provide the age range of the carers who are more likely to experience increased level of stress, and the findings of some data, such as a descriptive analysis of the RSS scores, are not presented. Therefore, the external validity of these findings is questionable. On the contrary, Jones et al. (2000) used similar tools and found a strong correlation between increased carer stress and types of stroke, rate of recovery and stroke-related disability, but not patient age. Arguably, both studies suffer from limitations. The psychometric properties of the RSS was developed to assess the burden on the relatives of patients with dementia, and it has not been clinically validated on stroke patients (Rigby et al., 2009). Thus, the findings may be misleading and were interpreted with caution.

In a longitudinal mixed methods study, King et al. (2010) identified the negative impacts of caregiving on carers’ interpersonal relationships; intimacy problems, conflicts with family members or friends, problems with social involvement and negative behaviour towards carers (e.g. verbal abuse), were rated as the most stressful events, and carers were least effective in managing these problems. King et al. (2010) explained that carers' experience of interpersonal disruptions during the acute stage of patients' rehabilitation are indicative of severe stress at 4 months post-discharge. The strength of this study is related to its research design and sequential follow-up in assessing the changing nature of the caregiver burden over time. This study strongly supports the view that negotiating these changes and the tension between patients and carers are important in alleviating carers' feeling of stress. As Camak (2015) noted, carer stress can have negative impacts on the emotional, social and environmental health of both the stroke patient and the carer. Therefore, O'Shea and Goode (2013) suggested that health professionals should include an assessment of carers' psychological needs and identify any potential support, such as the provision of information, that will help carers to manage these problems.

2.5.3 The impact of caregiving on the carer's psychosocial functions and relationships

Numerous studies have shown that carers of stroke patients experience problems with social functioning and interpersonal relationships. These can be a considerable concern, as a supportive social environment and access to community resources were found to ease the burden and strain of carers (White et al., 2007). In a prospective longitudinal study, Visser-Meily et al. (2008) assessed the psychosocial functioning of 119 spouses of patients at 1 and 3 years post-stroke. They measured five domains of psychosocial functioning; burden, life satisfaction, depression, harmony in the relationship and social support. It was found that 27% of the spouses reported problems with psychosocial functioning during the first year, which increased to 57% by the third year. This study implies that declining psychosocial functioning was associated with patient impairment (cognitive and communication), and a spouse having a family with young children. Visser-Meily et al. (2008) speculated that parenting duties and providing care for patients with cognitive problems seem to affect spouses' social activities.

Likewise, the amount of time spent on caregiving and the patient's disability can restrict carers' social participation. In a cross-sectional study, Yu et al. (2013) measured social support, coping strategies and health-related quality of life among 121 Chinese carers of stroke patients. They identified that the carers' mean scores were markedly low on the perceived social support subscale (from family, friends, and significant others), suggesting that carers experience severe social restrictions. Yu et al. (2013) explained that this problem was attributed to the patients' high degree of dependency on their carers and the duration of the caregiving. It was reported that about 67.8% of patients are dependent regarding daily tasks, and around 52.1% of carers spend over 8 hours on daily caregiving activities. This study observed that carers who experience reduced social activities might suffer from a long-term poor quality of life.

In a qualitative study carried out in the UK, Cecil et al. (2013) interviewed 30 home carers of stroke patients to explore their experience of caring and coping with their caregiving role. They found that the carers' health status and well-being were enormously affected. It also emerged that the carers' experience of caregiving was influenced by three key factors; the impact of the stroke on the carer, the extrinsic factors that support the caring scenario, and the intrinsic factors that help the carer to cope with the new role. In relation to the psychosocial restriction, carers highlighted how their lives had changed after the stroke. For example, a few carers had to leave their job to assume a full-time caring role, some found it more difficult to socialise with friends, while others felt that their time and resources were occupied with the therapeutic planning of the stroke patient, such as making hospital appointments. Cecil et al. (2013) proposed that their findings can be used by health professionals to identify carer needs and plan supportive interventions.

Overall, the reviewed studies highlighted considerable evidence that carers experience psychosocial problems as a result of their caregiving commitments. However, these findings may not be transferable to Brunei, due to differences in the socio-cultural context and family structure; the majority live together within a family unit. Thus, the support networks among carers in present study were explored.

2.5.4 The positive impact of the caregiving role

The available studies showed that some carers felt that caring for stroke patients is beneficial. In an epidemiological study, Haley et al. (2009) investigated the problems and benefits associated with caregiving among carers of stroke patients (*n*=75). It was found that the prevalence of carers stress instigated by patient problems, such as those related to mood or physical care, was lower. It was reported that the carers felt positive about their caregiving role. Over 90% of the carers asserted that they had an increased appreciation on life, about 86% felt that their relationships with others were strengthened, almost 85% developed more a positive attitude, and 81% stated that their role had given their life greater meaning. Haley et al. (2009) pointed out that the ability of carers to perceive the benefits of caring positively may be related to their coping mechanisms.

Correspondingly, O'Connell and Baker (2004) explored the strategies used by 37 carers in coping with their caregiving role. Out of the 7 themes identified, five positive aspects of coping were illustrated; keep remaining positive, adapting to change, comparing their situation with others who were worse off, using humour and taking time out from their caring role. However, the link between coping and a positive attitude remain unclear. Mackenzie and Greenwood (2012) explored whether a positive attitude results in better coping or whether strategies of coping lead to a positive attitude. Thus, the direction of these findings was unclear. Moreover, any confounding factors, such as community-based support, that may influence these positive outcomes were not discussed. Therefore, the evidence of these studies is weak and was interpreted within the context of the study setting.

In a recent longitudinal cohort study, Cameron et al. (2014) assessed the psychological well-being of family carers of stroke patients (*n*=399) over two years. The findings showed that the carers' psychological well-being scores were better and consistent over time. Cameron et al. (2014) reported that carers' positive psychological outcomes were associated with patients' better cognitive functioning, fewer depressive symptoms, and having suffered a more severe stroke. It was also found that carers who spent longer on caregiving tend to develop higher levels of caring skills and enjoy better physical health and improved psychological well-being. This study provides a strong indication that delineates a positive caregiving experience in the long-term. However, the findings of quantitative research are often broad and difficult to explain, so integrating both a quantitative and qualitative design into a single study may give complete understanding about the area being study. Therefore, a mixed methods design was considered for current study.

On the contrary, there is little evidence concerning caregivers' practice of spirituality as a positive coping strategy. In a web-based study using email as a platform for dialogue, Pierce et al. (2008) explored spirituality as expressed by carers (*n*=36) during their first year of caring for stroke patients. It was found that over two-thirds of carers (69%) mentioned spirituality in their email replies. For example, they described feeling the presence of a greater power as assisting them with the physical care; they believed that performing spiritual practices (prayer) eased their caring experience; carers meditated to connect with nature as a strategy to relieve stress; or feeling blessed with emotional and tangible support from their family and friends (Pierce et al., 2008).

In another study, Gholamazadeh et al. (2014) found that carers who practice positive religious coping strategies have higher psychological well-being. The study elucidated that faith can play a vital role in helping carers to appraise the caregiving situation positively and assisting them to adjust with difficult experiences (Gholamazadeh et al., 2014). However, both studies have limitations. The impact of coping on patient outcomes and the extent to which carers practice religious activities as a coping strategy were not discussed. Therefore, these findings provide weak evidence from which to conclude that there is a positive impact on the caregiving role. Nonetheless, these studies highlight how carers might practise spirituality as a way of coping with their daily caring activities. As religion is central to the lives of people in Brunei, this was explored in the present study.

2.5.5 Summary on the impact of strokes on caregivers

The review found considerable evidence exists to suggest that the caregivers of stroke patients experience negative health and social well-being. The intensity and demand of providing care can be overwhelming. Without support, carers are at risk of suffering from emotional and psychological distress which leads to reduced quality of life. Although a few studies have identified the positive impact of the caregiving role, these findings are weak in terms of making broader inferences. Nonetheless, taken together, assessing the needs of carers as part of stroke rehabilitation planning may help to improve the quality of life for both patients and carers. Subsequently, various aspects of rehabilitation and support needs will be explored.

2.6 The ICF activity limitations and participation restriction – The rehabilitation and support needs of stroke patients and their carers in the home

The impacts of stroke on the individual body structures and functions, and the consequences of caregiving, may lead to activity limitations and participation restrictions. In the ICF core for stroke, this domain encompasses disruptions to learning and applying knowledge, general tasks and demands, communication, mobility, self-care, domestic life, interpersonal interactions and relationships, major life areas and community, social and civic life (Geyh et al., 2004). Published studies have shown that problems with activities participation are associated with life dissatisfaction (Bouffioulx et al., 2011), depression (Lo et al., 2008) and poor quality of life (Almborg et al., 2010). Thus, rehabilitation that focuses on improving the physical and psychosocial functioning of patients and their carers can be essential in promoting social participation.

2.6.1 The rehabilitation and support needs of stroke patients

Most patients requires rehabilitation after a stroke in order to help them to resume their previous activities and roles (Young & Forster, 2007). Walker et al. (2013) reported that rehabilitation delivered within a community-based setting improved patient recovery, helped them to regain their independence and promoted activities of daily living functioning. However, not all patients received out-patient rehabilitation support. In a Cochrane review, the need for the rehabilitation and support of patients with stroke was apparent, but the home-based rehabilitation services remain inconsistent (Aziz et al., 2009).

In an earlier study carried out in the UK, Lincoln et al. (1998) explored the rehabilitation needs of 93 stroke patients who were not admitted to hospital. Baseline and outcome assessments, such as information regarding the independence of activities of daily living (ADL), before and one month post-stroke, were assessed using the Barthel Index and the Extended Activities of Daily Living (EADL) scales. The findings showed that the patients' experience substantially declined in terms of both personal abilities and functioning before and after their stroke. It was found that the proportion of patients who were dependent on the EADL were high. These include problems with advanced mobility, such as walking over uneven ground (31%), walking outside (28%) and getting in and out of cars (27%); difficulties with household tasks, such as doing one's own shopping (23%), and participating in leisure activities, such as going out socially (17%). Despite these problems, the provision of community rehabilitation services was reported lacking. This study indicated a considerable need for rehabilitation for patients with stroke who live at home. Although the reliability of the tools used in this study for measuring disability was supported (Gompertz, 1993), the findings are debatable. Lincoln et al. (1998) assessed premorbid patients' independence retrospectively by relying on the patients' experience. Notably, the participants in this study are older (mean age = 74.7, SD=9.3) and the majority reported cognitive difficulties (91%). Consequently, the accuracy of the findings may be compromised.

In another study, Nilsson et al. (2000) followed-up the rehabilitation needs of 68 patients two years post-stroke and found that a higher frequency of needs encompasses aspects of special support and services (66%); leisure/spare time (62%); diet/weight/exercise (49%); social function (44%) and self-care (38%). The findings from the Instrumental Activity Measure (IAM) showed that over 70% of patients were dependent on I-ADL. These include shopping, cleaning, washing, using public transportation, and cooking. It also reported that more than 50% of the patients were dissatisfied with their life in general, self-care, work, leisure/spare time, economic situation and social relationships, which was associated with reduced health-related quality of life. This study implied that home-based rehabilitation oriented towards addressing individual needs regarding ADL participation is required (Nilsson et al., 2000). However, it was unclear whether the problems of the patients, such as I-ADL, changed over the two years. The level of patients' dependency was not assessed after stroke onset, following discharge or in-between the study. This limitation, therefore, affected the reliability of the findings.

In a population-based study, Vincent et al. (2007) interviewed four different groups of participants; stroke patients, caregivers, health professionals and healthcare managers, to explore their views on the partially met or unmet rehabilitation needs of older adults (aged 65 and over) who had suffered a stroke and were living at home. The needs of these older adults were classified based on the Disability Creation Process model, described under three main components; needs related to personal factors (e.g., intellectual, language, behaviour, balance), needs related to environmental factors (e.g., the utilization of health and social services), and needs related to life habits (e.g., individual daily activities, social roles). The findings showed that the participants felt the needs of older adults who have suffered a stroke are partially met or unmet with regard to the majority of the three components. The participants stated that older adults who had suffered a stroke needed the most help in carrying social functioning, such as sexual relationships, walking, keeping fit, visiting friends, driving, using public transport and cooking. The participants also reported disparities and delays in the rehabilitation services provided within the community. This study presents a strong research methodology related to various samples who have been recruited to investigate the phenomena under study. All of the participants indicated that many older stroke patients continue to experience difficulties with social participation, and suggested that this group's post-rehabilitation needs in this respect have not been met (Vincent et al., 2007).

On the contrary, a recent study highlighted that continuing long-term rehabilitation is essential to promote patient social participation. In a prospective cohort study, Adamit et al. (2015) followed-up 249 patients with mild stroke to examine their level of participation at 3 and 6 months post-stroke. It was found that the frequency of patient participation, according to the Reintegration to Normal Living Index scale, decreased when assessed at 3 months post-stroke. The patients reported difficulties participating in leisure activities (45.2%), trips out of town (24.8%), productivity (23.6%), mobility outside the home (24.4%), the ability to deal with live events (22%), self-care needs (21.1%) and social activities (19.2%). This study showed significant low to moderate correlations between the patient's cognitive impairment and social participation, whereby patients who experience activity limitation and restriction are more likely to have a reduced quality of life (Adamit et al., 2015). This study underlined that follow-up rehabilitation at home was needed to support the impairment and activity limitation of patients with mild stroke. However, it was noted that the sample attrition at 6 months was high. Thus, the findings are too weak to assure external validity.

2.6.2 Caregiver support needs during the rehabilitation phase of stroke patients

The role of carers in promoting the successful rehabilitation outcomes of stroke patients is apparent (Greenwood et al., 2008). Carers often play important supporting roles in stroke rehabilitation and are associated with improved care-recipient physical mobility, life satisfaction and quality of life (Bakas et al., 2014). However, caregiving roles are likely to affect the carer's own health and wellbeing. It was reported that dissatisfaction with the rehabilitation services, the adverse effects of strokes on patients, the higher level of caregiver burden, carer social isolation and low quality of life were attributed to the unmet support needs of carers during patient rehabilitation (Perry & Middleton, 2011).

In a systematic review designed to assess the support needs of carers of individuals following a stroke, MacIsaac et al. (2010) used the Supportive Care Needs framework to contextualize caregiver needs into six main domains; practical, spiritual, psychosocial, informational and physical needs. From the total of 17 studies reviewed, the information and psychosocial domains were found to be the most frequent needs reported by 15 studies, with emotional needs being the third most common need as described in 12 studies, whereas carer needs were least frequently reported in terms of physical (7 studies), practical (5 studies) and spiritual aspects (2 studies) (MacIsaac et al., 2010). This review indicated that, in addressing carers' unmet needs, support from social workers, therapists and physicians is essential. However, the findings of this review were based on the frequency of the needs identified in the reviewed studies. It was unclear whether carers perceived these needs as the most important. Thus, further analysis of this aspect may add robustness to the review.

In a longitudinal qualitative study to explore the needs, priorities and desired rehabilitation outcomes of family members of young adults who have suffered a stroke, Lawrence and Kinn (2013) conducted interviews with 11 family members; parents, spouses, children and siblings, at 6 monthly intervals over two years. It was found that the experience of these family members can be conceptualised as the disruption of their temporal being. Three overarching themes; uncertainty, disrupted and altered relationships, and situatedness, along with emerging sub-themes that illustrated carers' short, intermediary and long-term support needs post-stroke, were identified. Based on these findings, Lawrence and Kinn (2013) contextualised the needs of family members under six domains; education, information, medical, practical assistance, psychological support and rehabilitation needs. It was found that the family members expressed a greater need for psychological support than other needs over the years. For instance, they described feeling shocked during the initial stroke event, managing tension in the family-patient relationship, or acceptance of post-stroke “normality”. It was also reported that patients and their families had minimal contact and limited support services with rehabilitation health professionals. This study emphasised the importance of integrating family-centred care into the planning of care for young adults who had suffered a stroke and identifying the short, medium and long-term rehabilitation support needs of family carers (Lawrence & Kinn, 2013). This study however, has limitations; over 50% of the sample dropped-out after the first interview, and only one participant completed four interviews during the 2 year period. Arguably, there may also be selection bias inherent in constructing the themes based on the available data. Thus, the credibility of the study findings may be compromised.

In a recent community-based study, Chen et al. (2015) explored the initial perceptions of 22 patients and their caregivers on being engaged in rehabilitation post-stroke. It was found that the caregivers in this study experienced substantial difficulties and changing needs. Four major themes emerged; the readiness to return home, coping with care transitions, dealing with fragmented rehabilitation services, and uncertainty about ongoing rehabilitation. Chen et al. (2015) explained that one of their key findings was the notable lack of communication between caregivers and health professionals at every stage of the patient’s recovery. For example, caregivers reported not being prepared or supported during the patient’s transition from hospital to home, information and services about continued rehabilitation were not provided, and the provision of education, such as about stroke complications, was lacking. These findings indicated learning needs of the stroke patients and their caregivers on every aspect of the stroke care continuum (Chen et al., 2015). The strength of this study is its transferability; it provides a detailed description of the study design and method, such as an interview guide, to facilitate the replication and comparison of the findings with other settings.

2.6.3 Summary of rehabilitation and support needs

Considerable evidence suggests that stroke patients experience unmet rehabilitation needs that remain over time. The majority of the studies identified activities limitation and participation restrictions as a result of stroke that predominantly affect individuals’ personal and instrumental ADL. Although several methodological limitations of the reviewed studies were noted, there was convincing evidence to indicate that sustaining rehabilitation beyond the acute phase of the stroke is important in facilitating social reintegration and hence improving quality of life.

Existing studies of caregivers of stroke patients have identified substantial needs of support throughout the caregiving trajectory. Many caregivers consistently demonstrate a lack of understanding about their caring role and highlight unmet educational support;

a conclusion similarly reported in a systematic literature review (Hafsteinsdottir et al., 2011). A review of the published systematic reviews identified compelling evidence that providing education improved carers' knowledge and quality of life (Corry et al., 2014). Therefore, educational intervention, such as that led by nurses, is potentially effective (Larson et al., 2005). Subsequently, current evidence related to stroke care after discharge will be presented.

2.7 The ICF Environmental factors – current state of evidence for stroke care after discharge

The WHO (2001) describes the ICF environmental factors as those physical, social and attitudinal environments in which people live and conduct their lives. In ICF for stroke, it encompasses health and technology, services, systems and policies, support and relationships, and attitudes, which can serve either as barriers or facilitators that influence the stroke outcome (Geyh et al., 2004).This section discusses the environment factors concerning two aspects; (1) the current evidence for stroke care and rehabilitation support services after they have been discharged home, and (2) nurses' roles and educational needs in stroke rehabilitation. Selected stoke clinical guidelines will be appraised to identify best evidence for post-stroke rehabilitation provision and how this can be proposed to fill the service gaps in Brunei.

Over the years, major advancement have been made in stroke prevention, treatment and rehabilitation. The establishment of organised stoke unit staffed with multidisciplinary team have improved patients' survival rate, reduced dependency on ADL and prompt early discharge (Stroke Unit Trialist's Colloboration, 2013). However, many patients returned home with residual impairments due to their stroke. As healthcare service is shifting from hospital to community setting, the availability of support workforce along the recovery trajectory post-stroke, therefore, is paramount. Internationally, evidenced-based stroke guidelines continues to grow in order to provide practice guidance aims in improving the quality of care for all people affected by stroke.

In this review, recommendations relating to aspects of post-stroke rehabilitation service which relevant to this study will be considered. Existing guidelines from various countries, such as the UK, Canada, USA and Australia will be considered in order to capture the best evidence across the globe. No published guideline of stroke in Brunei was identified. The clinical guidelines, comprising the *National Clinical Guideline for Stroke*[1] (Royal College of Physicians Intercollegiate Stroke Working Party, 2016), *Stroke Rehabilitation in Adults*[2] (NICE, 2013), *Guidelines for Adult Stroke Rehabilitation and Recovery*[3] (American Heart Association/American Stroke Association, 2016), *Clinical Guideline for Stroke Management 2017*[4] (Stroke Foundation, 2017), the *Canadian*

Stroke Best Practice Recommendations: Stroke Rehabilitation Practice Guidelines, update 2015[5] (Hebert et al., 2016), *Guidance for Nurse Staffing in Stroke*[6] (National Stroke Nursing Forum, 2016) and *World Stroke Organization Global Stroke Service Guidelines and Action Plan*[7] (Lindsay et al., 2014) form the basis of the review.

2.7.1 Post-Stroke Rehabilitation Guidelines

Stroke rehabilitation is a “progressive, dynamic, goal-orientated process aimed at enabling a person with impairment to reach their optimal physical, cognitive, emotional, communicative, social and/or functional activity level” (Hebert, et al. 2015). One of the purposes of post-stroke rehabilitation is to assist the survivors accomplish independency so that they can reintegrate into the society at earliest recovery (Reunanen et al., 2016). Therefore, structured and intensive post-stroke rehabilitation is crucial to maximizing functional outcomes, avoiding hospital readmission and decreasing long-term costs (Langstaff et al., 2014). Existing guidelines related to post-stroke rehabilitation service have outlined strong evidence that required the stroke survivors and their carer are supported by organised multidisciplinary stroke team to facilitate transition from the hospital to home. However, a study by Pindus et al. (2018) who reviewed 51 stroke research studies involving 168 stroke survivors and 328 caregivers concluded that the participants often feel abandoned and marginalised by the healthcare service and they were not prepared with skills to adapt into the community.

Guideline Recommendation for Support Network

> *‘People with disability after stroke should receive rehabilitation in a dedicated stroke inpatient unit and subsequently from a specialist stroke team within the community’*[2 7]

Existing evidence has shown that coordinated multidisciplinary team greatly improved the quality of patient care within both inpatient and community settings (Clarke, 2013). A recent study to investigate the effectiveness of interdisciplinary approach to community stroke rehabilitation on participants’ functions, psychosocial wellbeing and caregiver burden was undertaken by Allen and colleagues. Their results showed significant differences was found on participants’ (*n*=794) functional outcomes (assessed by Functional Independence Measure, p=<0.001), psychosocial functions (Reintegration to Normal Living Index, p=0.01; Hospital Anxiety and Depression Scale Anxiety subscale, p <0.001), and caregiver outcomes (measured by Bakas Caregiver Outcomes Scale, p<0.001; Caregiver Assistance and Confidence Scale assistance subscale, p=0.005), between recruitment, discharge from program and at 6 months follow-up. The researchers also observed significant gains on the strength, communication, activities of daily living, social participation, memory, and physical domains of the Stroke Impact

Scale (all p <0.001). They conclude that interdisciplinary team working was effective at improving the functional and psychosocial recovery of patients after stroke, and can sustain up to 6 months after discharge (Allen et al., 2014).

Whereas, another study by Fern et al. (2013) who reviewed fourteen RCTs, involving 2389 participants aims to explore the effectiveness of multidisciplinary care for the stroke in the community. They found that two of eight RCTs reviewed shown favourable effects on participants’ quality of life which was relate to the team interventions on assessments, follow-up visits and rehabilitation care. However, the researcher did not find any favourable effects of the multidisciplinary interventions on participants’ activity of daily living (11 RCTs). The authors suggested that lack of clarity on reporting the RCTs’ findings made the reliability of their review was inconclusive.

Early Supported Discharge

The important of Early Supported Discharge (ESD) service as part of the post-stroke rehabilitation service provision is found in the clinical guidelines. The ESD offers a model of care which links inpatient care with the community service and deliver by coordinated Multidisciplinary Stroke team. The purpose of ESD is to accelerate discharge from hospital with the provision of therapy that the patients would normally receive is continued at home by the rehabilitation team (Hebert et al., 2016). Fisher et al. (2011) suggested that, for ESD to be effective, the team; consisting the rehabilitation therapists, therapist assistant, nurses, healthcare assistant and physician, should have weekly meeting to plan individualised patient care and coordinate both discharge and therapy continuation in the community.

Recent meta-analysis, involving 17 clinical trials and 2422 mild moderate disability stroke patients, to compare outcomes of ESD intervention vs. inpatient hospitalization on patients’ recovery showed that the intervention groups’ length of hospital stay is reduced to approximately 6 days and had five fewer adverse outcome per 100 patients compared to the control groups (Langhorne & Baylan, 2017). They also found significant reduction of death for ESD groups (16 trials; 2116 participants, OR 1.04, 95%; CI 0.77 to 1.40, P = 0.81) and death or requiring institutional care (12 trials; 1664 participants, OR 0.75, 95%; CI 0.59 to 0.96, P = 0.02). Small improvements were also identified in ESD participants' extended activities of daily living scores and satisfaction with the services. However, Langhorne and colleague did not observed any clear differences in participants' ADL scores, patients’ subjective health status or mood, or the subjective health status, mood or satisfaction with services of carers between both sample groups.

There was low-quality of evidence to suggest risk of readmission to hospital for the ESD group is similar to the conventional care group. The benefits of ESD at one and five years follow-up was not proven. The estimated costs from six individual trials ranged from 23% lower to 15% greater for the ESD group in comparison to usual care. The study concluded that ESD services can reduce long-term dependency and admission to institutional care as well as reducing the length of hospital stay for mild stroke patients, if supported by co-ordinated multidisciplinary team (Langhorne & Baylan, 2017). Whereas in another updated meta-analysis, Gonçalves-Bradley et al. (2017) investigated benefits of ESD compared to in-hospital care on patients' health outcomes and cost from 3 separate group of participants; recovering from stroke, mixed medical conditions and patients undergoing elective surgery. They found that ESD services have no significant difference to patient health outcomes, readmission to hospital and decrease hospital length of stay between the three groups. However, patients who receive care at home might be more satisfied and less likely to be admitted to institutional care. The review provides insufficient evidence of economic benefit (through a reduction in hospital length of stay) or improved health outcomes due to the ESD service (Goncalves-Bradley et al., 2017). Findings from the above meta-analysis showed moderate evidence for outcomes measured; death, discharge home disability, length of stay and health cost. But, it does proved that ESD with increased coordination of services between team members is associated with an improved patients' health outcomes.

Guideline Recommendation for Early Support Discharge

> *Offer early supported discharge to people with stroke who are able to transfer from bed to chair independently or with assistance, as long as a safe and secure environment can be provided. Early supported discharge should be part of a skilled stroke rehabilitation service and should consist of the same intensity of therapy and range of multidisciplinary skills available in hospital. It should not result in a delay in delivery of care'.*[1 – 6]

Nurses' contributions in ESD Stroke service

Research that looks into the role of nurses within the ESD was very limited. However, the clinical guidelines reviewed suggested that nurses have salient role in MDT team in delivering stroke service provision. Clarke (2014) indicate that nurses can make an active contribution to stroke rehabilitation and can integrate rehabilitation principles into their routine practice. The national nurse forum suggested that stroke nursing has essential role in providing rehabilitation emphasis, working closely alongside their allied health professional and enrich a multidisciplinary team approach (National Nurse Stroke

Forum, 2016). Moreover, a trained specialist stroke rehabilitation nurse may has set of competency to deliver rehabilitation interventions that can support the intensity and frequency of rehabilitation activities essential for improving patient's recovery (Royal College of Physicians Intercollegiate Stroke Working Party, 2016). A study by McGinnes et al. (2010) who explored roles of community nurses as part of ESD team suggested that the therapeutic role can be multifaceted, such as physiological monitoring, continence assessment, pain management or therapy 'carry on', which reflects to the diverse needs of patient throughout the recovery process. Thus, Willis (2015) recommends roles of nurses in stroke rehabilitation should be valued and further develop through accredited stroke training, such as the Stroke Specific Educational Framework.

Guideline Recommendation for Nurses in Early Support Discharge

'It is essential that there is recognition of multidisciplinary working and the role of the stroke nurse within this team, and close multidisciplinary working is not seen as a reason to economise on nursing numbers due to sharing of skills'.[1, 4, 6]

The evidence presented suggests that organized MDT for post-stroke rehabilitation is essential to promote patients' optimum health outcomes and facilitate community reengagement. Thus, it is crucial to prepare rehabilitation setting which is most appropriate and safe for the patients (Stroke Association 2017). Generally, rehabilitation in the community can take place either as a hospital-based (outpatient) or home-based rehabilitation. However, evidence required to appraise the implication of both settings on patients' therapy outcomes or the quality of the therapy provided. This will be discuss below:

Rehabilitation at Home

With the practice of ESD as model of community stroke rehabilitation is widely accepted, the delivery of therapy at home seem inevitable. Mayo (2016) indicates that rehabilitation at home is generally undertaken for three primary reasons; to replace acute care as part of the ESD model; to replace institutional rehabilitation; and to prevent deterioration and promote health through physical activity, in particular for chronic stroke survivors. Newer study to compare the effectiveness of rehabilitation between at home and hospital-based is limited.

In a systematic review, Hillier and Inglis-Jassiem (2010) evaluated research trials to investigate whether the community-dwelling people with stroke should receive rehabilitation at home or at the health centre, based on functional outcome, carer satisfaction and cost. Eleven randomized control trials involving 1711 patients with less than 12 months post-stroke were identified. They used the Barthel Index score to reports on the patients' functional independence. Findings from the review showed no difference of scores between home or centre care were identified in four study trials. However, Hillier and Inglis-Jassiem found the remaining seven trials indicate greater benefits for home rehabilitation pertaining to cost, satisfaction and caregiver strain. There was significant effect in favour of home-based rehabilitation compared with the hospital based at 6 weeks (p=0.03) and between 3 to 6 months (p=0.01), though the effects is less clear after this period. They concluded that home-based service for rehabilitation should be offer to the patients, at least for the first 6 months post-stroke. This length of time also similarly found by Chaiyawat and Kulkantrakorn (2012) who suggested that home rehabilitation in the first 6 months after the stroke can lead to rapid improvement in function, reducing disability and increase stroke patients' quality of life, compared with outpatient rehabilitation.

In non-comparative study that examine the benefits of outpatient rehabilitation on patients' functional outcomes has shown very favorable result. An observational study by Dawn et al. (2018) aimed to investigate whether rehabilitation environment between home or hospital have influence on time spent sitting upright and walking after stroke. A total of 34 stroke patients from two inpatient rehabilitation unit and community centre were recruited. The participants worn an activity monitoring device continuously for 7 days before discharge and continue during the first week at home. Dawn and colleagues found that the patients sit 45 minutes less (95% CI -84.8, -6.1; p=0.02), stand upright 45 minutes (95% CI 6.1, 84.8; p=0.02), walk 12 minutes more (95% CI 5, 19; p= 0.001), and completed 724 additional steps each day compared to when the patients were in the hospital setting. The study conclude that providing rehabilitation therapy within patients' home environment can promote physical activity, hence improve quality of life (Dawn et al., 2018).

Poole et al. (2019), meanwhile, evaluated an in-home, patient-centered intensive therapy intervention to improve performance and satisfaction with daily activities, upper extremity function, and quality of life. The therapy was conducted in patients'' homes 3 to 4 hours per day, 5 days per week, for 2 weeks and they used the Canadian Occupational Performance Measure as outcome measurements. They recruited a total of six participants, aged from 23 to 77 years and has had time since stroke from 8 months to nearly 9 years. Poole and colleagues reported that participants' scores improved significantly on the Canadian Occupational Performance Measure, the Fugl-

Meyer Assessment motor section, and the Stroke Impact Scale 3.0 from pre-intervention to immediately post-intervention (*p* < .05). Improvements were maintained for all measures from immediately post-intervention to 2-month follow-up (*p* < .05), with exception the Stroke Impact Scale hand domain scores. They suggest that patient-based intensive therapy intervention at home may lead to improve performance and satisfaction with upper extremity function after stroke. However, finding from Poole et al.'s study should be interpreted with caution due to wider heterogeneous sample background, small sample size, varying degrees of motor function, and lack of a control group. Thus, proper study trials is needed to confirm the efficacy of this intervention.

Rehabilitation at hospital-based setting

On the other hand, Rice et al. (2016) examined the effectiveness of interdisciplinary stroke rehabilitation program that was delivered as outpatient basis. They assessed patients' physical functioning, mobility, and balance at recruitment and after discharge from the program as outcome measures. A total of 271 patients were recruited into the study. The findings showed significant improvements on patients' Functional Independence Measure (FIM), grip strength, Chedoke-McMaster Stroke Assessment, two-minute walk test, maximum walk test, Timed Up and Go, Berg Balance Scale, and one-legged stance (P < .003 for all). Rice et al. suggests that the interdisciplinary rehabilitation program was effective at improving the physical functioning, mobility, and balance of individuals after a stroke and proposed a hospital-based, stroke-specific rehabilitation program should be considered when patients continue to experience deficits after inpatient rehabilitation (Rice et al., 2016).

In another cross-sectional study, Vincient-Onabajo and Shaphant (2019) examined the relationship between functional independence and psychosocial quality of life among 59 stroke patients who attended the outpatient rehabilitation therapy session. They used the Functional Independence Measure (FIM) and the Stroke Specific Quality of Life Scale 12 (SS-QoL-12) as measurement tools. The findings showed the overall outcomes of the correlation analysis between the motor FIM scores and the psychosocial subscale was weak and lack statistical significance (*r*=0.24; *p*=0.07), with exception for 'mood' item (*r*=0.29; *p*=0.02) on the psychosocial subscale. The researchers explained the lack of significance between both outcomes measurements were due to inability for the participants fully function into to the community, but positive mood indicates the patients have better perception about their future. However, findings from this study, in particular with positive mood, should be interpret with caution due to issue with desirable bias. Data was collected through interviews by one of the physiotherapist, whom likely known to the participants, hence positive mood outcome is expected. Nonetheless, this finding suggest that targeting functional outcomes in rehabilitation may not necessarily translate to improvement of patients' quality of health.

Guidelines Recommendation for post-stroke rehabilitation setting

> *'Stroke survivors with ongoing rehabilitation goals should continue to have access to specialized stroke services after leaving hospital. This should include in-home or community-based rehabilitation services'.*[2, 3, 6]

The benefits of home-based therapy seem superior to the hospital-based settings. It can be deduced that home therapy is feasible, require less expensive equipment, implementation can be deliver with smaller number of staff and being at home, patient will be most likely to adhere with their therapy and keep motivated. However, issue with staff constraint, travelling and facilities should be taken into consideration. The intensity of rehabilitation interventions often provided based on the context of the setting or the patients' impairments status. It is not clear if there is a minimal threshold for benefits of therapy. Evidence with regard to this aspect will be presented as follow:

Amount, Intensity and timing of rehabilitation

Timing and intensity of rehabilitation are important for patients' recovery post-stroke. It has been reported that commencing the therapy at the earliest stage of the stroke is better (Horn et al. 2005). Lohse et al. (2014) found that there was positive relationship between scheduled therapy time and outcomes of the stroke. Higher intensity of therapy is shown to give better recovery and reduced length of hospital stay (Diane et al., 2005). However, evidence to guide the precise timing of therapy and level of intensity is inconclusive.

A meta-analysis by Langhorne et al. (2018) evaluates whether very early mobilisation and not later than 48 hours after the stroke onset improves recovery compared with usual care. The review include 9 trails involving 2958 patients with one trial provided the most of the reviewed result (2104 participants). The findings showed that the median delay to starting mobilisation between the 'very early mobilisation' groups was 18.5 hours, compared with 33.3 hours in the usual care group (median difference between trials was 12.7 hours). They found low quality of evidence to support that the 'very early mobilisation' groups improved ADL functions or reduced length of hospital stay. However, the review identified that time-to-first mobilisation within 24 hours was associated with the lowest odds of death or poor patients outcome, compared with earlier or later mobilisation. The authors concluded that starting intensive mobilisation within 24 hours of stroke may carry some increased risk, at least for some people with stroke, thus, more research is still required to examine the rehabilitation timing (Langhorne et al., 2018). In another study from Turkey, Alkan et al. (2013) compared the results of early and delayed inpatient stroke rehabilitation among 138 stroke patients, and suggested that providing therapy within 100 days after the stroke onset remain efficacious on functional status as early rehabilitation.

Another meta-analysis, Lohse et al. (2014) explored the relationship between time scheduled for therapy and improvement in motor scores by comparing high to low doses and to quantify dose-response relationship. Thirty studies involving 1750 participants were included in the meta-regression models analysis. The pooled analysis showed the duration of therapy in treatment group was 49.56 ± 68.12 days, and for control groups was 49.60 ± 68.10 days. Whereas, time scheduled for therapy for treatment group was 57.41 ± 44.8 hours and for control group was 24.08 ± 30.39 hours. Average difference between both groups was 33.33 ± hours. The findings of the study showed overall small benefits of augmented time therapy and positive dose-responses relationship across studies with different impairments and functions, suggesting more therapy is better. The study also found a significant positive effect of time scheduled for therapy on outcomes even when controlling for time after stroke (treatment groups 1.01±1.49 years; control group 1.02±1.63 years). Loshe and colleagues concluded that time in therapy is a robust predictor of recovery across different types of therapy and suggested that therapist should consider multiple ways to increase therapy time, both within and outside formal sessions.

Meanwhile, in a single-blind randomised controlled trial with a 26 weeks follow-up, Askim et al. (2010) aimed to evaluate the effectiveness of a community-based intensive motor training program combined with ESD after treatment in a comprehensive stroke unit. The intervention group (*n*=30) received 3 additional sessions of physical therapy and a structured home exercise program, on top of the standard treatment, every week for the first 4 weeks after discharge from hospital. Those in control group (*n*=32) received standard care. Each session lasted about 30 to 50 minutes. Berg Balance Scale, the Barthel Index, Motor Assessment Scale, Step Test, 5-Meter Walk Test and Stroke Impact Scale were used as the outcome measures. Findings from the study showed that scores for both groups for all outcome measures were comparable. Akim and collegaues concluded that increasing intensity of physical therapy during the first 4 weeks after discharge did not show significant improvement on balance or any other functional outcomes, indicating that the standard dosing was the limits threshold of tolerable amount.

Guidelines Recommendation for timing and intensity of rehabilitation

‘Offer initially at least 45 minutes of each relevant stroke rehabilitation therapy for a minimum of 5 days per week to people who have the ability to participate, and where functional goals can be achieved. If more rehabilitation is needed at a later stage, tailor the intensity to the person's needs at that time’.[1,2,4,5]

Evidence presented suggests that increasing rehabilitation intensity at early stage after the stroke results may improve patients’ functional outcomes, though the evidence to support this was not robust. But, most study reviewed applied level of intensity of therapy within the recommended by stroke quality standard. There was less evidence to support longer terms benefits of increased rehabilitation intensity after four weeks. Nonetheless, the evidence indicates that timing, including initiation, intensity, consistency and frequency, are crucial to improve patients’ physical functions.

Providing support and information

The provision of information support for the stroke patients and their family or carer is essential for coping with the aftermath of stroke and prevention of secondary stroke. But, many studies have reported that stroke survivors and their carers often not been given adequate information about the stroke and recovery process. They often reported of feeling unprepared for the live event after discharge from hospital. Despite the importance of providing right information to these individuals is well documented, but studies to suggest the best way to deliver education after stroke is unclear. Current evidence to explore this issue will be discussed as follow:

In an updated Cochrane review that examined the effectiveness of information provision for stroke patients and their caregivers after discharge, Forster et al. (2012) reviewed 21 trials involving 2289 stroke patients and 1290 caregiver participants and evaluated the impact of information on participants’’ health and wellbeing. They characterised information interventions into two types, namely ‘passive intervention’ where information was provided as a single occasion only and no further follow-up or reinforcement given, and secondly ‘active intervention’ refer to purposeful attempts to make the participants absorbed the entire information and plan for subsequent clarification, consolidation or reinforcement. The review found that ‘active’ and ‘passive’ information intervention for stroke patients significantly improved their knowledge about the stroke, had greater benefits for feeling of anxiety and depression, however not on patients’ activity, participation or mortality. Whereas for caregivers, any approach of information provided will improved their knowledge base. But, there was no effect on family/carer mood, quality of life and satisfaction. Forster et al. (2012) concluded the review by stating that active involvement of patients and carers and include planned follow-up for clarification and reinforcement have a greater effect on patient mood. Managing mood after stroke is vital because it was found that depressed mood is associated with long-term disability (Willey et al., 2010).

In another literature review, Daviet et al. (2012) examined various therapeutic patient education (TPE) programs for stroke survivors in order to verify content and efficacy of the intervention. They identified seven articles which focuses on improving quality of life and alleviating patients or carers' psychosocial impacts of stroke. The review found that education modalities provided for the stroke patients and the carer were highly variable and inconsistent. Most often, the educational session were set-up during the initial post-stroke hospitalization period consisting several approaches such as theoretical training, theory/practical session, discussions and debates. Daviet and colleagues also reported the duration and frequency of the sessions were varies which can last between 30- to 45-minute per sessions, with six separate sessions for total of nine hours or one session every two weeks. Overall, the findings of the review indicates that the TPE programs for stroke has overall positive effect on improving knowledge and satisfaction, but improvement needed to standardized the educational interventions. They concluded that specific training for health care professionals is necessary in order to provide continuous provision of information throughout patients' recovery (Daviet et al., 2012).

Guidelines Recommendations for provision of information

- *Patients, families, and informal caregivers should be provided with information, education, training, emotional support, and community services specific to the transition they are undergoing.*[1-7]
- *Provide appropriate information, education and training to the multidisciplinary stroke team to enable them to support and communicate effectively with the person with communication difficulties and their family or carer.*[1-7]

2.7.1.1 Synthesis of stroke evidence

The growing emergence of evidence-based approaches to stroke prevention, acute stroke management, and stroke recovery for the last two decades have seen a major transformation of care and management in the area of strokes. The quality of patients care continued to improve and rapidly increases the survival rate for stroke suffers. The development of clinical guidelines provide quality measurement and standard for provision of stroke services. But, the current challenge lies in implementing these standard, particularly in regions with high incidences of stroke and limited healthcare resources, such as Brunei.

Evidence have shown that organised inpatient stroke care that staffed with highly competent healthcare professionals can make a huge different to patients' chances of recovery. In Brunei, this was evident with the establishment of its first Stroke Centre in 2010. This development marked a milestone towards improving the quality of stroke care in this country (Thien, 2010). However, evidence suggest that stroke unit can only work optimally if there is a well-established referral and rehabilitation network within the community (NICE, 2013). This includes co-operation with primary care professionals within the primary and secondary healthcare settings. In Brunei, this support network appears inconsistence, or to certain extent remain lacking.

Early post-discharge period often reported as the most challenging experience by the patients and families. Thus, navigating the patients and the caregiver during this transition period from hospital to home is vital. The stroke quality standard has underlines the need to identify a stroke team who can provide link between inpatient care and the community. The role of this team is crucial, such as in identifying patients' needs, preparing the carer and classify support resources outside the hospital setting. The importance of the multidisciplinary stroke team, as part of the Early Support Discharge service is well documented in the stroke guideline. Evident strongly indicated that multidisciplinary ESD team reduced length of hospital stay, lower health costs, enhance functional recovery, improve psychosocial functions and facilitate early reengagement to the community (Stroke Foundation, 2017). A core of this team include consultant physicians, nurses, physiotherapists, occupational therapists, speech and language therapists, clinical psychologists and social workers (NICE, 2013). In Brunei, ESD service is not exist. Thus, how the patients and their carer experience the transition home is unknown. This will be address in our study. The establishement of ESD service in Brunei, is timely needed.

Evidence to compare the best therapy setting was presented. But, arguments relating home versus hospital-based rehabilitation settings remain continued. Issue with regard to availability of resources is acknowledged. However, the key message underlying the World Stroke Organisation Global Stroke Quality Action Plan that highlight 'even with the absolute minimal service available, at least something can be done for the people with stroke that could make a difference to their recovery and outcomes' (Lindsy, 2014), necessitate consideration.

Evidence have shown that timing and intensity of therapy is crucial to expediate stroke patients' physical recovery. The national standard of 45 minutes per day, delivered in 5 day each week has proven to benefit functional outcomes. In Brunei, this is the area which required urgent attention. Increasing face-to-face therapy time and reducing time spent on administration should be the priority. This indicate recruitment of new therapist or training the nurses in stroke care so enable them to take active role in supporting functional practice of activities of daily living (Royal College of Physicians Intercollegiate Stroke Working Party, 2016). Therefore, nurses seem has great potential to bridge the service deficit. Next section discuss roles of nurses in stroke rehabilitation.

In summary, investing the best practice tools and resources that are available globally is needed. However, future stroke research in Brunei is necessary in order to fit with cultural diversity and religious practie among the population of Brunei.

2.7.2 Rehabilitation and Post-Stroke Nursing Care

This section discusses the involvement of nurses in stroke rehabilitation, describing interventions tested, quality of studies reviewed and summary of best practice for nursing in stroke care. Finally, justification will be provided for roles of nurses in the community and their potential integration with therapy service. This section begin by describing the concept of rehabilitation nursing.

Overview of Rehabilitation Nursing

Nurse formed one of the core team members of the Multidisciplinary stroke team (NICE, 2013). Thus, their continued presence throughout the stroke care pathway can be a vital source of support continuum (Winstein, et al., 2016). Rehabilitation nursing is a specialist from of rehabilitation requiring specialist nursing care. It was defined as a "speciality practice that involves in the diagnosis and treatment of human responses of individuals or group to actual or potential health problems, resulting from altered functional ability and altered lifestyle. The goal of rehabilitation nurses is to assist individuals with disabilities or chronic illness in the restoration, maintenance, and promotion of optimal health" (Association of Rehabilitation Nurses, 2015).

A rehabilitation nursing begins with immediate preventive care in the beginning stages of accident or illness, is continued through the restorative stage of care, and involves adaptation of the whole being to a new life. The rehabilitation nurse provides care, education, and support for the patient and the family. They play an active role in encouraging the patients to develop abilities on their own as much as possible, such as meeting basic needs, activities of daily living (eating, drinking, excretion, dressing and undressing), and taking protective measures (Koc, 2012).

Description of nurses’ roles in stroke care and rehabilitation

To date, little is known about the role of nurses in supporting patients in stroke rehabilitation outside hospital. The Royal College of Nursing (2019) describes the important role and responsibilities of nurses when caring for people with a stroke. This include providing physiological monitoring and maintenance of homeostasis, reducing morbidity and mortality, detection of cerebral oedema, prevent complications, understanding stroke aetiology, facilitate patient recovery, assist multidisciplinary assessment and prevention of recurrent stroke.

As part of multidisciplinary stroke team, role of nurses encompass performing comprehensive nursing assessments, help managing aspect of patient care, such as observations, swallowing, mobility, continence, skin integrity, pain control and prevention of complications (Stroke Association, 2017). Moreover, nurses provide specialist stroke care in acute, rehabilitation and community context as well as deliver palliative and terminal care. They provides 24 hours in patient centred-care and assist coordination of care, discharge planning, support and education.

In a service development project, McGinnes et al. (2010) explored the role of community stroke rehabilitation nurses as part of the early support discharge (ESD) team. All team members from the ESD were invited to discuss the contribution of nurses to stroke rehabilitation. It was found that the majority of team members agreed that nurses can play an integral role in providing long-term rehabilitation support, such as mobility assessment or therapy ‘carry on’ role. However, impact of these roles on the patient’s recovery was not evaluated thus, finding of this project is weak. Nonetheless, the study indicated that nurses, as part of an established team, can contribute to stroke rehabilitation (McGinnes et al., 2010).

Meanwhile, Kirkevold (2010) extended her earlier ethnographic study that explored role of nurses in rehabilitation of acute stroke. She identified four therapeutic functions of nurses and labelled them as conserving, interpretive, consoling and integrative. She argued that role of nurses in stroke rehabilitation should move beyond the task-oriented care in order to understand the complexity of patients’ experience and needs. Thus, kirkevold proposed a practice-oriented approach which require nurses to extend their focus of care beyond the acute and initial rehabilitation phase of individuals’ recovery.

In Brunei, the role of nurses in rehabilitation is not explicitly defined. However, the therapeutic elements of nurses, such as demonstrating effective conflict-resolution skills, according to the Standard of Practices for Registered Nurses and Midwives in Brunei (Nursing Board for Brunei, 2010), seems to capture the essence of the rehabilitative role, as described by the international literature. Therefore, the roles of nurses were explored and illustrated in the findings of this research.

Nursing Interventions for Stroke Rehabilitation and Care

Current study that investigate nurse interventions for stroke was limited. This can be due to lack of nurses' involvement in post-stroke rehabilitation as previously reported (Clarke, 2014). If any, the rehabilitation interventions of nurses often part of larger multidisciplinary team. Hence, this collaborative study will be consider to support the literature review. The nursing interventions will be group under the therapeutic functions proposed by Kirkevold (2010), and outline below:

The Consoling Function

The consoling function is defined as those actions or interventions that nurses initiate in order to relieve patients' emotional pain and suffering following stroke (Kirkevold (2010). The following studies illustrates the consoling interventions of the nurses.

Burton and Gibbon (2005) evaluated the outcomes of nurses' interventions in supporting patients' rehabilitation after discharge from hospital. A total of 176 patients with stroke and carers were randomized to receive continuing education and support from a trained nurse in strokes (n=87) or usual care and follow-up (n=89). The patients in the experimental group were followed-up on average for 3 visits over a year, and were given education (stroke prevention, medication adherence, transfer of care), and assessments (physical functions in ADL, knowledge on aspects of stroke, emotional functions, home environment in supporting recovery). The patient outcomes from these interventions included ADL dependency, perception of general health, depression, ADL performance and carers' strain, as assessed at 3 and 12 months. The findings failed to demonstrate any significant differences in the patients' level of depression, physical dependency and ADL performance between the two groups, although the patients in the intervention group reported perceived better health as well as a low level of emotional distress and social isolation. Burton and Gibbon (2005) suggested that nurses can play a key role in supporting the rehabilitation of stroke patients within community settings. Although the generalizability is limited due to the small sample size, this study provided meaningful evidence that providing nursing support for patients' psychological wellbeing following discharge is effective in improving the perception of their health.

In a study involving carers, King et al. (2007) undertook a single-group repeated study to evaluate the impact of nurse interventions on carers' wellbeing. These interventions comprise providing information (stress management, self-care, resources, behaviour management, and risk factors for recurrent stroke), and skill training (coping with stress and emotional responses), which was delivered across 10 sessions; initially as small groups and then by telephone contact, over two months. The carers' outcome measurements (burden, preparation for caregiving, depression, anxiety, perception of life changes, taking care of one's own needs, and motor and cognitive functions for stroke patients) were assessed at baseline (pre-intervention), post-intervention (after 8-10 weeks), and 2 months after discharge. Non-random sampling of 15 carers was matched with other similar groups who received usual care, to compare the study findings. This study demonstrated that those interventions significantly improved carers' level of depression, preparedness, and anxiety as well as patients' motor functions over time, compared with the matched group. Although no significant improvement in carer burden, social functioning and taking care of one's own needs measured at the three intervals were found, King et al. (2007) suggested that problem-solving nurse interventions have the potential to support carers and stroke patients in rural communities. However, in their follow-up study designed to examine the outcomes of a similar intervention a year after caregiving, King et al. (2012) concluded the need to sustain those interventions as carer problems fluctuated over a lengthier period of time. Both of the studies by King et al. reported considerable issues of sample drop-out, so the findings may be influenced by sample bias. Therefore, this limitation may affect the validity of the findings.

The Conserving Function

The conserving function refers to nursing interventions that was undertaken in order to protect the bodily and cognitive integrity of the patient and prevent secondary consequences of the stroke (Kirkevold, 2010). The conserving function of nurses can be illustrate at below studies.

In a community-based nursing study, Wang et al. (2013a) evaluated the roles of nurses in educating and supporting the rehabilitation of patients with mild stroke. The intervention group (*n*=65) was recruited from the health community setting, and the control group (*n*=52) from an outpatient hospital. The intervention group attended three 2-hour sessions of stroke intervention per week for 8 weeks, consisting of educational lectures (sign of stroke, risk factors, healthy diet, social activities), rehabilitation training, and organised sessions on patient support activities. The control group received a general outpatient educational programme. The primary outcomes of these interventions (knowledge of stroke, behaviour and self-efficacy) were assessed using the designed questionnaire at baseline, after 8 weeks and at 6 months follow-up. This study found significant differences in the scores on all scales, as measured between both groups. The findings indicated a better improvement in knowledge, behaviour and self-efficacy among the intervention group from baseline to 6 months, compared with the control group. Moreover, a positive correlation was identified between improved behaviour and increased social participation after the interventions. Wang et al. (2013a) suggested that incorporating a community-based nursing education and rehabilitation programme after patient discharge is imperative for reducing subsequent stroke. However, the comparability of the two samples is debatable. Although the authors indicated that both groups had received hospital-based post-stroke education, it was unclear whether the patients from the control group continued to receive this education on every outpatient visit or whether it was given once, prior to discharge. Arguably, positive outcomes would have been expected in the intervention group. The findings of this study can be misleading and biased regarding the effect of the intervention group. Thus, the validity of the findings may be compromised.

In another study, Dowswell et al. (2000) evaluates a nurse-led stroke support service interventions that addresses problems facing the stroke patients and the carers in the first year following stroke. Five specialist nurses were asked to maintain comprehensive written records of their involvement and contacts with all participants (*n*=120 including patients and carers) who participating in a randomized controlled trial. A total of 101 completed records were collected for content analysis. Findings from the record showed patients and carers encountered numerous, diverse, complex problems that changed over time. Initial problems were related to practical difficulties, but progress to psychological needs over longer period. Dowswell et al. noted that the nurses responded by providing information, advice, support and monitoring using a flexible, individualized approach. They also collaborated with other healthcare professional groups and provided direct support to carers. This study emphasise the need for stroke patients and their carers professionally supported at first year after discharge,

The Interpretive Function

The interpretive function is refers to nurses' interventions that focus on assisting the stroke patients and their carer to understand about stroke and its complication, so that improving the wellbeing of these individuals (Kirkevold, 2010). Below study is example of nurse intervention as interpretive function.

Larson et al. (2005) employed longitudinal, randomized controlled trial to evaluate impact of a nurse-led support and education programme for improving the spouses' perceived general quality of life, life situation, general well-being and health state. A total of 100 spouse participants were randomly assigned to intervention group (*n*=50), who received support and 6 sessions of education interventions during the first 6 months, and control groups (*n*=50) who received usual information on patient's stay and at discharge. The outcome measurements were assessed at 6 and 12 months. All groups were follow-up for 12 months. The findings from the study failed to prove any significant differences for all outcome measured between both groups, over time. Although, Larson and colleagues reported significant decrease of negative well-being and increased quality of life for the intervention group who attended the education programme for 5–6 times. Whereas, both groups who attended less had a significant decrease in positive well-being and health state. The study concluded that nurse-led education interventions delivered at least five times may give positive effect on spouses' well-being (Larson et al. 2005). The limitation of this study is concern with small sample power, low number of participants, instrument tool not sensitive to capture outcome measure over times and participants blinding was not reported. Thus, this finding is interpret with caution.

Another study in Thailand, Oupra et al. (2010) developed a nurse-led Supportive Educative Learning programme for family caregivers of stroke patients and evaluate the effect of this programme on their strain and quality of life. The program comprise didactic education sessions, hands-on training, a book-let describing about stroke care and 3 follow-up calls provided by 2 trained nurses. A non-randomised comparative study with concurrent controls, using a two-group pre-test and post-test design was employed. A total of 140 stroke survivors and 140 family caregivers were recruited; 70 patients/caregiver pair in each group. Caregivers of patients admitted to the intervention hospital following an acute stroke received the intervention, while caregivers of patients admitted to the comparison hospital received the usual care provided at the hospital. The data were collected during hospital stay, prior to discharge and 3 months after discharge. The study showed that the family caregivers from the intervention group had a significantly better quality of life at discharge and 3 months follow-up, compared with the control group. It also found significant different between caregiver strains, where participants in control group experience higher level of strain at 3 moths follow-up. This research demonstrated that nurses' education interventions and support to the family caregiver of stroke survivors can reduce caregiver strain and enhance their quality of life (Oupra et al., 2010).

The Integrative Function

The integrative function refers to those actions or interventions that was undertaken by nurses in order to assist patient integrate newly learned activities of daily living skills and techniques in their daily activities (Kirkevold, 2010). Example of nurse intervention related to integrative function is describe below:

Kim (2012) explored effects of an enjoyable nurse led intervention to promote limbs movement in post-stroke inpatients. A non-synchronized, non-equivalent control group pretest-posttest design was used. Twenty participants were recruited into the intervention group and another 25 into the control group. The intervention group participated in 30- to 40-minutes group sessions three times a week for 2 weeks. The intervention employed a competitive team game using football or golf sets to be used with the affected limb. Functional status (motor, cognitive, and total), fatigue, sleep, and depression were measured as outcome variables. Findings from the study showed significant improvement for all outcomes measures for the intervention group, except for cognitive function, compared with the control group. Kim concluded that the enjoyable nurse-led intervention was effective in improving patients' functional status and promote their long-term health (Kim, 2012). This intervention proved that nurse-led activity is feasible and may expand the scope of practice for rehabilitation nurses in stroke.

In a systematic review, Rensink et al. (2009) evaluates whether task-oriented training in rehabilitation after stroke can be applied as nurses' interventions in the ward or home. They described task training as activities which focus on patient's own needs and not therapist focus, such as walking, cycling, sit-to-stand exercise, grasping or mental imagery. A total of 42 RCTs, including 9 systematic studies were identified. Task training starting with balance training and proceeding to sitting and reaching, sit to stand training gait training and interventions for physical fitness were reviewed. The review suggests in favour of task-oriented training in daily nursing care. Nurses, in close collaboration with other professionals, can use wide range of interventions, such as functional balance training during reaching and standing up, walking training, arm training and exercises for physical fitness that tailored to patients' needs. Reinsink et al. (2009) concludes that active use of task-oriented training in daily nursing care for stroke will lead to improvements in functional outcomes and overall health-related quality of life. Although the study indicates favourable benefits of the interventions to nursing practice, the clinical benefit on patients' outcome is unknown. Thus, more research is needed to support this review finding.

Summary of best practice for nursing in stroke care

Rehabilitation stroke nursing is a specialist area of nursing practice. Nurses have been recognized as one of the core multidisciplinary stroke rehabilitation team members in stroke quality standard (NICE, 2013). Hence, nursing commissioner needs to improve the quality standard of care through best available evidence in order to ensure optimum health. Selected studies have provide overview of available evidence with regard to nursing interventions for stroke care. Overall, the quality of the studies reviewed are generally weak. This may relate to methodology weaknesses of the study or low sample power.

A framework proposed by Kirkevold's (2010) therapeutic functions for stroke care; consoling, interpretive, conserving and integrative was used to illustrate the overall nurse interventions for stroke care. Whilst the limitations of the reviewed studies were considered, they imply that nurses interventions focuses on recovery by maintaining and restoring function; promoting health; and preventing and minimising disability, predominantly through information exchange. This intervention does provide complementary roles and possible integration with therapy services. Thus, opportunity to work collaboratively with the therapists exist, as stated in the standard 'Healthcare staff who support people with stroke to practise their activities should do so under the guidance of a qualified therapist' (Royal College of Physician Intercollegiate Party, 2016). Next, the need for nurses to have appropriate skills and knowledge in stroke rehabilitation is explored.

2.8 The ICF Personal factors – Training and educational needs of nurses with regard to stroke rehabilitation

The WHO (2001) describes the ICF personal factors as those that represent influences on functioning that are particular to the individual, such as gender, age, race, lifestyle, habits, education and profession. In the context of this literature review, personal factors refer to the training and educational needs of nurses in stroke rehabilitation. In the UK, the importance of stroke education for healthcare professionals has been highlighted in several government initiatives. For example, the National Stroke Strategy strongly recommended that the provision of stroke care is manned by experienced, expert, knowledgeable and competent personnel related to strokes (Department of Health, 2007). However, many nursing studies based on strokes indicate that the needs of nurses with regard to stroke education are evident.

In a quantitative study in Glasgow, Smith et al. (2008a) surveyed the educational needs of care home nurses (*n*=73) and senior care home assistants (*n*=14) in stroke using posted and/or emailed questionnaires. Descriptive findings related to the educational needs of nurses demonstrated that the difficulties associated with undertaking stroke education are due to a lack of awareness of the available training (61.6%, *n*=45), lack of employer encouragement (21.9%, *n*=16) and staff shortages (12.3%, *n*= 9). Furthermore, some nurses (49.1%, *n*=28) felt that stroke training is not a priority learning need and considered it a time-consuming activity (26.3%, *n*=25). The study also showed that nurses most frequently need education in rehabilitation and the prevention of disability (79.5%, *n*=58), acute stroke interventions (78.1%, *n*=57), stroke assessment tools (83.6%, *n*=61), continence care (42.5%, *n*=31) and moving and handling (52.1%, *n*=38). In the aspect of rehabilitation interventions, it was reported about 25% of the nurses did not view 'encouraging independence' as part of their role. This study indicated a considerable need for training among care home nurses with regard to stroke patients (Smith et al., 2008a). However, this study has limitations; a strategy for testing the internal validity of the constructed questionnaire, such as a pilot study, was not discussed. Hence, the issue of the validity of the findings was raised.

In another study in UK, Murray et al. (2004) investigated the roles and training requirements of district nurses (*n*=50) with regard to stroke care using a survey questionnaire. This study showed that the nurses variably described their salient roles in stroke rehabilitation, and recognised the need to provide continuing care support for patients at home. The majority of the nurses (80%, *n*=40) have had contact with patients, either through home visits or by telephone. As a result, over half of the nurses (52%, *n*=26) have been involved in activities related to rehabilitation, such as providing education and support. However, it was reported that most of these nurses had not received any stroke training during the last year (82%, *n*=41) or even the last five years (66%, *n*=33). Moreover, half of the nurses were unaware of the published National Clinical Guidelines for stroke. Although many nurses identified the negative impact of strokes on patients' mood, they omitted psychological support as part of their recommendations for improving stroke care. This study indicated the nurses' need for education and training on aspects of communication and the psychological care of stroke patients (Murray et al., 2004). Despite these key findings, the study raised major ethical concerns. There was no explanation about obtaining ethical approval, seeking informed consent and ensuring the confidentiality of the questionnaire. Therefore, the conduct of this study is questionable.

A study to evaluate the effects of stroke education on the practices of nurses in community stroke rehabilitation was absent. However, as an example of a study from a ward-based setting, Booth et al. (2005) undertook a 90-minute, non-participant structured observation to compare between the control group (*n*=16 nurses) and the intervention group (*n*=22 nurses) based on their interactions with patients during 100 morning care sessions. The nurses in the intervention group were given 7 hours of formal education consisting of positioning, therapeutic handling and facilitation of morning care activities, delivered by rehabilitative therapists. The practices and processes of both groups were recorded before and after the educational intervention. The findings failed to illustrate any statistical differences between the pattern of morning care activities and the mean time spent between the groups, although significant differences were found regarding how the nurses performed their morning care and the style of the nurse-patient interaction. Booth et al. (2005) explained that the nurses in the intervention group appeared to use the ‘doing for’ style of interaction less frequently, compared with the control group. This emerging evidence suggested that providing education was effective in changing nursing practice related to their role in stroke rehabilitation (Booth et al., 2005). However, the impact of these changes on patient recovery was not discussed, and whether it can be sustained over time is unclear. Nonetheless, this finding revealed that education tailored to the needs of nurses would be more appropriate for changing their practices. Hence, the educational needs of nurses in the present study were explored.

In a review of 15 related papers, Edwards (2006) examined the impact of nurse education and training related to stroke from several aspects; outcomes of care, attitudes and practices, the utilization of resources and delivery methods, contents of the programme and perceptions of training needs. It was found that the number of empirical studies on nurse education related to strokes was limited. The available evidence to suggest the impact of training on improving nursing practices and patient outcomes is weak. Nonetheless, the review showed that the nurses valued and responded positively to the training programme. However, Edwards (2006) argued that a failure to consider leadership input in the reviewed studies may not lead to sustained changes in practice. Therefore, key professionals involved in the provision of stroke care were recruited in the second phase of my study.

In the UK, few studies have suggested that nurses’ training and education in rehabilitation were lacking at all levels of nursing education programmes. Long et al. (2002) explored qualified nurses’ (*n*=137) perceptions of the relevance of education preparation to their role during rehabilitation, and found that nearly two-thirds (64%, *n*=87) of the nurses indicated that the training in rehabilitation provided during their pre-registration education was inadequate. At the post-registration level, the majority of nurses reported ‘learning by experience’ and ‘picking things up as you go along’ as their main source of learning rehabilitation. The nurses frequently encountered difficulties related to attending rehabilitation education due to staffing problems (33%), funding issues (15%) and a lack of relevant courses (21%), whereas a recent study designed to evaluate the knowledge and experience of final year nursing students (*n*=117) found substantial gaps in several fundamental aspects of stroke education; symptoms, complications, risk factors and long-term care (Mason-Whitehead et al., 2013). Most of the nurses involved in both studies indicated their desired to learn more about stroke and rehabilitation. These nurses believed that stroke-specific education is needed to improve their knowledge and skills. Indeed, a study by Mauk (2013) designed to evaluate the effect of advanced practice nurse-modulated education concluded that significant improvements in nurses' knowledge related to rehabilitation competency were demonstrated after the educational intervention. Fundamentally, all of the studies described informed the direction of the present research.

In the UK, a professional development web-based tool, the Stroke Specific Education Framework (Department of Health, 2009), was developed to endorse stroke-specific training for all health professionals. It covers the entire stroke care pathway and consists of 16 elements of care. Each element is underpinned by the key competencies of ''knowledge and understanding' and 'skills and abilities'. These competencies were required by individuals who work in care provision for stroke patients, to prepare them for delivering appropriate and standardised patient care (Department of Health, 2009). Given this, key competencies from one element of this framework, high quality specialist rehabilitation, was adapted to construct part of the nursing questionnaire for the current study. However, the applicability of the SSEF framework in the Brunei context is unknown. Hence, my study may provide information about the generalisability of this framework.

2.8.1 Summary of the training and educational needs of nurses

The contributions of nurses to the care of stroke patients is apparent. However, the reviewed nursing literature raises considerable concerns about the knowledge of strokes, and implies that it is essential to provide specialised training and education. Although these findings may not be transferable due to the methodological weaknesses identified, emerging evidence indicates that education may be central to advancing and changing the practices of nurses involved in the field of stroke care. Therefore, developing the role of nurses in stroke rehabilitation through education may potentially improve the care of stroke patients and their carers. Next, the existing models for the provision of community-based stroke rehabilitation to support patients and carers at home will be briefly discussed.

2.9 Community-based stroke rehabilitation service provision

The WHO describes community-based rehabilitation as a strategy within community development for rehabilitation, the equalization of opportunities and social inclusion of all children and adults with disabilities (World Health Organization, 2003). In the existing literature, various community-based provision of stroke rehabilitation care models were described, such as extended stroke/hospital services (e.g. out-patient follow-up), therapist-led home-based interventions, and multidisciplinary community-based approaches (e.g. early supported discharge). In Brunei, the provision of follow-up care for the community-based rehabilitation of stroke patients is provided by therapists. However, these services were observed to be fragmented and inconsistence due to the limited staff resources.

The benefits of community-based rehabilitation for patients and carers' outcomes were evident. In a review of 11 study trials, involving 1711 community-dwelling people with stroke, who received home-based (intervention group) or centre-based (control group) rehabilitation, Hillier and Inglis-Jassiem (2010) found significant improvements in patients' independence at 6 weeks and 3-6 months, in favour of the intervention group. The review also reported that home-based rehabilitation reduced the cost of hospitalisation and increased carer satisfaction. However, a Cochrane review showed that the effectiveness of these services in improving patients' recovery after one year is unclear (Aziz et al., 2009). Nonetheless, these reviews provide a valid indication that providing support in the early period following patient discharge is crucial for reducing disability and improving quality of life.

Numerous studies have described how nurses, as part of a community-based rehabilitation multidisciplinary team, work together to contribute to positive patient and carer outcomes. For example, in an RCT, Rasmussen et al. (2015) evaluated the impact of home-based rehabilitation between an intervention group (*n*=31), and patients receiving standard care (*n*=30). The intervention group was given rehabilitation training by therapists one to five days per week, for up to four weeks after discharge from hospital. In between these interventions, a nurse conducted a follow-up visit to deliver educational support, such as in subjects related to stroke sequelae or lifestyle, or facilitated patient referrals to their general practitioner. The findings showed that no significant differences in physical functions, ADL independence, cognitive and motor functions, quality of life and total cost were found at 3 months between the groups. However, Rasmussen et al. (2015) identified that patients who were rehabilitated at home demonstrated improved functional independence and experienced better quality of life, compared with the control group.

Lincoln et al. (2004), meanwhile, undertook an RCT to evaluate the effectiveness of a multiprofessional community stroke team by assessing patient and carer outcomes; independence of activities of living, mood, carer's strain, quality of life, knowledge of stroke and satisfaction with services, at 6 months after recruitment. Patients were randomised to receive coordinated rehabilitation support (*n*=189), from a multidisciplinary team, consisting of occupational therapists, physiotherapists, speech and language therapists, and a mental health nurse, or routine care (*n*=232), including day hospital, out-patient follow-up and social services. The results showed that no statistical differences were found in all outcome scales as measured between both groups. However, it was reported that the carers in the intervention group were significantly more satisfied with the education and emotional support provided, which consequently reduced their caregiving strain.

2.9.1 Summary of community-based stroke rehabilitation service provision

The provision of sustainable community-based post-stroke rehabilitation is important for providing long-term care and support for patients and carers. The reviewed studies provide strong evidence that employing various skilled professionals to establish a specialist multidisciplinary community stroke team was associated with improved patient and carer health and wellbeing. Therefore, my study is intended to propose that the role of nurses complements the existing services, in improving the provision of home-based stroke rehabilitation support in Brunei.

2.10 Chapter summary

The ICF was used as a conceptual framework to represent the relationship between domains and stroke. The existing literature illustrated that the impacts of stroke on individuals and caregivers were substantial, and may continue to be so over time. Their need for ongoing rehabilitation and support post-discharge were increasingly evident. However, post-stroke rehabilitation service provision remains in disparity and inconsistent. This could be due to funding issues, limitations of available resources (e.g. staffing), inequality of service provision or a lack of knowledge about stroke among healthcare professionals.

The literature reveals compelling evidence that nurses can embrace key roles in post-stroke rehabilitation. Community nurses who complement the existing stroke rehabilitation therapists have been previously reported. However, despite the recognition of the role of these nurses in stroke rehabilitation, studies of their role are scarce. Moreover, the review found a paucity of research that investigates the training and educational needs of nurses related to strokes. The lack of study about the contribution of community nurses to stroke rehabilitation, compared with nurses in stroke units (Clarke, 2014), was indicative that further research is necessary. More evidence is needed to clarify the role of community nurses and how specialist competency-based stroke rehabilitation training could fulfil their potential. Given that the focus of healthcare is shifting towards a community setting, improving the service provision becomes increasingly crucial.

Hence, understanding the perspectives of patients and carers, as service users, and nurses, as service providers, is required to guide therapists, nurse researchers, policy makers and stakeholders to improve service delivery. Therefore, this study is relevant and timely, particularly for Brunei.

2.11 Research goal

The overall goal of this study was informed by the local context and the review of the literature:

- To identify issues pertaining to the home-based stroke rehabilitation service provision and recommend strategies for improvement

2.12 Overarching research question

How and in what way (s) can the rehabilitative needs and support of home-based stroke patients and their carers be improved?

Next succeeding chapter presents research design and methods that were employed in the first phase study.

Chapter 3: Research Design and Methods – Phase 1 and Phase 2

3.1 Introduction

The literature review demonstrated the current paucity of knowledge regarding the roles of nurses and the inconsistency within community stroke rehabilitation service provision to support stroke patients and their carer at home. Moreover, no related studies in Brunei were found. Little is known about the experience of patients and carers following discharge, or the potential role of nurses to support the stroke patients and their carer at home. How these might help to improve the service provision remains unclear. Therefore, this study employed two distinct phases in order to achieve its goal, which is to identify issues pertaining to the home-based stroke rehabilitation service provision and recommend strategies needed for improvement. The first phase explored views of patients with stroke, carers and community nurses concerning the existing stroke rehabilitation service delivery. The second phase consist discussing the key findings identified from the first phase study with expert healthcare professionals, to ensure that any future strategies developed to improve the provision of home-based stroke rehabilitation will be feasible and acceptable.

This chapter outlines the research design and methodology pertaining to the two phases of the study. A detailed description of the aim, discussions of the methods and methodology, ethical considerations, sampling and recruitment, pilot study, data collection and analysis related to each phase will be provided. This section begin with the statement of the overarching aim of the study and the related aims for each phase of the research. The subsequent sections describes the research paradigm and adapted research design. Then, follow by description regarding reflexivity during the conduct of this research. Next, the overall features of the study design will be outlined. Finally, this chapter concludes with a summary.

3.2. Overarching research aim

The overarching research aim of this study was to explore the different aspects of home-base stroke rehabilitation service provision in order to identify areas needed for improvement. The first phase of the research aims to critically explore areas for improvements regarding home-based stroke rehabilitation service delivery from the perspectives of patients with stroke, carers and the community nurses. Whilst the second phase aims to seek expert comments regarding the key findings identified in the first phase of the study and establish priority for addressing the issues related to home-based stroke rehabilitation service provision.

3.3 Research paradigm

The research paradigm applied in this research is pragmatism. Teddlie and Tashakkori (2009) assert that pragmatism is concerned with solving practical issues in the real world rather than presenting assumptions about the nature of knowledge. It discards the concept of “truth” and “reality”, focusing instead on “what works” and is practical for finding the truth about the phenomena under study (Creswell & Plano Clark, 2011). Moreover, pragmatism views knowledge as being both constructed and based on the reality of the world which one experiences and in which one lives (Johnson & Onwuegbuzie, 2004).

Pragmatism is not attached to any specific philosophical orientation or method (Teddlie & Tashakkori, 2009). The researcher decides what study is required, whom the most appropriate informants are and how the data should be collected. Thus, assumptions can be mixed and matched, along with appropriate methods, to answer the research inquiry (Greene & Caracelli, 1997). From a methodological stance, pragmatism often chooses multiple methods of data collection which are most appropriate to answering the research questions (Teddlie & Tashakkori, 2009). As a result, pragmatists maintains that mixing qualitative and quantitative approaches is feasible for producing defensible and usable research findings (Johnson et al., 2007) Thus, pragmatism is well aligned with the aims of my research and facilitated the exploration of the problems been studied.

3.4 Research design

This study is intended to identify practical strategies to improve the home-base stroke rehabilitation service delivery for patients with stroke and their carer. This process involve recognising the different needs of the service users; stroke patients and their carer, and service providers; the healthcare professionals. The first phase of this study comprise exploring the rehabilitation support needs of the home-based stroke patients and their carer, and the training needs of nurses in stroke rehabilitation. Hence, specific concepts of ‘need’ analysis were considered to support the design of this research.

Various definitions and concept of ‘need’ has been developed. According to the Royal College of Surgeon and Physician of Canada (2012, p. 3), ‘need’ is described as “gaps between a current and a desired state of wellbeing which can be objective (measured) or subjective (perceived) and physical or psychological”. Asadi-Lari, Packham and Gray (2003, p. 3), citing from the health of the nation: a strategy for health in England (Department of Health, 1992), meanwhile defined ‘need’ as “the requirement of individuals to enable them to achieve, maintain or restore an acceptable level of social independence or quality of life, as defined by particular care agency or authority". Additionally, the concept of 'need' can be illuminate in several ways. Cookson, Sainsbury and Glendinning (2013), referring to Jonathan Bradshaw's Taxonomy of Need proposed four types of needs; normative needs (define by expert professionals), felt needs (equated to what people want), expressed needs (demand for unmet service) and comparative needs (relative needs of different group). Whereas, Endacott (1997) identified multifaceted concepts such as an undesirable states of affairs, necessity and a deficit identified through a value judgement and conferring responsibility, which are attributes to a 'need'. The overarching definitions and concept of needs described were used to guide the analytical interpretation of the experiences among the patients with stroke and their carer in this present study. This research, therefore, was an exploration of felt needs of the targeted population, focusing on the partially met or unmet rehabilitation support needs within one year following discharge from the hospital.

Another method that can add value to this study is the training needs analysis (TNA). Carlisle, Bhanugopan and Fish (2011) describes TNA as a method to investigate the current and desired performance levels of staff and support networks within a particular setting. In the context of the present study, this approach was considered as initial step in the process of identifying the needs of training and education in stroke rehabilitation among targeted nurses within the community setting. Gould, Kelly and White (2004) suggested TNA framework, such as involving stakeholder, identifying organisational and staff needs, appropriate sample and data collection methods, and indication of how the finding will be used for training purposes, which were considered in the conduct of this research.

Both 'needs' analysis approaches as described above were integral in the present research. However, this study is intended to provide complete understanding regarding issues surrounding the home-based stroke rehabilitation service provision from various sample groups. Therefore, the best research design that is consistent with my research paradigm and the aim of this study is a mixed methods design. Mixed methods research has been described as combining elements of the quantitative and qualitative approaches (e.g. the use of qualitative and quantitative worldviews, samples, data collection, analysis, inference technique) in a single research project to increase the breadth and depth of understanding and corroboration (Johnson et al., 2007). There are many advantages related to this design, such as providing more evidence, helping to answer questions that cannot be answered with a single approach, allowing 'practicality' where researchers may use a variety of methods to answer a research question, producing stronger inferences and providing a greater assortment of participants' views (Creswell & Plano Clark, 2011; Teddlie & Tashakkori, 2009). Therefore, these descriptions have informed the design of this research study.

3.5. Other research design

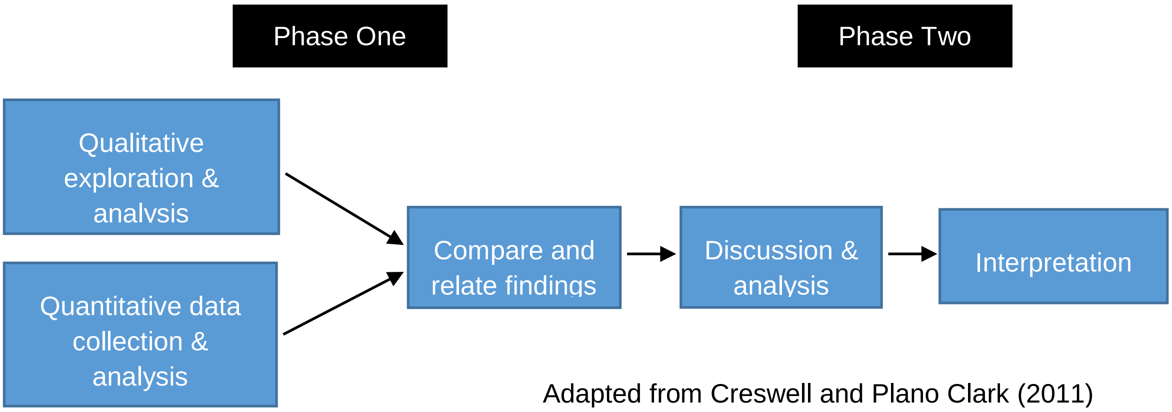
Other relevant research designs that may suit the conduct of this study were considered. The health needs assessment was one of established strategies commonly employed by healthcare professionals or policy makers to identify healthcare needs and priorities of the population. Wright et al. (1998) describes health needs assessment as "a systematic method of identifying unmet health and healthcare needs of a population and making changes to meet these unmet needs. It involves an epidemiological and qualitative approach to determining priorities which incorporates clinical and cost effectiveness and patients' perspectives". The health needs assessment is a tool to review the public health issues, leading to agree priorities and allocate resources that will improve health of all people and reduce health service inequalities (Cavanagh & Chadwick, 2005). Essentially, these descriptions means understanding the healthcare needs and pattern of the population in order to plan and meet particular needs of the people, taking into consideration on efficacy, equity and affordable of services.

Thus, the health needs assessment seem fit with the approach of the present research, whereby the approach may likely capture various needs of the people irrespective of diseases, age or society. Moreover, this tool was widely used among the health governance across countries worldwide to evaluate the health status of the population. Hence, future findings of present study may more applicable to vision of the Ministry of Health Brunei, which is *Towards Healthy Nations 2035.* Few studies have reported benefits of health needs assessment as methods for planning and improving stroke care services. As example, Moreland et al. (2009) assessed needs of individuals with stroke following discharge from the hospital. The study found that physical domain was the most support frequently needed which regarded as importance to participate in daily activities. Another study which assessed the efficacy of stroke service provision in Canada also demonstrated that needs assessment was a useful tools to evaluate the evidence-based stroke services for the community (Hunter et al., 2004). Importantly, health needs assessment offers viable strategy for addressing issues on inequalities pertaining to the healthcare service provision for population of the country (Wright et al., 1998).

However, despite the potential merit of health needs assessment as primary research design of the current study, it was not clear if this method was sensitive enough to capture specific needs of the Bruneian stroke survivors and caregivers, in particular considering the culture of Malay and Islamic religion. As published studies regarding this aspect was not found, the appropriateness of health needs assessment from perspective of culture and religion remains unknown. Moreover, health needs assessment strategy often involved larger population-based survey to generate meaningful results. As such, using this approach will be time consuming and required higher cost. Nonetheless, the concepts of health needs assessment, such as exploring agreed priorities and allocation of potential supportive nursing resources, were incorporated within the chosen mixed methods design. The subsequent section will described features of the mixed method design of the present study.

3.6 Theoretical model of the Mixed Methods design

There are various types of mixed-methods design. However, the convergent extended mixed methods (CEMM), adapted from (Creswell & Plano Clark, 2011), were employed in order to provide complete understanding of the research problems. This method consists of two distinct phases. The first phase was an exploratory phase, involving two separate components; the qualitative strand and the quantitative strand. The findings from both sets of data were compared and relate in order to identify the key findings in the phase one study. The second phase study designed to further explore the key findings identified during phase one. Data from the second phase were analysed and interpreted to describe the overall findings of the research. Diagram 7 illustrates the CEMM design.



Adapted from Creswell and Plano Clark (2011)

Diagram 7: The Convergent Extended Mixed Methods design

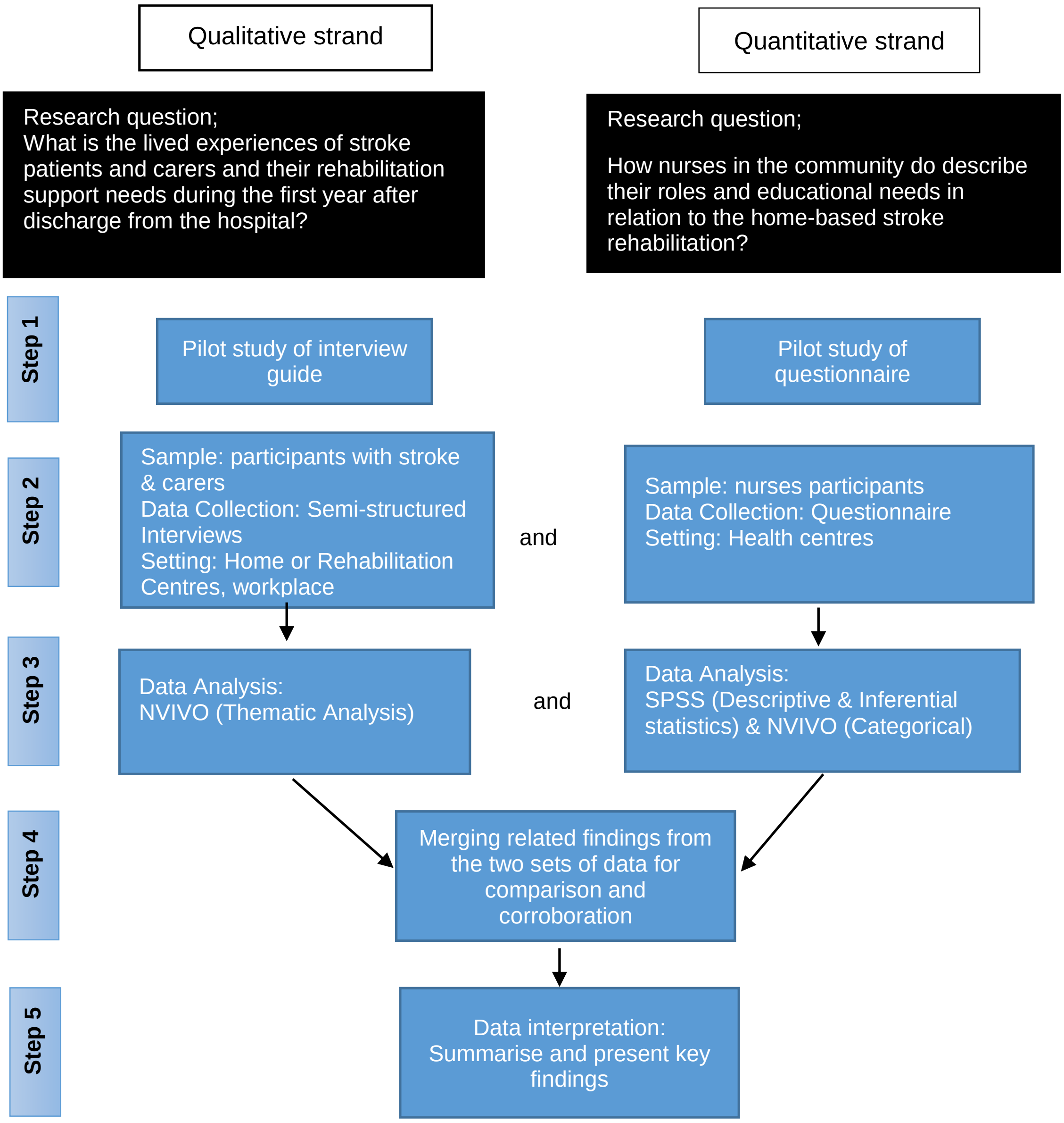
3.7 Overall features of the research design

The study is sought to explore the experiences of stroke patients and their carers, the perspectives of nurses from a larger sample, and the views of expert healthcare professionals regarding the home-based stroke rehabilitation service provision. Phase one concerned with collecting baseline information from the stroke patient participants and their carer through one-to-one interviews, and nurses in the community using a survey questionnaire. Both data collection were conducted simultaneously. The information gathered from the phase one study was analysed for further examine at the second phase of the study. Details of the research process for phase one study is provided in section 3.9.

Phase two commenced upon analysis of data from phase one were completed. Phase two consist meeting with specific expert healthcare professionals to discuss key findings identified from the phase one study. Comments and feedbacks from these participants were used to establish the priority for addressing the issues related to home-based stroke rehabilitation service provision. Details of the research process for phase two study is outline in section 3.11.

3.8 Research design - Phase 1

This section describe research design for phase one study. This phase consists two separate components: qualitative strand and quantitative strand. Each of this strand has its own specific research question, sample participants, methods of research inquiry and analysis. The process of research for phase one was conducted simultaneously. The flowchart 2 illustrates procedure in implementing the first phase study. There are five main steps involved. The first step consists of piloting the developed questionnaire and interview guide. Following this, study samples were identified and recruited. Both qualitative and quantitative data were collected concurrently. Step three involves analysing sets of data using specific approaches. The process of data collection and analysis are equally treated as important in addressing the research aim. Step four consists of merging the related findings from the two sets of data for comparison and corroboration. Finally, the findings were interpreted and summarised in preparation for the second phase of the study. The detailed features of qualitative strand and quantitative strand will be described in section 3.9 and 3.10 respectively.



Adapted from; Creswell and Plano Clark (2011)

Flowchart 2: Procedure in implementing first phase of the study

3.8.1 Aim and objectives of phase 1 study

The aim is to explore critically areas for improvement regarding home-based stroke rehabilitation service delivery from the perspectives of patients, carers and community nurses.

The objectives are to:

1. explore the lived experiences of stroke patients and their carers living at home, focusing on their perceived rehabilitative support needs

2. identify any potential roles and educational needs of the community nurses with regard to stroke rehabilitation
3. analyse critically the two sets of results in order to identify the key findings which contribute to the improvement of home-based stroke service provision

The succeeding section outlined the qualitative strand of phase one study.

3.9 Research design Phase 1 – QUALITATIVE STRAND

This section describes specific research question and research process of the qualitative strand.

3.9.1 Research question

- What is the lived experience of stroke patients and the carers and their rehabilitation support needs during the first year after discharge from the hospitals?

3.9.2 Research method

The research method of qualitative inquiry was the one-to-one interview. Parahoo (2006) suggested that interviews offer explorations of individuals' experiences and enable probing for more information and the clarification of answers. They allow researchers to gather the participants' perspectives and uncover their thoughts and feelings, which will help to understand the participants' points of view (Patton, 2002). A semi-structured interview was employed. This strategy is more flexible and provides an opportunity for the interviewees to explain their answers in great detail. In addition, it also allow the interviewers to probe further and seek clarification during the interview (Fielding, 1994). The reviewed literature shows that a similar technique was used in previous explorative studies of stroke patient participants (McKevitt & Wolfe, 2000) and carers of stroke patients (Greenwood & Mackenzie, 2010). Thus, interviews were an appropriate method for eliciting in-depth information about the experience of the participants in this study.

An interview guide, the Brunei Home-Based Interview for Stroke (Bru-HIS), was developed by the researcher (available in Appendix 1). The questions were translated into Malay, as most of the participants were not fluent in English language. Issues relates to analysing translated data will be discussed in section 3.9.13. The interview questions were informed by the study objectives and derived from the literature reviewed. The framework of the ICF was adapted to structure the interview questions. The Bru-HIS is divided into two parts. The questions in the first part was intended for interviews with the participants with stroke, and the second part formed questions that guide interviews with stroke carer participants. Both parts of Bru-HIS comprise 4 sections, namely participants' demographic details in section one, next in section two contains questions that consider participants' understanding about stroke and rehabilitation, follow by questions that identify participants' ADL limitation and restrictions in section three, and finally participants' rehabilitation support needs and aspects of community stroke nursing were explored in section four.

In Bru-HIS section 3, part 1 and part 2, an approach of the Canadian Occupational Performance Measure (COPM) (Law et al., 2005) was adapted into the interview guide. The COPM was described as an individualized outcome measure that was designed to assess client's self-perception of occupational performance and satisfaction with that performance over time by identifying problems in performing activities of living (Law et al. 2005). It was reported that COPM reinforced the clients at the centre of their care, enabling them to identify the priorities related to their own problems and empowering them to be more critical of their own performance (McColl et al., 2000). One of the objectives for the stroke and carer participants in this present study is to explore their rehabilitation support needs after discharge home. Therefore, the methodology of COPM helped identifying those priority needs of these participants. Questions that was developed in section 3 of the interview guide demonstrates integration of COPM (see Appendix 1). The questions focus on identifying the participants' occupational or caregiving performance problems that they would like to do or need to do, and then ranks each of the activities according to their perceived individual importance. The process of collecting data using adapted COPM approach can be briefly describe as once the participants have described their typical daily activities, participants would then asked to identify and rank the importance of those activities, rate their level of performance and state their feeling of satisfaction on doing the activities. A scoring card was designed to facilitate participants' level of ranking and rating (see Appendix 1).

The integration of COPM as part of the interview guide is arguably opened to debate. The methodological and ethical fitness for purpose issues that may affect the process and outcome of the present study, therefore, must be evaluated. The validity and reliability of psychometric properties of the actual COPM standardized assessment tool was well established (Yang et al., 2017). Whereas, the adapted approach in our study never been clinically evaluated or tested. Furthermore, COPM was designed primarily for use by the occupational therapists and other multidisciplinary them. The use of COPM by nurses, as was the researcher's background, in practice or research was not found in the existing literature. It was reported that the success of an assessment using COPM relies on the participants' input and motivation to give honest appraisal of his or her strength, weakness, and goals and, importantly guidance from the therapist (Law et al., 2005). Thus, the competency and understanding of the researcher about adapting the tool in this study is questionable. In addition, the assessment tool is intended for use to assess outcome measure, and should be administered at the beginning of the therapy and at appropriate interval. Our study does not provide any occupational interventions to the participants, nor the researcher was aware the start and extent of the therapy for the stroke participants. For this reason, the application of the adapted COPM in the present study may not be at appropriate timing. This, consequently, may influence participants' responses to their performance. Finally, the use of the tool to explore caregiving performance among stroke carers or other disability diseases was not previously reported. Hence, the appropriateness of this tools for assessing carer's caregiving performance can be criticised.

Nevertheless, our study which adapted the approach of COPM in identifying the individuals' priority problems in relation to rehabilitation support, has helped illuminate participants' 'felt' needs that was met, partially met or unmet. The findings of the interviews will be presented in Chapter 4.

3.9.3 Pilot interview

The interview guide was piloted with two stroke patients and their carers, identified from the rehabilitation centre. The pilot interview allowed the researcher to become familiar with the procedure and modify the techniques, approaches, or questions to improve the quality of the main data (Davies, 2007). During the pilot study, one stroke patient withdrew because she cried when asked about the impact of stroke. Initially, the question was, "Does the stroke affect you physically? Can you explain how?" Perhaps the question's emphasis was on an individual's impairment, so it was revised to "Can you explain how your stroke affects you in general?" Overall, no major changes to the content and focus of the interview were required. Thus, data from this pilot were included in the analysis of the main data to supplement the future findings.

3.9.4 Study setting

This study was conducted in Brunei, where participants were identified from two rehabilitation centres within Brunei Muara district. Relevant information regarding the study setting were described and provided in Chapter One.

3.9.5 Sample participants

The sample comprised two groups: individuals with stroke and their primary caregiver. Traditionally, the carer and the stroke patient live in the same house. In Brunei, there is no nursing home or elderly care centre.

The inclusion criteria for stroke patient participants were:

a) previous admission to hospital or a stroke centre due to sustaining a first stroke, as confirmed by medical diagnosis,
b) having been discharged from hospital or a stroke centre within a year,

c) having residual impairments or problems with performing the activities of daily living tasks as a result of a stroke,
d) having attended or currently attending rehabilitative programmes as out-patients, organised by therapists,
e) demonstrating an ability in verbal communication and cognitive status by answering simple orientation questions (e.g. demographic details) accurately,
f) willing to give consent and participate in the study,
g) living in Brunei Muara district, including in the water village areas.

The exclusion criteria were:

a) having been discharged with reported serious comorbidities or unstable medical conditions (e.g. chronic neurological impairment). Due to the complexity of care that these patients may receive, these conditions may distort their responses during the interview. This was assessed by a therapist prior to their inclusion into the study
b) stroke patients who have speech difficulties. This group of patients were purposely omitted from the study considering the skills of the researcher were limited to interviewing through active conversations. The researcher was concerned that the interviews may risks patients develop emotional and physical strain due to trying hard engaging with the conversations. Secondly, the research was not being prepared or trained in non-verbal communication technique. Whereas, the use of proxy to understand the problems of the stroke patients may not entirely uncover the reality of patients' experience.
c) recovered from stroke and able to manage at home independently

The inclusion criteria for the stroke carer participants were:

a) having experience of caring for a stroke patient at home for more than three months, to ensure they have reasonable experience of the caring role,
b) designated the primary carer,
c) willing to give consent and participate in the study

No exclusion criteria for carer was applied.

With regard to the sample size, a predetermined sample when using qualitative data is less important. However, Ritchie et al. (2003) suggested that individual interviews should involve fewer than 50 participants to provide consistency in the data collection and manageable data analysis. Thus, the sample size from previous relevant studies was identified as guidance. A systematic review of 28 studies of the early discharge experiences of stroke survivors and their carers involved samples of between 5 and 144 participants. Eleven of these studies recruited more than 20 participants (Pringle et al., 2008). Therefore, the target sample size in the present study was 20 for each group of participants.

However, Morse (2000) warned of the risk of taking the sample size of other studies at face value, as an oversized sample may lead the researcher to “drown in data”. Conversely, an inadequate sample may risk collating data that is “thin” and not “thick” (Polit & Beck, 2004). Parahoo (2006) suggested that the number of participants required in interviews is considered as adequate if the data collected have reached the point of saturation; i.e. where no new data emerging from the interview are found. In this study, the point of saturation was achieved as no new information were identified following completion of data analysis. The description and process of achieving data saturation will be described in section 3.9.10

3.9.6 Ethics

Ethical approvals encompass the phase one and phase two of the study has been given. This study was approved by the University of Southampton ethic committees on June 17, 2014 and on July 16, 2014 after amendment was requested. This study also got permission from two ethic committees in Brunei. Approval from the Medical Health Research Ethic Committees (MHREC), Ministry of Health Brunei was obtained on July 1, 2014, and the JPMC Ethic Committees was given on August, 18 2014. The ethics documentations are provided at appendix 2.

Issues related to participants right to self-determination, right to full disclosure, right not to be harmed and right of privacy, anonymity and confidentiality (Parahoo, 2006), that relevant to nurse participants were discussed.

The process of seeking consent was carried out during the sample recruitment and prior to the interviews (see subsection 3.9.8). With regard to issue of potential harm, this study does not involve any invasive procedures. However, the reviewed literature indicates that strokes negatively affect patients and carers’ emotional or psychological functions. Therefore, several measures to avoid harm were undertaken, as explained below.

For the stroke patient participants, a family member or personal carer was present throughout the interview. This strategy was undertaken to avoid potential risks, such as feelings of discomfort, distress, or falls. The majority of the interviews went well, but two participants shown signs of depression (feeling low or down), and another three were emotionally disturbed (shedding tears or abrupt silences). Thus, the interviews were suspended to give the participants a 10 minute break to recompose themselves, or they could ask for the interview to be rescheduled or withdraw from the study at no cost. Generally, the participants were happy to resume and complete the interview. Throughout the study, only one pilot participant withdrew due to intense feelings of sadness. Follow-up with a relevant health professional was offered, but the participant felt that this was unnecessary. Hence, the participant was reassured and comforted before being allowed to leave.

For the carer participants, most of the interviews were undertaken individually in a separate room. This approach ensured confidentiality so that the carers could express their views freely. However, two carers were interviewed in the presence of the stroke patients, who refused to leave and the carers were concerned about their safety. One carer was worried that the stroke patient might fall off the bed if left unattended.

Regarding confidentiality and anonymity, any information pertaining to personal details, such as reply slips and consent forms, was stored in sealed envelopes and kept in a locked cupboard in the researcher’s home. Copies of the transcripts and recording were stored using a similar method. Any information that identified the participants in the interviews was omitted during the data transcription and reported. The transcripts were coded for anonymity prior to analysis. Pseudonyms were used for transcripts requiring expert translation. A pseudonym in coded form was used in reporting the findings. Data were only shared with the supervisory team for study purposes.

3.9.7 Approval by the ‘gatekeepers’

Similar approval from the one of the directors from the Ministry of Health was used. Verbal approval from the ‘gatekeeper’ of the stroke centre was granted through intermediary person of the JPMC. No letter was issued in response to my application. However, an initial email correspondence, dated June 14, 2014, from the ‘gatekeeper’ of the stroke centre indicated support for the present study. Permission from the ‘gatekeepers’ of the rehabilitation centres and the neurology clinics were also sought. Documentation regarding approval from ‘gate keepers’ are available at appendix 3.

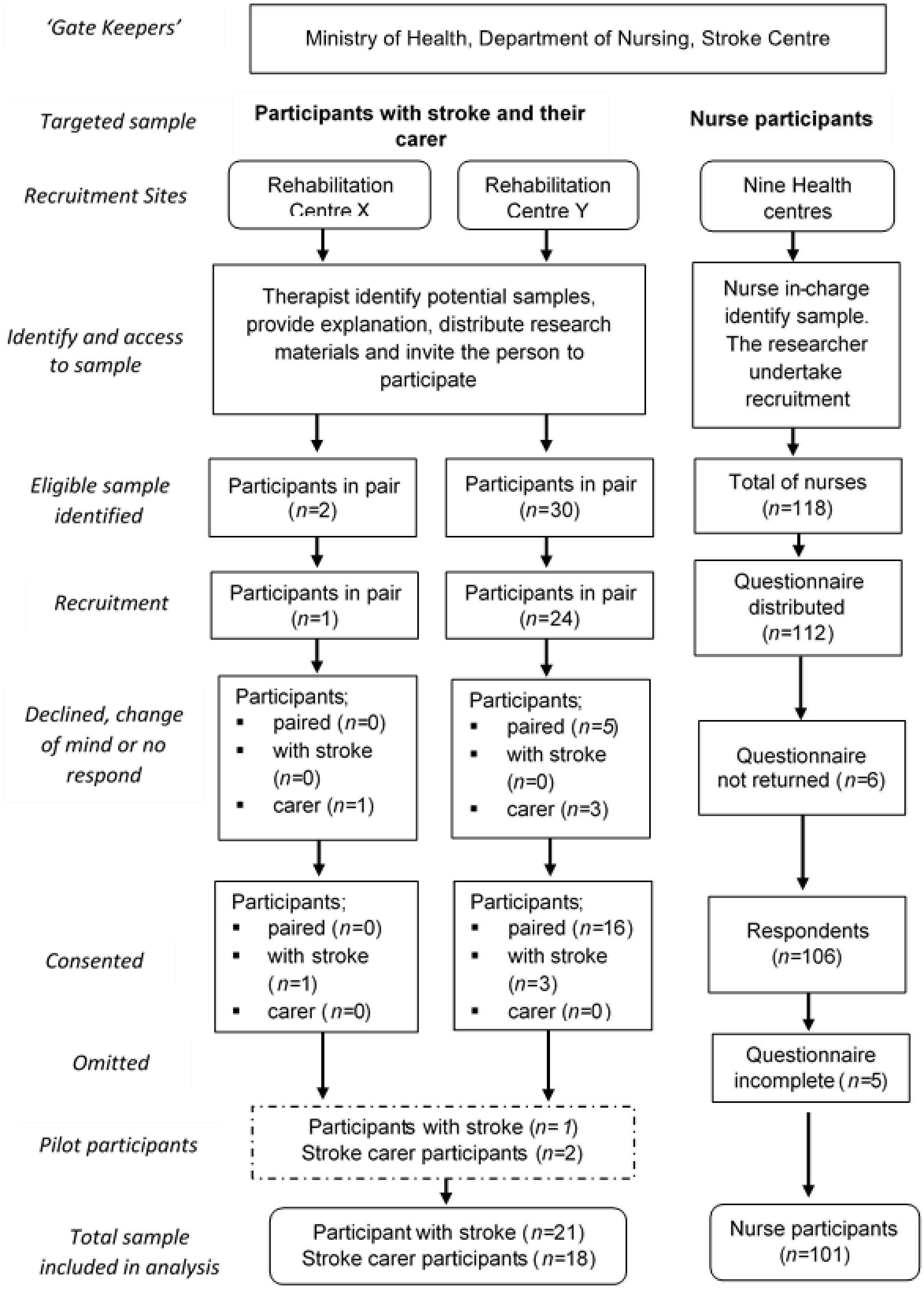
3.9.8. Recruitment and providing informed consent

Participants were recruited from two rehabilitation centres; Centre X and Centre Y (pseudonyms). Prior to the recruitment, the researcher organised meetings with the respective heads of the rehabilitation departments to discuss the study and seek agreement to assist with recruitment. Subsequently, specific therapists were assigned to act as the researcher’s intermediary in identifying potential participants. This strategy ensured that the individuals would not feel coerced to take part in the study.

