Exploring the Care Needs of Stroke Dyads in Hospital-to-Home Transition From Perspectives of Stroke Dyads and Health Professionals

by

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Contents

Summary

Stroke occurs when cerebral blood flow is disrupted by vascular occlusion or rupture, causing brain tissue damage. It is a leading cause of adult disability worldwide. Hospital-to-home transition is a challenging period for stroke dyads (people with stroke and their caregivers) due to shortened hospital stays and complex care needs, as they must now take charge of care. Although stroke dyads demonstrate dyadic interdependence in the transition, few studies have explored their individual and dyadic care needs and expectations during the transition.

Aim

The aim of the study was to understand the care needs and expectations of stroke dyads during the hospital-to-home transition from the perspectives of stroke dyads and health professionals in South Australia.

Methods

Gadamer’s philosophical hermeneutics guided the study. Thirty stroke dyads and 31 stroke care clinicians, including two general practitioners, participated in the study. Data were collected through interviews with stroke dyads before hospital discharge and at 3 and 6 months after discharge. Focus groups and interviews were used to collect data with stroke care clinicians.

Results

Stroke dyads’ perceived preparedness in managing post-discharge care was influenced by psychological and emotional state, resilience, and level of engagement in discharge planning. Returning home was seen as a significant milestone in the post-stroke trajectory. However, compared with people with stroke, caregivers perceived profound uncertainties about their role and how to take over care after discharge as a result of inconsistent engagement in discharge planning.

After discharge, stroke dyads experienced a sense of setbacks due to physical and psychosocial factors. They perceived a dyadic interdependence, which generated positive impacts on their adaptation to challenging situations. Caregivers played a key role in providing psychological support for people with stroke, but such a role was not fully recognised nor supported in the healthcare system. Moreover, stroke dyads expected enhanced communication, engagement in discharge planning and needs-driven service provision. Additionally, health professionals believed that prioritising the safety and continuity of care enhanced the transition and helped health professionals to cope with work-related challenges.

Discussion

Findings support previous studies that found that equal attention to stroke dyads' psychological and physical recovery facilitates the development of their self-management ability during the transition. The findings also add new understandings that people with stroke mainly rely on caregivers to provide psychological support, while caregivers also show vulnerability in their role and unmet self-care needs. Such situations underscore the significance of dyad-centredness in care needs assessment and discharge planning. Additionally, findings suggest an innovative nurse-led, stroke-specific hospital-to-home transition care framework. This framework emphasises the partnership between the healthcare organisation, health professional and stroke dyad as the foundation for stroke-dyad-centred transition care at three key time points—during the hospital stay, arriving home and during formal rehabilitation programs, and after separation from formal rehabilitation programs and during community dwelling.

Conclusion

Findings support a dyad-centred and interdisciplinary care approach to hospital-to-home transition care that emphasises collaboration, communication and continuity of care across different care settings and service providers. Findings also support the need for further studies on the feasibility, acceptability and effectiveness of the nurse-led, stroke-specific hospital-to-home transition care framework.

Keywords: *people with stroke, caregivers, stroke dyads, transition care, discharge planning*

Declaration

I certify that this thesis:

1. does not incorporate without acknowledgment any material previously submitted for a degree or diploma in any university
2. and the research within will not be submitted for any other future degree or diploma without the permission of Flinders University; and
3. to the best of my knowledge and belief, does not contain any material previously published or written by another person except where due reference is made in the text.

Signed ___Langduo Chen_________

Date ______07/09/2923_______________

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List of Abbreviations

ACSQHC	Australian Commission on Safety and Quality in Health Care
ADLs	activities of daily living
AIHW	Australian Institute of Health and Welfare
APA	American Psychological Association
ARNA	Australasian Rehabilitation Nurses' Association
CASP	Critical Appraisal Skills Programme
CCM	chronic care model
CERQual	Confidence in the Evidence from Reviews of Qualitative Research
COREQ	Consolidated Criteria for Reporting Qualitative Research
FIM	Functional Independence Measure
GP	general practitioner
ICF	International Classification of Functioning, Disability and Health
MoCA	Montreal Cognitive Assessment
NDIS	National Disability Insurance Scheme
PEO	population, exposure, outcome
PICF	patient information and consent form
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
PSD	post-stroke depression
WHO	World Health Organization
WSO	World Stroke Organization

Glossary

Term	Definition
Care coordination	The deliberate organisation of patient care activities and sharing of information among all care providers to achieve safe and effective care (Agency for Healthcare Research and Quality, 2014).
Depression	The feeling of persistent sadness and/or loss of interest in activities an individual once enjoyed (World Health Organization, 2017a).
Disability	An umbrella term for impairments of body function or structure, activity limitations or participation restrictions. It is not only related to pathology and impairment but also considers the individual's interaction with environmental and social circumstances (Australian Institute of Health and Welfare, 2022; World Health Organization, 2022a).
Functional recovery	The recovery of cognitive and motor impairments affecting activities of daily living, such as mobility, showering, feeding and toileting (Branco et al., 2019; Grefkes & Fink, 2020).
Haemorrhagic stroke	Classified into intracerebral and subarachnoid haemorrhage, refers to blood vessel ruptures causing abnormal accumulation of blood within the brain. This type of stroke accounts for approximately 10%–15% of the stroke population (Kuriakose & Xiao, 2020).
Health	A state of complete physical, mental and social wellbeing and not merely the absence of disease or infirmity (World Health Organization, 1948).

Term	Definition
Health system	All organisations, people and actions with the primary purpose of promoting, restoring or maintaining health, which includes endeavours to influence determinants of health and direct health-improving activities (World Health Organization, 2007).
Healthy transition	Subjective wellbeing, role mastery and wellbeing of relationships during the transition (Meleis, 2010).
Informal caregivers	People caring for those in need within the context of an existing relationship, such as a family member, friend or neighbour (Australian Institute of Health and Welfare, 2021).
Ischaemic stroke	Ischaemic stroke is caused by a thrombus or embolus that obstructs the cerebral artery, resulting in infarction of the parts of the brain the artery feeds. About 85% of stroke patients suffer from ischaemic stroke (Kuriakose & Xiao, 2020).
Interdependence	Interdependence presents in a relationship when one person's emotion, cognition or behaviours affects those of a partner (Cook & Kenny, 2005).
Interprofessional approach	An approach that enables interprofessional healthcare teams to practice collaboratively to enhance person-centred care and improve patient and health systems outcomes (McLaney et al., 2022).
Interdisciplinary team approach	Multidisciplinary team members collaboratively set goals with patients and families and implement plans. There is a high degree of communication and cooperation among the team members (Körner, 2010).

Term	Definition
Interprofessional education	An education strategy to promote two or more professionals learning about, from and with each other to enable effective collaboration and improve health outcomes (World Health Organization, 2010).
Micro-credentials	Certified documents that provide recognised proof of the achievement of competency-based skills and learning outcomes from shorter-duration educational or training activities. (McGreal & Olcott, 2022).
Patient safety culture	A pattern of individual and organisational behaviour, based upon shared beliefs and values, that continuously seeks to minimise patient harm that may result from the process of care delivery (Australian Commission on Safety and Quality in Health Care, n.d.-a).
People with stroke	Individuals who have survived stroke and are living with the sequelae of stroke.
Person-centred care	An approach that responds to the needs, preferences and values of individuals, families and communities in humane and holistic ways and through education and support to promote their participation in their own care (World Health Organization, 2015). The terms ‘person-centred care’ and ‘individualised care’ are used interchangeably within this thesis.
Primary care	The essential, first-contact care that is provided in a community setting (World Health Organization, 2021).
Resilience	The ‘processes and skills that result in good individual and community-health outcomes despite negative events, serious threats and hazards’ (World Health Organization, 2017b, p. 6).

Term	Definition
Self-management	An individual’s ability to manage a chronic condition in collaboration with the caregiver, family, community and appropriate health professionals (Satink et al., 2016).
Social integration	Reflects the extent of one’s social connections and access to support, often in important roles such as marriage, friendship and in volunteer organisations (Uchino et al., 2018, p. 463).
Stroke	‘Stroke is an acute episode of focal dysfunction of the brain, retina, or spinal cord lasting longer than 24 [hours], or of any duration if imaging ([computerised tomography] or [magnetic resonance imaging]) or autopsy show focal infarction or haemorrhage relevant to the symptoms’ (Hankey, 2017, p. 641).
Stroke dyad	An individual with stroke and their caregiver form a stroke/caregiving dyad (Jacops et al., 2022).
Stroke multidisciplinary team	A stroke multidisciplinary team includes stroke-specific medical, nursing and allied health clinicians (Stroke Foundation, 2022).
Stroke nurse navigators	Specialised stroke nurses, practising at an advanced level, play a crucial role in facilitating and managing care transitions, which leads to improved continuity of care, reduced service fragmentation, enhanced quality of care for stroke dyads and decreased hospital readmissions (Byrne, Hegney et al., 2020; Camicia et al., 2021).
Stroke recovery	Improvement across a variety of outcomes, beginning with biological and neurological changes that manifest as improvement in performance and activity-based behavioural measures (Belagaje, 2017, p. 239).

Term	Definition
Stroke rehabilitation	A proactive, person-centred and goal-oriented process facilitated by a multidisciplinary team in a culturally appropriate environment and a health strategy aimed at optimising function and enabling social reintegration for people with stroke (Stroke Foundation, 2022).
Team resilience	The collective capacity of all team members to respond well to change, pressure and disruption (Hartwig et al., 2020).
Telerehabilitation	A model of rehabilitation services that uses information and communication technologies to remotely deliver rehabilitation consultations, assessments and therapies. It forms part of various post-stroke services in South Australia (Laver et al., 2022; SA Health, 2023).
Transition	‘A passage from one life phase, condition, or status to another, is a multiple concept embracing the elements of process, time span, and perception … [it] refers to both the process and the outcome of complex person-environment interactions. It may involve more than one person and is imbedded in the context and the situation … Defining characteristics of transition include process, disconnectedness, perception, and patterns of response’ (Chick & Meleis, 1986, pp. 239–240).
Uncertainty in illness	The inability to determine the meaning of illness-related events or to accurately predict outcomes (Mishel, 1990).
Wellbeing	A positive state experienced by individuals and societies. It is a resource for daily life and is determined by social, economic and environmental conditions (World Health Organization, 2021).

Chapter 1: Background

1.1 Introduction

Stroke (cerebrovascular accident) is a common and serious health condition and a prominent cause of disability worldwide (Feigin et al., 2022; Stinear et al., 2020). Despite a reduction in the age-standardised stroke mortality rate in the past two decades, the overall burden of stroke is substantial and continues to increase with an ageing population (Feigin et al., 2022; Gorelick, 2019). The sudden onset and catastrophic nature of stroke brings enormous physical and psychosocial challenges to people with stroke and their families. Over 60% of people with stroke live with disabilities that require them to be cared for by informal caregivers (hereafter, ‘caregivers’; Stroke Foundation, 2020b).

Rehabilitation involves stroke dyads (people with stroke and their caregivers) regaining independence and being prepared to return to the community (Stroke Foundation, 2022). For most stroke dyads, the transition from hospital to home is an exciting but also difficult time. Homecoming marks a great improvement in post-stroke recovery. However, this is also a time to face the real world out of hospital and to adapt to the various changes in their lives (L. Chen et al., 2020; Connolly & Mahoney, 2018). The care needs and expectations of health and social care services from stroke dyads change from time to time during the transition. However, what these needs and expectations during transition are and how they are met is under-researched. Furthermore, most studies on transition care have described issues from the perspectives of people with stroke and/or caregivers. Health professionals’ views regarding the approaches to identifying and meeting the care needs of stroke dyads are also largely under-researched.

Nurses have been key members of multidisciplinary rehabilitation teams and act as case managers, care coordinators and educators for stroke dyads to enable continuum of care and optimise rehabilitation and recovery (Camicia et al., 2022; Purvis et al., 2021). It is evident that nurses equipped with comprehensive assessment knowledge and skills are able to reduce post-stroke readmission rates and adverse events through prevention strategies and timely intervention (Deen et al., 2016; Jun-O'Connell et al., 2023). Stroke-care-nurse-led studies on the care needs of stroke dyads during the hospital-to-home transition are much needed to inform person-centred and consumer-directed quality improvement strategies and nursing interventions in stroke care.

The present chapter highlights the background of the study. It begins with a discussion of stroke in the global and local context, outlining its prevalence, incidence, recovery and the impact that stroke has on people's lives as well as its economic implications for health and social care systems. Next, an overview of stroke care organisations and information on stroke rehabilitation, clinical guidelines for stroke management and available post-stroke community programs for stroke dyads is presented. The social and political context of transition care for people with stroke and support for their caregivers are also discussed. This chapter also outlines the present study's significance, research design, aims and objectives. Finally, the structure of this thesis is introduced.

1.2 Stroke in a Global and an Australian Context

1.2.1 Stroke and Brain Recovery

The brain is one of the most complex organs of the human body. It is the command centre of the nervous system and interprets senses, controls body movement and behaviour, and is 'the source of all the qualities that define our humanity' (National Institute of Neurological Disorders and Stroke, n.d.). Normal function of the brain relies on adequate cerebral blood circulation for the supply of oxygen and nutrients as well as the removal of waste products. Alterations to the cerebral vascular function cause brain injury, resulting in changes to normal human body function (Chrissobolis & Sobey, 2015).

Based on clinical presentation, a stroke, also known as a cerebrovascular accident or brain attack, is defined by the World Health Organization (WHO) as 'rapidly developed clinical signs of focal (or global) disturbance of cerebral function, lasting more than 24 hours or leading to death, with no apparent cause other than of vascular origin' (Aho et al., 1980, p.

114). This traditional definition has been challenged by experts due to advances in stroke management, especially imaging technology, in the 21st century (Coupland et al., 2017). With expert consensus, the definition of stroke has been updated as:

> an acute episode of focal dysfunction of the brain, retina, or spinal cord lasting longer than 24 [hours], or of any duration if imaging ([computerised tomography] or [magnetic resonance imaging]) or autopsy show focal infarction or haemorrhage relevant to the symptoms. (Hankey, 2017, p. 641)

This definition was adopted for this study because it is based on both imaging and clinical presentation and thus includes patients who may be excluded by the traditional definition.

There are two major types of stroke: ischaemic and haemorrhagic (Kuriakose & Xiao, 2020). Ischaemic stroke is caused by a thrombus or embolus that obstructs the cerebral artery, resulting in infarction of the parts of the brain the artery feeds. About 85% of stroke patients suffer from ischaemic stroke (Kuriakose & Xiao, 2020). Haemorrhagic stroke, classified into intracerebral and subarachnoid haemorrhage, refers to blood vessel ruptures causing abnormal accumulation of blood within the brain. This type of stroke accounts for approximately 10%–15% of the stroke population (Kuriakose & Xiao, 2020).

Since the groundbreaking discovery in the past century of the brain’s ability to remodel, studies on neural plasticity have increased dramatically (B. P. Johnson & Cohen, 2022; Su & Xu, 2020). Neural plasticity refers to changes occurring in the central nervous system in response to intrinsic and extrinsic stimuli. These changes occur at functional and structural levels. They can be beneficial or can become plasticity diseases based on individual or genetic differences (B. P. Johnson & Cohen, 2022; Su & Xu, 2020). For example, ischaemic stroke causes loss of neurons and damages the normal function of synapses. This may result in cognition and memory impairment in people post-stroke (Nie & Yang, 2017). The brain’s remodelling ability is reflected in the modulation of synaptic plasticity stimulated by physical exercises. Through energy metabolism and synaptic plasticity, physical exercise training has been found to be beneficial to brain health and cognition (Nie & Yang, 2017). This also explains why exercise training has been the primary post-stroke rehabilitative therapy (Nie & Yang, 2017).

Among all types of stroke, the highest percentage of stroke patients experience ischaemic insult, including delayed ischaemic events due to arterial vasospasm for some people with subarachnoid haemorrhage (Kuriakose & Xiao, 2020; Tobin et al., 2014). Over the past two decades, there have been advances in acute ischaemic stroke treatment, including the use of thrombolytic agents and endovascular therapy (Hollist et al., 2021). Through the use of multimodal computerised tomography and magnetic resonance imaging, the approach to acute stroke management is now shifting from a standard time-window approach to one of brain tissue preservation and individualised treatment (Hollist et al., 2021). Research on other possible novel therapies is underway as a result of increasing evidence of the complex bidirectional interplay between the central nervous system and the immune system (Magnus & Liesz, 2023). Although further insight is required into the interaction between inflammation and the central nervous system, and the role that the immune response plays after ischaemic stroke, evidence shows that ischaemic inflammation contributes significantly to the irreversible damage of neurons at the ischaemic site. While reperfusion of the site by dissolving the clot re-establishes perfusion of the infarcted area, it can also worsen injury by increasing local inflammation, causing further neuronal damage (Magnus & Liesz, 2023). In other words, this autoimmune response could potentially affect neural plasticity and functional recovery, which may contribute to the incidence of vascular dementia after stroke (Doyle & Buckwalter, 2020).

In addition to post-stroke pathogenesis exerted by activation of the immune system, brain injury after stroke also has a large effect on the system that triggers immunosuppression. It is reflected in the clinical manifestation of systemic infections, such as pneumonia and urinary tract infection, in people with stroke (Faura et al., 2021). Though further understanding is required, the above findings provide exciting avenues for further studies aiming to reduce the burden of disability and death from stroke.

1.2.2 Aetiology and Clinical Presentation

Causes of stroke include genetic factors and modifiable risk factors. Studies on genetic factors have revealed several genetic loci that are related to ischaemic stroke, suggesting that genetic variants may contribute to intracranial haemorrhage (Kuriakose & Xiao, 2020). Further studies are required under this causal category to inform the development of novel therapeutic approaches to stroke prevention.

Researchers have also identified potentially modifiable risk factors associated with stroke. These factors include hypertension, dyslipidaemia, atrial fibrillation, diabetes mellitus, current cigarette smoking, alcohol abuse, obesity, poor diet, low physical activity and psychosocial factors (Feigin et al., 2021; Kuriakose & Xiao, 2020). Furthermore, an acute stroke is usually associated with multiple risk factors. Globally, approximately 87% of stroke is attributed to these risk factors (Feigin et al., 2021). Among the risk factors, hypertension has been found to be significantly associated with all types of stroke, especially intracerebral haemorrhage. Smoking, diabetes mellitus and dyslipidaemia are important risk factors for ischaemic stroke (Feigin et al., 2021; Kuriakose & Xiao, 2020). Therefore, the prevention of stroke should consider patient education with regard to both lifestyle changes and medication management. These intervention strategies should be an integral part of discharge planning.

Despite the aetiology of stroke and the variation of associated symptoms, the most common symptoms suddenly presented by people with stroke include weakness and numbness to one side of body, involving the face, arm and leg; unilateral or bilateral visual loss or disturbance; change in cognitive status, speech or understanding; altered mobility, balance or coordination; and severe headache with an unknown cause (Freytes et al., 2021). Public education on the recognition of these symptoms helps improve clinical outcomes through the early detection and treatment of stroke (X. Chen et al., 2022). Despite mixed results, public health campaigns, such as Act FAST (face, arm, speech, time), have contributed to an increased public awareness of stroke signs and symptoms and timely stroke diagnosis (X. Chen et al., 2022).

1.2.3 Epidemiology

Stroke is recognised as a common healthcare problem and the leading cause of disability in the world (Feigin et al., 2022; Stinear et al., 2020). Globally, stroke is ranked the second most prevalent cause of death (Feigin et al., 2022) and the third main cause of death and disability combined (Feigin et al., 2022). Every year, approximately 15 million people worldwide are diagnosed with stroke, 30% of whom die, and another 30% of whom are permanently disabled because of stroke (WHO, 2023a). In the last two decades, there has been a significant increase in stroke prevalence for people younger than 70 years. It has been suggested that, although the age-standardised stroke mortality rate has decreased, the general global burden of stroke is huge and continues to increase (Feigin et al., 2021).

In Australia, stroke is considered the leading cause of death and disability (Australian Institute of Health and Welfare [AIHW], 2023). In 2021, deaths with stroke recorded as the underlying cause accounted for 6% of all deaths in Australia (AIHW, 2023). In 2018, approximately 387,000 Australians were diagnosed with stroke or recurrent stroke (AIHW, 2023). Approximately 70% of people with stroke were over 65 years of age. This number is predicted to increase with an aging population (AIHW, 2023; Stroke Foundation, 2020a). In 2020, South Australia was one of the Australian states with the highest number of people on a per capita basis experiencing first-time stroke (Stroke Foundation, 2020a).

1.2.4 Impact

Stroke has a massive economic impact. The estimated global cost of stroke is over US$891 billion (Feigin et al., 2022). In Australia, the total economic costs of stroke were projected to be AU$6.2 billion in 2020 (Deloitte Access Economics, 2020). The cost for people younger than 65 years with stroke is higher than for their older counterparts due to stroke-induced productivity loss, unemployment and psychosocial complications (Tan et al., 2022).

The effect of stroke is heterogeneous. Depending on the location and size of the stroke lesion, it is common for people with stroke to live with a wide range of disabilities, such as dependence on assistance to walk and to conduct activities of daily living (ADLs);

fatigue; communication or swallowing impairments; visual deficits; incontinence; cognitive and personality changes; and depression and anxiety (Bernhardt et al., 2020). About 80% of people with stroke suffer from impairments that affect control of movement or coordination of one side of the body (Ingram et al., 2021). Among non-motor impairments, the incidence of cognitive impairments is over 70% after stroke, and dementia occurs in about 15% of the stroke population. These cognitive impairments are associated with disability, dependency and morbidity, presenting a major burden to patients, caregivers and healthcare systems (Craig et al., 2022; Rost et al., 2022). In Australia, among all people with stroke with disabilities, about 88% live in households, and the rest reside in cared accommodation (AIHW, 2013). In addition, approximately 65% of people with stroke live with disabilities that require them to depend on others to conduct ADLs (Stroke Foundation, 2018). The majority of people with stroke who return home are cared for by their caregivers (Lobo et al., 2021). Stroke caregiver burden is discussed in the next section.

Apart from post-stroke disabilities, the risk for people with stroke to develop another stroke is high. A number of longitudinal studies have followed up on people with stroke for up to 5–10 years. Despite differences in the location and time of the studies, researchers have reported a similar substantial risk of recurrent stroke (Kolmos et al., 2021). Compared to the onset of the first stroke in the general population, the risk of another stroke after the initial stroke is six times higher (Hardie et al., 2004). However, the stroke recurrence rate remains controversial. The cumulative risk of recurrent stroke is 7% at 1 year, 16%–20% at 5 years and 25% at 10 years (Dhamoon et al., 2006; Hardie et al., 2004; Mohan et al., 2009). After 10 years, people with stroke have an approximately 4% accumulated risk per year of developing a subsequent stroke (Hardie et al., 2004). The good news is that, with a combination of lifestyle modifications and preventative medical treatment, the risk of recurrent stroke could be reduced by about 80% (Linsay et al., 2017). Hence, it is essential for health professionals in hospitals and the community to work collaboratively to support people with stroke in secondary stroke prevention during post-stroke rehabilitation (Stroke Foundation, 2022).

Stroke also has a significant impact on people's mental health. Among various stroke-associated neuropsychiatric disorders, post-stroke depression (PSD) is the most common. Depression refers to the feeling of persistent sadness and/or the loss of interest in activities an individual once enjoyed (WHO, 2017a). It affects approximately 30% of the stroke population, with the cumulative percentage ranging from 39% to 52% within the first 5 years after stroke and up to 70% among all people with stroke over the longer term (da Rocha e Silva et al., 2013; Robinson & Jorge, 2016). Although the relationship between lesion location and the development of PSD remains controversial, it has a significant impact on stroke recovery and rehabilitation.

Studies have reported that depression and cognitive decline are closely related. Neurological and neuroendocrine changes caused by depression may accelerate the rate of cognitive decline (Olazarán et al., 2013; van den Kommer et al., 2013). PSD has a close correlation with the severity of deficits in ADLs and cognitive function, especially executive function and social functioning. Additionally, people with stroke who develop PSD have poor functional outcomes during rehabilitation (Ahn et al., 2015; Robinson & Jorge, 2016). In their retrospective study, Ahn et al. (2015) also found that people with stroke with PSD who were cared for by informal caregivers had better outcomes compared to those cared for by paid professional caregivers. Considering the impact of PSD on the health and wellbeing of people with stroke, early identification and treatment are crucial in post-stroke rehabilitation. Education and information on how to report early signs of PSD and to seek help for timely treatment need to be included in discharge planning for these patients and their caregivers.

1.2.5 Informal Caregivers

Caregivers are people caring for those in need within the context of an existing relationship, such as a family member, a friend or a neighbour (AIHW, 2021). They play an important role in post-stroke rehabilitation and recovery. In Australia, approximately 88% of people with stroke live in households, and 65% of them live with a disability that requires assistance from caregivers to conduct ADLs (Bakas et al., 2022; Stroke Foundation, 2018). Caregivers spend, on average, over 40 hours a week caring for people with stroke (AIHW, 2013). They are unsung heroes in supporting people with stroke in rehabilitation and recovery and are often overlooked in the healthcare system regarding their need for education and psychosocial support (Camicia et al., 2023).