At the beginning, it was proposed that the therapist would contact potential participants and then post out the study package if the person agreed to participate. However, the therapist was concerned about the delivery time and effectiveness of this approach. Therefore, the therapist suggested identifying potential participants in advance from the outpatient rehabilitation appointments lists.

The process of recruitment operated in a consistent manner. Eligible stroke patients and their carer were approached and informed about the study by the therapist. If one or both were interested in participating, the study package including invitation letter, information sheet and reply slip, (available in Appendix 1) was handed out. Those who agreed to take part returned the reply slip the following week. Then, the researcher contacted the pair or individual concerned and assessed their understanding of the study. Each of them would be given an opportunity to ask questions and seek clarification. If they were happy to participate, a mutually agreed date and time for the interview were scheduled.

Following the recruitment, two stroke patients and their carers were identified from rehabilitation centre X. One pair returned the reply slips and was contacted, but only one stroke patient participant agreed to be interviewed, as the carer was no longer interested. Thirty suitable pairs were eligible from rehabilitation centre Y. Of these, twenty-four pairs returned the reply slips and agreed to be contacted. However, five pairs eventually declined and another three carers were not interviewed because two were unavailable for the scheduled interview and one was excluded due to being a young aged ten. Therefore, the remaining sixteen pairs and three individual stroke patient participants were interviewed. However to supplement the lack of recruits, interview data from two carers and one stroke patient participant from the pilot study were included in analysis. Therefore, the overall total of participants recruited and interviewed in this study was twenty-one stroke patient participants and eighteen carer participants. Flowchart 3 outline the process of participants' recruitment.



Adapted from; CONSORT (2015)

Flowchart 3: Participants' recruitment process

3.9.9 Interview procedure and seeking consent

The arrangement of the interviews were set during the researcher's first contact with the participants. The timing and location of the interviews were decided based on the participant's convenience. On the whole, interviews with four pairs of participants were undertaken at home, one stroke patient participant asked to be interviewed at the workplace, and the remaining participants were interviewed at the rehabilitation centre.

Moule and Goodman (2009) highlighted the importance of a quiet and comfortable environment to facilitate engagement and establish trustworthy interviewer–interviewee relationships. Thus, an appropriate room for each interview was considered. At the rehabilitation centre, the speech therapy or paediatric assessment rooms were provided. Although the noise from the adjacent therapy area could be minimised, the inadvertent entrance of the staff occasionally disrupted the flow of the interviews. Interviews at home were undertaken in a living room. This provided a conducive environment as the participants could feel more comfortable and confident and stay focused. By contrast, it was difficult to control the interview setting in the workplace. At times, the phone ringing, printing sounds or someone entering the room were unavoidable. It is worth considering if these different settings influenced how the participants shared their experiences. While it was difficult to determine this, I considered the participants' narratives as the reality that was constructed through their experiences.

During each interview, the researcher shared his student identification card with the participants to confirm his personal credentials. This minimised the participants' feelings of anxiety as the researcher was not known to them. The researcher briefly discussed the purpose of the study and offered the participants an opportunity to reread the information sheet and ask any questions. All of the participants were assured that their participation was fully voluntary and that they might withdraw at any time without cost. The participants' understanding about the study was checked to ensure that they were giving informed consent. Once the participants were satisfied and had their questions answered, written consent to participate and audio-record the interview was sought. If the stroke affected the participant's dominant hand, verbal consent was obtained and digitally recorded. The interviews began by obtaining the participants' demographic information, followed by the study questions. The majority of the interviews were held in the local Malay dialect. However, three carer participants were interviewed in English because they were judged to have sufficient language competency.

During the interviews, the researcher often responded either by nodding or repeating the participant's last word as ways of showing active engagement (Patton, 2002). For most, these research interviews were the participants' first experience of being interviewed.

Hence, it proved challenging to encourage them to elaborate on their thoughts and feelings. Occasionally, questions were rephrased as closed-ended before being followed-up with further exploration. For example; 'What roles do you think nurses should have…?' was rephrased as 'Do you think nurses can help you…?', then, 'How do you think nurses can help…?' Furthermore, some carers intervened, despite being told not to, in-between conversations and at times signposted answers to the participants. Three stroke participants thought that the study was related to welfare, particularly the entitlement to disability allowance. Based on these observations, it is worth noting the possibility that socio-cultural issues may affect how the participants responded during these interviews. This will be reconsidered during discussion of the findings.

For the interviews with the carers, the stroke patients were politely asked to remain in their bedrooms. However, two interviews were conducted in their presence. The potential implications of this, such as hindering carers from sharing their thought freely, were noted and recorded in the field notes to assist with the description of the participants' experiences. Generally, most interviews went well and lasted, on average, 40 minutes to an hour.

Throughout the interviews, field notes were kept to record any observations during or after the interview. These notes were used to reflect on the participants' behaviour, events or other features raised by the study setting. Recommendations raised by the participants were followed-up by posing questions during subsequent interviews. Additionally, a reflective diary for recording the researcher's emotions, thoughts, feelings, and unexpected findings were documented. Thus, the field notes and diary were useful in assisting the researcher to answer the research questions and describing the experiences of the participants. A reflective sheet was adapted to record field notes and reflective dairy, and is available at appendix 4.

3.9.10 Analysis for qualitative data

This section describes analysis of the interview data for the participants with stroke and their carer. The analysis of data for these participants were undertaken twice. The first analysis were completed prior submission of the final thesis. The second analysis including restructuring themes of stroke patient participants and separate analysis of interview data with the carer participants. Discussion of data analysis for questionnaire will be provided at separate section (see Section 3.10.11). The thematic analysis was adapted in this study because it does not subscribe to any specific epistemological background, and thus fits with the present mixed-method research paradigm. Thematic analysis is a form of qualitative analysis method that assists in identifying, analysing, and reporting patterns within textual data (Braun & Clarke, 2006). Moreover, this analysis strategy helps in encoding qualitative information through the generating of codes (Boyatzis, 1998). These codes serve as labels for sets of data, and collated codes can be transformed into lists of themes, sub-themes or models, that are causally related. In addition, the exploratory features of thematic analysis facilitates interpretations of various descriptions of research topics, particularly those related to new or under-researched areas (Boyatzis, 1998). Essentially, this method provides systematic ways of working through textual data to identify the key themes and address the current research question.

The adapted thematic analysis consist (1) familiarising with the data, (2) generating initial codes, (3) categorisation of codes, (4) searching for preliminary themes, (5) reviewing the themes, (6) defining and renaming the themes, and (7) is producing report or findings of the research (Braun & Clarke, 2006).

Analysis of interview data for stroke patient participants

The first analysis of data was undertaken using computer-assisted qualitative data analysis software - QSR NUD.IST Vivo^{TM} version 10 (NVivo^{TM}) to facilitate data management and analysis. The software enables the handling of large amounts of data, allows rapid searching and retrieving of data, provides a facility to attach memos and notes, facilitates detailed analysis, allows the visual production of indexed data and explores the relationships between themes and data in coherent ways (Woods & Roberts, 2000). However, this software was not an analytical tool as generating codes and interpreting data rely on the researcher's intuitive judgement (Gibbs, 2002). Blismas and Dainty (2003) suggest adopting an analytical strategy to avoid the software dictating that researchers follow a particular analytical approach. Therefore, NVivo^{TM} applications guided by thematic analysis was employed. The process of analysis data is described briefly as follow:

1. Analysis processes began with identifying repeated patterns of experiences or concepts during the interviews. Discovered patterns were recorded in the field notes to allow comparison and identification of possible themes.
2. Transcripts were re-read to allow immersion and familiarity of the data (Braun & Clark, 2006). Any initial ideas or potential coding were recorded.
3. All transcripts were imported into the NVivo^{TM} software. Initial codes were generated to describe the content of data in a meaningful way regarding the phenomena (Boyatzis, 1998).
4. The initial codes were collated and analysed to identify relationships between the descriptive codes and considered combing to develop overarching categories. Visual

presentations in the form of thematic map within NVivo™ were used to sort out the difference codes into categories. Diagram 8 illustrates example of thematic map.

5. Each category was then reviewed and reconsidered whether data within the categories form a coherent pattern or if a new category is required.
6. Themes were identified and refined to determine the essence of data captured in each theme. If necessary, sub-themes were generated to demonstrate the hierarchy of meaning within data. Thematic matrices of NVivo™ were used to review the themes identified.
7. Further analysis of themes identified earlier was undertaken following the first submission of the thesis. The process of analysis involves using the Microsoft Words application, as the NVivo software was no longer usable. Firstly, all earlier themes were imported to words document. Then, all data extracts belong to the carer participants were removed. Next, each of the existing themes were re-reviewed in accordance with step 5 in thematic analysis approach. All data extracts from each theme were re-read and, it was necessary that the original data sources will be retrieved in order to add more data extracts or to ascertain that all data captured the underpinning themes. Subsequently, some themes underwent refinement and renamed to fit with the overall descriptions of each themes and in relation to the research question of the stroke participant group. Finally, all themes and subthemes were organised to illustrate the overall experiences of the stroke patient participants. Interview findings of these participants will be presented in Chapter 4.

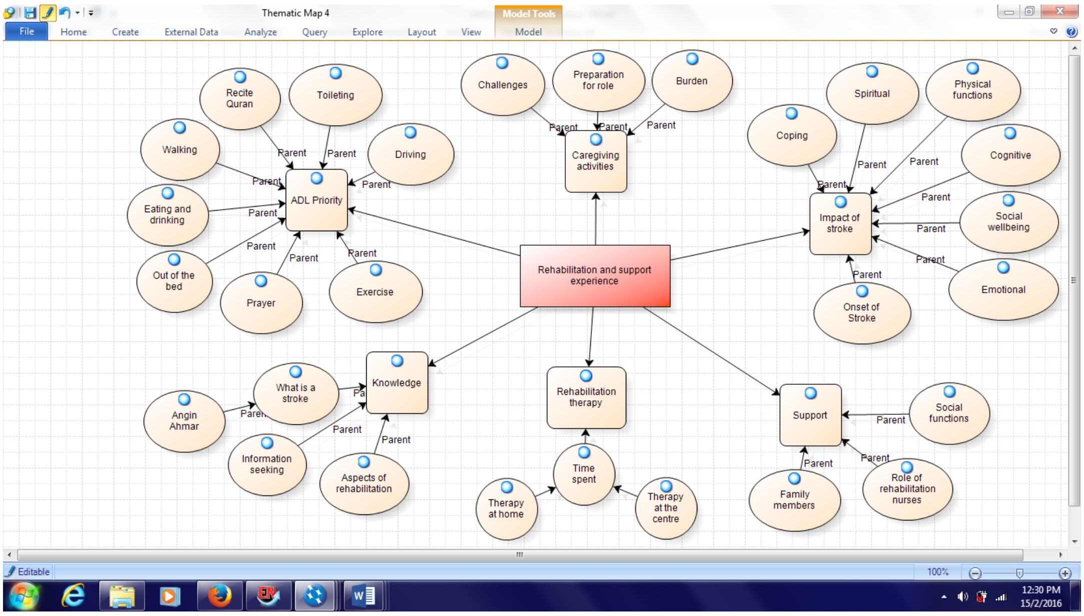


Diagram 8: Example of thematic map in NVivo™

The second analysis of the carer participants’ interview data, meanwhile, was undertaken using Microsoft Words document. The first step is the preparation stage where the interview data was transcribe verbatim. A table that illustrate the steps in the thematic analysis was used to assist with the process of identifying themes (See Diagram 9).

Interview Transcript	Line no.	Searching for patterns or meanings	Initial coding	Categorisation	Searching for preliminary themes
	1 2 3 4 5 6				

Diagram 9: Sample of table for process of analysis

The second step of data analysis was the process of immersion into the data. Each interview transcripts were read, typically more than once, in order to familiar with the data. Any interesting aspects in the data sets that form the basis of repeated patterns or meaning will be extracted and place under ‘patterns or meaning’ heading. Thus, the original ‘voice’ of the participants were retained before the next process of data analysis begun.

The third step involves generating initial codes. The interview extracts that represents patterns or meanings were coded and given specific name. The descriptive name (code) were generally derived from the original words of the data or new name were used if the existing name did not match up. Braun and Clarke (2006) underlines that importance of acknowledging the researcher’s own theoretical position and values in relation to the qualitative data. Therefore throughout this analysis process, the researcher will remain conscious about his background that can influence analysis, being open-minded, keeping notes, constantly staying close to the data and retaining as much of the participants’ ‘voice’ in the codes (See reflexivity section 3.12). Following completion of this process, the next step of data analysis precede.

All initial codes identified across the data set were grouped into specific categories. This step involves sorting out the different codes, along with the data extract, and collating the relevant codes into category. This process was undertaken in order to consider how the initial codes can be combined in preparation for identifying potential themes and subthemes. This process ends with list of categories outlined which represent individual codes. Next step involve searching for preliminary themes.

The process of searching the preliminary themes consist analysing the relationships of the categories with the other categories identified. All categories were reviewed and any related categories will be combined to form the theme, or new category will be develop. In this step, the process of analysis was centered on identifying wide-ranging themes. The level of themes identified typically focus on ‘semantic’ level of the data (Braun & Clarke, 2006). This was described as identifying theme within the surface meanings of the data which would provide interpretation to explain the experiences of the carer participants in rehabilitation support provision. This was taken into account as the study was not intended to generate theory, but to develop theoretical knowledge and understanding about the issues explored.

The next step involve reviewing the preliminary themes to ascertain whether the individuals’ data extracts and across the data sets within each themes were adequately captured the underpinning themes. Any themes that not fit well with the data extracts or there was not enough data to support the theme, this theme will be refined or combined with other theme. The approach of analysis in this step involve iterative process, whereby all the collated data extracts at each theme were read and reread. The stage of reviewing and refining the themes undertaken at two ways; firstly, reviewing for each transcript and then, in relation to the entire data set. A table display for assisting in reviewing and refining the themes was developed with new words document. The related data extracts from all transcripts were copied and pasted under the data extract column and the underpinning themes were written in the next row of the table. This approach facilitates cross-data analysis without losing track of the raw data, thus assisted in reviewing and refining the themes. Following completion of this step, a more defined themes and subthemes were identified, which represent the next step in data analysis. In this step, the analysis was focuses on identifying themes that would tell the overall descriptions of the data extracts and addresses the research question for carer participants of this study. Diagram 10 provide sample of displayed table that was used to identify the themes and subthemes.

Data Extract	**Preliminary themes**	**Defined Themes**	**Sub-themes**

Diagram 10: Sample two-by-two displayed table

Data Saturation

The analysis of data took account of data saturation; i.e. where no new data emerging from the interviews were found. During the data reanalysis process, similar pattern of responses was identified after completing interviews with 10 carer participants. Further analysis of data for the remaining 8 carers confirmed that now new information emerged. Thus, numbers of sample was considered appropriate in providing reasonable insights and understanding about the phenomenon being explored. This experience and technique was previously applied with the data for stroke participants in this study.

The processes of data analysis were undertaken by researcher and in collaboration with supervisors. Where possible, each interview was transcribed verbatim immediately after data collection and given a pseudonym. Data were not routinely translated into English as the analysis was undertaken in the source language (Malay). Twinn (1997) suggested that translation may affect the reliability and validity of qualitative data due to absent of equivalent word in the target language and the influence of grammatical style on translated data. Wong and Poon (2010) stated that omission of words or phrase in translated texts or differences in translation could have significance influence in data interpretation, meaning construction and representation of participants' experiences. Therefore to ensure credibility of data, the process of translation were undertaken at later stage of defining the themes. Issues relates to analysing translated data will be discussed in section 3.9.13.

3.9.11 Integrated data analysis strategy

Related findings from the interview data will be integrated with the questionnaire data. Detail descriptions regarding how the data sets in phase one study were mixed and how divergent or convergent data were managed will be explained in Chapter 7.

3.9.12 Considerations regarding the quality of the qualitative data

To ensure the rigour of the qualitative data, Guba and Lincoln (1989)'s criteria for trustworthiness (credibility, transferability, dependability and confirmability) were applied. Various practical measures that reflected the application of this framework were considered.

Guba and Lincoln (1989) described credibility as whether the researcher's reconstruction of the phenomena are credible from the perspective of participants who have experienced the reality. It is linked to researchers' confidence that they have accurately recorded the phenomena under study (Shenton, 2004). Some measures undertaken to promote credibility include the triangulation of the data sources and from where the sample were drawn. Thus, views and experiences of participants were verified against each other's so richer picture of the phenomena can be constructed based on multiple perspectives. Likewise, credibility can be enhanced by triangulating a sample from heterogeneous backgrounds in order to provide a diversity of views. Other strategies to ensure credibility were frequent debriefing sessions with the supervisory team, peer scrutiny, considering issues related to coercion; participants were accessed through an intermediary, and thus genuinely willing to offer data freely; retaining the source of the language during the data analysis; and acknowledging the researcher's reflexivity.

In promoting transferability, Guba and Lincoln (1989) suggested providing 'thick descriptions' of the phenomena under study. Here, detailed accounts of the participants' cultural and social backgrounds, study setting and the overall context of the study were presented. Thus, other researchers can draw comparisons and conclusions regarding the transferability to other study contexts.

Dependability is concerned with whether the findings are consistent and can be applied at other times (Bryman, 2012). To establish this criterion, Guba and Lincoln (1989) proposed a dependability audit. This entails involving external audits to examine the process of data collection and methodologies. Hence, this study will be subjected to scrutiny by internal and external examiners on completion of the final thesis.

Confirmability is described as the extent to which the results are grounded in data and not influenced by researcher motivation, interest or bias (Patton, 2002). One strategy to ensure this criterion is a confirmability audit (Guba & Lincoln, 1989). This relates to the examination of the resulting phenomena by an auditor who is not directly involved in the study. Other methods include triangulation of analysts (collaboration with supervisors), admission to the researcher's beliefs and assumptions, in-depth descriptions of the methodology and providing an audit trail (Shenton, 2004).

3.9.13 Issues with translation

Several measures were undertaken to address issues with translation. Prior to the data collection, the English and Malay versions of all study materials and research instruments were reviewed and compared by local Ethic Committees. Any discrepancies and ambiguities were corrected before ethical approval was granted.

Much of the qualitative data were gathered in Malay. As the findings from the source language were presented in English, therefore the researcher's background, the roles of the translator, and the process of translation influenced the data analysis process. These issues will be subsequently discussed.

There were no standard guidelines identified for translation in mixed-methods research. Thus, the epistemological and methodological position of the current research informed the translation-related decision. However, Tsai et al. (2004) cautioned about the risk of 'insider' bias if a researcher/translator assumes the data translation role. Hence, being self-reflexive; avoiding obvious, conscious or systematic bias, and being as neutral as possible throughout the data analysis process were considered.

In many qualitative studies, data collected in the source language and published in other languages often lacks an explanation about the translation process. Squires (2008) emphasised the need to address these issues to ensure the trustworthiness of a research project. Therefore, decisions related to the data translation will be made explicit. This process is vital, as it determines the meaning equivalence of the data translated and the interpretation of the findings (Birbili, 2000).

Tsai et al. (2004) imply that a researcher's background in cross language studies influences the decision about who carries out the translation. Thus, Chen and Boore (2009) suggested that a translator who is fluent in both the source and target language, as well as knowledgeable about the culture of the participants being studied. Such a translator can be crucial so that the equivalence of cultural meanings is not lost (Suh et al., 2009). As the researcher shared the linguistic and socio-cultural background of the participants, a dual translator/researcher role was assumed.

In addressing the issue of timing, Suh et al. (2009) described three primary strategies; (1) before the data analysis, translation occurs immediately after the transcription of the interviews; (2) during the data analysis, translation occurs at a later stage of data categorisation, and; (3) after the data analysis, which refers to translation following the completion of the study. Although several qualitative researchers have proposed the translation of whole transcripts after interviews (Chen & Boore, 2009; Tsai et al., 2004), Temple and Young (2004) argue that translating the language of participants' lived experience prior to the analysis may risk losing the meaning equivalence and affect the interpretation of the phenomena. Mustapa (2013), who compared Brunei Malay news reports, identified considerable omissions of text and changes of theme after these were translated into English. Given this and the study objectives, the translation process was undertaken during the data analysis. This strategy was employed by Mohd Anuar et al. (2012), who interviewed stroke patients in Malay and translated the themes into English at a later stage of the analysis. To retain the context of the interviews, data translation aims to produce more conceptual equivalence (meaning-based) than literal translations (word-by-word). Table 3 illustrates an example when quote literally translated and compared with a meaning-based translation.

Original quote;
"…kerana kepentingan tentang strok dalam kominiti tidak berapa di titik beratkan. Dengan adanya latihan dan pembelajaran di dalam bidang ini,

Insya Allah sedikit sebanyak amat membantu dan menguntungkan kerana kemahiran ini tidak semua berpeluang untuk mengikutinya".
Literal translation; "...because of the importance of stroke in the community can not quite at the point of focus. With the proper training and education in this field, *Insya Allah* some very helpful and beneficial because these skills do not all have the opportunity to follow it ".
Meaning-based translation; "…because the importance of a community stroke care is less emphasized. This training, *Insya Allah* [God in Muslim], will give nurses opportunities to improve their skills [in stroke]

Table 3: Example of literal and meaning-based translation

Other issues considered were the process of the data analysis, the validity of the conceptual equivalence of the data and the research paradigm. To address the issue of the analysis process, the reliability of generating codes was tested. Selected transcripts were translated in full and coded by the researcher and other Bruneians who were fluent in both languages. The codes were then compared and any discrepancies were discussed in order to agree upon the main codes. This procedure was shared with the researcher's supervisors to ensure consistency with the Thematic Analysis. Additionally, a few transcripts were translated in full in order to agree on a coding strategy with the supervisory team before the analysis of the Malay transcripts began.

Regarding the issue of validation, the translated themes were evaluated using a back translation strategy (Brislin, 1970) by a colleague who is experienced in qualitative research.

3.9.14 Section Summary

In summary, the qualitative methodology from one strand of the convergent extended mixed methods design was presented. The process of ethical approval, sample recruitment, data collection, procedure for data analysis, strategy to merge data and possible issues with translation were described. Next succeeding section outlines the quantitative strand of the phase one study.

3.10. Research design phase 1 – QUANTITATIVE STRAND

This section describe specific research question and research process of the quantitative strand.

3.10.1 Research question

- How do nurses in the community describe their roles and educational needs in relation to home-based stroke rehabilitation?

3.10.2 Research method

A questionnaire was used as the method of inquiry as it helped to gather data from a larger sample, was relatively cheap, reduced the required data collection time and was convenient for the participants (Kumar, 2011). As the total number of eligible nurses identified at the health centres was over hundred, a questionnaire was employed to collect data about the wider perspectives of these nurses. A similar approach was found in the reviewed literature, and thus considered appropriate.

The Brunei Nurse Education Inquiry of Stroke (Bru-NEIS) questionnaire was designed by the researcher. It was written in English, along with a Malay translation, to facilitate participant understanding, and aimed to attract a higher number of respondents. Issues with regard to analysing translated data were previously discussed in section 3.9.13. The ICF framework outlined the structure of the questionnaire. The main questions were adapted from one element of the SSEF framework: high quality specialist rehabilitation (Department of Health, 2009), and related literature reviewed. The questionnaire comprised 3 sections; (1) demographic details; (2) previous stroke education and experience in caring for stroke patients; (3) participants’ views on training and educational needs of nurses with regard to stroke patients. A summative scale was developed to measure three main constructs; knowledge and understanding, skills and abilities derived from the SSEF, and barriers to attending training. The participants rated the predetermined statements within each construct using a five-point likert-type scale; ranging from 5 (strongly agree) to 1 (strongly disagree). Additionally, three open-ended questions: the roles of nurses in stroke rehabilitation, the services of the allied health professionals and the possible introduction of community stroke rehabilitation nursing, were incorporated to add deeper understanding about the topic investigated. Participants were allowed to answer either in Malay, English or both. The Bru-NEIS in English version was available in appendix 5. The usability and validity of the questionnaire will be discussed in section 3.10.4.

Although the usability of Bru-NEIS was considered, potential issues in relation to the methodological and ethical fitness for purpose of this tool may influence findings of the study. The appropriateness of the questionnaire, in particular items derived from the SSEF rehabilitation elements, is therefore examined. The psychometric properties of Bru-NEIS never tested or retested, thus feasibility of this tool was not established. All 16 elements of the SSEF framework were set of key competencies encompassing ‘knowledge and understanding’ and ‘skills and abilities’ that was principally required by all staff who works along the area of stroke care pathways (Department of Health, 2009). This framework allows the individuals to do self-assessment on their educational needs in stroke and match against the SSEF elements in order to identify areas of professional development. This description highlights that the SSEF was primarily intended for members of established stroke care team who able to judge their capability and confidence to provide care.

Whereas, the nurse participants in our study were not presently have any defined roles in care provision of stroke and nor directly involve in stroke care. This indicates that our nurse participants’ understanding and ability to support stroke rehabilitation were limited. Moreover, the nurses may unable to judge their educational requirement for stroke due to lack of experience in this area. For these reasons, incorporating the SSEF elements in the questionnaire items was arguably ill-fitted with its intended purposes. However, it should be noted that one of our research objectives was to explore, rather than assess, the educational needs among the nurses in stroke rehabilitation. Therefore, the rehabilitation element from the SSEF that form Bru-NEIS questionnaire was deliberately designed in order to explore the nurses’ views about what knowledge and skills are required for the proposed stroke rehabilitation nurse training. The frequently identified key competencies of the rehabilitation element would then provide the basis to develop internationally recognized and quality-assured educational programme in stroke. The adaptation of the SSEF items in the questionnaire, thus, meet the standard of training comparable internationally.

Another critic of the questionnaire was that the nurse participants may not familiar with the rehabilitation elements of the SSEF, thus their interpretation of what competencies needed may varies among the nurse participants. Nonetheless, the future outcomes of the questionnaire would help to understand about rehabilitation knowledge and skills needed, hence, using SSEF items within the Bru-NEIS was considered justified.

3.10.3 Pilot study

The questionnaire was piloted with five nurses from a health centre outside the main study district. Data from the pilot study were not included in the main analysis. The initial proposal to present the study as a large group did not prove feasible. Most nurses were fully occupied with their workload and there was a shortage of staff available. Following advice from the nursing officer, the recruitment strategy was revised. The new strategy involved a small group presentation to one to two nurses, invited to the nursing officer’s room. These nurses were encouraged to ask questions and seek clarification. Once they agreed to participate, the study materials were handed out. This recruitment process continued consecutively until all of the nurses had been invited. Pilot participants were given a week to review the questionnaire.

At follow-up, two nurses were away and left the questionnaires with the nurse officer. Hence, comments and feedback from the remaining nurses were sought. A cognitive interviewing technique (Willis, 2005) was employed. In the researcher’s presence, the participants reviewed the questionnaire and provided comments as they answered. Feedback regarding the content, clarity, their understanding of the questions and instructions, and the time taken to complete the questionnaire were noted. One nurse commented that he had difficulty understanding English. Therefore, a Malay translation was added to the main questionnaire to address this issue. This pilot study highlighted five important points; (1) problems with English language; (2) the collection of the questionnaire after a week; (3) the need to reconsider the strategy of sample recruitment; (4) the participants indicated that about 15 minutes was needed to complete the questionnaire, and (5) a possible lack of respondents for the main study.

3.10.4 Strategies for ensuring validity and reliability

The validity and reliability of the questionnaire were considered to ensure that measurement errors were kept to a minimum. Validity is described as whether an instrument truly measures what was set out to measure. Reliability is concerned with whether the instruments can be interpreted consistently across different situations (Field, 2013).

Three major kinds of validity were considered; construct validity, internal validity and external validity. Construct validity is related to whether the questions devised to explore a concept successfully measure and represent the phenomena under study (Balnaves & Caputi, 2001). The main body of the questionnaire was adapted from one element of the SSEF. This framework was developed by a steering group and four task groups of the UK Stroke Forum for Stroke Training (UKFST). These committees advocated the ‘knowledge and understanding’ and ‘skills and abilities’ that a member of staff should possess in the area of stroke care pathways (Stroke-Specific Education Framework, 2015). For this reason, the validity of the constructs was considered acceptable.

Internal validity is described as the extent to which a definite conclusion about the casual relationships between the study variables can be drawn. It is related to the researcher's confidence to make casual inferences from the study undertaken (Balnaves & Caputi, 2001). This type of validity is often employed in experimental study designs and usually measured by a statistical test of significance, such as a *t*-test (Field, 2013). Thus, Pearson chi square will be used to test for significance during data analysis.

External validity is concerned with whether the findings of the study can be generalised to other populations (Bryman, 2012). This study was explorative in nature; thus generalisability is not intended.

Other validity indicators, such as face validity, were also determined. Following the pilot study, the questionnaire was reviewed by four experienced nurses, who were not included in the main study, from the stroke centre, home-based nursing, and the Neuro-medical clinic. This strategy was used to establish whether the questionnaire reflected the concept concerned. Following this, comments pertaining to the ambiguity of certain items led to revisions, but no major amendment was required.

In assessing reliability, this indicator can be achieved through testing the instrument twice with the same group at different intervals. However this approach, known as test-retest reliability, is not applicable to this study. Hence, the statistical method; the cronbach's alpha was used to measure the internal consistency reliability. A computed alpha (α) coefficient test showed both constructs; knowledge and skills abilities, to have $\alpha = .80$, which indicated high internal consistency reliability. Field (2013) argued that a higher value of alpha is possible, but this could be influenced by the number of items on the scale, and may not necessarily mean that the scale is reliable. Correspondingly, the number of items on each scale ranged from 17 to 19 items. Thus, the result of (α) was interpreted with caution. The result of the internal consistency and reliability for the BruNEIS is reported in Chapter 6 questionnaire findings.

3.10.5 Study setting

This study was undertaken in Brunei, consisting nine health centres located at the Brunei Muara districts. Relevant information regarding the study setting were described and provided in Chapter One. However at completion of this study, three health centres have ceased their operations and been consolidated in to one new larger health centre. While, others remain function independently.

3.10.6 Sample participants

The approach to the sampling was based on the convenience technique. This refers to sampling participants for reasons of convenience, accessibility, ease of recruitment, near at hand and likely to respond (Bowling, 2009).

The sample consists of registered nurses who currently work in community health centres within the outpatient departments. These nurses have had appropriate qualifications in nursing education, such as a Certificate in Nursing, Diploma, Post-basic Diploma, Degree or Master level, and are registered with the Nursing Board for Brunei. They held a post either as Nursing Officer, Senior Staff Nurse, Staff Nurse, Senior Staff Nurse or Assistant Nurse. They were selected because their views on perceived stroke rehabilitation and educational needs are crucial for understanding how community nurses can contribute towards improving service provision. Therefore, the findings of the research will be more relevant and tailored to their needs.

The inclusion criteria include all registered nurses working within outpatient departments from nine health centres in Brunei Muara district. The exclusion criteria were midwives and community health nurses from Maternal Child Health care services, as they did not provide care for stroke patients.

Sample Size

Adequate sample size is considered to provide meaningful analysis. In previous related studies (Murray et al., 2004; Smith et al., 2008a) recruited 50 and 115 nurses respectively. Sample calculation was undertaken following two approaches; first determining the minimum sample requirement, and secondly calculating sample power for inferential statistic tests. Sample population of 118 eligible nurses were identified from the community nursing services staff census 2011 (Community Nursing Services, 2012). Table 4 illustrates predetermined sample size formula as recommended by the National Education Association (Krejcie & Morgan, 1970). This sample calculation provides minimum sample requirement for describing the data (descriptive analysis). Using their published chart, 86 nurses were required to provide meaningful data for analysis. But, to offset any possible non-respondents or incomplete questionnaires, a sample of 96 was targeted.

$$s = X^2 NP\,(1 - P) \div d^2\,(N - 1) + X^2 P\,(1 - \mathrm{P})$$

s = required sample size

X^2 = the table value of chi-square for 1 degree of freedom at the desired confidence level (3.841)

N = the population size

P = the population proportion (assumed to be .50 since this would be provide the maximum sample size

d = the degree of accuracy expressed as proportion (.05)

Table 4: Determining sample size

Sample Power Calculation

For calculating sample power for inferential statistic (chi-square or Fisher's exact test), the PS software (Power and Sample Size Calculations) by Vanderbilt University was used to determine the sample power of the study retrospectively (Dupont & Plummer, 1998). The following parameters were applied; P_1= 0.50%, P_2=0.115% (Murray et al., 2004; Smith et al., 2008a), Alpha=0.05 and sample acquired = 101, Power = 1.000. Using similar software, the size of sub-sample to reasonably likely detect an effect of a given size was calculated using the following parameters; P_1= 0.50%, P_2=0.115% (Murray et al., 2004; Smith et al., 2008a), Alpha=0.05 and Power = 0.80, Case sample size = 21.

The calculation of sample power in this study showed above 80%, which indicates the probability to detect the effect of the statistical significance was higher. Whereas, a minimum of 21 sample size was required to make comparisons between different statistical testing procedures.

3.10.7 Ethics

The overall ethical approvals of this study was previously described at section 3.9.6. Specific ethical issues related to participants right to self-determination, right to full disclosure, right not to be harmed and right of privacy, anonymity and confidentiality (Parahoo, 2006), that relevant to nurse participants were discussed.

The process of seeking consent was carried out simultaneously during the recruitment and data collection processes (See subsection 3.10.9). In considering the potential harm, although unlikely, answering the study questionnaire may evoke feelings of uneasiness. Hence, the nurses were reminded to have a break if they felt uncomfortable and to resume answering the questionnaire in their own time. If this strategy proved unsuccessful, the nurses were encouraged to raise concerns with their respective nursing officer or to contact the researcher. The nurses were informed that they were under no obligation to complete the questionnaire. They were free to withdraw from the study, with no negative impact on their professional role. Throughout the data collection process, no such cases were reported.

This study complied with the UK's Data Protection Act 1998 and the University Of Southampton Data Protection Policy 2008. All information was kept strictly confidential. No personal information or place of work were requested on the questionnaire. All participants returned their completed questionnaire to the nurse officer in a sealed envelope. On the scheduled date, the completed questionnaires were collected by the researcher. All of the questionnaires were coded in SPSS during the analysis to maintain anonymity. Data were only shared with the supervisory teams for academic purposes.

Regarding data security, the collected data were kept in sealed envelopes and stored in a cupboard in the researcher's home. All electronic data were stored on a password-protected computer that was accessible only by researcher. Data were owned by the University of Southampton and will be retained for 10 years, in keeping with the university's research governance and insurance requirements. After this period, all data will be disposed off securely.

3.10.8 Approval from the 'gatekeepers'

Approval from the 'gatekeepers' was required in order to access the targeted sample. A 'gatekeeper' is a leader of an organisation who has direct authority over the targeted sample population. Approval from one of the directors from the Ministry of Health was obtained on June 24, 2014. Another approval from one of the principal nursing officers from the Department of Nursing Services, was given on June 19, 2014. Approval documentations from respective 'gatekeepers' are available at appendix 3.

3.10.9 Recruitment and providing informed consent

Participants were recruited from nine health centres. Following approval by 'gatekeepers', the researcher liaised with one of the nursing officers from the Department of Community Nursing Services. Then, she contacted all of the nurse in charge of the community health centres to introduce the researcher and inform them about the study. Subsequently, the researcher contacted each nurse in charge to arrange a presentation of the study. The process of recruitment involved inviting two or three nurses to the nurse officer's room. The researcher explained the purpose and nature of the study, and encouraged the nurses to ask questions. They were assured that participation was entirely voluntary. The nurses were informed that they could withdraw or refuse to take part, with no implication for their present role. This approach continued sequentially until all eligible nurses had had an opportunity to attend. This process of recruitment was identical for all health centres. Out of the 118 nurses identified, 112 questionnaires were distributed. A total of 106 were returned, but only 101 proved usable for data analysis. The reasons for the questionnaire not being distributed or returned were that the nurses were on holiday or presumably not interested. The flowchart of participants' recruitment is outlined at page 82.

3.10.10 Data collection and seeking consent

If a nurse was interested in participating, the study package (invitation letter, information sheet and questionnaire) was handed out. All nurses were advised to contact the researcher if they required further information. The completed questionnaires were returned in the sealed envelope provided to their nurse in-charge after two weeks. Consent to participate was indicated if the nurses returned the questionnaire. The study package is available in appendix 5.

3.10.11 Data analysis

A parallel mixed methods data analysis (Teddlie & Tashakkori, 2009) was employed. This refer to separate approaches of analysis based on types of data. Thus, a thematic analysis (Braun & Clarke, 2006) for open-ended answers from the questionnaire, and the IBM Statistical Package Social Science Software (SPSS) package for numeric data, were employed.

All returned questionnaires were checked for the omission of questions or errors. Questionnaires that were deemed usable were coded (e.g. NP 001), and data were entered into SPSS software. Before the analysis, data were screened for errors or any outliers (values that fall well below or above the other scores). The screening process involved comparing the entered data with the questionnaire manually. Then, using SPSS, the frequencies of each categorical variable were inspected. For instance, gender was coded as 1=male and 2=female. Frequency scores that showed values that fell outside this range were indicated as errors or missing data. Following this, the frequencies of all of the continuous variables, such as those individual items (predetermined statements) that made up the scores of the three main constructs, were checked. For example, the Minimum and Maximum values for individual item scores were coded, from 1=strongly disagree to 5=strongly agree. Any values identified beyond these scores were indicated as errors.

Descriptive and inferential statistical tests using the SPSS package was undertaken. A descriptive statistical analysis was employed to summarise the total scores of each individual item for the three main constructs. Summative findings of these data were illustrated as mean, percentages (%), number of nurses (*n*) and graphs. In addition, descriptive analysis was also used to describe the socio-demographic characteristics of the sample, to check the participants’ variables for any violations of the underlying assumptions of the statistical tests, and to identify the frequency distributions, the mean, standard deviation, range of scores, skewness and kurtosis of the participants’ variables.

With regard to inferential statistical tests, the Pearson chi-square test at the 5% significance level was used to compare preparedness and education necessity with demographic variables. Where those with expected count more than 20%, categories were combined where indicated. If expected count was not met after cell combination, Fisher's exact test, as indicated, will be used. The findings of the questionnaire data will be presented in Chapter 6.

The qualitative data derived from the open-ended questions, meanwhile, were analysed following the process of thematic analysis. However, due to the type of data presented (i.e. most participants offered explanations in the form of short statements), the analysis was typically limited to the surface meaning of the data. Ryan and Bernard (2003) implied that identifying the themes in short responses was inappropriate because of the difficulty of analysing whether missing statements represent a new theme or as a result of data elicitation techniques. Hence, the answers were coded and condensed, then grouped into named categories. Although other text analysis such as content analysis can be useful, this method was inappropriate for answering the research objective. This technique frequently emphasises the prevalence of the categories identified. Thus, the context of the data were placed on what is measurable rather than what is theoretically important (Bryman, 2012). Moreover, Driscoll et al. (2007) argued that quantifying qualitative data may reduce its depth and flexibility to one-dimensional dichotomous variables. Therefore, a thematic analysis approach is considered appropriate.

3.10.12 Integrated data analysis strategy

The process of merging related questionnaire data with those interview data from stroke patient and carer participants will be described in Chapter 7.

3.10.13 Section Summary

In summary, the quantitative methodology from one strand of the convergent extended mixed methods design was presented. The process of ethical approval, sample recruitment, data collection and procedure for data analysis and integration of data were explained. Next following section describes the research design and methods of the second phase study.

3.11 Research Design Phase 2

This section describes the methodology and methods applied during the second phase of the study. The direction of this phase originated from the convergent extended mixed method design and focuses on examining the key findings identified during the phase one study. This sections will outlines overall features of the phase 2 study, comprising the aims and objectives, the data collection method, the study setting and the sample participants. Further, the participants' recruitment strategy, ethical considerations and the strategy for seeking consent from the participants will be presented. Finally, the procedure for data analysis is described, and concludes with a summary of the phase 2 research design.

3.11.1 Aims and objectives of the second phase of the study

The second phase of the study had two main aims:

1. to seek expert comments regarding the six key findings identified during the first phase of the study from healthcare professionals, and
2. to establish the priority for addressing the issues related to home-based stroke rehabilitation service provision

The objectives are to:

1. identify what rehabilitation support resources were presently available for the stroke patients and their carers following discharge from hospital,
2. explore potential strategies for improving the provision of home-based stroke rehabilitation, and
3. explore any potential role of nurses in community stroke rehabilitation

3.11.2 Research question

What are the views of expert healthcare professionals with regard to the six key findings identified during the first phase of the study?

3.11.3 Research method

The research methodology adapted in the second phase of the study was informed by the research question. Thus, a qualitative design using one-to-one interviews with expert healthcare professionals was employed. These interviews sought to generate a pool of opinions, explanations, interpretations, agreements and disagreements regarding each of the key findings discussed. Therefore, the participants were free to provide critical comments and arguments related to the findings presented. A semi-structured interview guide was developed by the researcher. However, the interview guide was not piloted due to the limited time available to complete the second phase of the study and the difficulty in identifying appropriate expert professionals. The interview questions were guided by the aims and objectives of the second phase of the study. The participants were first asked to share their background expertise and involvement in service planning in order to initiate conversation and establish researcher-participant rapport. However, their responses from these questions will not be included as part of the analysis of the research findings. This is because the discussion was not directly concerned with findings from phase one study and not relevant to the issue explored. Therefore, data from phase two will be used for the purpose of exploring possible solutions to the need identified in phase one study. Following this, the participants' comments on each of the key findings identified from the first phase study were discussed. Then, questions with regard to identifying priority areas needed for improvement and their proposed strategy for addressing these problems were explored. The interview guide is available at Appendix 6.

Other methods of inquiry, such as focus group discussion (FGD), can provide a valuable alternative to individual interviews. Goodman and Evans (2010) assert that FGD can be a useful data collection method for clarifying, exploring or confirming ideas with a range of participants on a predetermined set of issues. It can also offer the advantage of making use of group dynamics to stimulate discussion, gain insights and generate ideas in order to pursue a topic in greater depth (Bowling, 2009). However, despite the merit of using FGD during the second phase of the study, it was found that most of the participants already have tight work schedules and so it was difficult to arrange a convenient time for the group to convene. Therefore, one-to-one interviews were considered an appropriate substitute as the method of inquiry.

3.11.4 Study setting

The study was undertaken in Brunei, where all of the participants were employed within various organisations within the Brunei Muara district. The participants were identified from five different areas; namely the government hospital, the rehabilitation centre, the stroke centre, the higher education institution and the Department of Nursing of the Ministry of Health. Relevant information regarding the study setting was described and provided in Chapter One.

3.11.5 Sample participants

The sampling approach was the expert sampling technique. This strategy refers to purposely sampling individuals who are known to have expertise in the area related to the study (Kumar, 2011). The focus of this sampling was on the participants' professional experience, who represented a diverse group of disciplinary areas. The participants comprise rehabilitation therapists (*n*=2), a stroke consultant (*n*=1), a specialist neuro-rehabilitation physician (*n*=1), a nursing officer (*n*=1) and a nurse educator (*n*=1). These participants had a great deal of expertise in management (83%), service evaluation (100%) and decision-making had an appropriate education background in relation to the study topic. The sample size was limited to six due to the lack of eligible participants, and a few (*n*=3) declined to take part.

The used of expert healthcare professionals to provide critical feedback during this second phase of the study is considered an integral part of the research. The involvement of these participants will provide greater understanding about the experiences of the stroke patients and their carers regarding their rehabilitation support needs at home, as well as the potential role of nurses in stroke rehabilitation. Therefore, findings of this study will be more relevant and may give a larger impact on the future service improvement.

3.11.6 Ethics

Ethical approval for the second phase of this study was sought at the same time as that for the first phase of the study. The overall ethical approval is described in section 3.10.6. The ethical issues specifically related to the expert healthcare professional participants will be discussed.

The process of seeking consent was carried out during the sample recruitment and prior to the interviews (See section 3.11.7). This study does not involve invasive procedures, and so no potential harm to the participants was anticipated.

With regard to maintaining confidentiality and anonymity, the researcher took similar actions as with the stroke patient participants (See section 3.9.6). Information regarding the participants' personal details, reply slips and consent forms, copies of the transcripts and recordings were stored in a locked cabinet at the researcher's home. The transcripts were coded for anonymity and pseudonyms were used prior to the analysis. Although pseudonyms will be used when reporting the findings, the participants' quotes or references to their professional background may still be identifiable. For example in Brunei, there is only one specialist neuro-rehabilitation physician in the public hospital and very few local stroke neurologists. Therefore, the risk for this individuals being identifiable in interview quotes used in future study report was explained and permission was sought.

3.11.7 Recruitment and providing informed consent

The process of recruitment began upon completing the data analysis of the first phase of the study. Eligible expert healthcare professionals were identified from their organisational web address or after being introduced by the research participants. All correspondence with these individuals was undertaken through e-mails, as the researcher was in the UK. The first contact involved inviting the expert healthcare professionals and explaining the nature of the study. All of the study materials: the invitation letter, participant information sheet and reply slip (available in Appendix 6), were provided electronically. The participants were given a week to inform the research of their decision regarding participating in the study, and a further e-mail was sent after a fortnight, as a reminder.

Of the six eligible expert healthcare professionals contacted, five replied to the invitations. However, only three agreed to participate. One of these participants then recommended another expert healthcare professional. The two individuals who replied but declined to take part meanwhile mentioned the study to one of their eligible colleagues. This two new additional sample was later contacted and eventually was happy to take part. Overall, six expert healthcare professionals were recruited and agreed to participate in the study. Subsequent e-mail contact with these participants was made to arrange a mutually agreeable date and time for the interviews.

3.11.8 Interview procedure and seeking consent

The interviews with each participant were scheduled at numerous locations and on different dates. Overall, five interviews were conducted at the participants’ work office and one participant was interviewed in the UBD staff room. All of the interviews took place in Brunei.

The approach for obtaining consent before the interviews was similar to that for the participants with stroke and the carer participants (See section 3.9.9). In brief, each of the participants was given an opportunity to reread the information sheet and ask questions. They were assured that their involvement was fully voluntary and that they might withdraw at any time without affecting their professional role. Once the participants were willing to proceed, written consent to participate and audio-record the interview was sought. The interviews began by obtaining the participants’ demographic information, followed by giving a summary of the first phase of the study and then discussing the key findings from it. Most of the interviews were conducted in English, apart from that with one participant, who used Malay and English interchangeably during the interview.

During the discussion, the comments of the participants were explored in order to understand their insights and reactions to the key findings presented. The common key prompt questions, such as what, why and how in relation to the participants' responses, were often used to initiate in-depth discussion. Generally, most of the interviews went well and progressed in a warm, friendly manner. However, one participant appeared over critical of the way in which the participants in the first phase of the study responded to the questionnaire or interview questions. As an example, this expert healthcare professional argued that no nurses would refuse if offered training because nurses would be happy to get off the duty roster. This seemed to indicate issues related to a lack of mutual trust between nurses and other healthcare professionals. The working culture in Brunei, where other healthcare professionals are often seen as superior to nurses, may have influenced this participant's answer. This respond would be consider in discussion of the finding. On average, the interviews lasted from one to two hours.

Throughout the interviews, field notes and a reflective diary were kept. The preparation and approach regarding this were similar to that undertaken during the first phase of the study.

3.11.9 The data analysis

The approach to the data analysis follows the thematic analysis process (Braun & Clarke, 2006). This process was similar to that employed when analysing the interview data for the stroke patient and carer participants. An overview and detail descriptions of the thematic analysis were provided in Section 3.9.10. In brief, the analysis involved identifying any repeated patterns during the data collection, follow by re-reading data and noting the initial ideas, assigning the data for the initial codes, combining the codes into potential themes, reviewing the themes for appropriateness with the coded extracts, defining and renaming the themes, and finally selecting extracts to produce the findings.

To assist the data management and analysis, NVivo^{TM} was used. The participants' comments on each of the key findings were initially collated and grouped together for analysis and summary. As the analysis progressed further, the relationship between the emergent categories was appraised in order to develop the initial thematic framework. These themes and their coded data were then reviewed in order to generate the main themes. The analysis of the data was informed by the aims and objectives of the second phase of the study. Thus, the resultant themes provided descriptive illustrations that further support the stroke patients and their carers' experiences as well as the views of the nurses on the rehabilitation support roles. Additionally, the data from the panel of expert uncovered issues with regard to the home-based stroke rehabilitation service delivery. A conceptual model derived from the interviews was developed. Findings of phase 2 will be discussed in Chapter 8.

In summary, this section presents the methods and methodology applied during the second phase of the study. The purposive sample comprised six expert healthcare professionals who represented various disciplines and institutions. The potential ethical issues related to reporting the findings and the actions taken were discussed. The data were collected through one-to-one interviews and thematic analysis was employed to analyse them.

3.12 Reflexivity

The importance of reflexivity in qualitative research is well documented. However, reflexivity was equally important in this mixed method research due to the predominant data collection methods employed was one-to-one interviews. Therefore, a detailed methodological discussion pertaining to reflexivity and how it was operationalized will be illustrated in this section. Reflexivity was described as a process whereby the researcher constantly reflects critically on his/her own beliefs, actions, values and perception that may impact upon the research process and interpretation of data (Gerrish & Lacey, 2010). It encourages the researcher to 'position' themselves away from influencing the conduct of the research (Creswell, 2013).

In describing reflexivity undertaken during this study, I have made every attempt to ensure that my beliefs and values remain explicit and taken into account. The process of reflexivity is an ongoing throughout conducting this study. Initially, in Chapter one, I have made clear the origins and my interest in this study and how it can influence the design of this research. I am conscious that my experience as registered nurse, my understanding about patients' suffering after stroke and my religious and cultural orientation may affect how I think or write throughout this research. Therefore, the process of being reflexive was undertaken during data collection, analysis, interpretation and writing this research. Few methodological examples of reflexivity will be discussed as follow:

In reflecting my approaches during data collection process, I am acutely aware about my dual roles, as a researcher and experience nurse, that I bring into this research. McKegany and Bloor (1991) suggested that age and social class are some of the variables that may have impact during data collection process. Thus in every interview session, I introduced myself as a research student from the University of Southampton and emphasised to the participants that I am not representing any health organisations or any disciplines. By positioning myself in this status, I tried to ensure the participants feeling comfortable in sharing their experience and allows them to reveal any dissatisfaction with the existing healthcare service provision. Evidently, several participants disclosed their unhappiness regarding the duration of therapy times provided for the stroke patients. Arguably, this could not be revealed if I had position myself as a healthcare professionals or someone who has personal relationship with the therapist.

Listening to the plight of the participants, particularly concerning with their financial burden and absence of support at home, I felt I could do nothing but felt sympathetic. But, I saw the importance of conveying this issue to those who can render action in response to the hardships of these participants. Although it was equally important to understand the sentiments of the participants, but I remain aware not to dwell on them and led my emotion being affected. As this could bring about biases, being reflexive in this situation has helped me to refocus to the objective of the interview. Having gone through this hands-on-experience, I realised that I was challenged to develop my skills as a researcher and to make sense of participants’ responses to the interview in order to draw essential ‘voice’ for supporting this research. Therefore, the interactions among the researcher, study setting and participants of this study were constantly appraised through the process of reflexivity.

Another challenging experience was when I confronted with one expert healthcare professionals who appeared depreciate the intention of nurses to seek for educational training. As a nurse myself, the participant critical comment challenged my professionalism, but aware that the behaviour was indicative of participant’s personal views that derived from previous experience or observation. The complexity of this experience consequently shaped my reflexivity that can affect or possibly transformed myself as professional, researcher and as person. In engaging with the process of reflexivity, a field dairy was kept throughout the period of data collection, enabling my feelings, thoughts, emotions and experience to be recorded. This diary was re-read and reflected upon prior subsequent interviews, in doing so allows me to identify any possible bias and undertake course of actions to minimise my interpretation on participants’ behaviours and responses.

The process of coding and data analysis demand tedious work. With about a total of sixty hours of interviews and over forty interview transcripts, the value of being concise and accurate in identifying themes during analysis was paramount. Most data analysis were undertaken using participants’ source language (Malay). Translation to English was only made once themes were finalised. On being reflexive, I always being mindful about detaching my personal and professional interpretation at every stage of data processing and translation. The concept of ‘bracketing’ was applied (Fischer, 2009). As I listened to the narrative and reading the transcripts of the participants, I remained conscious and attentive to code data that were given due importance by the participants. I stayed close to the data and allows the participants’ narrative to inform the development of the themes. Thus, the resulting themes identified represent the overall ‘story’ of the participants which illustrate their lived experience aftermath of the stroke. In the process of analysing the data, I wrote memos to assist my thinking and inform data analysis. This memos helped me to recall any significant issues pertaining to analysis process, and hence allows me become more sensitised with the data. I realised potential issues with regard to translation (Section 3.9.13). Thus, being reflexive allows me to translate the data without losing the original context of the source language. An example of memo can be found in Appendix 8.

3.13 Chapter summary

This chapter provides an overview of the study design and methods of this research, aims to explore different aspects of the home-based stroke service provision in order to identify area for improvement. A convergent extended mixed-method design, guided by pragmatism, was adopted as it is the best approach for gaining a complete understanding and knowledge of the issues surrounding service delivery, through the perspectives of the stroke patient participants, the caregivers, nurses at the community health centres and selected expert healthcare professionals. Participants were purposely selected from two rehabilitation centres, nine health centres in Brunei Muara District and education institution. Semi-structured interviews and questionnaires were developed to collect the data. The analysis of the interview data followed a thematic analysis approach, and a statistical analysis of the questionnaire data was undertaken using SPSS software. Process of data integration was presented. Potential ethical issues during the conduct of this study was considered. Other issue related to the translation of the interview data were presented. Strategies for ensuring the quality of this study were identified and justified. Description of reflexivity undertaken during this study was provided.

Next, Chapter four discusses the interview findings from stroke carer participants.

Chapter 4: Interview findings for the Stroke Patient Participants – Phase 1 study

4.1 Introduction

This chapter presents the findings from the interviews with the stroke patient participants during the first phase of the study. Findings from data that were collected through the interviews with the carers, nurse questionnaire and discussion with the expert healthcare professionals will be provided in Chapter 5, 6 and 8 respectively. Firstly, an overview of the participants' socio-demographic characteristics is provided. Next, themes identified from the interview data will be discussed. This chapter conclude with a summary of the findings.

This chapter sought to address the following research question:

- What is the lived experience of stroke patients and their rehabilitation support needs during the first year after discharge from the hospitals?

A total of twenty one (*n*=21) stroke patient participants were recruited in this study. All interviews data were analysed and presented. Themes that emerged from data were discussed, with evidence to exemplify and illustrate the findings presented in the form of quotes. The Malay excerpts were written in italics and an English translation was provided in brackets.

4.2 Demographic profiles of stroke patient participants

Table 5 presents the demographic profiles of the participants. Twenty one stroke patient participants were recruited. The proportion of males was higher (*n*=14, 66.7%) than that of females (*n*=7, 33.3%). Their ages ranged from 34 to 85 years, with a mean age across all participants of 56.4 years [SD 13.9]. Six participants (28.6%) were aged below fifty, and another four (19%) were above 65 years. However, more than half of the participants were aged between 50 and 64 years (*n*=11, 52.4%). All stroke patient participants were Bruneian and over 95% were Malay Muslim. Only one participant was a Chinese Christian.

The distribution of gender and age group in this sample was typical representative of the population of stroke patients found in the literature. However, the characteristics of the participants' ethnicity and religion could be unique to this sample and so the findings may benefit from others cross-cultural stroke research globally.

Demographic profiles (N=21)

Dichotomous / Categorical		Participants with stroke		Total
Gender		Male *n*=14, 66.7%	Female *n*=7, 33.3%	*n=21*
Age in years	<=33	0	0	0
	34 – 49	3, (14.3%)	3, (14.3%)	6, (28.6%)
	50 – 64	8, (38.1%)	3, (14.3%)	11, (52.4%)
	65 - 85	3, (14.3%)	1, (4.8%)	4, (19.0%)
(Mean age)				*(56.4)*
[Standard Deviation]				*[13.9]*
Nationality	Brunei	14, (66.7%)	7, (33.3%)	21, (100%)
	Indonesia	0	0	0
	Philippines	0	0	0
Ethic group	Malay	14, (66.7%)	6, (28.6%)	20, (95.2%)
	Chinese	0	1, (4.8%)	1, (4.8%)
	Others	0	0	0
Religion	Islam	14, (66.7%)	6, (28.6%)	20, (95.2%)
	Christian	0	1, (4.8%)	1, (4.8%)
Living area	Onshore	14, (66.7%)	7, (33.3%)	21, (100%)
	Water Village	0	0	0

Table 5: Demographic profiles of the stroke patient participants

4.3 Social demographic information about the stroke patient participants

Table 6 presents the social demographic profiles of the participants. The majority of the stroke patient participants were married (*n*=18, 85.7%) and more than half (*n*=11, 52.4%) lived with 5 or more children in the same home. Most of the participants had completed their education at primary school and obtained a certificate (*n*=17, 81%), and two (9.5%) had a postgraduate degree. Nearly half (*n*=10, 47.6%) were employed by the government, and the other half were either retired (*n*=8, 38.1%) or unemployed (*n*=3, 9.5%). The mean duration since the stroke across the participants was 8.57 months [SD 3.38]. Over 60% of the participants (*n*=14) had suffered a stroke in the last 6 to 12 months, and one-third (*n*=7, 33.3%) within the last 6 months. Fourteen participants (66.7%) were supported by their spouse or family members, while another three (14.3%) were assisted by a paid-carer. All participants have not had any previous injuries that affected their physical functioning.

Social demographic information

Dichotomous / Categorical		Participants with stroke (*n*=21)	
		n	(%)
Marital Status	Single, never married	3	14.3
	Married	18	85.7
	Divorce	0	0
	Widow/widower	0	0
Number of children living together	1 – 2	3	14.3
	3 – 4	4	19.0
	5 and above	11	52.4
	Not applicable	3	14.3
Highest education attained	None	1	4.8
	Certificate	17	81.0
	Diploma	1	4.8
	Bachelor Degree	0	0
	Master	2	9.5
Employment status	Government sector	10	47.6
	Private sector	0	0
	Self-employed	1	4.8
	Retired	8	38.1
	Unemployed	2	9.5
Duration since stroke	1 to <3 months	3	14.3
(Mean duration 8.57)	3 to <6 months	4	19.0
[Standard Deviation 3.38]	6 to 12 months	14	66.7
Cared by paid carer	Yes	3	14.3
	No	14	66.7
	#Not identified	4	19.0

Participant with stroke were interviewed individually

Table 6: Social demographic information of stroke participants and carers

4.3.1 Participants Geographical living location

With regard to participants' geographical location, all participants recruited were living onshore. During the study, none of stroke patients who lives at the water village (*Kampung* Ayer) were eligible to take part. Explanation given by the researcher's intermediary person was that most of the patients who lives at this area often suffered a long-term chronic stroke, severely disabled or have problems with speech. Therefore, findings from the interview would not represent views of stroke patients and carers who lives at the water village, hence reduce the strength of the study. Nonetheless, overall demographic characteristics of the sample were heterogeneous. This can be valuable to the study as the participants were likely have a wide range of experience and views about rehabilitation needs that could be explored. Moreover, findings of this study may be transferable to other similar populations in difference districts of Brunei, or other study settings.

4.4 Findings from the interviews with the stroke patients participants

Diagram 11 provides overall mapping of the themes and subthemes identified. The analysis of the interview data was an iterative process that was carried out over a period of approximately over two years, including revising the themes for presentation in this amendment thesis. The primary focus of analysis was to identify the support needs of participants in rehabilitation following discharge, and thus possibly uncover issues surrounding home-based service provision. Not everything shared by the participants was directly related to their rehabilitation needs. For example, issues raised by four participants regarding disability allowances may require policy changes outside the Ministry of Health in order to be rectified. Arguably, this laid beyond the remit of the current study, but still represents important findings that require attention from the relevant departments in other ministries.

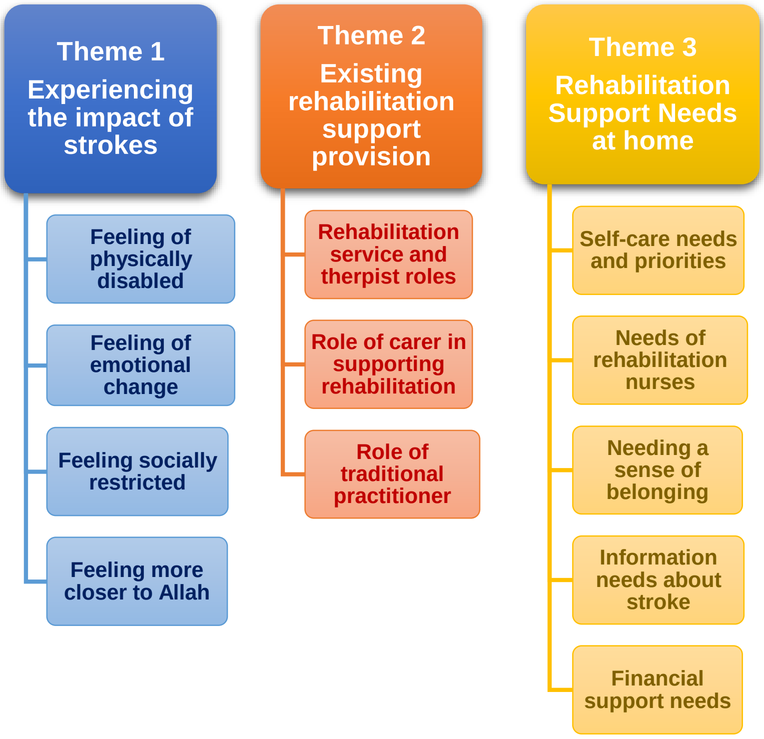


Diagram 11: Overview of themes and subthemes for stroke patient participants

An analysis of the stroke patient participants' experiences of rehabilitation needs revealed three over-arching themes; *Experiencing the Impact of Strokes*, *Existing Rehabilitation Support Provision* and *Rehabilitation Support Needs.* The themes that were identified are divided into further subthemes and presented as follows:

4.4.1: Theme 1 Experiencing the impact of strokes

The impact of strokes was described as a highly significant event for most of the participants. The majority reflected on their difficulties during the "early onset after the stroke" (typically during the first three months) following discharge from the hospitals. Four key subthemes were identified: (1) feeling of physically disabled, (2) feeling of emotional change, (3) feeling socially restricted, and (4) feeling more closer to Allah.

Feeling of physically disabled

This subtheme described the participants' experience of the physical restrictions due to the residual impact of stroke. The interviews identified that the participants' problems related to physical functioning were substantial. The stroke patients described how their physical weaknesses affected their lives and led to dependency on their carer in order to carry out their daily activities. The accounts of the stroke patient participants suggested that their physical impairment due to stroke was more noticeable and often recognised in the first instance. One stroke patient participant stated:

> *"Eh melamah kan semua sekali anggota..yang paling ketara kaki dan tangan.. yang lain nada cuma ani aja...kaki dan tangan..patut anu nya..patut melemah kan otot otot melemahkan seluruh anggota" (SP – 13)*
>
> TRANSLATED TO: ("I feel all my limbs are weak]. The most obvious is my feet and hand. There are no other body parts affected. Only my feet and hand. It [stroke] has affects the muscle and the limbs.") (SP – 13)

Another participant, meanwhile, described an inability to manage oneself after a stroke. It appeared that the impact of the stroke has disempowered the patient from being active and often left him/her feeling physically incapacitated.

> *"…macam inda dapat bejalan sendiri…macam kehilangan…apa tu…inda dapat bejalan atu..." (SP – 02).*
>
> TRANSLATED TO: ("…it's like I'm unable to walk on my own…I feel like I'm losing my ability to walk…") (SP – 02).

In contrast, five stroke patient participants mentioned that the presence of a carer can compensate for their physical impairment. The availability of a carer was regarded as a vital source of support and a way of enhancing encouragement. For example, one stroke patient participant said:

> *"inda jua eh! Pasal bini saya selalu menolong kan, inda tia, inda berapa, inda kerasaan" (SP – 01).*
>
> TRANSLATED TO: ("Not necessarily eh! [a Malay slang to express disagreement] because my wife always helps me, so I don't feel it [difficulty due to physical impairment].") (SP – 01).

In summarising the above subtheme, participants with stroke reported considerable physical dysfunctions following stroke. This finding appears to be common issue among other sectors of the general population with stroke. Hence, the experience of these participants was comparable across other settings outside Brunei.

Feeling of emotional change

This subtheme concerned the impact of a stroke on the participants' emotional wellbeing. It was observed that the participants exhibited various types of emotional disturbance as a result of their stroke. The sudden loss of physical functions significantly influenced the stroke patient participants' emotions and was more apparent during the "early onset after the stroke". These participants spoke of feeling sad, frustrated, agitated, resentful, and uncertain, as well as being quiet and seeking attention. The account of one participant showed that his feeling of emotional vulnerability was apparent. For instance, this stroke patient participant experienced difficulty related to accepting the sudden loss of his bodily functions, which left him feeling depressed and hopeless. He expressed his frustration as follows:

> *"Masa awal awal atu pemarah tu..macam nya kitani inda dapat menerima bah kenyataan atu...kan sebelum ani tani sehat kan..tau tau lumpuh. Macam fikiran tani atu kan macam jadi cacat tia kediaku ani seumur idup." (SP – 07)*
>
> TRANSLATED TO: ("at the beginning, I was so angry. I can't accept this reality [having stroke]. I was physically healthy before this, only then I suddenly disabled. I feel that I am gonna be like this for the rest of my life.") (SP – 07)

Moreover, the data also revealed that a few patients were highly emotionally sensitive to their surroundings and responded negatively with anger. They displayed difficulty in controlling their emotions and reacted unintentionally towards non-threatening stimuli. This was exemplified by an excerpt from one stroke patient participant who revealed:

> *"Kadang kadang marah jua..kalau anu di tv yang atu yang kelai kelai..tangan ani idup ni..kan ikut kan marah kan marah bah rasa nya..dulu inda macam atu sudah ku kena strok..kalau ku meliat main TV dvd kan belawan..kalau aku kalah marah ku."* (SP - 12)
>
> TRANSLATED TO: ("When I watched actors act aggressive scene, I immediately reacted angrily. I didn't realised my finger roll back [performing a fist] as if I am ready to join the fight. I didn't have this before the stroke. This happen whenever I watch DVD movie involving fighting. When I think I lost during the fight, I often feel irritated and angry.") (SP – 12)

For the majority of the male stroke patient participants, however, their emotional disturbances were frequently caused by their impaired role as a husband, father or head of the family. Several participants indicated feeling less masculine because their duties as a 'man' were taken over by their wife. The data revealed that this role transfers led the husband to feel frustrated and depressed, which he not disclosed to his spouse. For instance, one stroke patient participant disclosed:

> *"Ada jua rasa sedih jua lah selalu nya menjaga anak apa..mengantar anak sekolah apa..ani payah diri kana nu payah bah segala gala nya payah." (SP – 19)*
>
> TRANSLATED TO: ("I do feel very sad because I used to help my wife look-after the kids, sending them to school and so forth. But, now I feel frustrated. Everything were difficult…so difficult.") (SP – 19)

The data showed that long-standing negative feelings which remained undetected by healthcare professionals can cause significant concern. This stroke patient participant revealed how he felt so hopelessness that he contemplated ending his life. He confessed:

> *"Perasaan..kadang terasa putus asa..kadang kalau teruk..kadang mudah pemarah…terasa inda sanang..teringat mau mati saja..fikiran macam macam." (SP – 05)*
>
> TRANSLATED TO: ("I feel miserable and hopeless. I feel angry and didn't feel reassurance…feeling about wanting to die…thinking many things negatively about myself.") (SP – 05)

Therefore, being complimentary about any progress that the stroke patient achieves during therapy appears crucial in managing his/her emotional problems. The data suggested that stroke patients may perceive practical comments from their carer, or perhaps therapists, as offensive. As an example, one stroke patient participant revealed feeling dejected because her carer was unhappy with the progress of her therapy. She commented:

> *"Kalau di rumah okey pulang..kadang kadang ia tah tu nyangku..kadang kadang nya orang sekali sekala atu ada jua kadang kadang rasa marah walau pun durang menganu kitani dengan baik..kerana dengan setiap pekerjaan tani buat atu..sentiasa macam ada lah macam nya orang seorang seorang ah punya buat coz anu..macam apa yang ku buat atu macam salah lah apa kan..tapi perasaan ku okey..tapi kadang kadang my sister ucap inda okey..iatah kadang kadang rasa atu marah bah macam jauh hati (menaggis)" (SP – 16)*
>
> TRANSLATED TO: ("…sometime I feel so angry. I knew that the purpose of having a carer is to help people like us. But, sometime I feel mad and offended. I believed that I already did the exercises accordingly. However, my sister [carer] disagreed. This raise my anger and feeling dejected.") (SP – 16)

This participant, meanwhile, suggested that stroke patients should have a "strong heart" to heal themselves from the impact of strokes. Enthusiasm was considered a vital tool for enabling patients to continue with their life and achieve independence. He implied:

> *"Mula mula pakai wheel chair apa..sekali Alhamdulilah..mula mula dapat pakai tongkat..lapas atu berdiri..dengan support orang Alhamdulilah..anu lah di kuat kan hati..memang lah macam permulan saja permulan saja..udah biasa karang mudah tia."* (SP – 17)

TRANSLATED TO: ("At the beginning I am using a wheelchair, [now] *Allhamdulilah*...initially using walking stick...then I managed to stand with minimal support. *Allhamdulilah* .You needs to have a strong heart [courage and determination]. Of course it was difficult at the earlier stage, but once you used to it [being independent], then it will be easier.") (SP – 17)

In summarising the above subtheme, the stroke patient participants in this study display substantial emotional problems resulting from the stroke. Although this finding was similar to that of other international studies, the manner in which the participants frequently concealed their emotions was arguably worrying. The implication of this to practice will be discussed in Chapter 9.

Feeling socially restricted

This subtheme demonstrates issues concerning resuming previous activities and roles before the stroke. The stroke patient participants described how their stroke adversely affected their social activities and functions. The data suggested that many stroke patient participants would like to go out but were hindered from doing so by their physical impairment following their stroke. Moreover, the account of one stroke patient participant revealed that a lack of facilities and negative views among the public of people with a disability appeared to discourage individuals who have had a stroke from re-engaging in their social functions. A quote from a stroke patient participant exemplifies this:

"…even with family pun kadang nya they kan ke mana saja. I cant turut kan..macam with this condition at the the time aku makai tungkat…so it so difficult to ikut durang…Its not because they don't want to bring me….I felt limited macma kalau kan bejalan payah..and then kalau cari jamban payah…semua payah…so felt macam inda mau pegi ke mana-mana lah..And at time jua masa atu kan ke kedai pun malu bah malu org liat liat kan so that that part of the anu lah consequences" (SP – 18)

TRANSLATED TO: ("…even with my family if they wanted to go anywhere, I can't join them. Like with this condition at that time, I am still using the walking stick…so it was difficult to join them. It was not because they don't want to bring me…I felt limited and difficult to walk…and then if I wanted to use the [public] toilet...it will be very difficult [to find toilet for people with disability]. Everything were difficult. So [I] felt like didn't want to go anywhere. And at time, I felt embarrassed to go for shopping because everyone's eyes will be on me. So that part of negative consequences [of stroke on social activities].") (SP – 18)

Additionally, the data showed that carers may have direct influence on how the stroke patient re-engages with social activities. The data illustrated that the presence of a carer may either promote or hinder the stroke patients' needs regarding social functions. As an example, one stroke patient participant indicated his intention to leave his bedroom, but was warned by his carer not to do so. It was found that this participant often stayed at home alone due to the fact that his carer was out at work. He described his restriction in resuming his hobbies as follows:

> *"Dulu semasa ku sebelum strok..di belakang rumah ku menyangkul menanam apa..be cucuk tanam..mata kucing..mangga..ubi kayu apa..tanam ubi..Masa ani nada apa2 lagi..duduk saja meliat TV..Abis ku makan ubat naik ke bilik..buka ku air con..tonton TV 24 jam..Kalau ku kan turun ke bawah..kaka ku bising..jangan lagi nya takut kena lagi tepijak..parah lah..Ani yang kedua dah ku ni..kalau ke tiga parah lah."* (SP – 12)
>
> TRANSLATED TO: ("Before I got stroke, I like doing gardening at our backyard. But now [after has a stroke], I am only watching TV. On my typical day, I took my medicine, went to my room, switch AC and then watch TV for 24 hours. If I wanted to go downstairs, my sister [carer] already warned me not to leave my room. Because she concern that I may fall which can be fatal.") (SP – 12)

In summarising the above subtheme, the participants' problems associated with resuming their social functioning appeared to be affected by contextual factors: the external environment and controlling behaviours of the carer to the stroke person. This finding may be unique to the study setting, and thus add new knowledge to the existing relevant literature.

Feeling more closer to Allah

This subtheme describes the views of the participants concerning impact of the stroke on their spiritual practices. The Muslim stroke patients talked about how their religious obligation of the five Pillars of Islam, such as daily ritual prayers, reciting the Quran (Holy book for Muslims) or fasting during the month of Ramadhan changed following their stroke. Some participants indicated that their spiritual practices were badly affected, but others asserted that the stroke brought them closer to Allah (God for every Muslim) and increased their devotion to Him (Allah). The data revealed that participants who perceived spirituality more positively were most likely to report significant spiritual growth. A quote from this stroke patient participant exemplified this:

> *"…nada masalah. Macam nya tani tekana strok atu pulang mudah tani macam nya tani sembahyang atu ah beramal ibadat atu…atu pulang macam banyak pulang masa bah dari badan tani sehat"* (SP – 04)
>
> TRANSLATED TO: ("…no problem. Performing prayers and spiritual practices were easier after the stroke… [there were] plenty of time compared to when I was healthy.") (SP – 04).

Most of the participants interpret their stroke as a message from Allah to remind them of the consequences of neglecting their religious duties. The data showed that surviving an acute stroke episode was perceived as an opportunity for self-reflection and to offer repentance to Allah. Thus, worshipping Allah was a way to express faith and gratitude towards Him. This participant revealed:

> "Another grateful thing was...this is one of the thing that gave me strength…till I didn't feel the negative side of the stroke…which is I still could breathe…I still have time to repent. It not that Allah took my life immediately, but He introduce it [feeling of dying] gradually. He still give me chance to repent, where some people may didn't have any chance to repent at all and they just passed away. So, that was the one [surviving stroke] I focus on. I feel closer to Him [Allah] and be on the right path…so that how I goes back to Him [Allah]." (SP - 18)

In contrast, a few of the stroke patient participants admitted that their religious practices had been adversely affected by the stroke. For example, this participant revealed feeling regret about his inability to accomplish his religious obligations, but acknowledged that Allah knows best the implications of his actions. He said:

> *"Rasa ku Allah Ta'ala jua yang tahu. Inda tahu sembahyang inda puasa. Mana gaya ku kan puasa. Banar Tuhan punya tahu tu"* (SP – 14)
>
> TRANSLATED TO: ("I believe, Allah Ta'ala knows. I didn't pray, didn't fast...how can I fast? Really, Allah knows [whether this is sinful or not].") (SP – 14).

Meanwhile, issues related to the performance of religious duties were also raised by another stroke patient participant. This participant indicated difficulty in praying due to the physical restriction related to specific movements during prayer, such as standing up after *Ruku* (bowing forward at 90 degrees with both hands on the knees) or *Sujud* (flexion with the hands and forehead flat on the floor) (Bangash et al., 2016). This participant stated:

> *"Sebalah patang duduk..berdikir..berdoa..bila masa mau baik..sembahyang jarang jua…sembahyang duduk ada lah sekali..dan..kalau sembahyang berdiri..duduk payah..bangun pun payah..."* (SP – 05)
>
> TRANSLATED TO: ("In the afternoon, I often sit on the chair recite *zikir* and pray to Allah for speedy recovery. I hardly perform the five day prayers because it was difficult to sit and stand during the prayer.") (SP – 05)

In summarising the above subtheme, accounts of these participants demonstrated that fulfilling their religious obligations was possible, irrespective of their physical restrictions. They indicated that the stroke brought them more closer to Allah, hence increases their spiritual devotion. This finding further complements the existing body of knowledge and contributes to the emergence of research in this area.

Overall summary of the Theme 1

The example quotes from this theme: *experience on the impact of strokes,* illustrates how strokes negatively impact upon individuals' various important functions. Most of the participants reported having problems related to performing their daily activities and emotional disturbance, particularly immediately after the stroke. However, the continued spiritual growth following stroke seemed gave positive approaches to cope with the impact of the stroke.

4.4.2: Theme 2 Existing rehabilitation support provision

This theme describes the current rehabilitation support provision for the participants within the hospital-based and community-based settings. The participants talked about their rehabilitation support services after discharge from the hospital, which were provided by the therapists, family members and traditional practitioners. The experience of the stroke patient participants illustrated that the availability of support was crucial for facilitating adaptation, to home, avoiding *"mudarat"* (detrimental effects as a result of actions) and continuing recovery. Three existing rehabilitation support provision, represented as subthemes, were identified: (1) rehabilitation service and therapist roles, (2) role of carer in supporting rehabilitation, and (3) role of traditional practitioner.

Rehabilitation service and therapist roles

This subtheme refers to the existing role of therapists and rehabilitation service delivery, whereby the stroke patients attend therapy largely as outpatients. The majority of the stroke patient participants agreed that the present services provided numerous benefits, such as available facilities, therapy-led intervention and structured therapy that contributed to the recovery of the stroke patients. The accounts of the stroke patient participants indicated that the benefits of attending this therapy in terms of improving physical functioning were indispensable. As an example, this stroke patient participant said:

> *"kitani datang kemari terapi ani bah..dari nya orang tani inda tahu jadi tahu...macam inda dapat di buat di buat" (SP – 17)*
>
> TRANSLATED TO: ("we came here for the therapy, [the benefits] we learn [about the exercise] that I didn't know before…and from not able to do, [now] I able to do.") (SP – 17)

Moreover, the data also revealed that accessing the therapy might give the participant hope and ease their emotional disturbance. One stroke patient participant stated:

> *"Kalau bagi saya penting lah..selain dari pada atu kan nya orang macam exercise jua buleh menenenangkan kitani bah....macam ada harapan tani kan." (menanggis)* (SP – 16)

TRANSLATED TO: ("Personally, exercise can comfort me emotionally and give us hope [to recover].") (with tear) (SP – 16)

Crucially, many stroke patient participants implied that the benefits of attending outpatient therapy extend beyond the stroke patients' physical recovery. The participants suggested that the current follow-up care, which focused on out-patient therapy, positively influenced their psychosocial wellbeing. The accounts from the stroke patient participants showed that meeting other patients could promote their emotional health and psychosocial functioning. This is illustrated by the following quote:

> *"…bukan pulang ke sana atu pasal ...inda tekurong kan..bejumpa sama pesakit lain atu kan dangan becakap itu ini..kalau di rumah sama siapa dangan becakap..nada ke lain yang becakap" (SP – 15)*
>
> TRANSLATED TO: ("…because of I don't felt stuck at home. I wanted to meet other patients so that I have someone to talk with. If I am at home, nobody is around to talk with.") (SP - 15)

The data also revealed that meeting other stroke patients creates a supportive atmosphere among all survivors. As an example, this participant spoke about how the group therapy sessions allowed every patient to recognise if any of their friends who had a stroke were likely to experience emotional problems. Then, those who were identified as having a problem would be consoled and comforted to help them regain their motivation. This stroke patient participant disclosed:

> *"Ada jua kawan kawan di sini ani kan..sama sama terapi untuk memberi semangat terapi atu lah..masa kami ada satu group d sini masa atu seminggu masa ber terapi..iatah keadaan macam kawan atu ada happy bah..macam keadaan macam ani..yang seorang ani lamah..nya kami bagi semanagat semangat unutk kau macam ani nya kami..macam aku dulu macam ani tu nyangku…sekarang aku semanagat macam atu lah pandangan atu…nya orang ..ada yang inda anu lah..beri semangat kami ah."* (SP – 10)
>
> TRANSLATED TO: ("There were few friends here who often provide necessary support [motivation] to other patients during the group therapy. Patient who joined the group therapy may appear happy or sad. Thus, we give support to those who was less motivated. I am like you before [less motivation], but now I am motivated than before. I think there always someone in group therapy will give you support.") (SP – 10)

Five stroke patient participants, meanwhile, spoke about kind attributes of the therapists. This characteristic appeared an important source of encouragement for patients' attendance at the outpatient therapy sessions. One stroke patient participant exemplified this:

> "Durang di sini..bahagian terapi anu bah nya orang.. yang mengajar atu nya orang ada ada keistemewaan nya..lambut lambut bah..layanan nya atu bagus bah….rasa gembira lah…nya orang susah hati atu nada wah" (SP – 08)
>
> TRANSLATED TO: ("The therapists here…at this rehabilitation centre…those who teaches us about the exercises were so special…they

> were gentle and showed continue support and care. I feel very happy…there was no worry at all.") (SP – 08)

On the other hand, nearly half of the stroke patient and their carer identified the limitations of the current out-patient therapy provision. For example, this stroke patient participant raised an issue with regard to logistics and the dependency on others to mobilise, as he asserted:

> *"Iatah yang payah macam orang membawa kediaku ani. Masalah pengangkutan untuk membawa ke sana. Macam kedia ku ani macam kan di kira kira macam beangkat angkat. Banar mun inda inda dapat. Bagi ku pun payah bagi orang memeduli memangkat menolong kediaku .pun payah"* (SP – 14).
>
> TRANSLATED TO: ("it was difficult for other people [my son] to bring me [to attend therapy at the centre]. It was problem with transportation. [Additionaly,] people have to lift me [from my bed into the car]. Really, it was difficult. For me, it was not convenient for others to care for, transfer and help me.") (SP – 14).

Moreover, the data also revealed that over three quarters of the stroke patient participants were felt dissatisfied with the extent and duration of the existing outpatient therapy. These participants believed that thirty minutes of therapy delivered once a week was simply not enough. The views of these participants showed that the current therapy time was insufficient to ensure maximum recovery. For instance, this stroke patient participant criticised the timing issue, stating:

> *"…seminggu sekali inda mencukupi bah…kalau dua kali atu…macam dulu dua kali seminggu" (SP – 03)*
>
> TRANSLATED TO: ('…one week [of the therapy] is not enough…if two…like previously twice a week.") (SP – 03).

Another stroke patient participant agreed with this view, and felt discontent regarding the allocated thirty minutes of therapy time. She stated:

> *"Macam inda cukup bah masa nya di sini bagi 30 minit inda cukup. Kalau buleh sejam satu sessi atu sejam" (SP – 04).*
>
> TRANSLATED TO: ("…the timing [of the therapy] is not enough. Here [at the rehabilitation centre], it was allocated 30 minutes…not enough. Preferably one hour per session…") (SP – 04).

However despite reporting the insufficient therapy time, the majority of the stroke patient participants agreed that coming to the centre was vital in ensuring continued recovery. As an example, this stroke patient participant asserted that attending the therapy prepared him to self-manage his recovery at home. He mentioned:

> *"…kalau tani inda datang for terapi…lambat tani kan anu bah macam baik macam sehat.tani kan mau pulih kan.. Dengan ada nya rehab di sini ani Alhamdulilah...at least macam di rumah dapat jua tani membuat exercise atu kan"* (SP – 04)

> TRANSLATED TO: ("…we want to recover [from stroke]. If we didn't come here [rehabilitation centre], our recovery will be slower. But with existing rehabilitation therapy here, *Alhamdulillah*…at least we can reapply the exercises at home.") (SP – 04)

In summarising the above subtheme, the data suggested that the benefits of existing support provision from the hospital have the potential to expand beyond physical recovery. However, the participants' reported dissatisfaction with regard to the therapy schedules may pose challenges to achieving this goal. This finding indicates an organisational structure issue, which requires attention from the relevant policymakers.

Roles of carer in supporting rehabilitation

This subtheme refers to support from carers or family members in helping the stroke patients manage their life after stroke and continue their therapy at home. More than half of the stroke patient participants mentioned about the important roles of carers in maintaining their progress and recovery after the stroke. For example, this participant suggested how the presence of external support was key to continued recovery.

> *"Mana yang ku dapat buat..atu ku buleh tu..Kalau inda sama bini anak macam untuk mengangkat kaki atu exercise atu lah." (SP – 10)*
>
> TRANSLATED TO: ("Whatever I can do, I will do myself…but if not, I asked my wife to help me, such as lifting the affected feet for exercises.") (SP - 10)

However, the interview data revealed that a minority of stroke patient participants live alone or that their home support network was entirely lacking. For example, an account by this stroke patient participant illuminated how, since his wife's death a few years ago, all of his six children live independently after marrying and so he has to manage himself and also look after his 10-year-old son. This participant expressed grief concerning his lack of capacity to bring up his son alone, doing the housework, preparing food and attending to their daily needs. This participant illustrated his struggle and perceived that needs of others to be more important than his, as he revealed:

> *"...ia tah tu perhubungan payah wah...kalau kan ke mana ke kedai apa..nada transport..kalau barang rumah kurang..aku harapan..orang jiran saja..kalau jiran atu inda sibuk..baru tah anu membantu...kalau ada anak sendiri yang pandai drive atu..cakap saja..antar ku ke kedai sekajap..sekajap atu tah tu yang yang capat atu kan..kalau inda terpaksa tah umpama nya kan suruh memasak apa kan tangan lagi karau kan...kan memasak membeli barang atu untuk memasak kan..anak ani lagi seorang kan..aku tah..inda kan di ingau kan..anak ani wah damit lakat bah..lapar bah..apa kan di makan ni."* (SP – 15)
>
> TRANSLATED TO: ("...transportation is difficult. I can't go anywhere because of no transport. If we run out of our food supply, I only hope for my neighbour [to drive for shopping], but only if he is available to help. I tried to call my son who can drive and request to send me to the shop. [But] he [son] didn't turn-up. Eventually, I have to prepare the foods from whatever stock available. But it was difficult to do this [cooking] because of my stroked hand.

> I don't mind not eating but how about my son. He's still very young...he will feel hungry...but what can he eat?") SP - 15

Due to the decreasing support from the immediate family, therefore, few participants sought outside help such as hiring a personal trainer or paid carer (*amah*). For instance, this stroke patient participant recognised the issue of the family support system and the need to outsource supportive care privately, as she explained:

> "I need certain people such as outsider. If siblings…they have their own work to do. So I need someone who are really free and not someone who mostly occupied. Like most of my family members already married and I know they have their own responsibilities….Similarly my mum. So, I have to out-source my support care." (SP – 18)

However, not many stroke patient participants afforded to hire personal trainer or *amah.* For instance, this stroke patient participant raised issues related to the financial constraints caused by hiring an *amah* and the power mismatch due to a conflict over gender, as he expressed:

> *Amah atu saja.. Tapi yang payah nya membayar gaji durang…kaka ku mau laki laki ia inda mau bini bini…kalau bini bini siap…Tapi kalau laki laki bagus..dapat menolong aku apa kan..kalau bini bini..apa kan di angkat."* (SP – 12)
>
> TRANSLATED TO: ("It will be a constraint to pay the *amah's* wage. Again, my sister preferred male *amah* who will be much stronger for transferring task. [Whereas] female *amah* may struggle with this duty.") (SP – 12)

In summarising the above subtheme, the fundamental importance of continued support at home for stroke patients was identified in this study. However, the accounts of the participants revealed that the issues with this support were substantial. This finding proved that establishing a long-term support care service and sustain throughout the period of stroke recovery were essentially required.

Role of traditional practitioner

This subtheme refers to the common strategy undertaken by the stroke patients in order to have additional support for continue rehabilitation at home. The accounts of these participants showed how seeking the traditional practitioners was a customary practice which was regarded as an effort to expedite patients' recovery. As an example, this stroke patient participant mentioned:

> *"Ada jua lah berubat di luar lah macam ber urut bebekam apa atu kan secara islam lah...ada jua lah berusaha lah..tapi Alhamdulilah ada jua peningkatan."* (SP – 16)
>
> TRANSLATED TO: ("I normally attempt finding outside therapy such as massage or cupping from traditional practitioner. *Alhamdulillah,* there are some progress.") (SP – 16)

One common practice provided by the traditional practitioners found in this study was the application of massage (*urut*). Nearly all stroke patient participants indicated that *urut* was essential and formed part of their rehabilitation. About one-third of the stroke patient participants mentioned how the application of *urut* could improve their general wellbeing. Quotes from these participants revealed that *urut* contributes to patients' physical recovery and promotes psychosocial health. For instance, one of the stroke patient participants indicated the ability to walk again following a series of *urut*, thus enhancing his confidence, as he asserted:

> *"Kadang kadang anu macam ada orang datang seminggu sekali ada orang mengurut lah...Yang bagus nya berurut atu...ia lapas di urut nya ia di suruh nya bejalan sendiri tanpa tongkat...suruh nya belatih..iatah bagus nya ia buleh motivate kitani jua bah." (SP – 17)*
>
> TRANSLATED TO: ("sometime in once a week, the traditional massager will come to perform the *urut*. The benefit of the *urut* is…after the person do the *urut*, he [the traditional massager] will ask me to walk without the stick. He encourages to continue practice…that's why I feel this [*urut*] is good because it can motivate us.") (SP - 17)

The advantages of *urut* were similarly experienced by another stroke patient participant. However, this participant argued that *urut* was a complementary therapy to modern treatment, so that employing both approaches would be vital for the maximum impact on recovery.

> "Actually half of my body was affected...but through therapy somehow and also massage…traditional *urut*…somehow I could walk again." (SP – 18)

Another stroke patient, meanwhile, indicated that maximising the use of *urut* services was required due to a lack of therapy time at the rehabilitation centre, as she implied:

> "Because the current therapy was not enough, now I am just focusing mainly on applying *urut* …that traditional *urut*." (SP – 18)

Another stroke patient participant emphasised the importance of managing the self through seeking treatment outside the hospital. This participant suggested that employing *urut* was required for every stroke patient and was far more effective for improving recovery than depending on the outpatient therapy alone. An excerpt from this participant highlighted:

> *"..berusaha lah sendiri..ber urut kampung kah..jangan nya orang berpandukan di sini...saya inda jua berpandukan ke mari kan.. macam di rumah pun cari kan orang pemandai macam mengurut apa tu...Ia tah kalau anu kalau kan bercerita banyak macam cerita kes kes macam ani..nada ubat lain bah..mesti berurut atu jua bah."* (SP – 17)
>
> TRANSLATED TO: ("We need to be independent such as getting some traditional *urut*. Do not only rely here [rehabilitation centre]. I didn't depending on therapy here. I always look for traditional practitioner who knows *urut*. There

were so many treatments on stroke but won't work. Thus, *urut* must be part of the therapy.") (SP – 17)

The increasing use of *urut* among the stroke patients appears inevitable. The data revealed that most of the stroke patients who improved following *urut* were likely to introduce their regular traditional practitioner to other stroke patients. This information exchange appears influential and generally accepted by the majority of the patients. A quote from this stroke patient exemplifies this:

"Kadang kadang ada yang mengajar..camani camani..macam aku ber urut macam ani ia memberi pendapat lah..kalau kan mau baru tah..Atu buleh lah..atu okey tu." (SP – 16)

TRANSLATED TO: ("Sometime, other patients will tell me how this person getting better after performing the *urut.* They gave me information [about the *urut*]. If I want details of the traditional practitioner, they usually happy to share.") (SP – 16)

The data also revealed that some patients seemed desperate to find the service of an *urut.* It was apparent that patients were prepared to seek a reliable traditional practitioner for *urut* as far as to nearby neighbouring countries of Brunei. For instance, this stroke patient disclosed:

"Ada rasanya orang berabar..orang pandai mengurut..masa ani aku kadang kadang..seminggu sekali ke limbang.. berurut tapi bukan orang kitani orang islam..orang philippine..ia pandai nya orang strok..di urut nya buleh bejalan nya" (SP – 02)

TRANSLATED TO: ("I heard from other [stroke patients], someone know how to perform the *urut*. Sometime I went to neighbouring country about once a week to get the *urut*. This massager was not a Muslim…a Pilipino…people said that his *urut* can help stroke patient walk again.") (SP – Pilot02)

In summarising the above subtheme, the role of traditional practitioner in providing *urut* among the participants in this study was evident. The data indicate that this cultural practice was inseparable from and considered an important source of the rehabilitation support. Thus, recognising the complementary effect of this *urut* on modern therapy was necessary in order to maximise recovery and sustain rehabilitation therapy outside hospital care.

Overall summary of the Theme 2

The example quotes on this theme: *existing rehabilitation support provision,* indicate that the period following a stroke can adversely impact on individuals' capacity and requires support from healthcare professionals and caregivers. The data revealed that the existing rehabilitation support from the hospital were largely inadequate or lacking. Hence, utilising external source from traditional practitioners to support recovery seemed a sensible alternative. This finding illustrates the gaps in the present healthcare support service provision, and the issues that require immediate intervention in order to improve the quality of life among the stroke patients.

4.4.3: Theme 3 Rehabilitation support needs for stroke patients

The residual impact of stroke on participants' health and wellbeing was considerable. The availability of an immediate support network was to be found crucial in assisting these individuals to continue their daily lives. The changing needs of the participants throughout their recovery continuum suggested that recognizing daily activities that are regarded as priority is vital. The stroke patient participants talked about their rehabilitation support needs after discharge. Five subthemes representing the support needs were identified: (1) self-care needs and priorities, (2) needs of rehabilitation nurse, (3) needing a sense of belonging, (4) information needs about stroke, and (5) the financial support needs.

Self-care needs and priorities

This subtheme was results of data collected using the adapted COPM approach. It describes the stroke patient participants' perceived daily occupational priorities that they would like to do, but are unable to do, or feel dissatisfied about doing them. The accounts of the participants demonstrated that the stroke patients were determined to perform their desired activities but often experienced problems due to physical impairments. The following quote illustrates this stroke participant's priority:

> *"selalu aku punya aktibiti inda pulang ada..ia tah ganya bejalan jalan atu....supaya jangan mati bah tenaga atu. Ada rasa nya kan bejalan jalan atu bah..kan belari pun rasa nya ada..tapi inda buleh..lamah" (SP – Pilot02)*
>
> TRANSLATED TO: ("I am not often do strenuous activities…I only walk very slowly. I wanted to walk more…or jog to improve my strength [limbs] so that the stroke limbs would not die. But, I can't because I feel [physically] very weak.") (SP - Pilot02)

The account of the following participant, meanwhile, showed that her priority was to perform prayers as normal people usually do. This participant talked about her wish to do *sujud* (flexion with the hands and forehead flat on the floor) during prayer, but felt incompetent because the stroke had impaired this action.

> *"All this while I just duduk sembahyang duduk kan..I can't sembahyang sujud because payah kan bangun..so that's one thing that I really I wanted to do" (SP – 18)*
>
> TRANSLATED TO: ("All this time, I have to sit when performing a prayer. I can't bend my body forward because it will be difficult to get up again…so that's one thing that I really wanted to do.") (SP - 18)

The married men who had had a stroke, however, appeared to emphasise their capacity to manage the wellbeing of their family. The majority of these participants mentioned resuming their family roles and functions as a priority that they would like to do, such as playing with their children, sending or collecting their children from school, and doing housework, grocery shopping or driving. A quote from this stroke patient exemplifies this:

> *"Sebelum ani duduk di kursi..main sama peranak..kalau lama duduk sakit punggung jua"* (SP – 05)
>
> TRANSLATED TO: ("Previously, I used to sit on the chair and play with our children. But, I can't do this any longer because it will hurt my back if sitting too long.") (SP – 05)

On different aspect from the adapted COPM, this study also explored the stroke patient participants' level of performance in doing the activities of perceived importance. The accounts of these participants indicated that activities associated with doing exercise, walking and praying were rated to a moderate to low level of performance. For instance, this stroke patient participant pointed out the difficulty of performing regular exercise due to a fear of falling. He stated:

> *"Kadang kadang berupaya..kadang kadang inda berupaya..contoh nya kalau bejalan ani ah..kadang kadang inda berupaya..Kadang kadang aku wang..kalau anak ku membawa bejalan kadang kadang liat keadaan anu liat mental ku kadang kadang..kadang kadang aku sempai terduduk sendiri tu (gugur) atu teriak teriak sakit nya..Allah...sakit sakit." (SP – 13)*
>
> TRANSLATED TO: ("Sometime I can do [the exercise], but sometime I can't…For example, if I want to walk, sometime I cannot perform. If my son wanted to bring me for a walk, it depend on how I feel and my mental status [mood]. It happened before that I fell while [walking]…Oh Allah, it was so painful…so painful.") (SP - 13)

This stroke patient participant, meanwhile, indicated a moderate level of performance in performing prayer, and described how he managed to perform his daily prayers by sitting instead of standing. He said:

> *"Sembahyang sama jua lah..apa yang dapat ku buat…ku buat. Biasa nya kurang lah keupayaan atu. Biasa sembahyang duduk saja. Atu pun apa yang ku mampu buat saja."* (SP – 17)
>
> TRANSLATED TO: ("Performance of prayer was based on what could I do best. But, most of the time it was not entirely perfect. I only can sit to perform prayer and do how much I can do.") (SP – 17)

Further, all of the participants were asked to rate their level of satisfaction with their performance in carrying out the perceived important activities. The interview data suggested that the majority of the participants rated their level of satisfaction at five and above, which indicates that they generally felt satisfied. As an example, this stroke patient expressed feeling a higher level of satisfaction for his performance on going out of the house, as he mentioned:

> "*Puas tah tu sudah. Kalau keluar rumah macam merasa ku keluar rumah ani samapi pukul lima balik ku tidur melimpang. Numbor tujuh lah."* (SP – 14)
>
> TRANSLATED TO: ("I do feel satisfied [after going out]. If I can get out from the house until five in the afternoon, then go back inside lying on my bed. [Rate of satisfaction] rated as seven.") (SP – 14)

Another stroke patient participant, meanwhile, talked about the intensity of the therapy exercises that were currently provided as the out-patient visits. The account of this participant showed that her level of satisfaction with the exercise performance was affected due to the limited therapy given, as she expressed:

> *"Kurang sikit lah. Enam..sebab nya ia seminggu sekali bah ..kalau dua minggu sekali..eh apa dua kali seminggu bisai..at least.. ada anu kan."* (SP – 16)
>
> TRANSLATED TO: ("[my level of satisfaction] a bit low. [Rated] six only, because it [exercise] only provided once a week. If the therapy was undertaken about tow times per week would be preferable. At least there are [improvement].") (SP – 16)

The data revealed that, although the participants rated moderately their performance level with regard to praying, the majority still indicated a significant feeling of satisfaction. The views of these participants suggested that the impact of praying on their cognitive and emotional wellbeing was positive. One stroke patient participant commented:

> *"Kalau sembahyang atu tentram bah rasa nya jiwa kitani tenteram bah. Buat sembahyang walau pun di atas keursi roda sal nya kitani boleh sembahyang duduk kan, walau pun duduk boleh sembahyang. Tapi untuk kan menenenag kan jiwa, sembahyang atu lah yang bagus nya."* (SP – 04)
>
> TRANSLATED TO: ("If I pray, I feel my mind and emotion were peaceful. We can still perform prayers by sitting on the chair, because this was allowed. So, I [always] pray while sitting. [I believed] that only doing prayer can comfort our emotion.") (SP – 04)

The data also showed that the stroke patients' perceived level of satisfaction was frequently influenced by the amount of support that they received from the carer. The accounts of these participants suggested that carers could be key to improving patients' physical performance and emotional wellbeing. As an example, this stroke patient rated his level of satisfaction following toileting activity that were supported by his carer, as he stated:

> "*Puas hati sabab nya orang mendangani. Mun nada inda jua eh. Kalau sendiri membuat inda tebala eh..inda rasa puas hati. Mun beria bekamih inda puas hati tu."* (SP – 14)
>
> TRANSLATED TO: ("I felt satisfied because there is someone who help. If no [nobody provide help], I will not [feel satisfy]. If I do it [toileting] alone, I just can't…I will not feel satisfy.") (SP -14)

On the other hand, five stroke patient participants were extremely dissatisfied with the performance of their perceived important activities. Perhaps these activities require an extensive length of therapy and substantial amounts of time to accomplish. For example, this patient declared:

> *"Masa ani inda dapat drive eh…numbor satu lah"* (SP – 03)
>
> TRANSLATED TO: ("At this moment, I can't drive yet. So, [rating for level of satisfaction] is one.") (SP – 03)

In summarising the above subtheme, the data showed that the participants' perceived important activities were related to social functioning, performing religious duties and resuming roles in their family. The stroke patient participants' rated outcomes on their level of performance of and satisfaction about these activities were fairly average. Perhaps this finding indicates a mismatch between the occupational priorities of the participants and the existing individual therapy provided. Thus, it may be necessary to re-evaluate the current therapy programmes and aim for patient-centred care.

Needs of rehabilitation nurse

This subtheme presents the views of the participants with regard to the possible introduction of stroke rehabilitation nurses for continued support at home. Differing views emerged concerning the role of nurses in rehabilitation and the rationales for introducing such services. Nearly all stroke patient participants indicated that the potential service could be a vital resource for continued supportive care after discharge. As an example, this stroke patient revealed how stroke nurses would be a valuable support for patients without family, as he implied:

> *"Kalau ada bagus dapat memata matai pesakit atu kan..kalau nada be keluarga..nada pertolongan...selain dari kabajikan..bahagian terapi kan..jururawat atu membantu dari segi kesihatan...membantu lah."* (SP – 15)
>
> TRANSLATED TO: ("If there is any [stroke nurses], this will be beneficial for monitoring stroke patients, especially for those who lacked family support, no immediate assistance apart from the Welfare section...so the nurses [stroke nurses] can help these patients from their aspect of health.") (SP – 15)

Moreover, the data showed that access to stroke nurses after discharge could offer a sense of reassurance. The accounts from one-quarter of the stroke patient participants stated that the continued presence of stroke nurses could positively benefits patients' emotional wellbeing. This view was illustrated by one stroke patient participant, who indicated:

> *"Lagi bagus kan…pasal nya kalau kira tani durang atu macam kira tau kan kan apa apa atu jadi bagus lah kalau ia ada sama kitani. Membagi kitani anu..apa nama nya…membagi kitani semangat bah…Jadi buleh membantu pemulihan sama anu anu apa tu boleh mengontorl mengajar kitani macam emosi atu inda boleh macam anu lah ah… macam ada orang memerhati kan kitani bah"* (SP – 04)
>
> TRANSLATED TO: ("it will be good if they [nurses] are available to us. They can give us courage…and so can help our recovery…then can help teach us how to control emotions. It was like someone is monitoring us.") (SP - 04)

The stroke patient participants were asked to give their perspective regarding the expected roles of nurses in stroke rehabilitation. The majority indicated wider competencies related to skills and knowledge about strokes. The participants, in particular, hoped that these proposed nurses would have a substantial understanding and skills to support patients' transition from the hospital to home. As an example, the following stroke patient participant mentioned the therapy carry-on role in order to sustain a stroke care continuum, as he stated:

> *"kalau ada pun exercise pulang tu..apa yang suruh buat atu..mesti di buat lah..bagus lah jua kalau di adakan..nya orang untuk menganu kan bah..nya orang di tahap kan lagi pemulihan atu..lapas di sini ah" (SP – 10)*
>
> TRANSLATED TO: ("If there is one role of the nurses, it will be with regard to exercise that was taught by the therapist. It will be good if the nurses available so that they can improve our rehabilitation after coming from here [the rehabilitation centre].") (SP - 10)

Another stroke patient participant, meanwhile, talked about the importance of these proposed nurses acquiring good problem-solving skill. The account of this participant seemed to suggest that nurses should have an ability to think 'outside the box' in order to devise rehabilitation stimuli at home. This aspect of the skill set could be a vital resource and way of enhancing recovery, as this participant implied:

> "…maybe they [nurses] be able to give a different way to help me. Like some people if they [nurses] think this person can't do this, then they [nurses] will improvise… so maybe in a way something that we couldn't think, but they [nurses] will able to think…that will be a great help." (SP - 18)

The same participant provide different perspective with regard to role of rehabilitation nurses relating to religious obligations. This attributes appears important to assist the stroke patients' recovery by means of spiritual practices as a therapy. This stroke patient proposed:

> "[Role] as someone who, from religious perspectives [may say this]…Okey, lets stop doing the therapy. Islam asked us to pray, so let's pray together. You know, nurses who are strong religious background…We should have this kind of nurses at least." (SP – 18)

Conversely, the experience of this stroke patient participant pertaining to caring roles of ward nurses for stroke patient appeared contradictory. His account suggested that he was often neglected by the ward nurses whenever support was required, as he reported:

> *"durang atu lambat bah lambat…pengalaman ku di hospital ah..apabila tani kan rasa atu kan betindak..kan beria kan apa..durang lambat bah..lambat untuk memberi perhatian kitani bah*."(SP – 08)
>
> TRANSLATED TO: ("They [ward nurses] always delay and very slow to respond. My experience staying in the hospital, whenever I need them [nurses] to help with my morning care, they [nurses] often took times to come and give me attention.") (SP – 08)

Thus, to ensure effective care delivery, this stroke participant suggested that stroke rehabilitation nursing should only be assigned to senior nurses, as he suggested:

> *"Jangan tah orang jururawat macam orang baru lah..baru kan mengalami orang macam kami ani..jadi durang pun nada pengalaman*."(SP – 10)
>
> TRANSLATED TO: ("That [stroke nurses] ideally not for new nurses…who just started to experience caring us [stroke]. Because they [new nurses] didn't have experience [to competently care for a patient].") (SP – 10)

On the other hand, a few of the stroke patient participants argued against the proposed introduction of stroke rehabilitation nursing. The data revealed that these participants were sceptical regarding the relevance of stroke nurses to patients' needs, the likely negative implications of home visits and the constraint on resources. For example, this stroke patient participant opposed nurse home visit due to feeling satisfied with the existing support provided by her carer, as she said:

> *"…not need. Tidak mau nurse datang rumah. Now no no. No need nurses lah….sebab pandai jalan sudah bah. Pandai lah sikit sikit. Amah ada udah bantu di rumah. Boleh buat sendiri di rumah lah" (SP -20).*
>
> TRANSLATED TO: ("[stroke nurses] were not needed. Don't need nurses to do home visits. Now, not needed because I can walk now. My walking is slowly improving. I have maid to help me at home. Additionally, I can do it [self-care] independently at home.") (SP – 20)

Moreover, the interview data also revealed conflicting views with regard to the effect of the continued presence of nurses on patients' emotional wellbeing. This stroke patient participant argued that nursing home visits might have negative implications for stroke recovery. The views of this participant indicate that regular visits could result in patients relying entirely on stroke nurses, and thus neglecting the importance of managing their therapy independently. This participant explained:

> *"Perkara atu baik jua kalau nda macam orang yang menghadapi kesulitan memandu apa kan tapi kalau macam boleh ke sana kah ke hospital, inda perlu kali eh..durang di sana saja". "Kalau durang ke rumah, masalah nya mungkin nada inisiatif kan anu.. berubah...Ia kalau di kesana orang penyakit atu mesti anu bah apa ni membuat determination nya tinggi. Setiap hari ani ingat ia kan ke sana…kesana tia" (SP – 01)*

TRANSLATED TO: ("That matter [stroke rehabilitation nurses] can be beneficial for those who have transport problems coming to the centre. But, if they [the stroke patient] can come to the hospital [rehabilitation centre], that [stroke rehabilitation nurses] is probably not needed. If they [the nurses] come to our home, my concern is that maybe the person has no initiative to change [relying on the visit]. If the therapy is at the centre, the person will be very determined. Every day, the person will remember when to go for the therapy...then he will go there [the rehabilitation centre]") (SP – 01).

Another stroke patient participant, meanwhile, disagreed if the proposed stroke nursing service was superior to family support. He stated:

"Ku fikir inda memadai jua..keluarga jua yang penting bah..keluarga yang penting.' (SP – 08)

TRANSLATED TO: ("I don't think that [support from stroke nurses] was enough [compared to family]. [Support] from family was more important. Family support was important and needed most.") (SP – 08)

In summarising the above subtheme, the proposed introduction of stroke rehabilitation nurses seemed well supported by the majority of the participants. Although a minority of participants appeared concerned, encouraging views from most of the participants proved the need to consider inclusion of the nurses in future improvements of stroke service provision.

Needing a sense of belonging

This subtheme described the needs of the participants regarding meeting other individuals and being part of the larger society. The data from the stroke patient participants showed that many indicated their desire to reintegrate into the community. As example, the accounts from one-quarter of the stroke patient participants revealed that they wished to "go out", "drive" or join a "family gathering". However, the lack of existing resources, public facilities or equipment to support people with disabilities was a major concern. The data from the interviews suggested that most of the stroke patient participants spent their time mainly at home. When views about the possibility of setting up a place for stroke patients in the community were explored, nearly all of these participants reported the potential benefits of this. One stroke patient exemplified the benefits of being together with other stroke patients, who stated:

"...au ada pulang tu kira menolong pulang tu macam kitani atu we need jua anu lah keluar daripada rumah atu macam gathering macam open bah macam baibun baibun apa jadi lupa kitani kan penyakit atu. Pasal nya kalau sendiran kadang2 tani memikirkan penyakit atu bah" (SP – 04)

TRANSLATED TO: ("…yes, it [the community stroke centre] might help us. We need to go out from the house…so like that gathering [with other patients], can be an open conversation and making jokes so we can forget

> about our condition. If we are alone, we tend to think about the condition [problems].") (SP – 04)

The following quote further confirm previous finding regarding benefit of meeting with other stroke patients on emotional wellbeing, as this participant illustrated:

> *"Bagus pulang tu .. ia bekumpul atu beimpun kiranya. Macam kiranya di kampung ani mau empat orang lima orang kiranya bekumpul... jadi becerita cerita. Iatah baik pulang rasanya pulang tu macam menyehat kan badan menyaman kan hati jua bah" (SP – 14)*
>
> TRANSLATED TO: ("It can be good...get together...If we can gather four to five people [stroke patients]...can share stories. I think it will good to make our body healthier and comfort our feelings.") (SP – 14)

Moreover, the views of this stroke patient participant emphasise the importance of a supportive environment from others. He illustrated how patient networks could turn into therapy that extends beyond physical recovery, as follows:

> *"Ialah environment atu is penting lah bagi aku..bagi pesakit pesakit strok. Atu pun kira daripada terapi tu daripada terapi..terapi yang paling penting tu...Bukan nya orang terapi dari segi fisikal, nya orang cara mentality kitani atu is a terapi."* (SP – 17)
>
> TRANSLATED TO: ("For me, that [supportive] environment is so vital for the stroke patients. This [environment] can be regard as important therapy. Not only therapy for aspect of physical, but also mentality.") (SP – 17)

Crucially, this stroke patient participant observed that being together could create group harmony which results in every stroke patients feeling a sense of belonging, as this participant described:

> "[I observed] they [stroke patients] still there [gathering]. Although they have more severe impairment than me, they still come, they mingle, we laugh together. The feeling is…I don't know how to say it…it is not like we had similar problems [disabilities], but [yet] you get the sense of belonging." (SP – 18)

In contrast, this stroke patient participant was concerned about the possible drawbacks of creating stroke group. This participant indicated that meeting together on a regular basis might provoke negative feelings and views about themselves. A quote from this participant revealed:

> *"Kalau aku mungkin baik pulang tu ganya inda dapat di amal kan takut karang nya orang sama sama atu fikiran macam down saja sentiasa macam inda pernah terasa kan independent bah..tapi buleh pulang macam nya orang kalau macam terasa sunyi inda bekawan kan buleh lah di tamu tamu kan tapi kadang kadang takut ada keburukanya ia tah tu bah macam sudah ter kumpul atu nya orang fikiran pun eh..kami ani orang macam ani..what for kan orang macam ani..takut inda lagi macam inda putus asa bah."* (SP – 16)
>
> TRANSLATED TO: ("For me, that [meeting] is good, but it shouldn't be conducted frequently. Being together may invite depressive feeling and lacked stimulus to achieve independent [patients feel overwhelmed with problems and seeing various ranges of disabilities among themselves].

Nonetheless, the meeting can helpful for patient who is alone or need friends. But, the drawback is patients may start to think…we are disable people…what are the purpose [living] for people like us…[regretfully] patients may lost hope.") (SP – 16)

In summarising the above subtheme, the data indicated severe deprivation in terms of the participants' social functioning and access to the community. The views of the stroke patient participants about the benefits of potential community stroke settings appeared to be encouraging. This finding may assist relevant policymakers in considering planning of a community-based stroke centre, such as a stroke club.

Information needs about stroke

This subtheme concerned the stroke patient participants' views and understanding regarding the nature and causes of a stroke. The interview data revealed that the majority of the stroke patient participants did not clearly mention a stroke as a disease that disrupts the blood supply inside the brain. This misconception about stroke indicated that awareness about stroke was lacking. The accounts of stroke participants demonstrated that many described strokes was physical weakness in one or several parts of the body. For example, this stroke patient participant commented:

"Strok ani macam lamah badan, sudah atu macam uruat urat atu lamah bah macam inda berfungsi. Macam semua urat2 macam tangan kaki apa semua. Macam atu bah macam nya kitani nada berfungsi ah badan atu. Tekana atu urat atu ya") (SP – 04)

TRANSLATED TO: ("A stroke resembles weaknesses of the body parts, like the muscles are weak and not functioning. All muscles of the limbs. [Stroke] affecting the muscles.") (SP - 04)

Nearly half of the stroke patient participants, meanwhile, defined a stroke using a culture-specific term. The views of these participants suggested that a stroke was caused by an evil wind, locally known as *Angin Ahmar*. This terminology appeared more sensitive to the cultural context of the wider community. This stroke patient participant exemplified:

"Tapi sebenar nya strok ani inda pulang pulang tahu..tapi kalau perkataan macam doktor kan strok ani durang manggil..doktor..kalau kitani kampung kan kena angin ahmar pulang tu...pasal kena angin ahmar atu kan pasal awal kena biut ni mua ani" (SP – 07)

TRANSLATED TO: ("I actually don't know about a stroke. But this term usually used by the doctor. In our local understanding, it [the disease] is caused by Angin Ahmar…because of Angin Ahmar…led to weaknesses on half of my face.") (SP - 07)

One-third of the stroke patient participants, meanwhile, mentioned that strokes were sent by Allah (God for every Muslim) in order to test the individual's faith and devotion towards Him. Thus, these participants believed that enhancing their spiritual practices was key therapy for recovering from the stroke. One stroke patient participant stated:

> *"…tapi tah kitani..kadang kadang...kehendak Allah..jadi tani inda dapat buat apa apa..semua daripada ujian Allah...ani tani dapat ber doa saja" (SP – 13)*
>
> TRANSLATED TO: ("…for us, this stroke was given by Allah. So we cannot do anything. All of these were test from Allah. We can only pray [summon help from Allah to seek for recovery]") (SP – 13)

Another stroke patient participant believed that only Allah can cure a stroke and restore health, as he asserted:

> *"nya orang daripada sendiri yang membuat sakit atu..Ia yang maha penyembuh kan..mana ada lagi yang lain..Allah Ta'ala lah jua menyembuhkan..Ia jua mendatangkan penyakit...Ia jua menyembuh kan...ia tah tu berdoa lah."* (SP – 17)
>
> TRANSLATED TO: ("This stroke was result of our sinful [not maintaining religious obligations]. But, Allah is the Greatest Healer. Allah gave us the illness and only He can heal us. Therefore, we must pray [repent and seek Allah's Blessing].") (SP – 17)

Further, the data showed that many stroke patient participants experience the early signs of stroke, but were unaware of the importance of seeking immediate health support. An excerpt from this stroke patient participant illustrated that a lack of education was evident:

> "…I could felt before the stroke attack, blood rush into my brain. During that event, I was doing office works. Suddenly, I feel very weak and immediately sat on my chair. I can feel that the blood was gushing into my head, but I taught it was normal. So, I didn't immediately go to the hospital." (SP – 18)

The data also revealed the existence of misconceptions concerning age-related risk factors for stroke. For this stroke patient participant, she assumed that strokes were a disease among the elderly. When explanation for her difficulty to accept her stroke was sought, she replied:

> "I think it something to do with age factor…I am still young…it is...I thought it was not possible to have that stroke at the young age." (SP – 18)

In summarising the above subtheme, the data showed that substantial problems exist with regard to the participants' education and awareness about strokes. Most notably, false beliefs about the nature of the disease and delays in seeking immediate support were of significant concern. This finding proved that the educational intervention among the public should be enhanced.

Financial support needs

This subtheme may not be directly linked to the rehabilitation aspect of stroke, but the lack of financial support would most likely increase the life burden, thus affecting the lived experience of both patients and carers. Numbers of stroke patient participants reported on financial constraints for buying their daily necessities or supporting the needs of others. For instance, this stroke patient participant talked about the financial implications as a result of living with his son. The account of this patient implied that his presence may consequently place a considerable financial burden on his son to support him and the other occupants of the house. The data revealed that the participant was hesitant to rely on his children to fund his daily essentials. However, because he was retired and his current elderly allowance was limited, this participant appeared to feel distressed at being unable to offer financial support. He stated:

> *“Iatah ganya pasal kewangan ani tah ganya sal pebelanjaan..pasal kedia ku tinggal di rumah ani...galak jua rasanya kan minta bantu kanak. Bukan nya lagi bekeraja...payah....macam miatu bah. Macam kewangan pemakanan apa ani. Kita ani bantu ku. Ani macam membantu anak cucu ku ani. Tahu tah karang ani bila ada pulang macam kewangan ku jua ....???....durang! Macam gaji ku tua...banar...kenapa ku jua”* (SP – 14).
>
> TRANSLATED TO: (“...it’s about financial matters...about spending. Because I live with my son and didn’t feel right asking help [money] from him. I am no longer work. So it was difficult [problems other than the stroke]. I spent my elderly allowance to buy foods and helping my grandchildren. But, the allowance was not enough.”) (SP – 14).

Twelve participants comprising the stroke patients and the carers currently receiving monthly B$250 as part of the sixty years old-age pensioners’ allowance provided by the government. However, four stroke patient participants reported that the financial aid was inadequate to fund their daily needs. These participants appeared hopeful about receiving the allocated financial benefit for disability people, but felt frustrated that stroke-related disabilities were yet to be considered part of this claim. For example, the account of this stroke patient participant revealed:

> *“...musim ani cuma dapat 250 gaji tua ganya kan..[inda mencukupi] eh. Jauh..Wang nada...Ya Allah..nada mencukupi. Bantuan ani penting ni..kadang kadang bantuan yang dapat bulan bulan dari kebajikan bah sampai tiga ke empat ratus.* Mudah mudahan pihak atasan memikirkan lah..jangan camatu saja cukup ni dengan gaji tua..dengan bersara atu...Macam di Ripas bah..ada orang sakit..orang sakit TB sakit apa..dapat tiga empat ratus sebulan..” (SP – 13)
>
> TRANSLATED TO: (“...at this moment, I only received $250 old-age pensioner’s allowance. It was far from enough....Ya Allah...it was not enough. Normally, the assistance [financial] given by the Welfare Department is about $300-$400 per month. I hope the authority concerned can consider us [entitlement]. Relying on existing allowance was not enough.”) (SP – 13)

In summarising the above subtheme, these data raised questions regarding the extent of the welfare support provided by the government or private agencies for this group within the community. This finding suggests that the current policy concerning allowance entitlement for people with disabilities required a reconsideration of the inclusion of people who have had a stroke, so that the quality of life for these individuals can be improved.

Overall summary of Theme 3

The example quotes on this theme demonstrates diverse support needs of participants in this study. The data indicate that support was required for activities related to mobility, social functioning, community re-integration, performing prayer and financial aids. Similarly, the educational needs of the participants regarding strokes was apparent. Arguably, stroke rehabilitation nurses, complemented by other rehabilitation professionals, may assume roles in addressing those rehabilitation needs, with exception on those financial needs which require attention from relevant department. The views of the stroke patient participants regarding these nurses indicates potential benefits for the provision of care outside the hospital setting. Thus, the direction of this study with regard to future planning in improving the home-based rehabilitation support for stroke was strengthen by the findings of this research.

4.5 Overview of the conceptual model

Diagram 12 demonstrates the conceptual model that was developed based on the analysis of the participants' experiences of stroke and their rehabilitation support needs after discharge from the hospital, named as 'Feel Able Model' (FAM). The model represents a theoretical illustration, in which the most relevant concept that relates to the individuals' performance toward achieving own needs and priority was considered. As such, the concept of 'able' underpin by the interview themes: *Experiencing the impact of strokes, Existing rehabilitation support provision* and *Rehabilitation support needs at home,* that formed the key features influencing the stroke patients' living experience was proposed. No existing model of stroke rehabilitation support needs was found in Brunei. Therefore, this model will provide a basis for discussion with relevant stakeholder in planning stroke care services, teaching purposes and act as platform for further stroke research in Brunei.

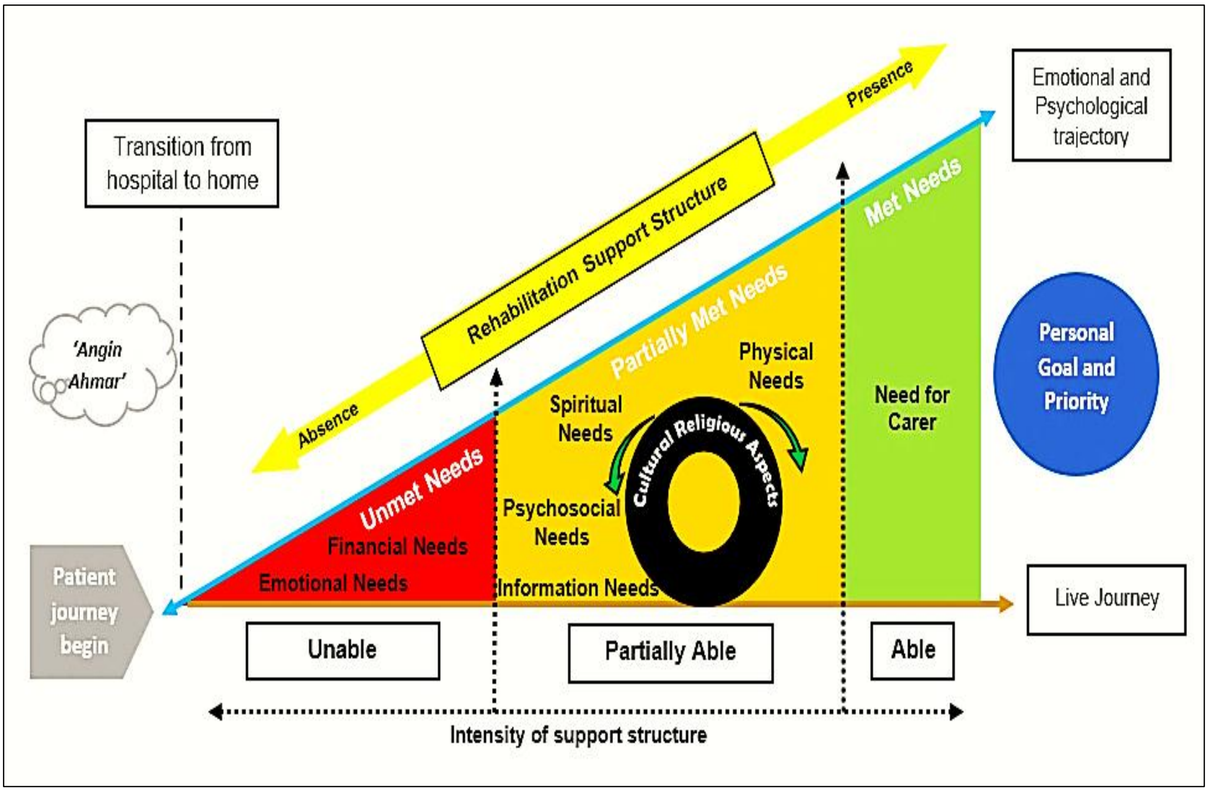


Diagram 12: Conceptual Model for Stroke Rehabilitation Needs (Feel Able Model)

Defining the concept

In defining the concept, certain phrases from adapted COPM and the context of the study was considered in order to illustrate the lived experience of the participants. Thus, the definition of the concept may specific to the individuals' presentation, and described as follow:

- 'Able' is refer as having the power, skill, means to do something and feeling very satisfied.
- 'Partially able' is describe as having some ability to do something, but aren't satisfied how it was done.
- 'Unable' is defined as total loss of ability to function or do something.

The above concepts have different meaning from the concept of 'enablement', in which this was described as a 'professional intervention aiming to recognise, support and emphasize the patient's capacity to have control over her or his health and life (Huddon, Bravo & Poitras, 2011). The concept applied in our model was a way of representing the stroke patients' rehabilitation needs and considering several factors or processes that can facilitate or hinder their goal accomplishment.

Describing the ‘Feel Able Model’ (FAM)

This section attempts to describe the key processes that constitute to development of the model. It was anticipated that for the stroke persons to transcend from one concept to others, their needs have to be met. The interpretation of FAM will be describes through the ‘lens’ of the individuals with stroke. The patients who have survived the acute episode of *Angin Ahmar;* this term was preferred to capture cultural sensitivity of Bruneian understanding about stroke, and demonstrates satisfactory recovery with minimal dependency, will often allowed to go home. Leaving the hospital will marked as the starting point for these individuals as home-based stroke survivors and enters the transitional period of care form the hospital to the community. This transition, signify as broken line at the left side of the model, indicated that hospital care that the patients normally received will suddenly discontinued. The patients then will embark on life journey, denote by arrow at the base of the triangle, which involve multifaceted and unpredictable recovery. This uncertainty may result devastating effect on patients’ emotional and psychological health, as illustrated by direction of the trajectory on the model.

The shape of a left triangle that formed the main block of the FAM design illustrates the needs of the stroke participants in this study. The triangle which comprise 3 distinct segments and shapes feature a narrow angle that represent as unmet needs, the middle segment as partially met needs and the wider end of the model which signify met needs. The surface dimension of this segment will indicates the degree of participants’ needs that were met or unmet. The model reveals that our participants experienced considerable unmet needs on the aspect of emotional wellbeing and financial resources. This follow by the physical, spiritual, psychosocial and information needs that were identified as partially met needs, meanwhile, having a carer at home was regarded as met needs.

In order to ease the stroke survivors’ journey towards attaining own goal and priority needs, interventions are required to address those unmet or partially met needs. The availability of the rehabilitation support structure; the therapists, caregiver, family members, traditional *urut* person and *Ustaz* (religious individual), as identified in this study thus vital. With continued presence of this support group, the two vertical dotted lines will shift to the left increasing the surface dimension of met needs segment and reducing the others. By contrast, the unmet segment become larger if support was lacking. The FAM suggests that progressing between the ‘able’ concepts and meeting the needs of the survivors are made of interrelated links between multiple factors, including greater presence of rehabilitation support structure, intensity of support, emotional and psychological trajectory and the stroke survivors. Therefore, availability of support structure was integral to improve survivors' emotional and psychological wellbeing and addressing their needs. However, the model indicates that any support interventions must consider the cultural and religious aspects of the individuals. This, represent as a wheel in the model, acts as the 'mover' that strongly influence the needs of the stroke survivors. For example, it was found that daily prayer provides positive impact on survivors' coping strategy. Thus, facilitating the survivors to maintain this practice would improve their motivation to recovery.

Limitation of the model

It should be noted, however, that our conceptual model may have limitations. Firstly, it was a simplified depiction, thus may not perfectly provide accurate representation of real experience which is more complicated and complex. It also may lack complete details regarding the experience, thus may lead to misunderstanding or misinterpretation. Although the analysis represents the best interpretation of the interview data, our model should be then interpret with caution given the limitations discussed.

Section Summary

This section presents overview of the 'feel able model' as a concept that illustrate our participants' lived experience and needs after the stroke. The concept of 'able' was chosen to demonstrate participants' progression to recovery and achieving their goal. The model suggests interrelated links between multiple factors in order to meet participants' needs. The consideration of culture and religion on addressing the needs was apparent. Finally, possible limitations of the model was discussed.

4.6 Chapter Summary

Semi-structure interviews were employed to explore the experience of participants with stroke (*n*=21) after discharge from hospital. The data from the interviews were analysed using a thematic analysis approach. Three main themes and their related subthemes that describe the lived experiences and rehabilitation support needs of these participants following a year after discharge to home were identified. The data revealed that the participants experience considerable issues on their physical, emotional and social functioning due to consequences of the stroke. However, the practice of faith and spiritual growth following the stroke were encouraging. The data also suggested gaps with regard to the current rehabilitation service provision from the healthcare organisations, in particular the limited out-patient therapy provision. Given this, support from traditional practitioners as a form of providing *urut* was sought to expedite recovery. Furthermore, the data unexpectedly revealed that the Brunei traditional family structure as extended unit was no longer reliable for offering continuous support at home. The participants described various areas of support needs that were partially met as a result of the existing support structures, or remained unmet needs. The participants' views with regard to the potential introduction of the stroke rehabilitation nurses were perceived with mixed responses. The interview findings provide an understanding about issues surrounding the stroke rehabilitation service provision among the stroke patients. A conceptual model to illustrate participants' experience was developed. Next subsequent chapter will presents interview findings from the carer participants of the stroke patient.

Chapter 5: Interview findings for Carer Participants – Phase 1 study

5.1 Introduction

This chapter presents the findings from the interviews with the carers of the stroke patients during the first phase of the study. Most interviews were undertaken at the same day and immediately after completion of interviews with the stroke patient participants. This chapter begins with presenting an overview of the participants' socio-demographic characteristics. Then, themes identified from the interview data will be discussed. This chapter conclude with a summary of the findings.

This chapter sought to address the following research question:

- What is the lived experience of the carers and their rehabilitation support needs during the first year after discharge from the hospital?

A total of eighteen (*n*=18) carer participants (CP) were recruited in this study. All interviews data were analysed and presented. Themes that emerged were discussed, with evidence to exemplify and illustrate the findings presented in the form of quotes. The Malay excerpts were written in italics and an English translation was provided in brackets.

5.2 Demographic profiles of participants

Table 7 presents the demographic profiles of the stroke carer participants. Of the eighteen carers who participated in this study, nearly 90% were female and only two were male. All of the carers lives with the stroke patient and provide daily care at home. The age range was from 24 to 64 years, with a mean age across carers was 44.4 years [SD 14.2]. Most carers were between 50 and 64 years old (*n*=7, 38.9%). Five carers (27.8%) were older adults aged 34 – 49 years, while another six (33.3%) were younger carers, aged 33 and below. Over 70% of the carers were Malay Bruneian and the majority were Muslim (*n*=16, 89.9%). Four carers (22.2%) were non-local and, of these, two (11.2%) were Christians. Three of the non-local carers were employed as paid-carers and one was the spouse of a stroke patient.

Demographic profiles of participants (N=18)

Dichotomous / Categorical				Total
Gender		Male *n*=2, 11.1%	Female *n*=16, 88.9%	*n*=18
Age in years	<=33	1, (5.6%)	5, (27.8%)	6, (33.3%)
	34 – 49	0	5, (27.8%)	5, (27.8%)
	50 – 64	1, (5.6%)	6, (33.3%)	7, (38.9%)
	65 - 85	0	0	0
(Mean age)				*(44.4)*
[Standard Deviation]				*[14.2]*
Nationality	Brunei	1, (5.6%)	13, (72.2%)	14, (77.8%)
	Indonesia	1, (5.6%)	1, (5.6%)	2, (11.1%)
	Philippines	0	2, (11.1%)	2, (11.1%)
Ethic group	Malay	1, (5.6%)	13, (72.2%)	14, (77.8%)
	Chinese	0	0	0
	Others	1, (5.6%)	3, (16.7%)	4, (22.2%)
Religion	Islam	2, (11.1%)	14, (77.8%)	16, (88.9%)
	Christian	0	2, (11.1%)	2, (11.1%)
Living area	Onshore	2, (11.1%)	16, (88.9%)	18, (100%)
	Water Village	0	0	0

Table 7: Demographic profiles of participants

5.3 Social demographic information about the participants

Table 8 presents the social demographic profiles of the participants. Over 80% (*n*=15) had a primary school certificate and another three (16.7%) had completed their education at undergraduate level or higher. Five carers (27.8%) were employed by the government, and another four (22.2%) worked in the private sectors. However, most of the carers were either retired (*n*=6, 33.3%) or unemployed (*n*=2, 11.1%). Their relationship with the stroke patient varied, with 38.9% (*n*=7) being a spouse, 27.8% (*n*=5) an offspring, 11.1% (*n*=2) a siblings, and 16.7% (*n*=3) an employee. The mean duration of their experience in the caring role was 8.33 months [SD 3.86]. The longest experience was between 9 months and 1 year (*n*=8, 44.4%), and six carers (33.3%) had 3 to 6 months of experience of caring the stroke patient.

Social demographic information about carer participants (N=18)

Dichotomous / Categorical			
Highest education attained	None	0	0
	Certificate	15	83.3
	Diploma	1	5.6
	Bachelor Degree	2	11.1
	Master	0	0
Employment status	Government sector	5	27.8
	Private sector	4	22.2
	Self-employed	1	5.6
	Retired	2	11.1
	Unemployed	6	33.3
Relationship to person with stroke	Spouse	7	38.9
	Parent	5	27.8
	Siblings	2	11.1
	Employee	3	16.7
	*Not paired	1	5.6
Duration of experience in caring role	3 to <6 months	6	33.3
(Mean duration 8.33)	6 to <9 months	4	22.2
[Standard Deviation 3.86]	9 months to 1 year	8	44.4

* Carer was interviewed individually

Table 8: Social demographic information of stroke carer participants

5.4 Findings from the interviews with carers

Diagram 13 provides overall mapping of themes and subthemes identified from the interviews. The data for the carer participants were re-analysed as part of the revised thesis requirement, undertaken approximately over the period of two months. Similarly to the stroke patient participants, the primary focus of the analysis was centred to identify the support needs of the stroke carer participants in rehabilitation following discharge, thus the data may help to address the service gaps relating to the home-based service provision.

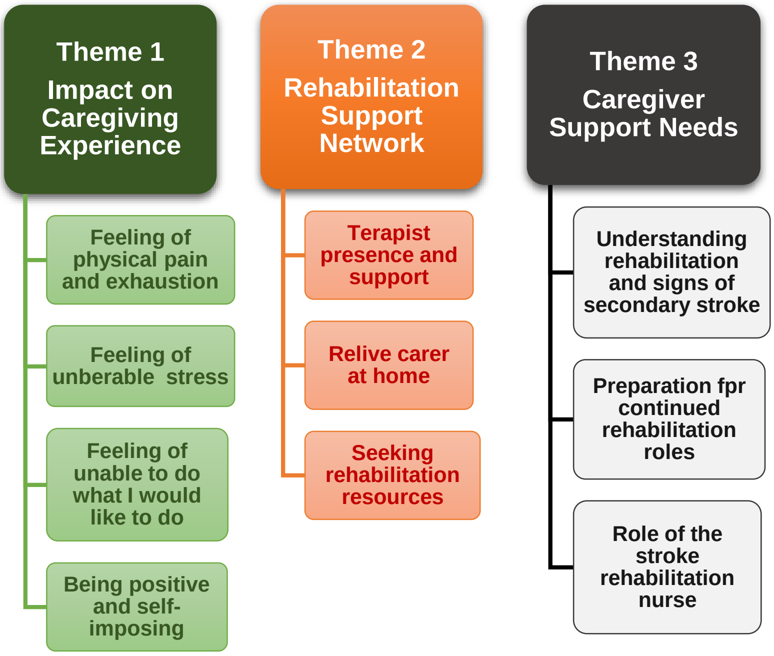


Diagram 13: Overview of themes and subthemes for carer participants

An analysis of participants' experiences of rehabilitation support needs revealed three over-arching themes: *Impact on Caregiving Experience, A Rehabilitation Support Network* and *Caregiver Support Needs.* The themes that were identified are divided into further subthemes and presented as follows:

5.4.1: Theme 1 Impact on Caregiving Experience

The carer participants' talked about their experiences on providing daily care activities for the stroke patients. The impact of caregiving roles appeared considerable, particularly during the initial adaption to home, which affects carers' health and well-being. Four keys, represented as subthemes, were identified: (1) feeling of physical pain and exhaustion, (2) feeling of unbearable stress, (3) feeling of unable to do what I would like to do, and (4) being positive and self-imposing.

Feeling of physical pain and exhaustion

All carer participants in this study care their respective stroke patient at home. Hence, required a great deal of physical effort from the carers, especially when the usual assistance from the healthcare providers suddenly discontinued after discharged home. The carer participants found themselves being alone and having to cope with responsibility of caring for the stroke patients. This abrupt roles and an expected events have led carers experience ongoing physical pain and exhaustion. For example, one carer participant stated:

"..ganya terpaksa inda bedangan..terpaksa tah..jua iatah ku kalau kadang kadang macam..cuba tah kau ani jangan camani..cuba tah anu bah..kau sendiri cuba..sendiri bejalan nyangku aku mendangani kau di belakang supaya ringan lagi badan mu atu nyangku..camatu bah..Aku yang kan [impak fisikal]"..(CP– 16).

TRANSLATED TO: ("I am often doing it [caregiving activities] alone. That's why I always encourages him [the stroke patient] to walk independently and I am only provide minimal support from the back. But this not happening. Consequently, I am physically suffered [in pain]") (CP – 16).

Another carer participant talked about a mismatch that existed between her physical size and that of the stroke patients. This unfavourable balance has gave negative consequences to carer's physical strength. This carer participant revealed:

"Memang mula mula inda biasa kan…sakit pulang badan ku…pasal barat kediaku dulu banar 60 okey lah..masa ani 56..takaut ku bah..kedia barat nya dalam dulu masa ia betahan di hospital 70 kan..masa ani dalam 80 labih kan..jadi kedia ku sakit badan" (CP – 09)

TRANSLATED TO: ("Of course at the beginning I am not used to it [caring a stroke patient]. I feel pain all over my body…because my weight is 60 kilograms before, and now is 56. I am worry. When he [the stroke patient] is admitted at the hospital, his weight is 70 kilograms…and now he is over 80 kilograms. So my body can't tolerate [to support him] which led to pain.") (CP - 09)

Furthermore, another carer stated a lack of adequate rest due to her caregiving responsibilities. This carer talked about how she has to stay awake at almost every night because the stroke patient was unable to asleep, and the following morning she has to provide care-related duty. She spoke of her physical exhaustion as follows:

"Kan kami kan sudah 24 jam..bedangan haji atu kan banyak jua kan harus di tolong..bukan nya exercise saja..jadi aku sudah macam ngaleh lah..kurang tidur juga ..aji kan kalau malam tidak tidur siang nya tidur..jadi kami pun ikut macam atu juga…jadi aku siang malam aku tidak tidur.. Jadi masalah fizik aku jua bah." (CP – 13)

TRANSLATED TO: ("I stay with Haji [stroke patient] for 24 hours. There were so many to do, not only exercises. So, I am physically exhausted and don't have enough sleep too. Haji didn't sleep in the evening, but during day time. Thus, I hardly have enough sleep throughout the day and night. It was physically demanding.") (CP – 13)

In summarising the above subtheme, the carer participants reported about the consequences of their caregiving roles on their well-being and shared their physical struggles, particularly during the beginning after discharged home. This finding seems to be similar problems facing other carers of the general population with stroke. Hence, the experience of the carer participants in this study was comparable across other settings outside Brunei.

Feeling of unbearable stress

This subtheme described the emotional impacts of caregiving roles on carer participants. Various reactions in the form of emotional disturbances were observed during the interviews. These include abrupt silences, weeping, holding back tears, sudden changes in intonation or carers' facial expression. As an example, the interview flow with the following carer was paused several times because she fell silent following interviewing few of the questions. It was found that this carer was experiencing a significant emotional burden, but was holding back her feelings every times she provides care in order to avoid offending the stroke patient. This carer participant disclosed:

> *"…ada merasa anu lah….macam kalau sudah ngalih atu kan…mudah rasa tertekan…tapi cuba jangan lah…macam atu…selalu mudah tersinggung….jadi kalau tersinggung karang…macam susah jua kan…jadi biar kan lah…buat aja macam atu.."* (CP – 02)
>
> TRANSLATED TO: ("…I do feel stress especially if I feel tired. But I try to control this feeling [stress]…not to feel offended [by too much care activities works]. If I am too sensitive, at the end I am the one who suffer too. So, I just leave it as it was.") (CP – 02)

Further, the data indicate that the authoritative behaviour of stroke patients towards their carer can adversely affect the carer's emotional wellbeing. For instance, this carer participant shared how the stroke patient was impatient and urged her to carry out caregiving tasks quickly, but this carer often lacked the capacity to keep pace with demands of the patient. This carer participant revealed:

> *"…aku pun ikut stress Lai. Sebab ikut stress…apa yang di mau nya atu…di kehendak nya tu…mau secepat nya bah…apa saja…mau mandi capat…mau makan capat…mau kan itu ani itu…semua capat bah… atu yang….aku tertekan…stress bah.. Sal kaki ku kan sakit kan bejalan capat…inda dapat…lapas atu marah tia…lambat nya"* (CP – 03).
>
> TRANSLATED TO: ("I do feel stress too. Whatever he [the stroke patient] wants, that needs to be done quickly. For example, helping him with shower, preparing meals…everything needs to be hurried. I often feel pressure and stress. It hurts my feet when I walk too fast. I just can't [walk fast]. But, this [delay] made him resent and said that I am so slow.") (CP – 03).

It appears that the demanding behaviour of stroke patients was an issue that was commonly confronted by carers. This carer participant explained how the patient became too demanding following the stroke and felt offended easily if his request was not fulfilled. The patient's insistent manner caused this carer to experience unavoidable stress. She stated:

> *"dulu inda pulang…now ia time nya sakit ani demanding berabis…kalau ia inda mau macam…ia mesti dapat kan jua apa yang ia mau…kalau inda ia menyamal the whole day..ia inda mau cakap sama the one yang ia mau atu…so catu lah..demanding lah. Membagi stress pulang jua."* (CP – 17)

> TRANSLATED TO: ("Before he is not [demanding]. But, after the stroke he became too demanding. He insisted to get all what he wants. Otherwise, he feel upset and will not talk to us. He's really really demanding and as a result made me stress.") (CP – 17)

Moreover, the account of one carer revealed that patients' negative behaviour may go beyond being demanding. This carer participant disclosed how the patient, who was her employer, appeared to be verbally abusive. Although this carer felt emotionally affected, this feeling was often ignored. The data implied that the employer-employee status seemed to prevent this carer from being emotionally open. She stated:

> "…sometimes she will said to me 'stupid idiot' like that… so it not nice to hear. Sometime I feel want to cry, but you are [only] *amah* [housemaid]…but she [stroke patient] should understand that we hurt too" (CP – 04)

Another paid carer, meanwhile, was seemed implicit regarding her displeasure of additional workload in caring a stroke patient. When this was explored, this carer participant appeared defensive and avoid direct confession for any negative consequences of caregiving on her health and well-being. However sharing her emotional disturbance, this carer participant hinted:

> "…sometimes I didn't always become happy. [But] I didn't want to think about the problem because I became stress. If I stress, my body and mind didn't relax." (CP – 20)

In summarising the above subtheme, the carer participants in this study displayed significant emotional disturbances resulting from the caregiving role. This finding appears comparable to that of other international studies. However, the manner in which the carer participants frequently conceal their emotions was arguably worrying. This proved that identifying carers' emotional problems may pose a greater challenge for healthcare professionals to ensure quality of life for these carers.

Feeling of unable to do what I would like to do

This subtheme described ongoing disruptions on carers' social activities and functions. For the majority of the carer participants, their feeling of being unable to socialise was predominantly due to the dedicated time spent with the stroke patient. Many carers reported intense difficulty of distancing themselves from the stroke patient or having some time for themselves, particularly during the first few months after the stroke where the patients were heavily dependence on the carer. For example, this carer participant stated:

> *"Dalam sebulan..sebulan atu full time tu. Kali paksa cuti kan, inda dapat mengerjakan yang lain tu because anu aa…daripada macam membersihkan apa kan…membersihkan ia apa itu ini* (CP – 01)
>
> TRANSLATED TO: ("Around one month, I have to do the task [caregiving activities] for full time. I have to take emergency leave. I cannot do any other tasks because I have to be with him…help him with bathing and so forth...") (CP – 01)

Moreover, the data revealed that the stroke patients' feeling of fatalism or negative thinking about their relationship with their carer appeared affect the carers' social functioning. A quote from this carer illustrated how she being preoccupied with care activities on a daily basis and explain the negative consequences if she was not around next to the stroke patient, as she said:

> *"Kalau masa first time ia kana atu..24 hours tu…menghadap ia saja tu…ada pun dalam mandi apa atu pun.bagi nya masa tu lima minit saja nya…even though macam menyediakan makan nya apa itu ini..inda dapat batah..kalau batah saja di cari nya..menanggis tah tu ia..fikir nya aku meninggal kan ia kan…iatah dalam masa nya anu atu… baru baru kana atu..buleh di kata kan 24 jam lah sama sama ia."* (CP – Pilot02)
>
> TRANSLATED TO: ("When he first got the stroke, it was like 24 hours. I need to stay with him. I can't take my own leisure time. In fact, he [stroke person] only allowed me to take shower for five minutes. If I wanted to prepare meal for him, I need to be hurry because he will started searching [calling] me. If I late attending him, he will started to cry because he taught that I'm abandon him. That's why during the early stage he has the stroke, I am beside him for most of the 24 hours.") (CP – Pilot02)

The social restricted times shared by the above carer was similarly experienced by the following carer. This participant disclosed how the stroke patient would verbally react if she was not in view. The quote from this carer indicates the severe interruption to her social functioning, as she sadly said:

> *"aku inda pernah tinggal kan dia..Pasal dia di tinggal pun teriak teriak..masih sampai sekarang."* (CP – 13)
>
> TRANSLATED TO: ("I never left him alone because he will shouted angrily if I'm not next to him…until today.") (CP – 13)

Meanwhile, accounts from one-third of the carer participants suggested that they tend to sacrifice their personal interests due to their caregiving demands. The over reliance of the stroke patients on the carer has caused carers' own will was not fulfilled. Quote from this carer illustrated:

> *"…aku payah kan jalan take care of him…macam aku pun payah cari keraja...thats why masa ani pun aku mengagur inda dapat keraja lah pasal aku menjaga ia" (CP – 17)*
>
> TRANSLATED TO: ("…it is so difficult socialise because I have to care and stay with him [stroke patient]. Because of this, it can't find a job. That why I am still unemployed. Because I need to care him.") (CP - 17)

Additionally, the data also revealed that the carers' personal goals were considered less of a priority, compared with the importance of providing care. As an example, one carer spoke of abandoning her plans to find a job or start her own business after her mother had a stroke. She stated:

> *"…aku jenis bini bini suka berdikari dari dulu…maksud ku suka bekeraja mencari duit..aku dari dulu lah..before ada business jua apa kan..so bekeraja..then aku beranti...so aku plan kan bekeraja lagi..tapi tekana my mum sakit atu..macam my plan atu inda lagi lah."* (CP – 06)
>
> TRANSLATED TO: ("I am type of person who like to be independent…earn income through my own business. I temporarily stop [business] due to illness. I did planned to resume working. But, since my mum has a stroke then I have to discard my planning [to work again].") (CP – 06)

In summarising the above subtheme, the care participants in this study described their limitation with regard to social functioning was largely related to their expected responsibilities as primary caregiver and the behaviour of the stroke person. This finding may be unique to the study setting, and thus add new knowledge to the existing relevant literature. In particular, the findings concerning the stroke patients' feeling of fatalism and unfavourable manners towards carers, denying the emotional burden, plus the carers' sacrifice of their personal agenda to give care, warrant immediate attention.

Being positive and self-imposing

This subtheme describes the carer participants' strategies for coping with the aftermath of the person's stroke. The data showed that many of the carer participants in this study applied the essence of Islamic faith and turned to Allah [God for every Muslim] for self-comfort and reassurance. Various expressions were illustrated by these participants to indicate their coping approaches, such as believing in *Hikmah* [reaping the benefits of the stroke], *Redha* [accepting the stroke with peace internally, often involving a high degree of faith in response to Allah's test], belief in *Rahmat* [good things will come] and being *Tawakal* [surrendering and feeling certain that Allah will help]. For example, this carer participant mentioned:

> *"…Memang beban lah..tapi sekarang alhamdulilah ada kurang..alhamdulilah..kami banyak support aji jua banyak kasi nasihat..kan…kalau memang ini satu anugerah..mesti sabar tawakal terima dengan ikhlas..Insya Allah semua ini akan sembuh..Insya Allah…Aamin."* (CP – 13)
>
> TRANSLATED TO: ("It is a burden…But I always support him and gave advice. If this [the stroke event] is a 'gift' from Allah, I must be *tawakal* and accept sincerely. *Insya Allah* [with God's willing], he will recover.") (CP – 13)

The interviews revealed that seeing the positive aspect of the stroke event appeared to involve a degree of acceptance of becoming a carer. The carer participants in this study asserted that the assumed caregiving role was a predetermined destiny set by Allah, and so represented part of the carers' fate. Over half of the carers indicated that being sincere was essential in order to cope with undesirable outcomes of the stroke. For instance, this carer deliberately ignored the burden of becoming a carer, and instead sought Allah's mercy to help her perseverance and endurance. She suggested:

> *"…jadi aku macam malas kan di fikir fikir kan mun sudah di takdir kan macam ani menjaga orang sakit nyangku..ku nya orang rela lah..redha lah nya orang….ia tah biasa saja lah" (CP – 12)*
>
> TRANSLATED TO: ("…for me, I don't want to think too much about it [caring a stroke patient] because I believed it was destiny to look after sick people. I am sincere and being redha...thus I feel normal [no negative impact from caring a stroke patient].") (CP - 12)

Likewise, the data revealed that the coping mechanisms for the non-Muslim carers were comparable to those of the carers who were Muslim. For instance, this carer participant appeared to adopt a positive thinking approach and to engage in self-appraisal. The account of this carer illustrated how she looks at the brighter side by living with her employee, although she disclosed that she was not entirely happy. This paid carer asserted:

> "…sometime she made me sad and sometime she made me happy..aa. And again I proud to say that I live with her. Because i didn't miss my family in the Philippines."(CP – 04)

Another carer participant, meanwhile, proposed three interconnected religious attributes that were crucial in enabling carers to cope with their caregiving difficulties. A quote from this participant indicates how these attributes can give carers internal strength and a feeling of acceptance following the stroke. She stated:

> *"Yang pertama mesti dulu menerima kenyataan..menerima kenyataan..aa iatah tu anu yang di berikan Allah Ta'ala ani tah ani. Kemudian yang kedua apabila kitani sudah menerima kenyataan, redha. Selepas redha, baru tah kitani dapat menghadapi atu semua atu kan"* (CP – 01).
>
> TRANSLATED TO: ("First, accept that the stroke is sent by Allah Ta'ala. Secondly, feel *redha* [approval, often involving a degree of fondness]. After *redha*, only then we can cope with this situation [the aftermath of the stroke].") (CP – 01).

On the other hand, the interviews revealed that an intimate relationship between the carer and stroke patient enabled the carers to cope more positively with their caregiving experience. Many accounts of the carer participants indicated that providing care for stroke patients was regarded as a cultural and religious obligation. Thus, most of these carers would not perceived that their duties were physically or mentally burdening, despite the intensity of care activities provided by carer was evident. One carer illustrates this and affirmed:

> *"…beban atu ada jua…tapi terpaksa jua kan kitani nya orang berkorban. Sebab ia macam kira…kitani punya…sudah family atu macam inda dapat kitani biarkan jua bah….sebab nya…ia kesian jua kan ia nda upaya".* (CP – 03).
>
> TRANSLATED TO: ("…there is a burden…but I have to make the sacrifice. Because he [the stroke patient] belongs to us…as part of the family…I cannot ignore him…because I felt pity for his condition now [physical impairment].') (CP - 03).

This view was also shared by another carer, who was the wife of the stroke patient. This participant indicated how honouring her wedding vows was key to resisting the challenges and bearing the burden of caring for her husband. She asserted:

> "*Walaupun ia payah..tapi ku kuat kan jua hati ku..rasa ku kan kedia atu ah…rasa kan laki..paksa ku kuat kan hati ku tenaga ku semua lah untuk membangun kan ia lah..and then apa yang ku buat arah nya atu..macam tindak balas nya ada bah..iatah aku rasa puas macam aku inda menyesal apa yang ku bagi ia penjagaan semua lah ah..atu yang ia ada tindak balas atu tah membuat puas lah..Satu memang sudah tanggung jawab sebagai isteri."* (CP – Pilot02)
>
> TRANSLATED TO: ("Although it was difficult, I forced myself to do it [caregiving tasks]. Because he is my husband, so I need to be strong emotionally and physically to help him recover. I felt satisfied because he responded well to activities that I gave him. I don't felt regret. Furthermore, it [caring role] already part of my duty as his wife.") (CP – Pilot02)

A similar comment was reported by a carer who was the husband of the stroke patient, who indicated the importance of the contractual obligation between husband and wife. He declared:

> *"Tapi ada orang tu kalau malas..inda rajin kan..eh sama jua bini ani..apa nya..tapi inda guna camatu..macam aku satu kewajipan lah..satu kewajipan aku lah bini ku atu."* (CP – Pilot01)
>
> TRANSLATED TO: ("some spouse carers may feel reluctance to help their wife. This is not acceptable. For me, she is my obligation…my obligation as my wife.") (CP – Pilot01)

For a daughter who assumed the carer role, the data revealed that she felt very little burden due to caring for the stroke patient. This participant described how her current duty was regarded as an opportunity to repay her dad, who successfully brought her up from childhood. This carer confessed:

> *"I don't feel rasa burden lah I think…pasal that's my dad…ia pernah bersusah payah macam tani dulu damit so ani masa nya untuk berdikari…ani lah masa nya untuk membalas jasa nya."* (CP – 17)
>
> TRANSLATED TO: ("I don't feel burden because he [stoke patient] was my dad. He ever struggled to look after us when we were young. So now it was the right time to be independence and repay his good deeds.") (CP – 17)

For the paid carers, however, the data suggest that being positive was motivated by financial gain as a result of being employee. A quote from this paid carer participant exemplifies this:

> "Because she hired me to be her maid. So, I have to do it [caregiving tasks] even it was though. I wanted to resist, but I cannot resist because it was my duty to take care of her." (CP – 04)

In summarising the above subtheme, the data illustrated that a strong faith and a close carer-patient attachment were reasons for the participants feeling positive. This finding can be unique to the sample of this study, in particular the coping strategies that appeared associated with religion and culture. Although the benefits of this strategy was evident, arguably, these coping motivators may not be sustainable without an appropriate supportive network. This finding indicates that involvement by individuals outside the health organisation seems necessary.

Overall summary of the theme

The example quotes from this theme: *impact on caregiving experience,* illustrates how the stroke carer participants endure considerable amount of physical, emotional and social problems as consequence of providing care for the stroke patients. Evidently, the carer participants in this study remained being positive about their caregiving burden and utilised faith as coping approach. The absence of home-based provision to support these carers, perhaps, necessitate such coping strategies.

5.4.2: Theme 2 Rehabilitation Support Network

This theme refers to the carers existing support network that would assist them in continuing rehabilitation therapy for stroke patients at home. The carer participants spoke about the importance presence of the therapist, availability of another caregiver and outsourcing treatment for recovery of the stroke patients, as central to facilitate carer adaptation to home and avoiding *"mudarat"* (detrimental effects on stroke patient as a result of carer actions). Three supportive network, represented as subthemes, were identified: (1) therapist presence and support, (2) relieve carer at home, and (3) seeking rehabilitation resources.

Therapist presence and support

This subtheme refers to the importance of therapist presence throughout the stroke patient rehabilitation session and the professional qualifications of the therapists. Accounts from the carer participants illustrated that the skills and knowledge competencies of these therapists were fundamental for the stroke patients' recovery. For example, this carer participant talked about the advantage of expert therapist whom could help carer understand about the therapy provided, as she stated:

> *"…Kalau kebaikan..of course lah durang dapat membantu kami kan ..tapi kalau ada yang macam yang lebih berkemahiran atu..kalau ada lah ah..Alhamdulilah okey lah..supaya dapat membantu kami dalam terapia nya tu lah"* (CP – 08)
>
> TRANSLATED TO: ("Of course, the benefits of the therapist is that they can help us [understand about the therapy]. Those therapist who are expert in this field (rehabilitation) can ease us in caring him [the stroke patient]") (CP - 08)

Moreover, the continued presence of therapist can be central to show and guide carers on how to monitor progress of the stroke patient's responses to the therapy and as a source of support. For example, this carer was feeling uncertain regarding rehabilitation exercises that best suit to the changing needs of the stroke patients' recovery. Thus, this carer revealed that the presence of therapist could ease this concern. Quote from this carer participant illustrates:

> *"Kadang nya sebanar nya Lai…ia macam…ia ber step-step...anu terapi atu kan, jadi nya kalau step nya atu hari macam…ani step sudah bagus ani…step ani lagi…jadi kitani kadang kadang buleh kitani lupa bah yang step atu…jadi kitani buleh lagi…kalau datang kesana lagi…step atu kitani lupa…buleh tanya durang lagi…jadi kitani di berinya tahu…aa…baru kitani buleh lagi membuat lagi di rumah."* (CP – 03)
>
> TRANSLATED TO: ("The rehabilitation therapies have different steps. If this step already successful, then need to move to next step. At times, I forgot [the subsequent exercise]. If we came here [the out-patient session], the therapist will be around to help.") (CP - 03)

The majority of the carers agreed that attending the out-patient therapy and the support of the therapists on the stroke patients' physical and emotional well-being were notable. The carer participants described how the structured therapy gradually improved the stroke patients' recovery and physical independency. As example, this paid carer participants stated:

> *"…peningkatan nya yang paling atu lah..dulu cakpa ngak berapa tembus..terus dulu tak bias bangun…sekarang bias bangun" (CP – 13)*
>
> TRANSLATED TO: ("The most notable improvement is speech. Before he [stroke patient] cannot speak clearly. Additionally, before he cannot stand …now he can do it alone.") (CP - 13)

However, about one-third of the carer participants argued that patients' recovery resulting from the rehabilitation exercises was hardly noticeable. These carers commented that the lacked of recovery on the stroke patients was down to the limited therapy duration. For this paid carer participant, he observed that the therapy provided was very brief and he seemed not satisfied with the allocated timing, as he reported:

"…Masa nya menurut saya si kurang masa nya tu. Pasal cuma itu kena suruh melimpang buat macam ni cuba beberapa minit terus sudah. Terus ganti sama yang lain. Cuma masuk tangan, dalam lilin, sudah. Cuma kurang masa nya" (CP – 16)

TRANSLATED TO: ("…In my opinion, the duration of the therapy is less. [For example] he [stroke patient] was asked to lay down on the couch for few minutes. Follow by treatment of hand using the candle. [These completed the therapy session]. I felt the timing is not enough") (CP - 16)

Hence, few participants viewed that sending patients for their therapy was considered non-rewarding. As an example, this carer appeared to be discouraged by the outcomes of the limited therapy provided and suggested that more time was needed to reap the maximum effect. She explained:

"I think macam kalau ia datang sini atu macam inda jua ia ada baik atu macam inda jua baik macam nothing ia came here every week one day saja..kalau ia datang sini everyday yes atu tantu ia macam exercise oeky…ani macam every week atu one day saja datang…so I think macam nothing macam nada bah…Sal it only take you like thirty minutes to foty-five minute doing jalan saja. So not really so important lah…if ia every day yes it important but if one day like only take 45 minutes I don't think so." (CP – 17)

TRANSLATED TO: ("I think if he [stroke patient] come here only once a week, I don't' think he's improving. But, if he come here every day, definitely yes. His exercise will be okey. But, for now only once in each week. So I think like there is nothing. Because it [therapy] only last about thirty minute to forty-five only. So I don't think attending the current therapy is important, unless it [therapy] was provided every day. [However], if one day and 45 minutes only, I don't think so [important].") (CP – 17)

Nonetheless, numbers of carers aware that recovery from stroke would be gradual and took several months. These carers agreed that the stroke patients may not 100% recovered completely and being normal as before. Hence for this spouse carer participant, it still crucial to attend the weekly therapy and maximised the allocated out-patient therapy schedules. She stated:

"… Pasal masa di sini inda cukup bah..its limited kan. Iatah macam rugi bah rasa nya kalau inda datang kah apa kah..kalau..pasal kalau di sini seminggu sekali..dalam sebulan pun kira kan dalam empat kali saja'. (C – 02Pilot)

TRANSLATED TO: ("The therapy time is not enough…it's very limited. Therefore, it was a loss if we didn't attend the out-patient therapy. It only once a week, and total of four sessions per month") (CP – 02Pilot)

In summarising the above subtheme, the data suggested that the carer participants in this study help differing views with regard to the rehabilitation support provision provided by the hospital. The presence of the therapists and their roles on the stroke patients' recovery were valued. However, the issue with regard to the inadequate therapy duration may consequently place more demand on carers to provide continued therapy at home. This over reliance on carers suggests that a community-based stroke rehabilitation to support these carers is needed.

Relieve carer at home

This subtheme refers to the available support for the carers at home from other individuals within the family or hired personnel. It was observed that most of the carer participants in this study live within extended family orientation. The carers would have children, siblings or closed family members who formed wider familial support network. However, the data revealed that availability of relieve carer was often inconsistence or unavailable on daily basis. This was due to the family members staying at separate house or was not regularly at home due to work commitment. As an example, this carer participant spoke about support from her son who was not regularly present due to them living separately. She indicated:

> *"Lebih Lai …macam rasa ku inda banyak…inda banyak ku anu bah….banyak nya yang sama ia bah…kadang-kadang…hari minggu atu Alhamdulilah…lah… ada..hari jumat atu kanak-kanak menolong memandihi "* (CP – 03)
>
> TRANSLATED TO: ("I didn't have time [for myself]. [I spend] lots of time with him [the stroke patient]. Our children only come to help occasionally, either Sunday or Friday. But, *Alhamdulillah* [feel relief if children come to give support].") (CP – 03)

Evidently, caring the stroke patients alone appeared the recurrent narratives identified from the interviews data. Despite the larger family set-up, lacked of anticipated relieve carer was inevitable. For example, this daughter carer of stroke patient spoke about being alone particularly during working or school hours. She stated:

> *"Macam macam kalau sekiranya macam my mum kan keraja..my sister my second sister and the bungsu and my kaka durang keraja seorang sekolah…and I am the one yang tinggal di rumah..aku paksa menjaga ia" (CP – 17)*
>
> TRANSLATED TO: ("My mum is at work. All my sisters are at work. My other sibling is at school. I am the only one who stay at home alone with him [stroke patient].") (CP - 17)

Another carer participant, meanwhile, revealed that caregiving tasks that required physical effort often delayed due to absence of help from other family member. This carer participant talked about waiting her sibling from work before able to accompanying her with lifting the stroke patient to the washroom. This participant described:

> *"Mula mula payah pulang tu ia inda dapat bejalan atu..membawa ia ke jamban apa..membawa ia ke kursi roda apa payah. Kalau ia udah di ruma atu..sanang tia..kadang nya di rumah pun kami..tiga bulan ni kami tinggal di tanah jambu..iatah kena paksa lah ikut..tunggu adi ku lah mendangani membawa ia ke jamban apa.. (CP – 05)*

> TRANSLATED TO: ("At the beginning after his discharge, we have to stay temporarily at Tanah Jambu [grandfather house]. I have to wait for my sister from work to help me with showering our dad". (CP – 05)

One the other hand, the account of this carer revealed that family member would decline sharing responsibility with caring the stroke patient. This carer participant stated that her sibling was reluctant to become involved, and thus left the care duties alone to her. She said:

> *"..ada pulang peradian lain ani..aduh malas cakap yang laki laki lah..mungkin abang ku seorang atu lah.. langsung nda anu inda berapa berapa peduli..iatah atu lah saja kami anu saja membantu..ia kan..Kesian jua kan..kalau inda di bantú..karang siapa yang susah..sendiri jua.."* (CP – 12)
>
> TRANSLATED TO: ("I have other brother, but he hardly give attention and keen to involve. So, I have to care him [stroke patient] alone. I feel pity at him [stroke patient], but if nobody care him, then eventually I will suffer too.") (CP – 12)

For minority of the carer, hiring private helper such as experience *amah* (housemaid) is considered a viable option to provide additional support or act as care substitute. The data suggested that the *amah* is often employed following the stroke patient discharged home. One of the participants stated:

> *"..Aku sama my maid saja..yang lain atu inda… My maid ani pun alhamdulilah…aku baru dapat kedia..baru mengaji kedia..tapi ia so far ia ada pengalaman menjaga orang sakit macam ani wah..alhamdulilah lah..* (CP – 06)
>
> TRANSLATED TO: ("I only have my maid. Other [family members] are often not around. I am grateful [*Alhamdulillah*] to get this maid because of her previous experience looking after stroke patient. I just hired her recently. *Alhamdulillah*".) (CP – 06)

However, the capacity of the paid carer (*amah*) to provide the anticipated standard of care for stroke patients was viewed with caution. This carer participant indicated concerns regarding the knowledge and skills of these relieve carers about managing a stroke, as the quote from this carer participant exemplifies:

> *"Tapi kalau di rumah, aku inda tedapat pembantu rumah..inda ku tedapat..mungkin inda tahu lah satu satu masa akan datang kali lah..mungkin kali ada..baru tah ku ngambil pembantu rumah..atu pun alum jua harap nanti..sebab apa kan..baik ia tahu..ujung ujung..catu lah."* (CP – Pilot01)
>
> TRANSLATED TO: ("At this moment I do not have *amah* (paid carer). Probably I'll get one in the future. I am not sure yet. But, if there is *amah*, we can't certain that she knows how to care a stroke patient, thus [hiring them] can be risky.") (CP – Pilot01)

Crucially, the effectiveness of support network at home was succinctly summarised by this carer participant, who suggested three inter-related individuals; the carer, the stroke patients and the family members that should work collaboratively, as she described:

> "…the thing [about rehabilitation support at home] is depend on the carer…the patient and the family member. If the famly member didn't support..or maybe because they have like work…like for married people, they have other commitments. But like us, we didnt have much commitment beside house chores….so it was fine [providing full attention for the stroke patient".] (CP – 11)

In summarising the above subtheme, the accounts of the carer participants in this study illustrates considerable issues with regard to availability of continue support for carer at home. The manner in which carers have to provide full-time care duties alone, indicates that strategy to support these carers, such as providing rehabilitation nursing home visit, was essentially needed. This finding suggest existing service gap in the provision of support for carers of stroke at home, thus appropriate intervention was urgently required to ensure carers' quality of health and well-being is improve.

Seeking rehabilitation resources

This subtheme refers to the initiatives undertaken by the carers in seeking external source of treatments in order to expedite recovery of the stroke patient. It was a common practice in Brunei that people would seek the traditional healers as form of supplementary treatments to the modern medicine after ill-health. Typically, the application of massage (*urut*) by the *Ustaz* (religious person) was considered relevant to stroke. The positive perceptions among the wider population regarding the benefits of *urut on* stroke, many carers remained committed to involve *urut* practitioner as part of additional rehabilitation support. As example, this carer participant disclosed:

> *"Usaha kami lah ah..kami panggil ustaz untuk mengurut…"* (CP – 08)
>
> TRANSLATED TO: ("Our effort is to summon *Ustaz* (traditional massager) to provide *urut* [massage]".) (CP – 08)

The data also showed that many carer participants held firm believe that traditional practice of massage (*urut*) could significantly improve stroke patients' physical functions. This was evident, as illustrates by an excerpt from one of the carer participants who stated:

> *"Macam awal awal atu ia inda dapat bejalan kan tu..kami panggil ada orang macam kita mengubati orang di luar..mengurut..di rumah..baru tah..kuasa Allah Ta'ala..baru tah ia buleh begarak inda mengunakan wheelchair..pakai tongkat saja"* (CP – 10)
>
> TRANSLATED TO: ("At the beginning he [stroke patient] cannot walk. So we called someone to do *urut* at home. By Mercy of God (Allah Ta'ala), only then he can walk again without using a wheel chair…he only uses walking stick.") (CP – 10)

Moreover, the apparent benefits of *urut* on the stroke patients often influence others to seek similar approach. This information exchange for finding an established traditional *urut* person often shared among the stroke patient groups. This carer participant reported:

> *"Bertoleh-tolehan tah durang among durang ani.."wah ok aji buleh bergarak sudah..bah bergarak" macam atu. Masing-masing memberikan encourage among persakit atu bah. And then memberi information.."eh..capat jua kau bergarak ah? Apa kau anu?"…"eh…aku berurut" .. macam atu bah."* (CP – 01)
>
> TRANSLATED TO: ("The stroke patients will look at each other and compared their physical improvements. All will encourages and exchange information about how they quickly recover. They will asked how they improve. They will recommend a known *urut* practitioner" (CP – 01)

Conversely, the application of *urut* was not necessarily effective. The account of this carer reveals how seeking modern therapy is often only considered if *urut* was not work. This delaying time for seeking hospital care may detrimental to the stroke patient's outcome. A quote from this carer illustrates:

> *"katanya inda dapat bejalan...kali ber urut lagi lah memanggil lagi orang apa ber urut kan…mudahan aja dapat bejalan lain inda pulang…asal ia dapat bejalan..inda jua dapat..bukan ia..dari atu..mesti jua bawa ke hospital kan."* (CP – 12)
>
> TRANSLATED TO: ("He [patient] complained cannot walk. So, I called the traditional practitioner to perform *urut* hoping this treatment can make him walk again. Unfortunately, the *urut* was not effective. Only then we bring him to the hospital." (CP – 12)

This carer, meanwhile, mentioned the therapist's disapproval of the uses of an *urut.* This carer participant was taught about the importance of continued modern rehabilitation therapy and avoidance of *urut* in order to prevent unknown harmful effects, as he mentioned:

> *"Durang ajar bahangin exercise..macam exercise sakit punggung atu..mengurut apa..kata nya inda buleh di urut,"* (CP – 05)
>
> TRANSLATED TO: ("They [therapists] taught us about exercises. Such exercise on this lower waist. But, *urut* they [therapists] said was not recommended." (CP – 05)

In summarising the above subtheme, it was evident that carer participants in this study sought external sources of support to manage the stroke patients' rehabilitation. Although the broader acceptance of the *urut* among the carers is apparent, the unknown harmful effects of this practice and the unnecessary delay time caused by seeking *urut* as the first line of treatment for stroke were ostensibly worrying. This finding indicates urgent needs of educational intervention on the importance of timing in acute episode of a stroke.

Overall summary of Theme 2

The example of quotes on this theme: *rehabilitation support network,* indicates that carer participants in this study experience substantial difficulties to establish sustainable support from the healthcare professionals and immediate family. The issues pertaining to duration of therapy, as similarly reported by the stroke patient participants, and absence of relieve carer were of a considerable concern. Outsourcing the rehabilitation support for stroke using the traditional practice of *urut* seem risky and debatable. This finding illustrates service gaps in providing support for carers of stroke at home setting, therefore introducing the stroke rehabilitation nurses, complement the existing service, may have potential to address this shortfall.

5.4.3: Theme 3 Caregiver Support Needs

This theme refers to the needs of the carers with their rehabilitative support roles for stroke patients at home. It highlight the carers' daily activities and functions that frequently fluctuated throughout the stroke patient recovery continuum. The interviews explored the carer participants' support needs at home. Three 'felt' needs, represented as subthemes, were identified: (1) understanding rehabilitation and signs of secondary stroke, (2) the preparation for continued rehabilitation roles, and (3) the role of the stroke rehabilitation nurse.

Understanding rehabilitation and signs of secondary stroke

This subtheme refers to the educational requirement of carers in relation to the aspects of strokes and their understanding regarding providing continued rehabilitation for the stroke patients. The importance of carers and other family members of the stroke patients in recognising the warning signs and symptoms of secondary stroke, or the significant of rehabilitation for stroke were vital in reducing post-stroke mortality. However, the data reveals that the majority of the carer participants have limited understanding about these aspects, particularly before the stroke events, and appeared uncertain with what constitute post-stroke rehabilitation. More than half of the carer participants attributes stroke that was caused by stress, over work, general malaise, poor diet, ignored medications or to certain extent factors that cause of a stroke was unknown. For example, this carer participant was uncertain why her father had a stroke, despite his general health is satisfactory, as she claimed:

> *"Kalau punca strok not sure lah..tapi kalau my dad ani…ia nada penyakit…tapi jantung pulang saja..tapi ia ani maybe telampau banyak berfikir..pasal kami pernah check macam ia punya darah tinggi apa..semua normal."* (CP – 08)
>
> TRANSLATED TO: ("If causes of stroke, I am not really sure. My dad has no previous medical problems, apart from heart. Maybe, [cause of stroke]

> is due to him thinking too much. We have checked his heart and blood pressure before and the result was normal.") (CP – 08).

For minority of carers, meanwhile, stroke is believed to cause by evil wind, locally known as *Angin Ahmar.* The carers' description of this stroke appears inherited from older generations and often related to the Malay culture and religious belief. As example, this carer accurately identified facial weaknesses as typical signs for stroke, but failed to associate the impairment with the modern clinical diagnosis. This carer participant reveals:

> *"Strok ani…ia macam cakap melayu nya…angin ahmar…aa ia kadang kadang macam kana angin ahmar ani mulut singit..atu saja yang ku faham…yang lain2 atu inda pulang tahu."* (CP – 12)
>
> TRANSLATED TO: ("This stroke, in Malay terminology was known as *Angin Ahmar.* Often, this *angin ahmar* caused drooping at one side of the lips. This what I only know. Others [caused of stroke] are unknown.") (CP – 12).

The data also showed that carers' understanding about rehabilitation and what it entail was lacking. It was observed that 'rehabilitation' is an unfamiliar term to most of the participants, and instead substitute it with 'exercise' in their daily conversation. As example, this carer participant talked about observing initial exercise for the stroke patient, but she was uncertain the importance of this session for stroke recovery. Quote from this carer illustrates her lacked of understanding concerning rehabilitation for the stroke patient, as she stated:

> *'… (suami) inda dapat berdiri kan tu,just melimpang saja and then berpusing di pusing kan. Sekali mula mula masuk atu di beri tahu cara nya berdiri macam mana, macam mana kan bangun, and then goyang goyang badan atu rupa-rupanya untuk anu balancing…balancing, mula mula blank pulang..."* (CP – 01)
>
> TRANSLATED TO: ("My husband was physically dependent. When the therapists came, they assisted my husband how to stand, get out of bed, and move his body. I initially felt blank [thoughtless]. Until at a later stage I then realised that those [activities] actually were for balancing and important for the recovery...") (CP – 01).

The interviews explored carers' views regarding the benefits of rehabilitation therapy for the stroke patients. Most of the carers talked about how the therapies would focused primarily on re-establishing the stroke patients' physical functions. The data revealed that none of the carer participants recognised that rehabilitation may equally improve the stroke patients' emotional, cognitive or social functioning. It appears that the visible effects of the therapy on the stroke patients' physical recovery influenced how these carers contextualised rehabilitation. One of the carer participants mentioned:

> *"Atu untuk memulihkan ia balik lah supaya ia inda macam..kalau orang banar2 strok ani..yang ku tahu lah ah..kalau orang banar banar nda membuat apa2..ia jadi macam banar banr lumpoh lah..lumpoh inda dapat bergarak apa semua…semua kan di buat kan..sekiranya kalau kan di angkat..mengangkat tah kitani..atu camatu bah..so dengan*

> *pemulihan yang ada di JPMC ani atau pun mana mana hospital..mungkin ada baik nya juga..kebaikan nya supaya macam ada otot otot nya bejalan bah begarak…apa oleh durang apa kan… Alhamdulilah sedikit..tangan nya ni yang pandai mengaras..catu wah.."* (CP – 06)
>
> TRANSLATED TO: ("That [rehabilitation] is for physical recovery. For stroke, they will permanently disabled if he didn't do anything. But with the availability of therapy such as in JPMC, it improve the body muscles so that the person can walk again. *Alhamdulillah,* now he's able to use his stroked hand after the therapy.") (CP – 06).

The needs for continued rehabilitation therapy at home was broadly acknowledged by the majority of the carers. However, the data showed that carers' knowledge about the appropriate ways of performing those rehabilitation exercises, as comparable to that of the healthcare professionals, was inconsistence. Few carers spoke about limited skills to support rehabilitation of the stroke patient at home. For example, this carer participant illustrates:

> *"Atu memang perlu lah..perlu di sokong..pasal macam kitani inda tahu (macam mana) memperbaiki keadaan atu lagi lah…atu lah yang penting..kitani….macam kami kan..inda lagi..pengalaman inda nya orang..cuma tahu dari jururawat.tapi yang baik nya jururawat lah paling penting lah..untuk menunjukkan cara..exercise."* (CP – 09)
>
> TRANSLATED TO: ("We needs support [from the healthcare professionals] because we didn't know how to manage the stroke patient's condition. This is important as we didn't have any experience. We relied on the nurses to show us how to do the exercises.") (CP – 09).

Essentially, this carer participant highlight the importance of having a knowledge in rehabilitation for ensuring the wellbeing and safety of the stroke patient and carer, as she disclosed:

> "I think transferring her [stroke patient] onto the wheelchair is challenging. If you don't learn the technique properly, you might hurt her or you might get hurt. I frequently get hurt. To adapt is very difficult." (CP – 11)

In summarising the above subtheme, carer participants' understanding with regard to a stroke and the physical exercises of rehabilitation for the stroke patient were intangible. The various interpretations for factors caused a stroke and uncertainty about the rehabilitation exercises suggested that providing access to appropriate health resources may improve the carers' awareness about secondary stroke and lessening post-stroke disability.

Preparation for continued rehabilitation roles

This subtheme refers to any formal or informal training that was provided by the healthcare professionals to prepare the carer on resuming exercises (rehabilitation) whilst the stroke patients are staying in the hospital and prior discharge home. Accounts from the carer participants suggested that the existing training in this aspect was largely undertaken as ad hoc basis or it was completely absent. About one-third of the carer participants revealed that they were not shown about how to continue the therapy and frequently left with feeling of uncertainty. As example, this newly experience carer participant talked about lacked of information provided regarding continue exercises and handling of stroked limb, as she stated:

> *"And then early stage pemulihan macam mana..kan…early stage pemulihan. Masa ia belum bangun atu..what can we help..untuk ia dapat bergarak…Tapi dari segi pergarakan, apa pergarakan yang boleh di buat pesakit atu at the early stage. Nada kan ia melimpang-limpang saja kan. Inda jua sehat tu. Mesti ada sesuatu macam di garak kan tangan..macam mana mengarak kan tangan nya..macam mana apa kan..Ia kan kena beritau jangan anu kan takut dislocate kan, tapi macam mana? What is the right way? Kalau kitani kan meengangkat, kalau kitani kan mengarakkan, supaya ia dapat activate balik ia punya anu atu kan."* (CP – 01)
>
> TRANSLATED TO: ("At the early stage of the rehabilitation, what can we help [the stroke patient] to recover quickly. In the aspect of physical movement, what can the stroke patient do at the early stage? They cannot be laying on the bed whole times. There should be exercises that we can do to help him recover. I was cautioned about shoulder dislocation, but how [to prevent this?]. What is the right way? I wish to perform the exercises so he can reactivate his stroked limb.") (CP – 01)

Moreover, the data indicates that some carers took own initiative to observe the therapist actions during the stroke patient rehabilitation out-patient session. This indirect self-learning strategy seemed triggered by carer personal determination so that they can apply the therapy at home. This, in turn, enhanced the recovery of the stroke patients. One of the paid-carer participants mentioned:

> *"Aku selepas di sini liat itu fisoterapi nya tu sal dia kan buat buat aku liat kan senang aja aku buat exercise di rumah…macam atu..ani gerak kan gerak kan… dari sini ke belakang ke depan..macam atu."* (CP – 14)
>
> TRANSLATED TO: ("When I came here [rehabilitation centre, I frequently observed the physiotherapist activity, such as moving the limbs or walking forward and backward. This help me learn easily and applied the exercise at home.") (CP - 14)

The interviews found that the difficulties for the carers to manage the stroke patients following discharge usually felt during the early transitional period after they went back home. The data showed that many carer participants highlight their early struggle to cope with unexpected roles and the complexity of the caregiving tasks. For example, this daughter carer participant appeared felt not prepared to assist her stroked dad with daily routine, as she revealed:

> *"I don't think they prepare about the role.I felt difficulty during transitional period from hospital to the house. Yang paling di rumah paling payah lah. For the first time I felt lost..pasal kan kalau tani mandi kan atu we didn't…pasal my dad is my dad..i am a girl that my dad..kinda awkward...so catu lah seksi bah…feel awkward."* (CP – 17)

> TRANSLATED TO: ("I don't think they prepare about the role. I felt difficulty during transitional period from hospital to the house. At home, it was extremely difficult. For the first time I felt lost. To help him [her dad] with shower, I felt so embarrass and awkward.") (CP - 17)

On the other hand, the majority of the carers agreed that certain teachings or training about the importance of continuing rehabilitation therapy at home and how to do the exercises were normally given. This on-site teaching frequently delivered by the therapists, and very rarely provided by the ward nurses. One of the carer participant illustrates this in her quote:

> *"…Kadang-kadang nurse….yang buat di ward….physio di sini….durang lah yang mengajar. Pasal selalu nya aku yang ikut ke sini… macam antar ke sini…jaga di ward di atas…jadi durang ajar lah untuk membuat di rumah"* (CP – 02)
>
> TRANSLATED TO: ("At times, the nurses provided the teaching in the ward. Here, [rehabilitation centre] the exercise was taught by the Physiotherapist. I knew this because I always sent her to the centre and look after in the ward. So, they whom actually taught us on what and how to do it [exercise] at home.") (CP - 02)

However despite the teaching activities were evident, the data suggested that most of these educational engagements took place as ad hoc basis. Collectively, the carer participants talked about how the demonstration of the rehabilitation exercises were typically conducted whilst the stroke patient is undergoing the therapy session. But, it is not clear if the carer would be given opportunity to show their competencies to the therapist after the skills was taught, and neither their techniques were being evaluated. This unstructured teaching method seemed the common practices in the rehabilitation centre. Quote from this carer participant exemplified current carer preparation teaching approach:

> *"…Kalau terapi aku selalu yang tunggu…jadi aku tahu dari situ lah..Ada terapi ajar…memang terapi itu memang mengajar aku jua..kadang kadang kalau dia buat aku di suruh nya buat jua di sini.."* (CP – 13)
>
> TRANSLATED TO: ("If we went to the rehab centre, I am the one who accompany him. Here, the therapist will teach me about how to do the exercises and advise me to do them [exercise] at home.") (CP - 13)

The preparative teachings for the carers pertaining to continue rehabilitation therapy at home, nonetheless, was viewed positively by many of the carer participants. The emphasis on rehabilitation exercises has given carers certain degree of understanding and skills that would contributes to the recovery of the stroke patients. The carers were grateful about the assistance provided and felt that the teaching were sufficient in preparing them with carry-on exercise role at home. One of the participants illustrates:

> *"…Alhamdulillah lah banyak membantu..pasal kami di rumah pun inda banyak tahu bah macam mana..jadi nya…durang di sini banyak membantu mengajar kami..camatu kan..macam camana cara nya mengerak kan apa memandi kan…camatu kan…so far okey Alhamdulillah durang banyak membantu kami lah."* (CP – 08)
>
> TRANSLATED TO: ("*Alhamdulillah* [feeling grateful to God]…they [therapists] have helped us a lot. Here, they help to teach us what and how to do the exercise on the stroked limbs and assist with showering the stroke patient. So far, *Alhamdulillah*, they really have helped us a lot.") (CP - 08)

In summarising the above subtheme, the data showed that carers in this study were not fully prepared to assume the rehabilitation therapy support roles at home. The initial transition from the hospital to home were perceived as the most difficult and challenging period. The existing carer preparation before going home was generally lacked of structure and can be inconsistence. Finding of this study which reveals some carers adopted self-directed learning to gain skills about the rehabilitation therapy may indicates that the current preparative teaching approach was limited. Thus, it may be necessary to re-evaluate the provision of teaching for this carers in order to facilitate adaptation and improving their quality of health.

The role of stroke rehabilitation nurses

The interviews explored the potential introduction of the stroke rehabilitation nurses in addressing the needs of the carer at home. This subtheme presents carers' objective views regarding the possible roles of the stroke rehabilitation nurses and how this service may help the wider stroke carers within the community. The study reveals dividing perspectives with regard to opinions of the carers in this aspect. Many of the carers have welcomed the prospect idea of this new support service provision, but for the minority, the stroke rehabilitation nurses won't add further benefits on the existing support system. For carers who viewed positively about this future planning, they felt that this nursing service could reduce carers' caregiving burden. As example, this carer participant showed signs of relief, as the excerpt illustrated:

> *"Atu bersyukur jua ku tu ah..kalau pun nada pembantu sebab nya aku pun buleh menganu kedia…tapi kalau ada lagi bagus."* (CP – 16)
>
> TRANSLATED TO: ("I would be very grateful. Although I can still manage to care independently, but if there was [stroke nurse] it even better.") (CP – 16)

In exploring the potential roles of the stroke rehabilitation nurses, meanwhile, the carer participants described these nurses as those who are able to complement the rehabilitation therapist roles. The key requirement of skills competencies and knowledge in every aspect of stroke care were frequently mentioned by the carers. The data revealed that the rehabilitation nurses was regarded as potential long-term care support providers. Thus, the carer participants in this study hoped that the rehabilitation skills of these nurses would be comparable to those of the therapists. One stroke patient participant stated:

> *"Yang ku mau pandai exercise kan ia kan..kemahiran terapi.. supaya pesakit atu lakas baik lah kan ia ada pengalaman terapi tu kan..ia mesti ada bah..jururawat atu mesti ia pandai membuat pesakit atu baik bah..menolong ia anu lah memulih kan"* (CP – 12)
>
> TRANSLATED TO: ("What I want was the nurses know how to do the exercise…skills in therapy…so that the patient can recovery soon. And the nurses have experience about the therapy and provide support to assist with the stroke patient recovery.") (CP - 12)

The implications of the nation philosophy, the Malay Islamic Monarchy, appears important in shaping the attributes and roles of nurses in rehabilitation. Many carer participants proposed the stroke nurses with those who integrate features of the typical Malay Bruneian characteristics. The cares spoken about several Malay attributes encompassing being patience, giving attentiveness, respectful, very gentle, persistence, assertiveness, hard-working, showing empathy, be friendly and being a practising Muslim. As example, this carer participant mentioned about '*Calak'* Brunei as one of the attributes and recommended:

> *"I think yang di tekan kan ialah apa tu..treatment calak Brunei dan keIslaman. Dua atau bah yang penting. Of course lah kitani dari segi perubatan internationally kan..piawian International. Tapi I think yang perlu di terapkan jua ialah keBruneian dan Islamic atu. Because Islamic atu..kitani ada doa-doa, so kitani berikan tah risalah…doa ani atu atu..macam atu.* (CP – 01)
>
> TRANSLATED TO: ("I think what needed to be emphasised in treatment of stroke is the integration of Bruneian Malay identity (*Calak Brunei)* and Islamic practices. Both of these elements are essential. Of course, we follow the international standard, but I think the Bruneian and Islamic approaches of treatments, such as prayer, must be embraces by the nurses.") (CP – 01)

Moreover, another carer reflected on her experience observing the roles of ward nurses in caring her dad. This carer credited the courteous attitudes of the ward nurses and wished that the proposed stroke nurses would be as attentive as these nurses, as she recalled:

> *"Kalau tah ada yang macam jururawat yang di sini ani lah..macam pemedulian..macam anulah okey lah..yang di sini ani..Alhamdulilah lah sepanjang beberapa bulan..dari bulan tiga..enam bulan kami di sini..ah..dari ICU ke wad strok..Alhamdulilah lah jururawat nya..paling pemedulian..ramah."* (CP – 08)
>
> TRANSLATED TO: ("If it was possible the stroke nurses [attributes] like here [Ward]. The nurses in the ward were very attentive. *Alhamdulillah,* throughout our stay for the past three to six months, *Alhamdulillah* the nurses here were so courteous and warming.") (CP – 08)

Essentially, the data suggested that the imminent role of the future stroke rehabilitation nurses' remains confined to those associated with the traditional nursing principle, which is caring. This role appears synonymous with the global image of nursing and reflect the wider acceptance of nursing as care professionals. As an example, this carer participant suggested:

> *"Untuk merawat….pengetahuan dari segi rawatan..dan kemahiran dari segi tunjuk ajar macam mana menjaga pesakit strok.".*(CP – 09)
>
> TRANSLATED TO: ("The nurses must be knowledgeable in providing treatment and being skilful in the aspects of providing health teachings and how to caring the stroke patients.") (CP - 09)

A quarter of carer participants, meanwhile, postulated that role of nurses in rehabilitation could bridge the gap relating to the existing outpatient rehabilitation service provision. The carers indicated that the issues concerning the limited therapy time could be resolved through the role of nurses in providing home visits. The views of the carer participants suggested that regular visits could increase the health professional-patient contact, and thus crucially promote goal accomplishment for the stroke patient. This spouse carer participant commented:

> *"Aa..rasanya kalau ada jururawat datang ke rumah..atu lagi tah baik tu..inda pun nya orang dalam masa sejam atu pun cukup tu..untuk exercise..inda usah banyak exercise..macam pebinian..dari sakit sakit orang lain lah umpamanya..macam bini ku atu inda dapat bejalan..jadi exercise bejalan saja"* (CP – Pilot01)
>
> TRANSLATED TO: ("I think if there were nurses doing home visit, it would be better. One hour performing the exercise should be enough. Such as, my wife still has problem with walking, so those exercise could focus on supporting her to walk.") (CP – Pilot01)

This view was shared by another carer who agreed that the role of nurses in home visit could have potential to address the lacked of the therapy time. Moreover, the individual therapy session would help the carer learn and develop new experience, as she explained:

> *" Kitani masa ani alum ada kan. Macam kami datang, sekirnya kami ke …. dua kali seminggu, berapa saja… setangah jam saja…berapa lama saja exercise nya. Buat itu ini…kadang kadang durang bagi lilin apa…atu..atu saja tu… Kalau macam di rumah, kitani meliat….kira tia ah sejam ia kerumah… ia membuat aktibiti-aktibiti…tani sudah puas ada pengalaman atu meliat… "* (CP – 03)
>
> TRANSLATED TO: ("At this moment, we don't have that [stroke rehabilitation nurses]. For example, we went to the rehabilitation centre…[therapy] for half an hour only. Did a few exercises then stopped. [But] if the therapy was provided at home, like for an hour…the nurse did activities [rehabilitation]…by observing them, I would feel satisfied and gain [new] experience.") (CP – 03).

In contrast, few of carer participants rejected the roles of nurses in stroke rehabilitation. For example, this spouse carer was confidence and felt self-sufficient to look after the stroke patient independently. Her extended experience on caregiving role seemed empowered her to manage the patient's daily activities alone. Thus, she was hesitant to allow nurses to get involved, as this carer participant declared:

> *"Tapi ku rasa keran aku ini buat sendiri mungkin inda payah lah..pengalaman dah cukup untuk membantu suami..Pasal selama ini aku sudah biasa menjalankan menjaga haji bisa..aa..apa ya..menjaga haji dengan baik bah..jadi rasa berpuas hati lah."* (CP – 13)
>
> TRANSLATED TO: ("But, because of I have done this [caring the stroke patient] for so many years, I don't feel this [nursing home visit] is necessary. I already have experience which was enough to assist him [stroke patient] well. All this while, I have been doing this task alone and I felt very satisfied with his progression.") (CP – 13)

Furthermore, insights from different carers also illustrated that support from stroke nurses was not needed. The data reveals that carers may perceived their tasks and roles were similar to that of a nurse. As such, this carer participant indicated that support for the stroke patients was more important than herself, as she stated:

> *"Kepentingan ku..inda pulang ada..pasal nya aku ani macam jururawat sudah di rumah..kepayahan atu nada bah..nada…macam maksud ku..apa yang jururawat nada…aku macam nada lah nada..Macam tiap tiap kali durang ambil BP, check gula..atu pun ku buat di rumah."* (CP – Pilot02)
>
> TRANSLATED TO: ("I don't think support from them [stroke nurse] was for me. Because at home, my duty was like a nurse. I can do whatever the nurses does such as check BP, blood sugar…So I don't felt any difficulties [burden], even if without the nurses' presence [home visit].") (CP – Pilot02)

Another carer participant, meanwhile, spoke about constraint relating to the available staff capacity that could deter the prescribed roles of nurses in stroke rehabilitation. This carer gave her sentiment about possible challenges and the downside of introducing the stroke rehabilitation nursing services, whereby she implied that the proposed plan may not workable. An excerpt from this carer demonstrates this:

> "I think it is good as they [stroke nurse] are helpful. But for the nurses, we understand that they already have a lot of tasks...and then they have a lot of commitment for sure...and then if they have to [introduce stroke nursing]...yep it might help us if they have that skills and if they have time. But, they may over work...we also understand that they are over work." (CP – 11)

In summarising the above subtheme, the data illustrates that role of nurses in stroke rehabilitation, particularly in the context of this study, can be unique and culturally driven. The influence of the Malay Islamic Monarchy as way of living in Brunei was key to ascribed roles of nurses in stroke rehabilitation. The possible role of these nurses to address shortfall in the existing out-patient service provision was identified in this study. However, the limitation of such service and disagreement from minority of the carer participants regarding the contribution of stroke nurses should be considered. This finding suggested that strong collaboration between the service provider and the higher educational institution were required in order to formulate effective and feasible planning of stroke rehabilitation nurses.

Overall summary of Theme 3

The example of quotes on this theme: *caregiver support needs,* suggests that needs of carer participants was complex and individualised. The participants' prior knowledge about stroke and rehabilitation was found to be limited, even after the stroke occurred. The preparative home teaching relating to caring for stroke patients roles appears less structured and varying. The perceived roles of nurses in stroke rehabilitation were centered on attributes that reflect to the Malay Islamic philosophies. This finding illustrates the 'felt' needs among carer participants in this study, thus addressing these needs warrant urgent attention. The direction of this research towards potential introduction of the stroke rehabilitation nurses, therefore, has potential to address carers' supportive needs.

5.5 Overview of carers' conceptual model

Diagram 14 presents an overview of conceptual model for stroke carers with regard to their preparation for living aftermath of a stroke. The model was developed based on the analysis of the carer participants' lived experience living with stroke person and their needs on providing continued rehabilitation support at home. This model represents a theoretical illustration, in which the concept of 'preparedness' was considered as an overarching interview themes: *The impact on caregiving experience, Rehabilitation support network,* and *Caregiver support needs.* No existing model of stroke carer preparedness was found in Brunei. Therefore, this model will provide a basis for discussion with relevant stakeholder in planning carer support services, teaching purposes and act as platform for further stroke caregiver research in Brunei.

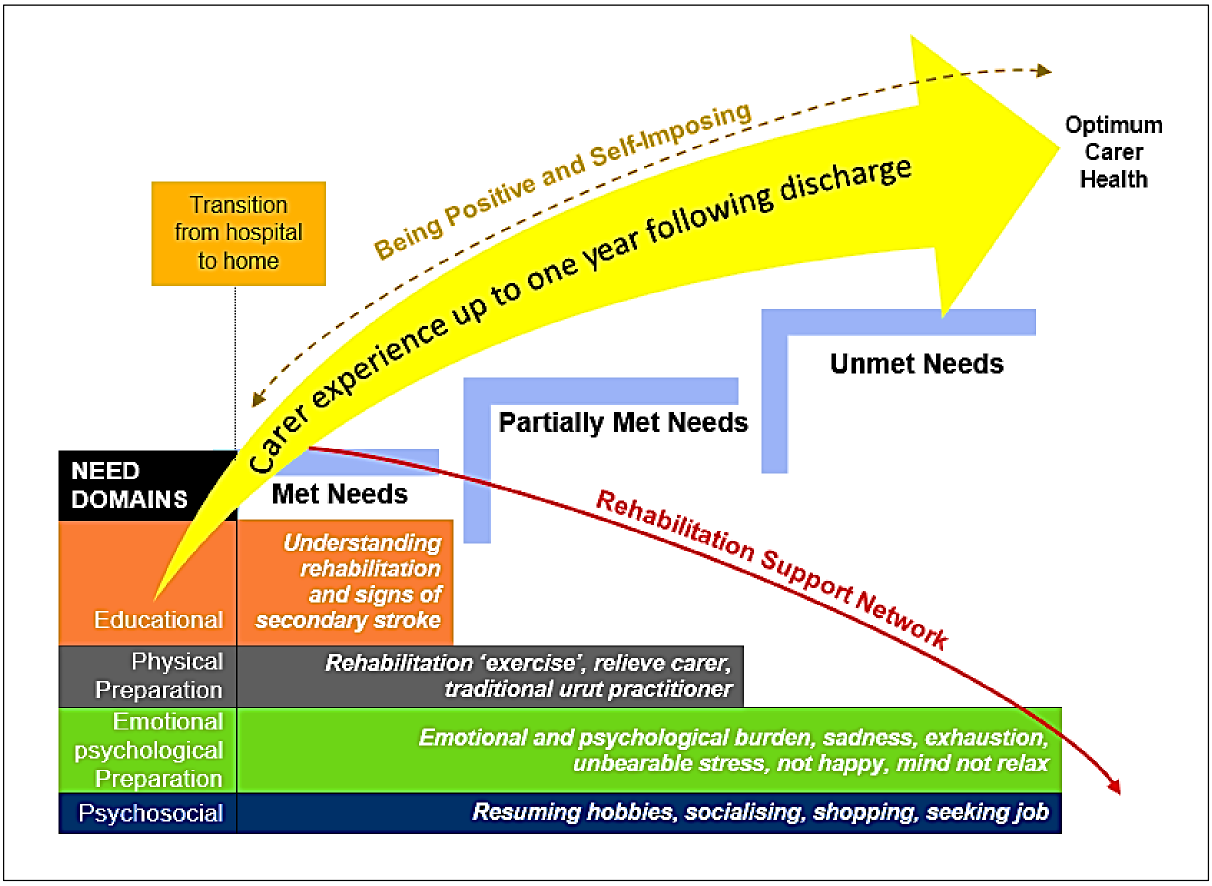


Diagram 14: Overview of conceptual model on carers' preparedness for life after stroke

Description and interpretation of the model

The importance of carers for their role to support recovery of stroke patients at home are well documented. Similarly, research also found that carers faces overwhelming challenges and issues due to their caregiving duties. Therefore, it is crucial that every carers are adequately trained, educated, and prepared before the discharge. Adequate preparation can help the carers cope with physical and psychological problems that may arise due to impact of caring for the stroke survivor.

Our model suggests that experiences of the carer participants during the duration of a year after discharge was complex and multifaceted. The carers were expected to provide continue care for the stroke patients, but their preparedness to assume as full-time carer during the transitional period, typically for the first 3 months, from hospital to home can be inadequate. The interviews found that the carers' preparedness for their caregiving roles rely upon addressing 5 different domain of needs; educational, physical preparation, emotional and psychological preparation and psychosocial functions. The model illustrates that throughout the carer progressive experience, represent as upward arrow, these domain of needs were not satisfactorily being met. Our study revealed that the carers constantly experience emotional, psychological and psychosocial problems that were not resolved up to one year following discharge. It also found that the needs of carers with regard to physical preparation and support was partially met. The carers support network that form by the therapist, family members and traditional *urut* practitioner was crucial to improve carer living experience aftermath of the stroke. However, our model suggests that the availability of this support network often inconsistence and to certain extent was declining, in particular support from family.

On the contrary, our study found that cultural and religious values can have direct influence on carers' health and wellbeing. It was revealed that carers' obligation to honour carer-survivor intimate relationship and their strong devotion to Islamic faith were keys for positive coping strategy. This self-imposing approach often grew alongside with carer daily living experience. However, this coping approach arguably may not be reliable or sustain after one year. Therefore, our model suggests that meeting the carers' domain needs and assimilating the cultural religious practices in support interventions would lead to carers' optimum health.

Limitation of the model

The limitation of this model will be similar to that of the stroke model (see Section 4.5)

Section Summary

This section presents an overview of carers' preparedness on living after the stroke through illustration of a conceptual model. The model suggests that carer endure considerable unmet needs that last up to a year, with support available were inconsistence or gradually declining. The importance of cultural and Islamic religious values appeared integral in providing carers with coping strategy from the impact of caregiving roles. Therefore, our model can assist the stakeholder in planning support provision within one year or beyond.

5.6 Chapter Summary

Semi-structure interviews were employed to explore the lived experience of carer (*n*=18) after the stroke and their rehabilitation support needs following discharge from hospital. Three primary themes and their related subthemes were identified and presented. The data revealed that the impact of a stroke on the carer participants in this study was considerable, although faith and religion appeared central to the coping strategies of these individuals. The findings suggested that disparities exist within the current support services provision for these carers. The lacked of support from family members to substitute care could lead to participants experiencing a poor quality of life. The importance of outsourcing supportive resources to supplement the deficits of the existing rehabilitation service provision was considered necessary. The participants' views with regard to the potential introduction of the stroke rehabilitation nurses were perceived with differing views. The needs highlight carer participants' broader problems and considerable challenges immediately after at home, thus immediate interventions by relevant stakeholders were required to improve the health outcomes of these carers. A conceptual model to illustrate carers' preparedness living aftermath of the stroke was developed. The interview data provide an understanding with regard to the issues surrounding the stroke rehabilitation service provision in Brunei from perspectives of carer. Next proceeding chapter presents questionnaire findings of nurse participants.

Chapter 6: Questionnaire findings for Nurse Participants – Phase 1 Study

6.1 Introduction

This chapter presents findings from the nurse questionnaire (Bru-NEIS). The layout of the findings will be divided into three main sections; (1) socio-demographic variables of the participants, (2) quantitative findings of the questionnaire, and (3) results from qualitative data inquiry (open-ended questions). Firstly, the internal consistency of the questionnaire is provided. Then, the overall response rate and participants' socio-demographic characteristics are outlined. Next, findings related to the aspects of stroke education and training needs, knowledge and competencies for specialist stroke nurse, and barriers to attending training will be presented. All of the questionnaire data were analysed using statistical test. The descriptive statistic using the mean as the statistical model was used to illustrate the central tendency of the score and summarise the data. To further explore descriptive findings, a contingency table was used to compare frequencies between two variables. The inferential statistic employed chi-square test or Fisher's exact test for significance to compare between socio-demographic and questionnaire variables. Finally, summary of findings will be provided at end of chapter.

This chapter sought to address the following research question:

- How do nurses in the community describe their roles and educational needs in relation to home-based stroke rehabilitation?

6.2 Internal Consistency and Reliability of BruNEIS Questionnaire

Table 9 demonstrates the discriminant validity and internal consistency reliability of the Brunei Nurse Education Inquiry of Stroke (Bru-NEIS) questionnaire. Kaiser-Myer-Olkin estimates showed good variability for factor analysis (KMO = 0.842, Chi-square = 4923.9, $P < 0.001$), which provided cumulative variance explained of about 56.8%. The factor loadings showed good discriminant validity where all items loaded above 0.40 in respective scales. Internal consistency reliability was very good where Cronbach's alpha coefficient was above 0.80 for all scales. Therefore, the internal consistency and reliability of the questionnaire used was considered acceptable.

	Factor loadings		
	1	**2**	**3**
	0.77	0.48	0.56
	0.84	0.50	0.51
	0.78	0.43	0.48
	0.73	0.40	0.58
	0.83	0.42	0.67
	0.80	0.46	0.69
	0.83	0.42	0.64
	0.83	0.59	0.57
	0.78	0.56	0.74
	0.80	0.46	0.50
	0.83	0.43	0.50
	0.78	0.38	0.66
	0.78	0.47	0.74
	0.77	0.44	0.47
	0.61	0.46	-0.50
	0.65	0.44	-0.60
	0.71	0.41	-
	-	0.49	-
Alpha	**0.96**	**0.97**	**0.87**

1. *Knowledge and understanding about stoke rehabilitation nursing scale*
2. *Skills and abilities about stroke rehabilitation nursing scale*
3. *Barriers about educational training on stroke rehabilitation nursing scale*

Alpha = Cronbach's alpha

Table 9: Factor loadings and Cronbach's alpha for discriminant validity and internal consistency reliability of "Brunei Nurse Education Inquiry of Stroke (Bru-NEIS)" (N=101)

6.3 Overall response rate

A total of 112 questionnaires were distributed to eligible registered nurses. Of these, 106 questionnaires were returned. All of the returned questionnaires were checked for usability for the data analysis. Three questionnaires were returned blank and two questionnaires were incomplete as the participants answered the demographic section only. These questionnaires were omitted from the analysis. Therefore, the overall response rate was 101 (90.1%), and hence the sample target was achieved.

The participants were required to answer the Likert-type scale items, ranging from "5 strongly agree" to "1 strongly disagree". Higher score indicates participant's greater degree of agreement with the statements asked, and vice versa. All of the participants answered the Likert-type questions. However, only 84% (*n*=85) of the 101 nurses offered answers to the open-ended questions. Of these, 35 questions were answered in English, 45 in Malay and 5 were written in both languages.