Studies have shown that caregivers experience stress and burnout in caring for people with stroke, and the caregiving experience affects their long-term wellbeing (Akinwuntan et al., 2021; Camicia et al., 2023). During the hospital-to-home transition, caregivers have to commence and adapt to the caregiving role and start to assist people with stroke with ADLs, health condition management and navigate the healthcare system simultaneously. Most have never been a caregiver and, pre-morbidly, had shared household tasks, including financial management, with people now with stroke. Young adult caregivers also have competing duties to their own family as well as their job (Camicia et al., 2023; L. Chen et al., 2020). L. Chen et al. (2016) found that caregivers felt vulnerable and helpless soon after discharge when they were left alone to navigate the healthcare system. In their study, some caregivers felt unprepared, with a lack of caregiver training prior to discharge, and rehabilitation and care services were not designed to accommodate their daily routines. They had to change their daily routines to meet service provision times.

Interventional studies to improve the stroke caregiver experience and reduce caregiver stress have demonstrated some effect. Lin et al. (2022) discovered positive outcomes of a nurse-led intervention for stroke dyads in reducing caregiver burden and unplanned hospital readmission. They recommended a health coaching approach incorporating stroke-related knowledge and self-efficacy building. A meta-analysis of dyadic psychosocial interventions confirmed the above positive outcomes and suggested the significance of early implementation of face-to-face interventions and continuing out-of-hospital support (X.-Y. Zhang et al., 2023). Despite the positive effects, the result of these studies may not be generalisable due to limitations in methodology and the heterogeneity of interventions. Developing individualised interventions to alleviate stress during the hospital-to-home transition is, therefore, a gap in research. Besides this, few studies have specifically focused on the hospital-to-home transition. Consequently, how to realise the early detection of caregivers' needs and problem-solving during the transition to sustain their caregiving role has yet to be explored.

1.2.6 Dyadic Interdependence

Interdependence presents in a relationship when one person's emotion, cognition, or behaviours affects that of their partner (Cook & Kenny, 2005). As discussed above, stroke affects both the person with stroke and their caregiver and changes family relationships. A person with stroke and their caregiver form a caregiving dyad (Jacops et al., 2022). An important attribute of the caregiving dyad is interconnected mutuality: dyadic members experience and follow a trajectory of the disease together. Their relationship reflects dyadic interdependence, leading to collective emotions and coping (Boyer et al., 2017; Jacops et al., 2022).

Stroke intervention studies have revealed positive outcomes of dyadic interventions. Psychosocial interventions have been found to improve depressive symptoms in stroke dyads (Minshall et al., 2020). The systematic review and meta-analysis by Pucciarelli et al. (2021) indicated that educational interventions improve physical functioning, quality of life and memory in people with stroke and relieve depressive symptoms in caregivers. The reviewers suggested that these interventions should be dyad-focused instead of just dyad-based (Pucciarelli et al., 2021). Another review examining the effectiveness of dyadic psychoeducational interventions showed improvement in functional independence and long-term quality of life for people with stroke and in improving their family caregivers' burden (Mou et al., 2021). However, both reviews suggested further well-designed large-scale trials, prior to implementation in clinical practice, to determine the effectiveness of dyadic interventions in diverse functional and psychosocial health outcomes for stroke dyads (Mou et al., 2021; Pucciarelli et al., 2021). Despite the positive findings regarding these dyadic interventions, their effectiveness is inconclusive. Understanding the shared experiences of stroke dyads as well as their unique individual needs would guide the design of future dyadic interventional studies.

1.3 Post-stroke Services

1.3.1 Stroke Rehabilitation

In 2001, the introduction of the International Classification of Functioning, Disabilities and Health (ICF) provided a new conceptual framework for assessing post-stroke disabilities and facilitating the communication of multidisciplinary teams within stroke care (Quintas et al., 2012; Tempest et al., 2013). The definition of stroke-associated disabilities is not only related to pathology and impairment but also considers the individual’s interaction with environmental and social circumstances (WHO, 2022a). Thus, the new definition has significant influence on post-stroke rehabilitation: physical recovery is no longer the only focus. The psychological, social and financial challenges faced by people with stroke and their families also need to be addressed during rehabilitation (Stroke Foundation, 2022).

Post-stroke recovery is a complex, heterogeneous process and is associated with the size and site of stroke lesions. Recovery occurs through processes involving ‘restitution (restoring the functionality of damaged neural tissue), substitution (reorganisation of partly spared neural pathways to relearn lost functions), and compensation (improvement of the disparity between the impaired skills of a patient and the demands of their environment)’ (Langhorne et al., 2011, p. 1693). Although people with stroke experience spontaneous recovery for weeks and months after initial stroke, rehabilitation therapies that are designed to target specific areas of the central nervous and musculoskeletal system help support or induce these recovery processes (Carey et al., 2019; Stinear et al., 2020).

Rehabilitation is an integral part of stroke management. Stroke rehabilitation refers to a proactive, person-centred and goal-oriented process facilitated by a multidisciplinary team in a culturally appropriate environment and a health strategy aimed at optimising function and enabling social reintegration for people with stroke (Stroke Foundation, 2022). The multidisciplinary team provides rehabilitation interventions with a holistic approach through a cyclical process including ‘assessment, goal setting, intervention and reassessment’ (Brewer et al., 2013, p. 14).

The rehabilitation process is strongly influenced by support from the health and social care systems. In the current atmosphere of shortened hospital stays and early discharge in healthcare reform, stroke dyads are expected to encounter additional challenges in recovery and rehabilitation after discharge from hospital (Camicia, Lutz, Summers et al., 2021; L. Chen et al., 2020). Carefully structured pathways to enable them to cope with challenges and to seek help from health professionals when they need it are crucial for successful recovery and rehabilitation. Moreover, given the heterogeneity and complexity of post-stroke impairments, rehabilitation interventions are highly individualised and strongly influenced by the care needs and expectations of people with stroke. Engaging stroke dyads in the process is the way to identify and achieve their rehabilitation goals. This person-centred approach is also the key to the success of stroke rehabilitation (Stroke Foundation, 2022; WHO, 2023b).

1.3.2 Post-stroke Rehabilitation and Community Care Services

In Australia, the National Rehabilitation Stroke Services Framework (Stroke Foundation, 2022) outlines essential principles of post-stroke rehabilitation services, stating that all eligible people with stroke are entitled to participate in individualised rehabilitation services. Post-stroke rehabilitation services include inpatient stroke rehabilitation services; ambulatory rehabilitation services encompassing day hospitals, outpatient clinics and home-based services, including early supported discharge services; and telemedicine rehabilitation support (inpatient or community settings).

Telerehabilitation is a model of rehabilitation services that uses information and communication technologies to remotely deliver rehabilitation consultations, assessments and therapies. It forms part of various post-stroke services in South Australia (Laver et al., 2022; SA Health, 2023).

People with stroke can also access transition services. The Transition Care Program, also known as after-hospital care, provides a range of services, including therapy, nursing and personal care assistance and can be delivered in-home or in a facility (SA Health, 2022). The aim is to minimise unnecessarily extended hospital stays, optimise a person’s function and determine their long-term care arrangements. The Transition Care Program is a non-stroke-specific program that is goal-oriented and time-limited (up to 12 weeks) to support eligible people aged 65 years and above (45 years and above for Aboriginal and Torres Strait Islander people; SA Health, 2022).

Furthermore, eligible people meeting the same age criteria can access government-funded home care services through My Aged Care (2020). Home care services provide complex support, including personal care, support services, and nursing, allied health and clinical services through the coordinated and consumer-directed home care packages program. There are four levels of assistance, from basic care needs to high care needs (My Aged Care, 2020).

Despite their availability, these packages are difficult to access and navigate (Royal Commission into Aged Care Quality and Safety, 2021). The waiting list is too long to get access to care at home. In 2018–19 financial year, it took at least 7 months to access a Level 1 package and took as long as 34 months for a Level 4 package between the time of assessment and when a home care package was assigned (Royal Commission into Aged Care Quality and Safety, 2021).

Additionally, older people often lack the knowledge to navigate the complex aged-care services to make informed decisions about care services meeting their specific needs (Royal Commission into Aged Care Quality and Safety, 2021). The situation is further exacerbated for those with disability accessing services matching their needs due to the availability of these services only for people younger than 65 years of age (Royal Commission into Aged Care Quality and Safety, 2021).

Moreover, people can also access the Commonwealth Home Support Programme, which provides entry-level service to help with housework, shopping, personal care, meals, transport and short-term respite care to relieve people and their caregivers from usual care arrangements. Short-term restorative care services are also available to support people returning to independence in the home (My Aged Care, 2020).

In Australia, people with stroke who are younger than 65 years of age can access the government-funded disability service, the National Disability Insurance Scheme (NDIS). The NDIS provides funding to eligible people with disability to enable independent living, new skills, jobs or volunteering in their community to lead an improved quality of life (National Disability Insurance Agency, 2022). The NDIS funds a wide range of supports, from household tasks, equipment assessment and provision, to therapeutic support and accommodation (National Disability Insurance Agency, 2022). However, people with disability wait months or years in hospitals to be discharged with NDIS services due to a long application review and approval process (Winkler, 2022). This prolonged waiting in hospitals could have negative psychological impacts on stroke dyads during the transition.

Despite the availability of diverse stroke rehabilitation and community care services for stroke dyads, the National Stroke Audit 2021 on acute services identified that about 24% of people with stroke leave hospital without a discharge care plan (Stroke Foundation, 2021). Furthermore, only approximately 60% of people with stroke were discharged to the community with tailored information regarding stroke rehabilitation and recovery. In addition, as much as 80% of people with stroke did not receive information on post-stroke intimacy (Stroke Foundation, 2020a). These audit results highlight an inadequate preparation of stroke dyads prior to hospital-to-home transition. These results also suggest that an individualised discharge plan and post-discharge follow-up co-developed by stroke dyads and health professionals are imperative for improving the hospital-to-home transition for people with stroke.

1.3.3 Nurses' Role in Post-stroke Rehabilitation

Nurses play a crucial role in post-stroke rehabilitation. Working with stroke patients 24 hours a day, every day, rehabilitation nurses act as teachers, coaches and caregivers to help patients and their caregivers translate the knowledge they learn from therapists into a daily living environment. They also proactively prevent and manage clinical deterioration (Australasian Rehabilitation Nurses' Association [ARNA], 2018; Camicia, Lutz, Summers et al., 2021). As a key member of the multidisciplinary team, they usually act as care coordinators and case managers in the team to ensure a safe transition from hospital to the community (ARNA, 2018; Camicia, Lutz, Summers et al., 2021).

Despite the vital role of nurses in post-stroke rehabilitation, L. Chen et al. (2016) found that nurses were rarely mentioned by stroke dyads in the transition period. This was echoed by Loft et al. (2019), who found that nurses' role in post-stroke care was yet to be fully acknowledged. They also highlighted the ideal position that nurses are in regarding the provision of holistic care in stroke rehabilitation and advocated for strengthening nursing education on nurses' contribution to rehabilitation to enhance psychosocial support to stroke dyads. Camicia, Lutz, Summers et al. (2021) reaffirmed nurses' essential role in facilitating the transition of care and suggested the role of stroke nurse liaison/navigator to enhance the transition care.

The role of stroke nurse coordinator has been recommended in stroke management and the continuum of care (Camicia, Lutz, Summers et al., 2021; Stroke Foundation, 2023). George et al. (2017) found that nurses activated stroke alerts significantly earlier than physicians in the hospital setting, which greatly improves thrombolytic treatment after stroke onset. In Australia, an observational study revealed a positive association between the presence of stroke coordinators (mainly nurses), the hospital length of stay and the delivery of evidence-based care in a stroke unit (Purvis et al., 2018). In addition, a recent review on stroke nurses' contributions to mobile stroke units provided promising evidence to further expand stroke nurse coordinators' role to the pre-hospital context (Coote et al., 2022).

Furthermore, the role of nurse navigator has emerged in the management of cancer and chronic conditions, including stroke. Cancer nurse navigators enhanced support for patients with cancer early in their course, improved patient experience and reduced problems in care (Wagner et al., 2014). The role of nurse navigator also generated cost savings and improved the quality of perioperative care for patients undergoing elective total knee or hip arthroplasty (Phillips et al., 2019). Moreover, stroke nurse navigators' interventions showed positive outcomes on compliance with medication and follow-up appointments, reduced rehospitalisation and improved quality of life 12 months after hospital discharge (Deen et al., 2016). The growing role of stroke nurse navigators provides an evolving model of care that may enhance the quality of care and transition experiences for stroke dyads.