6.4 Socio-demographic characteristic of the nurse participants

Table 10 presents the demographic characteristic of the nurse participants. The majority of the nurses were female (*n*=75, 74.3%) and a quarter were male (*n*=26, 25.7%). The age distribution for all nurses were between 24 and 61 years (median 34.0, IQR 13). Almost half of the nurses were in their early thirties (*n*=42, 41.6%) and another one-third were above forty (*n*=33, 32.7%). A quarter of the nurses (*n*=23, 22.8%) had pursued an assistant nurse certificate course and were employed as assistant nurse (*n*=23, 22.8%). Further two-thirds had attained nursing diploma level (*n*=72, 71.3%) and were assigned to a staff nurse post (*n=74*, 73.3%). Additionally, six of the nurses had a bachelor's degree (*n*=6, 5.9%) and four of them were nursing officers, while the other two held a staff nurse post. About one-fifth of the nurses had been working as a nurse for less than 5 years (*n*=20, 19.8%), while over half had more than 10 years working experience (*n*=52, 51.5%).

N = 101	*n*	(%)	Median	IQR
Age* (Years)			34.0	13
24 - 33 years	42	(41.6)		
34 - 40 years	24	(23.8)		
41 - 61 years	33	(32.7)		
Gender				
Male	26	(25.7)		
Female	75	(74.3)		
Education level attained				
Certificate in Nursing[a]	23	(22.8)		
Diploma in Nursing[b]	48	(47.5)		
Post-Basic Diploma in Nursing[c]	24	(23.8)		
Bachelor Degree in Nursing	6	(5.9)		
Present work position				
Assistant Nurse Post[1]	23	(22.8)		
Staff Nurse Post[2]	74	(73.3)		
Nursing Officer	4	(4.0)		
Working experience as RN				
1 to less than 5 years	20	(19.8)		
5 to less than 10 years	29	(28.8)		
More than 10 years	52	(51.5)		

IQR = Interquartile range, n = frequency, RN = Registered Nurse
Academic equivalence according to the UK Qualifications and Credit Framework;
[a]Level 3 National Certificate; [b]Level 4 Higher National Certificate; [c]Level 5 Higher National Diploma.
Classification equivalence according to International Labour Organization 1977 (Nursing Personal Convention); [1]Auxillary Nurse; [2]Professional Nurse
*Missing data; *2*

Table 10: Socio-demographic characteristic of the nurse participants

6.5 Participants background education regarding strokes

Table 11 presents the participants' formal education regarding strokes. The findings showed that over two-thirds of the nurses have learnt about strokes (*n*=69, 68.3%) and about 32% (*n*=32) stated that they had not studied strokes formally throughout their nursing career. Further inspection revealed that nearly half of these nurses had been working over 10 years as registered nurses (*n=15*, 14.9%) and were aged over 41 years (*n*=13, 13.1%). For those nurses who had learnt about strokes (*n*= 69), the topics studied were frequently identified as nursing management of stroke (*n*=56, 81.2%), primary or secondary prevention of stroke (*n*=41, 59.4%), pathophysiology of stroke (*n*=39, 56.5%) and stroke assessment (*n*=35, 50.7%). Whereas in the aspect of continue long-term stroke care, only few of the participants stated that they had received training on stroke rehabilitation (*n*=14, 20.3%) or community post-stroke care (*n=26*, 37.7%).

N = 101	***n***	**(%)**
Stroke education received		
Yes	69	(68.3)
No	32	(31.7)
Topics covered in education training (MR, N=69)		
Pathophysiology of stroke	39	(56.5)
Stroke assessment	35	(50.7)
Nursing management of stroke	56	(81.2)
Aspect of stroke rehabilitation	26	(37.7)
Aspect of community care post-stroke	14	(20.3)
Stroke prevention (primary or secondary)	41	(59.4)
Experience in caring for stroke patient		
Yes	91	(90.1)
No	10	(9.9)
Workplace experience caring for stroke patients (MR, N=91)		
Hospital-based	78	(85.7)
Brunei Neuroscience Stroke Rehabilitation Centre	3	(3.3)
Healthcare Centres/Clinics	18	(19.8)
Home-based nursing unit	7	(7.7)
Working experience caring for stroke patients		
Less than 1 years	54	(53.5)
1 to less than 5 years	19	(18.8)
5 years and over	18	(17.8)

n = frequency, MR = Multiple responses

Table 11: Participants background education and work experience regarding strokes

6.6 Participants' background experience in caring stroke patients

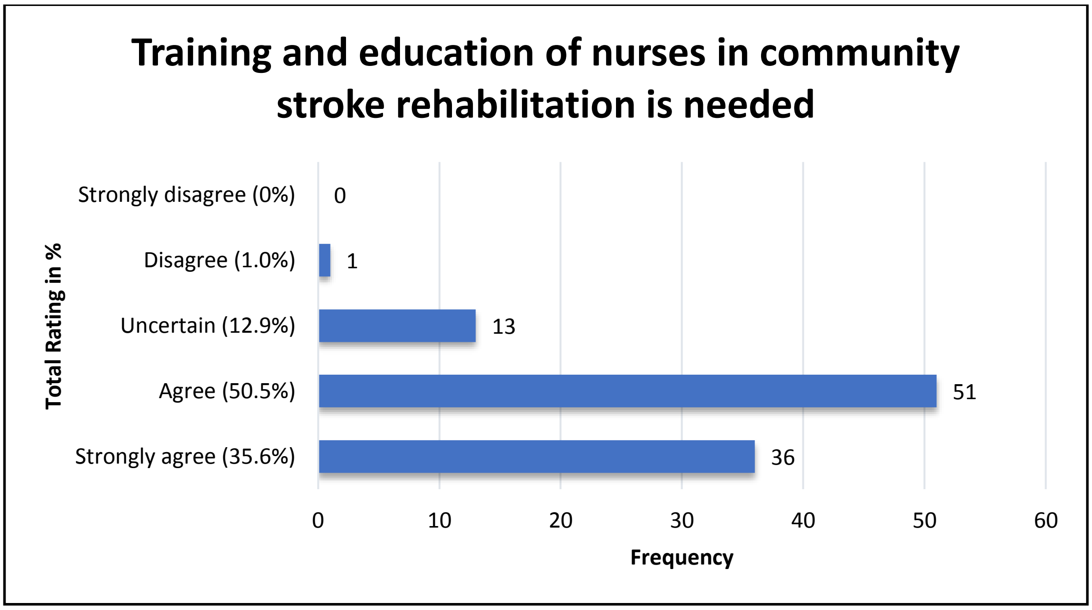
Table 12 presents the participants' working experiences of caring for stroke patients. The findings show that nearly all of the nurses were experienced in providing care (*n*=91, 90.1%). Most often, these nurses developed their experiences at the hospitals (*n*=78, 85.7%) and nearly twenty percent of these nurses (*n*=19) stated that they did so at their current work place. When asked about the length of their experiences of caring for stroke patients, almost half of the nurses have had experience less than a year (*n*=54, 53.5%) and another fifth stated that it was over five years (*n*=18, 17.8%). Further analysis identified that the nurses who were most experienced appeared to have work as registered nurses for more than 10 years (*n*=10, 9.9%) and were aged between 41 and 61 years (n=7, 7%). In contrast, one-fifth of the nurses did not have any working experience for caring patient with stroke (*n*=10, 9.9%). Subsequent analysis showed that most of these nurses were less than 33 years old (*n*=6, 6%) and in an early stage of their employment (*n*=4, 4%).

6.7 Quantitative findings of the Bru-NEIS Questionnaire

This section presents results of statistical analysis for all outcome variables of the questionnaire, comprising items derived from rehabilitation element SSEF and barriers to attend training. Data relating to each of the key constructs will be presented below:

6.7.1 Nurses' need on Stroke Rehabilitation Education

Graph 1 demonstrates descriptive findings of the nurses in respond to the statement, '*The training and education of nurses in community stroke education is needed in Brunei'.* The finding showed that about 86.1% (*n*=87) of the nurse participants agreed or strongly agreed that the educational training is needed [mean 4.21, SD 0.69]. On the contrary, another 13.9% (*n*=14) were felt uncertain or disagreed with regard to the necessity of such training.



Graph 1: Participants response about training and education need in stroke rehabilitation (N=101)

Inferential statistical test for significance was performed to compare between participants' socio-demographic variables and education necessity outcome. The Pearson's chi-square test (χ^2) was performed as the statistical calculation. Prior running the test, assumptions for chi-square were checked, including data must be in form of categories, total observation of need is over 20%, the expected frequency should not less than 5, and the observation should be independent and not influencing other (Field, 2009). Any non-categorical data (interval or ordinal) will be combined in the form of categories to enable chi square test. However, if expected count was not met after cell combination, Fisher’s exact test will be used, as indicated. An alpha level of .05 is used for all statistical tests. Exact P-values will be reported. The approach of statistical calculations were similar to all outcome measures.

Table 12 shows the proportion of nurse participants’ responses whether training and education in community stroke rehabilitation is needed for nurses, compared by socio-demographic and work factors. Overall, it was observed that majority (86.1%, *n*=87) of the participants agreed or strongly agreed on the need to have the training and education in stroke rehabilitation. In particular, those with experience in caring for stroke patients (89.0%) had significantly higher agreement on this need, compared to those without experience in caring the stroke patients (40.0%) (*p*=0.031). As indicated in the data, no further significant difference was detected with other socio-demographic and work factors.

	NEEDED		**NOT NEEDED**		
Dichotomous / Categorical	**n**	**(%)**	**n**	**(%)**	***P*-value †**
Age (Years)					
> 40	57	(85.1)	10	(14.9)	0.664
< 40	30	(88.2)	4	(11.8)	
Gender					
Male	22	(84.6)	4	(15.4)	0.752 ^{b}
Female	65	(86.7)	10	(13.3)	
Experience as Registered Nurse					
> 10 years experience	41	(83.7)	8	(16.3)	0.486
< = 10 years experience	46	(88.5)	6	(11.5)	
Education level attained					
Diploma & below	63	(87.5)	9	(12.5)	0.536 ^{b}
Undergraduate	24	(82.8)	5	(17.2)	
Present work position					
Assistant Nurse	21	(91.3)	2	(8.7)	0.514 ^{b}
Staff Nurse & above	66	(84.6)	12	(15.4)	
Stroke education received					
Yes	58	(84.1)	11	(15.9)	0.539
No	29	(90.6)	3	(9.4)	
Had experience in caring for stroke patients					
Yes	81	(89.0)	10	(11.0)	0.031 ^{b}
No	6	(60.0)	4	(40.0)	
Workplace experience in caring for stroke patients					
Hospital-based	40	(44.9)	49	(55.1)	0.093
Brunei Neuroscience Stroke Rehabilitation Centre	8	(80.0)	2	(20.0)	
Healthcare Centres/Clinics	0	(0.0)	1	(100.0)	
Home-based nursing unit	1	(100.)	0	(0.0)	
Years of working experience in caring for stroke patients					
Less than 1 year	65	(84.4)	12	(15.6)	0.509 ^{b}
More than 1 year	22	(91.7)	2	(8.3)	

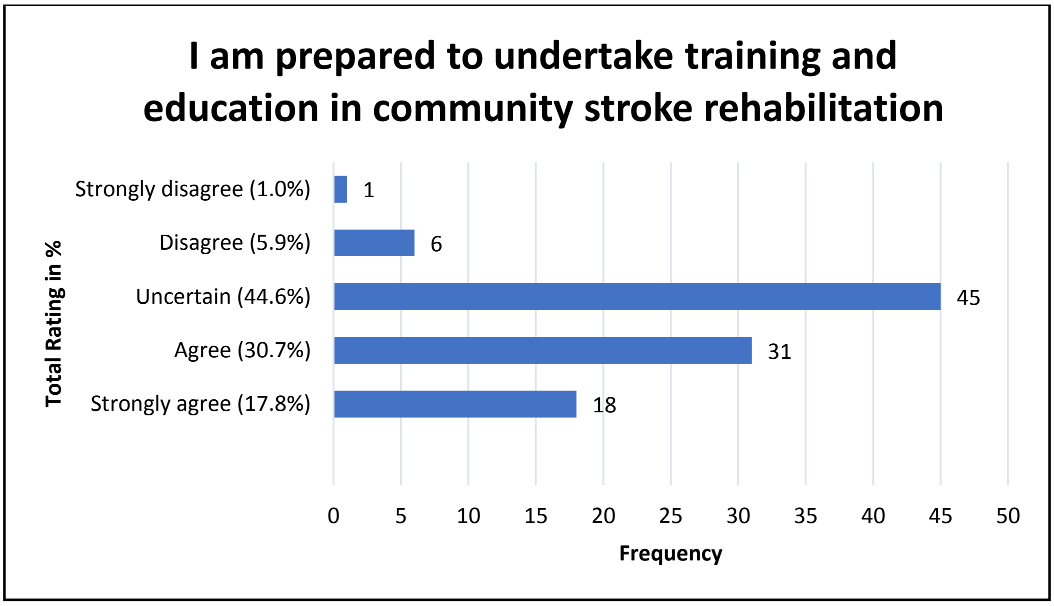
† Chi-square test, n = frequency, ^{b} Fisher’s exact test

Table 12: Participants response about training and education need in stroke rehabilitation by category (N=101)

In summarising the above finding, the nurse participants viewed that the training and education in the community stroke rehabilitation is needed in Brunei. No significant statistical differences were observed among participants' socio-demographic and works factors variables with regard to their need decision, except between those who have had experience in caring stroke patients.

6.7.2 Preparedness to undertake Educational Training

Graph 2 demonstrates descriptive findings of the nurses in respond to the statement, '*I am prepared to undertake the training and education in community stroke rehabilitation nursing'.* The finding showed that responses of the nurses with regard to their preparedness to undertake training and education in stroke rehabilitation were widely spread on scoring range from 1 – 5, [mean 3.58, SD 0.89]. Nearly half of the nurses (*n*=49, 48.5%) stated that they were strongly agreed or agreed with the statement. However, another half (*n*=52, 51.5%) were felt uncertain or to strongly disagreed about studying in community stroke rehabilitation educational training. The mean score and the standard deviation values suggested that opinions of the participants varies widely on the statement asked, even though the score was leaning positively to agree.



Graph 2: Participants response about preparedness to undertake training in stroke rehabilitation (N=101)

Table 13 shows the proportion of nurse participants' responses regarding their preparedness to undertake the training and education in community stroke rehabilitation, compared by socio-demographic and work factors. A chi square test for significance was used to analyse all variables. Overall, the data showed that nearly half of the nurses (48.5%) were prepared to undertake the training in the community stroke rehabilitation nursing. A significant difference of participants' decision were detected between nurses' years of working experience on providing care for stroke χ^2 (2, N=101) = 10.82, *p*=0.004. As the data indicated, nurses who had working experience caring for stroke patients for less than a year are likely attend the rehabilitation stroke training, compared with others more experience nurses. No statistical significant difference was further observed with other socio-demographic and work factors.

	PREPARED		NOT PREPARED		P-value
Dichotomous / Categorical	**n**	**(%)**	**n**	**(%)**	**†**
Age (Years)					
> 40	33	(49.3)	34	(50.7)	0.835
< 40	16	(47.1)	18	(52.9)	
Gender					
Male	13	(50.0)	13	(50.0)	0.860
Female	36	(48.0)	39	(52.0)	
Experience as Registered Nurse					
> 10 years experience	28	(57.1)	21	(42.9)	0.092
< = 10 years experience	21	(40.4)	31	(59.6)	
Education level attained					
Certificate	11	(45.8)	13	(54.2)	0.529
Diploma	26	(54.2)	22	(45.8)	
Undergraduate	12	(41.4)	17	(58.6)	
Present Work Position					
Assistant Nurse	11	(47.8)	12	(52.2)	0.718
Staff Nurse	33	(50.8)	32	(49.2)	
Senior staff nurse	5	(38.5)	8	(61.5)	
Stroke education received					
Yes	32	(46.4)	37	(53.6)	0.528
No	17	(53.1)	15	(46.9)	
Had experience in caring for stroke patient					
Yes	47	(51.6)	44	(48.4)	0.057
No	2	(20.0)	8	(80.0)	
Workplace experience in caring for stroke patient					
Hospital-based	40	(44.9)	49	(55.1)	0.093
Brunei Neuroscience Stroke Rehabilitation	8	(80.0)	2	(20.0)	
Healthcare Centres/Clinics	0	(0.0)	1	(100.0)	
Home-based nursing unit	1	(100.0)	0	(0.0)	
Years of working experience in caring for stroke patients					
Less than 1 years	24	(37.5)	40	(62.5)	0.004
1 to less than 3 years	11	(84.6)	2	(15.4)	
More than 3 years	14	(58.3)	10	(41.7)	

† Chi-square test, n = frequency

Table 13: Participants response about preparedness to undertake training in stroke rehabilitation by category (N=101)

In summarising the above finding, the nurse participants viewed that the training and education in the community stroke rehabilitation is needed in Brunei. No significant statistical differences were observed among participants' socio-demographic and works factors variables with regard to their need decision, except between those who have had experience in caring stroke patients.

6.7.3 Knowledge and Understanding required by rehabilitation stroke nurse

This sub-section presents descriptive findings on participants' opinions pertaining to knowledge and understanding from the rehabilitation elements of the SSEF. The nurses identified what specific knowledge and understanding would be required by a specialist stroke rehabilitation nurse. The majority of the participants indicated that having knowledge about the overall impact of strokes is the most important key competence required by stroke rehabilitation nurses. The learning requirements most frequently agreed by the participants were the impact of stroke on individuals, carers and the family and follow by the impact on the patient's activity of daily living and the cognitive functioning and ability to communicate. Overall, most frequently identified items showed higher mean scores, on the scale of 1 – 5, and smaller standard deviation values, which indicates positive direction and participants' degree of agreement on items from the knowledge and understanding scale.

On the other hand, about one-sixth of the nurse participants frequently stated uncertainty about several educational requirements for a specialist stroke rehabilitation nurse. In particular, items related to pharmacological and non-pharmacological interventions for secondary stroke, the therapeutic moving and handling of patients with stroke and the need to know about availability of support services for stroke. Nonetheless, these items showed higher mean scores, on the scale ranging 1 – 5, and low standard deviation values, which suggested that the samples' opinions was clustered towards positive score (agree). The result of all items from the question were presented in table 14.

	Items	***n***	**(%)**	**Mean**	**SD**
Most frequently agreed Items	The Impact of stroke on individual, carers and family	99	(98.0)	4.50	0.54
	The impact of problems after stroke to Activity of Daily Living	98	(97.0)	4.48	0.56
	Impact of stoke to cognitive functioning and ability to communicate	98	(97.0)	4.43	0.59
	Methods that will support those affected by stroke with their recovery and cope with problems after stroke	97	(96.1)	4.49	0.58
	Impact of stroke on patient's psychological and emotional well-being (e.g. depression, anxiety, emotionalism, confidence)	96	(95.1)	4.47	0.59
	The cause of, and how to assess, manage and treat problems after stroke	96	(95.1)	4.46	0.59
	The Implication of stroke for lifestyle, driving, work, family and acceptance in the community	96	(95.1)	4.45	0.59

	Impact of stroke to social and relationship (e.g. lifestyle, work/employment, driving, leisure, family, children, carers)	95	(94.1)	4.44	0.61
	The principles of stroke rehabilitation and rehabilitation referral; therapy techniques and their application	95	(94.1)	4.51	0.61
	Risk factors for further stroke events	93	(92.1)	4.43	0.64
	Impact of stroke to physiological, physical and functions of the body (e.g. rest and sleep, respiratory, mobility, balance, incontinence, swallowing, feeding, sexual, motor control)	93	(92.1)	4.43	0.67
Most frequently uncertain items	Pharmacological and non-pharmacological interventions for secondary stroke	15	(14.9)	4.27	0.71
	Therapeutic moving and handling	13	(12.9)	4.26	0.67
	Any supports services, organisations and resources available (e.g. social workers, multi-disciplinary team)	13	(12.9)	4.18	0.64
	A range of neurological treatment and approaches and their applications	12	(11.9)	4.27	0.66
	Impact of stroke to neurological, visual and sensory impairment and pain (e.g. shoulder pain, central post-stroke pain, spasticity, seizures)	11	(10.9)	4.36	0.72
	Methods to facilitate communication with those affected by stroke	11	(10.9)	4.25	0.64

SD = Standard Deviation; *n* = Frequency; Scoring (Lowest = 1, Highest = 5)

Table 14: Participants' degree of opinions for knowledge and understanding required by a specialist stroke rehabilitation nurse (N=101)

The views from majority of the nurse participants with regard to the knowledge and understanding required by the stroke rehabilitation nurses appears emphasising the consequences of stroke to the wider community. Therefore, providing education in this aspect may help the nurses in planning and making decision in relation to post-stroke care support.

6.7.4 Skills and abilities required for rehabilitation stroke nurse

This sub-section presents descriptive findings on participants' opinions pertaining to skills and abilities from the rehabilitation elements of the SSEF. The nurses identified what specific skills and abilities would be required by a specialist stroke rehabilitation nurse. Nearly all of the nurses indicated that providing health education and support are the most important skills required by a stroke rehabilitation nurses. The skill first three competencies that were frequently identified as most important for the stroke rehabilitation specialist nurse comprise providing advice and support, facilitating physical, social and cultural reintegration and recognising the impact of stroke on communication and identifying psychological and emotional problems of patients post-stroke. Overall, most frequently identified items on these scales showed higher mean scores, on the scale of 1 – 5, and lower standard deviation values, which suggested positive direction and participants' degree of agreement on items from the skills and abilities of stroke rehabilitation nurse scale.

In contrary, number of participants felt uncertain about some items related to skills and abilities required for the stroke rehabilitation nurse. In particular, items concerning identifying the resources to help patients' participation and inclusion within the community and managing patient's motivation issue were frequently identified. However, these items have higher mean score, on scale 1 – 5, and slightly higher standard deviation values, which suggested opinions of the nurses on skills and abilities item scale were widely distributed. Even though the scores were leaning positively towards agree. The results of all items from this question are presented in table 15.

	Items	***n***	**(%)**	**Mean**	**SD**
Most frequently agreed items	Provide advice and support; communicate and discuss of events, risk, need for interventions and treatments, rationales for treatment and possible side effects of treatments	98	(96.5)	4.41	0.55
	Assist, encourage and facilitate post-stroke physical, social and cultural integration	97	(96.1)	4.39	0.57
	Recognise the sign and symptoms and impact of cognitive communication problems after stroke	96	(95.1)	4.40	0.58
	Recognise the sign and symptoms and impact of psychological and emotional problems after stroke	95	(94.0)	4.40	0.60
	Plan and initiate assessments, interventions and information relevant to individual needs	94	(93.1)	4.34	0.61
	Recognise the sign and symptoms and impact of social and relationship problems after stroke	93	(92.1)	4.33	0.62
	Recognise the sign and symptoms and impact to physiological physical and functional problems after stroke	93	(92.0)	4.38	0.63
	Recognise the sign and symptoms and impact of neurological, visual and sensory impairment and pain problems after stroke	93	(92.0)	4.38	0.63
	Identify and use therapeutic methods of moving and handling the patient that are safe depending individual patient's needs	92	(91.1)	4.30	0.63
	Identify need and when to refer for more specialist rehabilitation therapist	91	(90.1)	4.28	0.67
	Recognise the sign and symptoms and impact of medicals problems/complications and help patients and families to cope, manage and encourage recovery	90	(89.1)	4.32	0.66
Most frequently uncertain items	Identify resources to help with participation and inclusion	20	(19.8)	4.08	0.73
	Assess motivation and take steps to augment management	15	(14.9)	4.12	0.68
	Monitor progress and agree or change a management plan	15	(14.9)	4.23	0.69

Provide range of neurological interventions processes and be able to clinically reason the selection and administration of an approach	12	(11.9)	4.22	0.64
Use a range of communication resources and approaches to ensure patients and their carers are fully involved in decision-making process and their care	11	(10.9)	4.29	0.70
Provide client-centred approach to care and manage any challenging behaviour	10	(9.9)	4.21	0.70

SD = Standard Deviation; *n* = Frequency; Scoring (Lowest = 1, Highest = 5)

Table 15: Participants' degree of opinions for skills and abilities required by a specialist stroke rehabilitation nurse (N=101)

To summarise the above findings, the broader views of the nurse participants indicated that the stroke rehabilitation nurses can be central in promoting and maintenance the health of the patients after the stroke. Thus, integrating these skills as part of the future nurse training in stroke may help improve the quality of life of patients post-stroke.

6.7.5 Barriers to attend educational training

This sub-section presents descriptive findings about participants' views on possible barriers to attend educational training in stroke rehabilitation. One of the most recognised barriers attending the training identified by the majority of the nurses was staff shortages. Others common barriers including a lack of practice experience in stroke care, low salary increments after completed a training and existing excessive workloads were similarly identified by the nurses as contributing factors that hinder commitment for educational training. Although these items had higher mean score respectively, on the scale of 1 – 5, the larger standard deviation values suggested that views of the participants varies widely across these items scale. Even though, the scores were leaning positively to agree.

On the other hand, over one-third of the nurses also felt uncertain about several items related to the barriers attending a training. The most frequently identified uncertain barriers were where nurses still working under three years provisional period and other staff being given priority. In contrast, nearly half of the nurses disagreed or strongly disagreed that satisfaction with their present salary, current job position and participants' present level of education would be barriers for them to continue on further training. Overall, the mean score, on scale of 1 – 5, for feeling uncertain and disagree were moderately high, which suggested that the nurses held differing views regarding these items. Moreover, the larger standard deviation values indicate participants' scores varies widely on these items scale. The results of all items from this question are presented in table 16.

Items		*n*	(%)	Mean	SD
Most frequently agreed items	Staff shortage	92	(91.1)	3.73	1.02
	Lack of experience in practice of stroke care	74	(73.3)	3.92	0.96
	Least attraction of salary increment after the course	71	(70.3)	3.97	0.93
	Already have too much work-related responsibility	71	(70.3)	3.81	1.12
	If the training is not accredited by relevant authority	67	(66.3)	3.88	0.89
	Too much personal responsibility	66	(65.4)	3.69	1.05
	No managerial support	63	(62.3)	3.73	1.02
	Lack of allocated time for study	62	(61.3)	3.77	0.95
Most frequently uncertain items	If the registered nurse is still under provisional period (< 3 years)	47	(46.5)	3.49	0.87
	Other staff needs were given priority	36	(35.6)	3.73	0.86
	Fear unable to cope with study demand	34	(33.7)	3.44	0.96
Most frequently disagreed items	Feel satisfied with present salary	49	(48.5)	2.67	1.06
	Feel satisfied with present job position	37	(36.6)	2.96	1.09
	Satisfied with current level of education	33	(32.7)	3.04	1.08
	Lack of interest	28	(27.8)	3.28	1.11
	The training is not related to my practice	24	(23.7)	3.35	1.15

SD = Standard Deviation; *n* = Frequency; Scoring (Lowest = 1, Highest = 5)

Table 16: Participants' degree of opinions regarding barriers to attend educational training (N=101)

In summarising the above finding, nearly all of the nurse participants in this study felt that the current state of the staffing level was not satisfactory. Therefore, this finding can be useful to directly influence the policy makers in future allocation of staffing in order to allow nurses attend educational training in stroke rehabilitation. Next section presents qualitative findings of the questionnaire from the open-ended questions.

6.8 Qualitative findings from the open-ended questions

This section presents the qualitative findings collected from the open-ended questions of the Bru-NEIS questionnaire. The qualitative data analysed were derived from participants responses to six explorative key questions, consisting (1) their explanation on why the educational training in community stroke rehabilitation is needed, (2) reasons on their decisions regarding preparedness to attend the educational training, (3) views of the participants about the potential roles of nurses in stroke rehabilitation, (4) the responses on how nurses complement the Allied Health Professionals rehabilitation service provision, (5) the participants' perspectives regarding potential introduction of community stroke rehabilitation services, and (6) recommendation given by the participants. The qualitative data were analysed following thematic analysis approach, with primarily focus on generating related categories, with evidence to exemplify and illustrate the findings presented in quotes. Malay excerpts were written in italics and translations in English are given in brackets. Over two-third of the nurses (84%, *n*=85) have provide answers to the open-ended questions. Of this, 35 questions were answered in English, 45 in Malay and 5 were written in both languages. The findings of the qualitative data will be presented under each of the question heading as follow:

6.8.1 Indications for the need of the training

This sub-section presents finding relating to the participants' reasons on the need for the community stroke rehabilitation training. Out of 87 nurses who strongly agreed or agreed, about 79% (*n*=69) offered some explanations as to why the training was needed. Moreover, from 14 nurses who were felt uncertain or disagreed, half of this provides reasons for their replies. Both data were compare and contrast in order to understand participants' differing views. Upon analysis, three categories were identified; (1) increasing prevalence of stroke, (2) the need to enhance own knowledge of strokes, and (3) to improve the home-based stroke patient care, described as follow:

(1) Increasing prevalence of strokes

Of the 69 nurses who provided explanations, about one-third (*n*=22) gave comments related to "the increased number of strokes in Brunei" (NP – 034). These nurses attributed the rising prevalence of strokes as the main reason for the need for nurse training. The nurses also recognised the importance of training, as exemplified by this comment:

> "…it is important due to increasing of stroke patients in Brunei." (NP – 037).

Another nurse suggested that training was needed to reduce the incidence of stroke, as she implied:

> "In order to reduce statistic of the increasing number of patient with stroke in Negara Brunei Darussalam." (NP – 015).

Furthermore, the nurses observed "increasing chronic diseases such as diabetes and hypertension which can lead to potential stroke" (NP – 025). This observation was supported by another participant, who has over 10 years' experiences as a registered nurse and stated "in Brunei, hypertension is affecting people at a younger age" (NP – 052). Moreover, one nurse participant (NP – 036) also suggested a similar disease, as she commented, "Majority of Bruneian have medical problems like the most common one is hypertension" (NP – 036). This incidence, as noted by nurse (NP – 041), "showed the disease [stroke] is not yet controlled or reduced". Thus, the nurses identified the importance of training to equip them with appropriate knowledge of strokes. For example, NP - 001 asserted, “nurses should be well prepared and educated in terms of stroke management”. Additionally, another nurse mentioned the importance of the caring role, as he highlighted the “increased number of patients [stroke], and needs more caring” (NP – 030). Crucially, one of the most experience nurses commented:

> *“Ini di perlukan untuk menyelesaikan masalah strok di Brunei Darusssalam yang semakin bertambah dari tahun ke tahun”* (NP – 070).
>
> TRANSLATED TO: (“This [training] is needed to manage stroke problems in Brunei Darussalam, which are increasing every year.”) (NP – 070).

(2) Enhancing own knowledge about strokes

Nearly two-thirds (*n*= 40) of the 69 nurses provided comments identified as the category of education on strokes. These nurses indicated having “more knowledge of strokes” (NP -34) as a reason for the need of the stroke training. For example, one nurse suggested that training on strokes would prevent her from feeling “clueless” (NP – 010). Moreover, the nurses identified the importance of having knowledge in providing appropriate care such as delivering treatments, giving health education, providing long-term support and preventing post-stroke complications. These views were encapsulated by one participant, a senior staff nurse, who commented:

> “…is needed for us [nurses] to know how to care for stroke patient in the community including give education for the family and caregiver.” (NP – 008).

Further, another participant noticed that some nurses appeared to lack of knowledge of strokes:

> “…even some nurses don’t have any knowledge to handle post hospital admission… As a result, we noticed some post-stroke patient walking gestures and way of speaking still not totally recovered even after years of stroke history.” (NP – 009).

However one participant, who has over 10 years of working experience, noted potential problems associated with undertaking training for some nurses, as she advised:

> “If want to start training, it should be started with freshies students not those nurses who already working for longer years as they may encounter mental block.” (NP – 006).

Whereas, one male nurse who was uncertain about the need of training observed:

> “Most of the community nurses have not and never have undertaken or not been caring patients with stroke for quite some time now.” (NP – 054).

Nevertheless, the nurses identified that training is needed to “upgrade and improve our nursing care in this [stroke] area” (NP – 016) and “increase knowledge and skills on caring for stroke patients" (NP – 018). One participant, who had over five years of experience in caring for stroke patients, commented, "nurses are the front line in giving education to patients/clients. More knowledge of strokes, including prevention, is needed". This nurse continued "…once the nurses understand about strokes, i.e. the pathophysiology, management, treatment, prevention, it will be easy for them to provide health education to patients/clients, with a simple explanation" (NP – 034).

(3) Improving the home-based stroke patient care

Over two-thirds (*n*=51) of the 69 nurses offered reasons related to improving the home-based stroke patient care. As an example, one participant (NP – 071), who was a senior staff nurse, explained that training was needed to "improve the care of stroke patients at home". The nurses identified several benefits of home-based care, such as providing "focused patient care" (NP – 072), "increased chances of recovery' (NP – 002) and improving "quality of life" (NP – 003). Moreover, one of the nursing officers believed "it is convenient for stroke patients if nurses in the community carry out rehabilitation and teach the carers at home" (NP – 024). Thus, the nurses commented that training is needed "to give proper care and rehabilitation for stroke patient in the community in Brunei Darussalam" (NP – 035). However, one nurse (NP – 031), who had cared for stroke patients for over eight years, identified, the "lack of stroke services". This same nurse asserted, "…no services such as community stroke rehabilitation yet in Brunei…"

In contrast, one of the staff nurses, concerned about the potential expansion of their services argued:

> "…sometime there are lot of patients, expertise and staff really needed. Salary stay the same, doing home visit should be provided with allowance, since working outside the clinic can be risky compare to hospital/clinic." (NP – 048).

Moreover one participant, who disagreed with the need for nurses to receive stroke training, suggested that the patients should remain in hospital for continued care:

> "Better at medical ward so primary health care can focus on out-patient clinic only".
>
> *Dan tidak menyusahkan kepada pesakit untuk pergi ke sana kemari untuk rujukan pakar*".
>
> TRANSLATED TO: ("…and will not cause inconvenience for patient to attend any referral to a specialist.") (NP -038).

Nonetheless, the importance of improving the home-based stroke rehabilitation services was highlighted by one of the nursing officers. This officer, who has a bachelor's degree, offered her views:

> “Because rehabilitation in stroke patient is crucial to meet the patient’s health needs and their quality of life. Community stroke rehabilitation therapy will increase community nurses knowledge and skills to care for patient with stroke as stroke patient have a long term complication and rehabilitation and care is crucial especially in community based or at their own home.” (NP – 003).

In summarising the above findings, the views of nurses suggested that these participants acknowledged the requirement of stroke education among nurses in Brunei and the potential introduction can be timely. The increasing number of stroke cases necessitate nurses to be well educated for providing supportive care and improve the provision of community stroke services.

6.8.2 Indications for preparedness to undertake training

This sub-section presents finding relating to the participants’ reasons whether they are prepared or not to undertake the education and training in community stroke rehabilitation nursing. In explaining their responses, about 75% (*n*=37) of the 49 nurses who strongly agreed or agreed with the statement supported their answers with comments. Whereas, about 49% (*n*=22) of the 45 nurses who were uncertain also offered some explanation of their replies. All of the comments were analysed. Two main categories and along with their sub-categories were identified; (1) personal and professional development, and (2) personal and contextual factors. Meanwhile, explanation given from 2 of the 7 nurses who disagreed or strongly disagreed will be incorporated under categories identified in order to understand the overall context of nurses’ preparedness to undertake the training. The categories identified will be described as follow:

(1) Personal and professional development

This category was the result of analysis derived from explanation given by those nurses who were felt prepared to undertake the training. This category refers to the perceived benefits of training to the nurses’ own career progression and expansion of skills. This category was divided into three subcategories, (1) opportunity to attend stroke education, (2) knowledge of rehabilitation techniques, and (3) providing support roles, described as follow:

Opportunity to attend stroke education

Out of 37 nurses who provided explanations, over two-thirds (*n*=25) of the comments fell into category about attending stroke education. These nurses attributed their preparedness to undertake the training to their desire to “gain knowledge and experience in managing stroke" (NP – 002). The nurses felt that the proposed educational training would be a new course which would help to improve their knowledge of stroke care. For example, one participant (NP – 008), who is a senior staff nurse, acknowledged "this could be good training, if any, because we [nurses] should know the basic things needed for stroke patients". Her view was supported by one of the nursing officers and offered her support:

> "I would like to encourage nurses to undertake the training because it is very useful." (NP – 024).

Whereas, one junior nurse who has worked in the health centre for less than five years observed the lack of stroke education during her previous nursing course. She reflected: "back in college, we [nurses] won't study specifically more about strokes, probably just the basic knowledge". This same nurse further underlined, "…so training a nurse with this profession, is better" (NP – 010). Her view was supported by another junior nurse who provided the reason that *"kerana alum ada pengetahuan mengetahui mengenai strok, hanya pathophysiology. Tentang penjagaan alum lagi fasih".* TRANSLATED TO: ("because [I] didn't have any knowledge of strokes, [probably] only pathophysiology. I am not yet competent with regard to caring [skills]") (NP – 050).

Nonetheless, many nurses recognised the proposed training as an opportunity to attend stroke education. These points were illustrated by various comments from the participants which indicated the existence of gaps in their knowledge about strokes. The importance of undertaking the training was exemplified by one of the senior staff nurses, who suggested:

> *"…penting bagi lapisan jururawat kerana melalui latihan ini, ia akan membantu mereka agar dapat memberikan rawatan dan pemedulian yans sepatutnya kepada pesakit-pesakit strok… tetap perlu untuk jururawat mengetahui sedikit sebanyak mengenai nya agar mereka dapat menangani sekiranya ada pesakit strok berjumpa di mana-mana pusat kesihatan"* (NP – 062).
>
> TRANSLATED TO: ("…it is important for all levels of nurses to have this training [community stroke rehabilitation], to help them to deliver appropriate treatment and care for stroke patients….nurses need to know about it [strokes] so that they can offer support to patients attending health centres.") (NP – 062).

Knowledge of rehabilitation techniques

Over half (*n*=22) of the 37 nurses wrote comments that were related to the knowledge of rehabilitation techniques. These nurses indicated that "learning stroke rehabilitation techniques" (NP – 056) inspired their preparedness to undertake the training. They suggested that nurses may practice skills in stroke rehabilitation, such as physical exercise and providing health education. For example, a nurse, who had attained a post-basic diploma in nursing, confidently stated:

> "I can educate the public/family in order to handle stroke patients. I also able to do the physical exercise/rehabilitation therapy and teach the patient/family toward stroke." (NP – 014)

Furthermore, another nurse felt that undertaking the training would help her to "master stroke rehabilitation techniques and teach concerned relatives" (NP – 009). This same nurse believed that rehabilitation supported the patient's wellbeing, as she continued "…so the post-stroke patient will live normally and improve his/her self-esteem and confidence". Additionally, one of the senior staff nurses agreed with this observation and recommended, "…we [nurses] can teach the family members/care givers to actively participate in this rehabilitation stage". She further stressed, "…so that the patient will be more physically and psychologically spirited" (NP – 008). Whereas the nurse participant (NP – 010) who had never had any experience of caring for stroke patients, indicated that the proposed training will "make our views more open towards stroke patients".

Essentially, the benefits of learning rehabilitation techniques in facilitating patient's recovery at home was noted by this nurse as follow:

> *"…kerana memberi rawatan di hospital atau klinik sangat berbeza memberi rawatan pesakit strok di rumah mereka sendiri. Di rumah pesakit tidak ada kemudahan seperti katil yang boleh turun dan naik. Tidak ada bed pan dan lain-lain"* (NP – 048).
>
> TRANSLATED TO: ("…because delivering treatment at the hospital or clinics are difference in comparison to provide care for patient with stroke at home. There are no facilities available at patient's home, no electrical bed, no bed-pan and so forth.") (NP - 048).

Providing support roles

About a quarter (*n*=13) of the 37 nurses gave explanations identified related to category of providing a support role. For example, a senior staff nurse, who has a bachelor's degree, recognised that training will "enhance [nursing] services for stroke patients and [their] carers" (NP – 025). The nurses indicated that stroke patients and their carers required appropriate care and support at home. They identified that providing appropriate support during the patient's rehabilitation process may help to "improve [the patient's] lifestyle" (NP – 075) and "reduce severe [stroke] complications" (NP – 059). The views of these participants are exemplified by this nurse, who stated that training was needed to help:

> *"memberi sokongan pesakit-pesakit dan keluarga menangani masalah selepas strok"* (NP – 043) .

TRANSLATED TO: ("provides support to patients and family members in managing problems after stroke.") (NP – 043).

One participant mentioned that the support role of nurses in the community may help to "lessen burden of home-based nursing and ward administration" (NP – 013). He further explained that its benefits could lead to "more focus in ward and patient nursing [care]". However, a male nurse, who agreed with the statement, provided contradictory comments. Despite agreeing that he was prepared to undertake the training, he suggested that stroke rehabilitation nursing should take place in the hospital. As he argued, *"jika di buka di hospital hospital kerajan dan bukan klinik kesihatan"* (NP – 038) TRANSLATED TO: ("…if it is to be set up, do it in the government hospitals and not at the health centres"). Equally, another male nurse, who disagreed with the suggestion about further training, held a similar view asserting that community stroke rehabilitation nursing was "only for home-based nursing" (NP - 051), whereas one female participant, who has yet to experience caring for stroke patients, rejected the idea of potential training and concluded:

> *"Saya tidak berminat dengan bidang ini (Stroke rehab nursing)"* (NP – 076).
>
> TRANSLATED TO: ("I am not interested in this area (stroke rehabilitation nursing)." (NP – 076).

(2) Personal and contextual factors

This category was the result of analysis derived from explanation given by those nurses who were felt uncertain about undertaking the training. This category refers to the participants' anticipated issues that they felt may deter their intentions to undertake the training. This category was divided into two subcategories, (1) personal factors, and (2) staffing issues, describe as follow:

Personal factors

Over half (*n*=15) of the 22 nurses provided comments that were identified as falling into the category of personal factors. These nurses explained that their uncertainty about undertaking training was due to reason, such as "fear about coping with study demands" (NP – 006) and issues with "current health conditions" (NP – 030), while a male nurse (NP – 033) stated feeling "unsure about it [his own ability to study again]". Additionally, one of the senior staff nurses, who has a degree in nursing, viewed "stroke rehabilitation as not her speciality interest" (NP – 007). To illustrate examples of quotes, a male participant who held a senior staff nurse post, was concerned with potential overlap with his current tasks. He commented:

> "I need to prioritise my current job situation whether I am able to cope doing two to three tasks at one time." (NP – 18).

However, two participants were uncertain but yet would like to experience the training. For example, a male nurse hinted:

> *"Kalau di beri peluang mau jua akan mencuba, sebab di takuti ada nya patient yang tinggi tekanan darah nya itu berjumpa doktor di klinik tiba-tiba mendapat strok di hadapan kami.* (NP – 052).
>
> TRANSLATED TO: ("I would like to apply [for stroke training] if I am given the opportunity. My concern [if don't receive training] is if a patient, who has a history of high blood pressure, suddenly suffers a stroke while seeing the doctor.") (NP – 052).

Furthermore, one nurse required further details of the training, as she asked:

> *"Kerana saya perlu tahu tugas tugas yang perlu di peratikan dan beberapa lama kursus itu di perlukan, di mana kursus itu di adakan dan apa kah kemudahan yang di berikan jika mengikuti kursus tersebut"* (NP – 061).
>
> TRANSLATED TO: ("because I need further information about the roles of this nurses [stroke rehabilitation], the duration of training, the location of the course, and what are the potential benefits [e.g. salary increments] provided after the completion of the training.") (NP – 061).

Staffing issues

Of the 22 nurses who provided explanations, six comments were identified as falling into the category of staffing issues. These nurses suggested that the staff shortage was one of the reasons that generated uncertainty about undertaking further training. They observed that a lack of staff had cause to an increased workload and work-related responsibility. For example, one nurse (NP – 026) mentioned multiple roles in her current work place, as follow:

> "…due to our position as a General Nurses in community have a lot of work to concentrate (admin work and daily clinic routine). Some nurses already assigned as a Pap smear/ DNE [Diabetic Nurse Educator]/ Asthma/ Health Screening health nurses. They do extra work as well as at the same time entertained walk in or elective patient in clinic. Short of staff is the main reason [for feeling uncertain to undertake the training]." (NP – 026).

Moreover, another female nurse also lamented the staffing issue, as she commented:

> *"Kerana kurang memerlukan, yang mana lagi kakitangan kami tidak cukup".* (NP – 079)
>
> TRANSLATED TO: ("Because [training] is not needed. At this moment our staff is insufficient.") (NP – 079).

The existing high workloads of the nurses were evident. This was illustrated by two male nurses. One explained; "I am currently working in community care which focuses more on the prevention of chronic disease/illness and emergency treatment" (NP – 028), while the other commented; “already have too much work-related responsibility”. He further affirmed that he was “satisfied with my current work load” (NP – 006).

On the other hand, one nurse suggested that community stroke rehabilitation is not needed due to the availability of social worker. She mentioned:

> *“Tidak begitu di perlukan ketika ini di sebabkan dalam kominiti ini ada social worker sudah.”* (NP – 080).
>
> TRANSLATED TO: (“presently not really needed as there are already community social workers services [available].’) (NP – 080).

In summarising the above findings, there were conflicting views with regard to nurses’ preparedness for undertaking the proposed stroke training. Although, several nurses anticipated the benefits of those training towards their professionals’ development, however factors that can hindered sustainability of the training need to be considered. This finding may have direct implications to education providers and nurse managers.

6.8.3 Expected roles of stroke rehabilitation nurses

This sub-section presents findings relating to the participants’ views regarding the potential roles of community stroke rehabilitation nurse. About 80% (*n*=68) of the 85 nurses who answered the open-ended questions have offered some suggestions. The initial coding identified 34 overarching roles. Upon analysis, four main categories and their subcategories were identified; (1) role as rehabilitation practitioner, (2), role as a supporter of the patient’s recovery, (3) role as a provider of a continuum of care, and (4) role those embraces the Malay Bruneian Malay attributes. These categories will be described as follow:

(1) Nurses as a rehabilitation practitioner

The role of nurses as a rehabilitation practitioner was identified as a category that referred to specialised rehabilitation nursing knowledge and skills related to stroke. This category was divided into two subcategories, namely knowledge competence and skills competence related to strokes.

Knowledge competence related to strokes

Nearly half (*n*=31) of the 68 nurses identified that having a “wider range of understanding and knowledge about stroke” (NP – 010) is one of the roles required by community stroke rehabilitation nurses. As an example, these two male nurses (NP – 013 and NP – 016) shared their views about the importance of having knowledge in recognising patients’ problems. Additionally, another nurse offered details about the nurses’ knowledge of strokes. She mentioned, “…knowledge about the consequences and implications of stroke, the ability to cope emotionally, support in the home environment, medication management and health promotion issues" (NP – 022).

Nurse (NP – 077), meanwhile, who had no previous education in stroke, indicated that this role encompassed providing an explanation about the disease. As she explained:

> *"Jururawat perlu menjelaskan kepada keluarga pesakit apa sebenarnya strok dan apa langkah pemulihan strok yang akan di berikan kepada pesakit"* (NP – 077).
>
> TRANSLATED TO: ("Nurses should provide an explanation to the patient's family about the nature of strokes and what rehabilitation therapy is planned for the patient") (NP – 077).

Therefore, the participants suggested that the community stroke rehabilitation nurses should be knowledgeable and able to translate this knowledge through nurse-patient communication. This view was illustrated by one of the most experienced nurses, who portrayed these roles as follows:

> *"Seorang jururawat mestilah tahu mengendalikan pesakit strok dan berperanan berkominikasi dengan ahli keluarga pesakit mereka"* (NP – 044).
>
> TRANSLATED TO: ("The individual nurse should have knowledge on how to provide care for stroke patients and embrace the role of facilitating communication with the patient's family") (NP – 044).

Skill competence in stroke

Less than a quarter (*n*=15) of the 68 nurses identified the ability to carry out rehabilitation therapy as another roles of community stroke rehabilitation nurses. For example, one nurse (NP – 060) proposed:

> *"Perlu ada asas kemahiran dalam mengendalikan pesakit strok terutama penjagaan dari segi fisikal"* (NP – 060).
>
> TRANSLATED TO: (There is a need for basic skills in managing stroke patients, especially in the physical aspect of care") (NP – 060).

Another nurse identified a technique to facilitate the patient's recovery:

> *"Tatacara memberikan semangat untuk pemulihan yang berkesan dan cepat"* (NP – 059).
>
> TRANSLATED TO: ("learn effective skills on how to motivate patients during rehabilitation") (NP – 059).

Additionally, the descriptions of skills were illustrated by one nurse who mentioned; "nurses have to check patient's blood pressure, sugar by using monitoring d'stix, any bed sores or blood taking, especially if the patient is bed bound after a stroke" (NP – 035), whereas another nurse noted skills in "speech therapy" (NP – 081). Nonetheless, the nurses indicated that the ability and sense of responsibility of individual nurses in caring stroke patients were the most important skills. This was encapsulated by the following comment:

> *“Keupayaan dan tanggungjawab seorang jururawat untuk menjaga pesakit strok”* (NP – 040).
>
> TRANSLATED TO: (“abilities and responsibilities of nurses to care for stroke patients”) (NP – 040).

In summarising the above finding, the data showed that the nurses participant in this study emphasised on appropriate education and training resources in order to prepare roles of nurses in stroke rehabilitation. Therefore, providing educational interventions may help facilitate their role as rehabilitation support practitioner.

(2) Nurses as supporters of patients’ recovery

This role category describes the maintenance and improvement of the patients and carers’ physical, social, emotional, psychological and social aspects of recovery. It refers to specific skills set that was required to support patient recovery. This category was divided into two subcategories, namely physical and social support, and emotional and psychological support.

Physical and social support

About a quarter (*n*=17) of the 68 nurses suggested that providing physical support is one of the roles of community stroke rehabilitation nurses. For example, one nurse (NP – 022), who has a bachelor’s degree, noted that the role consists “providing support to the stroke survivors with regard to the physical functioning and activity of daily living”. This same nurse further elaborated on the focus of support, adding, “…by focusing on maintaining bodily functions as well as facilitating the process of interpretation and adjustment in the post-discharge period”.

One nursing officer (NP – 003) identified the need “to involve family members in caring for stroke patients”. This view corresponded to that of another nurse who considered extending the support roles to the family members of stroke survivors. As she mentioned, the role of rehabilitation nurses is “to help and support patients, family and relatives to care for the stroke patients” (NP – 019), while, another nurse proposed “to support family members and patients in daily activities after a stroke” (NP – 035). Essentially, one of the senior staff nurses highlighted the importance of continued long-term support, as she commented:

> *"…membantu pesakit strok dan keluarga mereka menjalani tempoh pemulihan di samping memberi sokongan dan khidmat nasihat kepada mereka secara berterusan bukan saja dalam tempoh pemulihan malah sehingga pesakit sembuh"* (NP – 062).
>
> TRANSLATED TO: ("…to help stroke patients and their family during the rehabilitation therapy, in addition to providing continued support and advices not only during the recovery phase but until patient has fully recovered.") (NP – 062).

Providing emotional and psychological support

About one-third (*n*=23) of the 68 nurses identified providing emotional and psychological support as one of the roles of stroke rehabilitation nurses. These nurses suggested support roles that includes providing health education, emotional reassurance and motivation. As an example, one nurse (NP – 027) stated that the roles of nurses consist of "counselling [that is] focused on problem solving, social support, dealing with grief or loss as well as knowledge of stroke and the care rehabilitation process", whereas another nurse suggested "to give support and motivate the stroke patient with good and effective communication skills" (NP – 029).

Additionally, the nurses recognised the importance of psychological support through providing health education. This was illustrated by one of the senior staff nurses (NP – 007) who described the roles as follows:

> "…to educate family members and carers on strokes including physical, psychosocial and emotional and psychological impact." (NP – 007)

She further supplement this roles with:

> "Providing support to patients, carers and family in term of psychological and emotional well-being." (NP – 007).

Moreover, the nurses also identified the need to provide support beyond the patients' recovery period and the scope of the community setting. These views were shared by two nurses, who recommended, "educating patients and families regarding prevention of relapse or re-occurrence of stroke" (NP – 028). From different perspective, this nurse (NP – 032) suggested "to educate the public regarding the awareness and prevention of strokes".

Essentially, the roles of nurses as supporters of patients' recovery was illustrated by this senior staff nurse (NP – 040) who commented:

> *"Seorang jururawat mestilah ada pengetahuan mengenai strok, cara penjagaan semasa dan selepas pesakit keluar dari hospital"* (NP – 040).
>
> TRANSLATED TO: ("A nurse must have knowledge about stroke, skills in caring the patient during and after being discharged from the hospital.") (NP – 040).

The views of these nurses suggested that the stroke rehabilitation nurses may offer holistic patient care support. Thus, these roles may have potential supplementing the existing healthcare rehabilitation professionals' service provision.

(3) Nurses as providing continuum of care

The role of nurses in providing a continuum of care was identified as a category that referred to nursing activities as being rehabilitation advocate at home and coordinate therapies from various disciplines. This category was divided into two subcategories, namely nurses as care-coordinators of a multidisciplinary team, and continuing care providers at home.

Nurses as care-coordinators of a multidisciplinary team

Only eight nurses mentioned the potential role of community stroke rehabilitation nurses within the interdisciplinary stroke rehabilitation healthcare team. For example, one senior staff nurse described the role of nurses as a "link between patient and other multidisciplinary staff" (NP – 025). This view was supported by another nurse, who also indicated being "able to make referrals to other specialities for their assessment" (NP – 031). Another nurse (NP – 028) noted the importance of "integrating all related multi-professionalism roles in planning patient care", and another suggested that nurses are the "manager of multidisciplinary provision" (NP – 050). This nurse further described the role include "liaising, organising and mediating between the patient and carer".

Nurses as continuing care providers at home

Nearly half (*n*=31) of 68 the nurses identified continued care at home as one of the roles of stroke rehabilitation nurses. For example, one nurse (NP – 019) suggested that the role was "to look at the progress of the patient at home and identify the needs of the patients". This view was supported by one of the nursing officers who also believed that "continuity care of stroke patients can be done as soon as they discharged from hospital" (NP – 020). One nurse offered an example of continued nursing care, as she described "to give further care such as compliance with medication, to see if patients are able to take/not take daily medications given". Another nurse participant (NP – 050) suggested a role in "providing care in aiding with nutrition, hydration, elimination and hygiene". The importance of management and future planning was illustrated by this nurse, who suggested:

> "…to manage the problems and set up a good care management and future plan for the rehabilitation." (NP – 011).

Essentially, nurse participant (NP – 075) proposed the role of nurses in providing continued therapy at home, as he implied:

> *"…meyediakan kaedah cara pemulihan yang teratur dan mempu di ikuti oleh pesakit-pesakit strok dalam kaedah awal pemulihan sehingga ke peringkat seterusnya"* (NP – 075).
>
> TRANSLATED TO: ("…delivering appropriate rehabilitation therapy that can be practised by patients from the beginning of the therapy period until the next phase of recovery") (NP – 075).

However these two nurses (NP – 004 and NP – 051), who earlier felt uncertain or disagreed about the need to undertake training, maintained that stroke rehabilitation is the role of home-based nurses. For example, one of these nurses commented:

> "Not sure if relate to community nurses due to job prescription given. Stroke rehabilitation more towards home based nursing". (NP – 004)

In summarising the above finding, many participants believed that the continue present of the stroke rehabilitation nurses after discharge can be key to sustain patient's recovery. The data indicated this role may help contributed to the improvement on the available service delivery.

(4) Nurses' roles that embraces the Malay Bruneian attributes

The role of nurses that embraces the Bruneian Malay attributes was identified as a category that described nurses' attitudes, personality and interpersonal skills of typical Brunei population. Nearly two-thirds (*n*=41) of the 68 nurses identified that the demands related to caring patients for stroke are challenging. Thus, one nurse (NP – 070), who has worked for over 10 years, commented that nurses must showed *"bersabar dan bersedia untuk menerima sagala cabaran dan dugaan semasa menjalani/menjaga pemulihan strok kominiti".* TRANSLATED TO: ("patience and be prepared to meet various challenges and possibilities in providing community rehabilitation care"). Her view was supported by another nurse who suggested that nurses should *"…mempunyai daya tahan yang kuat dalam mengendalikan pesakit strok".* TRANSLATED TO: ("have strong resistance [perseverance] in managing stroke patients") (NP – 055).

Moreover, several nurses have suggested specific Malay attributes that they felt were necessary inculcated by a community stroke rehabilitation nurse. For example, these nurses mentioned roles such as being "committed and concerned" (NP – 016), "self-motivation" (NP – 030), "full responsibility in all aspects" (NP – 012), "independent" (NP – 009), "good listener" (NP – 023), *"tidak camah mata"* ("attentive") (NP – 071), "confidence in dealing with stroke patients" (NP – 021), *"mesra dengan pesakit serta dengan keluarga mereka"* ("friendly with patients and their family" (NP – 065), *"rajin* *terhadap pekerjaan*" ("hardworking") (NP – 064), *"serba boleh"* ("flexibility") (NP – 056) and those characteristics that reflect ways of "our Brunei culture" (NP – 018).

Further, this nurse also mentioned the importance of being stroke rehabilitation nurse who has high enthusiasm and interest, as she commented:

> *"Jururawat itu di khas kan untuk jawatan itu saja dan berminat dengan jawatan itu"* (NP – 079).
>
> TRANSLATED TO: ("a nurse who will be designated to that post [stroke rehabilitation] must have interest with the post.") (NP – 079).

Meanwhile, one participant (NP – 033) commented that rehabilitation nurse should only provide care for patients with stroke. This participant observed that nurses with specific speciality frequently required managing other patients' conditions who were outside the nurses' field of expert. Thus, this participant argued the need to have independent stroke rehabilitation department in order to provide patient-centered care. This male nurse participant said:

> "They should have a proper department and should not be bothered with other task (general) as this always with case in Brunei (hospital/clinics)." (NP – 033)

In summarising the above finding, this data provide new insight with regard to roles of community stroke rehabilitation nurses. These roles encompass the traditional description of a nurse. However, the element of the Malay culture behaviours viewed as part of the role were different from other published nursing studies. The findings can be unique to these participants and perhaps influence by the socio-cultural context of Brunei.

6.8.4 Nurses complement the Allied Health Professionals

This sub-section presents findings relating to views of the participants regarding how nurses can complement the stroke rehabilitation services of the Allied Health Professionals (AHP) within the community. About 60% (n=51) of the 85 nurses who responded the open-ended questions offered some comments. The initial coding identified 27 overarching codes. These were reviewed and condensed into three main categories and subcategories; (1) nurses as supporter of rehabilitation therapists, (2) facilitating patient referral, and (3) providing long-term care. These categories will be described as follow:

(1) Nurses as supporter of rehabilitation therapist

Nurses as supporter of rehabilitation therapists were identified as category that described complementary functions of nurses in providing stroke educations and rehabilitation support. This category was divided into 2 subcategories, namely nurse as educator, and nurses supplementing stroke care support.

Nurses as educators

Over a quarter (*n*=21) of the 51 nurses suggested that providing education to patients and families is one of the approaches to support the rehabilitation therapists. These nurses believed that they may help to reinforce the rehabilitation teaching provided by the AHP. For example, one nurse (NP – 001) mentioned that “nurses could assist in giving education to both family and friends”. Furthermore, another nurse explained the aspect of educations as to “deliver and educate patients and family regarding rehabilitation through physical, emotional, psychological and holistic support” (NP – 015). Essentially, this senior staff nurse (NP – 025) emphasised that “patients and families and carers can have continuous health education support”. Moreover, the nurses also indicated that supplementing the AHP by educating patients might improve care management. For instance, one nurse noted the time spent, as he illustrated:

> “Lessen the education time where nurses can educate, advice and promote stroke patient rehab” (NP – 013).

On the contrary, the nurses identified the importance of the AHP in preparing them to assume a role as a rehabilitation educator. This views was exemplified by one of the nurses, who implied that this would be possible:

> *“Dengan memberi bimbingan dan latihan yang cukup kepada jururawat yang di pilih mengikuti kursus mengeni penyakit strok”* (NP – 055).
>
> TRANSLATED TO: (“through providing sufficient guidance and training to nurses who were selected to undergo the stroke training”) (NP – 055).

Nurses supplementing stroke care support

Over one-third (*n*=19) of the 51 nurses identified that providing continued support to stroke patients and their families might complement the AHP rehabilitation. These nurses suggested various support roles, such as “providing moral support” (NP – 001), “encourage physical, social and cultural reintegration” (NP – 002), “”support physical, psychological and holistic supports” and *“memberi keyakinan kepada pesakit tatacare pemulihan yang berkesan”.* TRANSLATED TO: (“provide confidence to patients about effective rehabilitation therapies") (NP – 059). Furthermore, the nurses see stroke rehabilitation as a potential specialist profession. For example, one nurse commented:

> "If there is better support at workplace and there is no reason to stop them [nurses] from being trained. E.g. staffing, no time and is no interested. If this three reason exist, then there will be no support. It is nice to introduce to them [nurses] the beauty of being a specialised nurse towards stroke". [Explain as introducing the training to nurses with support of the AHP could led to a specialist nurse]." (NP – 010)

Therefore, the nurses suggested identifying potential stroke rehabilitation personnel and establishing them as part of the community nursing services. This view was put forward by one of the senior staff nurses who recommended that one could "put it [stroke rehabilitation] under primary health care, not under the medical care hospital services" (NP – 008). Another nurse also agreed with this proposal and suggested that there is a need to "form a department specialise for stroke rehabilitation" (NP 009).

However, one nurse viewed the potential specialised services with more caution. This nurse, who has a bachelor's degree, commented:

> "…it depends on the current statistic of stroke patient within the catchment area. If there is any possibility to set up stroke rehabilitation within the area clinic and/or with the appointment system may be it is much reliable. Somehow, it still depends and need support from other multidisciplinary team like medical officer as well as the medical equipment needs to be fully equipped." (NP – 018)

Further, this male nurse also suggested:

> "…to appoint nurses from each clinic and they should be given only that task [stroke rehabilitation] and not general duties from that of community tasks." (NP – 033).

In summarising the above finding, the data indicates that rehabilitation nurses can form an integral part of the AHP stroke team. The participants appeared emphasising more on delivering health education than physical intervention. These findings suggested that enhancing communication skills can be one of the focus on future nurses' training in stroke rehabilitation.

(2) Facilitating patient referral

This category refers to the vital presence of nurses as a patient link to other healthcare sources. About one-third (*n*=16) of the 51 nurses commented that they may help the AHP by facilitating patient referrals to other multidisciplinary team. For example, one senior staff nurse (NP – 025) suggested that nurses can become "a patient's link with other services and needs". Another nurse also supported her view by stating "do the needful referral to doctors or specialists if there are any abnormalities in the patient's conditions" (NP – 023). One male nurse listed specific patient problems, as he commented:

> "…by identifying survivors' changes such as behaviour, communication and cognitive which nurses can actually support their services by referring directly." (NP – 027).

The importance of establishing collaborate team working in facilitating patients referrals was noted by these nurses. For instance, nurse (NP – 034) identified "working together with other multidisciplinary team members in providing care for stroke patients", while another nurse proposed "invite and plan a talk or a meeting with other health professionals" (NP – 028). The benefit of this meeting was mentioned by this nurse who believed that it might reduce the burden of stress among health professionals, as she asserted:

> "…to reduce professional burden of stress, team work among AHP can discuss any problem facing by the patient and family." (NP – 035).

However, this male nurse recognised his limitation in offering support to the AHP, as he indicated:

> *"Menyediakan keperluan yang di perlukan oleh perkhidmatan strok pemulihan setakat yang mampu"* (NP – 075).
>
> TRANSLATED TO: ("preparing necessities needed by the stroke rehabilitation therapist as I possibly can.") (NP – 075).

The views from the nurse participants indicated that forming collaborative team work with the allied health professionals are one of the important aspect of continue care for post-stroke patients. However, the need to establish stroke support agencies become vitally crucial so that the nurses can offer the patients and the carers to appropriate care.

(3) Providing long-term care support

This category refers to the complementary role of nurses to sustain post-stroke recovery. Over half (*n*=27) of the 51 nurses suggested that the health centres or as home-based care unit can be the focal point for providing continue long-term patient care support. The importance of continued care was mentioned by one of the nurses. She noted "continuity of care that relates to nurse's continue presence with the patients, it facilitates patient adjustment and rehabilitation" (NP – 022). Furthermore, another nurse (NP – 019) recognised that "the relatives of patients will need support from them [nurses] to minimise their family problems". Importantly, one of the senior staff nurses affirmed that providing long-term care “ensues patients and carers receive the necessary support” (NP – 025).

Nurses suggested various care activities when patients were reviewed at the health centres. For example, these nurses wrote about continued care which includes “monitoring patient’s appointment with doctors” (NP – 049), “undertaking thorough nursing assessment” (NP – 025), “establishing a baseline data for further management for each patient” (NP - 023) or “prioritising stroke patients to be seen in a queue” (NP – 001). Additionally, nurses also indicated that home-based care involves continued activities to support the AHP rehabilitation. For instance, this nurse (NP – 024) noted “frequent home visit to stroke patients”. Another nurse suggested the number of home visits, as she stated “nurses can identify the improvement in patients by visiting one to two times a week” (NP – 019).

Furthermore, the nurses suggested some care activities, such as “promoting the relearning of functions and skills” (NP – 022), “assisting with visual and sensory impairment” (NP – 002), “assessment of the patient’s home” (NP – 071), “monitoring and giving treatment to patients” (NP – 049) and providing “nursing care” (NP – 011). One female nurse (NP – 050) offered details of care activities, including “teaching patients about positioning in bed and on chairs, regular toileting [training] to promote continence and encourage patients to express themselves through writing or [body] gestures”. However, one male nurse felt that complementing the rehabilitation services of the AHP was not his main role, as he argued:

> *“tidak bersesuaian, di rujuk pada yang pakar. Hanya dapat membantu yang pergerakan ringan saja”* (NP – 051).
>
> TRANSLATED TO: (“not that appropriate, [better] refer to specialist. I only can help with light exercises [task].”) (NP – 051).

In summarising the above finding, the data showed that nurses were aware about their complementary roles for the stroke rehabilitation multidisciplinary team. Contribution of the nurses to stroke management can be a welcome addition to counterweigh issues with shortage of available therapists. These findings can be useful to assist the policy makers in planning and revising staff structure so that the stroke patients and their carer can have immediate access for help outside their therapy setting.

6.8.5 Stroke rehabilitation nursing service

This sub-section presents findings relating to participants interpretations regarding possible introduction of a community stroke rehabilitation nursing services. About 80% (*n*=68) of the 85 nurses, who answered the open-ended questions offered their personal views. The findings showed that 57 nurses were in favour of the proposal. However, 11 nurses were uncertain about the possible introduction of the community stroke rehabilitation nurses. Views of these nurses were analysed and the initial coding identified 24 overarching codes. These were reviewed and condensed into two main categories, (1) upgrading nurse professionalism, and (2) improving community nursing services, described as follow:

(1) Upgrading nurses' professionalism

This category refers to the perceived potential benefits of the community stroke rehabilitation nursing service. Over one-third (*n*=21) of the 68 nurses felt that the existence of those service could enhance the nurses' practices and knowledge related to stroke rehabilitation. These nurses felt that the prospect of becoming a community stroke rehabilitation practitioner can led to becoming a "nurse specialist" (NP – 018). One male nurse believed that this speciality will "upgrade nursing professionalism in Brunei and make it standardized with nursing internationally" (NP – 027). Additionally, the nurses also indicated the possible introduction of community stroke rehabilitation as a positive career progression. For example, one nurse stated:

> *"Adalah satu kemajuan dalam kerjaya ini kerana dengan di latih dan di bantu dengan pemberian kursus yang asas dan kemaskini akan banyak membantu pesakit strok yang memerlukan sokongan"* (NP – 060).
>
> TRANSLATED TO: ("It will be one of advancements in this [nursing] career because with training and further foundation courses [in stroke] that is up to date, [nurses] can provide help and support to patient with stoke.") (NP – 060).

Moreover a male nurse, compared with other countries, felt that stroke rehabilitation nurses should be made available in Brunei. He stated:

> "Should have in Brunei where many countries already practice this type of nurses (i.e. Norway) due to increase in stroke patients in the hospital." (NP – 013).

The nurses equally noted the benefits of this speciality discipline in improving their knowledge and practices with regard to strokes. For instance, nurse (NP – 005) identified one of the advantages as "not being labelled as an unskilled nurse". Another nurse further commented, "a good idea due to not too much knowledge and information about community stroke rehab" (NP – 030), while this nurse showed her desire to become a stroke rehabilitation nurse, as she mentioned:

> "Would strongly agree if there is "Community Stroke Rehab Nurses". I would like to be the nurse and wish had this nurse earlier." (NP – 030).

However, some nurses sceptical about the applicability of skills and knowledge. For example one nurse, who had no previous experience of caring for stroke patients commented:

> “There is higher chances for them needed at certain area like wards or specialist clinic but as for us in Outpatient Department, it is ok to have nurses like these but skills and knowledge will not be applicable at most of time, depend if they do have those patients coming here [at the clinic].” (NP – 010).

In addition, one male nurse was also not convinced about the relevance of community stroke rehabilitation for all health centres. He further argued:

> *“Trial dulu di sebuah klinik yang banyak masalah berbangkit dengan strok, baru tahu resultnya”* (NP – 075)
>
> TRANSLATED TO: (“First, implement as a trial at one of the clinics which has existing problems with stroke, then we will know the result [implication of the services].”) (NP – 075).

Likewise, nurse (NP – 057) failed to see that the potential service is relevant to her current role, as she mentioned,

> *“Saya tidak nampak ianya berkaitan dengan tempat saya bekerja sekarang”* (NP – 057)
>
> TRANSLATED TO: (“I didn’t see its relevance to where I am working now.”) (NP – 057).

(2) Improving community nursing services

This category refers to broader benefits of the community stroke rehabilitation nursing service to the patients and general population. Almost two-thirds (*n*=43) of the 68 nurses provided views that were associated with “improving the community approach for stroke management” (NP – 001). These nurses identified the possible introduction of community stroke rehabilitation will help to provide “continued care and support to patients while they are in a community setting” (NP – 035). For example, one senior staff nurse (NP – 008) regarded the potential services as “very good”. She continued, “…so that it can help to improve our services in the delivery of health care to people especially the stroke patient him/herself”, whereas another senior staff nurse (NP – 007) also agreed and observed that the increasing prevalence of stroke may lead to survivors needing continued support. She stated:

> “Strongly agree with this services (if any). Stroke patients are increasing who need support to help them with their recovery.” (NP – 007).

The benefits of community stroke rehabilitation nurses were variably mentioned, such as continuing care at home, minimising patient stay in hospital, providing patient-centred care, facilitating recovery and reducing stroke mortality. To give examples, one nurse, who has over eight years of experience in caring for stroke patients, reflected:

> *"Pendapat saya, ia nya sangat di perlukan untuk pesakit strok dan ahli keluarga pesakit, kerana menjaga strok patient tidak lah mudah untuk di kendalikan"* (NP – 069).
>
> TRANSLATED TO: ("In my opinion, it [a stroke rehabilitation nurse] is really needed by stroke patients and their family, because managing stroke patients is not that easy.") (NP – 069).

Crucially one of the nursing officers anticipated, the existence of community stroke rehabilitation nursing service could reduce the stroke mortality in Brunei, as she explained:

> "If there will be a community stroke rehabilitation nurses, there's a possibility that there will be a decrease in number of stroke survivors living with disabilities as well as stroke mortality in Brunei." (NP – 022).

On the contrary, certain nurses argues against the introduction of community stroke rehabilitation nurses. These nurses identified several barriers such as staff shortages, a lack of increment and increasing workloads. To give examples, one nurse, whilst agreeing with the idea, commented:

> "It's a very good idea, but mostly in community all the nurses almost already assigned a Pap smear/DNE/asthma/Health screening nurse which already taken most of the time with their patient in certain day that can make really shortage of nurse" (NP – 026).

This view was also supported by one of the male nurses who felt dissatisfied with his work/salary balance. He observed:

> *"Tugas bertambah tapi gaji sama macam biasa saja, iatah inda berminat"* (NP – 046).
>
> TRANSLATED TO: ("Workloads increase but the salary remains as usual, that's why I'm uninterested.") (NP – 046)

However, some of the nurses were adamant, despite the impending problems, that the community stroke rehabilitation nursing services are needed. This view was illustrated by one of the male nurses (NP – 051), who was not prepared to undertake the training, but offered the following advice:

> "It's possible if there is enough manpower." (NP – 051).

Nevertheless, one of the nursing officers stressed the importance of the specific scope of community stroke rehabilitation nurses' role, as she recommended:

> “I strongly agree if there is a possible introduction of community stroke rehabilitation nurse but provided that the nurses are only doing community stroke rehabilitation and not the other roles.” (NP – 003).

In summarising the above findings, the nurse participants in this study indicated that the potential introduction of the stroke rehabilitation nursing can provide them with prospect of becoming a specialist nurse. The advancement of role was viewed as giving health benefits for the stroke patients and carers in the community. However, very few nurses refuted establishment of the rehabilitation nurses. The possible negative implications on the nurses’ current professional roles and lack remuneration were highlighted.

6.8.6 Provision of stroke nursing education and services

This sub-section presents findings with reference to participants’ recommendations that were given in relation to the study. This strategy is useful for exploring other valuable information that was not captured by the questionnaire. In responding to the question, about 35% (*n*=30) of the 85 nurses who answered the open-ended questions provided some recommendations. The initial coding identified 16 overarching codes. These were reviewed and condensed into two main categories, (1) organisational aspects of the training, and (2) nurse-led rehabilitation services.

(1) Organisational aspects of the training

This category refers to the scope of the proposed stroke rehabilitation educational training and how it should be structured. Over half (*n*=18) of the 30 nurses gave recommendations that described the organisational aspects of the training, such as the level of education, incentives after completing the training and the involvement of staff in the training. For example, one nurse, who was uncertain about the need for stroke education, suggested:

> *“Jika boleh jururawat yang di tugas kan untuk jawatan ini mempunyai kursus/degree dalam bidang ini”* (NP – 079).
>
> TRANSLATED TO: (“If possible, the nurses who were assigned to this role should have attended a course or hold a bachelor’s degree in this area [stroke rehabilitation].”) (NP – 079).

One of the senior staff nurses also agreed with this view and advised offering a course above diploma level:

> *“Kursus nya jangan setakat diploma bagi chance untuk naik lagi”.* (NP – 049)
>
> TRANSLATED TO: (“The course shouldn’t be at diploma level alone, but give a chance to further upgrade.”) (NP – 049).

Given the specialised disciplines, many nurses identified the need to provide appropriate "incentives after [completed] the training" (NP – 003). For instance, one nurse, who did not support the introduction of community stroke rehabilitation nurses, suggested:

> *"Menaikan gaji atau memberi elaun khas bagi jururawat tersebut"* (NP – 080).
>
> TRANSLATED TO: ("Increase the salary or provide a specific allowance to those nurses.") (NP – 080).

Essentially, this nursing officer (NP – 020) wished that a "community stroke rehabilitation centre make could be make available". Her recommendation was supported by a nurse who requested "please make it a reality because our country is in need of this nurse group" (NP – 009).

(2) Nurse-led rehabilitation services

This category refers to the stroke rehabilitation nursing services that should be managed independently and offered specialised stroke support care. About one-third (*n*=12) of the 30 nurses offered suggestions that were related to nurse-led rehabilitation practices. For example, one male nurse (NP – 078) recommended "*di tempatkan sekurang-kurangnya seorang jururawat yang paker dalam bahagian penjagaan stroke di setiap wad/klinik kesihatan".* TRANSLATED TO: ("at least, to assign one nurse who has expertise in stroke care to each ward/health centre"), while another nurse suggested "opening a led clinic [nurse led stroke clinic]" (NP – 014).

The importance of providing independent stroke rehabilitation services was highlighted. These nurses suggested that stroke rehabilitation should has its own department to facilitate patient care. For instance, one male nurses emphasised:

> "The community stroke rehabilitation should be set up in its own department or centre such as the Renal Centre, and SHOULD NOT [words originally capitalised] be included in Outpatient Department or any health care centre in order to run the services smoothly and accordingly." (NP – 027).

Different male nurses anticipated potential problems for stroke patients. Thus, he suggested that stroke rehabilitation should be provided at all health centres:

> "…it could be better if stroke rehabilitation services are offered to all area of clinic because some area are difficult to be reached. Patients may have transportation problems therefore, if this is done we could improve some stroke patients' condition gradually." (NP – 001).

On the other hand, a few nurses recognised that stroke rehabilitation is a collaborative approach between nurses and other allied healthcare professionals. For example, one male nurse (NP – 018) suggested “collaboration with other health care team members including physiotherapists, home-based nursing and psychologists”. Likewise, one nurse participant (NP – 028) felt that “stroke rehabilitation nurses can work together with the health promotion centre to promote the prevention of strokes”.

However, the same male nurse, who stated earlier that he was not prepared to undertake the training wrote his recommendation as:

> “…this service is just for home based nursing department and not under outpatient department.” (NP – 051).

In summarising the above finding, the data showed that the need for a structure stroke rehabilitation programme was recommended by several of the nurses. Moreover, these nurses suggested independent nurse clinic that function to coordinate care for the stroke patients to a multidisciplinary stroke teams is needed. This finding can be useful for higher educational institution and service provider in planning the structure of training and community stroke rehabilitation nursing service provision.

6.9 Chapter Summary

Self-administered questionnaire was developed to explore the perceived educational needs and the potential roles of nurses in stroke rehabilitation. A total of 101 nurse participants from various primary health centres locate within the Brunei Muara district took part in the study. The quantitative data obtained from the questionnaire were analysed and findings from the statistical tests were presented. The overall findings from the SSEF rehabilitation element items; ‘knowledge and understanding’ and ‘skills and abilities’ competencies frequently identified higher mean scores, on the scale of 1 – 5, and smaller standard deviation values, which suggests positive direction and participants’ degree of agreement on items from both scales. These findings, therefore, indicative of the participants’ rehabilitation role in stroke and their perceived needs for structured and formal training in stroke education. Moreover, these nurses viewed their roles in stroke rehabilitation as integral in complementing the existing rehabilitation professionals’ service delivery, although ongoing issues concerning staff shortages were perceived as a barrier to the introduction of specialist nurses on stroke rehabilitation. The questionnaire findings indicates existing gaps in relation to development of nurses’ educational training for stroke in Brunei. Therefore, implication of this study finding to higher educational institution is relevant.

Next proceeding chapter will presents the analysis of findings from phase 1 study. All findings from nurse questionnaire, interviews with the stroke patient participants and carer participants were further analysed. This information formed into meta-inferences, which describe an overall conclusion, explanation or understanding generated from the integration of the inferences obtained from the quantitative strands and qualitative strands of mixed method research (Tashakkori & Teddlie, 2009). Therefore, both set of data were linked, merged and compared in order to identify the key findings of the phase one study. The strategy for integrated data analysis and result of the integration process will be discussed in the following Chapter 7.

Chapter 7: Key Findings from Phase One Study

7.1 Introduction

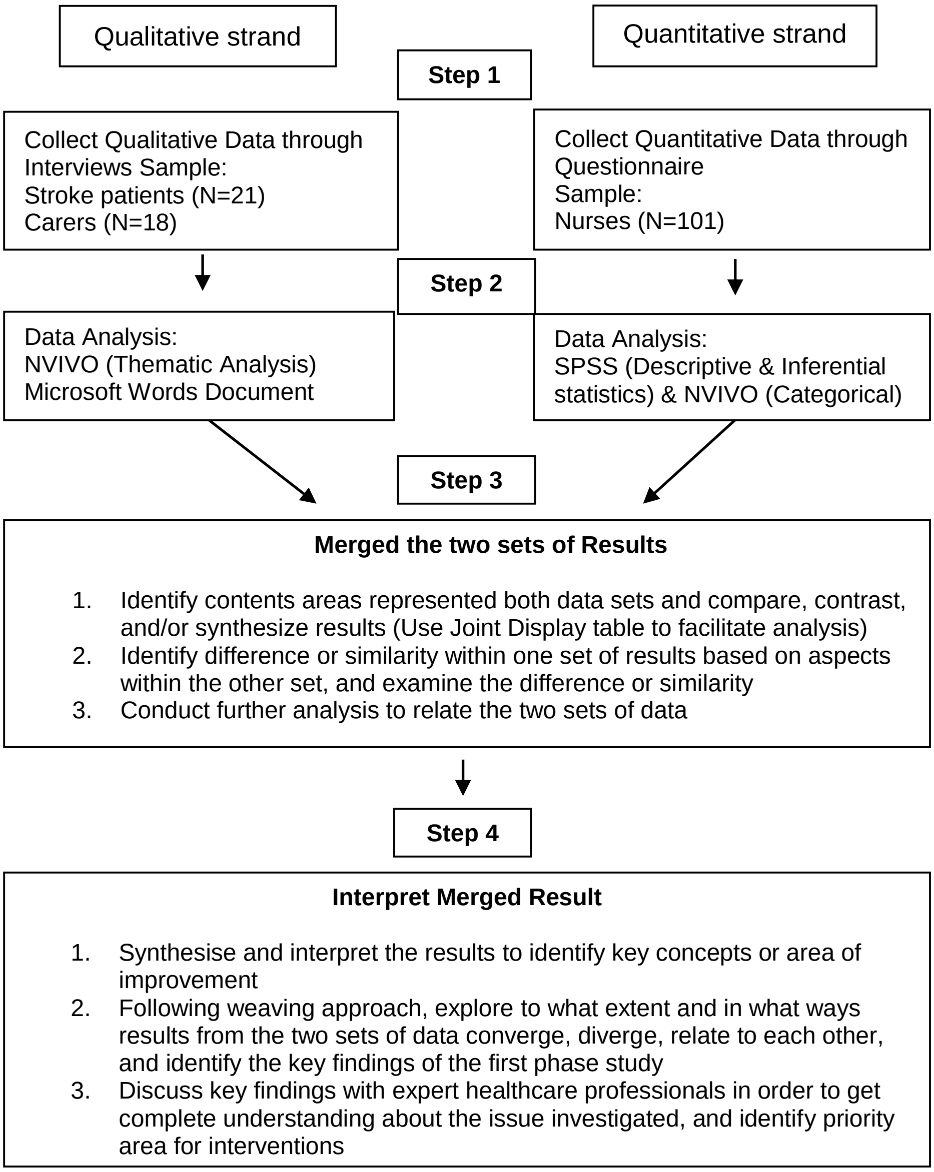
This chapter presents the process of integration for the qualitative and quantitative findings from the first phase of the study and aims to identify the key findings of the analysis. The chapter begins with an overview of the steps undertaken to integrate the findings. The use of a joint display table for the integrated process is provided followed by key findings from the data synthesis which are then clearly outlined and summarised. A discussion of convergent or divergent results from each data set is incorporated into the summary of the key findings. Finally, a summary of the chapter is provided.

This chapter sought to address the following research objective:

- To critically analyse the qualitative and quantitative results of the first phase study in order to identify the key findings which contribute to the improvement of home-based stroke service provision.

7.2 An overview of steps for integrating the findings

Flowchart 4 shows the research design of the first phase of the study and the steps undertaken to integrate and interpret the qualitative and quantitative findings. A parallel mixed methods data analysis (Teddlie & Tashakkori, 2009) was employed. Themes identified from the interviews with stroke patients (*n*=21), the carer participants (*n*=18) and the statistical outcomes from the nurse questionnaire (*n*=101) were synthesised in order to examine whether both sets of findings agreed (converged) or disagreed (diverged) on various aspects required to improve the provision of home-based stroke rehabilitation. A joint display integration table was formulated to facilitate any comparison between sets of findings. This comparison approach allows confirmation, disconfirmation, cross-validation or corroboration from both sets of findings (Creswell & Plano Clark, 2011), therefore it provides a better understanding of the issue being investigated.



Collect Qualitative Data through Interviews Sample:
Stroke patients (N=21)
Carers (N=18)

Collect Quantitative Data through Questionnaire
Sample:
Nurses (N=101)

Data Analysis:
NVIVO (Thematic Analysis)
Microsoft Words Document

Data Analysis:
SPSS (Descriptive & Inferential statistics) & NVIVO (Categorical)

Merged the two sets of Results

1. Identify contents areas represented both data sets and compare, contrast, and/or synthesize results (Use Joint Display table to facilitate analysis)
2. Identify difference or similarity within one set of results based on aspects within the other set, and examine the difference or similarity
3. Conduct further analysis to relate the two sets of data

Interpret Merged Result

1. Synthesise and interpret the results to identify key concepts or area of improvement
2. Following weaving approach, explore to what extent and in what ways results from the two sets of data converge, diverge, relate to each other, and identify the key findings of the first phase study
3. Discuss key findings with expert healthcare professionals in order to get complete understanding about the issue investigated, and identify priority area for interventions

Flowchart 4: Steps for integrating the Qualitative and Quantitative findings

7.3 Strategy for integrating the two sets of results

This section describes strategy that was undertaken to merge related sets of data from phase one study. Details description regarding how data sets were mixed and how divergent or convergent data were managed will be explained. The process of merging the data was undertaken during the interpretation stage of the phase one study. Both quantitative and qualitative data become interdependent in addressing the objectives of the phase one study. The purpose of data integration is to examine convergent or divergent findings that could be used either to provide complementarity (using one set of finding to enrich or explain the other), give inference, corroboration (Creswell & Plano Clark, 2011), comparison or contrast between both sets of merged findings. Outcomes of this analysis will help to identify priority areas or concern and key findings of the phase one study. A joint display integration table was formed to facilitate comparison between sets of findings. The process of analysis is describe as follow:

7.3.1 Analysis of Convergent Findings

Convergent data refers to the degree in which difference data sets indicated agreements with specific aspects of the research. The analysis process of convergent data incorporate two methods: (1) integrating and presenting convergent data using a joint display format, and (2) discussing integrated data in written analysis or a narrative approach using weaving approach (Fetters, Curry & Creswell, 2013). Explanation regarding these approaches will be provided in section 7.3.3.

7.3.2 Analysis of Diverging Findings

The process of analysing divergent data is similar to that approach of data convergent. Any interviews data that demonstrates opposing views from other qualitative data, and any negative response cases (disagreed or uncertain) from the questionnaire data will be identified. The related interview extracts and questionnaire data are then presented in joint display tables.

7.3.3 Integrating the data using the Joint Display Table

A joint display is refer to presenting the related qualitative and the quantitative data simultaneously in the form of a table or figure (Fetters et al., 2013). It brings both the qualitative and quantitative results together through a visual means which allows deeper understanding and new insights beyond the single data alone. Related findings from qualitative and quantitative strands from the phase one study that demonstrated agreement (convergence) or incongruence (divergence) were extracted and organised side-by-side in a joint display table. The process of integrating of related data for the phase one study is briefly describe as follow:

1. All data sets were reviewed. Data were compared and contrasted focusing on achieving the objective of the phase one study.
2. The related themes from the qualitative data and along with its interview excerpts were identified.
3. Relevant findings from statistical analysis of the questionnaire data (see Chapter 6) were identified.
4. Both identified data sets were extracted and prepared in words document.
5. Side-by-side, joint display integration tables were used to arrange both data. Analysis to compare and contrast related results of the interview data and statistical findings derived from the questionnaire constructs were undertaken.

6. The joint display consisted of a row for qualitative themes from interviews with the participant with stroke and the carers, and the corresponding quantitative variables of the nurses’ questionnaire which related to the themes.
7. Any differences or similarity within one set of results based on aspects within the other set will be examined.
8. Related data sets were synthesise to identify key concepts or themes.
9. Result of data synthesis were interpreted and brief explanation about the association will be given.
10. New interpreted findings from integrated analysis will be generated to form the key findings of the phase one study.

Once integration of data using join display is completed, the key findings generated from this integration process will be explained in written format following the weaving approach (Fetters et al. 2013). This approach refers to merging both the qualitative and quantitative findings under the themes (key findings) and provide narratives that explain comparison or concordance of results between samples. Both related results from the data sets are connected with each other and weave iteratively under the same themes. The outcome from this synthesis was interpreted and explanations for any association between sets of findings was given. Finally, key findings from the integration process were identified. Table 17 illustrates the joint display integration process. Divergent data was written in italic to facilitate comparison. The remaining joint display tables are presented in Appendix 7.

Descriptors:

SD=Standard Deviation, Scoring (Lowest = 1, Highest = 5)
KAU=Knowledge and Understanding (items a to q): ***SAB*=**Skills and Abilities (items a to r): ***BAR*=**Barrier to attend training (items a to q): **Q=**BruNEIS Questionnaire
SP=Stroke Participants (N=21), **CP**= Carer Participants (N=18)
Italic Statements = indicates Divergent Data

Findings and quotation from interviews with Stroke Participants (SP)			Findings and quotation from interviews with Stroke Carer Participants (CP)			Corresponding findings from the Questionnaire items (N=101)		
Theme	Subtheme	Examples of the Interview Quotes	Theme	Subtheme	Examples of the Interview Quotes	Questionnaire Main Constructs		
						KAU	***SAB***	***BAR***
Theme 1: Experience the impact of strokes	1.1. Feeling physically incapacitated	"I feel all my limbs are weak]. The most obvious is my feet and hand. There are no other body parts affected. Only my feet and hand. It [stroke] has affects the muscle and the limbs." (SP – 13) "…it's like I'm unable to walk on my own…I feel like I'm losing my ability to walk…" (SP – 02).	Theme 1: Impact on caregiving experience	1.1. Feeling of physical pain and exhaustion	"Of course at the beginning I am not used to it [caring a stroke patient]. I feel pain all over my body…because my weight is 60 kilograms before, and now is 56. I am worry. When he [the stroke patient] is admitted at the hospital, his weight is 70 kilograms…and now he is over 80 kilograms. So my body can't tolerate which led to pain." (CP – 09) "I stay with Haji [stroke patient] for 24 hours. There were so many to do, not only	The majority of the nurses (98%) agreed the need to have knowledge regarding impact of stroke on individual, carer and family. (Q14 item a: mean 4.50, SD 0.54) Over 95% of the nurses needs to know about methods to support patient with stroke (Q14 item l: mean 4.49, SD 0.58) About 92% of the nurses indicated that they need to	About 93% of the nurses agreed that recognising the symptoms and impact of stroke to physical (Q15 item m: mean 4.38, SD 0.63), and post-stroke pain (Q15 item n: mean 4.38, SD 0.63) are required skill competencies for stroke nurses.	More than half (73%) of the nurses agreed that lacked of experience in stroke patient care can be barrier to attend training in stroke. (Q16 item f: mean 3.92, SD 0.96)

	exercises. So, I am physically exhausted and don’t have enough sleep too. Haji didn’t sleep in the evening, but during day time. Thus, I hardly have enough sleep throughout the day. It’s physically demanding.” (CP – 13	have understanding about the impact of stroke on patients’ physical and physiological functions. (Q14 item g: mean 4.43, SD 0.67)
“*Not necessarily eh! [a Malay slang to express disagreement] because my wife always helps me, so I don’t feel it [difficulty due to physical impairment]” (SP – 01).*	*“…there is a burden…but I have to make the sacrifice. Because he [the stroke patient] belongs to us…as part of the family…I cannot ignore him…because I felt pity for his condition.” (CP - 03).*	*Over tenth (10.9%) of nurses were uncertain regarding the education requirement for post-stroke pain. (Q14 item h: mean 4.36, SD 0.72)*

Interpretation of merged data:
Findings from both the data sets showed concordance between sample groups regarding the physical impairment following stroke (qualitative data) and the requirement for stroke rehabilitation nurses to be knowledgeable and competence (quantitative data) for managing this problem. This finding demonstrate that nurses were aware and anticipate the physical challenges experience by patients with stroke and their carer following the stroke event. Although, minority of stroke patients were defensive about physical dependency or nurses felt uncertain about pain management post-stroke. For carer, despite of evident of physical strain, many would decline that they perceived their role as physically burdening.

Interpreted finding: Physical challenges after stroke

Table 17: Example of Joint Display integration between the Qualitative Findings (for Stroke Patient and Carers) and Questionnaire Data for the Phase One Study

7.4 Findings from Integrated Data Analysis

Diagram 15 presents an overview of interpreted findings identified through the integrated data analysis. Overall, the analysis revealed 12 preliminary key issues pertaining to rehabilitation support needs and home-based service provision for stroke victims. In both qualitative and quantitative results, the participants indicated that their lived experience aftermath of the stroke event was challenging and it is clear from the data that reconfiguring the provision of a rehabilitation support service within the community can be complex. For the stroke patients and the carers, the residual impact of a stroke on their physical, emotional, social, spiritual and financial resources was perceived as ‘felt’ needs that required attention from the healthcare provider. However, the indication was that there was a lack of continued support after these participants left the hospital, thus their personal needs and goals relating to therapy and caregiving roles were only partially met, or to a certain extent left unmet. The reliance on *urut* as a form of additional therapy as well as the participants’ cultural perceptions about stroke meant that an education intervention was necessary to correct this misconception. The potential involvement of nurses for improving the existing rehabilitation support provision was viewed favourably. However, the divergent results identified from the integrated findings suggested that the planning needed to introduce this new service may require significant appraisal.

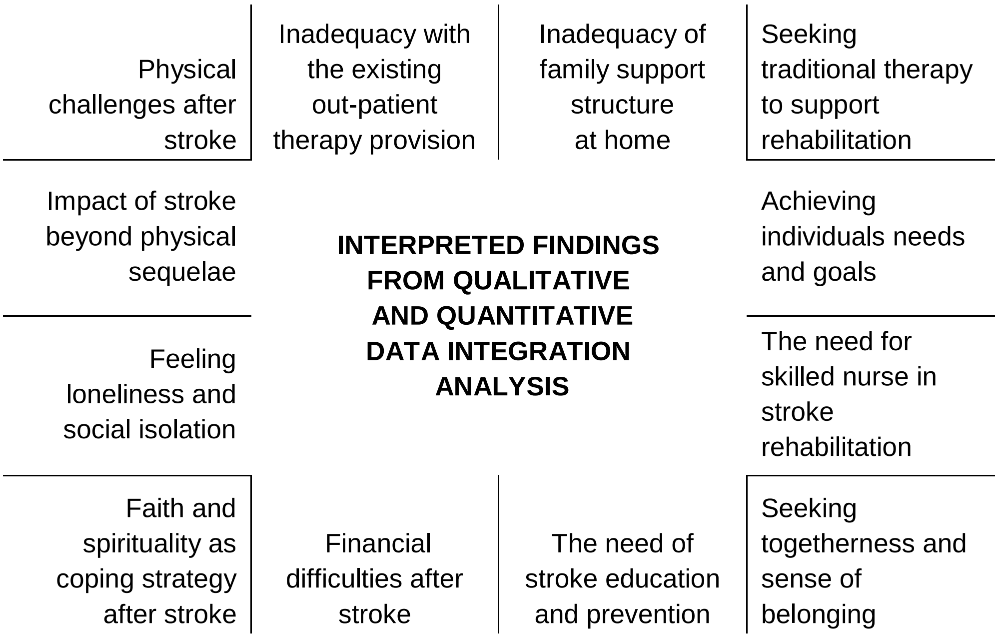


Diagram 15: Overview of interpreted findings from integrated data analysis

7.4.1 Prioritising key areas for improvement

The interpreted findings were further examined to ascertain priority areas of improvement. All of the 12 findings were reviewed for any duplication, similarity or association between each other. The process of prioritising key areas for improvement was informed by the following key determinant criteria:

Urgency and the importance of the issues

This criterion relates to the level of urgency and importance of the issue identified as informed by the data collected. It refers to the participants' priority needs relating to rehabilitation support that was considered essential and required considerable attention by the healthcare providers. This research revealed that the participants in this study experienced various support needs pertaining to rehabilitation within the community setting. The conceptual models for the stroke patients and carer participants illustrates a varying degree of needs that influenced the lived experience of these participants at home. The availability of existing support provision provided by the healthcare organization enabled needs such as physical challenges to be met or partially met. However, the present support service for specific needs, such as emotional disturbance, remained lacking or the issues were not adequately addressed. The interview data indicated that participants may endure considerable ill-health if these 'felt' needs were left unresolved. Therefore, the extent of the 'felt' needs among the study participants was considered in prioritising key areas for improvement.

The cause and effect of one intervention with respect to others

This criterion denotes the relationship between one interpreted findings with other related findings. It refers to whether one finding is a part of the problem or the primary root cause of other problems. The interpreted findings indicated some interconnecting issues, such as those relating to declining family support, impaired social functioning and seeking togetherness. Other related findings included the need for stroke education and the role of nurses in stroke rehabilitation. The service improvement for these interrelated findings may focus on achieving one goal, such as improving the social support. Hence, addressing any one issue from these interrelated problems may lead to broader improvements with respect to others issues. Therefore, all specific interpreted findings were critically examined and chosen as one of the priority areas for improvement.

The feasibility and practicality of potential interventions in addressing the issue

This criterion is well aligned with the research paradigm of pragmatism, in which the researcher explored what worked best to solve issues. It also determined how feasible and practical future interventions would be in addressing issues related to the home-based stroke rehabilitation service provision. The practicality of such interventions were underpinned by several supportive aspects such as existing resources, the capacity of individuals (stroke patients, carers and nurses) to change, a parallel vision from the Ministry of Health, existing collaboration between different stakeholders and any existing interventions which focused on issues identified from the interpreted findings. Therefore, these aspects were considered and provided guidance in prioritising key areas for improvement. On the other hand, unmanageable issues such as financial problems were considered beyond the scope of this research. Thus, the latter were deliberately omitted from priority areas for improvement.

New knowledge emerged from the research

This criterion considered what new knowledge, identified from this research, was unique to the context of Brunei. It provided a better understanding of specific considerations needed in improving the practice gaps relating to home-based stroke rehabilitation service provision. For example, the interview data showed that the use of faith and traditional practitioners in supporting rehabilitation appeared to be influential in stroke recovery. This finding suggested a viable opportunity to merge both modern and traditional care in stroke management. Hence, this criterion assisted decision making in prioritising key areas for improvement.

Following the criteria above, six of the 12 interpreted findings were considered as priority areas for improvement and formed the key findings of the first phase study. The six statements were refined to illustrate the underlying context of issues explored, and are outlined below:

- Support needs beyond physical sequelae
- Family support structure at home
- Provision of existing out-patient therapy
- The need for skilled nurses in stroke rehabilitation
- Seeking traditional rather than modern healthcare
- Religious and cultural practices to support recovery

7.4.2 Summary and interpretation of the key findings

This sub-section provides a summary of the six key findings identified. The approach of 'weaving' in the discussion of the integrated results was illustrated by evidence to exemplify and demonstrate the findings presented in the form of quotes. The Malay excerpts were written in italics with an English translation provided in brackets. Any divergent findings were used to contrast with convergent data. The key findings identified were discussed as follows:

Key Finding 1: Support needs beyond physical sequelae

The results from integrated data analysis showed complementarity views between both sample groups with regard to emotional disturbances after the stroke (qualitative data) and the requirement for stroke rehabilitation nurses to be knowledgeable and competent (quantitative data) so as to support patient and carer emotional crisis. The interview data suggested that the stroke patient participants needed support that went beyond their physical sequelae of a stroke. Feelings of anger, wanting to give-up, stress, being upset and sadness were described by many of the participants. The carers reported that the stroke patients were likely to feel angry at being unable to undertake simple tasks, such as putting on shoes and that the carer was slow to respond to provide help. For the carers, however, feeling stress was often due to failing to obtain adequate rest in their caregiving role. The findings also revealed that slow progress in terms of recovery led the stroke patients to feel frustrated which frequently resulted in them abandoning their exercises. Participant accounts showed that support regarding the emotional impact of a stroke is currently lacking or is left undetected by the healthcare professionals. For example, this stroke patient mentioned:

> *"Dalam bulan pertama lah…rasa sedih lah…Rasa perhatian lah yang di perlukan"* (SP – 02). TRANSLATED TO: ("In the first month…felt very sad…attention [from others] was what I needed.") (SP – 02).

On the contrary, the data also indicated that participants who experienced emotional problems often did not make their feelings explicit or known to the therapists. The divergent data revealed that participants' concealing behaviours were due to several factors; such as the carer relationship with the stroke patient; the employer-employee status; avoiding unnecessary arguments or due to factors which were simply unclear. This proved that identifying stroke patients or carers who were experiencing emotional disturbance can be challenging for healthcare professionals. As a case in point, the following carer advocated a 'leave it as it was' approach to hide her emotional distress; she implied:

> *"…ada merasa anu lah….macam kalau sudah ngalih atu kan…mudah rasa tertekan…tapi cuba jangan lah…macam atu…selalu mudah tersinggung….jadi kalau tersinggung karang…macam susah jua kan…jadi biar kan lah…buat aja macam atu.."* (CP – 02)
>
> TRANSLATED TO: ("…I do feel stress especially if I feel tired. But I try to control this feeling [stress]…not to feel offended [by too much care activities works]. If I am too sensitive, at the end I am the one who suffer too. So, I just leave it as it was.") (CP – 02)

Whereas for some participants, support from the healthcare providers for emotional distress was not necessarily needed. The data showed that the individual's perseverance, determination and positive coping skills were the most vital requirements to live with the aftermath of a stroke. Most importantly, many participants highlighted that going back to the path of *Allah* [the Islamic way of teaching] was an approach that was needed. This was exemplified by the following carer account:

> *"Yang pertama mesti dulu menerima kenyataan..menerima kenyataan..aa iatah tu anu yang di berikan Allah Ta'ala ani tah ani. Kemudian yang kedua apabila kitani sudah menerima kenyataan, redha. Selepas redha, baru tah kitani dapat menghadapi atu semua atu kan"* (CP – 01).
>
> TRANSLATED TO: ("First, accept that the stroke is sent by Allah Ta'ala. Secondly, feel *redha* [approval, often involving a degree of fondness]. After *redha*, only then we can cope with this situation [the aftermath of the stroke].") (CP – 01).

Meanwhile, the findings from the questionnaire showed that the views of the nurses with regard to providing support for stroke patients and their respective carers encompass physical, psychological, social and emotional recovery. The data indicated that assisting the patients with their physical functioning, providing counselling and supporting the carers were legitimate roles of the stroke rehabilitation nurses. Over 95% of the nurses agreed or strongly agreed that understanding the impact of a stroke on a patient's psychological and emotional well-being was one of the most important competencies by a stroke rehabilitation nurse. For example, this nurse suggested the following roles beyond the physical sequelae:

> "Providing support to patients, carers and family in term of psychological and emotional well-being" (NP – 007).