It is worth noting that the above-reviewed studies mainly focused on acute care in hospital settings or in the community, lacking follow-up on the continuum of transition. The follow-up period for most studies was limited, except for the 12-month intervention in Deen et al. (2016). However, the main focus of this study was stroke patients' self-reported post-discharge compliance and quality of life measures (Deen et al., 2016). Transition is a non-linear process, and care needs change over time (Meleis et al., 2000). Hence, it is necessary to obtain further insights into the role of stroke nurses, targeting the individual and dyadic care needs of people with stroke and their caregivers throughout the post-stroke trajectory, with a specific focus on the hospital-to-home transition.

1.4 Aim and Objectives

The aim of the present study was to explore the care needs and expectations of stroke dyads regarding the hospital-to-home transition in an Australian social context. The objectives were to:

1. understand the experience and perceptions of stroke dyads during the hospital-to-home transition in a global context
2. understand stakeholders' perspectives on approaches to identifying and meeting the transition care and rehabilitation needs of people with stroke in an Australian social context.

1.5 Research Design

This was a two-phased study. In Phase 1, a systematic review using meta-synthesis of qualitative studies was undertaken to address Objective 1. In Phase 2, a qualitative study informed by Gadamer's phenomenological hermeneutics was conducted to address Objective 2. In-depth interviews were conducted with stroke dyads and focus groups and interviews with health professionals involved in transition care and rehabilitation services to collect data.

1.6 Significance of the Study

Hospital-to-home transition is a challenging time for stroke dyads. The shortened hospital stays and early discharge due to healthcare reform add more challenges to transition care and may result in unintended consequences: for example, post-stroke-associated complications, such as falls, fall-related injuries, infections and functional declines; poor quality of life for stroke dyads; and increased readmission, health service utilisation and premature admission to residential care facilities during the transition. Despite abundant studies on issues and challenges faced by stroke dyads during the transition, studies determining post-stroke hospital-to-home transition care needs and the selection of services to meet these needs largely lack depth. In addition, studies on the experiences of stroke dyads have been descriptive of issues with little focus on shared experiences for stroke dyads and on the most appropriate way to meet their individual and dyadic needs. Furthermore, studies from the perspective of health professionals regarding evidence-based frameworks to determine and meet post-stroke rehabilitation and care needs during the transition are scarce. Finally, in spite of a sophisticated stroke management system in Australia, there is little research exploring stroke dyads' perspectives of the system during the transition.

The present study is significant as it would offer valuable insights into transition care, a crucial aspect for stroke dyads during their journey from hospital to home, from health to illness, and from their roles as spouses/parents to those of caregivers and care recipients. The study would advance the body of knowledge in the field of rehabilitation and care needs during poststroke hospital-to-home transition. In particular, the longitudinal approach of the study would enhance the depth of understandings on the changes of care needs during the transition. Furthermore, perspectives from both consumers and health professionals would contribute to the delivery of consumer-guided and person-centred poststroke rehabilitation services. This study would also help establish and enhance advanced stroke nurses’ role in the field of ever-evolving contemporary nursing profession.

The present study is expected to contribute to knowledge by developing deeper insights of care needs and the approaches to identify and meet the needs of stroke dyads in poststroke hospital-to-home transition care. Employing a longitudinal qualitative approach is expected to address gaps in the research domain by observing and analysing participants’ experiences over an extended period, which would empower the researcher to capture changes and develop a comprehensive and nuanced understanding of participants’ lived experiences. The temporal dynamics inherent in longitudinal studies would also allow the researcher to track the evolution of transition experiences to help develop insights into how and why changes occur (Holland et al., 2006). Moreover, including health professionals working in different specialised disciplines in the study would enable insights into health professionals’ perceptions of transition care for stroke dyads as they transition through different stages of recovery. Collecting data from multiple sources across time, space and person is considered data triangulation, which enables the researcher to validate data and gain multiple perspectives of the studied phenomenon (Denzin & Lincoln, 2018). This methodological strategy creates an innovative way to understand the richness and complexity of stroke transition experiences and addressed gaps in stroke transition care research.

1.7 Thesis Structure

This thesis is presented in 12 chapters. The current chapter, Chapter 1, outlines stroke as a health condition in the global and Australian contexts, detailing the pathophysiology, risk factors, management and prevention of stroke. Post-stroke rehabilitation and community care services for stroke dyads in Australia are elaborated, together with challenges in current healthcare systems relevant to the hospital-to-home transition. This chapter also introduces the significance, aim and objectives of the study.

Chapter 2 includes a published systematic integrative review that explored the challenges and opportunities for stroke dyads in hospital-to-home transition care. The review revealed that the transition care experiences of stroke dyads are influenced by health and social care system service coordination and health organisation resources in supporting health professionals' partnership and engagement with stroke dyads, and by stroke dyads' level of readiness to cope with challenges. Tailored supports for developing resilience in stroke dyads was emphasised.

Chapter 3 reviews the concepts and theories in transition care studies. Meleis's middle-range and situation-specific transitions theory is adapted for this study. In a systematic approach, Meleis's transitions theory guides the development of an interview guide and data analysis to help generate comprehensive insights into the transition experiences of stroke dyads and into health professionals' perceptions.

Chapter 4 incorporates a published systematic review and meta-synthesis that identified the enablers and barriers in hospital-to-home transition care for stroke dyads. The review underscored that partnerships with stroke dyads facilitate discharge preparation, fostering self-management capabilities. Furthermore, a lack of post-discharge support, coupled with inappropriate discharge planning, contributes to unmet needs for stroke dyads after returning home. Hence, stroke dyads expect integrated transitional care that empowers them to be involved in decision-making and enables long-term self-management in the community.

Chapter 5 discusses the methodology and methods used in this study. It describes Gadamer's philosophical hermeneutics and the methodological rationale that informed the research design and methods. It also explains participant selection, data collection and analysis methods, the sample size and ethical considerations.

Chapter 6 introduces the organisation of the findings chapters (Chapters 6–9), including participants' demographics and a summary of major themes and subthemes. This chapter also includes a published article that presents Part 1 of the findings, from interviews before hospital discharge, which encompasses three major themes and subthemes: (1)

psychological stress, (2) resilience and (3) certainty and uncertainty about post-discharge care. The first theme emphasises psychological stress with different causes among stroke dyads. The second focuses on stroke dyads' resilience, fostered by their own positive thinking and support from others. The third theme highlights stroke dyads' inconsistent level of certainty about post-discharge care; they prefer to co-develop and co-implement discharge plans with health professionals.

Chapters 7 and 8 present the study's findings under four major themes, identified from the interviews at 3 and 6 months after hospital discharge. Chapter 7 interprets the first two themes and subthemes: (4) coping with setbacks and (5) role transformation. Theme 4 reflects participants' perceptions of the impact of stroke on their psychological wellbeing and the resilience they demonstrated to reconcile and move forwards with the changes in their lives. Theme 5 focuses on stroke participants' self-management development and caregivers' evolving ability to build caregiving capabilities. The dyadic effects in dealing with challenges enabled them to transform and adapt to their post-stroke lives.

Chapter 8 interprets the remaining two major themes and their subthemes: (6) transitioning with support and (7) expectations in hospital-to-home transition care. Theme 6 presents the support that stroke dyads received from family, friends and health professionals. Positive effects arising from the support between dyadic members are identified. Theme 7 presents stroke dyads' expectations to be equal partners in discharge planning and their desires for flexible service provision to meet their individual needs.

Chapter 9 details the three major themes and subthemes that emerged from interviews and focus groups with health professionals. The themes are (1) transition shaped by care needs assessment, (2) transition challenged by constraints on service delivery and (3) transition enhanced by a commitment to the safety of care. Theme 1 highlights the significance of stroke care needs assessment and identifies a lack of caregiver involvement and an inadequate focus on psychological needs. Theme 2 interprets the challenges that health professionals encountered in supporting stroke dyads, including shortened length of stays and gaps in service accessibility, that may contribute to a mismatch between care needs and service provision. Theme 3 demonstrates a safety culture fostered through leadership and team resilience that may enhance and facilitate healthy transitions for stroke dyads.

Chapter 10 discusses the major findings of this study in an Australian and international context. These findings are compared with recent studies, looking for similarities and differences. The discussions in this chapter focus on the significance of balancing functional rehabilitation and psychological support for stroke dyads to facilitate the transition and on the benefit for health professionals in developing insights into dyadic interdependence to improve dyad-centredness and the engagement of stroke dyads in their own care planning. Moreover, the discussion highlights opportunities to enhance stroke nurses' contributions to facilitate the transition and relates Meleis's transitions theory to the study's findings that enrich the theory with stroke-specific perspectives.

Chapter 11 proposes a novel stroke-nurse-navigator-enabled hospital-to-home transition care framework. The framework emphasises gaps in the transition process, opportunities to bridge the gaps and the interprofessional collaboration and partnership with stroke dyads during the transition that is enabled by stroke nurse navigators.

Finally, Chapter 12 summarises the key research findings and highlights the main discussion points. It critically evaluates the limitations of the study and outlines implications and recommendations for practice, policy and future research and provides a reflective account of the researcher's experience.

1.8 Summary

This chapter has discussed the background of the study and provided an overview of stroke and stroke-transition-care-related challenges and opportunities in the global and Australian contexts. The aim and objectives of this study were introduced, with discussions on the significance of this study. The next chapter presents an integrated literature review to establish current knowledge and identify gaps in the research area.

Chapter 2: Integrative Review

2.1 Introduction

As introduced in the previous chapter, hospital-to-home transition is the most stressful period for stroke dyads, especially in the context of shortened hospital stays and early discharge. They face enormous challenges in adapting to their home care environments for continuing recovery after discharge. They also encounter great difficulties in exploring suitable rehabilitation and care services. This chapter presents a publication: an integrative review of the research to establish current knowledge and identify gaps in the research area.

The contribution of the first author to the paper is 70% to research design, writing and editing and 80% to data collection and analysis. The second and third authors together contributed 30% to research design, writing and editing and 20% to data collection and analysis.

This section presents a publication arising from this thesis that was published in the *Journal of Advanced Nursing*.

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2.2 An Integrative Review: Challenges and Opportunities for People With Stroke and Caregivers in Hospital to Home Transition Care

2.2.1 Abstract

Aim: To identify challenges and opportunities for people with stroke and caregivers in hospital to home transition care.

Background: Due to shortened hospital stays, people with stroke and caregivers must take responsibility for complex care on discharge from hospital to home. Gaps exist in the literature that synthesises studies on hospital to home transition care.

Design: A systematic integrated review.

Data sources: Six databases were searched systematically between 18 June 2018 to 31 October 2018 including Medline, CINAHL, Web of Science, ProQuest, Scopus and Science Direct. The search did not have a date limit.

Review methods: Studies that met the selection criteria were critically reviewed. Data were extracted from the studies for analyses. A convergent qualitative synthesis approach using inductive thematic synthesis was applied to the review.

Results: The analysis of 23 studies identified three major findings. First, health and social care systems influence transition care by either enabling people with stroke and caregivers to manage transition care via well-coordinated services or preventing them from accessing services. Second, health professionals' partnership with people with stroke and caregivers largely decides tailored support for them. Successful partnerships and engagements with people with stroke and caregivers depend on organisational resources.

Third, survivors and caregivers are at different levels of readiness to cope with challenges. Individualised support for them to develop resilience is highly regarded.

Conclusion: People with stroke and caregivers encounter enormous challenges in self-management of hospital to home transition care. Further research is required to address their expectations of support during transition care.

Impact: There is a lack of synthesis of studies on factors affecting hospital to home transition care for people with stroke. Health and social care system designs, health professionals' commitment to individualised care and the self-management capability of people with stroke and their caregivers have a profound influence on the transition care experiences.

Keywords: *Stroke, transition care, survivors, caregivers, nurses, health professionals, integrated review*

2.2.2 Introduction

Worldwide, 15 million people suffer from stroke (cerebrovascular disease) per annum and 5.8 million die from it (World Stroke Organization [WSO], n.d.). Despite a reduction in the age-standardised stroke mortality rate over the past two decades, the overall burden of stroke is substantial and continues to increase with an ageing population (Feigin et al., 2017; Kunst et al., 2011). Most people with stroke are discharged to home (Dutta et al., 2018; Ouellette et al., 2015). In the global context of shortened hospital stays and early discharge due to cost-saving pressure, people with stroke and caregivers are expected to manage more complex healthcare issues at home (Deloitte, 2018; Langhorne et al., 2017). However, they are largely unprepared with few self-management capabilities to take charge of transition care (Govender et al., 2019; Piccenna et al., 2016). The synthesis of studies exploring this increasingly important research field is much needed to gain a more comprehensive understanding of issues.

2.2.3 Background

Poststroke rehabilitation and recovery is a chronic process that requires ongoing adjustment and interaction with healthcare systems and service providers. Studies indicate unmet needs of people with chronic diseases due to healthcare system failures (Kadu & Stolee, 2015). The Chronic Care Model (CCM) was developed to transform the healthcare system from reactive to proactive and activate patients’ self-management capabilities (WHO, 2016). The CCM consists of six interrelated domains: community, health system, self-management support, delivery system design, decision support and clinical information systems (Accelerating Care Transformation Centre, 2023). The goal of the model is to provide high-quality care and improved outcomes through productive interactions between informed, activated patients and prepared, proactive practice teams supported by community resources and health care organisations (Accelerating Care Transformation Centre, 2023). This review adapted the CCM as a theoretical framework to analyse challenges and opportunities at the healthcare system, organisation, practice, and patient levels for people with stroke and family caregivers after hospital discharge.

Discharge planning is a crucial process to identify education and skill needs for people with stroke and caregivers to take responsibility for rehabilitation and recovery after discharge (Andrew et al., 2018; Waring et al., 2016). Yet, studies reveal people with stroke and caregivers are not actively involved in the discharge planning process, nor receive adequate education and caregiving skills training (L. Chen et al., 2016; Kable et al., 2019). Inadequate patient and caregiver education in discharge planning contributes to increased risk of deterioration and unnecessary hospital readmissions (Reeves et al., 2017; Ulin et al., 2016).

Due to functional impairments, people with stroke must learn to adapt to the home environment after hospital discharge (Connolly & Mahoney, 2018; Hodson et al., 2016). Resilience is described as the “processes and skills that result in good individual and community-health outcomes despite negative events, serious threats and hazards” (WHO, 2017b, p. 6). Survivors and caregivers with resilience are capable of adapting to and coping with poststroke care challenges at home (Z. Liu et al., 2019; Martz & Livneh, 2016). A sense of hope, past life experiences, learning over time and availability of supportive resources are some of the determinants of resilience (Aburn et al., 2016; American Psychological

Association, 2019). People with stroke experience self-stigma due to invisible impairments such as fatigue and depressive symptoms (Balasooriya-Smeekens et al., 2016; Wainwright et al., 2017). This self-stigma may prevent them from taking proactive actions to develop their resilience. Caregivers play a key role in providing everyday care and coordinating care services. For them, resilience acts as a moderator between stress and burnout (Epstein, 2015; Taku, 2014). Programs that support the caregiving role in the context of early discharge are scarce (Atteih et al., 2015; Pindus et al., 2018). This situation may affect their ability to develop resilience to sustain transition care at home.

Studies reveal a mismatch of rehabilitation goals between people with stroke and health professionals (Connolly & Mahoney, 2018; Koh et al., 2014). This care situation is attributed to the lack of partnership with survivors and caregivers in care plan development (L. Chen et al., 2016; Plant et al., 2016). Health professionals' desire for partnership with survivors and caregivers to implement the recommendations of stroke guidelines is limited by a lack of institutional support (Baatiema et al., 2017; Munce et al., 2017). Organisational structures and resource constraints prevent health professionals from delivering flexible and tailored rehabilitation, education and support to survivors and caregivers (Baatiema et al., 2017; Harrison et al., 2017).

Studies with various research designs have explored issues of concern in poststroke hospital to home transition care. However, synthesised research evidence about how best to support people with stroke and caregivers in hospital to home transition care in the first six months post-discharge are scarce. This systematic integrated review addresses this gap in the literature. Findings will inform the design of future research and service development.

2.2.4 The Review

2.2.4.1 Aim

The aim of this systematic integrated review is to synthesise research evidence on challenges and opportunities for people with stroke and caregivers in hospital to home transition care.

The review questions were:

1. What are the challenges faced by people with stroke and caregivers in hospital to home transition care?
2. What are the opportunities to improve hospital to home transition care?

2.2.4.2 Design

This mixed-studies systematic review applied an integrated design with a convergent qualitative synthesis approach (Pluye & Hong, 2014). This approach enables the synthesis of evidence generated from diverse research methodologies on a topic “to maximise findings -and the ability of those findings to inform policy and practice” (Pearson et al., 2015, p. 122). Quantitative data including those from randomised controlled trials or quantitative components of mixed-methods studies are usually transformed into qualitative themes for synthesis (Pearson et al., 2015; Pluye & Hong, 2014). The review protocol was registered on PROSPERO with registration number CRD42019136068 (Appendix 1).

2.2.4.3 Search Methods

A systematic electronic databases search was conducted between 18 June 2018 and 31 October 2018 for all English articles in six databases including Medline, CINAHL, Web of Science, ProQuest, Scopus and Science Direct. There were no limitations on the year of publication except for ProQuest and Web of Science. The limiter of publication dates between 2008 and 2018 was applied to these two databases due to the large number of articles generated. Search terms used were stroke, cerebrovascular accident, acquired brain injury, survivor, patient, caregiver, health professional, service provider, transitional care, discharge, continuity of care and community services (Appendix 2). We also manually searched reference lists for studies meeting the criteria.

2.2.4.4 Search Outcome

At least two independent reviewers conducted the screening and review of studies for eligibility (LD and either LX or DC). The initial search generated 5855 articles. After removing duplicate citations, 5773 article titles and abstracts were screened. Of those, 258 full-text studies were assessed for eligibility based on the inclusion/exclusion criteria (Table 2.1). Throughout the selection process, consensus was achieved on discrepancies through discussion. In total, 23 studies (Table 2.2, Appendix 3) were selected for appraisal including 20 studies identified from the electronic database search and three studies identified through the manual search of reference lists (Figure 2.1).

Table 2.1

Inclusion and Exclusion Criteria

Items	Inclusion criteria	Exclusion criteria
Types of study	Original qualitative, quantitative, mixed method studies	Pilot studies, scoping reviews, narrative reviews, systematic reviews, reports, conference proceedings, discussions or commentaries.
Population	Adult people with stroke, caregivers and health professionals aged 18 years and above.	• People with stroke younger than 18 years old. • Multiple patient population including brain tumour, traumatic brain injury, other neurological condition and/or other diagnosis where stroke specific data cannot be separated.
Intervention/ Exposure Context & Outcome	The experience, care needs, expectations of people with stroke, their caregivers and health professionals during hospital to home transition or a transition	• Poststroke long term experiences and needs (over 6 months after hospital discharge).

Items	Inclusion criteria	Exclusion criteria
	facilitating intervention up to 6 months after discharge.	• Discharges to facilities other than home. • Studies conducted across multiple period of stroke trajectory where the transition period cannot be separated.

Figure 2.1

Review Flow Diagram

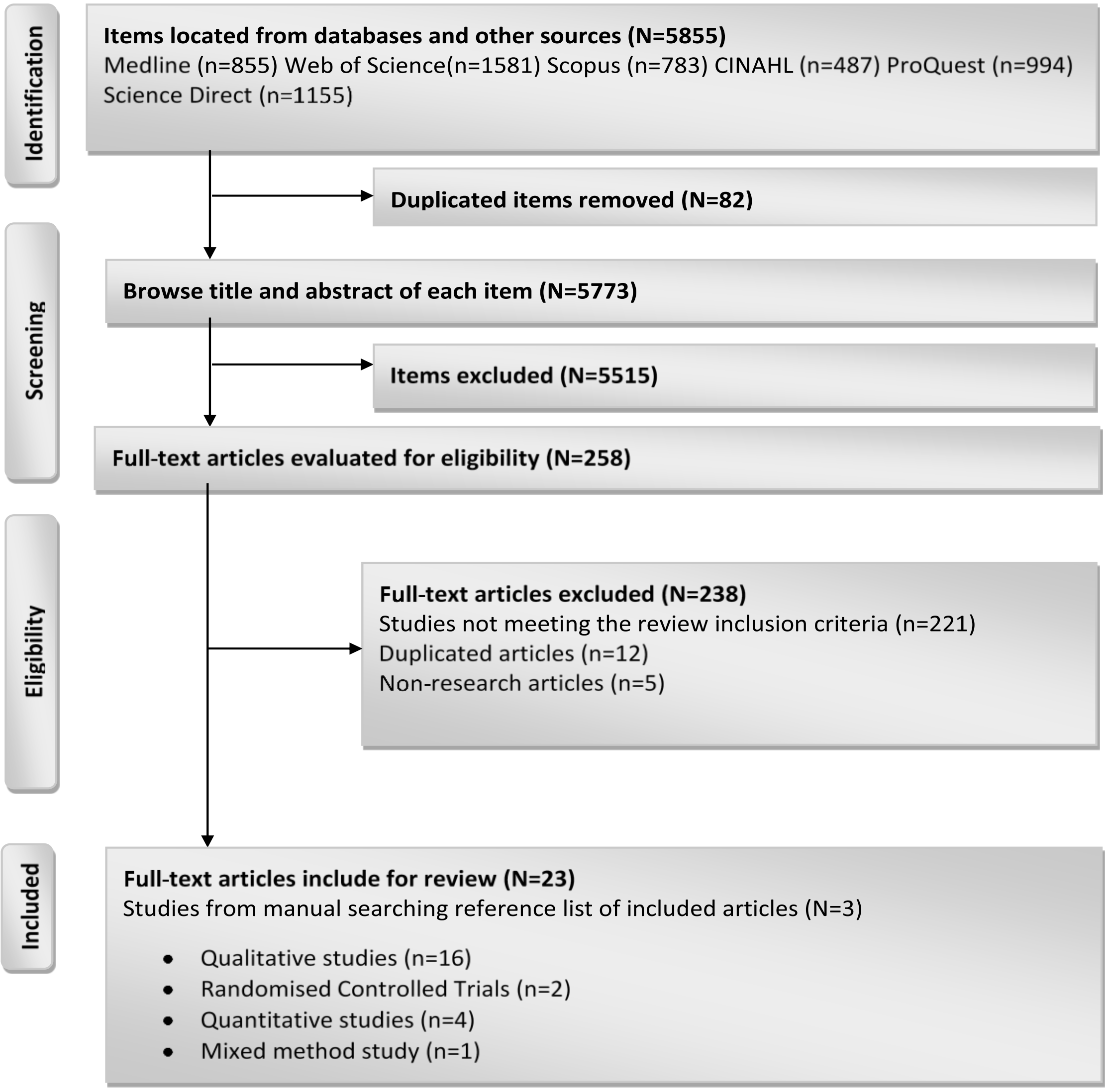


Table 2.2

Brief Summary of the Selected Articles

First author, year, country of origin	Brief summary of the selected articles (full description in Appendix 3)
1. Almborg (2008), Sweden	Cross sectional study examining stroke patients' perceived participation in the discharge planning process. Descriptive findings showed poor engagement in decision making and goal setting.
2. Almborg (2009), Sweden	Cross sectional study examining stroke patients' relatives' perceived participation in the discharge planning process. Descriptive findings showed 80% perceived no participation.
3. Bakas (2002), USA	Qualitative study exploring self-reported needs and concerns of stroke family caregiver after discharged home. Findings indicated needs and concerns on various aspects of care.
4. Cameron (2014), Canada	Qualitative study exploring perceptions on weekend pass – a discharge planning tool for stroke patients. Weekend pass provided in home practice and informs future inpatient rehabilitation.
5. Chouliara (2014), UK	Qualitative study investigating perceived facilitator and inhibitors for a stroke supported discharge service. Findings highlighted specificity of the service and fragmented stroke care pathway.
6. Cobley (2013), UK	Qualitative study evaluating experiences of people with stroke and caregivers on an Early Supported Discharge (ESD) service. Satisfied with home-based rehabilitation but post-ESD transition disjointed.
7. Ellis-Hill (2010), UK	Qualitative study to understand poststroke hospital to home transition experience. Recovery needs changed overtime. Stakeholders' shared models of recovery were needed.