In summarising the key finding, the current provision of rehabilitation support seemed to focus primarily on physical recovery after a stroke. Whereas, the study found that problems of stroke may go beyond the patients' physical sequelae, in particular the impact of a stroke on the patients and carers emotional well-being. The perceived educational requirement for a stroke rehabilitation nurse with regard to emotional support was evident in the study. However, the challenge to identify individuals with emotional issues was equally highlighted. The emotional concealing behaviours among several stroke patients and carer participants in this study suggested that different strategies may be needed to address the issue of emotional problems after stroke. The study revealed that spiritual and religious practices, perhaps, were needed to cope positively with emotional and psychological disturbance post-stroke. This key finding was discussed with expert healthcare professionals in the second phase of the study.

Key Finding 2: Family support structure at home

The results from the integrated data showed concordance between sample groups regarding the need for continued support at home (qualitative data) and the requirement for stroke rehabilitation nurses to be knowledgeable and competent (quantitative data) when managing this lack of support at home. It was known that most of the stroke patients traditionally lived with their carer or close family members in the same house. This extended family support structure could be valuable for the recovery of the stroke patients. However, a minority of the participants indicated that this support structure was not necessarily available. For example, one stroke patient shared his experience of being left alone at home when the carer was at work. Furthermore, another stroke patient who lived alone had to manage the needs of others as well as his own daily needs. These participants described that they felt very lonely, bored or even ‘crazy’. Moreover, the study also highlighted the challenges experienced by two of the carer participants who provided care on their own because their siblings were unwilling to become involved. An extract from one of these carers is as follows:

> *“..ada pulang peradian lain ani..aduh malas cakap yang laki laki lah..mungkin abang ku seorang atu lah.. langsung nda anu inda berapa berapa peduli..iatah atu lah saja kami anu saja membantu..ia kan..Kesian jua kan..kalau inda di bantu..karang siapa yang susah..sendiri jua..”* (CP – 12)
>
> TRANSLATED TO: (“I have other brother, but he hardly give attention and keen to involve. So, I have to care him [stroke patient] alone. I feel pity at him [stroke patient], but if nobody care him, then eventually I will suffer too.”) (CP – 12)

On the other hand, for a few stroke patient participants, the presence of a family carer was not necessary. These participants believed that outsourcing the support care to private individuals, such as a paid carer (housemaid) or personal trainer were viable strategies to address the issue of a lack of family support. The study revealed that hiring a housemaid was financially difficult for many or identifying an experienced paid carer to care for a stroke patient was challenging. One carer participant commented:

> *“Tapi kalau di rumah, aku inda tedapat pembantu rumah..inda ku tedapat..mungkin inda tahu lah satu satu masa akan datang kali lah..mungkin kali ada..baru tah ku*

> *ngambil pembantu rumah..atu pun alum jua harap nanti..sebab apa kan..baik ia tahu..ujung ujung..catu lah."* (CP – Pilot01)
>
> TRANSLATED TO: ("At this moment I do not have *amah* (paid carer). Probably I'll get one in the future. I am not sure yet. But, if there is *amah*, we can't certain that she knows how to care a stroke patient, thus [hiring them] can be risky.") (CP – Pilot01)

The findings from the nurse questionnaire, meanwhile, showed that the majority of the nurses (98%, *n*=99) frequently identified that stroke has a direct impact and negative implications for the stroke patient's family and carer. The need for the stroke rehabilitation nurses to have knowledge and understanding regarding these aspects was demonstrated in the integrated data. Furthermore, nearly 90% of nurses agreed that helping the family of a stroke patient to cope with the event post-stroke was a skill and ability needed for a rehabilitation stroke nurse. The qualitative data from one of the nurse participants indicated:

> *"…membantu pesakit strok dan keluarga mereka menjalani tempoh pemulihan di samping memberi sokongan dan khidmat nasihat kepada mereka secara berterusan bukan saja dalam tempoh pemulihan malah sehingga pesakit sembuh"* (NP – 062).
>
> TRANSLATED TO: ("…to help stroke patients and their family during the rehabilitation therapy, in addition to providing continued support and advices not only during the recovery phase but until patient has fully recovered.") (NP – 062).

On the contrary, very few nurse participants maintained that the supportive role for stroke patients or carers at home should be designated to staff from the home-based nursing unit, rather than to their current workplace. One of the nurses offered the following opinion:

> "Not sure if relate to community nurses due to job prescription given. Stroke rehabilitation more towards home based nursing". (NP – 004)

In summarising the key finding, the study uncovered the significant issue of a declining family support structure for stroke patients and carers at home. Although certain viable strategies to address the lack of family support were identified in this study, it was argued that these strategies may not be feasible or may be too financially demanding. The data from nurse participants identified an education requirement to support the family, carer or the patient following a stroke. However, conflicting views between nurses with regard to the support role at home indicated that establishing the nurses' role may require careful planning. The finding provided important insights that challenged the efficacy of the existing family support structure in Brunei, and thus raised the question of the availability of alternative support management, particularly for those individuals who did not have any immediate family members such as expatriates. This issue is discussed during the second phase of the study.

Key Finding 3: Provision of existing outpatient therapy

The results from integrated data analysis showed complementarity views between both sample groups with regard to the existing out-patient rehabilitation therapy provision. The participants with stroke and the carer sample groups revealed dissatisfaction with the timing and intensity of therapy provided (qualitative data) and how the nurses felt that this shortfall could be addressed by providing knowledgeable and competent (quantitative data) stroke rehabilitation nurses.

The views of many stroke patients and carer participants revealed that the duration of the existing out-patient rehabilitation therapy provided was very limited. These participants felt that the allocated time for individual therapy of 30-45 minutes, delivered once or twice per week was ‘not enough’. Participants were, however, uncertain about the international standard of rehabilitation therapy that a stroke patient should receive on a weekly basis. The study finding raised concerns about whether the rehabilitation that the patients received was tailored to their needs or did not meet the individuals’ expectations. One stroke patient participant commented:

> “I get from the centre is just one hour one hour...I believe it is not enough…that’s not enough.” (SP – 18)

Several other participants indicated that attending therapy, despite its time constraint, was still considered important. These participants believed that the stroke patients and the carers should maximise the therapy activities so that they could repeat the exercise and continue at home. The study revealed that few participants disagreed with the idea that stroke patients should be dependent on the out-patient rehabilitation service only, rather than motivating themselves to continue exercise at home. In support of this view, one stroke patient participant indicated that what was actually needed was the individual courage to manage oneself independently at home in order to improve one's well-being. He stated:

> *“…berusaha sendiri lah..nya orang berusaha atu..sendiri...membaiki diri sendiri lah...jangan bertumpu kan jangan bertumpu kan kepada khidmat orang lain untuk membantu kitani atu bah dibantu oleh orang lain bah..Atu tugas tugas macam terapi, bini tani anak tani tugas untuk menolong kitani bah..but seboleh boleh nya kitani kalau barang atu buleh sudah tani buat macam makai baju..pakai seluar...mandi..Lebih baik di lakukan sendiri..dapat tani tau sudah melakukan macam atu dengan sendirinya buleh kitani merubah kehidupan kitani bah..jangan tah..dari macam atu pun kira diri terapi jua tu bah terapi jua bah....”* (SP – 17)

> TRANSLATED TO: ("…we have to manage our own [therapy]. We must improve ourselves and not too reliance on the service [outpatient rehabilitation]. The therapist or the carer only provide minimal help. If we could do it independently, we should do on our own. For example, if we able to wear clothes independently, we should do this alone. This also consider as therapy which can improve our living.") (SP – 04)

The findings from the nurses' questionnaire, meanwhile, suggested that visiting the patients at home once or twice a week would complement the work of the stroke rehabilitation team. The nurses commented that they could reinforce rehabilitation exercises by providing education to patients and their families and encouraging moral support, which would do away with the need for referrals to other multidisciplinary healthcare team members. For instance, one nurse participant suggested that the nurses could complement the allied professional rehabilitation team through making "frequent home visits to stroke patients" (NP – 024). The potential home visit by nurses was viewed by some participants as complementing out-patient therapy. For example, this stroke carer stated:

> *" Kitani masa ani alum ada kan. Macam kami datang, sekirnya kami ke …. dua kali seminggu, berapa saja… setangah jam saja…berapa lama saja exercise nya. Buat itu ini…kadang kadang durang bagi lilin apa…atu..atu saja tu… Kalau macam di rumah, kitani meliat….kira tia ah sejam ia kerumah… ia membuat aktibiti-aktibiti…tani sudah puas ada pengalaman atu meliat… "* (CP – 03)
>
> TRANSLATED TO: ("At this moment, we don't have that [stroke rehabilitation nurses]. For example, we went to the rehabilitation centre…[therapy] for half an hour only. Did a few exercises then stopped. [But] if the therapy was provided at home, like for an hour…the nurse did activities [rehabilitation]…by observing them, I would feel satisfied and gain [new] experience") (CP – 03).

On the contrary, a few nurse participants were sceptical about the expansion of their existing role to include stroke rehabilitation care. These nurses felt that home visiting was the role of social workers, or if they were asked to provide this service then certain incentives, such as an allowance, should be provided. One nurse participant commented:

> "…sometime there are lot of patients, expertise and staff really needed. Salary stay the same, doing home visit should be provided with allowance, since working outside the clinic can be risky compare to hospital/clinic." (NP – 048).

In summarising the key finding, the integrated results from the stroke patients and the carer participants suggested that many would agree that gaps existed with regard to the present rehabilitation service provision for stroke, both in the form of out-patient services or long-term care at home. However, it was observed that most of these participants would not openly show their dissatisfaction regarding inadequate therapy duration, directly to the therapists. On the contrary, over reliance of stroke patients or carers on the existing out-patient rehabilitation service provision appeared to be opposed by a few of the participants. The importance of managing oneself independently was suggested as a vital need for the stroke patient to recover and improve their well-being. Furthermore, views of the nurse participants indicated that they should have a particular role to assist the therapist in home visits for stroke. However, a number of other nurses felt that expanding their role was neither appropriate nor cost-effective. The integrated finding provided an understanding that addressing issues with regard to home-based rehabilitation service provision can be complex. This issue was discussed with the expert healthcare professionals in the second phase of the study.

Key Finding 4: The need for skilled nurses in stroke rehabilitation

Findings from both the datasets indicated differing views between sample groups with regard to the potential roles of stroke rehabilitation nurses (qualitative data) and the skills and abilities required (quantitative data) for these nurses. The comments of the stroke patients and carer participants concerning stroke rehabilitation nursing indicated that this potential service can be a vital source of ongoing long-term rehabilitation as well as providing psychological support at home. The accounts of the participants suggested that they would like the nurses to monitor the stroke patient's recovery, give advice, reinforce the exercises and provide physical and emotional support to the carer. The following stroke patient participant commented as follows:

> *"kalau ada pun exercise pulang tu..apa yang suruh buat atu..mesti di buat lah..bagus lah jua kalau di adakan..nya orang untuk menganu kan bah..nya orang di tahap kan lagi pemulihan atu..lapas di sini ah" (SP – 10)*
>
> TRANSLATED TO: ("If there is one role of the nurses, it will be with regard to exercise that was taught by the therapist. It will be good if the nurses available so that they can improve our rehabilitation after coming from here {the rehabilitation centre].") (SP - 10)

On the contrary, the data also revealed that a few of the participants were sceptical about introducing home-based nurse rehabilitation support. The divergent views of these participants demonstrated concerns that stroke patients may not have the initiative to change or may prefer care to be provided by their immediate family. Further concerns emphasised lack of facilities at home or that carers felt that they could manage independently at home. One stroke patient commented:

> *"… tapi kalau macam boleh ke sana kah ke hospital, inda perlu kali eh..durang di sana saja". "Kalau durang ke rumah, masalah nya mungkin nada inisiatif kan anu.. berubah.."* (SP – 01)

> TRANSLATED TO: ("…if they [the stroke patient] can come to the hospital [rehabilitation centre], that [stroke rehabilitation nurses] is probably not needed. If they [the nurses] come to our home, my concern is that maybe the person has no initiative to change [relying on the visit].") (SP – 01).

Findings from the nurses' questionnaire, meanwhile, showed strong views about extending their roles and the need for stroke training; 86% (*n*=87) of the nurses agreed or strongly agreed that education about stroke rehabilitation was needed. These nurses explained that increasing stroke prevalence in Brunei and their desire to enhance their knowledge about strokes and improve home-based stroke patient care justified the need for training. The main aspect of stroke knowledge that was frequently rated as important by the majority of these nurses was a concern over the general impact of the stroke on the individuals, their families and their carers. The nurses' ability to provide advice and support was frequently identified as a very important skill set. For instance, this senior nurse explained the importance of the stroke rehabilitation nurse:

> "Because rehabilitation in stroke patient is crucial to meet the patient's health needs and their quality of life. Community stroke rehabilitation therapy will increase community nurses knowledge and skills to care for patient with stroke as stroke patient have a long term complication and rehabilitation and care is crucial especially in community based or at their own home." (NP – 003).

In contrast, issues with regard to staff constraints were identified as a barrier to undertake the training necessary to introduce stroke rehabilitation nursing. Other barriers were reported; such as a lack of interest, no previous experience caring for stroke patients, work overload, existing multiple roles and an absence of remuneration after training posed huge challenges to establish effective stroke nursing. One nurse participant declared:

> *"Saya tidak berminat dengan bidang ini (Stroke rehab nursing)"* (NP – 076).
>
> TRANSLATED TO: ("I am not interested in this area (stroke rehabilitation nursing)." (NP – 076).

In summarising the key finding, integrated data from the stroke patients, carers and nurse participants seemed to agree that the role of nurses in stroke rehabilitation should embrace being an education provider, overseeing 'homework' exercises as well as being patient and sensitive to the needs of both patient and carer. The views of nurses with regard to the need for stroke rehabilitation training was clearly demonstrated. However, the divergent views identified from both data sets suggested that utilising the available resources to overcome the barriers to training was a challenge for decision makers within both nursing and educational organisations. Despite the small number of participants who disagreed with the need for stroke rehabilitation nursing, the findings showed that working collaboratively with the relevant stake holders is a necessary pre-requisite to explore the relative merits of stroke rehabilitation nursing. This key finding was discussed with expert healthcare professionals in the second phase of the study.

Key Finding 5: Seeking traditional rather than modern healthcare

The findings from the integrated analysis showed corroboration between sample groups regarding the need for information about stroke (qualitative data) and the requirement for stroke rehabilitation nurses to be both knowledgeable and competent (quantitative data) in several aspects of stroke care and management. The accounts of the stroke patient participants showed that about one-third of the patients sought traditional healers over modern treatment as their first effort to manage their early stroke symptoms, such as drooping at one side of the mouth. The study found that the delay in seeking appropriate healthcare lasted for several days or weeks. It was revealed that the delay was often due to the stroke patients' refusal to go to hospital, family members being unaware about the signs and symptoms of a stroke or both of these factors. Some participants believed that the stroke was caused by a bad spirit. Many participants portrayed stroke as a physical weakness, which was caused by an '*evil wind'* (locally known as *Angin Ahmar*), as a test from God or misconceptions about the risk factors that can contribute to stroke. One stroke patient felt hopeless about modern treatment and therefore left the disease in the hands of Allah; he said:

> *"…kadang kadang...kehendak Allah..jadi tani inda dapat buat apa apa..semua daripada ujian Allah."* (SP – 13)
>
> TRANSLATED TO: ("…this [stroke] is Allah's Will. So we cannot do anything. All [suffering] are test from Allah.") (SP – 13)

Moreover, various stroke participants and their carers failed to understand that rehabilitation therapy may take several weeks or months before they were able to see any physical improvement of the stroked limbs. The data indicated that few participants associated this delay in recovery with the limited therapy time that was currently offered by the rehabilitation services. However, it was not clear in the study if this reason explained the participants' decision to seek traditional treatment, such as *urut,* to expedite stroke recovery. Another stroke patient observed that the therapy was not effective; he stated:

> *"Bila kediaku rasa nya exercise atu inda jua ada. Maksud ku inda macam berjaya di badan. Nada peningkatan yang baik apa, macam ubat ubat yang di beri nya inda jua. Inda ada kebaikan. Ku akui tu"* (SP – 14).

> TRANSLATED TO: ("For me, that exercise is not effective for my body. No positive improvement. All the treatments...no benefits. I admit that") (SP – 14).

Furthermore, the views of the nurses illustrated that there was a need to provide support outside the scope of the community healthcare setting. One nurse participant suggested that "educating the public regarding stroke awareness and prevention" (NP – 032) should be one of the roles of the stroke rehabilitation nurse. The questionnaire findings showed that the majority of the nurses agreed or strongly agreed that skills and abilities in providing health education were the most important competencies required by stroke rehabilitation nurses. Moreover, over 90% of these participants frequently identified that understanding the cause of, and how to assess, manage and treat problems after stroke, and risk factors for further stroke were necessary components for stroke rehabilitation nurses. Thus, the study indicated that nurses may have an integral role in education interventions to correct the public perception about stroke and improve the health-seeking behaviours among the general population. One of the nurse participants commented on providing a support role beyond the period of stroke recovery; she reported that:

> ""…the role of nurses may include educating the patients and families regarding prevention of relapse or re-occurrence of stroke" (NP – 028).

However, providing extended roles for the nurses with regard to stroke prevention and intervention can be challenging. The study showed that over half of the nurse participants were uncertain or disagreed with undertaking stroke rehabilitation training. It was found that a constraint in staffing (91.1%, *n*=92) was the main issue frequently identified as a barrier to undertake training. This finding suggested that resolving the staff shortage was needed before these nurses were prepared to assume new roles in providing community stroke rehabilitation services. One of the nurse participants commented:

> *"Kerana kurang memerlukan, yang mana lagi kakitangan kami tidak cukup".* (NP – 079)
>
> TRANSLATED TO: ("Because [training] is not needed. At this moment our staff is insufficient.") (NP – 079).

In summarising the key finding, the study showed that the views of the stroke patients with respect to stroke and rehabilitation were influenced by their cultural and religious beliefs. The drawback of this practice pertaining to the individuals' health-seeking delay behaviour to modern treatment was apparent. This integrated finding demonstrated the importance of promoting education about stroke to the public and nurses appeared willing to be part of the stroke education intervention. However, staffing issues may hinder the nurses' preparedness to undertake this role. The study finding revealed issues with regard to the educational provision for strokes and a reliance of the patients or carers on cultural and religious practices to manage the stroke patient's illness. Thus, how to utilise what was important to stroke patients as well as being aligned with modern healthcare in promoting stroke awareness, was discussed during the second phase of the study.

Key Finding 6: Religious and cultural practice to support recovery

This key finding highlighted unknown issues in relation to the wider practice of traditional massage (*urut*) in stroke. The study revealed that the stroke patient participants frequently sought religious and culture-bound practices in order to cope with and recover from their stroke. The role of the traditional practitioner in providing *urut* as a form of Malay traditional healthcare practice was believed to enhance rehabilitation therapy. The accounts of the stroke patient participants and carers indicated that they valued these practices greatly. One stoke patient participant illustrated the importance of traditional practices; he said:

> *"macam di rumah pun cari kan orang pemandai macam mengurut apa tu...la tah kalau anu kalau kan bercerita banyak macam cerita kes kes macam ani..nada ubat lain bah..mesti berurut atu jua bah..."*(SP – 17)
>
> TRANSLATED TO: ("if he (stroke patient) already at home, we [family] will search for someone who know how to apply *urut*. I heard a lot that so many [stroke patients] recovered [after *urut*]. There was no other treatment but *urut* is a must.") (SP – 17)

However, the study raised concerns regarding possible over reliance of *urut* among the stroke patients and carers. The benefits of *urut* were not clinically observed in this study. Issues regarding how these cultural and religious practices may impede or enhance the contemporary approaches to rehabilitation for improving the health outcomes of the stroke patients were not clear. But the study did reveal that attending *urut* may lead to delays in stroke patients receiving hospital treatment. One carer disclosed the following:

> *"katanya inda dapat bejalan...kali ber urut lagi lah memanggil lagi orang apa ber urut kan…mudahan aja dapat bejalan lain inda pulang…asal ia dapat bejalan..inda jua dapat..bukan ia..dari atu..mesti jua bawa ke hospital kan."* (CP – 12)
>
> TRANSLATED TO: ("He [patient] complained cannot walk. So, I called the traditional practitioner to perform *urut* hoping this treatment can make him walk again. Unfortunately, the *urut* was not effective. Only then we bring him to the hospital." (CP – 12)

The findings from the nurses' questionnaire, meanwhile, showed that well over three-quarters of the nurses (87.1%) agreed about the knowledge requirement for a stroke rehabilitation nurse in any existing support service and agreed about resources that should be available for stroke patients. However, it was not clear if these nurses regarded the traditional practitioner as an effective source of rehabilitation support. No data from the nurses' responses was available to support the latter viewpoint.

In summarising the key finding, the stroke patients and the carer participants in this study appeared to rely greatly on the practice of *urut* as part of their physical recovery. This strong cultural and religiously bound practice seemed inevitable. However, the study found that attending a traditional practitioner may have a negative impact on the outcome of the stroke. Although nurses identified the importance of existing support resources for stroke, incorporating information about traditional treatment as part of the education requirement in nurses’ stroke training seemed contentious. Therefore, there was a need to explore the complementary effect of *urut* in stroke recovery to ascertain its potential benefits to improve the home-based stroke rehabilitation service provision. This key finding was discussed in the second phase of the study.

7.4.3 Implications of not selecting other findings

The possible implications for not selecting the other six findings were considered. The criteria for prioritising areas for improvement was determined by the researcher and may well be influenced by a research paradigm bias. Hence, the selected priority areas may not fully represent the study participants' needs. Other factors such as being left unattended or participants feeling abandoned remain relevant issues. Only the six key findings from the phase one study were discussed with the relevant expert healthcare professionals in order to address issues identified. Therefore, these healthcare professionals were not aware of other issues raised by the participants. One implication for this decision would be that the gaps between current practice and ways to improve service provision remain large. Consequently, a major drawback for not selecting all of the findings was that the stroke patients and their carer may continue to live with a reduced quality of life.

However, as previously discussed when prioritising areas for improvement, the predetermined criteria were critically examined and guided by the data gathered. Moreover, most of the 12 interpreted findings were closely linked together. Hence, addressing one issue may likely give direct or indirect improvement for similarly related issues.

7.5 Chapter summary

This chapter provided summaries of the key findings derived by merging the relevant findings from the questionnaire and interview data. An overview of the data integration process and the joint display integration between both sets of data used to identify key findings of the phase one study was provided. The preliminary analysis identified 12 important areas of concern related to various aspect of rehabilitation support needs. A description of and a basis for prioritising the key areas for improvement was provided.

Overall, six out of 12 interpreted findings were prioritised; these were associated with the lack of emotional support; the impact of cultural and religious practices on rehabilitation therapy; dissatisfaction with the existing out-patient rehabilitation service provision; the efficacy of the existing family support system; public knowledge and awareness about strokes; and the need for skilled nurses in stroke rehabilitation. These formed the key findings of the phase one study. The weaving approach for intertwining of mixed data was used to explain the key findings and the inter-connected narrative or statistical analysis. These integrated findings revealed important insights into the numerous challenges or barriers which await healthcare professionals in order to improve the rehabilitation service provision for stroke in the community. Any implications for not selecting the remaining six findings were explained. The six key findings were discussed with six expert healthcare professionals during the second phase of study. The findings are presented in the next chapter.

Chapter 8: Findings for Phase 2 study

8.1 Introduction

This chapter presents a summary of the findings that were identified through discussion with six professional healthcare participants who were all experts in their respective fields. In relation to the six key findings of the phase one study issues which were not explicitly commented on or matters which did not refer to the key findings discussed were not included in the data analysis and did not form part of the themes presented. The socio-demographic profiles of the participants were provided, then, themes identified from discussion were discussed. Evidence which illustrated the themes presented was given in quotes. All of the themes were discussed under a separate heading for each key finding of the phase one study. Finally, the chapter was concluded with a summary of the findings.

8.2 Demographic profiles of the participants

A total of six healthcare experts were recruited for the second phase of the study. All of the participants were local Bruneians. Of the six participants, five were female and one was male. The age distribution was from 30 to 56 years, with a mean age across the participants of 40.5 years. The educational background of the participants ranged from diploma level to speciality training. Two of the participants had a nursing background, two were rehabilitation therapists and the remaining two were specialist consultants in the field of strokes. All of the participants held their current position for at least two years. A summary of the participants' socio-demographic profiles is provided in Table 18.

***Total of participant* (N=6)**

Categorical		***Total***
Age group	30 to 40 years	4
(Mean 40.5, SD 9.41)	41 to 56 years	2
Gender	Male	1
	Female	5
Qualification	Diploma	1
	BSc Degree	1
	MSc Degree	2
	Others[1]	2
Background of current position	Nursing	2
	Rehabilitation Therapist	2
	Specialist Physician	2
Number of years at current post	2 to 6 years	5
	Over 6 years	1

[1] *Fellowship training in Neurology or Rehabilitation Medicine*

Table 18: Expert Healthcare Professionals' socio-demographic profiles

8.3 Outline of discussion with the expert healthcare professionals

The healthcare experts were presented with the six key findings identified during the phase one study. Five interviews were conducted at the participants’ work office and one participant was interviewed in the UBD staff room. All of the interviews took place in Brunei and lasted between one to two hours.

The findings from the second phase of the study constituted the participants’ personal and professional views that were derived from experience. Thus, these views may not necessarily represent the individuals’ respective organisations. Hence, the researcher was fully aware that the participants might have reacted defensively or displayed bias regarding the key findings presented. Nonetheless, the collective views of these healthcare experts may prove crucial in providing information with respect to planning for the provision of future home-based stroke rehabilitation services and nurse education in strokes.

Overall, most of the participants agreed that the influence of Malay culture and religious practices in supporting patients with stroke recovery cannot be undervalued. Many of them also raised similar concerns about the declining family support structure and ongoing problems with staff shortages. However, there were different interpretations with regard to issues related to the emotional consequences of having a stroke and the existing out-patient rehabilitation service provision. Furthermore, two participants remained sceptical about the involvement of nurses or individuals outside the health sector in stroke rehabilitation. However, all of the participants maintained that non-government organisations can play a role in improving stroke rehabilitation services. The findings from the discussions were analysed and grouped into themes. The latter were reported under each key finding identified earlier and summarised as follows:

8.3.1 Key Finding One: Needs for support beyond the physical sequelae

The participants commented on the emotional impact of strokes on patients and their carers. Their interpretations suggested that patients experienced emotional problems as a result of the residual impact of the disease, of which the patients may be unaware. One participant stated that emotional problems encountered were influenced by the Malay culture of Bruneians, as often in Brunei culture, patients tended not to discuss their problems due to feelings of shyness or that patients were self-contained. All of the participants discussed various strategies for addressing the emotional impact of strokes on both patients and their carers and provided personal views regarding the role of nurses. The participant responses were analysed and grouped into five main themes as follows:

1. A normal part of the recovery process
2. The patients and carers' understanding of the impact of stroke on emotional well-being
3. The influence of Malay culture on patient approaches to therapy
4. Addressing emotional problems post-stroke
5. The role of nurses in the emotional support of stroke patients and carers

A normal part of the recovery process

This theme described the views of the participants regarding the emotional problems experienced by the stroke patients. All of them agreed that the location of a stroke in the brain may affect the patient's emotional response. Their comments with regard to this issue indicated that the emotional consequences of strokes were not an isolated problem post-stroke. Half of the participants explained that stroke patients should understand that emotional disturbances constitute normal recovery post-stroke. One participant, however, was critical of this finding and commented:

> "…many participants experience intense emotional problems at the early onset of stroke typically during the first three months after the stroke. That's the normal process of the diseases…so you will experience that everybody will. It is part of the normal recovery process after stroke" (EP – 03)

Another participant supported the majority view and commented:

> "Yea…definitely this is you know a good finding and typical finding of a problem (emotional) you (stroke patients) may face following discharge" (EP – 06)

Furthermore, the same participant pointed out that the impact of a stroke on the patient's emotions was due to a lack of support within the community setting. This participant, who compared services between the hospital and after discharge, identified gaps in the follow-up care, indicating the importance of continuing care throughout recovery:

> "Yea…definitely this is you know a good finding and typical finding of a problem you may face following discharge. Because typically inpatient rehab…there is nurses and other people…stroke patients they can talk to." (EP – 06)

On the other hand, another participant commented that carers would experience emotional burden at some point during their caregiving role. This participant seemed to suggest that Brunei lagged far behind other developing countries with regard to the services available for supporting carers' emotional problems. The participant was highly critical of the contribution from government agencies and stated:

> “I think in Brunei we are very limited… with like we don’t have hoist that they [carer] can help [use]. That [facilities] is really a great help if we can have that equipment that we can lend for the carer. So that will relieve a lot. But I think they still need the services. I think from the service… the government have to look in to this if they can actually provide…even for physical care…moving up the patient from the bed they [carer] need help. Giving shower…they also need help. If is totally on them…I am sure it must be very stressful. If it for a year…maybe for a few months is okey….for a year two years three years can be very stressful. I can’t image that situation” (EP – 04)

In summary, the emotional impact of a stroke on both patients and carers was viewed as a normal response following strokes. However, this finding indicated that there were several factors that negatively influenced stroke patients and carers’ emotional functions. In particular, the participants identified a lack of understanding by patients and carers about the impact of strokes, which can go beyond the physical sequelae.

The patients and carers’ understanding of the impact of stroke on emotional well-being

Half of the participants agreed with regard to the level of awareness of the potential emotional impact of strokes among stroke patients and their carers. Their comments suggested that patients lacked knowledge about strokes. One participant explained that stroke patients often ‘leave everything to the expert’ (EP – 03), while another felt frustrated that some stroke patients remained in denial and refused to accept help offered. In particular, one participant stated:

> “I think the emotional support must be good and the patient must have strength. Because if you [patient] give up…this is the patient that tend not to come…they just give up…Because there is not easy answer…but most of them don’t realise that… doesn’t matter how much you speak to them…if they are not willing to listen…they are not listening.” (EP – 02)

The same participant attributed the emotional problems experienced by the stroke carer to the latter’s lack of education about the consequences of strokes on a patient’s personality. She stated:

> “…a lot of this [emotional problem] is for the carers as well….and then some of them [asked] why their father, why their mother, cousin aunty whoever… is …personality is difference. You know... why are they [patient] inhibited…why they always angry….sometime it not just affects emotional… it also the fact where the stroke is.” (EP – 02)

This view was supported by another participant, who suggested that carers could experience a long-standing emotional burden due to a lack of understanding about strokes. This participant explained:

> "When you interview the family…a lot of time why they [stroke patient] have mood problem [is] when actually the stroke is in that area. That's why it change the personality of the patient. But they didn't know until two years later they questioning the doctor… this person is so moody… you know it hard to care this patient." (EP – 03)

The comments of the participants indicated that a lack of stroke education appeared to be the main cause of the stroke patients and carers' emotional problems. Therefore, enhancing education could be key to improving the emotional well-being of the stroke patients and their carers following discharge from hospital.

The influence of Malay culture on patient approaches to therapy

This theme related to typical Brunei Malay culture conduct, such as feeling shy about asking questions, keeping matters to oneself and being kind to others. One participant endorsed the idea that the Brunei Malay culture could be a factor that was detrimental to stroke patients' emotional functioning. This participant observed that Bruneian patients often felt shy in the presence of healthcare staff and frequently became passive recipients of care. The difficulty in penetrating this cultural behaviour to elicit positive or negative responses to therapy seemed to rest on a lack of communication between the therapist and the patient. The comment from the following participant revealed that the impact of culture could be of considerable concern:

> "…Bruneian again down to their culture. They are very nice…they won't tell the therapist that they [patient] are tired…that they [patient] just want you [therapist] to help them. They [patient] don't tell you [therapist] that. So the therapist assume they know and get them [patient] to do as much as possible. So then the communication is not occur. You [therapist] do not then explain to the patient why you must. And maybe the therapist is not well equip enough in term of getting the motivation to the patient because the patient don't tell you what they interested in and the therapist may not ask the right question….But because the patient don't tell…and maybe the therapist don't see sign of asking. Because we [Bruneian] tend to hide of our feeling a lot, they [patients] tend to tell other but the person involve… I think you know the culture very well. They are too nice in front of you but behind you they [patient] say a lot of things when those things should have been informed." (EP – 03)

Likewise, another participant identified that Brunei Malay culture was often demonstrated by individuals remaining quiet and being self-contained. This cultural behaviour could distort the planning for stroke patients. One of the participants explained that patient responses to therapy were ineffective without adequate communication:

> "Some of the patients they didn't say anything….but they just do it [exercise]. I think because of Malay culture." (EP – 01)

Meanwhile, two of the participants discussed difficulties with managing emotional problems in Brunei. The views of many Bruneians with respect to seeking psychological support for emotional problems appeared to be negative. One of the participants revealed that seeing a psychologist was frequently associated with psychiatric illness as exemplified by the following quote:

> “Well, what we offer is normally whether to have counselling… psychologist… If they are actually clinically depress…in other words…clinical depression…Okey? You give them some medication as well. Alright? But we offer. [But] They don’t always take. Because for them, when you see a psychologist, I am not crazy I don’t want to see a psychologist.” (EP – 02)

This earlier participant similarly agreed with these observations and commented:

> “In Brunei when you send somebody to see psychologist...it different thing. And when you send someone to a counsellor… that’s different.” (EP – 03)

In summary, the discussion with the participants revealed the importance of Brunei Malay culture regarding healthcare service utilisation. This finding provided valuable information regarding the need to consider culture when planning for the provision of home-based stroke rehabilitation in the future.

Addressing emotional problems post-stroke

All of the participants offered several strategies for addressing the emotional functioning of stroke patients and their carers. Most of the participants identified that the existing group therapy sessions organised by the rehabilitation centre was an effective approach towards managing patients and carers’ emotional disturbance. Other potential strategies, such as establishing a comprehensive multidisciplinary stroke team and involving private agencies to relieve carers, were also discussed by the participants. For example, one of the participants suggested:

> “This is where…you have to have a comprehensive outpatient multidisciplinary programme which not only have physical therapist, occupational therapist and doctor and nurses, we need to have the psychologist and the social worker which can advocate for their right…as well as peer support like support group perhaps like a stroke patient support group and also you know perhaps even a non-governmental that can advocate for person after suffering a stroke and having disabilities and their carers.” (EP – 06)

The establishment of healthcare agencies to take over caregiving tasks was viewed as a potential strategy for reducing carers’ emotional burden. One participant argued that ‘time off’’ was what carers actually needed rather than counselling. This participant proposed:

> “This where I think I mentioned earlier…there should be an agency…It could be either be private or government services who could provide just a minimal service to relieve them [carer] from their role. At least they can go somewhere and express…I think just to get away. I think you [carer] need time. You cannot be 24/7 looking after…there must be some kind of support. I think providing that kind of service will help the emotional sadness that was mention here. That how I feel when they say emotional. It could be not counselling that they needed. They need some time off. And they probably need some kind of support in term of relieving their stress.” (EP – 04),

On the contrary, one of the participants was critical of the commitments of certain stroke patients with regard to attending therapy sessions on a regular basis. A quote from this participant showed that most stroke patients were invited to join this group, but that the support was inconsistent. The participant suggested that the stroke patients were not aware of the relevance of the sessions in assisting individual needs and their indirect benefits to emotional health. This participant commented:

> “That’s why the rehab department runs their therapeutic group activities. Even though you know the patients don’t always need this rehab, but they [therapist] still do weekly or monthly and then they get down the patients to come. So whether they [patients] understand the emotional part of that is…because that is part of their emotional rehab too. Because they [patients] always be with other people. Sometime they come and sometime they don’t come.” (EP – 02)

Crucially, the importance of home-based stroke rehabilitation to support the patients and carers in the community was highlighted. One of the participants asserted:

> “…having community-based rehab or home-base rehab would also help by get the patient and the carer seeing the physical team in the home environment and studies have showed that this can help their emotional outlook and their abilities to get back home…much easier.” (EP – 06)

The data showed that the participants fully understood the available and potential strategies for managing the emotional well-being of the stroke patients and their carers. Therefore, these findings may be used by policymakers to address emotional problems post-stroke and improve the support services for stroke patients and their carers following discharge from hospital.

The role of nurses in the emotional support of stroke patients and carers

There were divided views with regard to the role of nurses in providing emotional support for stroke patients and their carers. Three participants agreed that the rehabilitation nurse had a role to play in addressing stroke patients and carers’ emotional problems. As a case in point, one of the participants observed that nurses may form important members of a multidisciplinary team for supporting stroke patients’ ongoing recovery. The nurses continued presence would help to identify emotional concerns at any stage of the patients' rehabilitation. This participant commented:

> "I think nurses….rehab nurses have a central role in multidisciplinary rehab team. Nurses are the one patients will spend most of the time with whether inpatient and definitely be a role for the community nurses as well for ongoing rehabilitation once the patient get discharge from the inpatient rehab stay. I agree that with all these things that you know nurses help them physically but also play important role in emotionally as well when the patient with stroke get their rehabilitation." (EP – 06)

Another participant, meanwhile, recognised the advantages of nurses' greater skills of observation. This participant stated that combining this skill with appropriate knowledge about strokes would help to facilitate the detection of patients' emotional problems at the earliest opportunity. Therefore, the need for nurses who are knowledgeable about strokes was emphasised. The participant proposed:

> "In term of emotional support…of course, nurses who are knowledgeable, they know and tackle [the emotional problem] from observing what the patient is suffering. Sometime, nobody know [understand] about the patient emotional problems. So with nurses, once they see the patients, they can differentiate….so that why these nurses should be aware [sign of emotional problems]. So they must be knowledgeable regarding the stroke so they know how to tackle the emotional…physical patient's needs." (EP – 05)

On the contrary, two participants raised questions about the competence of rehabilitation nurses and how their training could be structured. Although both agreed about the need to prepare nurses for their role in stroke rehabilitation, potential issues regarding the nature of the training and availability of educators were considered. One of the participants commented:

> "I think we need to prepare the nurses who can actually look into not only the physical care but also the psychological care and the emotional wellbeing of carer and the patient. I agree with that statement in term of competencies. But how many can do that? Have we really trained to be prepared?" (EP – 04)

Furthermore, another participant was sceptical about adding stroke training to the curriculum and questioned how such training could be evaluated. This participant argued:

> "So I understand yes. I think they [nurses] should know about this thing. But yes, it will be interesting to see how you…it [nurse rehabilitation] going to be incorporative in to the curriculum and how this will be tested." (EP – 02)

In summary, the participants offered conflicting views regarding the role of nurses in providing emotional support to stroke patients and their carers. These findings could be attributed to the lack of clarity about the role of rehabilitation nurses in Brunei. This information, therefore, may prove useful for education providers in future planning for stroke training of nurses.

8.3.2 Key Finding Two: Family support structure

All of the participants agreed that strong family support was central to stroke patients' continued recovery following discharge from hospital. However, the majority also voiced concerns about the effectiveness of the existing family support structure in Brunei. An analysis of the interview data identified three relevant themes as follows:

1. Changes to the family structure
2. The availability of a primary carer
3. Establishing home-care support agencies

Changes to the family structure

Many of the participants agreed that, traditionally, Bruneian families live within an extended family scenario. However, most of the participants also recognised that this existing family structure is currently changing. The participants commented that the shifting family structure was attributed to the increasing number of people who remain single, fewer children per family, married children tending to live separately from their parents or a lack of full-time family carers due to work commitments. These concerns were observed by one of the participants, who suggested that stroke patients might be left alone at home without proper care. The neuro-rehabilitation participant mentioned:

> "Brunei pride of ourselves for good or strong family structure. This has been the case for many - many years. But these days, with working families and less nuclear family….we do also [see] a lot of patients with severe stroke who has disabilities with little or no care at home." (EP – 06)

Three participants also discussed the decreasing number of children per family and the potential impact of this on family support for stroke patients in the years to come. One of the participants, who was a stroke consultant, revealed:

> "I am worry about this especially for the future. Because before you know, one family has like ten children. If this one doesn't want to look after [stroke patient], you try the next one or the next one then the next one. If this not success, we can try the patient's grandchildren or maybe one of the nephews or nieces. This will be a huge problem. This is a minority but can be a big problem later I am sure." (EP – 02)

Furthermore, the availability of family support for stroke patients could be observed from the moment the patient was admitted to the ward. One of the participants noted that support from the family was often inconsistent and in some cases completely absent. A quote from this participant illustrated the changing family structure:

> "Here [hospital], some of the patient have very good family support….some of the patient don't have family support. So…my comment is really kind of feeling sad especially when they don't want to care the patient." (EP – 01)

Most of the participants recognized imminent issues with regard to decreasing family support for stroke patients and carers. This finding suggested that measures to intervene in this problem by relevant decision makers were urgently required.

The availability of a primary carer

There was strong agreement among the participants that it was crucial to identify the primary caregiver before allowing the stroke patient to go home. The importance of this carer providing continued care at home was shared by most participants. However, the discussion also revealed that finding a 'willing carer' in the family could prove to be a major challenge. One participant argued that the existing Bruneian family structure may not necessarily indicate that a carer would be readily available after an individual suffers a stroke. This stroke consultant declared:

> "I find the issue here [is] that we have about discharging is…there is always no willing carer. Okey…so the carer is very-very big issue. If the family is a….how do you [describe]…actually it doesn't matter whether the family is extended or whether the family is barely circular. What matter is someone in the family is willing to take the responsibility." (EP – 02)

The sentiment voiced by this stroke consultant was shared by one of the other participants. The traditional belief that children would routinely offer caregiving support once a patient is discharged from hospital no longer seems valid. The following participant revealed that some children refused to help the stroke patient, leaving the care entirely to the patient's spouse:

> "I would agree with that because we have visiting one or two elderly who supposed stroke and whose look after by the elderly husband as well. We do encounter as well there is none of the children would like to be involved." (EP – 04)

Therefore, there seemed to be general agreement among the participants that hiring a carer from outside the family, typically a housemaid from overseas, to provide continuing care for the stroke patient was an indispensable measure. One of the participants underlined the importance of this paid carer:

> "I mean you almost always need a [paid] carer… almost… almost… always." (EP – 02)

However, some of the participants also observed potential difficulties related to employing a paid carer. These participants noted that the cost of hiring a paid carer could be expensive and might exceed the financial means of the stroke patient and his or her family. The financial barrier to obtaining a paid carer was mentioned by this participant who commented:

> "Unless they hire one specific carer to look after the stroke patient, but are they affordable to pay?" (EP – 05)

On the other hand, one therapist participant appeared sceptical about using paid carers as a substitute for family carers for stroke patients. She noted possible risks if a family relied too much on a paid carer and left the caregiving tasks entirely to the carer. A quote from this participant indicated that the main concern seemed to be related to negligence. She explained that due to the patient's physical or psychological impairment, the paid carer was in a position to take advantage of the situation which might lead to possible abuse:

> "…if you have a maid, you are always constantly worry that they are going to abuse your family member…take advantage of that…and you are paying for that. So to some extent you need to provide some sort of security." (EP – 03)

Various comments from the participants proved that finding a primary carer for stroke patients was a significant concern. The difficulties in finding a paid carer and the possible implications associated with this service were discussed. These findings can be of value to assist decision making to improve the patients' discharge planning.

Establishing home-care support agencies

Most of the participants agreed that solving impending issues with regard to the changing family structure in Brunei should be done in timely manner. Many participants shared the view that the government should consider adopting a support care model within the community, as is widely practised in developed countries, such as the Early Support Discharge services in the UK. The participants identified various support care services that were considered to have potential for addressing the lack of family support. These services included offering respite care, setting-up nursing home care, adult day care centres or more specific tasks such as a 'meals on wheels' service. The participants were familiar with these support services following their own training or work experience outside Brunei. One of the participants reflected:

> “What have I learn…from what I have seen from UK [that] they have meals in wheels. So meals on wheels mean the food is delivered to their home. So the elderly can be alone, *there is someone who can deliver the foods.”* (EP – 04)

Meanwhile, another participant mentioned the possibility of setting-up a day care service for stroke patients. This participant used the current practice of working parents who commonly send their children to day care during working hours as an example. The participant observed that day care services are often used by working parents who have issues with child-minders at home. Thus, the participant suggested adopting a similar approach in order to address the uncertainty regarding family support for stroke patients. This participant said:

> “Honestly I don’t know how that [lack of family support] will work in the future. Some people think about like how day centre for kids…maybe you have to have day centre for adults as well.” (EP – 02)

However, four of the participants voiced their concerns about the possible drawbacks of providing support agencies. For example, the neuro-rehabilitation participant mentioned the probable negative implications of nursing homes, which might be used as ‘dumping grounds' by the families of stroke patients. He commented:

> “Of course we are not going to…the concern is that people will start dumping elderly relative to this nursing home. Of course there has to be criteria if they are to be admitted to the nursing home”. (EP – 06)

Moreover, another participant noted the potential problems regarding home visit services. This participant cautioned that allowing strangers to enter the home might expose patients or family members to safety and security issues. She stated:

> “You know there need to be some policy to actually control this [respite service] because nowadays you might worry about people stealing from your home. There a lot of time that people do not welcome this because their afraid of insecurity.’ (EP – 03)

On the other hand, the consultant neurologist seemed to challenge the traditional Bruneian practice with regard to individuals’ reliance on family members. Although this participant highlighted the importance of support from the family, she also argued that, in other countries, stroke patients lived independently without family support. This participant explained:

> “In our country, because family is almost the key on all on everything…so if you don’t have that support it very-very difficult. There’s not much. I mean who else can you look to? You can’t ask the government to support you? You can’t. You can’t go to the nursing home, we don’t have one. Where can you go? You can only go home. Who’s gonna look after you? Searching for maid? And you know how difficult that [hiring maid] is now….so like yea… if you ask me simple most

> important thing is immediate family. But of course, it works in other countries that without family as well." (EP – 02)

Nonetheless, most of the participants were adamant that establishing private home-care agencies needed to be timely. This care service should offer alternatives for family caregivers and would probably prove popular among the general population of Brunei. One of the participants suggested that patients and families were in need of this service and were willing to pay for it; the participant commented as follows:

> "Maybe we do need that kind of services [private home-care agency] in Brunei. Because some of these people [stroke patients or family], they have money then is just we [Brunei] don't have that agency. Limited agency…there is agency but very limited." (EP – 04)

The discussion revealed that more involvement from private agencies to manage issues concerning lack of family support was required. The establishment of a community stroke centre was suggested as being potentially viable to address this issue. The findings necessitate policy changes in order to improve the long-term care provision for stroke within the community.

8.3.3 Key Finding Three: Provision of existing out-patient therapy

Opinions were divided among the participants regarding inadequate therapy time provided for stroke patients. The data indicated that most of the participants were aware of this deficit. A common reason shared by the participants appeared to relate to ongoing staffing shortages. All of the participants discussed the existing strategies for addressing the problem associated with the limited therapy duration and provided views regarding the role of nurses in complementing the home-based service provision. An analysis of the participants' responses generated four main themes as follows:

1. A lack of rehabilitation therapists
2. Patients' accountability for their own health
3. Stroke patients managing their own therapy
4. Nurses supplementing home-based service provision

A lack of rehabilitation therapists

Most of the participants agreed that rehabilitation therapy lasting between 30-45 minutes once a week was insufficient. The majority of the participants attributed this problem to staff shortages and the increasing number of stroke patients. The interviews suggested that compromising on out-patient therapy time was inevitable. In support of this view, one participant mentioned the mismatch of the therapist to patient ratio; she stated:

> "I am agreed with the allocated time…aa..basically so unfortunately we cannot give it extra because we have a lot of patients. So a lot of patients. Since we are quite tight of staff as well…so that the reason why we given 30 minutes." (EP – 01)

Another participant commented that staff shortages were a national issue which needed to be addressed by the government. This participant regarded the limited number of staff as a hindrance to the establishment of a comprehensive multidisciplinary rehabilitation programme in Brunei. This neuro-rehabilitation participant explained:

> "…again I agreed…Brunei outpatient therapy or rehabilitation…therapy programme is very limited. We don't enough therapy staff and we don't have good comprehensive multidisciplinary rehabilitation programme in one centre." (EP – 06)

On the other hand, two participants commented on the fact that some stroke patients undervalued the existing staff resources, as some patients frequently missed their therapy appointments. Consequently, timetabling for the intended therapy would not be effectively utilised, which would in turn impair the delivery of therapy services. One of the participants felt frustrated by the ignorance and attitudes of some patients towards their self-care. She explained:

> "When they go [discharge]…it's always like that whenever they come to clinic….are you still doing the exercise? I didn't know doctor. There is no further appointment given. Oh I see. Okey, let me see your book [appointment]….because they carry a book right…like could not [believe]….over half it's just the patient never turn up. And then after that of course they missed three appointments. So who's going to call them again right?" (EP – 02)

The similar participant comments showed that staff shortages were a major issue that constrained the existing services. Although this issue lies beyond the scope of this study, the finding may be of use to policymakers when considering their future recruitment strategy.

Patients' accountability for their own health

This theme described the views of the participants regarding the need for stroke patients and their carers to be more involved in the care and promote independence as much as possible. Three participants mentioned the over-reliance of some stroke patients on the existing therapy. These participants agreed that patients' accountability for their own health was essential in order to enhance their recovery. However, the observations of these participants suggested that some patients took advantage of the free healthcare services provided. For example, one participant revealed that some patients appeared to neglect their care and expected exercises to be performed at the rehabilitation centre only. This therapist participant commented:

> "….because of the health system here everything is free…they [patients] tend not to be accountable for their own life. To some extent they give their health to another person. Okey…they expect their healthcare givers to do everything for them. Because it is provided. The system allows it." (EP – 03)

This observation was also noted by another participant, who explained that it was in the 'mind-set' of Bruneian people, who thought that care should only take place within the hospital setting. An excerpt from this participant revealed:

> "…the perception….the mind set of our people ….they [patients] only do that [therapy] at the centre. When that [therapy] can be done at home actually." (EP – 04)

One participant, meanwhile, suggested that the stroke patients did not feel accountable for their own care due to unrealistic expectations. This participant explained that some patients expected the existing out-patient therapy was enough to ensure their recovery. Thus, the participant suggested that managing expectations could be crucial, but was concerned that the time spent on counselling might disrupt the therapy session. This participant explained:

> "….but they have to do the thing [exercises] at home as well. So you can't expect to come once a week [or] twice a week be good. You know. So I think for this is a lot of about expectation. The problem of managing expectation is a lot of it is talking. And if you spending half your time talking…how much time you spend doing actual exercises?" (EP – 02)

Various comments shared by the participants suggested that there was an issue with the stroke patients' awareness of the importance of self-care. The need to manage patients' expectations at the beginning of their stroke through appropriate education is required for effective recovery.

Stroke patients managing their own therapy

All of the participants agreed that issues related to staff shortages lay beyond their role and capacity. However, they recommended various strategies that would help patients to sustain their exercises outside the normal therapy sessions. Most notably, the participants emphasised the importance of education, the need for carers to be proactive and provide continued exercises at home, as well as providing transport for those who required it. In support of this one participant commented that providing education was integral to supplementing the inadequate therapy time:

> "…something need to be done in term of educating the carer or even the stroke patient itself how they can motivate themselves to carry on what has been taught at the centre to do it at home. Don't just rely on the rehab centre which is only once a week and only 30 plus minute. So the idea is to instil the awareness and understanding from the carer and the patient

> when they are in the rehab centre, they supposed to learn and bring it home so that [they] can [continue] practice." (EP – 04)

Furthermore, another participant commented that stroke patients needed to be more responsible regarding their home exercises and should avoid relying solely on out-patient therapy. This participant mentioned:

> "…we ask them to continue the exercises at home, so we give them homework to the patients and ask the carer to help the patient." (EP – 01)

However, two of the participants stated that providing education and advice to stroke patients and their carers with regard to continuing the exercises at home may not necessarily prove effective. One participant identified an issue related to patient compliance with respect to the therapy provided. This participant commented:

> "…you know…what they [patient] also don't do is… they don't do exercise at home. Even though they have been advised this all the times. You know…you cannot rely three times a week and expect to be good. You know…you [patient] need to be active at home… do the exercise at home." (EP – 02)

Another participant was critical of the fact that some carers tended not to get involved or to actively care for stroke patients at home. This therapist commented:

> "Of course carers need to be there to actually assist with some of the therapy at home. But most of the time like I said, they are not aware of their expectation when they go home…so they do not participate…even practice in the ward. One hour of therapy versus the rest of the 23 hours a day…they not doing anything… of course you have slow recovery….you need to keep practicing." (EP – 03)

In contrast, another participant doubted whether providing comprehensive out-patient rehabilitation programmes were feasible for all stroke patients. Therefore, the need to 'keep learning and stay motivated' when the patients were at home was recommended.

> "There's no use coming for five days a week for rehabilitation because that just not logistically possible and also too much for the patients to get five days in a week. You [patients] need rest day as well. But, during those days without the rehabilitation…patient need to learn and to be motivated." (EP – 06)

Discussion with the participants showed that providing educational interventions to continue physical rehabilitation remained the primary strategy to complement the short therapy duration that was currently provided. The need for the stroke patients and carers to be more proactive with respect to exercise at home appeared to be essential.

Nurses supplementing home-based service provision

The participants shared conflicting views with regard to the potential contribution of nurses in supplementing the therapists' home-based service provision. The participants raised several concerns that related to increasing the nurses' existing workloads, clarity about the training and issues with nurse-led rehabilitation provision. One participant anticipated that:

> "This [home-visit] will increases the present nurses' workloads." (EP – 05)

Another participant, meanwhile, agreed with the potential benefits of nurse home visits, but, was wary of patient over reliance on these potential services. This neuro-rehabilitation participant explained:

> "It will be good if the nurses can provide once or twice a week that will complement and reinforce what the stroke rehabilitation team is educating them. You just need to be careful that the patient or carer are not to reliance on nurses coming or otherwise that will make them more dependent on facilities." (EP – 06)

Meanwhile, there was a general concern over whether nurses were prepared to deliver health teaching or whether they were capable of running nurse-led rehabilitation clinics. One of the participants commented that nurses should be trained to develop the appropriate competencies before setting-up clinics. This participant stated:

> "Its good views…yea I agree with the view but are they prepared to teach….is that the area? Is the nurses expected to teach? .....it could be…..maybe it's true as well that they can…I agree with this the nurse-led rehabilitation clinic but we need to train the nurses to run the clinic and what are the competencies that are needed to run the clinic so that we are not reliance on the doctor or the physiotherapy." (EP – 04)

Furthermore, another participant was of the opinion that the role of nurses in stroke rehabilitation goes beyond the hospital setting and may encompass preventative education. He commented as follows:

> "I mean the nurses will help a lot more than the therapist with regard to living a healthy lifestyle, looking after their health and medication so these are the key roles of nurses to avoid people getting another stroke. So it is important for them a role in the community that way." (EP – 06)

The potential involvement of nurses in stroke rehabilitation was generally viewed with caution by the participants. Although a nurse-led rehabilitation support service seemed feasible, the need for proper competency training and education was emphasised.

8.3.4 Key Finding Four: The need for nurses with skills in stroke rehabilitation

The discussion revealed that there were differing views with regard to the need for nurses with skills in stroke rehabilitation. Although most of the participants agreed about the supplementary role of nurses with regard to strokes, others appeared more sceptical and wary. The participants spoke of the potential benefits of stroke nurses, as well as the likely barriers to providing training for the nurses. The participant responses were analysed and grouped into four main themes as follows:

1. Stroke nurses as an alternative for continued care
2. Clarity on the roles of stroke rehabilitation nurses
3. Issues with staff resources
4. A stranger in our home

Stroke nurses as an alternative for continued care

Many participants felt that stroke rehabilitation nursing could be a viable alternative to supplement the existing post-discharge support. They believed that the potential existence of rehabilitation nursing would allow stroke patients and carers the option of receiving support services that suited their needs. One of the participants suggested:

> “If it [nurse rehabilitation] is going to be in existence, it should be an option for the carer and the patient. If they want, then they probably will ask for it. So they are the one who are accepting the services compare to those who don’t want. And other some people probably prefer the centre because probably [they] still can still afford to send.” (EP – 04)

Another participant observed that rehabilitation nursing should not necessarily be offered to all stroke patients:

> “I believe the home-based nursing support is depend on patient’s condition whether the patient is alone at home, whether the carer is okey or not, whether is there any issue or not.” (EP – 01)

A further participant stated that knowledge of the family situation and the patient can influence the choice between nursing home visits and traditional treatment. This participant commented:

> “The view is depend on the situation of the family and the patient. If the family is educated, they knows the importance of continue nursing care [at home]. But for local villagers, they didn’t believe about the nursing [importance of home visit]. They believe more on their traditional ways. It depend, that’s why it was different. It’s depend on the knowledge of the family and the patient itself.” (EP – 05)

Various comments from the participants suggested that nurses can from part of the stroke rehabilitation team. However, careful planning is needed to ensure that this service is only offered to stroke patients who required it.

Clarity on the roles of stroke rehabilitation nurses

Many participants observed that currently there was a lack of trained nurses in stroke rehabilitation. The need for nurses skilled in stroke rehabilitation was mentioned by the following participant:

> "The nursing staff should have a knowledge about stroke. They need to have a rehabilitation stroke nurse which in this centre we didn't have. They need to have a skill especially the physical, the education wise…aa..that this centre need to have stoke nurse rehabilitation." (EP – 01)

Furthermore, one participant argued for clarity concerning the roles of nurses in stroke rehabilitation. This participant suggested that before nurses decide to become a stroke nurse specialist, they need to understand what the roles are and how this can affect their existing workload. This stroke consultant indicated:

> "You know, it has to be clear what its [stroke rehabilitation nurse] entail. You know what I mean? Because nurses generally I find always want to learn new things. Okey? But, it should be what exactly it is. Because most of the time, they doing it anyway." (EP – 02)

The same participant also expected that the role of nurses in stroke rehabilitation would be limited. She noted:

> "I don't foresee that you will be doing significant rehabilitation per say." (EP – 02)

Another participant, meanwhile, supported this point of view and suggested that the role of a rehabilitation nurse would not be much different from the traditional role of nurses in providing professional care. This participant stated:

> "I would not expect that they will provide the like the physiotherapist type of work. I won't expect that kind of role. They [nurses] still probably keep their nursing roles, such as the NG replacement, catheter replacement and that kinds of things." (EP – 04)

The potential role of nurses in stroke rehabilitation was noted by the participants. However, further clarity concerning specific roles and types of education required to prepare these nurses was needed.

Issues with staff resources

Most of the participants stated that the community stroke rehabilitation nurses have a different skill-set compared to nurses who work in a hospital setting. Thus, they felt that training would be necessary in order to prepare the nurses and provide them with the appropriate knowledge about strokes. One of the participants said:

> "Rehab nurses in particular have very different skill set to general medical surgical nurse. So that it is important to have this education whether it provided locally or internationally is another matter." (EP – 06)

However, three of the participants observed that currently there was a shortage of nurses, which was perceived as a barrier to establishing specialist nurses in the field of stroke rehabilitation. This participant commented:

> "But again you know…you trying to stretch resources so far. It's not enough. How you say….it not enough bank for your part….I mean it's a very nice idea but I don't know. Because…maybe for…some patients might be beneficial…but then how many can you do [home visit]? You know….my personal opinion is not enough bank for your part." (EP – 02)

Another participant noted that the biggest problem for the nursing profession was the lack of available training and resources; she commented:

> "Training…lack of training is one…lack of man power and resources is the other. That is the biggest disabilities I think to the nursing side this days." (EP – 03)

On the contrary, a further participant believed that staff shortages were the "business" of the administrative level, and therefore, staff shortages should not be given as a reason for preventing nurses from undertaking training. This participant declared:

> "If they [nurses] said there is not enough staffing, that is not their business. You go for study. That [staff shortage] will be deal by the admin level. That how we encourage them. We from the admin side…we encourage them to go [attend training]. I said this is for your own good. Don't worry about not enough staff. That is not your business. It's admin side." (EP – 05)

The barrier to introduce stroke rehabilitation nurses was acknowledged by the participants. The ongoing issue with staff resources needs to be considered in planning future stroke nursing services. These findings could then inform policy makers regarding the lack of nursing recruitment and the ineffective distribution of the nursing workforce in Brunei.

A stranger in our home

One participant observed that home visits by nurses may create conflict due to the prevailing Brunei Malay culture. This participant suggested that patients may not welcome a "stranger" into their home due to the prevailing culture, in which the family tends to maintain their privacy at all costs:

> "I know our culture in Brunei…we probably a bit reluctant to accept stranger in our home. And we are very cautious in term of our inside home. We don't want people to see…they might taught that it become a gossip. Because Brunei is very small. I think they want to keep the privacy anything that they want to hide….if they can hide…they will hide. They don't the nurses to see this is happening in their home. Oh….the children is not good…so she [patient] might [think]….the information could be informing others. Which probably they don't want. So they probably want to reserve the privacy. We are not really open to stranger." (EP – 04)

Furthermore, this participant noted that care provided by a "stranger" may result in the stroke patient feeling worse. This participant commented:

> "It is not enough that is stranger caring for you. How are you? Are you okey? You doing well? They [patients] feel it worse. This person [nurse] didn't know me…It feel worst" (EP – 02)

Thus, it was important that the nurses "made friends" and built a "rapport" with the patients and family as part of the pre-discharge planning. This participant commented:

> "If the doctor said that this patient can go home, first we must know his family. We must know with whom the patient lives. And then, we [nurse] make friend with them so there is a rapport. So then we discuss about their discharge. I think, the pre-discharge planning must be done first. If this not present, they [nurses] will not have rapport with relatives…so will be difficult." (EP – 05)

Meanwhile, the following participant proposed using a community hall to conduct group therapy rather than nurses visiting the home. This participant believed that group therapy would be more effective in providing emotional support for stroke patients.

> "It would be better...rather than going to the individual houses…for you to establish like a community support…go to certain kampong… maybe speak to ketua kampong [Head of village]… most village have their own little hall or something right… maybe meet the patients there. That mean you can see a few in one go…because what you talking about providing emotional support at the same time support of other patients. You know…you gonna do the exercise together…It is a lot…it is more fun…which is the therapeutic group activity are." (EP – 02)

The likely implications of home visits by nurses for the stroke patients were discussed. The use of existing community halls, instead of the home, to deliver group therapy for stroke patients within the community was recommended. This finding suggested challenges lay ahead for future rehabilitation nurses in providing home-care services.

8.3.5 Key Finding Five: Seeking traditional treatment rather than modern health

Nearly all of the participants raised similar concerns with regard to stroke patients and their families' preference regarding the use of traditional treatment to manage early stroke symptoms. Similarly, most of the participants acknowledged that changing the practices of these people would be a challenging mission. Therefore, most of the participants agreed that providing stroke awareness to inform the patients and their families about the complementary use of both traditional and modern treatments was necessary. An analysis of the participants' comments identified three main themes:

1. The belief in traditional medicine
2. Increasing stroke awareness education
3. Diversifying sources of stroke education

The belief in traditional medicine

The participants' comments indicated that seeking traditional treatment was a common practice among the population. The participants suggested that this was a practice followed by Bruneian families for generations. Thus, traditional medicine beliefs were strong. Three of the participants identified the adverse implications of these beliefs for the recovery of stroke patients. One of these participants noted:

> "…we can see some people didn't progress because they didn't come for the rehabilitation. I think the myth is very strong with the traditional belief." (EP – 04)

Moreover, another participant observed that family beliefs in traditional treatment influenced the initial management of the stroke patient. The following participant disapproved of this approach, which might result in unnecessary delays and so prove detrimental to the patient's health. This nurse participant commented:

> "…and then sometime this family believe that the stroke is caused by angin and this [traditional] is the only treatments. So toward the end [the stroke patient didn't improve], only then they go to the hospital…often after two to three days." (EP – 05)

Meanwhile, other participants suggested that elderly stroke patients were most likely to have strong beliefs in traditional medicine and thus delay seeking modern healthcare support. This participant identified issues with stroke education for this age group as being of considerable concern:

> “…this traditional is like for like the older generation. They believe of the angin. People knows what is like diabetes, heart diseases, kidney failure, cancer but they didn’t know what the symptoms of stroke.” (EP – 01)

In contrast, the view of the following stroke consultant with regard to the lack of public education about strokes contradicted those of the other participants. The comments revealed that the number of patients who attended hospital during the early stages of their stroke had improved remarkably. This participant also noted that the traditional perception of strokes among the population was shifting towards more modern knowledge:

> “Until now Alhamdulillah…I have to say…it has been much better…especially compare to when I came back ten years ago...much better. Now I seldom hear that, [when] they come….they been at home for months…or two weeks three weeks. Most of them come within 24 hours and some of them even come so early that we can thrombolysis. Alhamdulillah. And they less and less use this word angin…more of them are saying stroke. So it’s good.” (EP – 02)

The participants shared their concerns regarding the stroke patient’s firm belief in traditional medicine that unnecessarily delayed appropriate healthcare treatment. Although the participants recognized the challenges in disregarding this practice, the need to monitor this practice is essential.

Increasing stroke awareness education

The comments of the participants showed that education was central in encouraging the patients with stroke to attend modern healthcare services. Many participants agreed that improving the existing stroke awareness campaigns for the public was needed. The strategy of promoting “stroke awareness education” was suggested by various participants. There was strong agreement among the healthcare experts that stroke education should be initiated at a younger age. For example, one participant mentioned consistent stroke campaigns that targeted school-age pupils:

> “I think we need to upscale our education to the country. Lot of our younger population are internet savvy so I think that is one avenue we can target. I think the important even educating the children in the school about what to look out for. This can educate not only the children but also the teachers. So we need to do education blasts and not just once but we need to do regularly.” (EP – 06)

However, one of the participants argued that education delivered by health professionals might not be effective in changing the “mind-set” of the population. This participant explained that healthcare professionals might have difficulty in both understanding and conveying the experiences of the patients completely. Therefore, there was a need to find a spokesperson to promote stroke education for the public. As this expert nurse participant said:

> "I think if it [education] is from the nurses….yes but in term changing the mind-set, we need to identify the spoke person. Especially post stroke patient to be the right one to talk about it….I think that will be more effective rather than the nurses. Yeaa….because people love to hear true stories then we start to believe. I think that will influence our people." (EP – 04)

The participants were adamant that education intervention for the public was central to correct misconceptions about traditional and modern treatments for a stroke. The strategy of using a stroke survivor as a mediator to deliver stroke awareness education should be considered by the health promotion service.

Diversifying sources of stroke education

The participants discussed different strategies to diversify the sources of stroke education, in particular through non-healthcare professionals. The views of the participants revealed that patients' faith and spirituality played a significant role in recovering from a stroke. Their comments suggested that a sense of relationship existed between spirituality and the patients' responses to stroke recovery. It was thought that stroke patients who were practising Muslims believed that their stroke had either been caused by a lack of faith or was a punishment from God. These beliefs could have either positive or negative influences on recovery. One of the participants stated that the patient's degree of faith could determine a different direction of self-management post-stroke. This participant stated:

> "See they go one or two ways. Either they get angry…Allah or whichever God that they worshipped…or they go the other way. This is anugerah [Blessing]…and then they become more religious." (EP – 02)

Meanwhile, the following participant indicated that patients lacked understanding with regard to the positive association between spirituality and health. This participant suggested that the sense of fatalism experienced by some stroke patients could impede their recovery. This stroke therapist commented:

> "There is two aspects. One they accept it [stroke] that they are going to be disable for life. Because you know the Great Almighty wish...so they gonna not do anything about… They won't gonna work hard for their disability to get back to life….misconception" (EP – 03)

Therefore, the participants believed that the contribution of non-healthcare personnel such as *ustaz-ustaz* [religious personnel] was crucial in order to complement modern stroke management. Half of the participants agreed regarding the need for an *ustaz* to correct misconceptions and increase awareness among stroke patients. One of these participants stated:

> “I think the influence of religion…probably in a way they [ustaz] could also one of the key people who can influence our people in Brunei especially the Muslim people in order to increase the [stroke] awareness. “ (EP – 04)

Another participant also emphasised the involvement of an *ustaz* from the moment the person suffered a stroke. This participant indicated that the patients often felt devastated and experienced a period of denial after a stroke. Thus, incorporating spiritual care to complement the existing therapy was recommended. This therapist proposed:

> “Maybe the ustaz needs to be there early on because of the religion side of things. That hasn’t been in place. The ustaz need to be [there] because [of] religion and they need to talk about disability. Because a lot of people can’t accept it.” (EP – 03)

On the other hand, one participant talked about the need for an *ustaz* to undergo certified training regarding strokes. This participant explained that providing stroke education for an *ustaz* would help to consolidate his knowledge about strokes and associated religious aspects. This would help the *ustaz* to be better prepared and thus deliver advice regarding the application of faith in stroke recovery more appropriately. This participant said:

> “….probably the register of ustaz that has gone through education from expert [stroke]. And this registry of ustaz can carry on the good work in the community. For example we can [invite] ustaz from the four districts and maybe hold a seminar or workshop just explaining to them what a stroke is and how… why it causes such and such symptoms. Because a lot of the time when someone with stroke they can have normal behaviour…sometime you [ustaz] can just say due to evil spirit, where there is a rationales scientific explanation for the abnormal behaviour because of the stroke.” (EP – 06)

Different participants, meanwhile, identified the village head [*Ketua Kampong*] as a potential person for initiating stroke education. One of the participants anticipated the challenges faced by nurses related to inviting the village people for group gatherings. Thus, a closer bond between the *Ketua Kampong* and the residents could provide an opportunity to gain access to people. It appeared that the involvement of the village head was paramount, as this participant explained:

> “We go to ketua kampong. Anything we go to Ketua kampong. With the help… with the support of ketua kampong…then he [can] give advices to all his people. Then, from here we [nurses] can tap-in to access the villagers. If we doesn’t involve [ketua kampong]…because they [villagers] will no trust us [nurses]…that’s why we involve those ketua kampong in

> order for the villagers listen [take advises] from the healthcare staff." (EP – 05)

The comments from the participants revealed that a different approach to educational intervention was required to promote stroke education and access to the population. The contributions of religious personnel and the village head were viewed as having the potential to correct misconceptions of the public regarding a stroke. Such novel knowledge could be of value in health education planning, as well as being a source of useful information for countries similar to Brunei.

8.3.6 Key Finding Six: Religious and cultural practices to support recovery

The participants discussed the traditional practice of *urut* (massage) by stroke patients in order to support their recovery. All of the participants acknowledged that most stroke patients valued this practice. However, many were concerned about potential adverse effects of *urut* on the patient's stroked limbs. Some of the participants acknowledged that the practice of traditional medicine formed part of the Malay culture of Brunei. Thus, several participants suggested that integrating this traditional practice with modern therapy may prove rewarding. An analysis of the data revealed two main themes:

1. *Urut* as a traditional strategy to support rehabilitation
2. The benefits and risks associated with *urut*

***Urut* as a traditional strategy to support rehabilitation**

All of the participants discussed the possible reasons why stroke patients adopted religion and culture-bound practices in order to cope with and recover from their stroke. Most of the participants agreed that the belief in traditional medicine among Bruneians remained unwavering. The participants explained that patients with stroke used *urut* because it has been an integral part of Malay culture for many generations. A quote from this participant illustrated that stroke patients sought different options from modern medicine:

> "I think because of the generation in the Malay culture…. they [patients] didn't want only medicine… they need to have other extra medicine [treatment]." (EP – 01)

Another participant, however, commented that stroke patients felt dissatisfied with the progress they had made following rehabilitation therapy. This participant indicated that the duration of the therapy and intensity of the exercises were insufficient, so patients tended to turn to traditional practices as an alternative way to expedite their recovery. This participant explained:

> "….because they [patients] feel are not getting anywhere with medical or western rehabilitation and they look toward the more traditional or spiritual route.' (EP – 06)

Meanwhile, one of the participants disapproved of the use of traditional treatments to speed-up stroke patients' recovery. This participant was critical of some patients who wanted an 'easy fix' and were looking for a 'magic pill' to recover from their stroke. Moreover, this approach would not work, as this participant commented:

> "Everybody just want easy fix…that's why isn't it? I just want to take a magic pill and I want to be back the way I was. It's just not going to be happen. You know…well at the end of the day that the reason why people start looking for this [traditional treatments]." (EP – 02)

Various comments from the participants demonstrated that the cultural practice of *urut* among stroke patients was inevitable. The easy approach undertaken by the stroke patients and their carers appeared not to be supported by the participants. This finding indicated the need to educate patients regarding the use of *urut* and how this practice may supplement modern rehabilitation therapy with the most beneficial effects.

The benefits and risks associated with *urut*

The discussion with the participants revealed differing views with regard to the merits of *urut.* Two of the participants mentioned the positive effect of *urut* on stroke patients' physical functioning. In particular, one of the participants explained that the benefit of *urut* encompassed improving the physical and psycho-social functions of stroke patients. The participant quoted:

> "I think with regard to massage ah…massage….it is one of our culture for the Bruneian. Massage has been seen as good way to improve circulation. I think scientifically it has been proven as well that proper massage can improve circulation. I think not only that, it can improve emotional and psychological status of the patients." (EP – 04)

In contrast, the other participants were more cautious regarding the inappropriate application of *urut.* The comments of these participants suggested that the consequences of *urut* could cause potential problems, including skin oedema or increased pain. For example, one of the participants clarified:

> "Urut is interesting…you mention urut here as from of rehabilitation therapy. But we [patient] just need to be careful not to have too vigorous massage. Because some patients may be on medicine to thin the blood or some of the patient can have pain syndrome even mild urut can aggravate [the pain]." (EP – 06)

Furthermore, another participant was concerned that traditional healers may not possess the relevant knowledge about the negative implications of *urut.* This participant observed that stroke patients might suffer if *urut* were to be applied inappropriately:

> "Some of the urut a little bit aggressive. Some of our patient they did the urut and the hand become bulge...oedema." (EP – 01)

Crucially, all of the participants agreed that stroke patients should inform the therapist before deciding to apply for *urut*. These participants concurred that approval from the therapist was necessary to ensure that the patients were made aware of the 'boundaries' when applying *urut.* This was exemplified by one of the therapists, who proposed:

> "They need to see the boundary right. They can do the urut…or the 'bekam' [cupping therapy]…they can do it. But as long as they inform us what they do" (EP – 01)

Meanwhile, another participant suggested guidelines with regard to the use of *urut.* This participant would approve the application of *urut* as long as its benefits outweighed the risks, as illustrated by the following quote:

> "…things like the urut…we always get asked about this you know. My general rule is if it can make you feel good…as long as they don't press too hard…they don't leave bruises…that's fine." (EP – 02)

There appeared to be a general consensus among the participants with regard to the application of *urut*. However, one participant commented that traditional *urut* should not be applied on its own, but in addition to modern therapy. The importance of these complementary approaches were discussed by this participant, who mentioned:

> "I think it is important that we as Muslim as well we actually go for both routes. You do your medical and therapeutic rehabilitation plus as well as pray to God and ask other aspects. As long as you don't exclude one or the other." (EP – 06)

On the other hand, the following therapist commented on stroke patients' ritual prayers. The data revealed that prayer was considered a private issue for the patients. Thus, assessing their prayer performance could offend the patients' feelings. This participant said:

> "some of the patients a little bit sensitive…because this [ritual prayer] is quite sensitive issue right… whether we can ask if the patient pray or not? They may say yes but unfortunately no. When we ask the carer they [stroke patient] don't want to do prayer because of the incapability…un-capable to perform." (EP – 01)

The discussion showed that most of the participants agreed with the use of *urut*, even though they identified considerable concerns about the way it was used. The findings suggested that there was a need to include stroke education for traditional healers so that the benefits of *urut* could be fully utilised.

8.4 Overview of a conceptual model

Diagram 16 presents an overview of a conceptual model that was derived from analysis of the expert healthcare professionals' comments and propositions relating to the strategies for improving the stroke rehabilitation support provision. The model, named the *Collaborative Rehabilitation Stroke Support System* (CORES) represents a theoretical illustration that emphasize the stroke patients and their carer at the core of the support care. The involvement of various individuals and interrelated collaboration between multiple sectors form larger rehabilitation support network. No similar model was identified in Brunei. Therefore, this model will be used to initiate discussion with relevant stakeholder in planning service improvement for stroke and carer within the community.

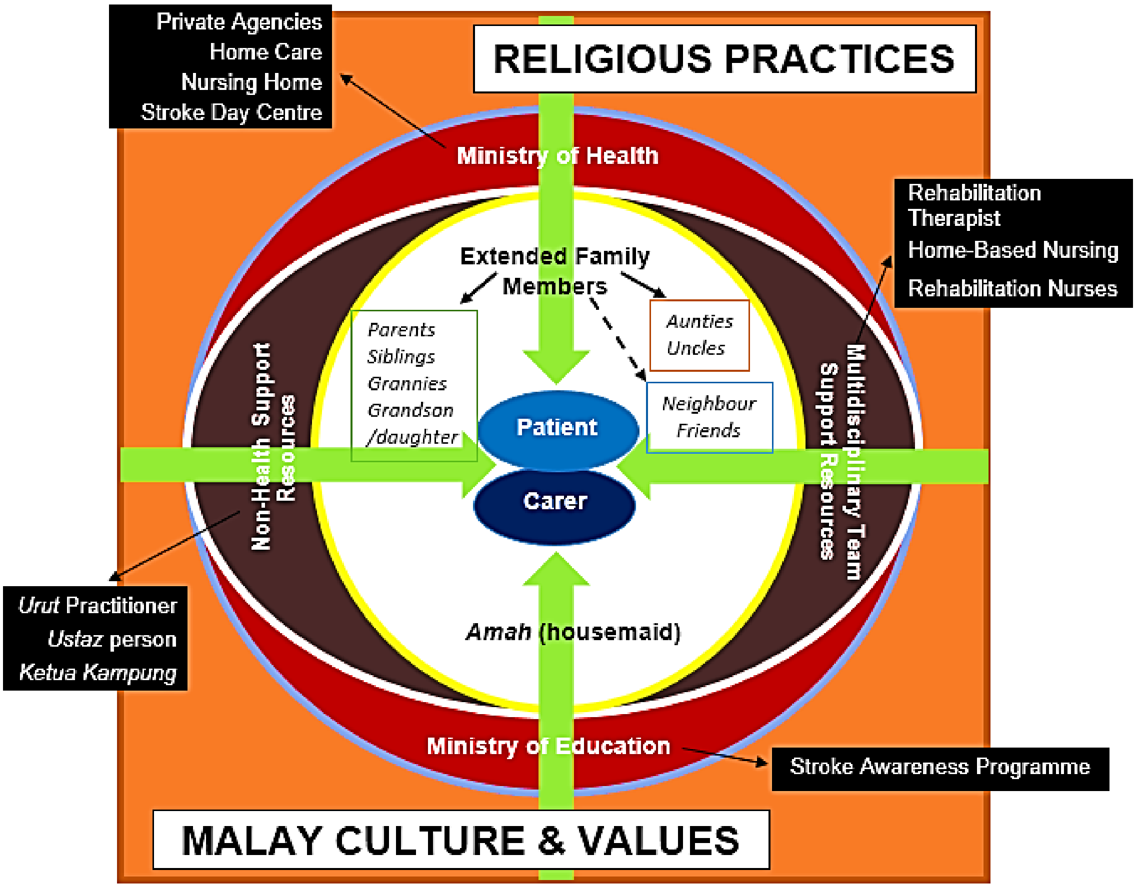


Diagram 16: Collaborative Rehabilitation Stroke Support System (CORES)

Describing and interpretation of the model

In describing the CORES, the centre circle illustrates the support network that was provided by various surrounding individuals who close to the patients or carers. The discussion with the expert healthcare professional revealed that family was regarded as the primary line of support which form the integral part for the stroke patients and carers' optimum health. The uniqueness of Bruneian family orientation is that members of family are not necessarily blood-related individuals, but may extend beyond non-familial connection such as neighbours or friends. This extensive support network seems ideal and was preferred by the healthcare professionals. However, the issue with regard to finding a “willing carer” or the stroke patients were left alone in the ward suggested that the family support structure is no longer dependable. Thus, hiring *amah* is considered as alternative support*,* though their credibility for delivering the required standard of care was questionable.

The support provided by family or *amah,* meanwhile, may not be sustainable throughout the years due to complexity of stroke recovery. Hence, our model suggests that involvement of personnel from health and non-health disciplines to counteract with the family care deficit is necessary. Both the multidisciplinary team (MDT) and traditionally known individuals, such as *urut* practitioners, provide as the second layer of the collaborative support system. The availability of these individuals can be valuable to ensure continuum of care support.

Our model further indicated that health and educational governance can play a major role in the collaborative support system. The discussion with the expert healthcare professionals revealed that establishing new community support centre, such as nursing home, and increasing stroke awareness programme which target at the school-aged pupils were considered timely. However, these propositions may not be accomplished without approvals from the two ministries, identified in the model, which are responsible for regulating all health-related and education planning in Brunei. Therefore, involving these policy makers for future planning and interventions is essential.

The model suggests that how the patients or carers respond to support provided can be influenced by their cultural and religious background. The significant of these aspects was found in the interview data. Therefore, appraising what these individuals valued can provide complementary care between modern and traditional approach, which in turn promote a person-centered care. The collaborative support network by all individuals and sectors will work together towards the core of the model, represent by the four arrows. This feature, ultimately, represent the strength of our CORES model.

Summary

This section presents overview of the conceptual model, named CORES, which illustrates the expert healthcare views regarding the possible strategy for improving the stroke rehabilitation service provision within the community. The model proposed various key roles from relevant individuals and agencies, which establish the larger support network for the stroke patients and carers. The consideration of culture and religious practice in the model formed the strength of the CORES model.

8.5 Reflecting the main areas of divergence findings

This section provides a brief reflection on divergence findings identified from the stroke patients, the carers, the nurses and the expert healthcare participants. Divergent findings were thus ensured to be taken into consideration in the overall findings of this research. Plyue et al. (2009) describe four strategies for using divergent findings: (1) reconciliation; which refers to the interpretation of data in a sense-making and plausible manner, (2) initiation; which refers to collecting new data to examine new perspectives, (3) bracketing; which is used when data is irreconcilable and (4) exclusion; used when data is incomplete or lacks validity (Plyue et al., 2009). In appraising divergent data from this research, reconciliation strategy was used and recommendations to reconcile dilemma identified in this study will be discussed in Chapter 9. Three main areas of divergent data were identified and described as follows:

1. Views on emotional changes after stroke
2. Views on the existing out-patient therapy sessions
3. Views regarding specialist stroke rehabilitation nurses

Views on emotional changes after stroke

The interview data from the stroke patient participants revealed that stroke negatively changed their normal emotional function. Furthermore, the stroke carer participants experienced significant stress due to the demands of caregiving. Findings from the nurse questionnaire with regard to knowledge and skill requirements about the impact of stroke on individuals, meanwhile, showed that many nurses agreed that stroke education was needed.

On the contrary, the study also revealed that some stroke patients and carers rejected the emotional consequences of stroke. In addition, several nurse participants were unsure regarding the competency needed for managing stroke patient’s motivation. Moreover, the healthcare expert participants were sceptical and commented on the stroke patients’ lack of understanding regarding the impact of stroke on emotional wellbeing. The discussions with these experts indicated wider arguments related to this issue and pointed to various contributing factors that led to emotional disturbance.

One plausible explanation for these divergent views was participants' different emotional perceptions, in particular when experiencing a situational crisis such as the aftermath of a stroke. Each individual may experience emotional changes influenced by several factors. For the stroke patients and the carers; the availability of family support, their level of understanding about stroke, their coping strategies and their cultural practices all may be associated with how they experienced a range of emotional changes. Whereas, for the nurses and the healthcare experts, their working experience in caring for stroke patients and their professional background may influence how they contextualise emotional problems. These healthcare expert participants regard emotional changes as part of the recovery process and predict that it is likely to get better over time.

Views on the existing out-patient therapy sessions

The interview data from the stroke patients and the carer participants revealed their dissatisfaction with the duration and extent of the out-patient therapy sessions. The current practice of rehabilitation therapy conducted for 30 – 45 minutes, delivered once or twice per week was regarded as insufficient. The stroke patients and carers indicated that more therapy time was necessary to sustain the patient's post-stroke recovery period. The nurse participants, meanwhile, agreed that having knowledge regarding the principles of stroke rehabilitation and their application was required to support patients' physical recovery.

The healthcare professionals were argumentative concerning the need to offer extended therapy time and the involvement of nurses in stroke rehabilitation. The discussions indicated that the healthcare experts were defensive with regard to the alleged inadequate therapy time. Although, these participants acknowledged staff constraints as the primary reason for limited services, they also commented on the lack of commitment of the stroke patients and carers in continuing therapy outside out-patient sessions. Furthermore, the healthcare experts indicated that most patients were over reliant on out-patient therapy services. The healthcare participants suggested that the stroke patients and carers non-compliance to continue rehabilitation during their own time was the reason for the inadequate therapy.

In resolution of the above conflict, the disparity could be due to the fact that stroke patients and carers did not make their dissatisfaction known to the therapist. Moreover, the therapist may have failed to inform the patients and carers regarding the staff constraint which affected the therapy schedules. This interpretation of the data suggested that poor communication between these groups of participants could be the underlying problem. The study data revealed that Malay cultural behaviour, such as keeping things to oneself, may have influenced the patients' openness toward the healthcare experts. Therefore, practical recommendation to address this issue will be discussed in Chapter 9.

Views regarding specialist stroke rehabilitation nurses

This study revealed conflicting views from all of the study participants with regard to the possible introduction of specialist stroke rehabilitation nurses. For the majority of the stroke patients and the carers, the potential merit of the stroke nurses in providing support at home was valued. The interview data from these participants suggested that providing health teaching and reinforcing therapy at home were viewed as part of the stroke rehabilitation nurses' roles. Most of the healthcare experts, meanwhile, agreed about the possible supplementary role of nurses in rehabilitation.

In contrast, the questionnaire findings from the nurse participants showed that nearly half of the nurses indicated their lack of interest with respect to future training in stroke rehabilitation. Moreover, a few of the healthcare experts were unconvinced about the proposed extended role of the nurses. Furthermore, several stroke patients and carer participants were wary of the possible negative implications of home visits by the stroke nurses. The interview data suggested that the stroke patients may experience a loss of motivation and lack of initiative to improve themselves, relying entirely on the support nurses.

The divergent views regarding the introduction of stroke rehabilitation nurses could be due to the absence of a clear framework regarding nurse rehabilitation in Brunei. Most often, rehabilitation therapy was regarded as the work of the allied health professionals, such as occupational therapists. Whereas, nursing activities were traditionally associated with providing bedside care. In interpreting these differing views, there was a significant indication that the prospect of developing future specialist nurses in stroke rehabilitation to support stroke survivors at home was questionable. The research findings suggested that improving the rehabilitation support provision was beyond the scope of nurses' roles in stroke therapy. Therefore, a strategy to reconcile the divergent views exemplified in the findings and address the dilemma concerning stroke rehabilitation nursing will be discussed in Chapter 9.

8.6 Chapter Summary

This chapter provides findings from discussion with six healthcare experts with regard to the six key findings identified in the phase 1 study. After presenting the findings from the phase 1 study, various issues and suggestions discussed by these participants were identified. The data analysis showed that the majority of the healthcare experts acknowledged the importance of the Malay culture and practice of the Islamic religion which formed an essential part of the rehabilitation support network for the stroke patients and their carers. One major concern reported by these healthcare experts that could affect long-term care for stroke patients was decreased support from patients' family members. Other ongoing issues discussed were related to the stroke patients and carers' lack of understanding about stroke, and potential barriers to introduce specialist stroke nurses due to staff resource constraints. Mixed responses regarding the stroke patients' emotional disturbance and the current out-patient rehabilitation services were found. The potential introduction of stroke rehabilitation nurses and non-health professions in managing stroke was viewed with caution. These areas of divergence were appraised and strategies were proposed to reconcile any dilemma. Furthermore, all participants suggested that involvement from non-government organisations in stroke care should be timely. A conceptual model to illustrate participants' views was suggested. Next, the findings from phase 1 and phase 2 of the study are considered with a view to how findings from both phases could address the objectives of this research. The latter are presented in the next discussion chapter.

Chapter 9: Discussion

9.1 Introduction

This chapter presents a discussion of the key findings of the research. The discussion is based on the six key findings discussed with the expert healthcare professionals that was generated through analytical weaving of data from patients, carers and nurses. The future implications of these findings for improving the home-based stroke rehabilitation service provision and the potential role of nurses related to strokes is explored and discussed. The overarching aim of this study was to explore the issues surrounding the different aspects of home-based stroke rehabilitation service provision in order to identify areas for improvement. A brief summary of the findings from the two phases of the study and the issues identified is presented in section 9.2. Subsequently, section 9.3 provides a discussion of the key study findings in relation to the research objectives and how these extend the existing knowledge base. Section 9.5 provide overall statement relating to addressing the research question and goal. Finally, section 9.6 provides a summary of this chapter. This chapter begins by restating the overarching research question and goal of the study.

9.2 Overarching research question and goal

Research question:

> How and in what way (s) can the rehabilitative needs and support of home-based stroke patients and their carers be improved?

Research Goal:

> To identify issues pertaining to home-based stroke rehabilitation service provision and recommend strategies for improvement.

9.3 Summary of the research and the main findings

Returning home after in-patient hospitalization for stroke survivors, family or carers can pose unanticipated challenges. The absence of the formal hospital support environment may result in stroke patients experiencing difficulties related to performing normal activities and resuming their daily life. Moreover, the families or carers of stroke patients have to assume greater responsibility for supporting the patient’s independence and recovery. Thus, providing continuity of support services following discharge is central to easing patients and carers’ reintegration at home. However, the international literature suggests that follow-up services for stroke survivors are often lacking (Andersen et al., 2002; Hickey et al., 2012; Mohd Nordin et al., 2014). In Brunei, this support service appeared too inconsistent and may have been largely absent. This indicated a need to plan appropriate home-based support services and thus formed the direction of this research.

This study, employed a convergent mixed-method design and consisted of two distinct phases that contributed towards understanding and identifying the issues surrounding home-based stroke service provision from three different perspectives: stroke survivors and their respective carers, nurses in the community and expert healthcare professionals. Phase 1 consisted of two separate strands: qualitative and quantitative, that aimed to critically explore the areas of rehabilitation support which required improvement, from the perspective of the patients, carers and community nurses. The qualitative strand employed one-to-one interviews that explored the experiences of participants who had suffered a stroke (n=21) and stroke carer participants (n=18) with regard to their lived experience of stroke and rehabilitation support needs following discharge from hospital.

The interview data from each of these participant groups was analysed separately. Findings from the stroke patient participants and carer participants were conceptualised into three thematic themes and presented in Chapter 4 and 5 respectively. The themes and their related sub-themes for the stroke patient participants illustrate the considerable impact of stroke on the individuals' physical, emotional and social functioning and how the existing out-patient therapy provision to support their problems was considered to be inadequate. The data revealed that the stroke patient participants sought traditional practitioners for *urut* services in order to expedite their recovery. It also found that family support at home for the stroke patients was inconsistent and often lacking. A conceptual model was developed to illustrate the participants various support needs that were either partially met or remained unmet. A concept of 'able' was used to demonstrate the main features of the model (see Section 4.5). The participants' views with regard to the potential introduction of stroke rehabilitation nurses elicited mixed responses. The interview findings provided an understanding concerning issues surrounding the stroke rehabilitation service provision among the stroke patients and the importance of the sociocultural context, which had a major influence on the lived experience of the participants following a stroke.

The themes and related subthemes from the carer participants, meanwhile, illustrated their complex lived experiences of the stroke. It was found that carers experienced a considerable burden as a result of their care duties, but often applied faith and cultural values to cope with their physical and emotional struggles. The lack of support from family members to supplement care was revealed in the interviews. The findings highlighted carers' broader problems and the challenges that the carer endured immediately after discharge in the home. A conceptual model to illustrate carers' preparedness living with the aftermath of stroke was developed (see Section 5.5). The interview data provided an understanding with regard to the issues surrounding the stroke rehabilitation service provision in Brunei from the perspective of carers.

Whereas, the quantitative strand employed a survey questionnaire which identified the potential roles and educational needs of the nurses with regard to stroke rehabilitation. The views of the 101 nurse participants showed that 86% (*n*=87*)* agreed or strongly agreed regarding the need for nurse training in community stroke rehabilitation and nearly half (*n*=49, 48.5%) stated that they were prepared to undertake the proposed training. In describing their roles, four categories were identified; nurses' role as a rehabilitation practitioner, supporter of patient recovery, provider of a continuum of care and roles that embraced Brunei Malay attributes. The views of these nurse participants indicated the existence of a service gap in the provision of stroke rehabilitation and how the nurses in the community could potentially fill this gap following appropriate stroke education and training.

Both sets of findings from Phase 1 of the study were merged together using integrated analysis strategy in order to examine whether the findings agreed (converged) or disagreed (diverged) on aspects required to improve the provision of home-based stroke rehabilitation. A joint display integration table to facilitate comparison between sets of findings was used (see Appendix 7). Following the analysis, 12 preliminary key findings pertaining to the rehabilitation support needs and home-based service provision were identified. These integrated findings were interpreted and further examined to ascertain priority areas for improvement. Overall, six of the 12 preliminary findings formed the key findings of the Phase 1 study which captured the 'felt' needs of the participants, the implications of culture and religious beliefs during rehabilitation, the existing rehabilitation service provision, the family structure and the potential roles of nurses in stroke rehabilitation. The six key findings identified were summarised in Chapter 7. These findings were discussed with expert healthcare professionals in the second phase of the study.

Phase 2 of the study employed one-to-one interviews with relevant healthcare professionals (*n*=6), which aimed to elicit expert comments regarding the six key findings and prioritise the issues related to home-based stroke rehabilitation service provision. The findings showed that the majority of these participants thought that many stroke patients and their carers lacked understanding regarding the impact of stroke and why continued therapy at home was crucial for sustaining recovery. Moreover, the discussion revealed the significance of Malay culture and practices and the traditional Brunei family orientation, which had a direct influence on the support resources of patients at home. With respect to the involvement of nurses and other non-health professional individuals in stroke care, the expert healthcare professional participants presented divergent views. A few of the participants raised concerns about staff shortages and the lack of clarity of nurses' roles with regard to strokes. However, most of the participants indicated that establishing non-government stroke agencies was timely in order to provide appropriate support for patients and family following discharge from the hospital. The findings from the second phase of the study were described in Chapter 8.

The following section considers how the findings of this study provides new knowledge regarding the provision of support care following stroke and how this information can extend the knowledge base across different settings outside of Brunei.

9.4 Extending the knowledge base

The section is presented under thematic headings based on the six key findings discussed with the expert healthcare professionals. The difference of opinions between the patients, carers, nurses and healthcare professionals in this study are discussed. How the outcomes of this study can make a unique contribution to the existing body of knowledge is interpreted in light of the contemporary literature. This study constituted the first empirical research in Brunei that explored various key stakeholders in the area of stroke and consequently offers novel knowledge and understanding in order to plan future supportive care. The six thematic headings of the discussion were as follows:

1. Discrepancy regarding the perceived emotional changes after stroke
2. The declining family support structure for stroke patients and carer at home
3. Inadequacy regarding the post-stroke rehabilitation and social support service provision
4. Complexity of nurses' role and training in stroke rehabilitation
5. Aligning the cultural and religious understanding about stroke with modern context
6. Recognition of *urut* and prayer as part of rehabilitation interventions

9.4.1 Discrepancy regarding the perceived emotional changes after stroke

The study revealed that there were differing views from all of the study participants with regard to the interpretation of emotional changes after stroke and the support needed after discharge from the hospital. The interview findings from the stroke patients and carer participants showed that the event of the stroke substantially affected their emotional functions. In this study, it was observed that several stroke patients and carer participants exhibited emotional disturbances, such as shedding tears or abruptly fell silent during the interviews. Furthermore, a few of the stroke patients expressed their feelings of frustration, sadness or anger due to loss of bodily functions. For carers, they experienced significant stress as a result of discharging their caregiving role. The participants indicated that the existence of their emotional problems were long standing issues following the stroke and suggested that support to address these emotional disturbances was absent.

The study suggested that the stroke patients and carer participants' emotional problems were most likely being overlooked and not receiving the required attention from the healthcare providers; this was similar to conclusions found from other international studies (Ferro & Santo, 2019; Ytterberg, Koh & Erikson, 2019). Findings from this study indicated that the support structure for addressing the stroke patients and the carers' emotional concerns was presently lacking, as was also highlighted in the UK *Life After Stroke Campaign Report* (Stroke Association, 2013). All of the stroke patients in the study and their respective carers returned home within a year post-stroke, and so may have endured emotional problems during this period that had gone undetected. Many studies have shown that emotional changes can occur from the beginning of stroke onset and may last for several years (Douiri et al., 2013; Hackett et al., 2010; Hackett & Pickles, 2014; Lincoln et al., 2016; Rohde at al., 2019). The consequences of these emotional problems, if left unmanaged, could prove detrimental to the stroke patients' recovery (Villain et al., 2016; Gunal, Baskurt and Baskurt, 2019) and carers' quality of life (Gbiri et al., 2015a; Yousaf et al., 2019). Evidently, this was observed in the current study, where a few of the stroke patients appeared to lack the motivation to continue their therapy at home or carers stated their feelings of intense distress. Therefore, immediately recognising the impact of a stroke on emotional wellbeing could help healthcare professionals to direct their patients and carers towards appropriate support. This practical support is crucial for preventing the risk of social isolation post-stroke, a similar conclusion was previously reported by systematic reviews of qualitative studies (Lou et al., 2017).

On the other hand, the study revealed opposing views between the expert healthcare professionals and the stroke patients with regard to the interpretation of emotional changes after the stroke. The healthcare professionals argued that the reported emotional problems were an expected outcome of a stroke that is triggered by specific areas of the brain (Warlow et al., 2008). The views of these experts reflected the outcome of a study by Farinelli et al. (2015) who found that stroke brain lesion significantly affects basic emotions which could induce sadness, fear and anger. Thus, it was normal for most patients who had a minor stroke to experience emotional changes as part of the recovery trajectory (Morsund et al., 2019). The healthcare professionals, instead, debated the reported emotional issues experienced by the stroke patients and carers. They commented that the stroke patients or carers' complaints about emotional disturbances were due to their lack of understanding about the impact of a stroke on this function. On the contrary, this study found that the stroke patients and the carers indicated substantial information deficits with regard to emotional and psychological management following a stroke. For example, there was confusion over what caused the stroke, the benefits of the therapy, the importance of managing oneself independently at home and how to manage the gap between their expectations and their physical capacity. These findings suggested a failure by healthcare professionals to communicate effectively with the patients or their carers regarding emotional changes after stroke. A similar issue was reported in earlier studies, where gaps in knowledge among stroke patients and their carers remained and existed both in the hospital (Harrison et al., 2017) and the community setting (Yeung et al., 2015).

This study revealed various reasons that might explain the emotional disturbance experienced by the stroke patients and carers which were not reported by the healthcare professionals. It was observed that the current rehabilitation therapy provision was largely focused on improving physical functioning or teaching the carers how to continue therapy for the patient at home. The findings indicated that the stroke patients or carers' emotional problems were given little attention. This approach in treatment suggested the dominance of care and therapy-related decisions which were dictated by the healthcare professionals. As a result, the patients may fail to fully understand their rehabilitation goals and therefore, become passive recipients of care. Arguably, this silence can be attributed in part to the Malay culture of Brunei; for example, it is considered impolite to disagree directly with someone. Such behaviour could cause that person to feel embarrassed or humiliated (losing face). Moreover, Bruneians strive to avoid confrontation and so adopt a policy of silence and ambiguity to avoid reacting negatively to unfavourable actions (Oxford Business Group, 2009). This observation reflects to study by Mastor et al. (2000) who reported that the Malay Bruneian tend to have tactful personality, reserved and low level of openness.

Correspondingly, the observations of the healthcare participants further suggested that the Brunei Malay culture may influence how patients respond to and approach their therapy. The interviews with the expert healthcare professionals suggested that the stroke patients or carers often failed to make their emotional problems known to the healthcare staff. Instead, the patients would share their concerns with their stroke friends or individuals who were not directly involved in their care, such as the researcher. One probable explanation for the patients' failure to express their feelings is due to the traditional perception that regard healthcare professionals as expert personnel and so patients tend to accept their advice without question. Currently, research on the impact of the cultural behaviour of stroke patients on healthcare service provision is lacking. However, to illustrate, Chong et al., (2008) found that some of the Bruneians who participated in their study consumed traditional remedies, often on the advice of a traditional practitioner who was regarded as an expert, even though the patients were not ill or were unaware of the ingredients of the medication. This finding suggests that some patients' behaviour reflect the Brunei Malay culture, such as "being too nice" (EP – 03) or "didn't say anything" (EP – 01). This may represent a significant barrier to self-efficacy in recovering from a stroke.

The views of the nurse participants suggested that they were prepared to embrace roles that support the stroke patients and their carers' psychological and emotional wellbeing needs. The role of nurses in alleviating stroke patients and their carers' emotional problems have been well documented in earlier literature (Burton & Gibbon, 2005; Steiner et al., 2008). Moreover, a recent study by Bennett (2016) concluded that nurses were capable of fostering a positive relationship with patients and their carers, which could help to improve the emotional wellbeing of these individuals. This finding concurred with the views of the nurse participants in the current study, who indicated that embracing positive attitudes, such as "being friendly towards patients and their family" (NP – 021), was vital for community stroke rehabilitation nurses. However, over 90% of the nurse participants in the current study frequently identified that training in the psychological and emotional aspects of stroke was needed in order to provide competent and effective care, as was also reported by Murray et al. (2004). The finding of this study, thus, was indicative of the knowledge gap that existed in the structure of nurses' training on strokes.

The discussion with the expert healthcare professionals regarding possible strategies to address issues with emotional changes after stroke revealed various challenges and complexity. The suggestion to include a stroke psychologist as part of the multidisciplinary stroke team or providing private agencies to relieve carer's caregiving duties could be a viable option. However, the study found existing scepticism among the stroke patients when seeking psychological support, whereby referring them to see a psychologist is frequently associated with mental illnesses. The hiring of a private agency could also prove challenging considering the financial constraints of the stroke patients and carers. Moreover, it was highlighted in this study that the contribution of nurses in addressing emotional changes after stroke was questionable. The health professionals were sceptical about the roles of nurses in this aspect and debated the competency requirements for the proposed stroke rehabilitation nurses. Several nurse participants, meanwhile, were uncertain as to the necessary motivation, skills and ability required to be a stroke nurse. These divergent findings, particularly with respect to the different emotional interpretations between the healthcare professionals and the stroke and carer participants, and subsequent reservations about the role of nurses in emotional management for stroke contributed to the dilemma identified in this research. A different strategy was necessary to reconcile this existing conflict. Therefore, improving communication transparency, was proposed to address this issue and is briefly described below:

Communication Transparency

Communication transparency is referred to an “open form of truthful communication between an organization, its employees or customers, which doesn’t conceal any hidden agendas or conditions” (Day, 2018). It promotes trust in the patients-healthcare professional relationships and the healthcare system (American College of Physicians, 2010). Thus, being transparent represents one of the requirements for effective communication.