First author, year, country of origin	**Brief summary of the selected articles (full description in Appendix 3)**
8. Greenwood (2009), UK	Qualitative ethnography exploring stroke caregivers' experience in the first 3 months after discharge. Findings revealed uncertainty most striking for new caregivers and situation improved over time.
9. Gustafsson (2013), Australia	Qualitative study to understand the first month post-discharge experience. Strategies were identified to better prepare for discharge. Caregiver support needs were highlighted.
10. Grant (2006), USA	Quantitative survey to identify issues and associated feelings for stroke caregiver 2-3 months post-discharge. Caregivers' needs changed during transition and coped with caregiving better overtime.
11. Hall (2012), Australia	Mixed method study exploring transition experiences of nontraumatic brain injury patients. At 6 months, physical and emotional function remained the same for 50% patients with lack of community support and difficulty navigating healthcare system.
12. Lou (2017), Denmark	Qualitative study investigating experience of ESD for mild stroke patients and partners. ESD supported a safe transition home but lacked focus on goal of returning to work.
13. Nordin (2015), Sweden	Qualitative study describing stroke patients' expectations of coming home with home rehabilitation service. Mixed feelings with unrealistic high expectations of functional status.
14. O'Brien (2014), Australia	Qualitative study examining healthcare providers' (HCP) perceptions of stroke caregiver needs. Support for caregivers were crucial at discharge point. HCPs' support to caregivers may be challenged by workload.

First author, year, country of origin	Brief summary of the selected articles (full description in Appendix 3)
15. Perry (2011), Australia	Quantitative survey to describe stroke caregiving 1- and 3-months post-hospital discharge. Services were least satisfactory where there were most needs. Pre-discharge involvement was lacking.
16. Pringle (2013), UK	Qualitative study to understand the first month discharged home experiences. One-month post-discharge a dynamic time. Family and social support facilitated reconnection to community.
17. Rittman (2007), USA	Qualitative study describing psychosocial experiences the first month after discharge. Survivors with high functional assessment scores could benefit from interventions preparing them for home.
18. Shyu (2008), Taiwan	Randomised controlled trial examining the effects of a discharge planning program. Experimental group had significantly better preparation and greater satisfaction with meeting discharge needs.
19. Simeone (2015), Italy	Qualitative study describing experience of people with stroke 3 months after discharge home. People with stroke experienced deeply changed life and viewed self as a burden to the family.
20. Wong & Yeung (2015), Hong Kong	Randomised controlled trial testing the effects of a stroke transitional care intervention. Significantly better outcomes for intervention group in physical and mental wellbeing.
21. Wood (2010), Canada	Qualitative study exploring perspectives on the process of community reintegration. Community reintegration is a process of transitioning through series of goals. More participation with time.
22. Wottrich (2012), Sweden	Qualitative study describing expectations of people with stroke 3 months after discharge home. Expectations changed over time. In-home practice beneficial prior to discharge.

First author, year, country of origin	Brief summary of the selected articles (full description in Appendix 3)
23. Young (2014), USA	Qualitative study exploring the needs of spousal caregivers during hospital to home transition. Unprepared caregivers would benefit from an early caregiver assessment with transitional planning.

2.2.4.5 Quality Appraisal

Critical Appraisal Skills Programme (CASP) tools were used to evaluate qualitative studies, qualitative component of the mixed-method study and RCTs (CASP, 2018a, 2018b). The quality of cross-sectional descriptive quantitative studies and quantitative component of the mixed-method study was assessed with a set of questions developed by Büttner and Muller (2015) for appraising epidemiological studies. No scores were placed during the appraisal. Researchers evaluated the quality of each study independently until a consensus was reached. All studies that met the selection criteria were included as every study provides a valuable perspective to achieve the aim of this review (Appendix 4).

2.2.4.6 Data Abstraction

Extracted data included participant quotations from qualitative studies and qualitative component of the mixed-method study, and numerical, narrative findings and quantitative component of the mixed-method study. Extracted data were organised into method-specific tables (see Appendices 5 and 6).

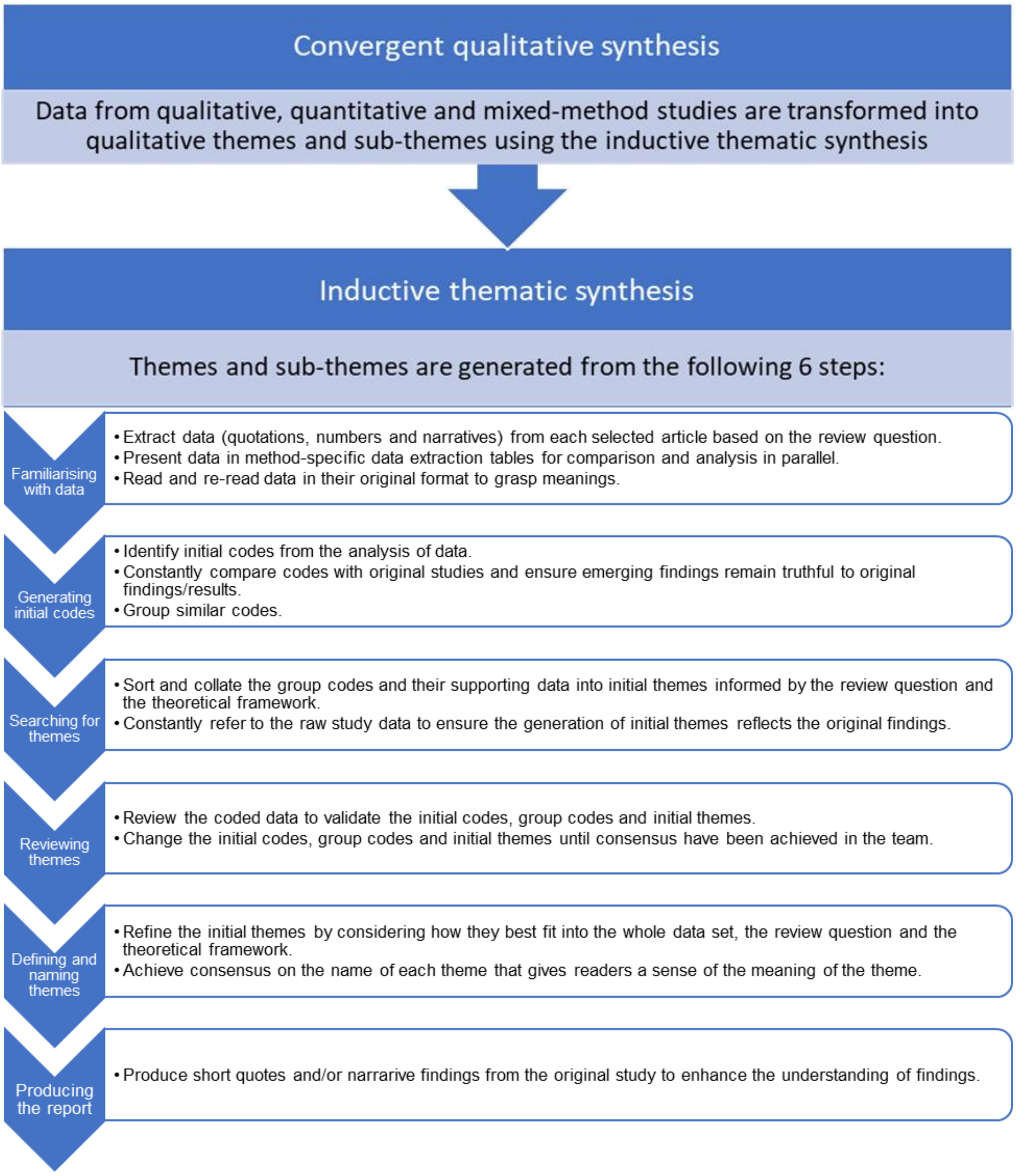
2.2.4.7 Data Synthesis

Informed by the convergent qualitative synthesis approach (Pluye & Hong, 2014), data synthesis was achieved using the inductive thematic synthesis method originally developed by Nowell and colleagues (2017) and adapted by Treacy and Stayt in their review (2019). The inductive thematic synthesis in this review includes 6 steps. First, we extracted data from selected articles that were relevant to the review question and presented data in method-specific data extraction tables for comparison and analysis in parallel (see

Appendices 5 and 6). Second, two researchers independently analysed and coded data from each article. Third, codes were collated into group codes and initial themes were identified and discussed in team meetings based on the review question and the theoretical framework. Fourth, codes, group codes and initial themes were cross-checked by researchers. Changes were made to reflect the raw data. Fifth, initial themes were refined by considering how they best fit into the whole data set, the review question and the theoretical framework. Additionally, final themes and sub-themes were presented with short quotes and/or narrative findings from the original studies to enhance the understanding of findings. Differences were resolved through elaboration and consensus in team meetings. The detailed data analysis and synthesis methods are illuminated in Figure 2.2.

Figure 2.2

Convergent Qualitative Synthesis (Adapted From Treacy & Stayt, 2019)



2.2.5 Findings

This review included 23 studies. Of those, 9 studies took place in stroke units and inpatient rehabilitation facilities respectively. The rest were conducted in inpatient wards (2), outpatient clinics (1), and discharge support services (2). The review report followed the Enhancing Transparency in Reporting the Synthesis of Qualitative Research (ENTREQ) guide (Flemming et al., 2018; Tong et al., 2012) and the PRISMA guidelines (Moher et al.,

2009) with greater emphasis on ENTREQ combined with some elements from PRISMA (Appendix 7). Three themes were identified regarding challenges and opportunities in transition care: (1) health and social care systems factors; (2) health professional and people with stroke/caregiver partnership factors; and (3) people with stroke/caregivers' self-management capability factors.

2.2.5.1 Health and Social Care Systems Factors

People with stroke require considerable social and health care services after discharge from hospital due to complex health conditions underlying stroke and functional impairments. Hospital to home transition care is enhanced if care services are integrated and well-coordinated. Conversely, transition care is compromised by fragmented care services and a lack of services for those with special care needs.

Enhanced transition care via well-coordinated services

Eleven studies discussed the benefits of stroke-specific transition care interventions. People with stroke and caregivers, who are on an ongoing journey of rehabilitation after discharge, perceive they have opportunities to enhance recovery in the transition to home care. They especially value care coordination provided by a rehabilitation team (Lou et al., 2017) and view a network of health professionals that they can call upon for advice as an opportunity to gain support after discharge from hospital (Bakas et al., 2002).

Three studies revealed that early supported discharge from stroke units enhances seamless hospital to home transition (Cobley et al., 2013; Lou et al., 2017; Nordin et al., 2015). Chouliara and associates (2014) described the specialist service as an opportunity in "bridging a big part of the gap in community-based rehabilitation" for people with stroke (Chouliara et al., 2014, p. 374). Newly discharged people with stroke perceive that support from an early supported discharge team provides them with a sense of control and security (Lou et al., 2017; Nordin et al., 2015).

The opportunity for practicing care at home through weekend stay at home programs helps people with stroke and their family attain skills to manage everyday care in a home environment. As a health professional stated: "When people get home, they realise what they can and…can't do, their limitations, and they realise… this is what I need to work on" (Cameron et al., 2014, p. 861). Weekend leave practice is considered an essential part of preparation for discharge. As a caregiver described:

> I think if she'd been in the hospital for the five months without coming home and then suddenly she was home…by herself, … [it] would be a real drama no matter who it was, So that slower introduction to home works. (Gustafsson & Bootle, 2013, p. 1384)

Compromised transition care due to gaps in services

Sixteen studies reported issues related to the continuity of rehabilitation and care services after discharge from hospital due to gaps in services. Many people with stroke and caregivers find themselves left alone without any help after discharge (Gustafsson & Bootle, 2013; Young et al., 2014). As a caregiver stated: "I felt like I was a little old Eskimo woman that they put on this ice block, chopped it off and sailed it out into the middle of the ocean" (Young et al., 2014, p. 1895). The feeling of being abandoned after discharge is further exacerbated if the decision to discharge is made under pressure (Ellis-Hill et al., 2009; Young et al., 2014). As one person reflected: "…with hindsight, it would obviously have been better for me to stay in C [a ward] because I would have had access to getting physio every day, but I realise that they need the beds…" (Ellis-Hill et al., 2009, p. 67).

The lack of coordination among care services and planning for ongoing rehabilitation not only inhibits poststroke recovery and aggravates uncertainty for caregivers but also creates challenges for service providers (Cobley et al., 2013; O'Brien et al., 2014). One community rehabilitation team reported the dilemma they experienced at the end of their service for people who still had potential for improvement: "There is dependence and reliance which is difficult [for them] to navigate, mainly because people need long-term support and we are the end of the line…There is still much more improvement to make…but there is no one else…" (O'Brien et al., 2014, p. 425).

The care needs of younger and working-aged people with stroke are often neglected as poststroke services are designed to meet the needs of older people who are the majority of people with stroke (Chouliara et al., 2014; Lou et al., 2017). Working-aged people with stroke felt that rehabilitation and community support services were more suited for retired or older people. The unmet needs of stroke caregivers after discharge and dissatisfaction with services further underscores the deficiency in person-centredness in hospital to home transition care (Perry & Middleton, 2011).

2.2.5.2 Health Professionals and People With Stroke/Caregivers Partnership Factors

Health professionals' commitment to partner with people with stroke and caregivers contributes to tailored services to meet care needs and achieve rehabilitation goals for clients. Otherwise, the lack of partnership leads to poor support for people with stroke and caregivers in transition care at home.

Tailored transition built on partnership with clients

Fifteen studies reported clients' satisfaction with tailored care services. Partnership between a multidisciplinary team of health professionals and people with stroke and their family provides opportunities to co-develop an individualised discharge plan. As a health professional stated: "It's never just one of us that is addressing the problem, if the whole team works together…with the family member and the patient – we can come up with…the best solutions possible" (Cameron et al., 2014, p. 860).

People with stroke and caregivers feel supported during the discharge planning process when they are treated as a valuable partner in discharge preparation to develop a sense of confidence in everyday activities. As a people with stroke described: "The occupational therapist took me into the OT kitchen … said 'Now I want you to make me a cup of coffee'…I did that without a single spill… so, yes, I knew I was ready to come home" (Ellis-Hill et al., 2009, p. 66).

A sense of confidence in self-management at home is also reflected in evaluation of caregiver preparations before discharge. Caregivers in an intervention group scored significantly higher than the control group on their preparation to care for older stroke patients at home (Shyu et al., 2008).

The lack of engagement with clients

The workload of clinicians hinders health professionals' engagement with families during discharge preparations (Cameron et al., 2014; Cobley et al., 2013; O'Brien et al., 2014). As a health professional said:

> I would like to give more time to families but feel constrained by my workload for the shift and sometimes you see…caregivers… are finding things difficult and this is very hard and I feel it is part of my work… (O'Brien et al., 2014, p. 425).

Relatives of people with stroke are poorly involved in information-sharing and expect more information than provided (Almborg et al., 2009). People with stroke with a higher level of dependency perceive less opportunity in decision-making about medical treatment compared to survivors with a lower level of dependency. This might imply use of a standardised rather than individualised approach to information-sharing (Almborg et al., 2008).

Caregivers play a crucial role in people with stroke' continued rehabilitation and recovery after discharge. The lack of engagement with caregivers regarding how to manage emotional and behavioural changes of people with stroke is evident and has a detrimental impact on caregivers' well-being during the transition (Bakas et al., 2002; Cobley et al., 2013; Pringle et al., 2013). As a caregiver highlighted: "I just don't know what to do [regarding his depression]. I cannot cope because I don't know what to do to stop it. When he is continuously crying, it can be really wearing because you are helpless" (Cobley et al., 2013, p. 754).

For caregivers who are to provide physical care to people with stroke, providing skills training is an essential component of discharge preparation. Yet, this vital need is often not met prior to discharge. As a caregiver stated, "I wasn't physically shown the best way to support him…it was all trial and error" (Cobley et al., 2013, p. 754). Even when caregiver training is provided, caregivers may not be able to translate knowledge and skills they have learned into the home care setting without ongoing support from health professionals (Young et al., 2014).

2.2.5.3 People With Stroke/Caregivers' Self-Management Capability Factors

People with stroke and caregivers are at different levels of readiness to take charge of transition care at home. In a supportive environment, they develop and strengthen resilience over the course of the transition. People with stroke can experience a sense of loss and feel burdensome on others which hinders their efforts to develop resilience.

Resilience as a key indicator of a smooth transition

The processes and outcomes in transition care reflect the concept of resilience in health care as defined by the WHO (2017). Factors contributing to the development of resilience for people with stroke and caregivers include spirituality-enhanced hope (Bakas et al., 2002; Rittman et al., 2007), reflection on past experiences in caregiving (Lou et al., 2017; Young et al., 2014) and self-learning of stroke-related knowledge and caregiving skills (Greenwood et al., 2009; Wottrich et al., 2012).

Moving focus away from one's own disabilities and recognising positive progress helps people with stroke to develop resilience and diminishes uncertainty in recovery: "I was in hospital with people … that couldn't walk properly… couldn't feed themselves… I could have been so much worse … each day when I see a light improvement … I am so thankful" (Pringle et al., 2013, p. 1995).

Having faith in God can be a coping strategy for caregivers to develop resilience and sustain caregiving at home (Bakas et al., 2002; Greenwood et al., 2009; Rittman et al., 2007). As a caregiver said: "…whatever happens, I always say that it is best. Better. God never wants to harm you... there is something always positive…" (Greenwood et al., 2009, p. 1129).

Time to learn and develop knowledge, skills and experience to manage transition care at home is closely related to the development of resilience (Greenwood et al., 2009; Lou et al., 2017; Young et al., 2014). Most people with stroke and caregivers show some levels of resilience and gradually adapt to life in the community between three and six months after discharge from hospital (Grant et al., 2006; Greenwood et al., 2009; Wood et al., 2010; Wottrich et al., 2012). As a person with stroke stated: "It was a bit difficult at first with everything new, but it gets better and better, one enjoys being at home more now than one did when one left hospital" (Wottrich et al., 2012, p. 1222).

Established stroke knowledge and skills from past caregiver experience also contributes to resilience for caregivers: "I didn't have to figure out anything because we had taken care of her mother for 17 years with a stroke…I more or less knew what we had to do" (Young et al., 2014, p. 1897).

Over the course of the transition, some practical solutions emerge through trial and error:

> We have learnt from last time…He doesn't have a lot of shirts with buttons because he had difficulty fastening buttons. To give him his independence, we have altered…so that he can still dress himself and doesn't rely on me (Greenwood et al., 2009, p. 1128).

Learning to accept support from others facilitates social reintegration and indicates people with stroke' resilience to adapt to changes: "When it comes to social events…I have to thank my friend because she drives and the same thing with my son…it's encouraging that these people are around me" (Wood et al., 2010, p. 1051).

Sense of loss and burden on others

People with stroke view discharge home as entering an unknown home situation with a new identity. Even for those who do not experience dramatic poststroke changes, life still needs to be adjusted (Chouliara et al., 2014; Lou et al., 2017; Nordin et al., 2015). They face enormous challenges to cope with emotional, cognitive and personality changes. As a caregiver described: "I feel I've got a different man home…, because before he was a very well educated man… and now he's not…even interested in anything" (Pringle et al., 2013, p. 1995).

However, the need for emotional support for people with stroke might not be determined by service providers due to a lack of access to specialist services. As a health professional stated: "I think the support around the emotional journey…is a big gap because if we had access to psychology or counselling, we could start…offering what they need as things change such as adjusting to their emotions" (O'Brien et al., 2014, p. 245).

The majority of studies in this review recognised the crucial and multiple roles that caregivers play in transition care. Firstly, existing and potential conflicts between people with stroke and caregivers has significant implications for caregiving at home (O'Brien et al., 2014; Young et al., 2014); Secondly, caregivers' readiness to take on the caregiving role impacts their capacity (Cameron et al., 2014; Perry & Middleton, 2011). Thirdly, caregivers' own chronic health issues might jeopardise their ability to sustain the role (Young et al., 2014). Therefore, it is essential to assess caregivers' readiness for their role and the need for support to develop resilience to sustain the role.

People with stroke can feel too guilty to bother family caregivers (Rittman et al., 2007; Simeone et al., 2015). As a person with stroke illustrated: "Do you see the condition in which I put my son? I forced my son to bounce among work, home, his family, and me. My son seems like a yo-yo attached to the rope running back and forth…" (Simeone et al., 2015, p. 166). This perception of burden on caregivers might inhibit people with stroke from seeking help to achieve their recovery goals, which in turn prevents caregivers from taking actions to support people with stroke to reintegrate into the community.

2.2.6 Discussion

Hospital to home transition is the most crucial time for people with stroke and caregivers to build capabilities to optimise poststroke recovery and manage health conditions at home. The synthesis of studies using different research designs enables a more comprehensive understanding of opportunities and challenges arising from health and social care systems, the interactions between health professionals and clients, and the capabilities of people with stroke and caregivers in transition care. This review demonstrates that despite challenges brought by stroke, effective hospital to home transition care can be achieved through the provision of stroke-specific integrated and well-coordinated care services; by enabling health and social care professionals to work in partnership with clients to determine and meet their individualised care needs; and by supporting people with stroke and caregivers to develop resilience in self-management of transition care at home.

The CCM facilitated a comprehensive understanding of the entwined associations between healthcare systems (system factors), service provider factors (proactive practice team) and individual factors (informed and activated patients) (Accelerating Care Transformation Centre, 2023). The findings of this review confirm the need for the healthcare system to shift from a reactive care to proactive care approach as advocated by the CCM (WHO, 2016). This integrated care approach requires effective partnership between healthcare teams and people with stroke and caregivers (WHO, 2016; Accelerating Care Transformation Centre, 2023). In addition, ongoing support for people with stroke and caregivers during the transition period is imperative to stabilise and instil self-care at home.

People with stroke are discharged from hospital with varying levels of impairments including inability to walk, visual impairment and executive dysfunction (Jokinen et al., 2015; Sörös et al., 2015). Some survivors achieve clinical recovery without physical disability but live with psychological morbidity (Jokinen et al., 2015; Wainwright et al., 2017). About 30% of people with stroke experience poststroke depression and fatigue concurrently (MacIntosh et al., 2017; N. Wei et al., 2015). These limitations are often hidden and cause misconceptions amongst the general public (Schwarz et al., 2018; Wainwright et al., 2017). The stigmatisation of these invisible limitations significantly impacts on ongoing poststroke recovery. Working-aged people with stroke find that the major barrier to returning to work is their self-stigma and colleagues' lack of awareness of these invisible conditions (Balasooriya-Smeekens et al., 2016; Schwarz et al., 2018). Caregivers of older people with stroke, who lack knowledge of depression and fatigue, may relate these symptoms to old age and therefore miss rehabilitation opportunities (Wainwright et al., 2017).

Stroke triggers a local inflammatory immune response in the brain and also causes systemic immunosuppression resulting in susceptibility to infection amongst people with stroke (Anrather & Iadecola, 2016; Pagram et al., 2017). Infection occurs in about 30% of the stroke population (Pagram et al., 2017) and is one of the major causes of poststroke readmission (Lord et al., 2016; Zhong et al., 2016). Identifying high-risk survivors and preparing them and caregivers with knowledge of potential complications and self-management skills empowers them to proactively prevent infection. Discharge preparation, structured post-discharge follow-up and early evaluation by health professionals, such as stroke nurses, could reduce avoidable hospital admissions due to complications (Condon et al., 2016; White et al., 2015).

A mismatch of goals between survivors and health professionals is a major barrier in the implementation of person-centred goal setting (Plant et al., 2016; Rosewilliam et al., 2016). Survivors' goals tend to encompass their aspirations to return to independence. Whereas health professionals' goals tend to focus on impairments and are mainly driven by organisational performance indicators (Plant et al., 2016). It is vital for people with stroke and caregivers to set goals for re-entering the community based on their individual situation. Rosewilliam and associates (2016) suggest changing the culture to facilitate person-centred goal setting by empowering health professionals with knowledge and skills to engage people with stroke and caregivers in the process.

People with stroke and caregivers must adjust to the physical and emotional sequelae of stroke and negotiate complex health and social care systems (Andrew et al., 2018; Nelson et al., 2016). After hospital discharge, people with stroke and caregivers experience a drastic contrast between the intensive support received in hospital and limited access to community rehabilitation and social care services. The perception of abandonment is intensified when expected support is absent (Lamontagne et al., 2019; Piccenna et al., 2016). Maintaining and developing resilience is a protective factor to manage stress and prevent negative outcomes (Epstein, 2015; Taku, 2014). To help sustain resilience, reduce avoidable hospitalisation and prevent institutionalisation, there is an urgent need to develop stroke-specific transition care pathways and care models.

2.2.6.1 Limitations

The review has enabled the synthesis of studies with diverse research approaches providing a range of perspectives. We included all studies regardless of their quality as each contributes to the narrative of the investigation. Therefore, this may affect the credibility of findings, and findings should be interpreted in this context. We limited the timeframe of transition care to six months not 12 months, as six months is the study timeframe for most poststroke transition care studies. This may have affected narratives, as transition experience is individualised, and transition care for some survivors and caregivers may extend beyond six months after discharge. Their perspectives are missed with the setting of this timeframe. Further reviews need to consider this limitation.

2.2.7 Conclusion

The first six months of the poststroke hospital to home transition is a challenging period for people with stroke and caregivers. They need to adjust to a new life as well as navigate health and social care systems solo. Disjointed service provision further exacerbates the situation, which causes unmet needs and increases potential risk of hospitalisation and institutionalisation. This review highlights complex issues in poststroke hospital to home transition care and identifies gaps for further research.