Findings from the study showed that the stroke patients and their respective carers were not transparent about their emotional concerns. The healthcare professionals, meanwhile, in spite of their understanding of the impact of stroke on emotional functions, did not communicate directly or inform the patients concerning emotional disturbance. These scenarios suggested that there was an underlying gap in this aspect of patients-healthcare provider communication. Thus, a specific strategy is required to promote effective communication through emphasising the importance of being transparent.

Promoting Communication Transparency

The aim of communication transparency is to achieve effective communication. Hence, some elements for effective communication strategy can be adapted to promote communication transparency. One of the most important strategies to promote transparency in communication is increasing self-awareness. In the context of this study self-awareness refers to the impact of stroke on emotional functions. Vorauer and Ross (1999) suggested that increasing self-awareness is associated with increased feelings of transparency. The approach for raising awareness requires collaboration between multiple stakeholders to ensure that the information is accessible in various ways. These approaches, such as using research evidence, web-based sources, print media, oral presentations, posters and other methods could help to improve emotional awareness.

Another strategy to promote communication transparency is by establishing therapeutic relationships. This refers to relationships that are “built based on mutual trust and respect, nurturing of faith and hope, being sensitive to self and others and assisting with the gratification of the patient’s physical, emotional and spiritual needs through knowledge and skills” (Pullen & Mathias, 2010; p.4). Noyce and Simpson (2015) found that therapists who disclosed health-related information of the patients were more likely to facilitate the establishment of a therapeutic relationship.

Providing a conducive environment for communication could give comfort and security. A poor environment is found to be one of the barriers to effective communication (Ali, 2018). Appropriate selection of a suitable room or timing of the conversation is important and can influence patient readiness to speak about their emotional problems. Other environmental factors such as noise, room temperature, lightning and the presence of other non-family members might require consideration (Kourkouta & Papathanasiou, 2013) in order to promote engagement.

Cultural values, beliefs and assumptions are other aspects that may hinder the patients from being transparent. For example, the role of space plays an important factor in engaging oral communication. The distance between the sender and receiver is classified as intimate (less than a foot); personal (2 to 3 feet apart); official (4 to 5 feet) and public talk (over 10 feet) (Communication Theory, 2010). Typically in Brunei Malay culture, personal space is required when in conversation. Any invasion of this space may result in awkward or embarrassing situations, which in turn impairs effective communication.

In summary, communication transparency offers a strategy to address issues with emotional conflict. The importance of raising self-awareness regarding the impact of stroke on emotional functions is highlighted. Several key strategies to promote communication transparency were discussed. Consideration of cultural values in communication is needed. The subsequent section discusses issues concerning the family support system.

9.4.2 The declining family support structure for stroke patients and carers at home

The family structure of Brunei is traditionally an extended family where parents, children, grandparents, uncles and aunties commonly live under one roof. This type of family structure allows its members to assume their respective roles and responsibilities towards helping and supporting each other’s needs (Thien, 2014). In Brunei, it is apparent that the government views a strong family institution as a vital part in shaping future healthy generations. Every first Sunday of the month of May each year, Brunei celebrates its Family Day nationwide. Thus, it is important to foster a stable family environment in order to promote meaningful community, society as well as developing the nation (Harris, 2014).

However, the study revealed that the present family structure to support the stroke patients and respective carers after discharge was inconsistent, or to a certain extent was absent. The healthcare participants in this study suggested that the declining family support structure could be attributed to various factors, such as people remaining unmarried or couples who decided to have fewer children. This assumption was supported by Ahmad (2018) who investigated the attitudes of young Bruneian towards family formation. His study revealed increasing numbers of Bruneian were married at later age, high proportions of female being singlehood and preferences for smaller family size. Evidently, numbers of crude birth rate for married Bruneians have decreased from 23.0 in 2000 to 15.3 per 1000 population in 2017 (Ministry of Health, 2017). This marked reduction of births may well contribute to issues identified in this study. The need to involve family as caregivers for chronic conditions, such as stroke, is crucial for continuity of care at home. Wong-Cornall et al. (2017) provide evidence that family carers could work closely with the healthcare providers in ensuring extended care at home. Thus, the caregiver can actively inform the service provider regarding the patient’s recovery whilst enabling the patient to receive consistent and flexible support.

On the other hand, the study revealed that the availability of family members, typically children, did not necessarily guarantee that a carer would be readily present. This study showed that identifying a “willing carer” (EP – 02) from the extended family members can be problematic. The health experts indicated that the traditional belief that children would routinely offer care for a stroked parent was no longer practically true. The absence of a carer was evident as early as the stage of the patient being hospitalized. One plausible explanation was that the elected children may not have a clear understanding or the required skills about stroke care, thus they were unwilling to take charge. The issue of the carer’s lack of preparedness to care for stroke patients before discharge is well documented. A recent study showed that stroke carers needed support interventions with regard to accessing the support services, enhancing their level of confidence in caring, information about rehabilitation and how to care for their own wellbeing (Jarvis et al., 2019).

This study, meanwhile, also revealed the issue of finding a substitute carer among the family members in order to replace the primary caregiver. Many of the primary carers were forced to spend their time with the patient on a daily basis as children or other siblings were reluctant to get involved. This lack of involvement from other family members to care for the stroke patient, perhaps can be explained by the Malay cultural behaviour relating to ‘leaving things to the expert’, as previously explained. The primary carer tends to develop experience and expertise to care for the stroke patient (Sadler & McKevitt, 2013). McDonald et al. (2016) suggested that these carers often underwent a series of learning processes involving concentrated periods of training given by the healthcare providers, taking caregiving responsibility on a daily basis and ongoing self-directed learning, which over time transformed them to become expert caregivers. There are no available studies that explore the relationship between Malay cultural behaviour and the practice of ‘leaving things to the expert’. However, on personal reflection my siblings frequently leave the entire responsibility to me; as an expert in nursing, to care for my parents if they reported any ill-health. Thus, the finding from this study seemed to be distant from the government’s aspiration to promote a good family dynamic and family support institution.

The suggestions proposed by some of the health experts about hiring a private individual to substitute the primary carer constituted mixed views. In Brunei, most paid carers are primarily employed as a domestic helper (addressed as *amah*). However, these domestic helpers were usually required to assume the role of caregiver for the stroke patient, even though they didn’t have any prior caring experience other than domestic work (Abdul Razak et al., 2015). Most of the paid carers were sourced from neighbouring countries, such as Indonesia, through private agencies. In general, the cost to employ a carer ranged from BND 3000 to BND 4000 with a capped salary of BND 350 per month. This significant financial requirement and uncertainty concerning the carer’s competency to provide the expected care for stroke suggested that hiring an *amah* was “risky” (CP - Pilot01). The total incidence of *amah* who reportedly fled from their employers between 2017- 2018 was 29 cases (Jabatan Majlis-Majlis Mesyuarat, 2019). Even though it was not clear what the reasons were for these runaway cases, it was plausible that multi-tasking inclusive of performing domestic chores and caregiving responsibilities became physically and mentally unbearable for the carer (Abdul Razak et al., 2015).

Another suggestion identified in this study addressing the lack of support care at home was to establish a community-based stroke support centre. This finding mirrored the current approach which was widely practiced by many developed countries worldwide.

In the UK, for instance, community-based stroke support is commonly stationed within the different regions throughout the country. The service provision consists of a wide range of support such as providing tailored rehabilitation therapy, stroke recovery, home visiting or giving access to stroke clubs and groups. The expert healthcare professionals in this study indicated that forming a community stroke centre in Brunei was needed. This centre could give stroke patients access to support resources such as therapy, or act as a meeting place for the patients during the day. The study revealed that group gatherings among the stroke patients could improve their psychosocial and emotional wellbeing. This peer support group appeared crucial to motivate other stroke patients who may hide their own problems from the healthcare providers. The benefits of this peer support was similarly reported in a previous study, whereby the support groups empowered the patients, cultivated a sense of community and was perceived as important to their recovery process (Christensen et al., 2019).

The findings from this study, however, suggested that the proposed establishment of a community stroke support centre could have negative consequences for the family institution. The expert healthcare professionals were concerned regarding the possibility of family members who might take advantage of the facilities provided. The issues identified included over reliance on the services provided or the care centre being used as a “dumping ground” (EP – 06) for families who neglected the stroke patients. There is no published record for the number of neglected stroke cases in Brunei. However, the concerns raised by the expert healthcare professionals in this study reflected my own observations, whereby several chronic stroke patients remained in hospital because no family members were willing to care for them or take them home.

The importance of family support for the stroke patients and respective carers was highlighted in this study. The findings indicated that without good family structure, recovery for the stroke patients or carer’s quality of life would almost certainly be disrupted. This finding echoed a study conducted in Malaysia which found a significant correlation between the availability of support from the family unit and successful recovery of the stroke patients (Mairami et al., 2020). In addition, the presence of family support for the caregiver could reduce their burden thus improving their quality of life (Kumar, Kaur & Reddemma, 2016). The impact of the country’s ideology; ‘*Melayu Islam Beraja*’ (MIB) or Malay Islamic Monarchy, was embedded as part of the Bruneian way of life and provided a strong influence on how the family was structured. The majority of the participants in this study were Malay Muslim, thus upholding family solidarity and societal cohesion was valued as part of MIB philosophy (Tuah, 2002). For example, one of the Qur’anic verses (religious text of Islam), maintains that strong ties between members of the extended family is an obligation for every Muslim. Allah the Almighty says *"Worship Allah and join none with Him in worship, and do good to parents, kinsfolk…"* (An-Nisa' 4: 36) (Pervez, 2014). Moreover, inculcating a sense of love and care towards the family was central within Malay society (Haji Abas, 2015). For Brunei Malay Muslims thus, the strong family bond was the "key for everything" (EP – 02) and was seen as an essential part of daily life. Arguably, the concept of MIB relating to family support structure could give undesirable outcomes with respect to stroke patients' recovery. The issue of 'expectation', whereby the stroke patients expected the family members to be continuously present may lead to feelings of over dependency. This mind-set is conflicting with the purpose of rehabilitation, in which regaining strength and self-encouragement are crucial to achieve independence and personal goals (Hartigan, 2013). The expert healthcare professionals indicated that living with little support from family remained feasible and was acceptable. The study findings, therefore, have implications as to the importance of exploring alternative strategies in promoting stroke recovery and reducing the carer's burden.

The overall discussion regarding the support structure for stroke patients and carers revealed complexity in addressing this problem. The differing findings, particularly in the aspects of utilising a paid carer, setting-up a community support centre and misconceptions of religious-cultural practices contributed to the dilemma in this research. A different model of care is required to reconcile this existing conflict. Therefore, a self-management model was considered to address family support issues and is briefly described below;

Self-Management Model

Self-management is described as 'an individual's ability to manage the symptoms, treatment, physical and psychosocial consequences as well as lifestyle changes inherent in living with a chronic condition' (Barlow et al., 2002; p.366). This can be achieved by "providing encouragement and support to a stroke survivor and their family or carers to allow them to take the main role in dealing with their chronic condition by making informed decisions about healthcare and by engaging in more healthy behaviours (Randall, 2017; p.22). Self-management is about patients working collaboratively with the healthcare professionals to manage their health and disease condition (Fletcher et al., 2019).

Self-Management evidence

Existing stroke literature that has examined the effectiveness of self-management interventions for stroke patients or carers has shown considerable benefits. Extensive systematic reviews or meta-analysis studies have been conducted to review the specific aspects of the self-management model. For example, in a Cochrane review Fryer et al. (2016) concluded that the self-management training improved the stroke patients' overall quality of life and empowered them to look-after their lives. Another meta-analysis (Sakakibra, Kim & Eng, 2017) found that the self-management interventions improved the stroke patients' behavioural lifestyle in controlling the risk factors for secondary stroke. However, in a meta-review of systematic literature reviews, Pearce and colleagues (2015) suggested that healthcare professionals should work closely with the patients at all stages of stroke recovery for the self-management strategy to be effective. The need to recognise the complexity of the recovery trajectory and the changing needs of the patients throughout the recovery phase was highlighted (Pearce et al., 2015).

Stroke Self-Management Programmes

Fletcher et al. (2019) suggested that self-management programmes for stroke often encompass strategies for optimising secondary stroke prevention, thereby increasing stroke survivors' general physical activity levels and enhancing survivors' activities of daily living, participation in society and quality of life. Various stroke self-management programmes have been published in international literature. It is beyond the scope of this thesis to describe the available interventions in detail. However, referring to one example which is relevant to stroke is the Stroke Self-Management Program (SSMP) (Damush et al., 2011). The content of this programme is structured based on input from key stakeholders, consisting of the stroke patients, carers and healthcare professionals as well as being adapted from the Chronic Disease Self-Management programme developed by the Straford Patient Education Research Centre (Lorig et al., 1999). Published randomized control trial studies (Cadilhac et al., 2011; Lo et al., 2018) and systematic reviews (Warner et al., 2014) have found that SSMP is both feasible and effective in improving self-management behaviours. Similarly, the Family Informal Caregiver Stroke Self-Management Program (FICSS) was found to reduce caregiver burden and improve their quality of health (Mores et al., 2018)

Relevant of the Self-Management model in a Brunei context

The issues identified in the study with regard to the declining support structure for stroke patients and carers necessitate a different strategy to promote recovery and to reduce the caregiving burden. Promoting independency for these individuals could be crucial to achieve good quality of health. The self-management programme seems to be a viable strategy to address this problem. The relevance of this strategy within the context of Brunei can be viewed from two different aspects; the nation's health planning and Islam.

Promoting self-management is in line with one of the Ministry of Health's strategic priorities; 'Health is everyone's business', which calls upon the whole of society to take responsibility for their own health and lessen the prevalence of non-communicable disease in Brunei (Brudirect, 2016). This strategic planning requires Bruneians to be continuously aware of the importance of managing oneself through health maintenance or disease management. It focuses on the individuals' needs for improvement. Whereas, from the religious perspective, Islam outlines numerous guidance principles and laws pertaining to managing self-health through Quranic verses or *Hadith* (record of tradition or saying of the Prophet Muhammad (Peace Be Upon Him)). Muslims believes that the body is on trust from Allah and every Muslim is accountable for preserving their body's health. A *hadith* narrated by Al-Dhahabi says, "A person's body has a due right over him" (cited by Koenig & Al Shohaib, 2014; p.46). In the Quran, Allah says, "O man! What has enticed you from your gracious Lord who has created and well-proportioned you, and given you a perfect moulding?" (82: 6-7) (Al-Awwa, 2002). Both *hadith* and Quranic verses indicate that submitting to Allah and following His commandments are vital for health. Thus, managing ones' health and body is considered as an obligation and an act of gratitude to Allah in the form of *ibadah* (worship) (Boktah, 2019). The concept of self-management in Islam can be best encapsulated by the following Quranic verse; "Verily! Allah will not change the (good) condition of people as long as they do not change their state of (goodness) themselves" (Al-Rad 13:11) (Abd. Rashid, 2013, p.5).

In summary, self-management offers a different strategy to address issues concerning family support structure identified in this study. The evidence for the effectiveness of self-management programmes was presented. The existing stroke self-management programme showed positive improvements in patients' overall health and wellbeing. This model of care seems relevant within the context of Brunei, thus it may potentially be feasible with respect to improving the health of Bruneians.

9.4.3 Inadequacy regarding the post-stroke rehabilitation and social support service provision

The primary goals of stroke rehabilitation are to "facilitate people with health state experiencing or likely to experience disability to attain optimal functioning in interaction with the environment" (WHO, 2001). The establishment of specialised stroke centre, the process of care delivery, early timing of rehabilitation and intensity of therapy are imperative for promoting the overall outcomes of stroke recovery (Teasell et al., 2018). All of our stroke patients in this study have had some residual physical impairment due to their stroke. Findings of this study showed that many of these participants have considerable problems with physical limitations and indicated that the rehabilitation healthcare professionals were one of the keys in improving their physical recovery. The majority of the stroke patients received their therapy provision from the private stroke centre (BNSRC) on a weekly basis.

One of the key findings of this study revealed that the provision of rehabilitation therapy for the stroke patients were presently inadequate. Typically, every stroke patients would be given about 30 to 45 minutes therapy interventions and scheduled every once or twice per week. Debatably, the intensity of this therapy fell below the required international rehabilitation standard. As an example, the NICE Stroke Quality Standard recommended giving initial therapy at least 45 minutes during each session for a minimum of five days per week. This intensity may increase if the patients are able to participate and continue to make functional gains. However if the patients are unable to participate, the timing can be reduced but the delivery of the therapy remains within the five days period (National Institute for Health and Clinical Excellence (NICE), 2019). Findings from our study revealed that the stroke patients often expressed a feeling of dissatisfaction as result of shorter therapy. The carer participants, meanwhile, reported of inadequate training in consistently overseeing and applying the patients' daily exercise. Consequently, the carer participants indicated that they feel felt ill-prepared to manage the therapy independently at home, which finding accords with other published studies (Brereton & Nolan, 2000; McKevitt et al., 2011; Woo Lee et al., 2015; Luker et al., 2017).

Our study showed that the primary reason for the limited therapy provided was due to lack of rehabilitation therapist. The issue of staff constraint can be explained by the disparity between the therapists to stroke patient ratio. According to the head of the rehabilitation department, there are 23 rehabilitation therapists; the physiotherapist, occupational therapist, the speech-language therapist and the cardiac rehabilitation therapist, who are currently employed at the PJSC (Pantai Jerudong Specialist Centre) Rehabilitation Centre (Tie, V., Personal Communication, October 20, 2019). Whereas, it was reported that the incidence of new stroke cases was around 300 every year (Norjidi, 2018). Considering this, the lacked of therapy provision appeared inevitable. This finding is comparable with McHugh and Swain (2013)'s study who identified that most of the in-patient stroke units were understaffed and they struggled to provide the amount of therapy and time as recommended by the NICE Stroke standard.

On the other hand, Clark et al. (2018) argued that issue with staff limitation was not the determinant factors affecting the intensity and frequency of therapy. They suggested that the time routinely spent by the therapist in information exchange with the stroke patients had influenced the therapy provision. It is not clear, however, in our study if this factor contributes to limitation of the existing therapy time or the therapist has other commitments. But, interview data with one of the expert healthcare professional participants indicated that therapist-patient communication engagement was not commonly occurred due to time constraint. The Royal College of Physicians (2016), in their National Clinical guidelines on strokes, thus, recommends reducing the therapists' bureaucratic work demands or establishing nurses' training in stroke rehabilitation. This strategy might help to increase the face-to-face contact between patients and healthcare professionals, and so improve the therapy duration.

The findings from our study indicated that the issue with inadequate therapy was compounded by the stroke patients' lacked of initiative to improve themselves independently. The expert healthcare professionals suggested that the behaviours of some stroke patients who often rely entirely with the service provided was unacceptable. The finding revealed underlying concern with regard to the stroke patients' accountability for their recovery and unrealistic expectation on therapy support. Findings of this study conflict with the national recommendations, such as by the Scottish Intercollegiate Guidelines Network (2010), which outlines the needs for the stroke survivors to take responsibility for their own recovery with minimum support from the healthcare professionals. Moreover, this study found that the stroke patients' "mind-set" (EP – 04) which expect therapy only to take place in a hospital setting were likely to contribute to delayed recovery. The impending problems relating to the stroke patients' expectation, perhaps, could be explained by the lack of understanding about the importance of continued rehabilitation.

Therefore, addressing this dilemma through communication transparency, as discussed in earlier section, could be vital to promote the continuity of rehabilitation outside the hospital setting. The therapist should actively engage, not only in physical but verbal action with the stroke patients and the carers. An appropriate medium of communication should be provided in order to encourage the patients and carers to share their concerns. For example, providing leaflets regarding the importance of self-care management at home, using phone contact for immediate response or preparing videos that demonstrate techniques on how to perform rehabilitation exercise without the presence of a therapist. These communication strategies may help to reconcile the divergent findings with regard to inadequacy regarding the existing out-patient therapy sessions.

On the other hand, the evidence shows that the extent of social support received during in-patient hospitalisation and after discharge was among one of the important determinants for overall stroke patients and carers' quality of life (Dabrowska-Bender et al., 2017; Kruithof et al., 2013; Tse et al., 2017; Yu et al., 2013). Social support can be acquired through various resources, including out-patient hospital services (e.g. early supported discharge, stroke clinic or social service centre), family members (e.g. parent, spouse, children, siblings, next of kin, and relatives) and community networks (e.g. friends, neighbours, public or private support groups). However, the present study revealed that the social support care appeared to be limited and, if present, was generally inconsistent. Moreover, our findings indicated that the social support needs of stroke patients and their carers extend beyond the healthcare milieu. The narratives from these participants suggested broader issues related to limited public facilities or resources for disabled people, negative perceptions within the community on individuals with disabilities, a lack of respite care services and a disparity of support provided by healthcare services. Issues pertaining to support services were similarly identified in the published report; 'Supporting life after stroke' (Care Quality Commission, 2011). This report found that the stroke survivors, their carers or family did not always received the required services after discharge, access to the services was often complex, the existing services were disorganised and did not meet individuals' needs and decisions regarding planning the transfer to home were frequently taken by the healthcare professionals.

More than a third of the stroke patients in this study indicated a desire to resume their previously valued-activities before the stroke. These included attending the weekly Friday prayers at the mosque, attending traditional family gatherings such as weddings, returning to work or engaging in recreational activities. However, these intentions are often left unfulfilled due to their physical impairments or lack of supportive facilities. The expert healthcare professionals equally found constraint on signposting stroke patients for social support services following discharge from hospital. As a result, the stroke patients were most likely to spend time at home and endure unavoidable social isolation, which in turn increases their risk of developing depression (Ayerbe et al., 2013).

Unexpectedly, the current study found that the stroke patients often look forward to attending their weekly outpatient therapy. The data revealed that attending the session enabled them "to meet with other patients' (SP – 15) or "sharing their stories (progress)" (CP – 01). When the views of these participants regarding the potential setting up of a community stroke centre, such as a stroke club, were explored, the majority appeared optimistic and indicated that the avenue would probably improve their psycho-social interactions. This feeling suggested that the stroke patients were desperate and hopeful about resuming their former social activities. The views of the stroke patients regarding the anticipated benefits of a community stroke centre were espoused by Brookfield and Mead (2016). They found that providing an environmental setting in the community where patients and carers meet can increase their participation in functional, social and recreational activities. Currently, there was no community stroke centre available in Brunei, therefore this finding suggested that setting up this service required consideration.

The findings of our study revealed issue concerning financial sources. The data showed that the stroke patients were struggling financially to fund their basic daily necessities and supporting the needs of other immediate family members. Half of the stroke patients and their carers were either self-employed, retired or un-employed. Hence, financial dependency on other members of the family or allowances from the government were inevitable. Currently, the government provides a monthly old-age pensioner allowance of B$250 to every citizen once they reached the age of 60. The data showed that twelve participants, comprising both stroke patients and their carers, currently received this benefit. However, more than five of these recipients reported that the existing allowance was “not enough” to buy disposable miscellanies or specialist equipment. In a government published report, it was stated, under the Old Age and Disability Pensions Act 1954, that a similar amount of funds was allocated to disabled people, but this financial assistance was purposely for blind people, those with mental illness, those who had been rejected by their family, or those born without limbs (Mohidin, 2013).

It was apparent that the stroke patient participants felt dissatisfied and frustrated with regard to their non-entitlement to this benefit, despite having a disability. They appeared to be poorly-informed about the entitlement procedure, and nor were they aware to whom to report their problems. In other countries, although financial needs were among the unmet needs reported (Care Quality Commission, 2011; McKevitt et al., 2011), arguably, these countries already have an established stroke association to offer financial benefits. For example, in the UK, benefits and financial assistance for stroke survivors and their carers were clearly signposted (Stroke Association, 2016). The findings of our study suggested broader issues regarding the current financial and welfare management for people with stroke-related disabilities, so a revision of the related policy was warranted. At the Asean Disability Forum held in Brunei in 2013, priority was given to ensure that people with disabilities have access to social funds and safety nets through private-public partnerships (Global Accessibility News, 2013), yet the inclusion of stroke disability in this planning remained unclear.

In summary, the provision of post-rehabilitation services outside the hospital setting was inadequate. The lack of the rehabilitation therapist to cater for the increasing number of stroke patients further exacerbate the service constraint. The commitments for the stroke patients in continuing rehabilitation independently at home was questionable. Therefore, promoting self-management strategy, as discussed in earlier section, perhaps, could improve the patients' awareness about the important importance of continued or continuous exercises outside the therapy setting. The limitation for the stroke patients to re-engage into the community was highlighted. The potential establishment of community support centre seems valuable to address the patients' social function needs. The issue with financial constraints was revealed in this study. It is beyond the scope of this study to address this issue. However, this finding provide implication to the relevant stakeholder, such as the Department of Welfare Services, for consideration of stroke-related disabilities as part of the Disability Act.

9.4.4 Complexity of nurses' role and training in stroke rehabilitation

The findings of this study with regards to the role of nurses and the training requirement in stroke rehabilitation suggest complexities in future planning and their establishment. It was revealed that views from all participants in this study relating to the potential introduction of specialist stroke rehabilitation nurses varied and were inconclusive. The findings showed that nurses may have the potential to be part of the stroke rehabilitation multidisciplinary team, or form a complementary support resource for the allied health professionals in emphasising therapy interventions through education. Conversely, the divergent findings identified in this study pertaining to the aspect of the stroke nurses' presence at patient's home, preferences of the stroke patients towards family carer, the prospect of role duplications with other healthcare staff and level of nurses' competencies in managing certain stroke-related problems, such as social isolation, hence, suggested that there is a need to weigh on the advantages or disadvantages on potential extending the current nurses' capacity and roles. Moreover, the questionnaire findings revealed over half of the nurse participants in this study felt unprepared to undertake stroke education, and the majority indicated difficulties in attending the training due to constraint with the current staffing level. This finding, therefore, provides direct implication on planning future stroke rehabilitation nurses in Brunei.

In this study, we have adapted one element of SSEF for our questions related to the requirement on the rehabilitation knowledge and skills competencies for stroke nurses. This initiative was based on evidence and theory that have showed very good practical foundation (Department of Health, 2009). However, we also took into consideration the limitations of the nurses' response to the question. Although most of the nurses stated that they had experience in caring for stroke patients, their activities that constituted to the rehabilitation may be unclear. The nurses may not be aware about skills or have understanding regarding stroke rehabilitation. Arguably, the response of these nurses to the questions may depend on the new knowledge developed from reading the questionnaire or recalled bias from their past experience. Therefore, the questionnaire findings are results of the nurse participants’ views rather than self-assessment to judge their capability and confidence to provide rehabilitation support care. Moreover, the nurse participants in this study were recruited from the health clinics, rather then the home-based nurses. Their demographic information (see Section 6.4) showed over 50% of the nurses only had experience care for stroke patients for less than a year. Thue, their interpretation of the questionnaire and understanding about stroke care may limited. Considering these limitations, the questionnaire findings may not illustrate true reflection of the nurses’ willingness to involve in stroke care, thus, interpreted with caution.

The advancement of stroke management and the constant changing in today’s care delivery for stroke require healthcare professionals, such as nurses, to keep abreast with this practice development. In Brunei, the establishment of the first Stroke Centre has improved the stroke patients’ survival rate and expedited hospital discharge. Many survivors tend to return home early, but, often with some residual impairment due to the stroke. With the current emphasis of care shifting largely within the community, preparing the support workforce appears imperative to ensure optimum recovery. However, the stroke education for community nurses in our study and their explicit role in rehabilitation are unknown. One of the initiatives of the UK government, “together we can conquer stroke” recommends that every stroke survivor should receive high quality evidence-based care from well skilled health and social care workforce across the stroke pathways (Stroke Association, 2015). Moreover, it was stipulated in the Standard of Practice for Registered Nurses and Midwives Brunei that required all registered nurses to enhance their competence and knowledge in order to remain updated with current practices’ needs (Nursing Board for Brunei, 2010). Therefore, our study explored the educational needs and potential role of nurses in stroke. No study, to date, has examined these aspects, thus the finding will provide novel information pertaining to the issues investigated.

New published studies that investigated the educational needs of community nurses and their potential roles in stroke rehabilitation appeared scarce. Perhaps, internationally, such as in the UK, the roles of nurses in stroke have been recognized by the allied health professionals. For example, this complementary role was outlined in the *Code for*

Nurses and Midwifery that requires registered nurses and midwives to practice effectively through giving help which includes providing preventative or rehabilitative care, on the basis of the best available evidence (Nursing and Midwifery Council, 2015). This suggests that the UK nurses are expected to assume rehabilitative roles in their daily practices. Moreover, specialist training in stroke was made freely accessible to any healthcare professional who directly works in the area of stroke care delivery, through the establishment of the online Stroke Specific Education Framework (Department of Health, 2009). Thus, these healthcare professionals may access the training resources and match the knowledge and skills required to fulfil their educational needs. This may imply that a study to investigate the need for stroke education for nurses is no longer seen as a priority area of research. Previous related studies, such as by Smith et al. (2008a) who surveyed care-home nurses' evidence-based stroke education requirement, and Burton (2000) who explored roles of nurses in stroke rehabilitation, provided valuable insight regarding issues surrounding nurses' knowledge and skills in stroke and their clarity of role to complement the stroke rehabilitation therapists. These studies informed the direction of our current research.

The existing stroke education in Brunei provided by the higher education institution appeared fragmented. Moreover, the clarity of roles of nurses in rehabilitation interventions were not explicitly defined in the Brunei's Standard of Practice for Registered Nurses and Midwives (Nursing Board for Brunei, 2010). On the other hand, our findings showed that the nurse participants in this study indicated their desire for formal and structured stroke training, and felt that their roles, complementing the allied health professionals' rehabilitation services, were integral in supporting patients with stroke within the community setting. Thus, our findings can be useful in assisting policy makers and the education organization to plan and structure nurses' training in stroke. The debate from the expert healthcare professionals regarding the need for nurses in stroke will be discussed as follows:

Training nurses for continued stroke care

Findings from the expert healthcare professionals indicated that providing training for the nurses would expand the support services for stroke within the community. The findings showed that the majority of the nurses were clear that stroke education is presently needed. The desire for the training was significantly higher for nurses who had more experience in caring for stroke patients, compared to nurses who had less experience. The higher preference on the training needs among the nurses in our study, perhaps, can be explained by their concern and awareness pertaining to the increasing prevalence of stroke in Brunei. Evidently, explanations given by the nurses for their views about the need for stroke training were related to the increasing prevalence of stroke mortality in Brunei. Many participants identified the common risk factors for stroke affecting the population was concerned with uncontrolled hypertension. Lupat et al., (2016) in their population-based survey that investigated the stroke risk factors in Brunei found nearly half of 5063 of the respondents were categorized as hypertensive (systolic pressure is 140mmHg, diastolic pressure is 90mmHg). Thus, it was likely the nurse participants in our study received a considerable number of out-patient visits due to various non-communicable diseases, such as hypertension, which might have formed their views regarding the requirement for stroke training. Moreover, the reason for the need for stroke training was related to care of the patients with stroke outside the hospital setting. The nurses seemed to recognize the current service restriction for supporting patients with stroke and their carer following discharge from hospital. A recurring issue was similarly reported previously in an international study (Hickey et al., 2012). The nurses acknowledged that community support for this patient was currently absent and they felt that stroke education would help them prepare to offer this service. Our study revealed substantial gap of stroke knowledge among the nurse participants. There was a strong indication that the nurses required formal training in stroke to enable them to function and provide evidence-based stroke care, a finding that concurred with Smith et al. (2008).

In contrast, our study showed that more than half of the nurses disagreed to undertake the proposed stroke training. These nurses attributed their decision not to pursue with the training to the conflict with their existing workload or the stroke rehabilitation nursing was not their field of interest. This finding was different from a previous study which identified the lack of time as the main barrier to attend training (Melissa, 2018). Findings from our study also highlighted the shortage of staff which hindered the nurses from attending the training. The issue of substitute staff replacing outgoing staff for training seemed unavoidable. However, the expert healthcare professionals affirmed that every nurse was given equal opportunity to apply and attend educational training without worrying about the issue of staff shortage. This finding suggests a communication barrier between the senior nurses and nurses who worked at operational level. One of the explanations for this communication breakdown is perhaps due to the lack of transparency regarding details of nurses who would be eligible to attend training. In Brunei, it is widely perceived that priority would be given to staff who have more seniority or have had many experiences in the particular setting. Thus, an open dialogue between senior nursing officers and all level of nurses to discuss the requirements for professional education development is necessary.

Clarity of roles and functions of stroke rehabilitation nurse

The expert healthcare professionals were sceptical regarding the explicit roles of nurses in stroke rehabilitation. The findings suggested concern about possible role duplication between the proposed stroke nurses and the existing allied health professional stroke team. Perhaps, this can be explained by the underappreciated role of nurses in rehabilitation (Burke & Doody, 2012) or rehabilitation is often considered as the role of the therapist. Our study has explored this aspect and how the nurses would function within the multidisciplinary healthcare team. The roles of nurses in stroke rehabilitation, in particular outside the hospital setting, appear scarce. Although, previous published studies (Booth et al, 2005; Burton & Gibbon, 2005, Forster et al., 1999; Jones et al., 1998) had explored the rehabilitative roles of nurses in inpatient settings, the definition to describe explicit roles of nurses in rehabilitation remains unclear. Findings from our study revealed that the perceived roles of the rehabilitation nurses encompass several key aspects, including knowledge and skill competencies as rehabilitation, long-term education support provider, care coordinator and portraying Bruneian Malay attributes. Of all, embracing the Malay attributes as part of stroke rehabilitation roles is an aspect not previously identified in other studies. One of the plausible explanations is perhaps due to different cultural context, study setting or socio-demographic of the participants which influences how these nurses conceptualised their roles in stroke rehabilitation. Findings from our study identified that the roles of the community nurses in stroke rehabilitation encompass four main categories; rehabilitation nurse practitioner, long-term education provider, therapist advocates and rehabilitation *'Calak'* Brunei.

Rehabilitation nurse practitioners are described by the participants as individuals who possess advanced sets of skill and a wide range understanding about stroke rehabilitation. The participants projected that nurses should be skilful and knowledgeable in every aspect of rehabilitative care. The participants believed that rehabilitation nurses can make valuable contributions on intervention related to supporting and reinforcing the 'exercise homework' implemented by the therapist. This finding supports the study by Wang et al. (2013) who found better improvement of behaviours, knowledge and self-efficacy for the intervention group following 8-week activities consisting rehabilitation training and support sessions that were undertaken by the nurses. It appears that nurse participants in our study emphasised their role on supporting the patients' physical recovery. Likewise, the stroke patients and carer suggested that future nurses embrace the 'therapy carry-on' role. It is not clear if the stroke patients conceptualised the therapy exercise as rehabilitation intervention. But Loft et al., (2017) found that patients were often unclear on the role of nurses in rehabilitation and frequently viewed the contact support as physical training. However, the expert healthcare professionals argued that the role of nurses in rehabilitation would remain limited to the traditional nursing activities. Theofanidis and Gibbon (2016) suggested that advance nursing interventions, such as early mobilization or continence care, were still applicable to support the stroke patients’ recovery. The broader views with regards to rehabilitative nurses’ role found in this study indicated a lack of agreement about what rehabilitation nursing entailed. This finding, thus, indicates an ongoing debate with regards to what the defined role of nurses in stroke is.

The other role identified in our study is rehabilitation nurses as a long-term education provider. This role is concerned with providing maintenance and improvement of the patients and carers’ physical, social, emotional, psychological and social functions through nurse-patient or carer interactions. Within this role, the nurses emphasised on good communication skills in order to offer the stroke patients and their carer the relevant health teaching, emotional reassurance, motivation, counselling, problem solving and help to deal with grief or loss. This finding indicates that the nurses viewed the prospect of rehabilitation nurses as someone who has the ability to actively engage with patients or carers and provide continued presence throughout the recovery process. A study by Ch’Ng et al. (2008) reported that stroke patients value information exchange, problem-solving strategies and engagement activities which assist them in recovery. For stroke patients, their journey to recovery can be complex and they often feel emotionally vulnerable, whereas the carer often experience a feeling of distress due to their caregiving roles. The nurses, meanwhile, identified that providing advice and support, communication and discussing of events as skills and abilities required for stroke rehabilitation nurses. Thus, our finding suggests that the rehabilitation nurses hold a key role in providing educational intervention to sustain the patients and carers’ long-term wellbeing. Several published studies explored the support roles of nurses in educational interventions, whereby positive outcomes were reported (Aslani et al., 2016; Sit et al., 2007; Larson et al., 2005). However, Baker (2012) suggested that nurses may lack preparation in providing education for patients with complex neurological needs. This finding, thus, provides an implication regarding competencies of nurses in providing stroke education interventions.

Another role suggested by the participants is nurses as a rehabilitation advocate. This refers to nurses’ involvement in complementing the work of therapists and coordinating care with other multidisciplinary healthcare teams (MDT). This role consists of supplementing the therapist’s home visit, monitoring patient’s progress, making referral and organising patient’s care. A description of the role is comparable to the ‘coordinating and leading' function as proposed by Kirkevold (2010). Our nurse participants in this study indicated that rehabilitation nurses can be an integral part of the multidisciplinary stroke team who ensure patients receive continued care at home. This finding is consistent with numerous other studies which suggested nurses can form part of the multidisciplinary stroke team (Compagnat et al., 2018). Gibbon et al. (2012) outlined specific roles of nurses in MDT, where they highlighted that nurses are to take responsibility for care management role, promoting patient's recovery, preventing complications, promoting and managing continence. In contrast, there is a lack of agreement to support that nurses are able to carry out coordinate care and rehabilitation role independently (Clarke & Holt, 2014). This critic suggests that further consideration is required to examine the feasibility of our nurses working together within the multidisciplinary stroke rehabilitation team.

The other role proposed in this study is rehabilitation nurses as '*calak'* Brunei. This role refers to the specific cultural traits that the nurses shall portray as a rehabilitation nurse. The nurses have identified various features that reflect the Malay Islamic Monarchy (MIB) practice (see Section 1.8.4), including being patient, persevering, committed, concerned, attending, confident, kind, hardworking, flexible, courteous and adhere to Islamic teaching. Application of MIB as a way of living perhaps explains the reason why the nurses placed considerable importance on this attribute, indicating it is necessary in order to embrace the challenge in caring the stroke patients. The description of this role seems to support Madeleine Leininger's transcultural nursing theory which emphasises the need to take patient's culture, values, belief and faith into consideration when deciding how to care for the patient (Petiptin, 2016). Moreover, practising in accordance with the MIB is outlined in the code of conduct for registered nursing and midwives (Nursing Board for Brunei, 2010). It is not clear if our nurses refer to Leininger' theory or the professional conduct, however, their views suggest that the role of the rehabilitation nurse is bound to the professionals' values, attitudes and behaviours of nurses. Our finding with regards to this aspect is not found in other literature thus, extend knowledge in role of nurses in rehabilitation.

In summary, the expert healthcare professionals' comments regarding role clarity for stroke nurses seemed warranted. Arguably, the potential roles of nurses identified in this study could equally be assumed by the therapist. This finding indicates complexity of describing the explicit roles of nurses in stroke rehabilitation, therefore, provides an implication on future decisions regarding involvement of nurses in this area of care.

Barriers to attend the stroke training are multifaceted

The findings of this study revealed that shortage of staff was the main barrier for the nurses to attend the stroke training. The expert healthcare professionals anticipated the difficulty in finding replacement staff to take over the role of the nurses, who wish to go for training, as they may have to abandon their plans due to the staff constraint. The issue with staff shortage appears not to be an isolated problem worldwide. It was reported that staff shortage was also one of the barriers for nurses to continue educational and professional development (Melissa & Sandra, 2019). Moreover, the WHO estimated that there will be a shortage of 12.9 million healthcare workers by 2035, if the problem is left unaddressed (WHO, 2013). It is beyond the scope of our study to address the issue with staff shortage. However, this finding gives valuable input regarding future strategy for an increase in recruitment of nurses. It is important to note that total number of nurses throughout Brunei in 2017 is 2713, with ratio of 155 population per nurse (Ministry of Health, 2017), whereas the overall nurses who work at the community health centres is 118 (Community Nursing Service, 2012). From these figures, it can be assumed that the nurses will find it hard to leave their current role due to absence of relief staff, as reflected by the qualitative findings from the nurse questionnaire, "….at this moment, our staff is insufficient." (NP – 079). The constraint of staff resources is similarly echoed by the stroke carer and the expert healthcare professionals, who commented that the "lack of manpower and resources is the biggest disability in providing nurses' training" (EP – 03). This finding suggests complexity of nurses to attend training which was affected by organisational structure of the nursing service, similar to a finding previously reported (Coventry, Maslin-Prothero, Smith, 2015).

Another frequently identified barrier includes a lack of practice experience in stroke care, low salary increments after completed training, existing working workloads, training not accredited by the relevant institution, too much personal responsibility and lack of allocated time for study. These organisational and personal barriers are consistent with results from other published studies (Ebrahimi et al., 2012; Chong et al., 2011; Shahhosseni & Hamzehgardeshi, 2014). With regards to a lack of practice experience that was perceived as a barrier to attend training, this response appeared to contradict with the participants' socio-demographic background given, whereby it was found that over 90% of nurses have had experience in caring for stroke patients. One probable explanation for this conflicting information is perhaps due to the questionnaire being specifically targeted on rehabilitation skill sets, which the nurses may feel is not relevant to their previous experience. This finding indicates that the role of nurses in stroke rehabilitation, at least for our participants, remains inexplicit (Clare, 2018).

Moreover, over half of the nurses identified that lack of support from the workplace manager as a barrier to attend training. This finding is a considerable concern because the manager is regarded as a key person to provide continued educational programmes for all nurses who work under him/her (Pool, Poell & Cate, 2013). The role of the manager as a facilitator to encourage the nurses in continuing professional development was outlined in the Standard of Practice for Registered Nurses and Midwives (Nursing Board for Brunei, 2010). However, our finding suggested that the nurse manager did not fulfil this standard. One of the reasons for this discrepancy is perhaps due to the lack of clear communication between both parties. It is often that the manager works at the administrative office rather than at the clinical site setting. Hence, nurses may not see their manager that frequently. Our finding indicates an unfavourable implication on practice improvement, so this may likely affect the quality of patient care.

On the other hand, nearly half of the nurses disagreed that their current salary, job position and current education level can hinder them from undertaking the stroke training. Majority of the nurses in our study held a diploma as their highest academic attainment and were given a post as a staff nurse with a monthly income scale ranging from £655 - £1157 (BND1310 – BND$2315). With increasing cost of living and stretching the budget to cater one’s own expenses and family, arguably this financial stability is unsustainable. This finding suggests that nurses who wish to undertake the training seem driven by financial gain, as reflected by qualitative finding of the questionnaire which indicated that new expertise in the field of stroke nursing was required, however their “salary stayed the same.” (NP – 048). Although in other qualitative findings given by the nurses related to various improvement on professional development were consistent with other previous studies (Chong et al., 2011; Shahhosseini & Hamzehgardeshi, 2014), conversely, our finding with regards to financial motivation is not mentioned in previous studies. Perhaps, our nurses openly express their dissatisfaction with the current nursing scheme of services which has not been improved for many years, despite the increasing standard of living in Brunei; GDP BND4.5b in 2018 (Hayat, 2019).

To summarise, barriers to attend the training are evidently challenging and appear beyond the merit of our study. Addressing the issue for staff shortage requires involvement from the higher authority and decision maker. This finding proves that future attendees for the stroke training would be very limited, therefore, developing the course does not seem cost-effective.

Controversy surrounding the proposed community stroke nursing

The findings from our study suggest that the community stroke rehabilitation nursing would be a viable strategy to offer supportive care for the stroke and carer at home. A similar strategy was proposed in a health service research conducted in a neighbouring country, Malaysia (Mohd Nordin et al., 2014). Many of our participants in this study viewed favourably regarding the potential introduction of this community service. For the stroke and the carers, this centre may provide an avenue for continued presence of support which could promote community engagement or reducing carers' distress. The expert healthcare professionals, meanwhile, indicated that the centre may act as another alternative for rehabilitation support resources within the community setting. The findings from the nurses' data showed that the establishment of the centre would ensure the standard of stroke care in Brunei is comparable with other countries. The overall views of the participants in our study were consistent with the outcome from previous studies, (Hillier & Inglis-Jassiem, 2010; Gazipura, 2015; Lee et al., 2018) and were in favour of home-based service compared with centre-based rehabilitation. In contrast, Walker et al. (2014) who reviewed evidence in this aspect suggested that more study is required to ascertain its effectiveness and to justify the establishment. Correspondingly, our study revealed that the minority of the participants were sceptical regarding the proposal to introduce the community stroke rehabilitation nursing. There were concerns relating to the appropriateness of the service, cultural acceptance, staffing resources and if it tailored with the needs of the community. Most importantly, the finding revealed that the nursing home visit may be regarded as a 'stranger at home' (EP – 04). These differing views, perhaps, can be explained by lack of available support resources for stroke and the carer within the community setting. However, it was not clear whether those participants who viewed positively about the nursing services were desperate for support, neither did our data show that the participants whom disagreed have better support system. This finding, therefore, gives direct implication on future planning of community nursing services in stroke care.

In summary, findings from this study revealed various challenges with regards to establishing the future stroke nursing services in Brunei. The reservations shown by the participants suggested that more aspects surrounding the practical implementation of this nursing service need intense deliberations. This finding highlights the controversy surrounding nursing care for stroke, therefore, provides direct implication on service improvement.

Drawing from the discussion with regard to the needs of stroke rehabilitation nurses in Brunei, our findings revealed lacked of consensus with possible introduction to the community services. These divergent views contributes to the dilemma identified in our study. Thus, a different strategy is needed to reconcile the complexity of this issue. The overall indications emerged from our study is that cultural and religious beliefs are central to the people of Brunei. Perhaps, emphasising the nurses' understanding in the patients' cultural values is needed. The nursing education, therefore, would be more appropriate in promoting awareness in transcultural nursing. Brief discussion about the concept of transcultural nursing (Leininger, 1991), will follow.

Transcultural nursing

The theory of the transcultural nursing, also known as Culture Care theory, was introduced by Madeleine Leininger. She described her theory as "a practice that focused on comparative cultural care (caring) values, beliefs, and practices of individuals or groups of similar or different cultures with the goal of providing culture-specific and universal nursing care practices in promoting health or well-being or to help people to face unfavourable human conditions, illness, or death in culturally meaningful ways" (Leininger, 1995, p. 58).

Leininger beliefs believes that illness and wellness are influenced by cultural proposition of the individuals and how they defines health, illness and seeking medical treatments (Lineinger, 1991). This concept of health may result the use of traditional model of care are more prominent which may conflicting with the Western health practices. Therefore, nurses should possess cultural competence through intercultural communication and understanding about the socio-culture of the patients (Yakar & Alpar, 2018).

Culturally congruent care

The needs to consider the patients' cultural background is vital to promote culturally congruent care. This refers to applying evidence-based care that would be aligned with the patients' cultural values, beliefs, worldview and traditional health practices (Marion et al., 2016). The healthcare providers, such as the nurses, thus, must demonstrates competency in cultural practices in order to ensure the patients achieve positive care outcomes (Repo et al., 2017) and reduce service disparities (Butler et al., 2016). However, several published nursing studies relating to cultural competence found that the nurses were felt unprepared or their awareness on cultural congruent care were lacking (Lin et al., 2019; Farber, 2019; Byrne, 2020). Moreover, several review studies found that the impact of cultural-related interventions on the patients' health-related outcomes were inconclusive (Horvat et al., 2014; Alfred et al., 2016). Therefore, promoting awareness through training and educational development are necessary towards improving cultural competence in health and service delivery (Jongen et al., 2018).

Relevance of transcultural nursing in Brunei context

The Brunei population consists of a multicultural society and religion. Our study revealed that MIB was so integral in influencing views of the people about health and illnesses and in shaping their behaviours towards seeking healthcare service. The issues regarding concealing emotion, avoiding arguments, leaving to expert, keeping silence and health-seeking manners represents the cultural behaviours identified in this study. Available studies that explored culture-related issues in Brunei are lacking. However to illustrate, a study by Idris and Forrest (2019) found that being a Bruneian man could negatively influence their attitudes towards health and help-seeking. They concluded that being a healthy man was perceived as having the capacity to support parents, being a breadwinner, a good role model and leaders of family. Perhaps, this explain gender distribution of stroke cases identified in our study which showed that more men have had a stroke compared to women (see demographic details Section 4.2), implying delayed in health seeking. This assumption mirrored with the incidence of colorectal cancer in Brunei, whereby more men (57.6%) was were affected than women (Chong et al., 2015).

Another example relates to the influence of culture in decision making process, Ahmad (2014) found that the Muslim women decision-making towards childbearing was strongly attached to the traditional values (perception on ideal family size) and the concept of *rezeki* (divine provisions granted by Allah the Almighty). Thus, decision about not to have children was seen as a blasphemous act, or failure to conceive as a result of a sinful past (Ahmad, 2014). Whereas, Kamarudin and Kamarudin (2009) suggested that the Bruneian Malays are often incompetent in the handling of information, whereby giving them load of information will result in with confusion which will be affecting their decision making.

The preceding descriptions demonstrates that the Bruneian way of life, their behaviours and unique traditions immensely influence their approach to deal with illnesses, healing, disease, and deaths. For this reason, improving nurses' awareness on cultural congruent care is required, as outlined in the Codes of Ethics and Standard of Practice for Registered Nurses and Midwives in Brunei (Nursing Board Brunei, 2010). This finding, therefore, has direct implication on the initial direction of this research.

9.4.5 Aligning the cultural and religious understanding about stroke with modern context

Much of the international literature highlights the existing educational disparities concerning; the early prevention and identification of stroke symptoms among the general public (Alaqeel et al., 2014; Gomes et al., 2017); aspects of stroke-related topics and rehabilitation for stroke patients and their carers during hospitalisation (Faux et al., 2017; Luker et al., 2017); and the information support needs of home-based stroke survivors and their carers (Danzl et al., 2016; Luker et al., 2015). A lack of education appears to be an ongoing concern that affect the wider population globally, and thus evidently includes Brunei is no exception. The findings from the stroke patients and carers showed that the majority were uncertain about what a stroke was, and about two thirds of these participants failed to identify that high blood pressure or increased cholesterol levels were the most common risk factors of developing the disease. This finding is similar to that of a previously reported study in Malaysia, where the prevention and risks factors related to strokes were frequently identified as the main area where education is needed (Sowtali & Harith, 2014).

This study found that the participants' understanding about strokes was influenced by two major factors; socio-cultural background, and views of health and illness from the Islamic perspective. The term angin ahmar, a synonym universally used by Bruneians to refer to strokes, appeared more acceptable and culturally sensitive to the participants' level of understanding. A few of the participants linked their angin ahmar to exposure to an evil wind. This finding suggested that conflicting views exist between stroke patients and carers' belief in the existence of supernatural spirits and the scientifically proven risk factors for strokes, with the latter potentially being ignored. Evidently, the prevalence of hypertension was reported to be higher among Bruneians (Lupat et al., 2016), indicating that the public awareness regarding the risk factors related to strokes was poor. Furthermore, our study showed that the views of Muslims towards health and illness were religiously bound. Muslims believed that being ill, suffering from disease and dying were part of life and a test set by Allah, so embracing these hardships with patience, meditation and prayer was regarded as an act of faith. In the Quranic verses, Allah decrees "Be sure we shall test you with something of fear, hunger, some loss in wealth, lives or the produce (of your toil), but give glad tidings to those who patiently persevere" (Al-Baqarah 2:155), cited by (Rassool, 2000). The above findings suggested an important association between the participants' knowledge, cultural-religious beliefs and choice to access traditional or conventional treatments, as was also reported in a

Nigerian study (Gbiri et al., 2015b). Thus, it was likely that the participants' choice of treatments was informed by a strong engagement with their cultural-religious practices.

The findings of our study revealed considerable concerns with regard to delay health seeking following the stroke symptoms onset. About a third of the stroke patients sought a traditional practitioner as their first contact for managing their stroke. This finding concurred with recent Brunei study which explored initial stroke experience related to pre-hospital delay (Haji Md. Yamin et al., 2018). The expert healthcare professionals indicated that the strong cultural-religious influences might explain the late arrival at hospital for treatment. It was found that the delay may last for over three days after recognition of the stroke symptoms, whereas the recommended time window for initiating thrombolytic drug (IV ateplase) for an acute ischemic stroke was 3.5 – 4 hours from stroke onset, or up to 24 hours for intra-arterial thrombectomy for acute ischemic stroke with large vessel occlusion in order to achieve a better prognosis (Powers et al., 2019)

The finding of our study may explain a local news report that revealed half of the stroke patients failed to seek medical help (Tien, 2016). While many published studies (Ashraf et al., 2015; Barber et al., 2001; Mackintosh et al., 2012; Yu et al., 2002; Zhou et al., 2017), found similar patterns within the factors that lead to delayed presentation at hospital (i.e. a lack of knowledge about strokes, uncertainty about the time of stroke onset, unclear referral patterns, a lack of transportation to hospital, misperceptions of the seriousness of their stroke symptoms, waiting to see if symptoms disappeared, living far away from the hospital, delays in calling the emergency medical services, self-medication and a history of strokes), evidently, our study suggested that cultural and religious understanding about stroke could contribute to this delayed.

The issue between patients' level of education and their awareness about stroke was identified in our study. Previous published studies reported that stroke survivors aged below 65 years who had attained a higher level of education were independently correlated with a better knowledge of stroke and its related risk factors (Sundseth et al., 2014; Vincent-Onabajo & Moses, 2016; Zeng et al., 2012). In contrast, our study failed to support this association. It was revealed that, irrespective of the participants' educational levels and age groups (for the demographic details, see Section 4.2; 5.2), the data showed that a knowledge deficit regarding stroke and its risks factors was evident. Other plausible explanations for this outcome were due to existing medical conditions, a traditional lifestyle or dietary habits that could place these people at risk for stroke, regardless of their socio-demographic characteristics. Our study finding suggested that the current public awareness of strokes was poor and urgently required attention, and a similar gap was found in a reviewed study from a neighbouring country, Malaysia (Sowtali et al., 2017).

The narratives of the stroke patients and their carers indicated that the current provision of education throughout the stroke care continuum (i.e. pre-hospital, inpatient setting and post-hospital) seemed fragmented and inconsistent, thus, education intervention is urgently needed. However, the expert healthcare professionals suggested that aligning the patients understanding about stroke can be complex and challenging. They indicated that a different strategy is needed to penetrate the cultural/religious superstitions about stroke. Findings from our study revealed the needs to involve non-healthcare individuals in promoting stroke awareness. The expert healthcare professionals indicated that a spokesperson from various influential individuals, such as former stroke survivors, an Ustaz (religious person) or the head of the village, could increase the impact of stroke education and encourage knowledge retention. This finding was also proposed by attendees who took part in community-partnered participatory research (Bharmal et al., 2016), where individuals who were affiliated with a specific community through their faith, race/ethnicity, language or culture, were recommended to lead stroke awareness workshops in community settings, including churches, schools or senior centres. The views of the expert healthcare professionals in our study may reflect the socio-cultural context and small population of Brunei, so forming close partnerships with renowned members of the general public could add more effective advocates for stroke awareness campaigns. However, Rasura et al. (2014), who reviewed published literature on 21 stroke education interventions and five web-based campaigns found that a single approach to stroke intervention was insufficient.

Another recommendation proposed by the expert healthcare professionals is by targeting school-age children as a medium for improving families and communities' stroke literacy. Several control trial studies that evaluated a child-mediated stroke education strategy at three months follow-up demonstrated encouraging outcomes regarding the stroke-related knowledge of the children and parents in the intervention groups, who received specific stroke learning aids, compared with those in the control groups (Ishigami et al., 2017; João Pedro et al., 2017; Williams et al., 2015). An important observation that could be deduced from these findings in relation to stroke information provision was that integrating a multifaceted stroke awareness strategies in order to reach the wider community and address sensitive issues, such as prayer, was warranted. This proposal was illustrated in the Collaborative Rehabilitation Stroke Support System (CORES) (see Section 8.4) of the expert healthcare professionals, whereby involvement of various individuals and sectors are essential in order to provide sustainable and all-encompassing support system for the patients and the carers.

In summary, the stroke patients and carers' understanding about stroke were influenced by their cultural and religious context, which deviated from the scientific causation of the disease. The different interpretation of stroke and belief about what caused stroke contributes to patient delay to hospital seeking. The needs to penetrate towards the patients' cultural and religious understanding about stroke necessitate different innovative stroke education strategy. Therefore, multicomponent educational interventions from various agencies and disciplines seemed mandatory in order to adapt to the diverse needs of the population and the unique socio-cultural context of Brunei. This finding extends the knowledge base regarding the cultural-religious impact on stroke information interventions, and thus contributes to the emerging stroke research in this aspect, locally and internationally.

9.4.6 Recognition of *urut* and prayer as part of rehabilitation interventions

The findings of this study revealed that the influence of culture and religion were significant factors in the stroke patients' recovery. This was conceptualized by the Feel Able Model for stroke (see Section 4.5), which illustrates cultural and religious practices as a 'mover' that offer support to the patients in meeting their needs. One plausible explanation for this strong cultural influence is the impact of the national ideology; *Melayu Islam Beraja* (Malay Islamic Monarchy), which has been inculcated in the Bruneian way of life (Taib, 2002). Although the practice of MIB is advocated, other religious beliefs and cultural practices from different ethnic groups are freely allowed. Given the multicultural nature of society, Bruneians have their own unique traditional beliefs in preserving health or managing disease that are often defined by culture and religious values. The majority of the stroke patients and carers in this study were Malay Muslim, thus their traditional practices generally stemmed from Malay culture and the Islamic faith.

One of the common cultural practices that was observed in this study was the application of traditional Malay massage (*urut*). This practice is described as the manipulation of the soft-body tissue using the hands and fingers, frequently combined with both deep muscular tissue massage and spiritual rituals (Sejari et al. 2016). Findings from the study revealed that the application of *urut,* typically by a traditional practitioner who was well versed with religious knowledge (known as an *Ustaz* or religious person), was regarded as an important component of recovery following a stroke. The stroke patients and carers indicated that these traditional practitioners represented part of their external rehabilitation support structure that was deemed necessary. The application of *urut* service was often sought extensively during the early stages of a stroke and continued throughout the recovery trajectory. In this study, however, it was not clear whether the stroke patients applied *urut* predominantly due to a deficiency in the current conventional therapy. However, for the majority of the patients, *urut* was believed to have beneficial effects on their physical, emotional and psychological functioning (Mohd Anuar et al., 2012), and enhanced their spiritual engagement (Ahmad et al., 2014).

The findings of the study showed that the expert healthcare professionals were aware of the extensive practice of *urut* among the stroke patients. They acknowledged the difficulties in controlling the practice of *urut* due to its culturally-bound traditions. There seemed to exist a general acceptance among the health experts that the involvement of cultural practices in stroke care was unavoidable. The expert healthcare professionals' stance in this regard is perhaps justified. Existing studies have shown that cultural beliefs can directly influence how the patients seek healthcare and utilize the services (Sarfo, 2015; Ejike, 2017; Eley et al., 2019). Study findings from the stroke patients suggested that they sought *urut* in order to expedite their recovery. This reaffirmed earlier findings by Norris (2009) who found that stroke patients sought traditional healers due to the belief that the treatment could instigate functional change. On the contrary, the expert healthcare professionals indicated that the stroke patients' approach to *urut* for accelerating recovery was not effective. Instead, they suggested that the use of *urut* was regarded as an "easy fix" (EP – 02) which would not work. This observation echoed the principle of brain plasticity in stroke, whereby motor recovery could only be enhanced by optimising the neuron reengagement in the central nervous system through active and continuous application of physical rehabilitation (Hara, 2015; Maier et al., 2019). Furthermore, neuro recovery often occurs within 1 – 3 months after the onset of stroke, whereas 4 – 6 months may be required to observe functional gain (Schaetcher, 2004). This suggests that the link between *urut* and functional recovery is inconclusive. Perhaps, the desire for the stroke patients to seek traditional practitioners was driven by the cultural context. This was evident in the stroke patients and carers' narratives where information was exchanged about reliable practitioners, searching for the best *urut* provider or inviting the practitioner to the home; all were common practice among the stroke patients.

Generally, the expert healthcare professionals were supportive with regard to the application of *urut.* However, it is was not clear whether these participants recognised the clinical benefits of *urut*. Several studies have investigated the benefits of this intervention from the perspective of stroke patients, where it was found that *urut* improved physical functioning, reduced pain and improved quality of life (Ali et al., 2015; Kamaria et al., 2015; Sejari et al., 2014). Findings from the stroke patients, meanwhile, indicated that receiving *urut* improved their psychosocial and emotional health. Although the association between psychological outcome and massage therapy has been established (Ghesuiere et al., 2019), positive emotional outcomes for the stroke patients in this study could be due to their engagement with the *urut* practitioner, rather than a direct outcome of the *urut* intervention. While the impact of *urut* was clearly described by the participants, the study was unable to provide clinical justification for this impact. Nevertheless, this favourable outcome of *urut* suggested the possibility of blending complementary therapies with modern rehabilitation approaches so that the support structure for the stroke patients and their carers at home could be expanded and diversified. This finding, therefore, provides positive implications for improving stroke rehabilitation service provision in the future.

On the other hand, the expert healthcare professionals indicated that the practice of *urut* should be regulated and strictly controlled. In Brunei, most of the part-time traditional practitioners were not legally registered or certified with appropriate training. Hence, the quality and safe delivery of *urut* provided was questionable. It was found that the expert healthcare professionals were concerned that the drawbacks of *urut* may outweigh the benefits, such as bruising, swelling, increased pain and being allergic to the massage oil (Zaki & Hussin, 2019). Arguably, these concerns were warranted because scientific evidence that support the complementary benefits or adverse effects of *urut* on stroke patients have yet to be proven in the Cochrane review (Abdul Rani et al., 2015). In 2017, the Ministry of Health set-up a Traditional and Complementary Medicine Unit for the regulation of standard practices in this area. However, it was observed that registration for practitioners was not mandatory and seemed to encourage those who wished to run *urut* service as a business model, such as private clinics. This finding suggested that providing education for stroke patients, carers and traditional practitioners concerning the effectiveness or possible negative effects of *urut* was needed.

From the aspect of religious practices, meanwhile, our study found that the stroke patients’ abilities to perform religious duties, particularly in maintaining the five times daily Islamic prayer had changed remarkably. This study revealed that the challenges and burden associated with strokes had fundamentally promoted their spiritual growth and devotion to Allah, which had also been identified in previous studies (Norris et al., 2012; Omu & Reynolds, 2014). The stroke patients indicated that enhancing their faith provided them with inner peace and the physical perseverance to withstand the negative consequences of a stroke. These intrinsic benefits of ritual prayer yielded comparable results with other recently published studies (Ghous et al., 2017; Ilali et al., 2016; Munsoor & Munsoor, 2017), which described how individual or group worshippers tend to achieve positive physical, psychological, emotional and psycho-social benefits. Moreover, the findings revealed that the majority of the stroke patients applied faith and a connection to Allah as strategies for coping with the impact of the stroke. This was borne out by other research (Alqahtani, 2015), where praying and reciting the Quran were frequently reported. This finding suggested that, at least for the stroke participants in this study, Islamic contemplative practices demonstrated considerable benefits. Thus, promoting participants' spiritual and religious obligations is likely to complement their therapy interventions and health care support (Ali et al., 2015).

Performing the five times daily ritual prayers is obligatory in Islam to fulfil one of the requirements of the five Pillars of Islam. Individuals must maintain their prayers regardless of their altered health status, with the exception of conditions adversely affecting their cognitive functions. As such, Islam gives flexibility and allows adjustments to be made to the usual movements of prayer for physically impaired persons according to their capability, such as praying while seated rather than standing. Thus, it was apparent that most of the participants maintained their prayers, irrespective of their physical restrictions, although a few omitted these religious duties because of the perceived challenges and difficulties, as reported by a previous study (Mohammed et al., 2015).

The findings of the study revealed that addressing issues of spiritual practice, particularly prayer, can be complex. The stroke patients may have to abandon their prayers due to the difficulty to adopt normal prayer postures; standing, bowing, prostrating and sitting. The expert healthcare professionals indicated that asking about patients' prayer practices could be perceived as being judgemental and offensive. Generally, most adults regard prayers and religion as a personal matter which others should not question. One plausible explanation for this is the belief that any matters relating to *pahala* (reward from Allah for pious deeds) and *dosa* (punishment for impious actions) rests with Allah as the only authority. Zainan Nazri et al. (2011, p110) elucidate, "Only Allah has the power and right to set what kind of reward and punishment that will be received by His slaves of each single deed that they performed. Therefore, there is no one who can simply promise reward or punishment towards certain acts or deeds without His permission". Allah says "Hold not yourself purified. He knows best who has taqwa (piety)" [Al-Najm, 53:32] (Hameed, 2019). These findings indicated challenges in assessing the patients' prayer needs, thus, including religious personnel (*Ustaz*) in the rehabilitation support team was warranted.

Evidently, our 'Feel Able Model' for stroke illustrated that needs relating to spiritual practices were partially met. The narrative from the stroke patient showed issues with achieving the goal of *sujud* (flexion with the hands and forehead flat on the floor) during prayers. These issues, perhaps, could be due to the sensitive nature of the topic, the therapy prescribed was not targeted at accomplishing the participant's desired functional outcome, or the decision-making about goal-setting between the patient and therapist was not shared. Kristensen et al. (2016) emphasised that patients' involvement in decision making about their recovery was crucial for empowering self-care and meeting their functional needs. However, Rosewilliam et al. (2016) illustrated that cultural factors, individuals' behavioural and organisational strategies could influence how patient-centred goal-setting was met. As previously discussed, the behaviour of the participants that was ascribed to the Malay culture, such as being silent, might hamper communication and the prioritising of goals. Consequently, the participants' functional priority was not being assessed by the therapist, and hence not emphasised as part of achieving the rehabilitation outcome (Lynch et al., 2015).

In summary, culture and religion appear to be powerful factors which favourably influence the stroke patients and their carers' wellbeing. However, these participants might struggle to sustain their cultural and religious commitments due to the prolonged distress that results from coping with the unpredictability of stroke outcomes. Therefore, there is a need to integrate cultural and religious practices as part of the rehabilitation interventions. By recognizing and appreciating the local people's beliefs and practices, the healthcare professionals are better positioned to provide culturally competent care. Inclusion of the traditional practitioner and *Ustaz* (religious person) as a recognised part of the rehabilitation team seemed essential. The views of the expert healthcare professionals further validated the potential added value of an *Ustaz* as a spiritual support dimension of care regarding stroke recovery. While spiritual needs are often associated with end of life research (Churchill, 2015), the study findings pertaining to the inclusion of an *Ustaz* in the rehabilitation team extends the knowledge base in the area of stroke research, particularly in the context of Brunei.

9.5 Do findings address the research question?

The overall findings of this research have portrayed a fair and reliable accounts of the differing views generated from the data sets and analysis. Based on our findings, therefore, how and ways to improve the rehabilitation support needs of the stroke patients and their carer are through incorporating the religious-Malay and social cultural practices of Brunei into the existing contemporary rehabilitation support interventions. The involvement from various key stakeholders and policy makers from different organisations were imperative. This finding represents unique feature of this research and offer novel knowledge and understanding in order to plan future rehabilitation supportive care in Brunei.

9.6 Chapter Summary

This chapter discusses the six key findings related to improving the provision of home-based stroke rehabilitation and support in Brunei, aimed to explore areas needed for improvement. The six key findings were identified through integration of multiple data from the stroke patients, carers and the community nurse participants, and comments from panel of expert were sought to identify priority areas and strategies to address issues relating to rehabilitation provision. All of the six key findings were discussed and their unique contribution to the existing knowledge was justified. The complexity and dissonance raised by the data sets and analysis were considered, and practical recommendations on how to reconcile these divergent perspectives into an action plan were provided. The overall findings of this study have addressed the overarching research question and goal of the study. Next, subsequent section present conclusion and recommendation drawn from this study.

Chapter 10: Conclusion and Recommendation

10.1 Introduction

This chapter presents the overall conclusion of the thesis. The following section on the reflection of conducting this research will be described at section 10.2. Next, section 10.3 will describe the implications of the study findings and outline some of the recommendations. The limitations of the study will be discussed in section 10.4. Finally, section 10.5 offers a conclusion to the thesis.

10.2 Reflection and challenges related to conducting the study

In this section, I will provide a reflection on conducting this research and discuss particular key challenges that I encountered when completing this research journey. Some of these challenges have been briefly mentioned within the chapters of this thesis regarding the research design. The process of implementing the research design of this study took nearly four years to accomplish. There were a number of unforeseen challenges and hurdles that were inevitable. These difficulties necessitated me being more flexible in my research approach and developing innovative strategies to find solutions to the problems. The challenges identified will be discussed as follows:

Challenges related to being reflexive

Being a novice researcher and having a background in health, addressing issue with personal bias during data collection and analysis was very challenging. Several measures have been undertaken and discussed earlier (see Chapter, 3 section 3.4).

Accessing sample participants across different data collection settings

Recruiting the sample population across five different settings was not a straightforward process. Different written approval from each director or head of department was required before permission to conduct the study was granted. This was followed by arranging various meetings with the person in-charge of the study settings to explain about the study and seek their agreement to act as an intermediary in recruiting the targeted sample population. These procedures required plenty of paper work and were time-consuming.

The design of my research required the process of the data collection to be undertaken simultaneously. With the interviews and distribution of the questionnaire conducted at almost the same period, accessing different participants in different settings, (either in health centres, the participants’ home or the rehabilitation centre) involved a lot of travelling. Given this, the challenges related to ensuring my safety needed to be considered. Moreover, I had to return to Brunei over ten occasions throughout the process of my study. These self-funded trips were not only costly, but also physically tiring.

Obtaining ethical approval to conduct this study was a challenging process. Approval was first needed from the ERGO University of Southampton. Then, two separate study presentations were undertaken for two different ethic committees in Brunei. One committee was responsible for reviewing potential ethical issues related to accessing the nurses and expert healthcare professionals' sample, whilst the other controlled recruitment for the stroke patients and carers' sample. Before ethical approval was granted, the feedback from these committees was addressed and my initial proposal was amended, as required. This process was not only lengthy, but disrupted my initial plan to begin the data collection procedures as scheduled.

Challenges concerning the data collection instrument and approach

The difficulty for majority of my study participants to converse or comprehend English was noted. In order to encourage a large number of respondents to complete the nurse questionnaire and explore the experiences of the stroke patient and carers' participants in more detail, I deliberately avoided imposing any restrictions on these participants by asking them to impart their views solely in English, nor did I insist that the nurse participants should answer the questions in this language. I allowed all of the participants to respond both in English and Malay, whichever they felt more comfortable with, to ensure flexibility and linguistic comfort. This approach necessitated the nurse questionnaire being prepared in both languages and the interview was conducted primarily in Malay. The challenges related to translating the raw data into English during the analysis process can be immense and laborious, which requires consideration.

Another challenge was related to the quality of the interview data gathered from the stroke patients and their carers. For most of them, these interviews were their first experience of participating in a research study. Some of the participants appeared worried about providing the correct answers to the interview questions, despite having been told that there were no right or wrong answers. Thus, it was difficult to understand the participants' brief answers to some questions, and further probing or prompts to explore these did not necessarily prove successful. This challenge reflected my inexperience and limited interview skills in conducting qualitative research. Interviewing the expert healthcare professionals, meanwhile, raised a different challenge. While interviewing this group, at times, I received answers that seemed to devalue my professional background as a nurse. Although this particular participant may not have intended to criticise me directly, but the way in which nursing was seen as a peripheral role in stroke care made me feel underappreciated. This challenge requires patience and active reflection of myself as a researcher rather than a nurse during this study.

Challenges related to maintaining confidentiality and anonymity

This challenge was related to maintaining the confidentiality and anonymity of the expert healthcare professional participants' interview data. There is only one local neuro-rehabilitation specialist physician in Brunei and very few local consultant neurologists who work at the stroke centre. Furthermore, there is only one nursing and midwifery course leader at the higher institution education, and two senior nursing officers from the Department of Community Nursing. Thus, it was difficult to ensure the complete anonymity of these participants, particularly where the interview data were clearly indicative of their professional speciality. Therefore, I had to explain this to each participant and make them aware about this unavoidable circumstance. In reporting the data from these participants, I purposely omitted interview extracts that illustrated their background. However, in specific data, I felt that it was important to highlight these participants' professional roles in order to strengthen and further validate the credibility of the interview quotes.

Challenges related to the design of the research

Other challenges related to using a mixed method research design are described in the study's limitations section (Section 10.4).

Emotional challenges due to family bereavement

Throughout my journey in completing this study, we lost several immediate family members, but the most significant to me and my family was the unexpected death of my younger brother and the demise of my father in-law due to acute renal failure. These incidents, which happened barely six months apart, were emotionally challenging. We missed both of their funerals due to being in the UK. Although we returned the following day, the feeling of loss was indescribable. These challenges required myself, my wife and our four children to cope with bereavement that lasted for several months affecting the momentum of my study.

Summary on reflection

In reflecting on the process of conducting this research, several challenges arose that were inevitably beyond my control. Finding solutions to these hurdles required flexibility, reflexivity and patience. The support from the supervisory team throughout the study and open dialogue with the research participants were crucial in helping me to navigate these challenges effectively.

10.3 Implications of the study findings and recommendations

This section presents the implications of the study findings with regard to the current practice of home-based stroke rehabilitation service provision in Brunei. This study has offered valuable insights regarding the issues under study and provides avenue for further discussion among health and education service providers. Two key recommendations which merit consideration by relevant stake holders were identified, and described as follows:

10.3.1 Implications and recommendation for practice and education

This study demonstrates the current status of stroke rehabilitation service delivery outside the hospital setting. The establishment of the first Brunei stroke centre (BNSRC) indicates that the findings of our study are relevant and timely. Interviews with the stroke patient and carer participants in this study illustrate the complexity of their support needs following discharge from hospital, which are largely influenced by cultural and religious practices. There was reasonable evidence to suggest that a willingness existed among the nurse participants in this study regarding improving the provision of home-based stroke rehabilitation support care. Although, the evident is weak to justify how the stroke care can be improved. Thus, implication on nurse education in stroke rehabilitation was not considered as priority needs. Our study showed that involvement by non-government organisations to assist survivors to manage their life after stroke was needed. These findings highlighted the considerable implications for policy changes at the practice and service levels surrounding rehabilitative care post-stroke. Some of the implications and recommendations from this research have been described in Chapter 9. This section describes other key implications of the study and present as follow:

Integration of cultural and religious practice in stroke rehabilitation

The findings showed that the culture and religious beliefs of the stroke patients and carers were central in influencing their experiences on rehabilitation support at home. Thus, there is a need to consider these aspects with regard to delivering continuing care. It is recommended that the traditional *urut* practitioners for stroke should be registered legally under one regulatory body. This ensures that the practice of *urut* is safe, and its potential benefits can be utilised fully. Integrating this cultural practice as part of stroke recovery will complement modern rehabilitation therapy. It may reduce the public reliance on hospital therapists, where staff constraints remain an ongoing issue, and supplement the inadequate therapy time. Recognising patients' cultural practice, hence, can be adapted by other countries outside Brunei, specifically where service is limited due to limited staff resources. This measure underlined the importance of valuing, selecting and integrating cultural practice in a way that is sensitive to the needs of the local context.

The important of maintaining religious practice, particularly performing the five times daily ritual prayer, as a form of coping strategy was found in this study. Thus, it is recommended that therapists should integrate the cognitive and physical interventions to increase the stroke patients' ability to pray. The current guidelines used by the therapist in assessing stroke patients are based primarily on the western context. This required a modification to include an assessment that focuses on patients' physical functions in performing prayer. As the position for prayer in Islam is similar across the world, this approach is relevant to the majority of Bruneians and all Muslims. This recommendation, therefore, can be applicable applied to the general Muslim population globally.

The findings with regard to the cultural and religious approach can be shared and disseminated to relevant head therapists and teams through workshops, meetings or local conferences. In addition, this finding can be presented at international conferences or published in scholarly journals that aim to reach international audiences.

Multiple approaches on stroke educational activities

The findings suggested that the educational needs of stroke patients and the carers in this study related to their differing views on stroke from the perspective of culture and religious beliefs, the importance of continuing to exercise at home and the existing out-patient therapy services. Many strategies were mentioned by the healthcare professionals for promoting public awareness about strokes, such as initiating stroke education with school-age pupils, utilising religious personnel (*Ustaz*) or heads of villages (*Ketua Kampung*) and identifying previous stroke survivors as a focal person to share his/her experience of recovering from an acute stroke. In order to accomplish these educational approaches, it is recommended that a multi-sector stroke force team should be established and an appropriate leader appointed. This collaborative and team working strategy will provides a platform for accessing the wider population of Brunei and identifying individuals who are at risk of suffering a stroke. This recommendation can be shared with relevant organisations, including health, education, religious and internal affairs groups, through open dialogue or inter-department presentations. These different strategies of educational intervention are worth sharing through local or international conferences and journals.

Cultural awareness for the healthcare providers

This study showed that therapists need to be aware of the cultural behaviour that is likely to prevent stroke patients from voicing their emotional problems. These healthcare professionals require specific communication and assessment skills, as well as a broader understanding regarding the socio-cultural background of the Bruneian population. Therefore, it is recommended that the staff should undergo training on the Malay Islamic Monarchy concept. This internal educational programme can be expanded to include other healthcare professionals, such as ward or community-based nurses. The inclusion of transcultural nursing education as part of continuous professional development should be considered. To achieve this recommendation, discussions with the head of rehabilitation therapists or the director of nursing services can be arranged. Presentations to the participants in this study through seminars or local conferences can provide another avenue to share the study’s findings.

Establishing home care support services

This study revealed a growing issue with regard to the absence of a willing carer within the family or difficulties related to employing a carer due to financial limitations. The findings of our study suggested that the effect of the declining family structure can mean that patients or carers have to cope and live with their stroke independently. Although the self-management model was considered to address this issue, alternative support strategy within the community can be valuable. Thus, a policy change is recommended that would allow centralised home care services for stroke to be established. This setting, run either by government or non-government organisations, can be used for a short-term stay by stroke patients until an appropriate carer can be identified. The implementation of the new policy will include designing an in-patient discharge planning checklist. This can be used to evaluate eligible stroke patients who do not have a carer and signpost them towards home care services. It is important to share this recommendation with the relevant departments, including the Department of Community Nursing Services, Department of Community Development and the Rehabilitation Department through inter-departmental meetings, open-dialogue, seminars or local conferences.

Improving the social welfare of individuals with disabilities

This study found that the stroke patient participants reported financial constraints and problems related to maintaining their social functioning due to the fact that public facilities for disabled people are lacking. It is vital for this group of individuals to reintegrate into the community to avoid social isolation and to have sustainable funds to cover their basic daily necessities. Therefore, it is recommended that the government should improve its current policy regarding the provision of adequate facilities for disabled people in public buildings, recreational parks and shopping centres. The public and families of stroke patients similarly need to be educated regarding the importance of these individuals being part of the community. This recommendation can be shared with the public work service for consideration, or through media channels to improve public awareness on the rights of people with disabilities.

The present policy with regard to work status and monthly salary during sick leave varies between public and private employees. Although employment status is unaffected for those who work for the government, only two weeks' full pay is given to private employees. Our study showed that financial difficulties are more evident among stroke patients who have retired, are unemployed, work in the private sector, rely on the old age pension and/or lack family support. This requires national policy change, particularly the revision of the current financial aid for disabled people to include stroke survivors and increasing the allowance to keep abreast of the rising economic demands. The challenge to achieving this goal is anticipated and beyond the capacity of this research. Thus, it is recommended that Brunei should form its own stroke organisation, similar to Stroke Association UK, which would be responsible for planning and implementing the national strategy. This includes promoting public awareness about the prevention on stroke, as well as providing evidence-based treatment, and long-term care support and management. This recommendation needs to be discussed with the BNSRC and the Ministry of Health for their consideration delete so that they can assist with the decision-making.

Developing Stroke Policy and Guidelines

The existing policy on providing comprehensive services on rehabilitative care required clarity and detailed outline on what they entail. The need to publish recommended practice and standard for stroke care and management that cover throughout the stroke continuum is warranted. This need to be freely accessible to whole healthcare professionals, in particular to those involved in managing stroke patients. Developing this policy and guideline is timely. This proposal needs to be presented to the BNSRC and the Ministry of Health for their planning in introducing new policy.

Summary

To summarise, the integration of cultural and religious beliefs in stroke patients' rehabilitation interventions appears necessary. The need for therapists to acknowledge and value this practice is vital to maximise recovery. Providing effective stroke education for the public, promoting awareness through various channels is necessary. This requires collaboration and active involvement by various agencies. Careful planning concerning funding and the socio-cultural context of Brunei requires consideration by the relevant authorities. The need to develop the Brunei Stroke Association and stroke policy, meanwhile, is timely. This organisation may prove vital for regulation of policy related to supportive care for stroke patients and carers. Importantly, the findings of this study can be used as a point of reference by policymakers, administrators and therapists, in planning future stroke education and services.

10.3.2 Implications and recommendations for future research

This research is the first of its kind in Brunei and the findings offer a snapshot of the current status regarding stroke rehabilitation service provision. This study, thus, may inspire other local or international researchers to expand further the scope of this research and draw comparisons with other existing data. Two key areas of recommendation for future research are identified: the inclusion of other research participants and the utilisation of a single research design related to the findings of this study.

Recruitment of other research participants

A sample population of stroke patients and carers who live outside the Brunei Muara district or presently live in the water village areas was not included as participants in this research. Future study that includes this group of population could be valuable for understanding their rehabilitation support experience and establishing whether it is similar to or different from the findings identified from the interview data in this study. It could also prove useful to recruit non-Malay stroke individuals in order to determine whether their views about stroke, and cultural or religious influences are comparable to, or vary from, those of the Malay stroke participants. Furthermore, it would be interesting to compare the existing data with those related to stroke patients who have been discharged home over the period of a year to see whether their support needs change or remain comparable with the needs of the current participants in this study.

Moreover, the nurse population who lives outside the present study site or currently works within a hospital-based setting did not form part of the nurse participants in this study. A further study that recruits these nurses is necessary to investigate their views about educational recruitment and the potential roles of nurses in stroke rehabilitation, to identify whether their views about this aspect are similar to, or different from, those of the nurses in this study.

The recruitment of the expert healthcare professionals was deliberate and based on their professional credentials. The findings from our research showed that future research should include other expert individuals from non-health professional backgrounds. This would offer insights from different perspectives, in order to provide comparisons with, or corroborate, the existing data, and thus enhance the richness of the findings of this research.

Future research utilising a single research design

The value of mixed methods research in providing a complete understanding of the aspects of rehabilitation support needs in Brunei is indispensable. Numerous key issues or areas for improvement were identified. However, the extent of these issues and the reliability of the findings were opened to debate. Thus, future research should extract one element or issue from our findings and investigate it further by means of a single research design. Using an established standard measurement tool to quantify, for example the rehabilitation needs of stroke survivors, would lead to a stronger inference and generalisability of those study findings to the wider population. Similarly employing qualitative methods, such as ethnography, would provide a detailed explanation regarding the cultural practices of Malay society and their behaviour towards rehabilitation. Importantly, the findings from our research provide a basis for other researchers to focus on a specific area of interest. This would help to expand the stroke research in Brunei and create more evidence-based approaches to improve the delivery of stroke care services.

The use of a questionnaire for the nurse participants in this study is useful for exploring their general perspectives concerning the topic under study. Although the findings obtained from the questionnaire data were favourable, it is difficult to understand in detail the reasons for their answers. It is recommended that an appropriate number of these nurses is purposely sampled for one-to-one interviews. This method would add value to the present research, in which both findings can be compared and contrasted in order to provide an overview of the nurses’ roles and educational needs with regard to strokes.

Section Summary

Our study have laid the foundation for future study in this field that expands the sample population that was not included in this study. The potential to explore diverse areas of stroke in Brunei is apparent. However, the issues with funding, availability of researchers and time needed to conduct the study require consideration. Involvement by both private and public organisations to ensure continuity of stroke research is, thus, vital.

10.4 Limitations of the research

The following aspects are major limitations of the study and need to be considered in interpreting the study findings. Most importantly, this study was descriptive in nature and largely focused on exploring the experiences of rehabilitation support needs through the perspectives of patients and carers at home. It was outside the scope of this study to test the needs of these participants following a statistical analysis which could provide more significant inferences and generalisability of the findings. Thus, such study, using established standard measurement tools to examine the participants' rehabilitation needs and how these are associated with quality of life or other outcomes of interest, is urgently required. Other methodological limitations of this study will be described as follows:

Study sample and sampling procedure

The sampling strategy employed was primarily non-probability sampling. This suggested that all of the participants who took part in this study might have had a strong personal or professional interest in the studied topic, and thus they voluntarily contributed to this research. While measures were taken to avoid sampling bias in recruiting the sample, the limits of this sample need to be acknowledged.

All of the stroke patients and the carer participants in this study were recruited from Brunei District, hence the potential sample population from the other three districts of Brunei was not part of this research. Moreover, no stroke patients from the water village (*Kampung Ayer)* were eligible to participate in this study due to long-term chronic stroke condition and cognitive impairment. It is unknown if the needs of the stroke patients and carers from the other districts or who are living in the water village are similar or different from this study. Therefore, findings of our study were limited to the context of sample recruited.

Although a high response rate was generated by the nurse questionnaire, this sample was relatively small (*n*=101), as previous related study, (Baker, 2012) recruited a sample in excess of 300 to generate meaningful data. The nurses in this study were recruited from specific health centres/clinics in a district of Brunei and some nurses were on leave during the data collection. Thus, the findings generated from nurse sample would not generalizable to the whole nurse population in Brunei, but were specific to the views of the nurse participants in this study. Moreover, many nurses were known to the researcher due to being former nurse training colleagues, social friends and previous students from the local nursing college. Hence, the possibility of these nurses answering the study questionnaire in a socially desirable way needs to be considered. In order to minimise the response bias, all of the nurse participants were recruited through their respective nurse managers, who acted as the researcher’s intermediary in distributing the questionnaire and collecting the data.

Another limitation with regard to nurse sample is the omission of the home-based nurses from this study. Arguably, these nurses had vast experience in caring stroke patients and would give valuable input in questionnaire findings. However, they were deliberately not recruited because one of the focus of this study was to explore roles of nurses in supporting stroke patients who likely have potential to recover through rehabilitation therapy. Whereas, the care interventions of the home-based nurses are largely providing long-term care for stroke who have various complications and poor prognosis. Thus, findings from the nurse questionnaire may be limited to the interpretation of the questions by the nurse participants, rather than a reflection of experiences. This, represents another limitation of the questionnaire findings.

Only a few expert healthcare professional participants, meanwhile, agreed to take part in this study. Thus, the interpretations of the key findings from the first phase of the study might be limited to, or influenced by, personal bias or own professional experiences of these expert healthcare participants. For the stroke patient and carer participants, although data saturation was achieved through the interviews, it was important to note that the views of other stroke survivors and carers who live in the water village area or had been discharged home over one year were not obtained. Therefore, the themes identified during the interviews would have disregarded the experience of this group of the community, which might offer different insights about their rehabilitation needs and priorities.

Research instrument and analysis

The interview guide, the Brunei Home-Based Interview for Stroke (Bru-HIS), used for the stroke patients, carers and expert healthcare professional participants, was specifically designed for the purpose of this research. This guide consisted of a series of semi-structured interview questions that aimed to explore the views of the participants with regard to their rehabilitation support needs and identify aspects of the home-based stroke service delivery which required improvement. The BruHIS, therefore, has never been used outside the present study setting. As such, limitations in relation to the transferability and dependability (section 3.10.12) of the interview findings to the population outside Brunei need to be considered. Moreover, most of the interviews were held in Malay language and translated into English when reporting the findings. Given this, there was a risk of losing the original context of the interviews during the translation process. Hence, a limitation with regard to the credibility and confirmability of the findings derived from the interview guide needs to be acknowledged. Nonetheless, several strategies have been undertaken to minimise the limitations of Bru-HIS, including the pilot study, feedbacks from the Brunei ethics committee, undertaking translation at the final stage of the interview data analysis, discussion with the supervisory team and reviewing the raw data, reading the transcripts and revisiting the themes throughout the data analysis process.

The nurse questionnaire, the Brunei Nurse Education Inquiry for Stroke (Bru-NEIS), was used to describe the views of the nurse participants concerning their educational needs and potential role in community stroke rehabilitation nursing services. This instrument was adapted from one element of the Stroke Specific Education Framework (SSEF): high quality specialist rehabilitation (Department of Health, 2009), and other related literature. To the researcher’s knowledge, Bru-NEIS was the only research instrument that has been used to explore the knowledge and skill competencies’ standards of nurses, as advocated by the SSEF. Therefore, a limitation associated with the questionnaire’s internal validity and reliability (Section 3.11.4) should be taken into consideration. Nonetheless, several measures have been undertaken, such as formulating questions based on constructs that were developed by the UK Stroke Forum for Stroke Training task groups, piloting the questionnaire, performing relevant statistical tests, providing Malay translations for each question and holding discussions with the supervisory team in order to ensure the validity of the Bru-NEIS. A further limitation of the study was associated with the analysis of the data gathered from the questionnaire. The data analysis predominantly employed the descriptive statistical model. This statistical analysis, thus, could not provide statistically significant correlations or causations between the participants’ independent variables, such as gender, and responses to the questionnaire.

Research design and expertise

An explanation to why a mixed method design, the Convergent Extended Mixed Methods, was employed in the present study has been presented (Chapter 3). This design involves the simultaneous collection of qualitative and quantitative data, followed by discussing this set of data through separate interviews. Although this design accomplished the aim of the study, the resulting data collected were vast and required an excessive amount of time to analyse. Being a novice researcher, the analysis and interpretation of the data gathered for this research was influenced by knowledge constraints in both the qualitative and quantitative research process. As such, this might have limited the quality of the findings described, and thus needs to be recognised and taken into consideration. Moreover, having to think, analyse, evaluate, write and prepare a report on this study in second language proved a major limitation in producing a sound academic thesis.

Section Summary

Further improvements are still required in order to offset the limitations of this study. Employing a probability sampling strategy or expanding the sample recruitment may be necessary to capture the views of various participants from the general population of Brunei. The findings from this study suggested that the data collection instruments have the potential to explore the existing scope of rehabilitation services, which contributed to knowledge regarding how the provision of services can be improved. Next, the final chapter offers the conclusion to the thesis.

10.5 Conclusion

There is an extensive body of research examining the rehabilitation support needs of stroke patients and experience of caregiver in looking after these communities. The current body of knowledge, however, does not explicitly explore the influence of cultural to the rehabilitation trajectory of the stroke patients, the support environment of the carer at home and the use of specific constructs that investigate the training and educational needs of nurses in stroke rehabilitation. Moreover, existing research that recruited various demographic backgrounds of the participants that explore single phenomena in a study: rehabilitation support needs following discharged, was limited. Therefore, this study has attempted to fill the gaps.

The challenges and the impact of stroke to both the stroke patients were highlighted in this study. The residual impacts of this disease to these individuals’ daily activity of living and quality of life were apparent. This study has illustrated convincing evidence that the stroke patient participants in this study experience a long-standing difficulties to manage themselves and cope with the devastating consequences of the stroke. The extent to which the stroke patient participants in this study sought additional support on their rehabilitation, in particular with the practices associated with the Malay-Cultural tradition (*urut*), was an area that may be considered. The wide acceptance of by these communities on the application of *urut* in complementing the rehabilitation phase of the stroke recovery may have potential to integrate with the modern therapy. However, this study also highlighted that many stroke patient participants endured emotional disturbances that was not detected by the healthcare professionals. The concealing behaviours of the stroke patient participants in this study with regard to their emotional problems suggested that the involvement of psychologist, which is currently absent, within the Multidisciplinary stroke Team warrants consideration.

The impact of stroke to the carers were explored in this study. The importance of the carers for the stroke was well documented. In Brunei, the role of caregiving for stroke was largely assumed by family members, such as spouse or children. Evidence in this study showed that carer participants experience physical burden and considerable amount of emotional stress. The manner for these carers to manage with their difficulties and challenges in providing daily care activities for stroke, in particular those related to the Islamic faith, could be vital strategies to cope with the aftermath of stroke. However, it was not clear if this strategy can be sustained for a long period of time. The lack of support network for carers in this study was identified. This suggested that external support, as in the form of community services, is likely to benefit the carers and promoting their quality of life.

The educational needs and potential roles of nurses in stroke rehabilitation were identified in this study. Although majority of nurses viewed the needs of stroke training in Brunei, the data failed to convince that community nurses could offer immediate impact on improving the stroke rehabilitation provision in Brunei. However, findings from the study suggested that educational awareness in transcultural nursing would be more appropriate in nurses’ training.

The views of the expert healthcare professionals with regard to the integrated findings from the stroke patients, carers and nurses, illustrates conflicting opinions. The evidence of this study that showed mixed views in relation to the stroke patients and carers’ emotional problems after the stroke and the existing provision of rehabilitation out-patient therapy session seemed pointed to communication gaps between the healthcare professionals and the stroke communities. The growing emphasis of the application of traditional practices in rehabilitation and Islamic faith by the stroke patients and the carers in this study may suggest complementary approaches to the recovery of stroke and facilitate carers’ transition to home.

This research brought to light that the experiences of the stroke patients and caregivers of stroke was culturally influenced that embraces the national philosophy (the Melayu Islamic Beraja). The implication on planning future stroke service as identified in this research should be considered by the healthcare professionals. Further research involving diverse stroke population, in particular those who are aphasic and living in the water village area, would help to illustrate whether the experiences of were similar, or different from, those of the participants in this study.

Appendices

Appendix 1: Study Package for Participants with stroke and Carer Participants

This appendix consist:

1. Invitation Letter
2. Participants Information Sheet
3. Reply Slip
4. Consent Form
5. Bru-HIS Interview Guide
6. The Scoring Card

1. INVITATION LETTER

From;
Mursidi Haji Ali
Assistant Lecturer
Institute of Health Sciences PAPRSB
Universiti Brunei Darussalam

Dear ………………………………………..

I am one of the Assistant Lecturers (Nursing) from the Institute of Health Sciences, Universiti Brunei Darussalam. Currently, I am undertaking MPhil/PhD in Health Sciences at the Faculty of Health Sciences, University of Southampton, United Kingdom. The topic of my study is ***improving the provision of home-based stroke rehabilitation and support in Brunei Darussalam: the potential roles and educational needs of nurses in the community.*** This study is supervised by academic staff from the Faculty of Health Sciences, University of Southampton.

I am planning to study the experiences of 20 stroke patients and their care givers at home. The study will help to identify how to improve stroke care services in the community through providing education and identifying any nurses' roles in supporting people who have had a stroke. Information will be collected from people who had a stroke and their care givers, nurses and other healthcare professionals. From participants with stroke and their carers' views, the study will focus on understanding your experiences in how you manage daily activities, identify your needs in rehabilitation and your views about community stroke rehabilitation nursing services. Your experiences will be important to help inform nurses' training in stroke that can be relevant to patients with stroke and their care giver at home.

If you decide to take part in the study, we will agree a specific date and time for scheduled interview at your preferred place. I have provided the information sheet that will tell you more about the research and what is involved. If you or your family members would like to find out more about the study, I can be contacted through details provided below.

If you are happy to participate, please complete the reply slip attached with the information sheet and return to your rehabilitation therapists within a week. Or, you may contact me to let your decision known or to leave a text message and I will call you in return. However, this still does not commit you to taking part. You are free to decline and no impact will arise as result of your refusal. Where you decided to participate, you can withdraw from the study at any point of the research and your treatments will not be affected.

Thank you for taking time to read this letter.

Yours sincerely

Mursidi Haji Ali

Assistant Lecturer
PAPRSB Institute of Health Sciences
Universiti Brunei Darussalam.

MPhil/PhD student
Building 45
Room 001
Faculty of Health Sciences
Highfield Campus
University of Southampton

Hp: +673 8758027 (Brunei)
+44 (0) 7543375474 (UK)
Email: mursidi.ali@ubd.edu.bn
mha1g12@soton.ac.uk

2. PARTICIPANT INFORMATION SHEET

Study Title: **Improving the provision of home-based stroke rehabilitation and support in Brunei Darussalam: the potential roles and educational needs of nurses in the community**

Researcher: Mursidi Haji Ali **Ethics number**: University of Southampton 9791

: MHREC 2014/19(5)

Please read this information carefully before deciding to take part in this research. Before you decide, you need to understand why the research is being done and what it would involve for you.

Please take time to read the following information carefully. Talk to others about the research if you wish. Take time to decide whether or not you want to take part. If you are happy to participate you will be asked to sign a consent form.

Please contact me if there is anything that is not clear or if you would like more information (Contact number +673 8758027 or email mha1g12@soton.ac.uk)

What is the purpose of the study?
In 2010, the government has set up the first National Stroke Centre in order to provide better treatment and care for stroke patients. International studies in stroke found that improvement of stroke treatment has resulted in more people with stroke being likely to survive. But this individual may live with some disabilities and relied heavily on carers to continue their day activities. Researchers outside Brunei have showed that caring a stroke patient at home can be challenging. For this reason, the World Health Organization has suggested community-based rehabilitation to provide support for stroke survivors and their caregivers. Therefore, this study aims to identify ways to improve community home-based stroke services through providing education and identifying the potential roles of nurses in stroke rehabilitation.

Why have I been invited?
You have been invited to take part in this study because it is important to understand about your living experiences. This will help to inform nurses' training that is relevant to the needs of person with stroke and their carers at home. About 20 people who have had a stroke and 20 stroke carers will be studied in this research. The rehabilitative therapist has helped me to identify you as a possible participant for this study.

Do I have to take part?
No, it is up to you to decide. Participation in this study is fully voluntary and you are free to change your mind at any point without giving a reason.

What will happen to me if I take part?
After reading this Information Sheet and if you agree to take part, please complete and return the study reply slip to your rehabilitation therapist. Or, you may contact the researcher to inform about your decision through contact details provided. I will contact you to schedule an interview at your preferred place at time we both agreed. You will be required to sign a consent form before the interview to show your agreement to participate. I will ask questions regarding your understanding about stroke, activity limitations, your needs in rehabilitation and your thoughts on aspects of nurses' training in community stroke rehabilitation. There are no right or wrong answers and you are not required to answer any questions you may feel uncomfortable with. All of our conversations will be audio-recorded for documentation purposes.

For stroke participants, a member of your family or your personal carer may present but he/she will have no active role during the interview. Interview with informal carer will be undertaken at one-to-one basis. The interview may last approximately an hour and a break will be offered. If during the interview you begin to show feeling of distress or uneasy, I will stop the interview and allow you to rest before continue. You may end the interview completely and have it rescheduled if you are happy to continue to participate. Or, you may withdraw from the study at no cost to your treatment.

The date and time of the interview will be planned as your wish. A day before the interview, I will give you a phone call to reconfirm the interview scheduled. The interview session is expected to be conducted only once. However, follow-up visit may be necessary if you find the interview is too tiring to do at one session or if I need to clarify the interview transcripts. I will notify you through a phone call if this action is required.

Are there any benefits in my taking part?
There may be no direct benefit to you, but the information collected from the study will give understanding about stroke patients and their informal carers' experiences and may help to plan appropriates nursing education for their roles in supporting stroke survivors. Hence, it will be more relevant to the cultural needs in Brunei.

Are there any risks involved?
The interview may take time and focuses on recollecting of your memories and feelings. You may take a break during the interview or ask to stop completely and rescheduled for new session. Or, you may withdraw from the study at no cost.

Will my participation be confidential?
All information which is collected from you during the interview will be kept strictly confidential.

How would you protect information about me?
This study complies with the UK Data Protection Act 1998 and the University of Southampton Data Protection Policy 2008. Information will be kept strictly confidential and any information pertaining to your name and address will be kept in sealed envelopes and stored in a locked safe box of researcher's room.

All interview data will be written into words by the researcher. Any personal information that identified you in the interview will be omitted during reporting the data. Transcripts required expert translation will be made unidentified and will only use false name such as P1, P2 and so on, to ensure confidentiality. All transcripts and audio-recorded DVD will be stored in a locked safe box, within locked room, accessed only by researcher. Any electronic data will be stored on a password protected computer known only by researcher. Your data will only be shared with my supervisory team for academic purposes. Any interview quotes used in published materials will be made unspecified. It may be necessary your data will be used to inform future study related to stroke. Once the study has ended, records of all your personal details will be destroyed. As its usual practice, the University of Southampton will retain the data for 10 years and will dispose securely after this period.

What happens if I change my mind?
Your participation is completely voluntary. If you participate and change your mind, you have the right to withdraw at any time without giving explanation and nothing will happen to you. If you withdraw from the study, you may either allow the researcher to use recorded interview up to your withdrawal or to completely destroy all data and your name will be removed from the study.

Who organises this research?
This research form part of a PhD and is being organised through the University of Southampton. I am the principal researcher for this study. The study is funded and approved by the Government of His Majesty the Sultan of Brunei under sponsorship of the Ministry of Education via the Public Service Department through the Public Service Commission.

Who has reviewed the study?
The proposal for conducting this study has been reviewed by the following organisations:

1. The Government of His Majesty the Sultan of Brunei under sponsorship of the Ministry of Education via the Public Service Department through the Public Service Commission
2. University Senate, Universiti Brunei Darussalam
3. The Medical and Health Research Ethics Committee, Ministry of Health Brunei Darussalam
4. The Ethic Committees Brunei Neuroscience Stroke Rehabilitation Centre, JPMC
5. The Ethic Committees of the University of the Southampton
6. Peer reviewed by panel reviewers from the Faculty of Health Sciences, University of Southampton

What will happen to the results of the study?

The result of the study aim to be published in Brunei Darussalam Journal of Health, Brunei Medical International Journal (BIMJ) and other international journals in nursing and education. You may able to read the publication through respective journal website. If you wish to be informed about the result of the study, please state this in the consent form and I will send details of the study finding to you. The outcomes of the study may also be presented in local and international conferences. Your information will not be identifiable from the results unless you choose to do so.

What happens if something goes wrong?
If you having concern about any aspect of this study, you may speak to my supervisors at the University of Southampton, Dr Lesley Collier or co-supervisor in Brunei, Professor David Koh. Their contact details can be found the end of this information sheet. If you remain unhappy or if there is a problem and wish to complain formally, you can do this by writing a letter to the Chairperson, the Medical Health Research Ethic Committee, Executive Screening Suit, 1st Floor Car Park Level, RIPAS Hospital Brunei or the Chair of Ethic Committee, Faculty of Health Sciences, University of Southampton, Highfield Campus, Southampton SO17 1BJ. When contacting, please provide details of the name or description of the study (so that it can be identified), the researcher involved, and the details of the complaint you wish to make.

Where can I get more information?
After reading this information sheet and if you would like additional information, you may contact the following people who will be able to help.

1. Principal Investigator, Mursidi Haji Ali; +673 758027(Brunei) or +44(0) 75433 75474 (UK), email address mha1g12@soton.ac.uk or mursidi.ali@ubd.edu.bn
2. Primary supervisor (UK) Dr Lesley Collier at +44 (0) 23 80595284 or email lesley.collier@soton.ac.uk
3. Second Supervisor (UK) Professor Marry Gobbi at +44 (0) 02380598270 or email mog1@soton.ac.uk
4. Co-supervisor (Brunei) Professor David Koh at +673 2463001 Ext 2291 or email at david.koh@ubd.edu.bn.

If you happy to participate, please complete the reply slip attached with this information sheet and return to your rehabilitation therapist

Thank You

3. REPLY SLIP

REPLY SLIP FOR PARTICIPATION IN RESEARCH

Study title: Improving the provision of home-based stroke rehabilitation and support in Brunei Darussalam: the potential roles and educational needs of nurses in the community

Researcher name: Mursidi Haji Ali

Contact No: (Hp) +673 8758027 (e-mail) mha1g12@soton.ac.uk

Ethics reference: ______________________

*Please provide **initial** in the box if you agree with the statements:*

I am interested to take part in this research and agree for the researcher to contact me regarding the study. I understand that being contacted does not commit me to taking part. ☐

Name of participant: ___________________________________

Signature of participant: ________________________________

Date: ____

Email: ____

Telephone: ____

Preferred time for researcher to call me: ___________________

Please return this reply slip to your rehabilitation therapist within one week.
Thank you very much for your participation in this research

4. CONSENT FORM

Study title: Improving the provision of home-based stroke rehabilitation and support in Brunei Darussalam: the potential roles and educational needs of nurses in the community.

Researcher: Mursidi Haji Ali

Ethic No: University of Southampton 9791
: MHREC 2014/19(5)

Contact Details: +673 8758027 / e-mail: mha1g12@soton.ac.uk

Please ***initial*** *the box(s) if you agree with the statement(s):*

- I have read and understood the Participant Information Sheet and have had the opportunity to ask questions about the study and have these answered to my satisfaction. ☐
- I understand my participation is voluntary and I may withdraw at any time without my legal rights being affected. ☐
- I agree to take part in this research project and agree for the interview to be audio-recorded. ☐
- I agree to the confidentiality policy set out in the information sheet. ☐
- I agree for the data to be used for the purpose of this study and agree for the data to be used with other future study related to this area. ☐
- I give permission for the researcher to send my transcripts of my conversation (Malay only) with him for translation into English without quoting my name on the transcripts and using only pseudonym to appointed Translator. ☐
- I agree to the use of direct quotes in research reports and publications. ☐
- I consent to the University to retain my personal details on a database, kept separately from the research data detailed above. The 'validity' of my consent is conditional upon the University complying with the Data Protection Act and I understand that I can request my details to be removed from this database at any time. ☐

- ***I can confirmed that I have agreed to all the above.***

______________________	______________________	____________
Participant's name	Signature	Date
______________________	______________________	____________
Researcher name	Signature	Date
______________________	______________________	____________
Independent witness name	Signature	Date

❖ *I would like to have the summary of the study findings* (please TICK (/) where apply)

☐ Yes

Contact details	

☐ No

5. INTERVIEW GUIDE

Ethic No: University of Southampton 9791
MHREC 2014/19(5)

Interview Guide

BRUNEI HOME-BASED INTERVIEW OF STROKE
(Bru-HIS)

Research Title	**Improving the provision of home-based stroke rehabilitation and support in Brunei Darussalam: the potential roles and educational needs of nurses in the community**	
Researcher	Mursidi Haji Ali	
Position & contact details	Assistant Lecturer PAPRSB Institute of Health Sciences Universiti Brunei Darussalam. MPhil/PhD student Building 45 Room 001 Faculty of Health Sciences Highfield Campus University of Southampton	Hp: +673 8758027 (Brunei) +44 (0) 7543375474 (UK) Email: mursidi.ali@ubd.edu.bn mha1g12@soton.ac.uk
Supervisors & contact details	Prof David Koh (co-supervisor Brunei) Contact no: +673 2463001 Ext 2291 Email: david.koh@ubd.edu.bn	Dr Lesley Collier (Primary supervisor UK) Contact no: +44 (0) 2380595284 Email: Lesley.collier@soton.ac.uk Prof Mary Gobbi Contact no: +44 (0) 02380598270 Email: mog1@soton.a.cuk

Part 1: For participants with Stroke

Part 2: For Informal Carer of Stroke participants

Interview Date:	Time start:	
Interviewer:	Time completed:	

Section 1: DEMOGRAPHIC DETAILS

1. Gender.

   ○ Male ○ Female

2. When were you born? _________

3. Geographical area of residence.

   ○ Water-village
   ○ Land-living

4. Ethnicity.

   ○ Malay
   ○ Chinese
   ○ Others, please state ______________
   ○ I do not wish to say

5. Religion.

   ○ Islam
   ○ Christian
   ○ Others, please state ______________
   ○ I do not wish to say

6. Current marital status.

   ○ Single, never married
   ○ Married
   ○ Divorced
   ○ Widowed

7. Number of children living together: ________________

   ○ Not applicable

8. What is your **highest** education achieved?

   ○ Primary certificate
   ○ Diploma
   ○ Bachelor Degree
   ○ Master Degree
   ○ Others (Please specify): ___________________________________

9. Present employment

   ○ Government sector
   ○ Private sector
   ○ Self-employed
   ○ Retired
   ○ Other, specify: _____________________

10. Do you have informal carer to help you with daily activities?

    ○ Yes ○ No

    If yes, please specify (paid/unpaid): ________________________________

11. Previous significant injuries that had impact on physical functioning.

    ○ Yes ○ No

    If yes, please specify ____________________________

Section 2: Understanding about stroke and related functional problems

1. Can you tell me when you have had a stroke?
2. What can you understand about a stroke?
   (Prompt: Causes? Source of information?)
3. Can you explain how the stroke affect you in general?
   (Prompt: Physical, Psychological, Emotional, Spiritual)
4. What can you understand about stroke rehabilitation?

Section 3: ICF - Activity limitation and participation restriction

1. How do you spend your typical day at home?
2. Which daily activities do you feel you wanted to do, need to do or are expected to do but you can't do or aren't satisfied with how you do it?
3. Can you choose 3 of these activities you mentioned and tell me which do you feel are most important? Why? (Use scoring card to assist rating)

   i. Can you rate the importance of these activities using scale 1 – 10, (1 indicates not important at all and 10 indicate extremely importance).
   ii. Can you rate your ability to these activities using scale 1 – 10, (1 indicates not able to do it at all and 10 indicate able to do it extremely well).
   iii. Can you rate your satisfaction at being able to them using scale 1 – 10, (1 indicates not satisfied at all and 10 indicate extremely satisfied)

Section 4: ICF - Environmental and Personal Factors

The following questions will ask about the rehabilitation support you received following discharged and what you feel nurses should have to help you with.

1. Tell me about your follow-up arrangement with the rehabilitative therapist?
   (Prompt: Out-patient followup appointment, Home-based rehabilitation)
2. Who do you need most now to help with healthcare and rehabilitation? Why?
3. What is your view if there are community stroke rehabilitation nurses in supporting home-based stroke people like you?
4. What roles do you think these nurses should have to help you manage rehabilitation needs?
5. Is there any more about living with the effect of stroke that is important you need to talk about?

PART TWO: INTERVIEW GUIDE FOR INFORMAL CARER OF STROKE

Section 1: DEMOGRAPHIC DETAILS

1. Gender.

   ○ Male ○ Female

2. When were you born? _________
3. Nationality.
   - ○ Brunei
   - ○ Indonesia
   - ○ Philippines
   - ○ Other, specify _______________

4. What is your **highest** education attained?
   - ○ Primary certificate
   - ○ Diploma
   - ○ Bachelor Degree
   - ○ Master Degree
   - ○ Others (Please specify): ___________________________________

5. Present employment
   - ○ Government sector
   - ○ Private sector
   - ○ Self-employed
   - ○ Retired
   - ○ Other, specify: _____________________

6. Your relationship with stroke patient.
   - ○ Spouse
   - ○ Parent
   - ○ Relatives
   - ○ Employee
   - ○ Other, specify __________________

7. Working experience (months/years) as informal carer? _____________

Section 2: Understanding about stroke and related functional problems

1. Did you live with (name of stroke person) before he/she had a stroke?
2. Can you tell me what can you understand about stroke?
3. What do you think the cause of stroke for (name of person)?
4. How do you think the stroke has affected (name of stroke person)?
5. How is the stroke affect you as carer?
6. What can you understand about stroke rehabilitation?

Section 3: ICF - Activity limitation and participation restriction

1. In a typical day, how much time do you spend to provide care?
2. Can you describe what daily caregiving activities that you provide to (name of stroke person) at home?
3. Which are daily activities that (name of stroke person) needs help with, that you are not able to do, or are expected to do but you can't do, or aren't satisfied with how you do it?
4. Which of these 3 activities you mentioned are most important to (name of stroke person), that you need help most? And why? (Use scoring card to assist rating)

    i. Can you rate the importance of these activities using scale 1 – 10? (1 indicates not important at all and 10 indicate extremely importance).
    ii. Can you rate your ability to these activities using scale 1 – 10? (1 indicates not able to do it at all and 10 indicate able to do it extremely well).
    iii. Can you rate your satisfaction at being able to them using scale 1 – 10? (1 indicates not satisfied at all and 10 indicate extremely satisfied)

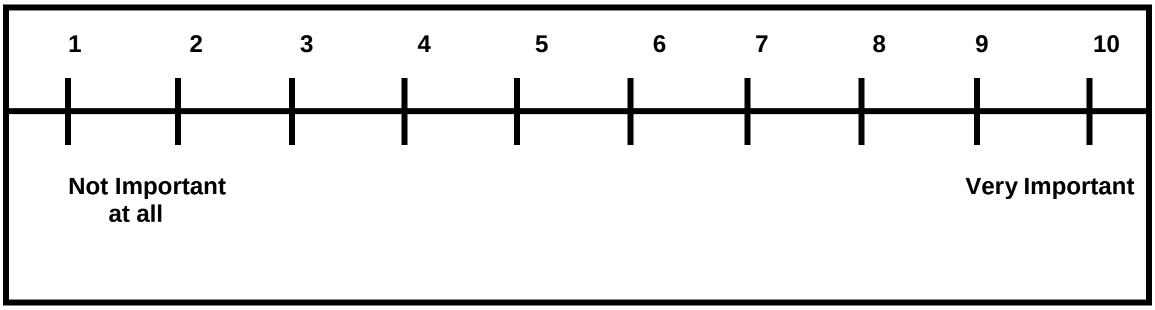
Section 4: ICF - Environmental and Personal Factors

The following questions will ask about the rehabilitation teaching that you may have learnt and what you feel nurses should have to help you with.

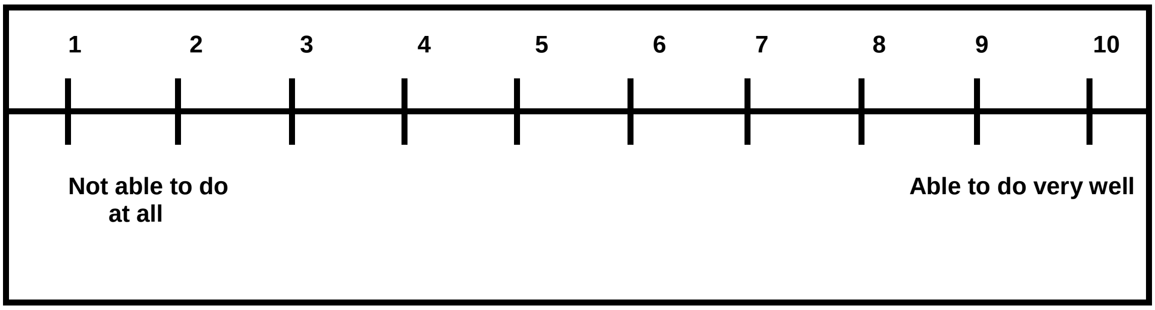
1. What information or education have health professionals provided about what you should do to help (name of stroke person) with his/her rehabilitation needs?
2. Who do you think you need most to help you with caring (name of stroke person)'s healthcare and rehabilitation? Why?
3. What is your view if there are community stroke rehabilitation nurses in supporting informal carer like you to help managing home-based stroke patients?
4. What roles do you think these nurses should have to help you manage rehabilitation needs of (name of stroke person)?
5. Is there any more about caring a stroke patient that is important you need to talk about?

6. SCORING CARD

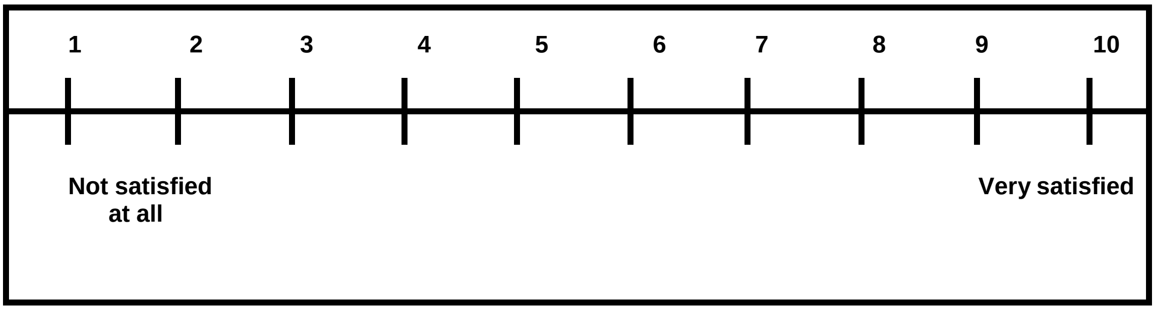
i. Level of Importance



ii. Level of Performance



iii. Level of Satisfaction



Appendix 2: Documentation of the Ethical Approval

This appendix presents three ethics documents:

1. Ethical Approval from the University of Southampton
2. Ethical Approval from the Medical Health Research Ethic Committees (MHREC), Brunei Darussalam

3. Ethical Approval from the Ethic Committees Jerudong Park Medical Centre (JPMC), Brunei Darussalam

Health
Sciences

UNIVERSITY OF
Southampton

Mursidi Haji Ali

PhD Student
Faculty of Health Sciences
University of Southampton

17th June 2014

Student ID: 22906231

Dear Mursidi Haji Ali,

Ethics Submission Number: 9791

Title: Home-Based Rehabilitation in Brunei: The Role and Educational Needs Of Nurses

I am pleased to confirm **full approval** for your study has now been given. The approval has been granted by the Faculty of Health Sciences Ethics Committee, via the Ethics and Research Governance Online (ERGO) system.

Yours sincerely

Alan Borthwick

Dr Alan Borthwick

Chair, FoHS Ethics Committee

t: +44 (0)23 80 95904
e: ab12@soton.ac.uk
Faculty of ealth Sciences,
University of
Southampton,

Tel: +673 2 242424 Ext 6205
Fax: +673 2 220293
E Mail medresearcch@moh.gov.bn
mhrecbrunei@gmail.com

MHREC
Executive Screening Suite
Basement Carpark Level 1
Raja Isteri Pengiran Anak Saleha Hospital
Bandar Seri Begawan BA1710
Negara Brunei Darussalam

Our Ref : MHREC/EDU/2014/19(5)

1st July 2014
3 Ramadhan 1435

To:
Mursidi Bin Hj Ali
Assistant Lecturer
Pengiran Anak Puteri Rashidah Saadatul Bolkiah
Institute of Health Sciences
Universiti Brunei Darussalam
Negara Brunei Darussalam

Dear Mursidi Hj Ali;

Re: : **Improving the provision of Home-based Rehabilitation and Support to stroke survivors in Brunei Darussalam: the potential roles and educational needs of nurses in the community.**

Thank you for applying for ethical review of your proposal entitled above. All documents that you have submitted on 28th June 2014 were reviewed.

The MHREC has approved your study from the ethical perspective. This approval is given for the proposed duration of your study or one calendar year from the date of this letter, whichever is shorter. If you are unable to complete your study within this period, please submit an application for extension at least 2 months before the expiry of the original MHREC approval. However, to facilitate extension of ethical approval after 1 year, you are required to submit an annual report. Please also notify the MHREC of any changes to the design of your study and inform us immediately of any adverse incidents.

I would like to wish you all the best with your study and would be grateful of if you could forward us a summary of your findings for our records.

Yours faithfully,

[redacted] Alice Yong
Chairperson of
al and Health
Research & Ethics Committee

Cc 1. Director General of Medical Services.
2. Director General of Health Services.
3 Timbalan Setiausaha Tetap (Professional & Technical).
4. Setiausaha Tetap.

TAT/AYML

ڤوست ڤراوبتن جرودوڠ ڤرك سنديرين برحد
Jerudong Park Medical Centre Sdn Bhd
Excellence in Healthcare ~ Serving You & Your Family's Health Needs

Our Ref: MD.055.2014rt

18th August 2014

Yang Mulia
Mursidi Bin Haji Ali
Assistant Lecturer
Pengiran Anak Puteri Rashidah Saadatul Bolkiah
Institute of Health Sciences
Universiti Brunei Darussalam

MPhil/PhD Student
Building 45
Faculty of Health Sciences
Highfield Campus
University of Southampton
Hampshire S017 1BJ
United Kingdom

Dear Awang,

Re: ETHICAL APPROVAL TO CONDUCT RESEARCH FOR PhD STUDY

This is to inform that the JPMC Ethics Committee has agreed to approve you to proceed with your study on the research of improving the provision of home-based rehabilitation and support to stroke survivors in Brunei Darussalam: the potential roles and educational needs of nurses in the community.

Thank you.

Yours sincerely,

Dato Dr. Isham [redacted]
Executive Direc
Chairman, JPM

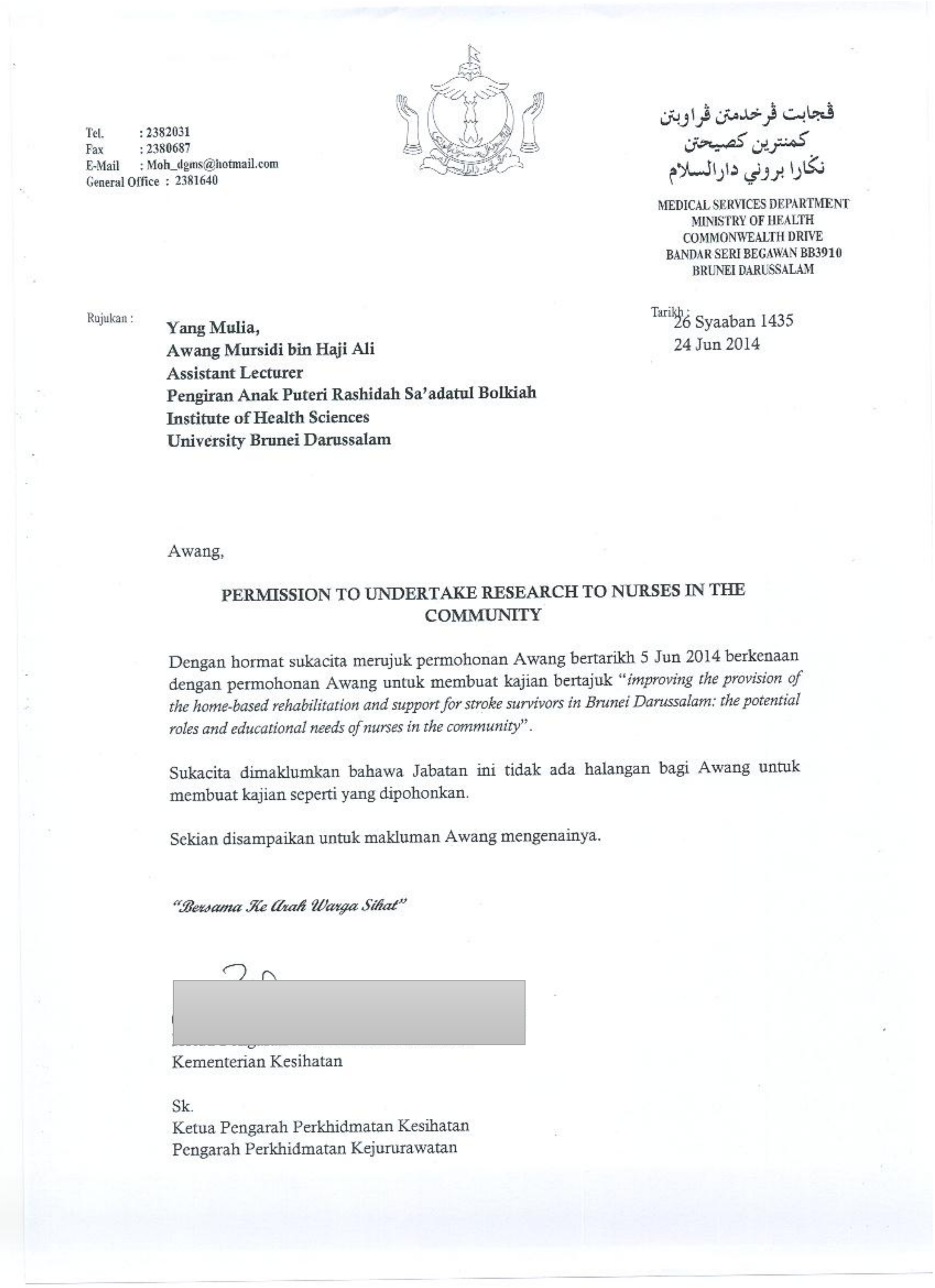
Jerudong Park BG 3122 Brunei Darussalam ☎ : (673) 261 1433 🖷 : (673) 261 2461 : www.jpmc.com.bn

Appendix 3: Approval from ‘Gate Keepers’

This appendix provides approval letter from two ‘Gate Keepers’:

1. Approval from the ‘gatekeeper’ Ministry of Health
2. Email corresponding from the ‘gatekeeper’ of the Stroke Centre
3. Approval from the ‘gatekeeper’ Department of Nursing Services
4. Permission from the Rehabilitation Centre Y
5. Permission from the Rehabilitation Centre X
6. Permission from the ‘gatekeeper’ neurology clinic

1. Approval letter from ‘gatekeeper’ Ministry of Health



Tel. : 2382031
Fax : 2380687
E-Mail : Moh_dgms@hotmail.com
General Office : 2381640

ڤجابت ڤرخدمتن ڤراوبتن
كمنترين كصيحتن
نڬارا بروني دارالسلام

MEDICAL SERVICES DEPARTMENT
MINISTRY OF HEALTH
COMMONWEALTH DRIVE
BANDAR SERI BEGAWAN BB3910
BRUNEI DARUSSALAM

Rujukan :

Tarikh : 26 Syaaban 1435
24 Jun 2014

Yang Mulia,
Awang Mursidi bin Haji Ali
Assistant Lecturer
Pengiran Anak Puteri Rashidah Sa’adatul Bolkiah
Institute of Health Sciences
University Brunei Darussalam

Awang,

PERMISSION TO UNDERTAKE RESEARCH TO NURSES IN THE COMMUNITY

Dengan hormat sukacita merujuk permohonan Awang bertarikh 5 Jun 2014 berkenaan dengan permohonan Awang untuk membuat kajian bertajuk “*improving the provision of the home-based rehabilitation and support for stroke survivors in Brunei Darussalam: the potential roles and educational needs of nurses in the community*”.

Sukacita dimaklumkan bahawa Jabatan ini tidak ada halangan bagi Awang untuk membuat kajian seperti yang dipohonkan.

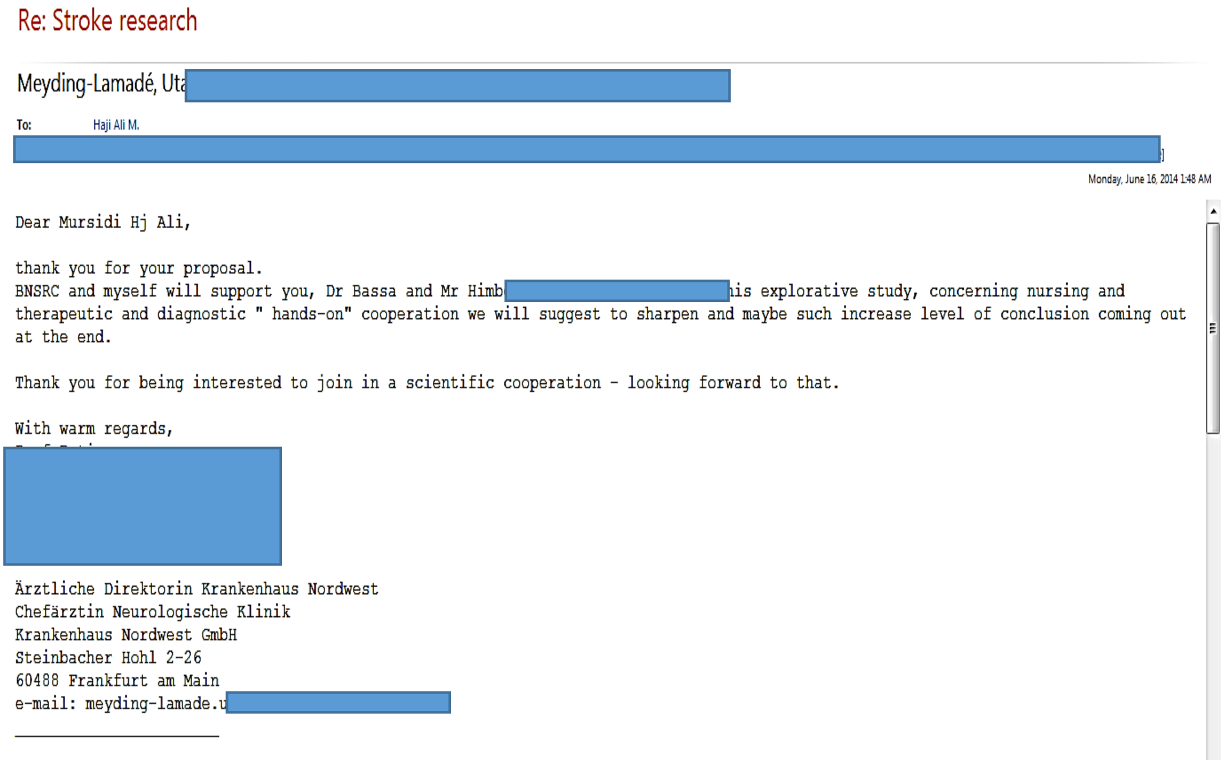
Sekian disampaikan untuk makluman Awang mengenainya.

“Bersama Ke Arah Warga Sihat”

[redacted]
Kementerian Kesihatan

Sk.
Ketua Pengarah Perkhidmatan Kesihatan
Pengarah Perkhidmatan Kejururawatan

2. Email Correspondence with ‘gatekeeper’ of the stroke centre



Re: Stroke research

Meyding-Lamadé, Uta[redacted]

To: Haji Ali M.

[redacted]]

Monday, June 16, 2014 1:48 AM

Dear Mursidi Hj Ali,

thank you for your proposal.
BNSRC and myself will support you, Dr Bassa and Mr Himb[redacted]his explorative study, concerning nursing and therapeutic and diagnostic " hands-on" cooperation we will suggest to sharpen and maybe such increase level of conclusion coming out at the end.

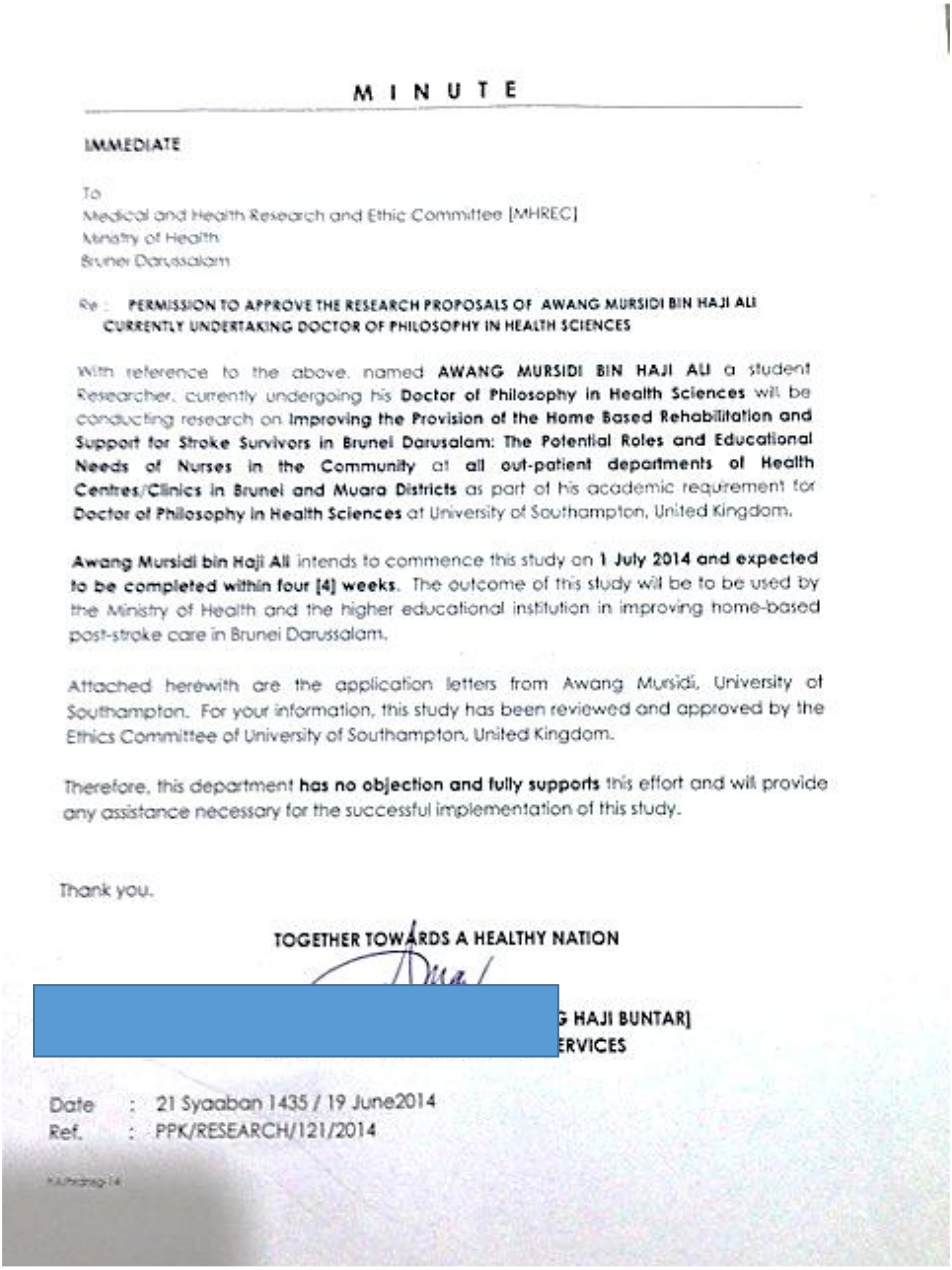
Thank you for being interested to join in a scientific cooperation - looking forward to that.

With warm regards,

[redacted]

Ärztliche Direktorin Krankenhaus Nordwest
Chefärztin Neurologische Klinik
Krankenhaus Nordwest GmbH
Steinbacher Hohl 2-26
60488 Frankfurt am Main
e-mail: meyding-lamade.u[redacted]

3. Approval letter from ‘gatekeeper’ Department of Nursing Services



MINUTE

IMMEDIATE

To
Medical and Health Research and Ethic Committee [MHREC]
Ministry of Health
Brunei Darussalam

Re : **PERMISSION TO APPROVE THE RESEARCH PROPOSALS OF AWANG MURSIDI BIN HAJI ALI CURRENTLY UNDERTAKING DOCTOR OF PHILOSOPHY IN HEALTH SCIENCES**

With reference to the above. named **AWANG MURSIDI BIN HAJI ALI** a student Researcher, currently undergoing his **Doctor of Philosophy in Health Sciences** will be conducting research on **Improving the Provision of the Home Based Rehabilitation and Support for Stroke Survivors in Brunei Darusalam: The Potential Roles and Educational Needs of Nurses in the Community** at **all out-patient departments of Health Centres/Clinics in Brunei and Muara Districts** as part of his academic requirement for **Doctor of Philosophy in Health Sciences** at University of Southampton, United Kingdom.

Awang Mursidi bin Haji Ali intends to commence this study on **1 July 2014 and expected to be completed within four [4] weeks**. The outcome of this study will be to be used by the Ministry of Health and the higher educational institution in improving home-based post-stroke care in Brunei Darussalam.

Attached herewith are the application letters from Awang Mursidi, University of Southampton. For your information, this study has been reviewed and approved by the Ethics Committee of University of Southampton, United Kingdom.

Therefore, this department **has no objection and fully supports** this effort and will provide any assistance necessary for the successful implementation of this study.

Thank you.

TOGETHER TOWARDS A HEALTHY NATION

[redacted]

Date : 21 Syaaban 1435 / 19 June2014
Ref. : PPK/RESEARCH/121/2014

[illegible]

4. Permission from the Rehabilitation Centre Y

ڤوست ڤراوبتن جرودوڠ ڤرك سنديرين برحد
Jerudong Park Medical Centre Sdn Bhd
Excellence in Healthcare ~ Serving You & Your Family's Health Needs

25 Jun 2014

To whom it may concern,

RE: Intermediary person to Mursidi Haji Ali to access potential stroke participants

It is my understanding that Mursidi's research project is to explore the experiences of stroke survivors and their informal carers following their discharge from the Brunei Neuroscience Rehabilitation Centre (BNSRC) and to understand their needs in stroke rehabilitation.

My team's role is to assist in identifying the population sample according to the inclusion and exclusion and assist in providing preliminary study information and seeking an informal consent to participate in the study from the patients. This is done before introducing the identified sample population to Mursidi to begin obtaining a written consent and undertaking the interview formally.

I have been provided with adequate information about this study to adequately help Mursidi in his research data collection. As the Head of the Rehabilitation Department, I agree to be his intermediary person to access these stroke participants on behalf of my colleagues. We believe that the data collected and the analyzed information would be very helpful in facilitating and improving the efficiency and effectiveness of our cause.

Please feel free to contact me if there are any queries.

Thank you.

Yours sincerely,

[redacted]

Vivian Suk Ke
BPhty (Hons1).
Physiotherapist
Head of Rehabi
Tel: +673 2 61
Email: vivian.ti

Jerudong Park BG 3122 Brunei Darussalam ☎ : (673) 2 612 612 ✆ : (673) 2 611 433 🖷 : (673) 2 612 461 🖱 : www.jpmc.com.bn

5. Permission from the Rehabilitation Centre X

To:

The Chair of Medical and Health Research and Ethics Committee Raja Isteri Pengiran
Anak Saleha Hospital Negara Brunei Darussalam.

Dear Madam Chair,

RE: PERMISSION FOR AWG MURSIDI BIN HJ ALI FOR HIS RESEARCH INTO

"IMPROVING THE PROVISION OF THE HOME-BASED REHABILITATION AND SUPPORT FOR STROKE SURVIVORS IN BRUNEI DARUSSALAM: POTENTIAL ROLES AND EDUCATIONAL NEEDS OF NURSES IN THE COMMUNITY"

I refer to your letter dated 23rd June 2014 and I am pleased to inform you that the Occupational Therapy Unit has no objection to the abovementioned request.

I have liaised with Awg Mursidi together with Ms Tai Mei Lan, the Occupational Therapist who is currently working in Neuromedical field. She has agreed to assist in identifying and providing potential participants for the research.

We look forward to the outcome of the study and hope it will pave the way for health professionals to enhance in the provision of home-based stroke rehabilitation and support for the stroke survivors in the country.

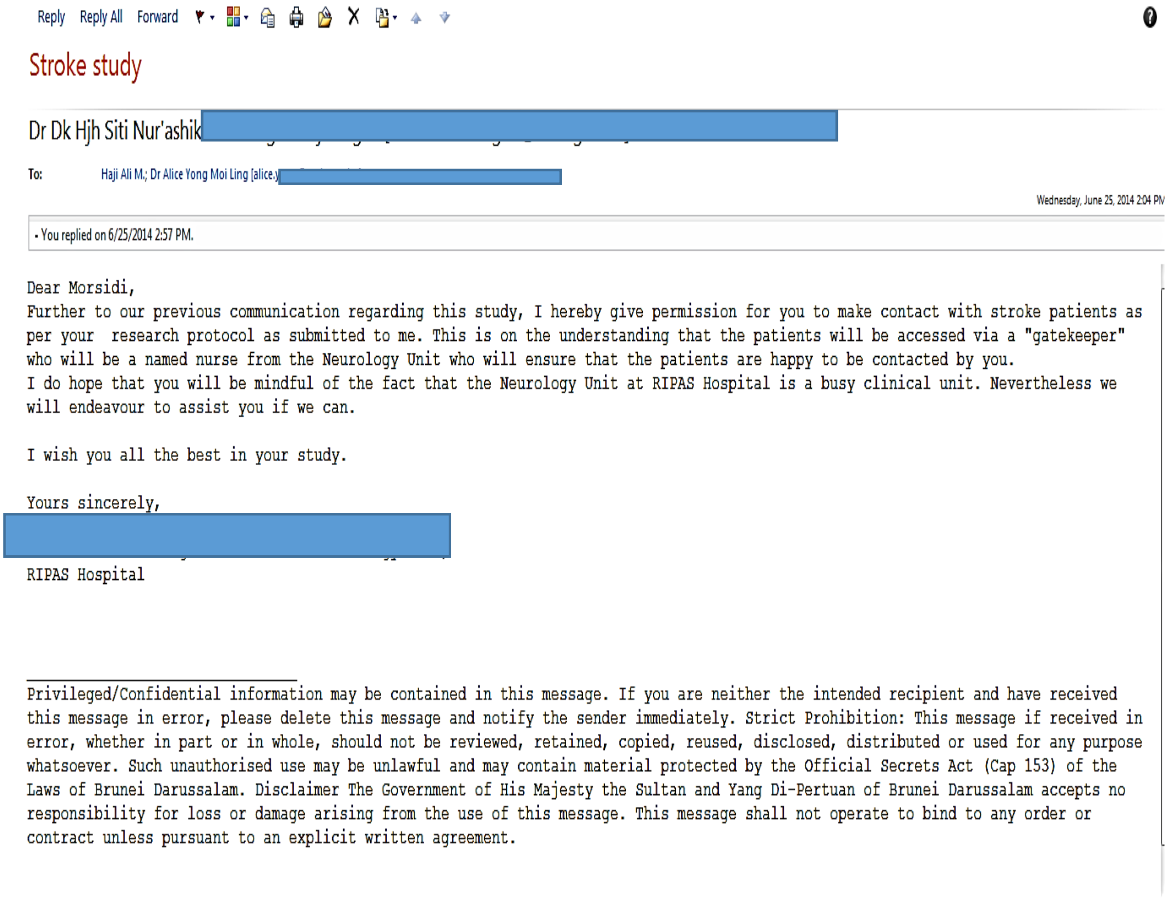
Thank you.

" SENTIASA BERWASPADA KESELAMATAN TERJAGA"

[redacted]

Date: 30 Syaaban, 1435H / 28 June, 2014M
Ref: 232/PCK/RSRIPAS/D11/1989 Pt. 10

6. Permission from ‘gatekeeper’ neurology clinic



Stroke study

Dr Dk Hjh Siti Nur'ashik [redacted]

To: Haji Ali M.; Dr Alice Yong Moi Ling [alice.y[redacted]

Wednesday, June 25, 2014 2:04 PM

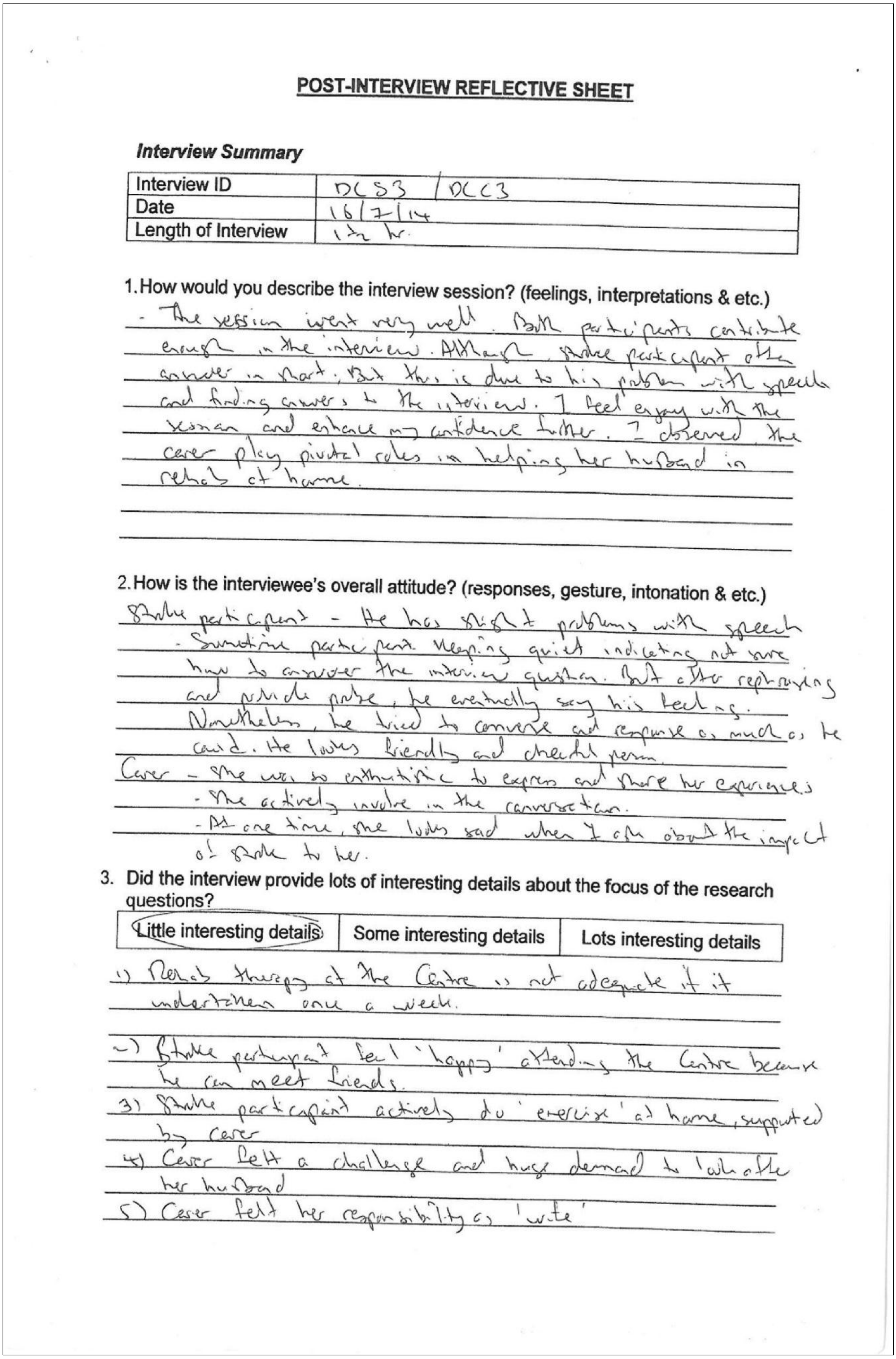
• You replied on 6/25/2014 2:57 PM.

Dear Morsidi,
Further to our previous communication regarding this study, I hereby give permission for you to make contact with stroke patients as per your research protocol as submitted to me. This is on the understanding that the patients will be accessed via a "gatekeeper" who will be a named nurse from the Neurology Unit who will ensure that the patients are happy to be contacted by you.
I do hope that you will be mindful of the fact that the Neurology Unit at RIPAS Hospital is a busy clinical unit. Nevertheless we will endeavour to assist you if we can.

I wish you all the best in your study.

Yours sincerely,
[redacted]
RIPAS Hospital

Appendix 4: Example of a Reflective Form



POST-INTERVIEW REFLECTIVE SHEET

Interview Summary

Interview ID	DCS3 / DCC3
Date	16/7/14
Length of Interview	1½ hr.

1. How would you describe the interview session? (feelings, interpretations & etc.)

- The session went very well. Both participants contribute enough in the interview. Although, stroke participant often answer in short; But this is due to his problem with speech and finding answers to the interview. I feel enjoy with the session and enhance my confidence further. I observed, the carer play pivotal roles in helping her husband in rehab at home.

2. How is the interviewee's overall attitude? (responses, gesture, intonation & etc.)

Stroke participant - He has slight problems with speech
- Sometime participant keeping quiet indicating not sure how to answer the interview question. But after rephrasing and provide probe, he eventually say his feelings. Nonetheless, he tried to converse and response as much as he could. He looks friendly and cheerful person.

Carer - She was so enthusiastic to express and share her experiences
- She actively involve in the conversation.
- At one time, she looks sad when I ask about the impact of stroke to her.

3. Did the interview provide lots of interesting details about the focus of the research questions?

[✓ Little interesting details]	Some interesting details	Lots interesting details

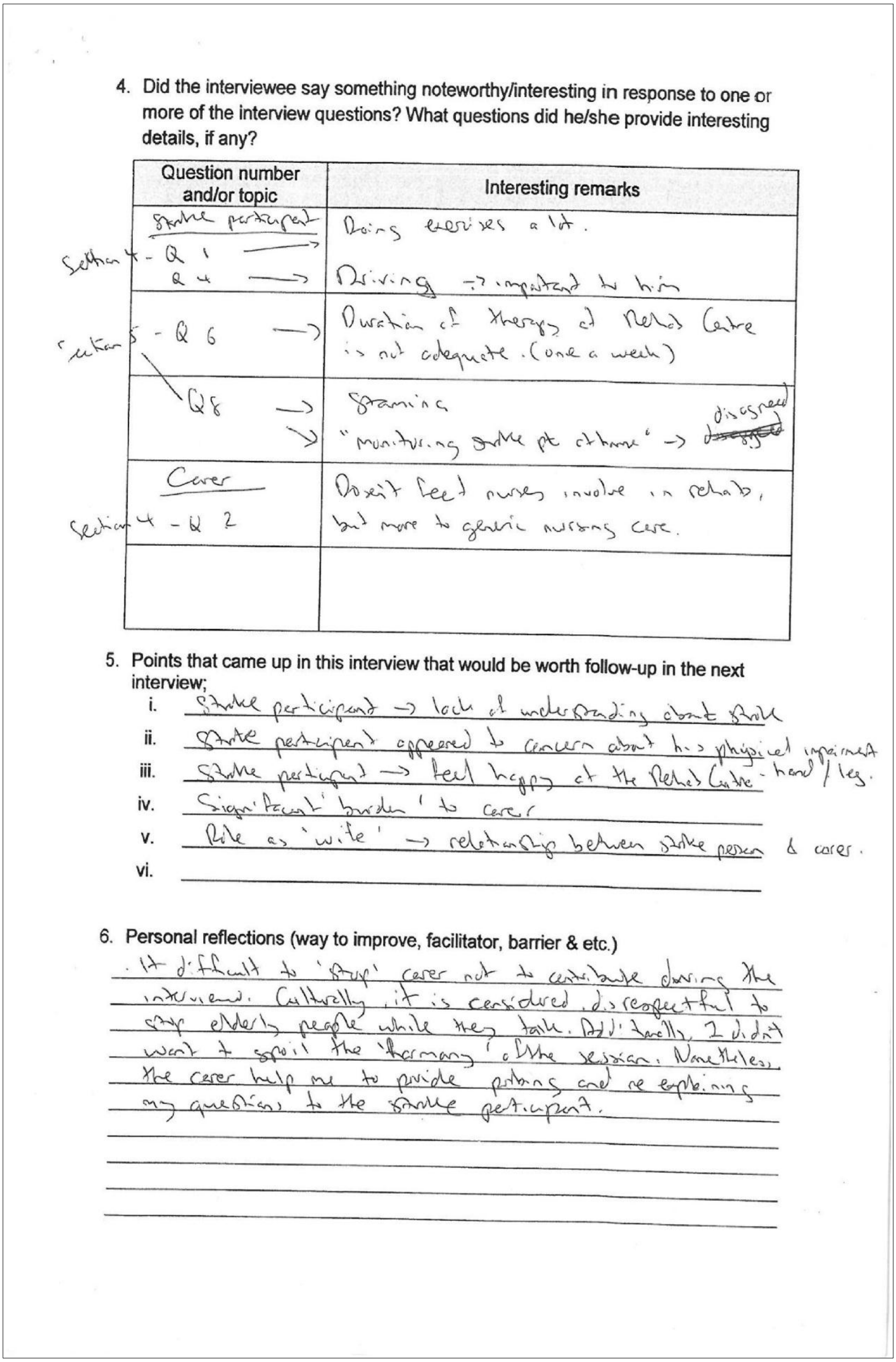
1) Rehab therapy at the Centre is not adequate if it undertaken once a week.

2) Stroke participant feel 'happy' attending the Centre because he can meet friends.

3) Stroke participant actively do 'exercise' at home, supported by carer

4) Carer felt a challenge and huge demand to 'look after her husband

5) Carer felt her responsibility as 'wife'



4. Did the interviewee say something noteworthy/interesting in response to one or more of the interview questions? What questions did he/she provide interesting details, if any?

Question number and/or topic	Interesting remarks
Stroke participant Section 4 - Q 1 → Q 4 →	Doing exercises a lot. Driving → important to him
Section 5 - Q 6 →	Duration of therapy at Rehab Centre is not adequate. (once a week)
Q 8 → →	Stamina "monitoring stroke pt at home" → ~~disagreed~~ disagreed
Carer Section 4 - Q 2	Doesn't feel nurses involve in rehab, but more to generic nursing care.

5. Points that came up in this interview that would be worth follow-up in the next interview;

i. Stroke participant → lack of understanding about stroke
ii. Stroke participant appeared to concern about his physical impairment - hand / leg.
iii. Stroke participant → feel happy at the Rehab Centre
iv. Significant 'burden' to carer
v. Role as 'wife' → relationship between stroke person & carer.
vi.

6. Personal reflections (way to improve, facilitator, barrier & etc.)

. It difficult to 'stop' carer not to contribute during the interview. Culturally, it is considered disrespectful to stop elderly people while they talk. Additionally, I didn't want to spoil the 'harmony' of the session. Nonetheless, the carer help me to provide prompts and re explaining my questions to the stroke participant.

Adapted from (Bates et al., 2008)

Appendix 5: Study Package for Nurse Participants

This appendix consist:

1. Invitation Letter
2. Participant Information Sheet
3. Bru-NEIS Questionnaire

1. INVITATION LETTER

From:
Mursidi Haji Ali
Assistant Lecturer
Institute of Health Sciences PAPRSB
Universiti Brunei Darussalam

Dear ……………………………………..

I am one of the Assistant Lecturers (Nursing) from the Institute of Health Sciences, Universiti Brunei Darussalam. Currently, I am undertaking MPhil/PhD in Health Sciences in the Faculty of Health Sciences, University of Southampton, UK. The topic of my study is ***improving the provision of home-based stroke rehabilitation and support in Brunei Darussalam: the potential roles and educational needs of nurses in the community.*** This research is undertaken towards an academic qualification and supported by academic staff from the Faculty of Health Sciences, University of Southampton.

The study is about identifying ways to improve community home-based stroke services through providing education and advancing potential roles of nurses in supporting stroke survivors. Information will be gathered from people who have had a stroke, informal carers of stroke survivors, nurses and other healthcare professionals. For your part, the study focuses on identifying educational needs of nurses in stroke and exploring your potential roles in community stroke rehabilitation nursing. Your knowledge and experiences will be important to help inform this training which can be applicable to your profession. This is an area of study where so far no research has been published in Brunei.

If you would like to find out more about the study, you are invited to attend the briefing of the study on ……………… (Time/date/place). There is no obligation for you to participate and no negative consequences will occur as result of your refusal. Where you decided to take part, you can withdraw at any point of the research and no impact on your professional roles will be affected.

Thank you for taking time to read this letter.

Yours sincerely

Mursidi Haji Ali

Assistant Lecturer
PAPRSB Institute of Health Sciences
Universiti Brunei Darussalam.

MPhil/PhD student
Building 45
Room 001
Faculty of Health Sciences
Highfield Campus
University of Southampton

Hp: +673 8758027 (Brunei)
+44 (0) 7543375474 (UK)
Email: mursidi.ali@ubd.edu.bn
mha1g12@soton.ac.uk

2. PARTICIPANT INFORMATION SHEET

Study Title: **IMPROVING THE PROVISION OF HOME-BASED STROKE REHABILITATION AND SUPPORT IN BRUNEI DARUSSALAM: THE POTENTIAL ROLES AND EDUCATIONAL NEEDS OF NURSES IN THE COMMUNITY**

Researcher: Mursidi Haji Ali **Ethics number**: University of Southampton 9791

: MHREC 2014/19(5)

Please read this information carefully before deciding to take part in this research. Before you decide, you need to understand why the research is being done and what it would involve for you.

Please take time to read the following information carefully. Talk to others about the research if you wish. Take time to decide whether or not you want to take part. If you are happy to participate you will be asked to complete the study questionnaire.

Please contact me if there is anything that is not clear or if you would like more information (Contact number +673 8758027 or email mha1g12@soton.ac.uk)

What is the purpose of the study?
Stroke is the second most common cause of morbidity and mortality worldwide. In Brunei, the incidence of stroke remains one of the top four leading causes of death after cancer, heart disease and diabetes over the past decade. Hence, the Government has established the first National Stroke Centre in 2010. International studies suggested that dedicated specialist stroke unit improved patients survival rate. But, these patients may have to live with residual impairments and relied heavily on carers to continue their day activities. Published studies indicated that the impact of caregiving role on carers can be substantial. A community-based rehabilitation provision, to support patients and carers at home, is therefore important.

However, the role of nurses in complementing existing multidisciplinary rehabilitation service is unknown. Moreover, accredited stroke training for nurses is not yet available. This research aims to explore different aspects of home-based, stroke rehabilitation service provision in order to identify areas needed for improvement, with specific focus on rehabilitative role and educational needs of nurses in the community. Future findings from this study are intended to use by relevant policy makers to plan post-stroke care services and the development of nurse training in stroke at Universiti Brunei Darussalam.

Why have I been invited?
About 100 registered nurses who currently work at the Health Centres in Brunei Muara District will be approached. Your views about role of nurses in stroke rehabilitation and educational needs is crucial to understand how community nurses can contribute to improvement of the service provision. Therefore, findings of this research would be more relevant and tailored to your needs.

I have to take part?
No, it is up to you to decide. Participation is entirely voluntary and you may refuse without giving a reason at no cost.

What will happen to me if I take part?
The study questionnaire is provided along with this Information Sheet. It consist nine main questions and may take approximately 20 minutes to answer all. If you agree to participate, two weeks were allocated to complete and return the questionnaire. Your completed questionnaire must be kept in a sealed envelope provided and return to your nursing officer for collection by the researcher. If necessary, your nursing officer will issue a gentle reminder about the need to return the questionnaire or to inform that he/she has extra copies if required. There is no obligation to complete and return the questionnaire. Your anonymity will be assured as no name or contact details are requested in the questionnaire.

How do I indicate consent to participate in this study?
Implies consent to participate is indicated if you have completed and return the questionnaire.

Are there any benefits in my taking part?
There may be no direct benefit to you, but a benefit to others perhaps, in respect of adding to current knowledge. There is some possibility that you will learn about caring for patients with stroke. The information from this study will help to describe needs of nurses in stroke education and propose appropriate programme for professional development.

Are there any risks involved?

There will be no risk or any negative consequences involved if you participate or refuse to take part in this study. Some questions may make you feel uncomfortable, though this rarely happens. If you do, you can either take a break or continue later or choose to withdraw at no cost. If necessary, you may speak with your nursing officer to discuss this concern.

Will my participation be confidential?

All information which will be collected from the questionnaire will be kept strictly confidential.

How would you protect information about me?

This study complies with the UK Data Protection Act 1998 and the University of Southampton Data Protection Policy 2008. Your information will be kept strictly confidential and any information pertaining to your name and address will not be requested in the questionnaire. Your questionnaire will be given specific codes (e.g. N1, N2) known only to researcher. All completed questionnaires will be stored in a locked safe box. Any electronic data will be stored on a password protected computer known only by researcher. Your data will only be shared with supervisory team for academic purposes. It may be necessary your data will be used to inform future study related to stroke. All data will be retained by the University of Southampton for 10 years and will be disposed securely after this period. At the completion of the study, all hard copies of the questionnaire will be shredded.

What happens if I change my mind?

Your participation is entirely voluntary. You have the right to withdraw at any time and your legal rights will not be affected. If you change your mind, you are not required to return the questionnaire.

Who organises this research?

This research form part of a PhD and is being organised through the University of Southampton. I am the principal researcher for this study. The study is funded and approved by the Government of His Majesty the Sultan of Brunei under sponsorship of the Ministry of Education via the Public Service Department through the Public Service Commission.

Who has reviewed the study?

The proposal for conducting this study has been reviewed by the following organisation:

1. The Government of His Majesty the Sultan of Brunei under sponsorship of the Ministry of Education via the Public Service Department through the Public Service Commission
2. University Senate, Universiti Brunei Darussalam
3. The Medical and Health Research Ethics Committee, Ministry of Health Brunei Darussalam
4. The Ethic Committees Brunei Neuroscience Stroke Rehabilitation Centre, JPMC
5. The Ethic Committees of the University of the Southampton
6. Peer reviewed by panel reviewer from the Faculty of Health Sciences, University of Southampton

What will happen to the results of the study?

The result of the study aim to publish in Brunei Darussalam Journal of Health, Brunei Medical International Journal (BIMJ) and other international journals in nursing and education. You may able to access the publication through respective journal website. The outcome of the study may also be presented in local and international conferences. All your information will not be identifiable in reporting the data.

What happens if something goes wrong?

If you having concern about any aspect of this study, you may speak to my supervisors at the University of Southampton, Dr Lesley Collier or co-supervisor in Brunei, Professor David Koh. Their contact details can be found the end of this information sheet. If you remain unhappy or if there is a problem and wish to complain formally, you can do this by writing a letter to the Chairperson, the Medical Health Research Ethic Committee, Executive Screening Suit, 1st Floor Car Park Level, RIPAS Hospital Brunei or the Chair of Ethic Committee, Faculty of Health Sciences, University of Southampton, Highfield Campus, Southampton SO17 1BJ. When contacting, please provide details of the name or description of the study (so that it can be identified), the researcher involved, and the details of the complaint you wish to make.

Where can I get more information?

After reading this information sheet and if you would like additional information, you may contact the following people who will be able to help.

1. Principal Investigator, Mursidi Haji Ali; +673758027(Brunei) or +44(0) 75433 75474 (UK), email address mha1g12@soton.ac.uk
2. Primary supervisors (UK) Dr Lesley Collier at +44 (0) 23 80595284 or email lesley.collier@soton.ac.uk
3. 2nd Supervisor (UK) Professor Marry Gobbi at +44 (0) 02380598270 or email mog1@soton.ac.uk
4. Co-supervisor (Brunei) Professor David Koh at +673 2463001 Ext 2291 or email at david.koh@ubd.edu.bn.

3. STUDY QUESTIONNAIRE

يونيبرسيتي بروني دارالسلام
Universiti Brunei Darussalam

UNIVERSITY OF
Southampton

Ethic No: University of Southampton 9791
MHREC 2014/19(5)

Study Questionnaire

BRUNEI NURSE EDUCATION INQUIRY OF STROKE
(Bru-NEIS)

Research Title	**Improving the provision of home-based stroke rehabilitation and support in Brunei Darussalam: the potential roles and educational needs of nurses in the community**	
Researcher	Mursidi Haji Ali	
Position & contact details	Assistant Lecturer PAPRSB Institute of Health Sciences Universiti Brunei Darussalam. MPhil/PhD student Building 45 Room 001 Faculty of Health Sciences Highfield Campus University of Southampton	Hp: +673 8758027 (Brunei) +44 (0) 7543375474 (UK) Email: mursidi.ali@ubd.edu.bn mha1g12@soton.ac.uk
Supervisors & contact details	Prof David Koh (co-supervisor Brunei) Contact no: +673 2463001 Ext 2291 Email: david.koh@ubd.edu.bn	Dr Lesley Collier (Primary supervisor UK) Contact no: +44 (0) 2380595284 Email: Lesley.collier@soton.ac.uk Prof Mary Gobbi Contact no: +44 (0) 02380598270 Email: mog1@soton.a.cuk

INSTRUCTIONS TO PARTICIPANT:

Thank you for agreeing to participate in this study. Please take time to read the questions. The questionnaire is divided into 3 sections.

Section 1,	Questions 1-6 are related to your demographic details.
Section 2,	Questions 7-11 are related to your stroke education and experiences.
Section 3,	Questions 12-20 are related to your stroke education and training needs.

- *In section 1 & 2, please tick (/) the statement that apply to you.*
- *In section 3, please tick (/) your responses in the circles to indicate your degree of agreement or disagreement at each statement, and/or to state your views at the space provided.*
- *It is important that you give honest opinion. Please do not go back and change any of your responses.*
- *Be assured that all your responses are strictly confidential. All information will be given specific codes and you will not be identifiable in future publications.*
- *Consent is implied if you have completed and submit the questionnaire.*
- *The questionnaire may take approximately 20 minutes and you are given two weeks to complete at your convenience.*
- *Completed questionnaire must be kept in a sealed envelope provided and return to your nursing officer for collection by researcher.*
- *If you have any concerns or issues about the questions, you may contact the researcher or speak to your nursing officer for advises.*

SECTION 1: Demographic Details

This part of the questionnaire is about your **DEMOGRAPHIC INFORMATION**. For each of the following statements, please tick (/) in the circle that applied to you.

1. In what year were you born? ________

2. Gender

   ○ Male ○ Female

3. What is your **highest** level of nursing education?

   ○ Certificate in Nursing
   ○ Diploma in Nursing
   ○ Post Basic Diploma (Nursing Speciality)
   ○ Bachelor Degree in Nursing
   ○ Others (Please specify): ___________________________________

4. What is your **current** job position?

   ○ Assistant Nurse
   ○ Senior Assistant Nurse
   ○ Staff Nurse
   ○ Senior Staff Nurse
   ○ Nursing Officer
   ○ Others (Please specify): ___________________________________

5. How long have you been working as a Registered Nurse?

   ○ 1 year to < 3 years
   ○ 3 years to < 5 years
   ○ 5 years to < 8 years
   ○ 8 years to <10 years
   ○ ≥ 10 years

6. Please select your **present** job description. (Please tick **one** only)

   ○ Managerial/Administrative
   ○ Doctor assistant
   ○ Triage Nurse
   ○ Treatment Nurse
   ○ Others (Please specify): ___________________________________

SECTION 2: YOUR STROKE EDUCATION AND EXPERIENCE

Please tick (/) in the circle that applied to you.

7. Did you receive any formal educational about stroke anytime throughout your nursing profession?

   ○ Yes (Proceed to next question)
   ○ No (Please go to question **9**)

8. Please tick the topic(s) that you have learnt during your educational study.

   ○ Pathophysiology of Stroke
   ○ Stroke Assessment
   ○ Nursing management of stroke
   ○ Aspect of stroke rehabilitation
   ○ Aspect of community care post-stroke
   ○ Stroke Prevention (primary or secondary)
   ○ Any others (please specify) ________________________________

9. Indicate if you have any **experience(s)** in caring a patient with stroke anytime throughout your nursing profession?

   ○ Yes (Proceed to next question) ○ No (Please continue to **SECTION 3**)

10. Which area of work did you get your experience from? (Please tick **ALL** that applies to you)

    ○ Hospital-based (Wards/Intensive Units/Rehabilitation Department)
    ○ Brunei Neuroscience Stroke Rehabilitation Centre
    ○ Healthcare Centres/Clinics
    ○ Home-Based Nursing Unit
    ○ Others (please specify): ___________________________________

11. How many year(s) you have had experiences in caring a patient with stroke?

    ○ None
    ○ Less than 1 year
    ○ 1 year to < 5 years
    ○ 5 years and above

SECTION 3: STROKE EDUCATION AND TRAINING NEEDS

This part of the questionnaire inquiries regarding **YOUR VIEWS ABOUT THE TRAINING AND EDUCATION OF NURSES IN STROKE REHABILITATION**.

Please tick (/) your choice in the circle to indicate your degree of AGREEMENT or DISAGREEMENT at each statement and/or state your views at the space provided.

Key: 'SA'= Strongly Agree; 'A'= Agree; 'U'= Uncertain; 'D'= Disagree; 'SD'= Strongly Disagree

12. The training and education of nurses in community stroke rehabilitation is needed in Brunei Darussalam. Why?

Strongly Agree (5)	○
Agree (4)	○
Uncertain (3)	○
Disagree (2)	○
Strongly Disagree (1)	○

Please state reason(s) for your view below;

13. I am prepared to undertake the training and education in community stroke rehabilitation nursing. Why?

Strongly Agree (5)	○
Agree (4)	○
Uncertain (3)	○
Disagree (2)	○
Strongly Disagree (1)	○

Please state reason(s) for your view below;

Remember:

The more strongly you feel about the statement, the further from the centre you should circle, with agreement to the left and disagreement to the right.

14.	**In your opinion, what knowledge and understanding are required by specialist nurse rehabilitation in stroke?**	Strongly Agree (5)	Agree (4)	Uncertain (3)	Disagree (2)	Strongly Disagree (1)
a.	The impact of stroke on individual, carers and family	○	○	○	○	○
b.	The implication of stroke for lifestyle, driving, work, family and acceptance in the community	○	○	○	○	○
c.	The principles of stroke rehabilitation and rehabilitation referral; therapy techniques and their application	○	○	○	○	○
d.	A range of neurological treatment approaches and their applications	○	○	○	○	○
e.	Impact of stroke on patient’s psychological and emotional well-being (e.g. depression, anxiety, emotionalism, confidence)	○	○	○	○	○
f.	Impact of stroke to cognitive functioning and ability to communicate	○	○	○	○	○
g.	Impact of stroke to physiological, physical and functions of the body (e.g. rest and sleep, respiratory, mobility, balance, incontinence, swallowing, feeding, sexual, motor control)	○	○	○	○	○
h.	Impact of stroke to neurological, visual and sensory impairment and pain (e.g. shoulder pain, central post-stroke pain, spasticity, seizures)	○	○	○	○	○
i.	Impact of stroke to social and relationship (e.g. lifestyle, work/employment, driving, leisure, family, children, carers)	○	○	○	○	○
j.	The causes of, and how to assess, manage and treat problems after stroke	○	○	○	○	○
k.	The impact of problems after stroke to Activity of Daily living	○	○	○	○	○
l.	Methods that will support those affected by stroke with their recovery and cope with problems after stroke	○	○	○	○	○
m.	Risk factors for further stroke events	○	○	○	○	○
n.	Pharmacological and non-pharmacological interventions for secondary prevention	○	○	○	○	○
o.	Any support services, organisations and resources available (e.g. social workers, multi-disciplinary team … etc.)	○	○	○	○	○
p.	Methods to facilitate communication with those affected by stroke	○	○	○	○	○
q.	Therapeutic moving and handling	○	○	○	○	○
r.	Others (please specify):	○	○	○	○	○

15.	**In your opinion, which skills and abilities are required by specialist nurse rehabilitation in stroke?**	Strongly Agree (5)	Agree (4)	Uncertain (3)	Disagree (2)	Strongly Disagree (1)
a.	Take and interpret thorough history, and assess mental capacity	○	○	○	○	○
b.	Plan and initiate appropriate assessments, interventions and information relevant to individual's needs	○	○	○	○	○
c.	Provide a range of neurological interventions processes and be able to clinically reason the selection and administration of an approach	○	○	○	○	○
d.	Provide advice and support; communicate and discuss of events, risk, need for interventions and treatments, rationales for treatment and possible side effects of treatments	○	○	○	○	○
e.	Identify need and when to refer for more specialist rehabilitation therapist	○	○	○	○	○
f.	Monitor progress and agree or change a management plan	○	○	○	○	○
g.	Identify resources to help with participation and inclusion	○	○	○	○	○
h.	Assess motivation and take steps to augment management	○	○	○	○	○
i.	Identify and use therapeutic methods of moving and handling the patient that are safe depending individual patient's needs	○	○	○	○	○
j.	Assist, encourage and facilitate post-stroke physical, social and cultural reintegration	○	○	○	○	○
k.	Recognise the sign and symptoms and impact of psychological and emotional problems after stroke	○	○	○	○	○
l.	Recognise the sign and symptoms and impact of cognitive and communication problems after stroke	○	○	○	○	○
m.	Recognise the sign and symptoms and impact physiological, physical and functional problems after stroke	○	○	○	○	○
n.	Recognise the sign and symptoms and impact of neurological, visual and sensory impairment and pain problems after stroke	○	○	○	○	○
o.	Recognise the sign and symptoms and impact of social and relationship problems after stroke	○	○	○	○	○
p.	Recognise the sign and symptoms and impact of medicals problems/complications and help patients and families to cope, manage and encourage recovery	○	○	○	○	○
q.	Use a range of communication resources and approaches to ensure patients and their carers are fully involved in decision-making process and their care	○	○	○	○	○
r.	Provide a client-centred approach to care and manage any challenging behaviour	○	○	○	○	○
s.	Others (please specify):	○	○	○	○	○

16.	**What do you think are the barriers to attend educational training?**	Strongly Agree (5)	Agree (4)	Uncertain (3)	Disagree (2)	Strongly Disagree (1)
a.	No managerial support	○	○	○	○	○
b.	Staff shortages	○	○	○	○	○
c.	Other staff needs were given priority	○	○	○	○	○
d.	Lack of allocated time for study	○	○	○	○	○
e.	Lack of interest	○	○	○	○	○
f.	Lack of experience in practise of stroke care	○	○	○	○	○
g.	If the training is not accredited by relevant authority	○	○	○	○	○
h.	The training is not related to my practise	○	○	○	○	○
i.	Fear unable to cope with study demand	○	○	○	○	○
j.	Least attraction of salary increment after the course	○	○	○	○	○
k.	If the registered nurse still in provisional period (less than 3 years)	○	○	○	○	○
l.	Too much personal responsibility	○	○	○	○	○
m.	Already have too much work-related responsibility	○	○	○	○	○
n.	Satisfied with current level of education	○	○	○	○	○
o.	Feel satisfied with present salary	○	○	○	○	○
p.	Feel satisfied with present job position	○	○	○	○	○
q.	Any others (please specify)	○	○	○	○	○

17. What do you think are the role(s) of nurses in community stroke rehabilitation should be?

18. How do you think nurses can complement stroke rehabilitation services of the Allied Health Professionals within the community setting?

19. What is your opinion concerning the possible introduction of the Community Stroke Rehabilitation Nurses?

20. Are there any other recommendations you would like to make?

End of Questionnaire

Please keep this questionnaire in a sealed envelope provided and return to your nursing officer

Thank you for your participation

Appendix 6: Study Package for Expert Healthcare Professional Participants

This appendix consist:

1. Invitation Letter
2. Participants Information Sheet
3. Reply Slip
4. Consent Form
5. Bru-HIS Interview Guide for Expert Healthcare Professionals

1. INVITATION LETTER

From:
Mursidi Haji Ali
Assistant Lecturer
Institute of Health Sciences PAPRSB
Universiti Brunei Darussalam

Dear ………………………………………..

I am one of the Assistant Lecturers (Nursing) from the Institute of Health Sciences, Universiti Brunei Darussalam. Currently, I am undertaking MPhil/PhD in Health Sciences in the Faculty of Health Sciences, University of Southampton, UK. The topic of my study is ***Improving the provision of home-based stroke rehabilitation and support in Brunei Darussalam: the potential roles and educational needs of nurses in the community.*** This research is undertaken towards an academic qualification and supported by academic staff from the Faculty of Health Sciences, University of Southampton.

The study employs two phases which aims to explore the different aspect of the home-based stroke rehabilitation service provision, in order to identify area needed for improvement. At the first phase, I have interviewed 21 stroke patients and 18 carers, and received 101 questionnaire from the community nurses, to establish areas needed for service improvement. Key findings from the first phase were identified and will be discussed with five expert healthcare professionals at the second phase of study. You are invite to participate because you are one of the expert professionals who can help validate the study findings. This will ensure that any future strategy developed on improving the service provision is feasible and acceptable.

I have enclosed an information sheet that will tell you more about the research and what is involved. If you are happy to take part, please complete the reply slip attached and return it as email attachment to my contact details below. Alternatively, you may contact me to notify your decision or leave a text message and I will contact you in return. However, this still does not commit you to taking part. Where you decided to participate, you can withdraw at any point of the research without any explanation. If you would like to find out more about the study, I can be contacted through details provided below.

Thank you for taking time to read this letter.

Yours sincerely

Mursidi Haji Ali

Assistant Lecturer
PAPRSB Institute of Health Sciences
Universiti Brunei Darussalam.

Tel: +44 (0) 7543375474 (UK)
Email: mha1g12@soton.ac.uk

MPhil/PhD student
Faculty of Health Sciences
Highfield Campus
University of Southampton

2. PARTICIPANT INFORMATION SHEET

Study Title: Improving the provision of home-based stroke rehabilitation in Brunei Darussalam: the potential roles and educational needs of nurses in the community.

Researcher: Mursidi Haji Ali **Ethics number**: University of Southampton 9791
: MHREC EDU/2014/19(5)

Please read this information carefully before deciding to take part in this research. Before you decide, you need to understand why the research is being done and what it would involve for you.

Please take time to read the following information carefully. Talk to others about the research if you wish. Take time to decide whether or not you want to take part. If you are happy to participate you will be asked to sign a consent form.

Please contact me if there is anything that is not clear or if you would like more information (Contact number +673 8758027 or email mha1g12@soton.ac.uk)

What is the purpose of the study?

Stroke is the second most common cause of morbidity and mortality worldwide. In Brunei, the incidence of stroke remains one of the top four leading causes of death after cancer, heart disease and diabetes over the past decade. Hence, the Government has established the first National Stroke Centre in 2010. International studies suggested that dedicated specialist stroke unit improved patients survival rate. But, these patients may have to live with residual impairments and relied heavily on carers to continue their day activities. Published studies indicated that the impact of caregiving role on carers can be substantial. A community-based rehabilitation provision, to support patients and carers at home, is therefore increasingly crucial.

However, the role of nurses in complementing existing multidisciplinary rehabilitation service is not clear. Moreover, how stroke patients and their carer perceived their rehabilitation support that they receive during the first year following discharge was unknown. This research aims to explore different aspects of home-based, stroke rehabilitation service provision in order to identify areas needed for improvement, with specific focus on rehabilitative role and educational needs of nurses in the community. Future findings from this study are intended to use by relevant policy makers to plan post-stroke care services and the development of nurse training in stroke.

Why have I been invited?

You have been invited to take part in this study because you are one of the healthcare professionals who can provide expert advises and help validate the findings of my 1st phase of study. This will ensure that future strategy developed to improve the provision of the home-based stroke rehabilitation is feasible and acceptable. I am looking to recruit about 5 expert healthcare professionals for this study.

Do I have to take part?

No, it is up to you to decide. Participation in this study is entirely voluntary and you may refuse without giving a reason.

What will happen to me if I take part?

After reading this Information Sheet and if you agree to take part, please complete and return the reply slip as email attachment to my contact details stated below. Or, you may contact the researcher via a text message to inform about your decision. I will contact you in return to discuss about the study and possibly arrange a meeting at mutually agreed schedule. The meeting will be undertaken in a private room at the Institute of Health Sciences, UBD. Any travel expenses (i.e. petrol) will be covered by the researcher if necessary. Before discussion begin, you are required to sign a consent form and a copy will be given to you for record. During the conversation, you will be asked about views on the home-based stroke rehabilitation services and potential role of nurses in community stroke rehabilitation. Following this, you will be presented with the findings of the phase one study for comments and advises. All of our conversation will be audio-taped to assist in future data analysis. The meeting may last approximately an hour and a break will be offer.

Are there any benefits in my taking part?
There may be no direct benefit to you, but a benefit to others perhaps, in respect of adding to current knowledge on home-based stroke services. The information gathered from this study is intended for use by the policy maker and relevant stakeholder in planning a community post-stroke services.

Are there any risks involved?
There is no known risk involved if participate in the study.

Will my participation be confidential?
All information collected from you during the discussion will be kept strictly confidential.

How would you protect information about me?
This study complies with the UK Data Protection Act 1998 and the University of Southampton Data Protection Policy 2008. All data will be transcribed verbatim by the researcher and no name will be included in the transcripts, but pseudonym will be used.

Information will be kept strictly confidential and any information pertaining to your name and address will be kept in sealed envelope and stored in safe locked box access only by researcher. All transcripts will be made anonymous and given specific code such as E1, E2 and so on, known only to the researcher. If necessary, your quotes from the conversation may be used in future publication. All transcripts and audio-recorded DVD will be stored in a safe locked box. Any electronic data will be stored on a password protected computer known only by researcher. Your data will only be shared with supervisory team for academic purposes. Once the study has ended, records of all your details and the interview transcripts will be properly destroyed. The data will be owned by the University of Southampton and will be retained for 10 years. After this period, all data will be disposed securely.

What happens if I change my mind?
Your participation in this study is entirely voluntary. You may refuse to participate in this research at any point. If you participate and change your mind, you have the right to withdraw at any time, without explanation and your legal rights will not be affected. If you withdraw from the study, you may either allow the researcher to use recorded session up to your withdrawal or removed from the study.

Who organises this research?
This research form as part of a PhD and is being organised through the University of Southampton. I am the principal researcher for this study. The study is funded and approved by the Government of His Majesty the Sultan of Brunei under sponsorship of the Ministry of Education via the Public Service Department through the Public Service Commission.

Who has reviewed the study?
The proposal for conducting this study has been reviewed by the following organisation:

1. The Government of His Majesty the Sultan of Brunei under sponsorship of the Ministry of Education via the Public Service Department through the Public Service Commission

2. University Senate, Universiti Brunei Darussalam
3. The Medical and Health Research Ethics Committee, Ministry of Health Brunei Darussalam
4. The Ethic Committees Brunei Neuroscience Stroke Rehabilitation Centre, JPMC
5. The Ethic Committees of the University of the Southampton
6. Peer reviewed by panel reviewer from the Faculty of Health Sciences, University of Southampton

What will happen to the results of the study?

The result of the study is aim to publish in Brunei Darussalam Journal of Health, Brunei Medical International Journal and other international journals in nursing and education. You may able to access the publication through respective journal website. If you wish to be informed about the result of the study, please state this in the consent form and I will send your details of the study finding. The outcome of the study may also be presented in local and international conferences. All your information will not be identifiable from the results unless you choose to do so.

What happens if something goes wrong?

If you having concern about any aspect of this study, you may speak to my supervisors at the University of Southampton, Dr Lesley Collier or co-supervisor in Brunei, Professor David Koh. Their contact details can be found the end of this information sheet. If you remain unhappy or if there is a problem and wish to complain formally, you can do this by writing a letter to the Chairperson, the Medical Health Research Ethic Committee, RIPAS Hospital Brunei or the Chair of Ethic Committee, Faculty of Health Sciences, University of Southampton, Highfield Campus, Southampton SO17 1BJ. When contacting, please provide details of the name or description of the study (so that it can be identified), the researcher involved, and the details of the complaint you wish to make.

Where can I get more information?

After reading this information sheet and if you would like additional information, you may contact the following people who will be able to help.

1. Principal Investigator, Mursidi Haji Ali; +44(0) 75433 75474 (UK), email address mha1g12@soton.ac.uk
2. Primary supervisors (UK) Dr Lesley Collier at +44 (0) 23 80595284 or email lesley.collier@soton.ac.uk
3. 2nd Supervisor (UK) Professor Marry Gobbi at +44 (0) 02380598270 or email mog1@soton.ac.uk
4. Co-supervisor (Brunei) Professor David Koh at +673 2463001 Ext 2291 or email at david.koh@ubd.edu.bn.

If you happy to participate, please complete the reply slip attached and return using self-address prepaid envelop provided

Thank You

3. REPLY SLIP

REPLY SLIP FOR PARTICIPATION IN RESEARCH

Study title: Improving the provision of home-based stroke rehabilitation and support in Brunei Darussalam: the potential roles and educational needs of nurses in the community

Researcher name: Mursidi Haji Ali

Contact No: (Hp) +673 8758027 (e-mail) mha1g12@soton.ac.uk

Ethics reference: ______________________

*Please provide **initial** in the box if you agree with the statements:*

I am interested to take part in this research and agree for the researcher to contact me regarding the study. I understand that being contacted does not commit me to taking part. ☐

Name of participant: ___________________________________

Signature of participant: ________________________________

Date: ____

Email: ____

Telephone: ____

Preferred time for researcher to call me: ___________________

Please return this reply slip to your rehabilitation therapist within one week.
Thank you very much for your participation in this research

4. CONSENT FORM

Study title: Improving the provision of home-based stroke rehabilitation and support in Brunei Darussalam: the potential roles and educational needs of nurses in the community.

Researcher: Mursidi Haji Ali

Ethic No: University of Southampton 9791
: MHREC 2014/19(5)

Contact Details: +673 8758027 / e-mail: mha1g12@soton.ac.uk

*Please **initial** the box(s) if you agree with the statement(s):*

- I have read and understood the Participant Information Sheet and have had the opportunity to ask questions about the study and have these answered to my satisfaction. ☐
- I understand my participation is voluntary and I may withdraw at any time without my legal rights being affected. ☐
- I agree to take part in this research project and agree for the interview to be audio-recorded. ☐
- I agree to the confidentiality policy set out in the information sheet. ☐
- I agree for the data to be used for the purpose of this study and agree for the data to be used with other future study related to this area. ☐
- I give permission for the researcher to send my transcripts of my conversation (Malay only) with him for translation into English without quoting my name on the transcripts and using only pseudonym to appointed Translator. ☐
- I agree to the use of direct quotes in research reports and publications. ☐
- I consent to the University to retain my personal details on a database, kept separately from the research data detailed above. The 'validity' of my consent is conditional upon the University complying with the Data Protection Act and I understand that I can request my details to be removed from this database at any time. ☐

- ***I can confirmed that I have agreed to all the above.***

______________________	______________________	____________
Participant's name	Signature	Date
______________________	______________________	____________
Researcher name	Signature	Date
______________________	______________________	____________
Independent witness name	Signature	Date

❖ *I would like to have the summary of the study findings* (please TICK (/) where apply)

☐ Yes

☐ No

Contact details	

5. INTERVIEW GUIDE FOR EXPERT HEALTHCARE PROFESSIONALS

Ethic No: University of Southampton 9791
MHREC 2014/19(5)

Interview Guide

BRUNEI HOME-BASED INTERVIEW OF STROKE
(Bru-HIS) – Expert Healthcare Professional Participants

Research Title	**Improving the provision of home-based stroke rehabilitation and support in Brunei Darussalam: the potential roles and educational needs of nurses in the community**	
Researcher	Mursidi Haji Ali	
Position & contact details	Assistant Lecturer PAPRSB Institute of Health Sciences Universiti Brunei Darussalam. MPhil/PhD student Building 45 Room 001 Faculty of Health Sciences Highfield Campus University of Southampton	Hp: +673 8758027 (Brunei) +44 (0) 7543375474 (UK) Email: mursidi.ali@ubd.edu.bn mha1g12@soton.ac.uk
Supervisors & contact details	Prof David Koh (co-supervisor Brunei) Contact no: +673 2463001 Ext 2291 Email: david.koh@ubd.edu.bn	Dr Lesley Collier (Primary supervisor UK) Contact no: +44 (0) 2380595284 Email: Lesley.collier@soton.ac.uk Prof Mary Gobbi Contact no: +44 (0) 02380598270 Email: mog1@soton.a.cuk

Interview Date:	Time start:	
Interviewer:	Time completed:	
Place of Interview:		

SECTION 1: DEMOGRAPHIC DETAILS

1. In what year were you born? _______

2. Gender

   ○ Male ○ Female

3. What is your **highest** level of qualification?

   ○ BSc
   ○ MSc
   ○ PhD
   ○ Post-Doctorate
   ○ Others (Please specify): ___________________________________

4. What is your current job description? _________________________________

5. How long have you been working in this type of role? ____________________

SECTION 2: INTRODUCTION

Thank you for agreed to participate.
Provide summary of the first phase study.
Participants' expertise and involvement in service planning.

- What is you key roles or responsibilities in (stroke care and management / utilisation of the community nurses / running nursing education)?
- What would you think that can make a critical difference to the rehabilitation of the stroke patients and the well-being of the carers at the early stage after discharge from the hospital?
- How much is your involvement in decision making with regard to planning or improving the (stroke services / Community Nursing services / developing new programmes for the nurses)?

SECTION 3: FINDINGS FROM THE PHASE ONE STUDY

Discussion of each findings from the phase one study;

Finding 1: Needs of support beyond physical sequelae

Finding 2: Religious and cultural practice to support recovery

Finding 3: Provision of the existing outpatient therapy

Finding 4: Family support system at home

Finding 5: Seeking traditional above modern healthcare

Finding 6: The need for skilled nurses in stroke rehabilitation

Probe Questions:

- *What is your comment about the finding?*
- *How to address this issue?*
- *Why this is so important?*

SECTION 4: ASPECT OF AREAS NEEDED THE MOST IMPROVEMENT

Probe questions:

- *Based on findings that we discussed, establish what would you consider the main priority to improve the provision of the home-based stroke rehabilitation?*
- *Why this area is very important above others?*
- *What is the strategy you have in mind?*
- *What form of resources are required?*
- *Who should be involved in the team?*
- *Who should lead the team? Why?*
- *How can we implement this?*
- *What is the possible barriers to implement this strategy?*
- *Any other comments that you would like to make or add in relation to the study?*

Thank you for your comments and participation in this study.

Descriptors:

SD=Standard Deviation, Scoring (Lowest = 1, Highest = 5)
KAU=Knowledge and Understanding (items a to q): ***SAB*=**Skills and Abilities (items a to r): ***BAR*=**Barrier to attend training (items a to q): **Q=**BruNEIS Questionnaire
SP=Stroke Participants (N=21), **CP**= Carer Participants (N=18)

Findings and quotation from interviews with Stroke Participants (SP)			Findings and quotation from interviews with Stroke Carer Participants (CP)			Corresponding findings from the Questionnaire items (N=101)		
						Questionnaire Main Constructs		
Theme	Subtheme	Examples of the Interview Quotes	Theme	Subtheme	Examples of the Interview Quotes	***KAU***	***SAB***	***BAR***
Theme 1: Experience the impact of strokes	1.1. Feeling of physically disabled	"I feel all my limbs are weak]. The most obvious is my feet and hand. There are no other body parts affected. Only my feet and hand. It [stroke] has affects the muscle and the limbs." (SP – 13) "…it's like I'm unable to walk on my own…I feel like I'm losing my ability to walk…" (SP – 02).	Theme 1: Impact on caregiving experience	1.1. Feeling of physical pain and exhaustion	"Of course at the beginning I am not used to it [caring a stroke patient]. I feel pain all over my body…because my weight is 60 kilograms before, and now is 56. I am worry. When he [the stroke patient] is admitted at the hospital, his weight is 70 kilograms…and now he is over 80 kilograms. So my body can't tolerate which led to pain." (CP – 09) "I stay with Haji [stroke patient] for	The majority of the nurses (98%) agreed the need to have knowledge regarding impact of stroke on individual, carer and family. (Q14 item a: mean 4.50, SD 0.54) Over 95% of the nurses needs to know about methods to support patient with stroke (Q14 item l: mean 4.49, SD 0.58)	About 93% of the nurses agreed that recognising the symptoms and impact of stroke to physical (Q15 item m: mean 4.38, SD 0.63), and post-stroke pain (Q15 item n: mean 4.38, SD 0.63) are required skill competencies for stroke nurses.	More than half (73%) of the nurses agreed that lacked of experience in stroke patient care can be barrier to attend training in stroke. (Q16 item f: mean 3.92, SD 0.96)

“*Not necessarily eh! [a Malay slang to express disagreement] because my wife always helps me, so I don’t feel it [difficulty due to physical impairment]” (SP – 01).*	24 hours. There were so many to do, not only exercises. So, I am physically exhausted and don’t have enough sleep too. Haji didn’t sleep in the evening, but during day time. Thus, I hardly have enough sleep throughout the day. It’s physically demanding.” (CP – 13	About 92% of the nurses indicated that they need to have understanding about the impact of stroke on patients’ physical and physiological functions. (Q14 item g: mean 4.43, SD 0.67) *Over tenth (10.9%) of nurses were uncertain regarding the education requirement for post-stroke pain. (Q14 item h: mean 4.36, SD 0.72)*

Interpretation of merged data:

Findings from both the datasets showed concordance between sample groups regarding the physical impairment following stroke (qualitative data) and the requirement for stroke rehabilitation nurses to be knowledgeable and competence (quantitative data) for managing this problem. This finding demonstrate that nurses were aware and anticipate the physical challenges experience by patients with stroke and their carer following the stroke event.

Interpreted finding: Physical challenges after stroke

Findings and quotation from interviews with Stroke Participants (SP)			Findings and quotation from interviews with Stroke Carer Participants (CP)			Corresponding findings from the Questionnaire items (N=101)		
						Questionnaire Main Constructs		
Theme	Subtheme	Examples of the Interview Quotes	Theme	Subtheme	Examples of the Interview Quotes	***KAU***	***SAB***	***BAR***
	1.2. Feeling of emotional change	“I feel miserable and hopeless. I feel angry and didn’t feel reassurance…feeling about wanting to die…thinking many things negatively about myself.” (SP – 05) “When I watched actors act aggressive scene, I immediately reacted angrily. I didn’t realised my finger roll back [performing a fist] as if I am ready to join the fight. I didn’t have this before the stroke. This happen whenever I watch DVD movie involving fighting. When I think I lost during the fight, I often feel irritated		1.2. Feeling of unbearable stress	“I do feel stress too. Whatever he [the stroke patient] wants, that needs to be done quickly. For example, helping him with shower, preparing meals… everything needs to be hurried. I often feel pressure and stress. It hurts my feet when I walk too fast. I just can’t [walk fast]. But, this [delay] made him resent and said that I am so slow.” (CP – 03).	Over 95% of the nurses agreed that knowledge about impact of stroke were required on cognitive functions (Q14 item f: mean 4.43, SD 0.59) and emotional wellbeing (Q14 item e: mean 4.47, SD 0.59)	About 94% of the nurses agreed that recognising the signs and symptoms and impact of psychological and emotional problems after stroke were need for stroke nurses (Q15 item k: mean 4.40, SD 0.60)	

and angry.” (SP – 12) “*At the beginning I am using a wheelchair, [now] Allhamdulilah...initially using walking stick...then I managed to stand with minimal support. Allhamdulilah. You needs to have a strong heart [courage and determination]. Of course it was difficult at the earlier stage, but once you used to it [being independent], then it will be easier.” (SP – 17)*	*“…I do feel stress especially if I feel physically exhausted. But I try to control this feeling [stress]…not to feel offended [by too much care activities works]. If I am too sensitive, at the end I am the one who suffer too. So, I just leave it as it was. Eventually, I will be fine and feel okey…no longer feeling stress.” (CP – 02)*	*About one-fifth (14.9%) of the nurses were uncertain about competency requirement to assess and manage patient’s motivation. (Q15 item h: mean 4.12, SD 0.68)*
Interpretation of merged data: Findings from both the datasets showed complementarity between sample groups regarding the emotional disturbances after the stroke (qualitative data) and the requirement for stroke rehabilitation nurses to be knowledgeable and competence (quantitative data) to support patient and carer’s emotional crisis. However, individuals’ interviews revealed that the emotional issues often left undetected or not shared with the therapists. This finding indicates that nurses recognised the consequences of stroke on patients and the carers’ emotional wellbeing. **Interpreted finding:** Impact of stroke beyond physical sequelae		

Findings and quotation from interviews with Stroke Participants (SP)			Findings and quotation from interviews with Stroke Carer Participants (CP)			Corresponding findings from the Questionnaire items (N=101)		
Theme	Subtheme	Examples of the Interview Quotes	Theme	Subtheme	Examples of the Interview Quotes	Questionnaire Main Constructs ***KAU***	 ***SAB***	 ***BAR***
	1.3. Feeling of socially restricted	"Before I got stroke, I like doing gardening at our backyard. But now [after has a stroke], I am only watching TV. On my typical day, I took my medicine, went to my room, switch AC and then watch TV for 24 hours. If I wanted to go downstairs, my sister [carer] already warned me not to leave my room. Because she concern that I may fall which can be fatal." (SP – 12) "…even with my family if they wanted to go anywhere, I can't join them. Like with this condition at that time, I am still using the walking stick…so it was difficult to join them. It was not because		1.3. Feeling unable to do what I would like to do	"When he first got the stroke, it was like 24 hours. I need to stay with him. I can't take my own leisure time. In fact, he [stroke person] only allowed me to take shower for five minutes. If I wanted to prepare meal for him, I need to be hurry because he will started searching [calling] me. If I delayed before attending him, he will started to cry because he taught that I'm abandon him. That's why during the early stage he has the stroke, I am beside him for most of the 24 hours." (CP – Pilot02)	Over 95% of nurses agreed that understanding the implication of stroke to social relationship (Q14 item i: mean 4.44, SD 0.61) and acceptance in the community (Q14 item b: mean 4.45, SD 0.59) were needed for stroke nurses.	Over 90% of the nurses agreed that recognising the sign and symptoms and impact of social and relationship problems after stroke is required abilities for stroke nurses. (Q15 item o: mean 4.33, SD 0.62) One-fifth of the nurses were uncertain that identifying resources to help with participation and inclusion were required competency	More than half of the nurses agreed that work related responsibility (Q16 item m: mean 3.81, SD 1.12) and own responsibilities (Q16 item l: mean 3.69, SD 1.05) could be barriers to attend training.

<table>
<tr><td>they don’t want to bring me…I felt limited and difficult to walk…and then if I wanted to use the [public] toilet...it will be very difficult [to find toilet for people with disability]. Everything were difficult. So [I] felt like didn’t want to go anywhere. And at time, I felt embarrassed to go for shopping because everyone’s eyes will be on me. So that part of negative consequences [of stroke on social activities].” (SP – 18)</td><td></td><td>for stroke nurse. (Q14 item g: mean 4.08, SD 0.73)</td></tr>
<tr><td colspan="3">Interpretation of merged data:
Findings from both the datasets showed agreements between sample groups regarding the social restriction after the stroke (qualitative data) and the requirement for stroke rehabilitation nurses to be knowledgeable and competence (knowledge and Skills abilities data) to support community reengagement and social relationships. However, the challenges for nurses to attend training related to personal and work-related commitment may suggest these nurses have potential roles to support the patients’ social functioning.
Interpreted finding: Feeling loneliness and social isolation</td></tr>
</table>

Findings and quotation from interviews with Stroke Participants (SP)			Findings and quotation from interviews with Stroke Carer Participants (CP)			Corresponding findings from the Questionnaire items (N=101)		
Theme	Subtheme	Examples of the Interview Quotes	Theme	Subtheme	Examples of the Interview Quotes	Questionnaire Main Constructs		
						KAU	***SAB***	***BAR***
	1.4. Feeling closer to Allah	“I have no problem. Performing prayers and spiritual practices were easier after the stroke… [there were] plenty of time compared to when I was healthy.” (SP – 04) “Another grateful thing was...this is one of the thing that gave me strength…till I didn’t feel the negative side of the stroke…which is I still could breathe…I still have time to repent. It not that Allah took my life immediately, but He introduce it [feeling of dying] gradually. He still give me chance to repent, where some people may didn’t have any		1.4. Being positive and self-imposed	“I don’t want to think too much about it [caring a stroke patient] because I believed it was destiny to look after sick people. I am sincere and being redha...thus I feel normal [no negative impact from caring a stroke patient].” (CP - 12) “I don’t want to think too much about it [caring a stroke patient] because I believed it was destiny to look after sick people. I am sincere and being redha...thus I feel normal [no negative impact from caring a	Majority of the nurses (97%) agreed that knowledge regarding impact of stroke to ADL is required by stroke nurse. (Q14 item k: mean 4.48,SD 0.56)	Most nurses (96.1%) agreed that stroke rehabilitation nurses should have abilities to assist post-stroke social and cultural integration. (Q15 item j: mean 4.39, SD 0.57)	

		chance to repent at all and they just passed away. So, that was the one [surviving stroke] I focus on. I feel closer to Him [Allah] and be on the right path…so that how I goes back to Him [Allah].” (SP - 18)			stroke patient].” (CP - 12)			
Interpretation of merged data: Findings from the qualitative data reveals the positive implications of stroke on patient’s religious and spiritual practices. The quantitative data support that recognising the Muslim’s daily activity of living, such as prayers, and integration to cultural practices were skills and knowledge required by the stroke rehabilitation nurses. **Interpreted finding:** Faith and spirituality as coping strategy after stroke								

Findings and quotation from interviews with Stroke Participants (SP)			Findings and quotation from interviews with Stroke Carer Participants (CP)			Corresponding findings from the Questionnaire items (N=101)		
Theme	Subtheme	Examples of the Interview Quotes	Theme	Subtheme	Examples of the Interview Quotes	Questionnaire Main Constructs		
						KAU	***SAB***	***BAR***
Theme 2: Existing rehabilitation support provision	2.1 Rehabilitation service and therapist roles	“We came here for the therapy, [the benefits] we learn [about the exercise] that I didn’t know before…and from not able to do, [now] I able to do.” (SP – 17)	Theme 2: Rehabilitation support network	Therapist presence and support	We didn’t know about the therapy. So we learn how to do the exercises at home. Even though there is no appropriate equipment at home. So far,	About 94.1% of the nurses agreed that having a knowledge regarding the principles of stroke rehabilitation and their	Over 90% of nurses frequently identified the need for stroke rehabilitation nurse have competency when to refer	Near half of the nurses (48.5%) agreed that the training is not related to their current

		"The therapists here…at this rehabilitation centre…those who teaches us about the exercises were so special…they were gentle and showed continue support and care. I feel very happy…there was no worry at all." (SP – 08) "One week [of the therapy] is not enough…if two…like previously twice a week." (SP – 03). "…the timing [of the therapy] is not enough. Here [at the rehabilitation centre], it was allocated 30 minutes…not enough. Preferably one hour per session…" (SP – 04). *"…we want to recover [from stroke]. If we didn't*			they [therapists] gave us lots of advices on how to do exercise at home." (CP - 08) I think if he [stroke patient] come here only once a week, I don't' think he's improving. But, if he come here every day, definitely yes. His exercise will be okey. But, for now only once in each week. So I think like there is nothing. Because it [therapy] only last about thirty minute to forty-five only. So I don't think attending the current therapy is important, unless it [therapy] was provided every day. [However], if	application were required to support patients' physical recovery (Q14 item c: mean 4.51, SD 0.61)	the patients for specialist rehabilitation therapy (Q15 item e: mean 4.28, SD 0.67)	practise (Q16 item h: mean 3.35, SD 1.15) is barrier to attend educational training

		come here [rehabilitation centre], our recovery will be slower. But with existing rehabilitation therapy here, Alhamdulillah…at least we can reapply the exercises at home." (SP – 04)			one day and 45 minutes only, I don't think so [important].") (CP – 17)			

Interpretation of merged data:
Findings from both dataset showed complementarity with regard to existing out-patient rehabilitation therapy provision. The participants with stroke and the carer sample groups reveals dissatisfaction with timing and intensity of therapy provided (qualitative data) and how this shortfall can be address by providing knowledgeable and competence (quantitative data) stroke rehabilitation nurses. However, number of nurses also felt that the rehabilitation stroke nurse training is not relevant to their present roles. This finding demonstrate that nurses were aware and anticipate the importance of continue rehabilitation post-stroke in order to sustain the recovery for the patients with stroke.
Interpreted finding: Inadequacy with the existing out-patient therapy provision

Findings and quotation from interviews with Stroke Participants (SP)			Findings and quotation from interviews with Stroke Carer Participants (CP)			Corresponding findings from the Questionnaire items (N=101)		
Theme	Subtheme	Examples of the Interview Quotes	Theme	Subtheme	Examples of the Interview Quotes	Questionnaire Main Constructs		
						KAU	***SAB***	***BAR***
	2.2 Roles of carer in rehabilitation	"Whatever I can do, I will do myself…but if not, I asked my wife to help me, such as lifting the affected feet for exercises." (SP – 10)		2.2 Relieve carer at home	"I have other brother, but he hardly give attention and keen to involve. So, I have to care him [stroke patient] alone. I	The majority of the nurses agreed that stroke has direct impact and negative implications on the stroke	Nearly 90% of nurses agreed that helping family of stroke patient to cope with the event after	

		"...transportation is difficult. I can't go anywhere because of no transport. If we run out of our food supply, I only hope for my neighbour [to drive for shopping], but only if he is available to help. I tried to call my son who can drive and request to send me to the shop. [But] he [son] didn't turn-up. Eventually, I have to prepare the foods from whatever stock available. But it was difficult to do this [cooking] because of my stroked hand. I don't mind not eating but how about my son. He's still very young...he will feel hungry...but what can he eat?" (SP – 15) *"I need certain people such as outsider. If siblings…they have*			feel pity at him [stroke patient], but if nobody care then eventually I will suffer too." (CP – 12) "I didn't have time [for myself]. [I spend] lots of time with him [the stroke patient]. Our children only come to help occasionally, either Sunday or Friday." (CP – 03) *"At this moment I do not have amah (paid carer). Probably I'll get*	patient's family. The need for the stroke rehabilitation nurses having knowledge and understanding regarding these aspects were demonstrated. (Q14 item a: mean 4.50, SD 0.54; item b: mean 4.45, SD 0.59 and item i: mean 4.44, SD 0.61)	stroke is a skills and abilities needed for a rehabilitation stroke nurse (Q15 item p: mean 4.32, SD 0.66)	

		their own work to do. So I need someone who are really free and not someone who mostly occupied. Like most of my family members already married and I know they have their own responsibilities….Similarly my mum. So, I have to out-source my support care." (SP – 18)			*one in the future. I am not sure yet. But, if there is amah, we can't certain that she knows how to care a stroke patient, thus [hiring them] can be risky.") (CP – Pilot01)*			

Interpretation of merged data:
Findings from both the datasets showed concordance between sample groups regarding the need for continue support at home (qualitative data) and the requirement for stroke rehabilitation nurses to be knowledgeable and competence (quantitative data) for managing this lacked of support at home. This finding demonstrate that nurses were aware and anticipate the challenges experience by patients with stroke and their carer during transition home from the hospital care.
Interpreted finding: Inadequacy of family support structure at home

Findings and quotation from interviews with Stroke Participants (SP)			Findings and quotation from interviews with Stroke Carer Participants (CP)			Corresponding findings from the Questionnaire items (N=101)		
Theme	Subtheme	Examples of the Interview Quotes	Theme	Subtheme	Examples of the Interview Quotes	Questionnaire Main Constructs		
						KAU	***SAB***	***BAR***
	2.3 Role of traditional practitioner	"I normally attempt finding outside therapy such as massage or cupping from religious		2.3 Seeking rehabilitation resources	"At the beginning he [stroke patient] cannot walk. So we called someone to do	Over three-quarter of the nurses (87.1%) agreed the		

<table>
<tr><td></td><td></td><td>practitioner. Alhamdulillah, there are some progress.” (SP – 16)
“if he (stroke patient) already at home, we [family] will search for someone who know how to apply urut. I heard a lot that so many [stroke patients] recovered [after urut]. There was no other treatment but urut is a must.” (SP – 17)
“Actually half of my body was affected...but through therapy somehow and also massage…traditional urut…somehow I could walk again.” (SP – 18)</td><td></td><td></td><td>urut at home. By Mercy of God (Allah Ta’ala), only then he can walk again without using a wheel chair…he only uses walking stick.” (CP – 10)
<i>“He [patient] complained cannot walk. So, I called the traditional practitioner to perform urut hoping this treatment can make him walk again.” (CP – 12)</i></td><td>knowledge requirement for a stroke rehabilitation nurse in any existing support services and resources available for stroke patients (Q14 item o: mean 4.18, SD 0.64)</td><td></td><td></td></tr>
<tr><td colspan="9">Interpretation of merged data:
Findings from the qualitative data reveals that the participants with stroke and their carer utilises traditional resources as methods to provide additional rehabilitation support and recovery. The nurses indicated that a stroke rehabilitation nurse should have knowledge about available support services for stroke. However, it was not clear if this traditional practices was included for stroke patients support resources. This finding demonstrate the importance of traditional and cultural practices as support resources in stroke rehabilitation.
Interpreted finding: Seeking traditional therapy to support rehabilitation</td></tr>
</table>

Findings and quotation from interviews with Stroke Participants (SP)			Findings and quotation from interviews with Stroke Carer Participants (CP)			Corresponding findings from the Questionnaire items (N=101)		
Theme	Subtheme	Examples of the Interview Quotes	Theme	Subtheme	Examples of the Interview Quotes	Questionnaire Main Constructs ***KAU***	***SAB***	***BAR***
Theme 3: Rehabilitation support needs for stroke patients	3.1 Self-care needs and priorities	"All this time, I have to sit when performing a prayer. I can't bend my body forward because it will be difficult to get up again…so that's one thing that I really wanted to do." (SP - 18) "Occasionally I sit on the chair and play with our children. But, I can't do this any longer because it will hurt my back if sitting too long.") (SP – 05) "Performance of prayer was based on what could I do best. But, most of the time it was not entirely perfect. I only can sit to perform prayer and do how much I can do." (SP – 17)	Theme 3: Caregiver support needs	3.2 Preparation for continued rehabilitation roles	"I felt difficulty during transitional period from hospital to the house. At home, it was extremely difficult. For the first time I felt lost. To help him [her dad] with shower, I felt so awkward. I don't know what to do." (CP - 17) "At the early stage of the rehabilitation, what can we help [the stroke patient] to recover quickly. In the aspect of physical movement, what can the stroke patient do at the early stage? They cannot be laying on the bed whole times. There should be		Over 90% of the nurses agreed that providing interventions relevant to the stroke patients and carer's individual needs (Q15 item b: mean 4.34, SD 0.61) and using therapeutic moving and handling (Q15 item i: mean 4.30, SD 0.63) were required competencies for stroke rehabilitation nurses.	

					exercises that we can do to help him recover. I was cautioned about shoulder dislocation, but how [to prevent this?]. What is the right way? I wish to perform the exercises so he can reactivate his stroked limb.” (CP – 01) “*At times, the nurses provided the teaching in the ward. Here, [rehabilitation centre] the exercise was taught by the Physiotherapist. I knew this because I always sent her to the centre and look after in the ward. So, they whom actually teaches us what and how to do it [exercise]*			

					at home.” (CP - 02)			

Interpretation of merged data:
Findings from both the datasets illustrates complementarity data between sample groups regarding the stroke patients’ priority needs and their performance. The qualitative data suggested that the participant with stroke daily needs were unmet or not satisfying. The quantitative data showed the requirement for stroke rehabilitation nurses to be skilful and competence to identify patients’ individual needs. This finding indicates the stroke rehabilitation nurses may have potential to facilitate the stroke patient accomplishing their goals
Interpreted finding: Achieving individuals needs and goals

Findings and quotation from interviews with Stroke Participants (SP)			Findings and quotation from interviews with Stroke Carer Participants (CP)			Corresponding findings from the Questionnaire items (N=101)		
						Questionnaire Main Constructs		
Theme	Subtheme	Examples of the Interview Quotes	Theme	Subtheme	Examples of the Interview Quotes	***KAU***	***SAB***	***BAR***
	3.2 Presence of rehabilitation nurses at home	“If there is any [stroke nurses], this will be beneficial for monitoring stroke patients, especially for those who lacked family support, no immediate assistance apart from the Welfare section...so the nurses [stroke nurses] can help these patients from their aspect of health.” (SP – 15) “..it will be good if they [nurses] are available to us. They can give us		3.3 Role of stroke rehabilitation nurses	“What I want was the nurses know how to do the exercise…skills in therapy…so that the patient can recovery soon. And the nurses have experience about the therapy and provide support to assist with the stroke patient recovery.”) (CP - 12) “Of course the nurses can help us. If there is nurses who are more competent,		The majority of the nurses (96.5%) agreed that a stroke rehabilitation nurse should have competency in the aspect of providing advice and support; communicate and discuss of events, risk, need for interventions and treatments, rationales for	Over one-third of the nurses (44.6%) indicates lack of interest (Q16 item e: mean 3.28, SD 1.11) is barrier to attend the educational training.

		courage…and so can help our recovery…then can help teach us how to control emotions. It was like someone is monitoring us.” (SP - 04) “If there is one role of the nurses, it will be with regard to exercise that was taught by the therapist. It will be good if the nurses available so that they can improve our rehabilitation after coming from here {the rehabilitation centre].” (SP - 10) *“…That [nurse visit] is not needed. Don’t need nurses to do home visits. Now, no no. No need for nurses because I can walk now. Gradually walking. My maid can help*			Alhamdulillah, they can support us in providing that therapy [on the stroke patient].”) (CP - 08) “I think if there were nurses doing home visit, it would be better. One hour performing the exercise should be enough. Such as, my wife still has problem with walking, so those exercise could focus on supporting her to walk.” (CP – Pilot01) *“I have done this [caring the stroke patient] for so many years, I don’t feel this [nursing home visit] is necessary. I already have experience which*		treatment and possible side effects of treatments. (Q15 item d: mean 4.41, SD 0.55)	

		me at home. I can do it independently at home." (SP – 20). *"., if they [the stroke patient] can come to the hospital [rehabilitation centre], that [stroke rehabilitation nurses] is probably not needed. If they [the nurses] come to our home, my concern is that maybe the person has no initiative to change [relying on the visit]". (SP – 01)*			*was enough to assist him [stroke patient] well. All this while, I have been doing this task alone and I felt very satisfied with his progression." (CP – 13)* *"I don't think support from them [stroke nurse] was for me. Because at home, my duty was like a nurse. I can do whatever the nurses does such as check BP, blood sugar…So I don't felt any difficulties [burden], even if without the nurses' presence [home visit]." (CP – Pilot02)*			
Interpretation of merged data: Findings from both the datasets indicates differing views between sample groups with regard to the potential roles of stroke rehabilitation nurses (qualitative data) and the skills and abilities required (quantitative data) for these nurses. Although, those who disagreed were represented by small number of participants. The potential barrier to attend the training in relation to lack of interest could be a challenge to assume those roles. This finding suggests that role of nurses in stroke rehabilitation were largely focuses on providing health teaching and reinforce therapy learnt. **Interpreted finding:** The need for skilled nurse in stroke rehabilitation								

Findings and quotation from interviews with Stroke Participants (SP)			Findings and quotation from interviews with Stroke Carer Participants (CP)			Corresponding findings from the Questionnaire items (N=101)		
Theme	Subtheme	Examples of the Interview Quotes	Theme	Subtheme	Examples of the Interview Quotes	Questionnaire Main Constructs ***KAU***	***SAB***	***BAR***
	3.3 Needing a sense of belonging	We need to go out from the house…so like that gathering [with other patients], can be an open conversation and making jokes so we can forget about our condition. If we are alone, we tend to think about the condition [problems].” (SP – 04) “It can be good...get together...If we can gather four to five people [stroke patients]...can share stories. I think it will good to make our body healthier and comfort our feelings.”) (SP – 14)				Over three-quarter of the nurses (87.1%) agreed the knowledge requirement for a stroke rehabilitation nurse in any existing support services and resources available for stroke patients (Q14 item o: mean 4.18, SD 0.64)	About 49.2 % (*n*=80) of the nurses agreed that identifying resources to help with the stroke patients’ participation and inclusion was required competencies for the stroke rehabilitation nurses (Q15 item g: mean 4.08, SD 0.73)	
Interpretation of merged data:								

Findings from both the datasets illustrates complementarity data where participants with stroke desire to seek companionship outside their home (Qualitative data) and the requirement for the stroke rehabilitation nurses to be skilful in assisting patients with stroke to reintegrate into the community through available resources (Quantitative data).
Interpreted finding: Seeking togetherness and sense of belonging

Findings and quotation from interviews with Stroke Participants (SP)			Findings and quotation from interviews with Stroke Carer Participants (CP)			Corresponding findings from the Questionnaire items (N=101)		
Theme	Subtheme	Examples of the Interview Quotes	Theme	Subtheme	Examples of the Interview Quotes	Questionnaire Main Constructs		
						KAU	***SAB***	***BAR***
	3.4 Information needs about stroke	“Before this…before I had the stroke, I was so afraid to read [about the disease]. I don’t want to read [fear that she will get a stroke]…in denial…But now…yes, I do read various books and sought info about stroke” (SP – 18) I actually don’t know about a stroke. But this term usually used by the doctor. In our local understanding, it [the disease] is caused by Angin Ahmar…because of		3.1 Understanding rehabilitation and signs of secondary stroke	“I think it was necessary for every family member to know about it [strokes]. Because, after the incident, the whole family…children surfed the internet. But I think each member of the family should know before a stroke occurs.” (CP – 01)	Over 90% of the nurses frequently identified understanding the cause of, and how to assess, manage and treat problems after stroke (Q14 item j: mean 4.46, SD 0.59) and risk factor for further stroke (Q14 item m: mean 4.43, SD 0.64) were required for the stroke	The majority of the nurses (96.5%) agreed that a stroke rehabilitation nurse should have competency in the aspect of providing advice and support; communicate and discuss of events, risk, need for interventions and treatments, rationales for treatment	

		Angin Ahmar…led to weaknesses on half of my face.”) (SP - 07)				rehabilitation nurses.	and possible side effects of treatments. (Q15 item d: mean 4.41, SD 0.55)	

Interpretation of merged data:
Findings from both the datasets showed concordance between sample groups regarding the need for information about stroke (qualitative data) and the requirement for stroke rehabilitation nurses to be knowledgeable and competence (quantitative data) in several aspects of stroke care and management. This finding demonstrate the importance of promoting education about stroke to the public and nurses may have a role in stroke preventative interventions.
Interpreted finding: The need of stroke education and prevention

Findings and quotation from interviews with Stroke Participants (SP)			Findings and quotation from interviews with Stroke Carer Participants (CP)			Corresponding findings from the Questionnaire items (N=101)		
Theme	Subtheme	Examples of the Interview Quotes	Theme	Subtheme	Examples of the Interview Quotes	Questionnaire Main Constructs		
						KAU	***SAB***	***BAR***
	3.5 Financial support needs	“...it’s about financial matters...about spending. Because I live with my son and didn’t feel right asking help [money] from him. I am no longer work. So it was difficult [problems other than the stroke]. I spent my elderly allowance to buy foods and helping my grandchildren. But,				About 95% (*n*=96) nurses frequently identified that the stroke rehabilitation nurses should have understanding and knowledge regarding the implication of stroke for patient’s		

		the allowance was not enough.” (SP – 14). “...at this moment, I only received $250 old-age pensioner’s allowance. It was far from enough....Ya Allah...it was not enough. Normally, the assistance [financial] given by the Welfare Department is about $300-$400 per month. I hope the authority concerned can consider us [entitlement]. Relying on existing allowance was not enough.” (SP – 13)				lifestyle, driving, work and family (Q14 item b: mean 4.45, SD 0.59)		

Interpretation of merged data:
Findings from the qualitative data reveals the implications of stroke on patient’s financial support and welfare. The nurses indicated that understanding the implication of stroke on patients’ lifestyle (Quantitative data) was required for promoting patients’ quality of life. This finding suggested that the scope of support care for stroke patients outside the hospital should consider financial challenges.

Interpreted finding: Financial difficulties after stroke

A Joint Display illustration for divergent findings from the Qualitative Findings (for Stroke Patient and Carers) and Questionnaire Data for the Phase One Study in relation to the aspect: The need for skill nurse in stroke rehabilitation

Descriptors:

SD=Standard Deviation, Scoring (Lowest = 1, Highest = 5)
KAU=Knowledge and Understanding (items a to q): ***SAB*=**Skills and Abilities (items a to r): ***BAR*=**Barrier to attend training (items a to q): **Q=**BruNEIS Questionnaire
SP=Stroke Participants (N=21), **CP**= Carer Participants (N=18)

Findings and quotation from interviews with Stroke Participants (SP)	Findings and quotation from interviews with Stroke Carer Participants (CP)	Corresponding findings from the Questionnaire items (N=101)
Examples of the Interview Quotes	Examples of the Interview Quotes	Construct: Training need for community stroke rehabilitation nurse
“[Stroke nurses] were not needed. Don’t need nurses to do home visits. Now, not needed because I can walk now. My walking is slowly improving. I have maid to help me at home. Additionally, I can do it [self-care] independently at home.” (SP – 20)	I have done this [caring the stroke patient] for so many years, I don’t feel this [nursing home visit] is necessary. I already have experience which was enough to assist him [stroke patient] well. All this while, I have been doing this task alone and I felt very satisfied with his progression.”) (CP – 13) “I don’t think support from them [stroke nurse] was for me. Because at home, my duty was like a nurse. I can do whatever the nurses does …So I don’t felt any difficulties [burden], even if without the nurses’ presence [home visit].” (CP – Pilot02)	About 13.9% (N=14) of nurse participants were either disagreed or uncertain about the need of nurses’ training in stroke rehabilitation.

Appendix 8: Example of Memo

I encountered a difficult translating one of the words in one interviews. I think the word is so important and very relevant to the study. Below the excerpt of the participant;

The scenario:

"I think yang di tekan kan ialah apa tu..treatment calak Brunei dan keIslaman. Dua atau bah yang penting. Of course lah kitani dari segi perubatan internationally kan..piawian International. Tapi I think yang perlu di terapkan jua ialah keBruneian dan Islamic atu. Because Islamic atu..kitani ada doa-doa, so kitani berikan tah risalah…doa ani atu atu..macam atu. (CP – 01)

TRANSLATED TO: ("I think what needed to be emphasised in treatment of stroke is the integration of Bruneian Malay identity (Calak Brunei) and Islamic practices. Both of these elements are essential. Of course, we follow the international standard, but I think the Bruneian and Islamic approaches of treatments, such as prayer, must be embraces by the nurses.") (CP – 01)

Memo

"This is a Malay word from 'Calak' which in direct translation to English can means 'mould' or 'shape'. But it goes beyond that translation. 'Calak' may also mean 'image', 'identity' or in traditional weeding custom can refer to 'make-up'. But, reading to the context of the interview, the participant referring to 'calak' Brunei. This means the role of the nurses should reflecting the concept of MIB

Some of the Malay words used by the participants are very difficult to give direct translation to the English words. If left untranslated or if I direct translate, the meaning may distorted and the context will not be understandable by the reader. Therefore, I decided to give translation of the words based on the approximate meaning. Because of this, I have decided to analyse the interview data and only translate at the end of the producing themes. This incident inform me how without retaining the context of the participants' experience, I may lost the essence of the true story and may not able to represent participants' voice. Secondly, I learnt that retaining participants' voice allow me to avoid my personal bias and interpretation.

List of references

Abdul Rani, AA, Shamsuddin, S, Abdullah, Z, Abdul Halim, NH, Mustaoha, N, & Muhamad, NA. (2015). Massage therapy for improving functional activity after stroke. Cochrane Database of Systematic Reviews, from John Wiley & Sons. Ltd. http://onlinelibrary.wiley.com/doi/10.1002/14651858.CD011924/pdf

Abd. Rashid, A. (2013) Investigating the Self-Management model from the Islamic perspective. *Asian Journal of Social Science & Humanities.* 2(2), 1 - 9.

Abdul Razak N.U., Anuar A.R., Pg Mohd Sahar, S.N.I. & Matsuni N.H. (2015) Domestic Maids in Brunei: A Case study. WOrking Paper No. 14. *Institute of Asian Studies*. Universiti Brunei Darussalam. Available at http://ias.ubd.edu.bn/wp-content/uploads/2018/09/working_paper_series_14.pdf

Adamit, T, Maeir, A, Assayag, EB, Bornstein, NM, Korczyn, AD, & Katz, N. (2015). Impact of first-ever mild stroke on participation at 3 and 6 months post-event: the TABASCO study. *Disability and Rehabilitation, 37*(8), 667-673.

Ahmad, K, Sulaiman, I, Ariffin, S, Mohd Yusuf, MY, & Abdullah, M (Eds.). (2014). *Religion and Alternative Medicine: Issues on using Ruqyah (Incantation) among Malay-Muslim Practices* (Vol. 1). Malaysia: Globalilluminators.

Ahmad, N. (2014) Fertility Decision-making among women in Brunei: Values and the fluid nature of rezeki. *Conference Proceeding for Korea-Asean Co-operation Project.* 28th - 31st October, 2014, Penang, Malaysia

Ahmad, N. (2018) Attitude towards family formation among young adults in Brunei Darussalam. *Pakistan Journal of Women's Studies: Alam-e-Niswan.* 25(1), 15 - 34.

Alaqeel, Ahmed, AlAmmari, AlBatool, AlSyefi, Nourah, Al-Hussain, Fawaz, & Mohammad, Yousef. (2014). Stroke Awareness in the Saudi Community Living in Riyadh: Prompt Public Health Measures Must Be Implemented. *Journal of Stroke and Cerebrovascular Diseases, 23*(3), 500-504. doi: http://dx.doi.org/10.1016/j.jstrokecerebrovasdis.2013.04.011

Al-Awwa, M. (2002) Some basic health principles. *Arab News.* [Online] Available at https://www.arabnews.com/node/222142. Accessed 30/11/2019

Alfred, M., Ubogaya, K., Chen, X., Wint, D. & Worral, P.S. (2016) Effectiveness of culturally focused interventions in increasing the satisfaction of hospitalized Asian patients: a systematic review. *JBI Database of Systematic Reviews and Implementation Reports.* 14(8), 219 - 256. DOI: 10.11124/JBISRIR-2016-003048

Ali, M. (2018) Communication 4: the influence of appearance and environment. *Nursing Times* [online]; 114: 3, 46-47.

Ali, M.F., Abdul Aziz, A.F, Rashid, M.R, Che Man, Z., Amir, A.A., Shien, L.Y & Zainal Abidin, N.A. (2015). Usage of Traditional and Complementary Medicine (T&CM): Prevalence, Practice and Perception among Post Stroke Patients attending conventional Stroke Rehabilitation in a teaching Hospital in Malaysia. *Medical Journal Malaysia, 70*(1), 18-23.

Almborg, AH, Ulander, K, Thulin, A, & Berg, S. (2010). Discharged after stroke - important factors for health-related quality of life. *Journal of Clinical Nursing, 19*, 2196-2206.

Alqahtani, MMJ. (2015). Understanding the Sociocultural Health Belief Model influencing health behaviors among Saudi Stroke survivors. *Neuroscience & Medicine, 6*, 149-159.

American College of Physicians (2010) Healthcare Transparency - Focus on price and clinical performance information. [Online] Availabe at https://www.acponline.org/acp_policy/policies/healthcare_transparency_2010.pdf Accessed 10/12/2019

Andersen, HE, Eriksen, K, Brown, A, Schutz-Larsen, K, & Forchammer, BH. (2002). Follow-up services for stroke survivors after hospital discharge - a randomised control trial. *Clinical Rehabilitation, 16*, 593-603.

Appelros, A, Stegmayr, B, & Terent, A. (2009). Sex differences in Stroke Epidemiology. *Stroke, 40*, 1082-1090.

Asadi-Lari, M., Packham, C. & Gray, D. (2003) Need for redefining needs. *Health Quality Life Outcomes.* 1(34), 1-5.

Ashraf, V. V., Maneesh, M., Praveenkumar, R., Saifudheen, K., & Girija, A. S. (2015). Factors delaying hospital arrival of patients with acute stroke. *Annals of Indian Academy of Neurology, 18*(2), 162-166. doi: 10.4103/0972-2327.150627

Aslani, Z, Alimohammadi, N, Taleghani, F, & Khorasani, P. (2016). Nurses' Empowerment in Self-Care Education to Stroke Patients: An Action Research Study. *International Journal of Community Based Nursing and Midwifery, 4*(4), 329-338.

Association of Rehabilitation Nurses. (2015). Certification: Definitions and scope of practice. Retrieved 14/10/2015, from http://www.rehabnurse.org/certification/content/Definition-and-Scope.html

Ayerbe, L, Ayis, S, Wolfe, CDA, & Rudd, AG. (2013). Natural history, predictors and outcomes of depression after stroke: systematic review and meta-analysis. *The British Journalof Psychiatry, 202*, 14-21.

Aziz, NA, Leonardi-Bee, J, Phillips, ME, Gladman, JRF, Legg, LA, & Walker, M. (2009). Therapy-based rehabilitation services for patients living at homemore than one year after stroke (Review). Retrieved from The Cochrane Library website: http://onlinelibrary.wiley.com/doi/10.1002/14651858.CD005952.pub2/pdf/standard

Bakas, T, Clark, PC, Kelley-Hayes, M, King, RB, Lutz, BJ, & Miller, EL. (2014). Evidence for stroke family caregiver and dyad inteventions: A statement for Healthcare Professionals from the American Heart Association and American Stroke Association. *Stroke, 45*, 2836-2852.

Baker, M. (2012). Education requirements for nurses working with people with complex neurological conditions: Nurses' perceptions. *Nurse Education Today, 32*(1), 71-77.

Balnaves, M, & Caputi, P. (2001). *Introduction to Quantitative Research Methods: An investigative approach*. London: Sage Publications Ltd.

Bangash, Mohammed Hasan, Alsufyani, Hadeel Ahmed, Karami, Mohammed Matoog, Qadi, Hasan Hatem, Khayat, Wujood, Adas, Maryam Ahmed, & Zaher, Mohammad Alameen Faisal. (2016). The effect of bowing and kneeling on lower back muscle.

Barber, P. A., Zhang, J., Demchuk, A. M., Hill, M. D., & Buchan, A. M. (2001). Why are stroke patients excluded from TPA therapy?: An analysis of patient eligibility. *Neurology, 56*(8), 1015-1020. doi: 10.1212/wnl.56.8.1015

Barlow, J. H., Sturt, J., & Hearnshaw, H. (2002). Self-management interventions for people with chronic conditions in primary care: Examples from arthritis, asthma and diabetes. *Health Education Journal*, *61*(4), 365–378. https://doi.org/10.1177/001789690206100408

Bates, C, Droste, C, Cuba, L, & Swingle, J. (2008). One-on-one interviews: A Qualitative Assessment Approach. http://web.wellesley.edu/NECASL/Pdf/11.10.08Mixed%20Methods%20presentation%20for%20web.pdf

BBC. (2015). Brunei country profile. Retrieved 21/12/2015, from http://www.bbc.co.uk/news/world-asia-pacific-12990058

Bennett, B. (2016). A culture of caring: how nurses promote emotional wellbeing and aid recovery following stroke. *British Journal of Neuroscience Nursing, 12*(Sup5), S20-S27.

Bharmal, N, Lucas-Wright, A, Vassar, SD, Jones, F, Jones, L, Wells, R, . . . Brown, AF. (2016). A Community Engagement Symposium to Prevent and Improve Stroke Outcomes in Diverse Communities. *Progress in community health partnerships : research, education, and action, 10*(1), 149-158.

Birbili, M. (2000). Translating from one language to another. *Social Research Update,* (31). http://sru.soc.surrey.ac.uk/SRU31.html

Blismas, NG, & Dainty, JR. (2003). Computer-aided qualitative data analysis: pancea or paradox? *Building research and information, 31*(6), 455-463.

Boktah, N (2019) Ramadhan Reminder: Loving Yourself is Loving Allah, why self care is Ibadah.*Amaliah.* [Online] Available at https://www.amaliah.com/post/43133/self-care-is-ibadah-muslim-womens-day-celebrates-self. Accessed 24/11/2019

Booth, J, Hillier, VF, Waters, K, & Davidson, I. (2005). Effects of a stroke rehabilitation education porgramme for nurses. *Journal of Advanced Nursing, 49*(5), 465-473.

Borneo Bulletin. (2014). *Borneo Bulletin Yearbook 2014*. Brunei: Brunei Press Sdn Bhd.

Bouffioulx, E, Srnould, C, & Thonnard, JL. (2011). Satisfaction with activity and participation and its relationships with body functions, activities, or environmental factors in stroke patients. *Archives physical Medical Rehabilitation, 92*, 1404-1410.

Bowling, A. (2009). *Research Methods in Health: Investigating health and health services* (3rd ed.). Maidenhead: Open University Press.

Boyatzis, RE. (1998). *Transforming qualitative information : thematic analysis and code development* London: Sage.

Braun, V, & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*(2), 77-101.

Brereton, L, & Nolan, M. (2000). 'You do know he's had a stroke, don't you?' Preparation for family care-giving - the neglected dimension. *Journal of clinical nursing, 9*, 498-506.

Brislin, RW. (1970). Back-translation for cross-cultural research. *Journal of Cross-cultural Psychology, 1*(3), 185-216.

Brookfield, Katherine, & Mead, Gillian. (2016). Physical environments and community reintegration post stroke: qualitative insights from stroke clubs. *Disability & Society, 31*(8), 1013-1029. doi: 10.1080/09687599.2016.1223606

Brudirect (2016) Health is Everyone's responsibility. *Brudirect.com* [Online] Available at https://www.brudirect.com/news.php?id=7503 Accessed 27/10/2019

Brunei Resources. (2012). Tourism. Retrieved 02/03/2015, from http://www.bruneiresources.com/tourism.html

Bryman, A. (2012). *Social research methods* (4th edn. ed.). New York: Oxford University Press.

Burton, C, & Gibbon, B. (2005). Expanding the role of the stroke nurse: a pragmatic clinical trial. *Journal of Advanced Nursing, 52*(6), 640-650.

Burton, CR. (2000). A description of nursing role in stroke rehabilitation. *Journal of Advanced Nursing, 32*(1), 174-181.

Butler, M., McCreedy, E., Schwer, N., Burgess, D., Call, K., Przedworski, J., Rosser, S., Larson, S., Allen, M., Fu, S. & Kane,R.L (2016) Improving Cultural Competence to Reduce Health Disparities. *Comparative Effectiveness Reviews,* No. 170. [online] Available from: https://www.ncbi.nlm.nih.gov/books/NBK361126/. Accessed 03/10/2019

Byrne, D. (2020) Evaluating cultural competence in Undergaraduate Nursing students using Standardized Patients. *Teaching and Learning in Nursing.* 15(1), 57 - 60.

Cadilhac, D.A., Hoffmann, S., Kilkenny, M., Lindley, R., Lalor, E., Osborne, R. & Batterbsy, M. (2011) A Phase II Multicentered, Single-Blind, Randomized, Controlled Trial of the Stroke Self-Management Program. *Stroke.* 42, 1673 - 1679.

Camak, DJ. (2015). Adressing the burden of stroke caregivers: a literature review. *Journa of clinical nursing, 24*, 2376-2382.

Cameron, JI, Stewart, DE, Streiner, DL, Coyte, PC, & Cheung, AM. (2014). What makes family caregivers happy during the first 2 year post stroke? *Stroke, 45*, 1084-1089.

Care Quality Commission. (2011). Supporting life after stroke: A review of service for people who have had a stroke and their carers. London.

Carota, A, & Calabrese, P. (2013). Poststroke Emotionalism. *Journal of Neurology Disorders, 1*(4), 1-4.

Catangui, EJ, & Stark, J. (2012). Development and evaluation of an interdisciplinary training programme for stroke. *British Journal of Neuroscience Nursing, 8*(1), 8-11.

Cavanagh, S, & Chadwick, K. (2005). Health Needs Assessment: A Practical Guide. https://www.k4health.org/sites/default/files/migrated_toolkit_files/Health_Needs_Assessment_A_Practical_Guide.pdf

Cecil, R, Parahoo, K, Thompson, K, McCaughan, E, Power, M, & Campbell, Y. (2010). 'The hard work starts now':a glimpse into the lives of carers of community-dwelling stroke survivors. *Journa of clinical nursing, 20*(11-12), 1723-1730.

Cecil, R, Thompson, K, Parahoo, K, & McCaughan, E. (2013). Towards an understanding of the lives of families affected by stroke: a qualitative study of home carers. *Journal of Advanced Nursing, 69*(8), 1761-1770.

Chan, GC, Bassa, B, & Meyding-Lamade, U. (2013). Demographic of stroke: A comparative study between Brunei Darussalam Neuroscience, Stroke and Rehabilitation Centre and Krankenhaus Nordwest, Frankfurt, Germany (Abstracts). *Journal of Neurological Sciences, 333*, e235.

Chen, HY, & Boore, JRP. (2009). Translation and back-translation in qualitative nursing research: methodological review. *Journa of clinical nursing, 19*, 234-239.

Chen, L, Xiao, LD, & De Bellis, A. (2015). First-time stroke survivors and caregivers' perceptions of being engaged in rehabilitation. *Journal of Advanced Nursing, 00,* 000-000.

Christensen, E.R., Golden, S.L. & Gesell, S.B. (2019) Perceived Benefits of Peer Support Groups for Stroke Survivors and Caregivers in Rural North Carolina. *North Carolina Medical Journal.* 80 (3), 143 - 148

Choi-Kwon, S, Han, K, Choi, S, Suh, M, Kim, YJ, Song, H, . . . Kim, JS. (2012). Poststroke depression and emotiional incontinence. *Neurology, 78*(15), 1130-1137.

Chong, V.H., Rajendran, N., & Wint, Z. (2008). Prevalence and predictive factors for complementary and alternative medicine use in Brunei Darussalam. *Singapore Medical Journal,* 49(12), 1012-1016.

Chong, V.H., Telisinghe, P.U., Bickle, I., Abdullah, M.S., Lim, E. & Chong, C.F. (2015) Increasing incidence of colorectal cancer, starting at younger age for rectal compared to colon cancer in Brunei Darussalam. *Asian Pacific Journal of Cancer Prevention.* 16(12), 5063 - 5067.

Churchill, LR. (2015). Embracing a broad spirituality in end of life discussions and advance care planning. *Journal of Religion and Health, 54*(2), 759-764.

Clarke, DJ. (2014). Nursing practice in stroke rehabilitation: systematic review and meta-ethnography. *Journa of clinical nursing, 23*(9-10), 1201-1226.

Clarke, DJ, Tyson, S, Rodgers, H, Drummond, A, Palmer, R, Prescott, M, . . . Forster, A. (2015). Why do patients with stroke not receive the recommended amount of active therapy (ReAcT)? Study protocol for a multisite case study investigation. *BMJ Open, 5*(8).

Code, C, & Herrmann, M. (2003). The relevance of emotional and psychosocial factors in aphasia to rehabilitation. *Neuropsychological Rehabilitation, 13*(1-2), 109-132.

Communication Theory (2010) Physical/Environmental Barriers. [Online] Available at https://www.communicationtheory.org/physicalenvironmental-barriers/. Accessed 13/11/2019

Community Nursing Services. (2012). *Total number of staff and distribution in Community Nursing Services*. Brunei: Community Nursing Services.

Connell, R.W. (2005). *Masculinities* (2nd edn ed.). Cambridge: Polity.

CONSORT. (2015). The CONSORT Flow Diagram. Retrieved 20/12/2015, from http://www.consort-statement.org/consort-statement/flow-diagram

Corry, YM, While, A, Neenan, K, & Smith, V. (2014). A systematic review of systematic reviews on interventions for caregivers of people with chronic conditions. *Journal of Advanced Nursing, 71*(4), 718-734.

Colacion, J.T., Naing, H.L., Harun, N. & Yassin, D.N. (2019) Strokes and Transient Ischemic Attacks in Young Adults in Brunei Darussalam: Demographics, Risk Factors, Etiology and Thrombolysis. Poster Presentation at BNSRC Frontiers Conference. *Brunei International Medical Journal.* 15(s1), s1 - s16, Available at http://www.bimjonline.com/PDF/BIMJ2019;15/BIMJ2019;15(Suppl1)/BIMJ2018;15(Suppl%20I).pdf

Creswell, JW, & Plano Clark, VL. (2011). *Designing and conducting mixed methods research* (2nd edn. ed.). Thousand Oaks, CA: Sage Publications Inc.

Critical Appraisal Skills Programme. (2013). CASP tools & Checklists. Retrieved 01/08/2015, from http://www.casp-uk.net/

Dabrowska-Bender, M, Milewska, M, Golabek, A, Duda-Zalewska, A, & Staniszewska, A. (2017). The Impact f Ischemic Cerebral Stroke on the Quality of Life of patients based on Clinical, Social and Psychoemotional Factors. *Journal of stroke and cerebrovascular diseases, 26*(1), 101-107.

Damush, T.M., Ofner, S., Yu, Z., Plue, L., Nicholas, G.A. & Williams, L.S. (2011) Implementation of a Stroke Self-Management Program: A randomized controlled pilot study of veterans with stroke. *Translational Behavioral Medicine*, 1(4), 561 - 572

Danzl, MM., Harrison, A., Hunter, EG., Kuperstein, J., Sylvia, V., Maddy, K., & Campbell, S. (2016). “A Lot of Things Passed Me by”: Rural Stroke Survivors’ and Caregivers’ Experience of Receiving Education From Health Care Providers. *The Journal of Rural Health, 32*(1), 13-24. doi: 10.1111/jrh.12124

Davies, MB. (2007). *Doing a successful research project; Using qualitative or quantitative methods*. New York: Palgrave Macmillan.

Day, J. (2018) The importance and benefits of transparency for Healthcare Providers. *SE Healthcare Data Analytics Solutions.* [Online] Available at https://www.sehealthcarequalityconsulting.com/2018/04/24/the-importance-and-benefits-of-transparency-for-healthcare-providers/. Accessed 10/12/2019

De Wit, L, Putman, K, Baert, I, Lincoln, NB, Angst, F, Beyens, H, . . . Feys, H. (2008). Anxiety and depression in the first six months after stroke. A longitudinal multicentre study. *Disability and Rehabilitation, 30*(21), 1858-1866.

Department of Health. (2007). National Stroke Strategy. http://www.dh.gov.uk/dr_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_081059.pdf

Department of Health. (2009). Stroke-Specific Education Framework. Retrieved 05/05, 2013, from http://www.stroke-education.org.uk/

Dewey, HM, Thrift, AG, Mihalopoulos, C, Carter, R, MacDonell, RA, & McNeil, JJ. (2002). Informed care for stroke survivors: Results from the North East Melbourne Stroke Incidence Study (NEMESIS). *Stroke, 33*(4), 1028-1033.

Douiri, A, Rudd, AG, & Wolfe, C. (2013). Prevalence of poststroke cognitive impairment: South London Stroke Register 1995-2010. *Stroke, 11*, 138-145.

Driscoll, DL, Appiah-Yeboah, A, Salib, P, & Rupert, DJ. (2007). Merging qualitative and quantitative data in mixed methods research: How to and Why not. *Ecological and Environment Antropology, 3*(1), 18-28.

Edwards, G. (2006). The training and education of nurses working in stroke care. *British Journal of Nursing, 15*(21), 1180-1184.

Ejike, C.N. (2017) The Influence of Culture on the Use of Healthcare Services by Refugees in South Central Kentucky: A Mixed Study.Dissertations Paper. [Online] Available at https://digitalcommons.wku.edu/cgi/viewcontent.cgi?article=1116&context=diss. Accessed 11/10/2019

Eley, N. T., Namey, E., McKenna, K., Johnson, A. C., & Guest, G. (2019). Beyond the Individual: Social and Cultural Influences on the Health-Seeking Behaviors of African American Men. *American Journal of Men’s Health*. https://doi.org/10.1177/1557988319829953

Emberg, I, Kirchberger, I, Stucki, G, & Cieza, A. (2010). The ICF Core set for stroke from the perspective of physicians: a worldwide validation study using Delphi technique. *European Journal of Physical Rehabilitation Medicine, 46*, 337-388.

Farinelli, M., Pankseep, J., Cevolani, D., Gestieri, L., Maffei, M., Agati, R., Pedone. V. & Northoff, G. (2015) Do brain lesions in stroke affect basic emotions and attchment? *journal of Clinical and Ecperimental Neuropsychology,*37:6, 595-613 DOI: 10.1080/13803395.2014.991279

Faux, Steven G., Arora, Pooja, Shiner, Christine T., Thompson-Butel, Angelica G., & Klein, Linda A. (2017). Rehabilitation and education are underutilized for mild stroke and TIA sufferers. *Disability and Rehabilitation*, 1-5. doi: 10.1080/09638288.2017.1295473

Ferro, J. M., & Santos, A. C. (2019). Emotions after stroke: A narrative update. *International Journal of Stroke*. https://doi.org/10.1177/1747493019879662

Fetters, MD, Curry, LA, & Creswell, JW. (2013). Achieving Integration in Mixed Methods Designs-Principles and Practices. *Health Service Research, 48*(6 Pt 2), 2134-2156.

Field, A. (2013). *Discovering statistics using IBM SPSS statistics* (4th edn. ed.). London: Sage Publication Ltd.

Fielding, N. (1994). Varities of research interviews. *Nurse Researcher, 1*(3), 04-13.

Fletcher, S., Kulnik, S.T., Demain, S. & Jones, F. (2019) The problemwith self-management: Problematising self-managementand powerusinga Foucauldian lens in the contextof strokecare and rehabilitation. PLoSONE 14(6):e0218517

Fryer, C.E., Luker, J.A., McDonnell, M.N. & Hillier, S.L. (2016) Self management programmes for quality of life in people with stroke. *Cochrane Database of Systematic Reviews,* Issue 8. Art. No.: CD010442. DOI: 10.1002/14651858.CD010442.pub2.

Ghazipura, M. (2015) Home-based versus Centre-based rehabilitation for Community-Dwelling Postacute Stroke Patients: A Rapid Review Toronto, ON: Health Quality Ontario, 18p. [Online] Available from: http://www.hqontario.ca/evidence/evidence-process/episodes-of-care#community-stroke.Accesse 27/08/2019

Gbiri, CA, Olawale, OA, & Isaac, SO. (2015a). Stroke Management: Informal caregivers' burdens and strains of caring for stroke survivors. *Annals of Physical and Rehabilitation Medicine, 58*(2), 98-103.

Gbiri, CA, Olawale, OA, & Obi, NJ. (2015b). Associations between knoeldge and belief of stroke and pathwyas to healthcare adopted by Nigerian Stroke Survivors. *International Journal of Therapies and Rehabilitation Research, 4*(1), 35-42.

Geyh, S, Cieza, A, Schouten, J, Dickson, H, Frommelt, P, Omar, Z, . . . Stucki, G. (2004). ICF core sets for stroke. *Journal Rehabilitation of Medicine, 44*, 135-141.

Ghesquiere, A., Wyka, K., Smith, M. & Kutner, J.S. (2019) Association between psychological symptoms and treatment outcomes of a massage therapy intervention: Secondary analyses of randomized controlled trial. *Complementary Therapy Medicine.* 46, 116 - 122.

Gholamazadeh, S, Hamid, TA, Basri, H, Sharif, F, & Ibrahim, R. (2014). Religious coping and psychological well-being among Iranian stroke caregivers. *Iranian Journal of Nursing and Midwifery Research, 19*(5), 478-484.

Ghous, M, Nawaz Malik, Imran Amjad, M, & Kanwal, M. (2017). Effects of activity repetition training with Salat (prayer) versus task oriented training on functional outcomes of stroke *Journal of Pakistan Medical Association, 67*(7), 1091-1093.

Giaquinto, S, Sarno, S, Dell'Armi, V, & Spiridgliozzi, C. (2010). Religious and spiritual beleifs in stroke rehabilitation. *Clinical and Experimental Hypertension, 32*(6), 329-334.

Gibbon, B. (1994). Stroke nursing care and management in the community: a survey of district nurses' perceived contribution in one health district in England. *Journal of Advanced Nursing, 20*, 469-476.

Gibbs, GR. (2002). *Qualitative data analysis: Exploration with NVivo*. United Kingdom: Open University Press.

Gillen, R, Tennen, H, McKee, TE, Gernert-Dott, P, & Affleck, G. (2001). Depressive symptoms and hsitory of depression predict rehabilitation efficiency in stroke patients. *Archives of Physical Medicine and Rehabilitation, 82*(12), 1645-1649.

Glassel, A, Kirchberger, I, Kollerits, B, Amann, E, & Cieza, A. (2011). Content Validity of the Extended ICF Core Set for Stroke: An International Delphi Survey of Physical Therapists. *Physical Therapy, 91*(8), 1211-1222.

Glassel, A, Kirchberger, I, Linseisen, E, Stamm, T, Cieza, A, & Stucki, G. (2010). Content Validation of the International Classification of Functioning, Disability and Health (ICF) Core Set for Stroke: The Perspective of Occupational Therapists. *Canadian Journal of Occupational Therapy, 77*(5), 289-302.

Global Accessibility News. (2013). Brunei to ensure people with disabilities given high priority in national agendas. from http://globalaccessibilitynews.com/2013/12/13/brunei-to-ensure-people-with-disabilities-given-high-priority-in-national-agendas/

Gomes, Ana Beatriz Ayroza Galvão Ribeiro, Henrique Jr, Mauro, Schoeps, Vinicius Andreoli, Santos, Mariana Monteiro Saldanha Altenfelder, Pellegrinelli, Ada, de Matos, Bárbara Pessoa, . . . Gagliardi, Rubens José. (2017). Popular stroke knowledge in Brazil: A multicenter survey during “World Stroke Day”. *eNeurologicalSci, 6*, 63-67. doi: https://doi.org/10.1016/j.ensci.2016.12.002

Gompertz, P. (1993). The reliability of stroke outcome measures. *Clinical Rehabilitation, 7*(4), 290-296.

Goodman, C, & Evans, C. (2010). Focus Group. In K. Gerrish & A. Lacey (Eds.), *The Research Process in Nursing* (6th ed., pp. 358-368). United Kingdom: Blackwell Publishing Ltd.

Government of Brunei. (2014). Brunei: the abode of peace. Retrieved 02/03/2015, from www.gov.bn

Grady, P.A. & Gough, L.L. (2014) Self-Management: A comprehensive approach to management of chronic conditons. *American Journal of Public Health.* 104 (8), e25 - e31

Greene, JC, & Caracelli, VJ. (1997). Defining and describing the paradigm issue in Mixed-Method Evaluation. *Advances in mixed-method evaluation, 74*, 5-17.

Greenwood, N, & Mackenzie, A. (2010). Informal caring for stroke survivor: Meta-ethnographic review of qualitative literature. . *Maturitas, 66*, 268-276.

Greenwood, N, Mackenzie, A, Cloud, GC, & Wilson, N. (2008). Informal carers of stroke survivors - factors influencing carers: A systmatic review of quantitative studies. *Disability and Rehabilitation, 30*(18), 1329-1349.

Guba, EG, & Lincoln, YS. (1989). *Fourth Generation evaluation*. Newbury Park: Sage.

Gunal A., Baskurt F. & Baskurt Z. (2019) The effect of emotional distress on functional outcomes in acute stroke patients. *Nigeria Journal of Clinical Practice,* 9(22), 1583 - 1589.

Hackett, ML, & Pickles, K. (2014). Part 1: frequency of depression after stroke: an updated systematic review and meta-analysis of observational studies. *International Journal of Stroke, 9*(8), 1017-1025.

Hackett, ML, Yang, M, Anderson, CS, Horrocks, JA, & House, A. (2010). Pharmaceutical interventions for emotionalism after stroke (Publication no. DOI: 10.1002/14651858.CD003690.pub3.). The Cochrane Library. (Art. No.: CD003690). Retrieved 28/09/2015, from John Wiley & Sons, Ltd.

Hafsteinsdottir, TB, Vergunst, M, Lindeman, E, & Schuurmans, M. (2011). Educational needs of patients with a stroke and their caregivers: A systematic review of literature. *Patient Education and Counselling, 85*(1), 14-25.

Haji Abas, N. (2015) Bina Keluarga Bahagia, Harmony (Building Happy and Harmony Family), *Pelita Brunei.* [Online] Available at http://www.pelitabrunei.gov.bn/Lists/Berita/NewDisplayForm.aspx?ID=8801&ContentTypeId=0x0100BC31BF6D2ED1E4459ACCF88DA3E23BA8. Accessed 13/08/2019

Haji Md Hashim, Z., Haji Morsidi, N., Haji Brahim, NS., Haji Anam, N., Haji Md Jafar, SF., Haji Abd Kadir, LH., Haji Yassin, A. & Ibrahim, A. (2015) *Health System and Infrastructure Master Plan for Brunei Darussalam Framework*. Ministry of Health: Brunei Darussalam. Reterived 11/08/2019 from http://www.moh.gov.bn/SiteCollectionDocuments/HSIMP/HSI%20MP%20Framework.pdf

Haji Md. Yamin, H., Pg. Hj Tengah, D.S.N., Hj Abd. Manaf, A. & Mohd. Noor, H.S. (2018) Exploring the initial experience of stroke patients related to pre-hospital delay in Brunei. (Unpublished manuscripts), Universiti Brunei Darussalam.

Haley, WE, Allen, JY, Grant, JS, Ckay, OJ, Perkins, M, & Roth, DL. (2009). Problems and benefits reported by stroke family caregivers. *Stroke, 40*, 2129-2133.

Hammed, S. (2019) Accountability and Day of Judgement. *Islam Online Archive.* [Online] Available at https://archive.islamonline.net/?p=6475. Accessed 09/01/2020

Hara, Y. (2015) Brain Plasticity and Rehabilitation. *Japan Nippon Medical School.* 82(1), 1 -10.

Haris, N. (2014) Foster family ties with right environment. *Brunei Times.* Retrieved from https://btarchive.org/news/national/2014/12/07/foster-family-ties-right-environment Accessed on 22/05/2019

Harrison, M, Ryan, T, Gardiner, C, & Jones, A. (2017). Psychological and emotional needs, assessment, and support post-stroke: a multi-perspective qualitative study. *Topics in stroke rehabilitation, 24*(2), 119-125.

Hartigan, I. (2013) Goal setting in stroke rehabilitation: part 1. *British Journal of Neuroscience Nursing.* 8(2), 65 - 69.

Hatano, S. (1976). Experience from a multicentre stroke register: a preliminary report. *Bulletin World Health Oganization, 54*, 541-533.

Health and Social Care Information Centre. (2012). HES on Stroke. http://www.hscic.gov.uk/catalogue/PUB06355/hes-on-stro.pdf

Hickey, A, Horgan, F, D, O'Neill., & McGee, H. (2012). Community-based post-stroke service provision and challenges: a national survey of managers and inter-disciplinary healthcare staff in Ireland. *BMC Health Services Research, 12*(111), 1-8.

Hickey, JV. (2009). *The clinical practice of neurological and neurosurgical nursing* (6th edn. ed.). New York: Lippincott Williams and Wilkins.

Hillier, S, & Inglis-Jassiem, G. (2010). Rehabilitation for community-dwelling people with stroke: home or centre based? A systematic review. *International Journal of Stroke, 5*, 178-186.

Horvat, L., Horey, D., Romios, P. & Kis-Rigo, J. (2014) Cultural competence education for health professionals. *Cochrane Database Systematic Review.* 5 (5) [online] doi: 10.1002/14651858.CD009405.pub2. Accessed 12/11/2019

House, A, Knapp, P, Bamford, J, & Vail, A. (2001). Mortality at 12 and 24 months after stroke may be associated with depressive symptoms at 1 month. *Stroke, 32*, 696-701.

House of Common. (2006). Reducing brain damage: faster access to better stroke care. Fifty–second Report of Session 2005–06. http://www.publications.parliament.uk/pa/cm200506/cmselect/cmpubacc/911/911.pdf

Hung, JW, Huang, YC, Chen, JH, Lio, LN, Lin, CJ, Chuo, CY, & Chag, KC. (2012). Factors associated with strain in informal caregivers of stroke patients. *Chang Gung Medical Journal, 35*, 392-401.

Hunter, D. J., Grant, H. J., Purdue, M. P., Spasoff, R. A., Dorland, J. L., & Bains, N. (2004). An epidemiologically-based needs assessment for stroke services. *Chronic Disease in Canada, 25*(3-4), 138-146.

Idris, F. (2012). Management of stroke in community. Brunei: Brunei.

Ilali, Ehteramosadat, Taraghi, Zohreh, Yazdani, Jamshid, Golmohammadi, Maryam, Savasari, Roghaieh, & Mosavi Jarrahi, Alireza. (2016). The Relationship Between Praying and Spiritual Health Among Iranian Older People With Cerebrovascular Accidents. *Iranian Journal of Ageing, 11*(3), 424-431.

Ilse, IB, Feys, H, De Wit, L, Putman, K, & De Weerdt, W. (2008). Stroke caregivers' strain: prevalence and determinants in the first six months after stroke, disability and rehabilitation. *30, 7*(523-530).

Intercollegiate Stroke Working Party. (2012). National Clinical Guidelines for Stroke. https://www.rcplondon.ac.uk/sites/default/files/national-clinical-guidelines-for-stroke-fourth-edition.pdf

Ishigami, A, Yokota, C, Nishimura, K, Ohyama, S, Tomari, S, Hino, T, . . . Minematsu, K. (2017). Delivering Knowledge of Stroke to Parents Through Their Children Using a Manga for Stroke Education in Elementary School. *Journal of Stroke and Cerebrovascular Diseases, 26*(2), 431-437.

Jabatan Majlis-Majlis Mesyuarat (2019) *Laporan Penuh (HANSARD) Mesyuarat Pertama Musim Permesyuaratan Ke Lima Belas*. Jabatan Percetakan Brunei; Brunei. [Online] Available at http://www.councils.gov.bn/JMM%20Images/laporan2019/Hansarrd%202019%20Jilid%201.pdf

Jarvis A, Smith M, McAlpine L, Gillespie DC (2019) Caring for the carer of someone who has had a stroke: findings from an innovative project. International Journal of Therapy Rehabilitation. 26(8):1–11. https://doi.org/10.12968/ijtr.2017.0167

João Pedro, M, Cláudia, B, Rita, F, Sofia, C, & Miguel, VB. (2017). Impact of stroke education on middle school students and their parents: A cluster randomized trial. *International Journal of Stroke, 12*(4), 401-411.

Johnson, RB, & Onwuegbuzie, AJ. (2004). Mixed methods research: A research paradigm whose Time has come. *Educational Researcher, 33*(7), 14-26.

Johnson, RB, Onwuegbuzie, AJ, & Turner, LA. (2007). Toward a definition of Mixed Methods research. *Journal of Mixed Methods Research, 1*(2), 112-133.

Jongen, C., McCalman, J. & Bainbridge, R. (2018) Health workforce cultural competency interventions: a systematic scoping review. *BMC health Service Research.* 18(232), 1 - 15. https://doi.org/10.1186/s12913-018-3001-5

Jokinen, H, Melkas, S, Ylikoski, R, Pohjasvaara, T, Kaste, M, Erkinjuntti, T, & Hietanen, M. (2015). Post-stroke cognitive impairment is common even after successful clinical recovery. *European Journal of Neurology, 22*(9), 1288-1294.

Jones, AL, Charlesworth, JF, & Hendra, TJ. (2000). Patient mood and carer strain during stroke rehabilitation in the community following hospital discharge. *Disability and Rehabilitation, 22*(11), 490-494.

Kalra, L, Evans, A, Perez, I, Knapp, M, Swift, C, & Donaldson, N. (2005). A Randomised controlled comparison of alternative strategies in stroke care *Health Technology Assessment* (Vol. 9). Kent: Gray Publishing.

Kamalakannan, S, Gudlavalleti, VM, Prost, A, Natarajan, S, Pant, H, Chitalurri, N, . . . Kuper, H. (2016). Rehabilitation Needs of Stroke Survivors after discharge from Hospital in India. *Archives of Physical Medicine and Rehabilittaion, 97*(6), 1526-1532.

Kamaria, K, Long, CM, & Nurhanisah, S. (2015). Traditional Malay massage as an alternative treatment approaches in rehabilitation: a narrative review the state of evidence (Vol. 101, pp. e706): WCPT Congress 2015.

Kamaruddin, A.R., & Kamaruddin, K. (2009). Malay Culture and Consumer Decision-Making Styles: An Investigation on Religious and Ethnic Dimensions. *Jurnal Kemanusian.*7(2), 1 - 14.

Kearney, PM, & Pryor, J. (2004). The International Classification of Functioning, Disability and Health (ICF) and Nursing. *Journal of Advanced Nursing, 46*(2), 162-170.

King, RB, Ainsworth, CR, Ronen, M, & Hartke, RJ. (2010). Stroke caregivers: Pressing problems reported durng the first months of caregiving. *Journal of Neuroscience Nursing, 42*(6), 302-3011.

King, RB, Hartke, RJ, & Denby, F. (2007). Problem-solving Early Intervention: A pilot study of stroke caregiver. *Rehabilitation Nursing, 32*(2), 68-84.

King, RB, Hartke, RJ, Houle, T, Lee, J, Herring, G, Alexander-Peterson, BS, & Raad, J. (2012). A problem-solving early intervention for stroke caregivers: One year follow-up. *Rehabilitation Nursing, 37*(5), 231-243.

Kirkevold, M. (1997). The role of nursing in the rehabilitation of acute stroke patients: toward a unified theoretical perspective. *Advance in Nursing Science, 19*(4), 55-64.

Kirkevold, M, Bronken, BA, Martinsen, R, & Kvigne, K. (2012). Promoting psychosocial weel-being following stroke: Developing a theoretically and empirically sound complex intervention. *International Journal of Nursing Studies, 49*(4), 388-397.

Kirkevold, M, Martinsen, R, Bronken, BA, & Kvigne, K. (2014). Promoting psychosocial weelbeing following stroke using narratives and guided self-determination: a feasibility study. *BMC Psychology, 2*(4), 1-12.

Knapp, P, Young, J, House, A, & Forster, A. (2000). Non-drug strategies to resolve psycho-social difficulties after stroke. *Age and Aging, 29*, 23-30.

Koenig, H.G. & Al Shohaib, S. (2014) Health and Well-Being in Islamic Societies: Background, research and applications. Springerlink: Bucher

Kourkouta, L. & Papathanasiou, L.V. (2014) Communication in Nursing Practice. *Mater Sociomed*. 26(1), 65 - 67

Krejcie, RV, & Morgan, DW. (1970). Determining sample size for research activities. *Educational and Psychological Measurement, 30*, 607-610.

Krishnamurthi, R, Feigin, VL, Forouzanfar, MH, Mensah, GA, Connor, M, Bennet, DA, . . . Murray, CD. (2013). Global and regional burden of first-ever ischaemic and haemorrhagic stroke during 1990–2010: findings from the Global Burden of Disease Study 2010. *Lancet Global Health, 1*, e259-e281.

Kristensen, Hanne Kaae, Tistad, Malin, von Koch, Lena, & Ytterberg, Charlotte. (2016). The Importance of Patient Involvement in Stroke Rehabilitation. *PLoS ONE, 11*(6), e0157149. doi: 10.1371/journal.pone.0157149

Kruithof, WJ, van Mierlo, ML, Vissser-Meily, JMA, van Heugten, CM, & Post, M. (2013). Associations between social support and stroke survivors' health-related quality of life - A systematic review. *Patient Education and Counselling, 93*, 169-176.

Kumar, R. (2011). *Research Methodology: a step by step guide for beginners* (3rd ed.). London: Sage Publication.

Kumar, R., Kaur, S. & Reddemma, K. (2016) Burden, its predictors and quality of life in Caregivers of stroke survivors at rural community, Punjab, India. *Journal of Neurology and Neurorehabililtation Research.* 1 91), 1 - 7. DOI: 10.35841/neurology-neurorehabilitation.1.1.3-9

Langhorne, P, Coupar, F, & Pollock, A. (2009). Motor recovery after stroke: a systematic review. *Lancet Neurology, 8*(8), 741-754.

Langhorne, P, Lwesey, JD, Jhund, PS, Gillies, M, Chalmers, JWT, Redpath, A, . . . MacIntyre, K. (2010). Estimating the impact of stroke unit care in a whole population: an epidemiological study using routine data. *Journal of Neurology, Neurisurgery and Psychiatry, 81*(12), 1301-1305.

Larson, J, Franzen-Dahlin, A, Billing, E, von Arbin, M, Murray, V, & Wredling, R. (2005). The impact of a nurse-led support and education programme for spouses of stroke patients: a randomized controlled trial. *Journal of Clinical Nursing, 14*, 995-1003.

Law, M, Baptiste, S, Carswell, A, McColl, MA, Polatajko, H, & Pollock, N. (2005). *Canadian Occupational Performance Measure* (4th ed.). Canada: CAOT Publications ACE.

Lawrence, M, & Kinn, S. (2013). Needs, prorities, and desired rehabilitation outcomes of family members of young adults who have had a stroke: findings from a phenomenological study. *Disability and Rehabilitation, 35*(7), 586-595.

Lee, YC, Chen, YM, Hsueh, IP, Wang, YH, & Hsieh, CL. (2010). The impact of stroke: Insight from patients in Taiwan. *Occupational Therapy International, 17*, 152-158.

Lee, I.F.K., Yau, F.N., Yim S.S.Y. & Lee, D.T.L. (2018)Evaluating the impact of a home-based rehabilitation service on older people and their caregivers: a matched-control quasi-experimental study. *Clinical Interventions in Aging.* 13, 1727 - 1737

Leininger M. (1991) *Culture care diversity and universality: A theory of Nursing*. New York: National League for Nursing Press

Leininger M. (1995) *Transcultural nursing: Concepts, theories, research, and practice.* Columbus, OH: McGraw-Hill College Custom Series

Lin, M.H., Wu, C.Y. & Hsu, H.C. (2019 Exploring the experiences of cultural competence among clinical nurse in Taiwan. *Applied Nursing Research.* 45, 6 - 11. https://doi.org/10.1016/j.apnr.2018.11.001

Lincoln, NA, Kneebone, II, Macniven, JAB, & Morris, RC. (2012). *Psychological management of stroke*. Wesr Sussex, UK: Wiley-Blackwell.

Lincoln, NB, Brinkmann, N, Cunningham, S, Dejaeger, E, De Weerdt, W, Jenni, W, . . . De Wit, L. (2013). Anxiety and depression after stroke: a 5 year follow-up. *Disability and Rehabilitation, 35*(2), 140-145.

Lincoln, NB, Gladman, JRF, Berman, P, Luther, A, & Challen, K. (1998). Rehabilitation needs of community stroke patients. *Disability and Rehabilitation, 20*(12), 457-463.

Lincoln, NB, Walker, MF, Dixon, A, & Knights, P. (2004). Evaluation of a multiprofessional community stroke team: a randomized controlled trial. *Clinical Rehabilitation, 18*, 40-47.

Lo, RSK, Cheng, JOY, Wong, EMC, Tang, WK, Wong, LKS, Woo, J, & Kwok, T. (2008). Handicap and its determinants of change in stroke survivors: One year follow-up study. *Stroke, 39*, 148-153.

Long, AF, Kneafsey, R, Ryan, J, & Berry, J. (2000). The role of the nurse within the multi-professional rehabilitation team. *Journal of Advanced Nursing, 37*(1), 70-78.

Long, AF, Kneafsey, R, Ryan, J, & Berry, J. (2002). Exploring qualified nurses’ perceptions of the relevance of education in preparation for their role in rehabilitation. *Nurse Education Today, 22*, 136-143.

Lou, S, Carstensen, K, Jorgensen, CR, & Nielsen, PN. (2017). Stroke patients' and informal carers' experiences with life after stroke: an overview of qualitative systematic reviews. *Disability and Rehabilitation, 39*(3), 301-313.

Louie, SWS, Liu, PKK, & Man, DWK. (2009). Stress of caregivers in carng people with stroke: Implications for rehabilitation. *Topics in Geriatic Rehabilitation, 25*(3), 191-197.

Lorig, K., Sobel, D., Stewart, A., Brown, B., Bandura, A., Ritter, P., GOncalez, V.M., Laurent, D.D. & Holman, H. (1999). Evidence Suggesting That a Chronic Disease Self-Management Program Can Improve Health Status While Reducing Hospitalization: A Randomized Trial. *Medical Care, 37*(1), 5-14.

Lui, MH, Ross, FM, & Thompson, DR. (2005). Supporting family caregivers in stroke care: a review of the evidence for problem solving. *Stroke, 36*, 2514-2522.

Luker, Julie, Lynch, Elizabeth, Bernhardsson, Susanne, Bennett, Leanne, & Bernhardt, Julie. (2015). Stroke Survivors' Experiences of Physical Rehabilitation: A Systematic Review of Qualitative Studies. *Archives of Physical Medicine and Rehabilitation, 96*(9), 1698-1708.e1610. doi: http://dx.doi.org/10.1016/j.apmr.2015.03.017

Luker, Julie, Murray, Carolyn, Lynch, Elizabeth, Bernhardsson, Susanne, Shannon, Michelle, & Bernhardt, Julie. (2017). Carers' Experiences, Needs, and Preferences During Inpatient Stroke Rehabilitation: A Systematic Review of Qualitative Studies. *Archives of Physical Medicine and Rehabilitation*. doi: 10.1016/j.apmr.2017.02.024

Lupat, A, Hengelbrock, J, Luissin, M, Fix, M, Bassa, B, Craemer, EM, . . . Meyding-Lamade, U. (2016). Brunei epidemiological stroke study: pattern of hypertension and stroke risk. *Journal of Hypertensions, 34*(7), 1416-1422.

Lynch, Elizabeth A., Luker, Julie A., Cadilhac, Dominique A., & Hillier, Susan L. (2015). Rehabilitation Assessments for Patients With Stroke in Australian Hospitals Do Not Always Reflect the Patients' Rehabilitation Requirements. *Archives of Physical Medicine and Rehabilitation, 96*(5), 782-789. doi: http://dx.doi.org/10.1016/j.apmr.2014.12.009

Mackenzie, A, & Greenwood, N. (2012). Positive experiences of caregiving in stroke: a systematic review. *Disability and Rehabilitation, 34*(17), 1413-1422.

Mackintosh, JE, Murtagh, MJ, Rodgers, H, Thomson, RG, Ford, GA, & White, M. (2012). Why people do, or do not, immediately contact emergency medical services following the onset of acute stroke: qualitative interview study. *PLoS One, 7*(10), e46124.

MacIsaac, L, Harrison, MB, & Godfrey, C. (2010). Supportive care needs of caregivers of individuals following stroke: A synopsis of research. *Canadian Journal of Neuroscience Nursing, 32*(1), 39-46.

Maier, M., Ballester, B.R. & Verschure P.F.M.J. (2019) Principles of Neurorehabilitation after Stroke Based on Motor Learning and Brain Plasticity Mechanisms. *Frontier. in Systems Neuroscience.* 13(74.), 1 - 18

Mairami, F.F., Warren, N., Allotey, P.A., Mak, J.S. & Reidpath, D.D. (2020) Documenting the impact of stroke in a middle-income country: a Malaysian case study, *Disability and Rehabilitation*, 42:1, 102-113

Mapsopensource.com.). Brunei Districts Maps. Retrieved 09/11/2014, from http://www.mapsopensource.com/brunei-political-map.html

Martin, BJ, Yip, B, Hearty, M, Marlette, S, & Hill, R. (2002). Outcome, functional recovery and unmet needs following acute stroke. Experience of patient follow up at 6 to 9 months in a newly established stroke service. *Scottish Medical Journal, 47*(6), 136-137.

Mason-Whitehead, E., Ridgway, V., & Barton, J. (2012). Passed without a stroke: A UK mixed method study exploring student nurses' knowledge of stroke. *Nurse Education Today*. doi: http://dx.doi.org/10.1016/j.nedt.2012.07.021

Mason-Whitehead, E., Ridgway, V., & Barton, J. (2013). Passed without a stroke: A UK mixed method study exploring student nurses' knowledge of stroke. *Nurse Education Today, 33*(9), 998-1002. doi: http://dx.doi.org/10.1016/j.nedt.2012.07.021

Mastor, K.A., Jin, P., & Cooper, M. (2000). Malay Culture and Personality: A Big Five Perspective. *American Behavioral Scientist*, *44*(1), 95–111. https://doi.org/10.1177/00027640021956116

Marion, L., Douglas, M., Lavin, M., Barr, N., Gazaway, S., Thomas, L., Bickford, C., (2016) Implementing the New ANA Standard 8: Culturally Congruent Practice. T*he Online Journal of Issues in Nursing,* 22(1) DOI: 10.3912/OJIN.Vol22No01PPT20

Matthew Mosses, B.A, & Teasell, R. (2013). Outcome Measures in Stroke Rehabilitation. *Evidence-Based Review of Stroke Rehabilitation*. [online] http://www.ebrsr.com/sites/default/files/chapter21_outcome-measures_final_16ed.pdf. Accessed 14/06/2018

Mauk, K.L. (2013). The effect of Advanced Practice Nurse-Modulated Education on rehabilitation nursing staff knowledge. *Rehabilitation Nursing, 38*, 99-111.

McColl, M.A, Paterson, M, Davies, D, Doubt, L, & Law, M. (2000). Validity and Community Utility of the Canadian Occupational Performance Measure. *Canadian Journal Occupational Therapy, 67*, 22-30.

McCullagh, E, Brigstocks, G, Donaldson, N, & Kalra, L. (2005). Determinants of Ceregiving Burden and Quality of Life in Caregivers of Stroke Patients. *Stroke, 36*, 2181-2186.

McDonald, J., McKinlay, E., Keeling, S. & Levack, W. (2016) Becoming an expert carer: the process of family carers learning to manage technical health procedures at home. Journal of Advanced Nursing 72(9), 2173– 2184. doi: 10.1111/jan.12984

McGinnes, A, Easton, S, Williams, J, & Neville, J. (2010). The role of the community stroke rehabilitation nurses. *Cardiovascular Nursing, 19*(6), 1033-1038.

McHugh, G. and Swain, I. (2013) A comparison between reported and ideal patient-to-therapist ratios for stroke rehabilitation. *Health*, 5(6A2),105 -112. DOI: 10.4236/health.2013.56A2016.

McKevitt, C, Fudge, N, Redfern, J, Sheldenkar, A, Crichton, S, Rudd, AR, . . . Wolfe, DA. (2011). Self-Reported Long-Term Needs After Stroke. *Stroke, 42*, 1398-1403.

McKevitt, C, & Wolfe, C. (2000). Community support after stroke: patient and carer views. *British Journal of Therapy and Rehabilitation, 7*(1), 6-10.

McKinney, M, Blake, H, Treece, KA, & Lincoln, NB. (2002). Ecvaluation of cognitive assessment in stroke rehabilitation. *Clinical Rehabilitation, 16*, 129-136.

Medical Record Unit (2015, 16/02/2015). [Stroke Patients Registration].

Meyding-Lamadé, U, Craemer, E , Chan, C, Yassin, N, Jacobi, C, Schwark, C, . . . Kress, B. (2015). Setting up a The Brunei Neuroscience Stroke and Rehabilitation Centre 12,000km away with the help of telemedicine (Abstracts from the World Congress of Neurology 2015). *Journal of the Neurological Sciences, 357*(Supplement 1), e370. doi: 10.1016/j.jns.2015.08.1325

Milone, G, Balucani, C, Hong, S, Stefanov, D, & Levine, S. (2015). Depression, not fatique, predicts quality of life after stroke (Abstract). *Neurology, 84*(14), Supplement P6.019.

Ministry of Health. (2009). Vision 2035: Ministry of Health Strategy *Minsitry of Health*. Brunei: Ministry of Health.

Ministry of Health (2013) Brunei Darussalam National Multisectoral Action Plan for the Prevention of Noncommunicable Disease (BruMAP-NCD) 2013-2018. Reterived 10/08/2019, from http://www.moh.gov.bn/SiteCollectionDocuments/Downloads/downloads/BRUMAPBOOK.pdf

Ministry of Health. (2014). Community Health Services. Retrieved 22/02/2014, from http://www.moh.gov.bn/medhealthservices/communityhealthservices.htm

Ministry of Health. (2015). *Health Information Booklet*. Brunei: Ministry of Health Brunei Darussalam.Retrieved from http://www.moh.gov.bn/Downloadables/HIB2015%20-%2028092016.pdf

Ministry of Health (2017). *Health Information Booklet*. Brunei: Ministry of Health Brunei Darussalam. Retrieved from http://www.moh.gov.bn/Downloadables/Health%20Information%20Bookler%202017%20(revised%20as%20of%20January%202019).pdf. Access 10/08/2019

Mohammed, CR, Nelson, K, Wood, P, & Moss, C. (2015). Issues post-stroke for Muslim people in maintaining the practice of salat (prayer): A qualitative study. *Collegian, 22*, 243-249.

Mohd Anuar, H, Fadzli, F, Ahmad, N, & Abd Ghani, N. (2012). Urut Melayu for poststroke patients: A qualitative study. *The Journal of Alternative and Complementary Medicine, 18*(1), 61-64.

Mohd Nordin, NA, Abd Aziz, NA, Abdul Aziz, AF, Ajit Singh, DK, Omar Othman, NA, Sulong, S, & Aljunid, M. (2014). Exploring views on long term rehabilitation for people with stroke in a dveloping country: findings from focus group discussions. *BMC Health Services Research, 14*(118), 1-10.

Mohidin, M. (2013). *Anual Report of Brunei Darussalam (2005 - 2009)*. (Part 1). Brunei: Department of Information Retrieved from http://www.information.gov.bn/Publication%20listsPDF/Annual_Report_BruneiDarussalam_2005-2009(Part_One).pdf.

Moreland, JD, Depaul, VG, Dehueck, AL, Pagliuso, SA, Yip, DWC, Pollock, BJ, & Wilkins, S. (2009). Needs assessment of individuals with stroke after discharge from hospital stratified by acute Functional Independence Measure Score. *Disability and Rehabilitation, 31* (26), 2185-2195.

Mores, G., Whiteman, R., Ploeg, J., Knobl, P., Cahn, M., Klaponski, L., Lindley. A., & Fisher, K. (2018). An Evaluation of the Family Informal Caregiver Stroke Self-Management Program. *Canadian Journal of Neurological Sciences, 45*(6), 660 - 668. doi:10.1017/cjn.2018.335

Morse, JM. (2000). Determining sample size. *Qualitative Health Research, 10*(1), 3-5.

Morsund, Å.H., Ellekjær, H., Gramstad, A., Reiestad, M.S., Midgard, R., Sando S.B., Jonsbu, E. & Naess, H. (2019) The development of cognitive and emotional impairment after a minor stroke: A longitudinal study. *Acta Neurologica Scandinavica*, 140(4), 281– 289. https://doi.org/10.1111/ane.13143

Moule, P, & Goodman, M. (2009). *Nursing Research: an introduction*. London: Sage Publication Ltd.

Munsoor, Mohamed Safiullah, & Munsoor, Hannah Safiullah. (2017). Well-being and the worshipper: a scientific perspective of selected contemplative practices in Islam. *Humanomics, 33*(2), 163-188. doi: doi:10.1108/H-08-2016-0056

Murray, J, Forster, A, & Young, J. (2008). Survey to investigate the role of the community stroke care coordinator. *British Journal of Community Nursing, 13*(1), 31-36.

Murray, J, Young, J, Forster, A, & Ashworth, R. (2004). A survey to investigate the role of the district nurse in stroke care. *British Journal of Community Nursing, 9*(8), 318-323.

Mustapa, N. (2013). Issues in Translation between English and Malay. *South Asia: A Multidisciplinary Journal, 13*, 27-34.

Nainar, SH, & Venketasubramanian, N. (2009). Burden of stroke in Brunei Darussalam. *International Journal of Stroke, 4*, 395-397.

National Audit Office. (2010). Progress in improving stroke care. http://www.nao.org.uk/publications/0910/stroke.aspx

National Institute for Health and Clinical Excellence. (2010). Stroke Quality Standard. [online]http://publications.nice.org.uk/stroke-quality-standard-qs2.

National Institute for Health and Clinical Excellence (NICE). (2019). Stroke Rehabilitation Therapy. [online] Available at http://pathways.nice.org.uk/pathways/stroke. Accessed 31/11/2019

Nilsson, AL, Aniansson, A, & Grimby, G. (2000). Rehabilitation needs and disability in community living stroke survivors two years after stroke. *Topic in Stroke Rehabilitation, 6*(4), 30-47.

Norjidi, D. (2018) 300 new cases of stroke every year. *Borneo Bulletin.* November 19, 2018. [online] Available at https://borneobulletin.com.bn/300-new-cases-of-stroke-every-year/. Accessed 10/10/2019

Norris, M. (2009) Curing the blood and balancing life: Understanding, impact and healthseeking behaviour following stroke in Central Acheh, Indonesia. (Unpublished doctoral dissertation). Retrieved from https://pdfs.semanticscholar.org/9716/a2b2b87a99bfb892a779ef7888f7c2d133ac.pdf

Norris, M, Allotey, P, & Barrett, G. (2012). "it burdens me": The impact of stroke in central Acheh, Indonesia. *Sociology of Health and Illness, 34*, 826-840.

Noyce, R. & Simpson, J. (2018) The Experience of Forming a Therapeutic Relationship from the Client's Perspective: A Metasynthesis, *Psychotherapy Research,* 28:2, 281-296

Nurolaini, K, Wintz, Z, Jaini, NH, Jaludin, NH, Hamid, MA, & Linda, YYL. (2014). Prevalence on the use of traditional medicine in Brunei Darussalam. *Journal of Homeopathy and Ayurvedic Medicine, 3*(3), 155.

Nursing Board for Brunei. (2010). Standard of Practice for Registered Nurses and Midwives. http://www.moh.gov.bn/bruneinursingboard/standards.htm

O'Connell, B, & Baker, L. (2004). Managing as carers of stroke survivors: strategies from the field. *International Journal of Nursing Practice, 10*, 121-126.

O'Cornor, S. (1993). Nursing and rehabilitation: the interventions of nurses in stroke patient care. *Journal of Clinical Nursing, 2*(1), 29-34.

O'Shea, R, & Goode, D. (2013). Effects of stroke on informal carers. *Nursing Standard, 28*(15), 43-47.

Omu, O, Al-Obaidi, S, & Reynolds, F. (2014). Religious faith and psychosocial adaptation among strke patients in Kuwait: A mixed method study. *Journal of Religion and Health, 53*(2), 538-551.

Omu, Onutobor, & Reynolds, Frances. (2014). Religious faith and self-efficacy among stroke patients in Kuwait: health professionals' views. *Disability and Rehabilitation, 36*(18), 1529-1535. doi: 10.3109/09638288.2014.892641

Oxford Business Group. (2009). *The Report: Brunei Darussalam 2009*: Oxford Business Group.

Pajalic, Z, Karlsoon, S, & Westergren, A. (2004). Functioning and subjective health among stroke survivors after discharge from hospital. *Journal of Advanced Nursing, 54*(4), 457-466.

Pallant, J. (2010). *SPSS Survival Manual* (4th edn. ed.). Australia: Allen & Unwin Book Publishers.

Paolucci, S, Grasso, MG, Antonucci, G, Bragoni, M, Troisi, E, Morelli, D, . . . Rizzi, F. (2001). Mobility Status After Inpatient Stroke Rehabilitation: 1-Year Follow-Up and Prognostic Factors. *Archives of Physical Medicine and Rehabilitation, 82*, 2-8.

PAPRSB IHS UBD. (2009). *Diploma in Health Sciences (Nursing) Curriculum*. Brunei: PAPRSB IHS UBD.

Parahoo, K. (2006). *Nursing Research: Principles, Processes and Issues* (2nd Edition ed.). Hampshire: Palgrave Macmillan.

Patel, M, Coshall, C, Rudd, AG, & Wolfe, C. (2003). Natural history of cognitive impairment after stroke and factros associated with its recovery. *Clinical Rehabilitation, 17*, 158-166.

Patton, MQ. (2002). *Qualitative research & evaluation methods* (3rd edn. ed.). London: Sage Publication.

Pearce, G., Pinnock, H., Epiphaniou, E., Parke, L.H., Heavey, E., Griffiths, C.j., Greenhalgh, T., Sheikh, A. & Taylor, S.J.C. (2015) Experiences of Self-Management Support Following a Stroke: A Meta-Review of Qualitative Systematic Reviews.*PLoS ONE.* 10 (12), 1 - 17.

Pellerin, C, Rochette, A, & Racine, E. (2011). Social participation of relatives post-stroke: the role of rehabilitation and related ethical issues. *Disability and Rehabilitation, 33*(13-14), 1055-1064.

Pendlebury, ST, Giles, MF, & Rothwell, PM (2009). *Transient Ischemic Attack and Stroke: Diagnosis, Investigation and Management*. Cambridge: Cambridge University Press.

Perry, L , & Middleton, S. (2011). An investigation of family carers' needs following stroke survivors' discharge from acute hospital care in Australia. *Disability and Rehabilitation, 33*(19-20), 1890-1900.

Pervez, S. (2014) Family: The Building Block of Society. [online] Available at https://www.whyislam.org/islamicteachings/family-in-islam/. Access 26/10/2019

Pierce, LL, Havens, H, & Tormoehlen, K. (2008). Spirituality expressed by caregiver of stroke survivors. *Western Journal of Nursing Research, 30*(5), 606-619.

Pierce, LL, Steiner, V, Hicks, B, & Hozaedfel, AL. (2006). Problems of new caregivers of persons with stroke. *Rehabilitation Nursing, 31*(4), 166-172.

Pluye, P., Grad, RM., Levine, A. & Nicolau, B. (2009) Understanding divergence of quantitative and qualitative data (or results) In mixed methods studies. *International Journal of Multiple Research Approaches. 3,* 58-72

Polit, DF, & Beck, CT. (2004). *Nursing Research, Principles and Methods* (7th Edition ed.). Philadelphia: Lippincott Williams and Wilkins.

Pollock, A, Baer, G, Campbell, P, Choo, PL, Forster, A, Morris, J, . . . Langhorne, P. (2014). Physical rehabilitation approaches for the recovery of function and mobility. *Cochrane Database System Review,* (4). http://onlinelibrary.wiley.com/doi/10.1002/14651858.CD001920.pub3/pdf doi:10.1002/14651858.CD001920.pub3.

Powers, W.J., Rabinstein, A.A., Ackerson, T., Adeoye, O.M., Bambakidis, N.C., Becker, K., Biller, J., Brown, M., Demaerschalk, B.M., Hoh, B., Jauch, E.C., Kidwell, C.S., Leslie-Mazwi, T.M., Ovbiagele, B., Scott, P.A., Sheth, K.N., Southerland, A.M., Summers, D.V., Tirschwell, D.L., on behalf of the American Heart Association Stroke Council. (2019) Guidelines for the Early Management of Patients With Acute Ischemic Stroke: 2019 Update to the 2018 Guidelines for the Early Management of Acute Ischemic Stroke: A Guideline for Healthcare Professionals From the American Heart Association/American Stroke Association. *Stroke.* 50(12), e344 - e418

Pringle, J, Hendry, C, & McLafferty, E. (2008). A review of the early discharge experiences of stroke survivors and their carers. *Journal of Clinical Nursing, 17*, 2384-2397.

Pullen, R.L. & Mathias, T. (2010) Fostering therapeutic nure-patient relationship. *Nurse made Incredibly Easy.* 8(3), 4

Randall, G. (2017) Self-management in Stroke (Report). STARR Project. [online] Available at http://www.starrproject.org/deliverables/D2.1-SelfManagementInStroke-TSA.pdf. Accessed 10/10/2019

Rasmussen, RS, Ostergaard, A, Kjaer, P, Skerris, A, Skou, C, Christoffersen, J, . . . Overgaard, K. (2015). Stroke rehabilitation at home before and after discharge reduced disability and improved quality of life: A randomised controlled trial. *Clinical Rehabilitation*, 1-12. doi: 10.1177/0269215515575165

Rassool, GH. (2000). The crescent and Islam: healing, nursing and the spiritual dimension. Some considerations towards an understanding of the Islamic perspectives on caring. *Journal of Advanced Nursing, 32*(6), 1476-1484.

Rasura, M, Baldereschi, M, Di Carlo, A, Di Lisi, F, Patella, R, Piccardi, B, . . . Inzitari, D. (2014). Effectiveness of public stroke educational interventions: a review. *European journal of neurology, 21*(1), 11-20.

Repo, H., Vahlberg, T., Salminen, L., Papadopoulos, I., & Leino-Kilpi, H. (2017). The cultural competence of graduating nursing students. *Journal of Transcultural Nursing*, 28(1), 98-107

Rigby, H, Gubitz, G, & Phillips, S. (2009). A systematic review of caregiver burden following stroke. *International Journal of Stroke, 4*, 285-292.

Ritchie, J, Lewis, J, & Elam, G. (2003). Designing and Selecting Samples. In J. Ritchie & J. Lewis (Eds.), *Qualitative Research Practice: A Guide for Social Science and Researchers* (pp. 77-108). London: Sage.

Rohde, D., Gaynor, E., Large, M., Conway, O., Bennett, K., Williams, D.J., Callaly, E., Dolan, E. & Hickey, A. (2019) Stroke survivor cognitive decline and psychological wellbeing of family caregivers five years post-stroke: a cross-sectional analysis, Topics in Stroke Rehabilitation, 26(3), 180-186, DOI: 10.1080/10749357.2019.1590972

Rosewilliam, S , C, Sintler., Pandyan, AD, Skelton, J , & Roskell, CA (2016). Is the practice of goal-setting for patients in acute stroke care patient-centred and what factors influence this? A qualitative study. *Clinical Rehabilitation, 30*(5), 508-519. doi: doi:10.1177/0269215515584167

Rosli, S. (2012, 22/04/2012). Alternative therapies for holistic health, *Brunei Times*. Retrieved from http://www.bt.com.bn/business-national/2012/04/22/alternative-therapies-holistic-health

Royal College of Nursing. (2007). Role of the rehabilitation nurse. RCN guidance. Royal College of Nursing. . http://www.rcn.org.uk/__data/assets/pdf_file/0017/111752/003178.pdf

Royal College of Physicians. (2008). National Collaborating Centre for Chronic Conditions. Stroke: national clinical guideline for diagnosis and initial management of acute stroke and transient ischaemic attack (TIA). http://www.nice.org.uk/nicemedia/live/12018/41363/41363.pdf

Royal College of Physicians. (2016). National Clinical Guidelines for Stroke. (5th Edition). https://www.strokeaudit.org/SupportFiles/Documents/Guidelines/2016-National-Clinical-Guideline-for-Stroke-5t-(1).aspx

Royal College of Physicians and Sureon of Canada (2012) Defining Societal Health Needs: Royal College Definition and Guide. [Online] Available at http://www.royalcollege.ca/rcsite/documents/health-policy/societal-health-needs-definition-and-guide-e.pdf. Accessed 25/05/18

Ryan, HW, & Bernard, HR. (2003). Techniques to identify themes. *Field methods, 15*(1), 85-109.

Saban, KL, Sherwood, PR, DeVon, HA, & Hynes, DM. (2010). Measures of psychological stress and physical health in family caregivers of stroke survivors: A literature review. *Journal of Neuroscience Nursing, 42*(3), 128-138.

Sadler, E. & McKevitt, C. (2013) ‘Expert carers’: An emergent normative model of the caregiver. Social Theory & Health 11: 40. https://doi.org/10.1057/sth.2012.17

Sakakibra, B.M., Kim, A.J., & Eng, J.J. (2017) A systematic review and meta-analysis on self-management for improving risk factor control in stroke patients. *International Journal of Behavioural Medicine.* 24 (1), 42 - 53.

Sarason, IG, Levine, HM, & Basham, RB. (1983). Assessing social support: The Social Support Questionnaire. *Journal of Personality and Social Psychology, 44*(127-139).

Sarfo, I.A. (2015) The power of beliefd on health seeking behaviour: Implication for therapeutic relationship for cardiovascular care. *European Journal of Medicine.* 10 (Is.4), 195 - 207.

Schaetcher, J.D. (2004) Motor rehabilitation and brain plasticity after hemiparetic stroke. *Progress in Neurobiology.*73(1), 61-72

Sejari, N., Kamaruddin, K,. Ramasamy, K., Meng-Lim, S., Fen-Neoh, C. & Chiau-Ming, L. (2016) The immediate effect of traditional Malay massage on substance P, inlfammatory mediators, pain scale and functional outcome among patients with low back pain: study protocol. *BMC Complement ALternative Medicine.* 16(16), 1 - 7.

Scottish Intercollegiate Guidelines Network (SIGN) (2010) Management of patients with stroke: Rehabilitation, prevention and management of complications, and discharge planning. A national clinical guideline. SIGN. Availabe at https://www.sign.ac.uk/assets/sign118.pdf

Sejari, N, Kamaruddin, K, & Ming, LC. (2014). The effectiveness of traditional Malay massage: A narrative review. *Archives of Pharmacy Practies, 5*(4), 144-148.

Shenton, AK. (2004). Strategies for ensuring trustworthiness in qualitative research projects. *Education and Information, 22*, 63-75.

Simon, C, & Kendrick, T. (2002). Community provision for informal live-in carers of stroke patients. *British Journal of Community Nursing, 7*(6), 292-298.

Sit, Janet W. H., Wong, Thomas K. S., Clinton, Michael, Li, Leonard S. W., & Fong, Yee-man. (2004). Stroke care in the home: the impact of social support on the general health of family caregivers. *Journal of Clinical Nursing, 13*(7), 816-824. doi: 10.1111/j.1365-2702.2004.00943.x

Sit, JW, Yip, VY, Ko, SK, Gun, AP, & Lee, JS. (2007). A quasi-experimental study on a community-based stroke prevention programme for clients with minor stroke. *Journal of Clinical Nursing, 16*(2), 272-281.

Smith, LN, Craig, LE, Weir, CJ, & McAlpine, CH. (2008a). The evidence-base for stroke education in care home. *Nurse Education Today, 28*, 829-840.

Smith, LN, Craig, LE, Weir, CJ, & McAlpine, CH. (2008b). Stroke education for healthcare professionals: Making it fit for purpose. *Nurse Education Today, 28*, 337-347.

Smith, LN, Lawrence, M, Kerr, SM, Langhorne, P, & Lees, KR. (2004). Informal carers' experience of caring for stroke survivors. *Journal of Advanced Nursing, 46*(3), 235-244.

Song, F, Eastwood, AJ, Gilbody, S, Duley, L, & Sutton, AJ. (2000). Publication and related biases: a review. *Health Technology Assessment, 4*(10), 1-115.

Sowtali, SN, & Harith, S. (2014). Educational Needs among Stroke Patients admitted to Hospital Universiti Sains Malaysia: Preliminary findings. *Malaysian Journal of Health Sciences, 12*(1), 67-74.

Sowtali, SN, Mohd Yussof, D, Harith, S, & Mohamed, M. (2017). Comparsion of Knowledge, Attitude and Practice on Stroke Knowledge in Malaysia and Other Nations: A review of Literature. *International Medical Journal 24*(2), 168-173.

Squires, A. (2008). Language barriers and qualitative nursing research : methodological considerations. *International Nursing Review, 55*, 265-273.

Statistic Unit Brunei. (2013). Health Information Booklet. (18th edn.) [Online] Available at http://www.moh.gov.bn/SiteCollectionDocuments/Health%20Indicator%20Booklet/HIB_2013.pdf. Accessed 13/03/2017

Steiner, V, Pierce, LL, Drahuschak, S, Nofziger, E, Buchman, D, & Sziorny, T. (2008). Emotional support, Physical help and Health of Caregiver of stroke survivors. *Journal of Neuroscience Nursing, 40*(1), 48-54.

Stroke-Specific Education Framework. (2015). Stroke-Specific Education Framework. Retrieved 18/03/2015, from www.stroke-education.org.uk

Stroke Association. (2013). Feeling Overwhelmed: The emotional impact of stroke. https://www.stroke.org.uk/sites/default/files/feeling_overwhelmed_final_web_0_.pdf

Stroke Association. (2016). Benefits and financial assistance. London: Stroke Association.

Stroke Unit Trialists' Collaboration. (2009). Organised In-patient (Stroke Unit) care for stroke. http://onlinelibrary.wiley.com/doi/10.1002/14651858.CD000197.pub2/pdf

Suh, EE, Kagan, S, & Strumpf, N. (2009). Cultural competence in qualitative interview methods with Asian Immigrants. *Journal of Transcultural Nursing, 20*(2), 194-201.

Sundseth, A, Faiz, KW, Rønning, OM, & Thommessen, B (2014). Factors Related to Knowledge of Stroke Symptoms and Risk Factors in a Norwegian Stroke Population. *Journal of Stroke and Cerebrovascular Diseases, 23*(7), 1849-1855.

Lo, S.H.S., Chang, A.M. & Chau, J.P.C. (2018) Stroke Self-Management Support improves survivors' self-efficacy and outcome expectation of self-management behaviors. *Stroke.* 49(3), 758 - 760

Talib, N. (2002). A resilent monarchy: the Sultanate of Brunei and regime legitimacy in an era of democratic nation-stated. *New Zealand Journal of Asian Studies, 4*(2), 134-147.

Tatemichi, TK, Desmond, DW, Stern, Y, Paik, M, Sano, M, & Bagiella, E. (1994). Cognitive impairment after stroke: frequency, patterns, and relationship to functional abilities. *journal of Neurology, Neurosurgery and Psychiatry, 57*, 202-207.

Teasell, R., Foley, N., Hussein, N., Wiener, J. & Speechly, M. (2018) The elements of Stroke Rehabilitation. *Evidence-based Review of Stroke Rehabilitation.* [Online] Available at http://www.ebrsr.com/sites/default/files/v18-SREBR-CH6-NET.pdf Accessed 21/10/2019

Teddlie, C, & Tashakkori, A. (2009). *Foundations of Mixed Methods Research: Integrating Quantitative and Qualitative approches in the Social and Behavioral Sciences*. United States of America: Sage Publication Inc.

Temple, B, & Young, A. (2004). Qualitative research and translation dilemmas. *Qualitative Research in Psychology, 4*(2), 161-178.

Teoh, V, Sims, J, & Milgrom, J. (2009). Psychosocial predictors of quality of life in a sample of community-dwelling stroke survivors: A longitudinal study. *Topics in stroke rehabilitation, 16*(2), 157-166.

Tein, R. (2014) Deputy minister reiterates the importance of family. *Brunei Times.* Retrieved from https://btarchive.org/news/national/2014/12/05/deputy-minister-reiterates-importance-family

Tien, R. (2016). Many unaware of stroke symptoms, *Brunei Times*. Retrieved from http://bt.com.bn/news-national/2016/07/13/many-unaware-stroke-symptoms

Townsend, N, Wickramasinghe, K, Bhatnagar, P, Smolina, K , Nichols, M, Leal, J, . . . Rayner, M. (2012). Coronary heart disease statistics 2012 edition. https://www.bhf.org.uk/~/media/files/publications/research/2012_chd_statistics_compendium.pdf

Tsai, JHC, Choe, JH, Lim, JMU, Acorda, E, Chan, NL, Taylor, V, & Tu, SP. (2004). Developing culturally competent health knowledge: Issues of data analysis of cross-cultural, cross-language qualitative research. *International Journal of Qualitative Methods, 3*(4), 16-27.

Tse, T, Yussof, SZ, Churilov, L, Ma H, Davis, S, Donnan, GA, . . . START team. (2017). Increased work and social engagement is associated with increased stroke specific quality of life in stroke survivors at 3 months and 12 months post-stroke: a longitudinal study of an Australian stroke cohort. *Topics in stroke rehabilitation*, 1-10. http//dx.doi.org/10.1080/10749357.2017.1318399 doi:10.1080/10749357.2017.1318339

Tuah, HD. (2002). *Brunei Darussalam Nation Building Based on Melayu Islam Beraja (Malay Islamic Monarchy Philosophy)*. Brunei: Civil Service Institute, Prime Minister Office.

Twinn, S. (1997). An exploratory study examining the influence of translation on the validity and reliability of qualitative data in nursing research. *Journal of Advanced Nursing, 26*, 418-423.

Van de Port, IGL, Kwakkel, G, Van Wijk, I, & Lindeman, E. (2006). Susceptibility to deterioration of mobility long-term after stroke: A prospective cohort study. *Stroke, 37*, 167-171.

Van der Riet, P, Dedkhard, S, & Srithong, K. (2012). Complementary therapies in rehabilitation: stroke patients' narratives. Part 2. *Journal of Clinical Nursing, 21*(5-6), 668-676.

Van Heugten, C, Visser-Meily, A, Post, M, & Lindeman, E. (2006). Care for carers of stroke patients: Evidence-based clinical practice guidelines. *Journal of Rehabilitation Medicine, 38*, 153-158.

van Wijk, I, Algra, A, van de Port, IG, Bevaart, B, & Lindeman, E. (2006). Change in mobility activity in the second year after stroke in a rehabilitation population: who is at risk for decline? *Archives of Physical Medicine and Rehabilitation, 87*, 45-50.

Villian, M, Sibon, I, Renou, P, Poli, M, & Swendsen, J. (2017). Very early social support following mild stroke is associated with emotional and behavioral outcomes three months later. *Clinical Rehabilitation, 31*(1), 135-141.

Vincent-Onabajo, G, & Moses, T. (2016). Knowledge of Stroke Risk Factors among Stroke Survivors in Nigeria. *Stroke Research and Treatment, 2016*, 1-5.

Vincent, C, Deaudelin, I, Robichaud, L, Rousseau, J, Viscogliosi, C, Talbot, LR, & Desrosiers, J. (2007). Rehabilitation needs for older adults with stroke living at home: perceptions of four populations. *BMC Greatics, 7*(20). http://www.biomedcentral.com/1471-2318/7/20

Visser-Meily, A, Post, M, De Port, IV, Van Heugten, C, & Van Den Bos, T. (2008). Psychosocial functioning of spouses in the chronic phase after stroke:

Improvement or deterioration between 1 and 3 years after stroke? *Patient Education and Counselling, 73*(1), 153-158.

Vorauer, J.D. & Ross, M. (1999) Sef-awareness and feeling Transparent: Failing to supress Ones' self. *Journal of Experimental Social Psychology.* 35(5), 415 - 440

Walker M, Sunnerhagen K, & R, Fisher. (2013). Evidence-based community stroke rehabilitation. *Stroke, 44*, 293-297.

Walker, MF, Sunnerhagen, KS, & Fisher, RJ. (2013). Evidence-based community stroke rehabilitation. *Stroke, 44*, 293-297.

Walsh, ME, Galvin, R, Loughnane, C, Macey, C, & Horgan, NF. (2015). Factors associated with community reintegration in the first year after stroke: a qualiative meta-synthesis. *Disability and Rehabilitation, 37*(18), 1599-1608.

Walton, C. (2012). Saving lives: 20 years of investing in vital stroke research (A report) *Stroke Association*. London: Stroke Association.

Wang, L, Chen, CM, & Hsiao, CY. (2013a). Evaluating a community-based stroke nursing education and rehabilitation programme for patients with mild stroke. *International Journal of Nursing Practice, 19*, 249-256.

Wang, L, Chen, CM, Liao, WC, & Hsiao, CY. (2013b). Evaluating a community-based stroke nursing education and rehabilitation programme for patients with mild stroke. *International Journal of Nursing Practice, 19*(3), 249-256.

Warlow, C, Van Gin, J, Dennis, M, Wardlaw, JM, Bamford, J, Hankey, G, . . . Rothwell, P (2008). *Stroke: Practical management* (3rd Edition ed.). Massachusetts: Blackwell Publishing.

Warner, G., Packer, T., Villeneuve, M., Audulv, A. & Versnel, J. (2015) A systematic review of the effectiveness of stroke self-management programs for improving function and participation outcomes: self-management programs for stroke survivors, *Disability and Rehabilitation*, 37(23), 2141-2163, DOI: 10.3109/09638288.2014.996674

Welcome2Borneo. (2010). Bandar Seri Begawan. Retrieved 20/12/2014, from http://www.welcome2borneo.com/2010/06/13/bandar-seri-begawan/

White, CL, Korner-Bitensky, N, Rodrigue, N, Rosmus, C, Lambart, S, & Wood-Dauphine, S. (2007). Barriers and facilitators to caring for individuals with stroke in the community: The family's experience *Canadian Journal Occupational Therapy, 29*(2), 5-12.

Williams, O, Leighton-Herrmann, E, DeSorbo, A, Hecht, M, Hedmann, M, Huq, S, . . . Noble, J. (2015). Hip Hop Stroke: Study Protocol for a Randomized Controlled Trial to Address Stroke Literacy. *Journal of clinical trials, 5*(5), 242.

Willis, GB. (2005). *Cognitive Interviewing: A tool for Improving Questionnaire Design*. Califronia: Sage Publications

Wolfe, CDA. (2000). The impact of stroke. *British Medical Bulletin, 56*(2), 257-286.

Wong, JPH, & Poon, MKL. (2010). Bringing Translation out of the shadows: Translation as an issue of methodological significance in Cross-cultural Qualitative research. *Journal of Transcultural Nursing, 21*(2), 151-158.

Wong-Cornall C, Parsons J, Sheridan N, Kenealy T, Peckham A. Extending “Continuity of Care” to include the Contribution of Family Carers. International Journal of Integrated Care. 2017;17(2):11. DOI: http://doi.org/10.5334/ijic.2545

Woods, L, & Roberts, P. (2000). Generasting theory and evidence from qualitative computerised software. *Nurse Researcher, 8*(2), 28-41.

World Health Organization. (2001). International Classification of Functioning, Disability and Health: ICF. Retrieved 11th April, 2013, from http://www.who.int/classifications/icf/en/

World Health Organization. (2003). International Consultation to Review Community-Based Rehabilitation. http://whqlibdoc.who.int/hq/2003/WHO_DAR_03.2.pdf

World Health Organization. (2012). Global Burden of Stroke. In J. Mackay & G. Mensah (Eds.), The Atlas of Heart Disease and Stroke (Vol. 2013, pp. 50-51). Geneva: World Health Organization. Retrieved from http://www.who.int/cardiovascular_diseases/resources/atlas/en/.

Wright, John, Williams, Rhys, & Wilkinson, John R. (1998). Development and importance of health needs assessment. *BMJ : British Medical Journal, 316*(7140), 1310-1313.

Yakar, H.K. & Alpar, S.E. (2018) Intercultural Communication competence of nurses providing care for patients from different cultures. *International Journal of Caring Sciences.* 11(3), 1396 - 1340

Yeung, EH, Szeto, A, Richardson, D, Lai, SH, Lim, E, & Cameron, JI. (2015). The experiences and needs of Chinese-CAnadian stroke survivors and family caregivers as they integrate into the community. *Health and Social Care in the Community, 23*(5), 523-531.

Yousaf, D. S., Khan, D. S., Azam, D. N., Mahmood, D. H., & Pervaiz, D. F. (2019). Needs of high-risk primary caregivers handling stroke patients: a mixed method study in a tertiary care hospital of rawalpindi. *Pakistan Armed Forces Medical Journal*, 69(SUPPL 2), S216 - 22.

Young, J, & Forster, A. (2007). Rehabilitation after stroke. *British Medical Journal, 334*, 86-90.

Ytterberg, C., Koch, L.V. & Erikson, A. (2019) Abandoned to the strains of daily life: a qualitative study of the long-term experiences in partners to persons after a mild to moderate stroke, Disability and Rehabilitation, 41(6), 649 - 655, DOI: 10.1080/09638288.2017.1401674

Yu, RF, San Jose, MZ, Manzanilla, BM, Oris, MY, & Gan, R. (2002). Sources and reasons for delays in the care of acute stroke patients. *Journal of the Neurological Sciences, 199*(1), 49-54.

Yu, Y, Hu, J, Efrid, JT, & McCoy, TP. (2013). Social support, coping strategies and health-related quality of life among primary caregivers of stroke survivors in China. *Journal of Clinical Nursing, 22*, 2160-2171.

Zainan Nazri, M.K.N., Ahmad, M., Mohammed Yusoff, A., Mohd. Amin, F., Mat Ishak, M., Mohd. Noor, M.R., Sidik, M.A,m Mohd. Khambali Hambali, K. & Sulaiman, I. (2011) The concept of Rewards and Punishments in religion: A special reference to *Kitab Al-Adab* of Sahih Bukhari. *World Journal of Islamic History and Civillization.* 1(4), 249 - 254.

Zainal, Z. (2010). JPMC medical staff get to train in Germany. http://www.bt.com.bn/news-national/2010/10/25/jpmc-medical-staff-get-train-germany

Zaki, F., & Hussin, S. (2019). Malay Massage and Leech Cupping Treatment for Stroke Patients. *International Journal of Academic Research in Business and Social Sciences,* 9(5), 1013–1021.

Zeng, Y, He, GP, Yi, GH, Huang, YJ, Zhang, QH, & He, LL. (2012). Knowledge of stroke warning signs and risk factors among patients with previous stroke or TIA in China. *Journal of Clinical Nursing, 21*(19pt20), 2886-2895.

Zhang, L, Sui, M, Yan, T, You, L, Li, K, & Gao, Y. (2017). A study in person later after stroke of the relationships between social participation, environmental factors and depression. *Clinical Rehabilitation, 3*(13), 394-402.

Zhou, Yanfeng, Yang, Tingting, Gong, Yanhong, Li, Wenzhen, Chen, Yawen, Li, Jing, . . . Lu, Zuxun. (2017). Pre-hospital Delay after Acute Ischemic Stroke in Central Urban China: Prevalence and Risk Factors. *Molecular Neurobiology, 54*(4), 3007-3016. doi: 10.1007/s12035-016-9750-4

End of Thesis