2.2.7.1 Implications for Future Research

Further research should focus on people with stroke and caregiver expectations of health and social care systems after discharge home, as this was not discussed in depth in the reviewed studies and post-discharge follow-ups were mostly short. Furthermore, health professionals’ perspectives of approaches to identifying and meeting transition care needs could be explored further. Moreover, there is scarce research evidence-informed clinical pathways and models particular to poststroke hospital to home transition care. Stroke-specific transition clinical pathways and care models will ensure consistent delivery of services and enable stakeholders to work in collaboration to meet care needs and expectations of people with stroke and caregivers.

Anonymised Conflict of Interest Statement

No conflict of interest has been declared by the authors.

This is the end of the publication.

2.3 Summary

This integrative literature review explored the factors that influence hospital-to-home transition care for stroke dyads. A synthesis of the study's findings revealed that hospital-to-home transitions were shaped by the health and social care systems, and health professionals and stroke dyads also had a role in influencing the transition. Multidisciplinary-team-coordinated stroke-specific transitional care programs, and social care services tailored to the needs of people with stroke, were found to facilitate the hospital-to-home transition. Likewise, during the course of the transition, resilience was gradually built on the development of confidence and competence with the mastery of stroke care knowledge and skills. The challenges that inhibited a successful transition included inappropriate discharge preparation, discontinuity of rehabilitation and social care support, and struggles with managing post-stroke disabilities.

The findings urge collaboration between all stakeholders of the stroke care chain to ensure consumer-directed hospital-to-home transition care for stroke dyads. However, the experiences and perceptions of the stroke dyads on their care needs and challenges during transition remain largely unknown. Their expectations of health and social care systems and service providers are key indicators for the development of a stroke hospital-to-home transition care framework.

The next chapter introduces the theoretical framework adapted for this study.

Chapter 3: Theoretical Framework

3.1 Introduction

The previous chapter discussed factors that influence hospital-to-home transition for stroke dyads at the health and social care systems level, health professionals' level and personal level. The self-management capacities of stroke dyads were found to be activated through collaboration with health professionals, continuity of health and social care support, and resilience developed over the course of transition with the mastery of self-management knowledge and skills. This chapter reviews concepts of transition in reviewed studies, analyses Meleis's transition theory and discusses how the framework is adapted for this study context.

3.2 Theoretical Frameworks Informing Studies in Transition Care

Theoretical frameworks enable researchers to integrate findings into a coherent structure and serve to guide researchers' understanding of the studied phenomena in a systematic way. The application of theories in research also provides opportunities for theories to be evaluated and critiqued (Polit & Beck, 2017).

3.2.1 Concepts of Transition in the Reviewed Studies

Nine studies in the integrative review (Chapter 2) linked their research to the concept of transition and transition care, but few had in-depth discussions of the theoretical underpinning. Hospital-to-home transition-related concepts were discussed in a number of studies. Almborg et al. (2008, 2009) connected discharge planning with the concept of 'participation' and referred to discharge planning as receiving information about stroke and related aspects of care and participating in decision-making. These studies mainly focused on one element of multiple factors affecting discharge preparation in hospital-to-home transition.

Ellis-Hill et al. (2009) related 'going home' to the concept of a 'model of recovery'. This model of recovery emphasised the concept of 'moving on through their life, with their own goals and plans' (Ellis-Hill et al., 2009, p. 69). This model seemed to be associated with the individual's expectations of recovery, their response to the situation and the interaction with health professionals. However, a shared model of recovery between people with stroke and health professionals and that is viewed as a better approach to recovery is overlooked in this model.

Three studies on stroke caregivers discussed concepts related to them during the hospital-to-home transition. The study by O'Brien et al. (2014) on an optimal health program discussed the concepts of self-efficacy and care coordination in caregivers. The program aimed to promote self-management for caregivers and their collaboration with health professionals. Similarly, the study by Shyu et al. (2008) discussed the concept of a family-caregiver-oriented discharge planning program and demonstrated the effectiveness of the program on enhanced caregiver preparation and improved satisfaction in caregivers during the transition. The concept of role preparation for caregivers was further explored by Huang et al. (2003), where the preparation for the new role for caregivers was essential before assuming the role. However, these studies have not elaborated on the transition experience nor examined the perspectives of stakeholders involved in the transition.

Young et al. (2014) advocated for the use of a crisis intervention approach (Palmer et al., 2004) to comprehensively assess caregivers' needs because a stroke event is an unexpected life crisis for caregivers. A crisis intervention approach emphasises situation-specific problem-solving methods for victims of catastrophic events, such as natural disasters, chronic diseases or death (Palmer et al., 2004). Young et al. (2014) believed that this approach might help uncover the unacknowledged grief and anxiety of caregivers and promote a better understanding of their needs. However, this approach only focused on a single element in the hospital-to-home transition.

Stroke was regarded as a biographical disruption in Lou et al.'s study (2017). This concept highlights that stroke brings people's attention to their subconscious awareness of their body state. Stroke stimulates a profound review of one's personal biography and self-concept. People respond to stroke by reorganising resources in the changed situation (Bury, 1982; S. Williams, 2000). The findings in Lou et al.'s (2017) study revealed that stroke was part of much turbulence in the lives that people with stroke encountered. Hence, specific timings, contexts, norms, expectations and the willingness of people with stroke to participate in the process of recovery need to be considered in order to understand their experiences (S. Williams, 2000).

Discharge home after stroke was conceptualised as a psychosocial transition in the study by Pringle et al. (2013). Pringle et al. (2013) viewed returning to home for people with stroke as a process involving changes to a person's 'assumptive world' (p. 1997). Many people with stroke previously assumed that ways of life may be changed after stroke. This theory highlighted that health professionals need to identify good support systems to help people cope with transition and to reconnect with the previous assumptive world.

A study on the psychosocial experiences during the first month home post-discharge by Rittman et al. (2007) was based on the concept that transition was a process, occurring over time and involving changes in identities, roles and behaviours (Schumacher & Meleis, 1994). This concept emphasises the importance for the person to be aware of the transition and to be willing to engage with it (Schumacher & Meleis, 1994). Rittman et al. (2007) found that, despite being scored high on functional assessment, people with stroke still experienced multiple psychosocial changes over time, and they could benefit from interventions to prepare them for these changes.

As discussed above, various conceptual frameworks were used in studies on hospital-to-home transition for stroke dyads. Although these frameworks enhanced understandings of biographical disruption, a model of recovery, crisis intervention, self-efficacy, participation and role development for caregivers, they may not have covered the complexity of transition care derived from health and social care systems, health professionals and stroke dyads as identified in the integrative literature review. Therefore, a comprehensive theory that informs a systematic approach to analysing hospital-to-home transition is much needed.

3.2.2 Meleis's Transitions Theory

The middle-range transitions theory developed by Afaf Ibrahim Meleis and colleagues (Chick & Meleis, 1986; Meleis, 2010; Meleis, 1975; Meleis et al., 2000; Schumacher & Meleis, 1994) was chosen as the theoretical framework to guide this study. Meleis's transition theory has been widely used and tested in various care settings with diverse populations. The theory focuses on the dynamic interactions among the person, community and society, as well as the role of nursing therapeutics in facilitating healthy transitions.

Transition is defined as:

> A passage from one life phase, condition, or status to another, is a multiple concept embracing the elements of process, time span, and perception … [it] refers to both the process and the outcome of complex person-environment interactions. It may involve more than one person and is imbedded in the context and the situation … Defining characteristics of transition include process, disconnectedness, perception, and patterns of response. (Chick & Meleis, 1986, pp. 239–240)

3.2.2.1 Nature of Transitions

Meleis et al. (2000) suggested four types of transitions with differing patterns of multiplicity and complexity:

- Developmental transitions occur in people's life cycle, such as becoming parents or going through adolescence.
- Situational transitions are changes such as those in family situations, family caregiving and in educational and professional roles.
- Health–illness transitions refer to the effects of illness-related transitions on individuals and their families.
- Organisational transitions focus on the changes in organisations or communities—for example, structural changes in an organisation and their effect on the employees.

Stroke dyads may experience both health–illness and situational transitions after discharge home as they need to adapt to a post-stroke physical and mental state, altered roles, as well as the new home and social environment that was once familiar before the stroke. They may experience these interrelated transitions simultaneously during the post-stroke trajectory.

Meleis's theory has also identified several essential properties that are interconnected in the complex transition process (Meleis et al., 2000):

- Awareness—this is associated with perception, knowledge and recognition of a transition experience.
- Engagement—this refers to the level of an individual's involvement in the process.
- Change and difference—these are essential properties of transitions but are not interchangeable.
    - Transitions both result in and are the result of change.
    - Individuals in transition confront differences at different levels. Changes include unmet expectations, feeling different, being perceived as different or viewing others or the world in different ways.
- Time span—this refers to flow and movement over time. The possibility of changes and fluctuation over time needs to be considered when evaluating transition experiences.
- Critical points and events—these are related to the increasing awareness of change and difference or to increased engagement in managing the transition experience. Critical points may be accompanied by a period of uncertainty and heightened vulnerability. Final critical points may be characterised by a sense of stabilisation in new routines, roles, skills and self-care activities.

3.2.2.2 Transition Conditions

The transition is influenced by a complex interplay between personal and environmental factors (Schumacher & Meleis, 1994). Personal, community or societal factors can facilitate or impede a healthy transition (Meleis et al., 2000).

'Personal conditions' are described as follows (Meleis, 2010, pp. 59–60; Schumacher & Meleis, 1994, pp. 121–122):

- Meanings—these are related to the subjective appraisal of transition in one's life. Meanings associated with transitions may be neutral, negative or positive.
- Expectations—these are influenced by previous experiences. The frame of reference may be uncertain or unrealistic. Surprise occurs when expectations mismatch reality.
- Cultural beliefs and attitudes—the transition experience may be influenced by the individual's cultural background and the related stigma attached to the transition.
- Socioeconomic status—low socioeconomic status may inhibit healthy transition.
- Preparation and knowledge—the level of preparation, planning and knowledge about what to expect before and during the transition and problem-solving strategies influences the success of the transition.
- Emotional and physical wellbeing—a wide range of emotions, especially stress and emotional distress, are common during the transition. The level of comfort with changes in the body influences wellbeing during the transition.

'Community conditions' refers to the availability of external facilitating resources, including formal social care support and informal support from family, friends and community (Meleis, 2010, p. 60). Advice from respected sources, consistent and sufficient information obtained from trusted healthcare providers, and timely answers to questions are facilitators during transitions.

'Societal conditions', such as stigmas and stereotypes attached to transitional events, interfere with a healthy transition (Meleis, 2010, p. 61). Other societal factors include policy, organisational and healthcare system support. These conditions shape an individual's transition experience.

The transition from hospital to home symbolises an achievement in the post-stroke trajectory for stroke dyads. A healthy post-stroke hospital-to-home transition depends on the harmonious interactions of transition conditions. Physical and emotional progress through post-stroke rehabilitation enhances self-appraised coping abilities. Adequate preparation and skills-building before hospital discharge, coupled with post-discharge community and societal support, further augment self-management capabilities that help transformation for both people with stroke and their caregivers and stabilise long-term home care.

3.2.2.3 Patterns of Response

A healthy transition is characterised with process and outcome indicators (Meleis, 2010). Transition is a process that unfolds over time. Identification of indicators of a healthy or at-risk transition prompts early intervention to enable positive outcomes (Meleis, 2010).

Meleis et al. (2000) discussed four dimensions of process indicators:

- 'Feeling connected' refers to contacts and connections with pre-transition personal social networks and health professionals who assist with the transition. A positive transition experience is indicated when individuals feel connected with healthcare providers.
- 'Interacting' denotes intradyadic interaction. The interactions between caregiver and care recipient create a context wherein self-management and caregiving can be balanced and sustained constructively.
- 'Location and being situated' indicates location change during transition. Making comparisons before and after transition provides ways to situate individuals in terms of time, space and relationships.
- 'Developing confidence and coping' refers to an increase of confidence over time in the transition process. Time provides individuals with progressive and

cumulative knowledge about the situation and coping strategies to manage the situation.

The mastery of new skills needed to manage the transition and the development of a fluid integrative identity are two outcomes experienced by individuals in a healthy transition (Meleis, 2010, pp. 62–63). The subjective elements of individuals who experience transitions influence the sense of achieving a healthy transition (Meleis, 2010). When individuals demonstrate proficiency in managing situations in transition, for example, caregivers feel able to take charge of care and navigate the healthcare system, and this indicates a successful transition.

An individual’s identity is redefined in the transition process. The redefined identity is dynamic and may change over time in transition. Situational and health–illness transition may be viewed from a bifocal perspective (Meleis, 2010). Settling in the new identity indicates that a healthy transition outcome has been reached.

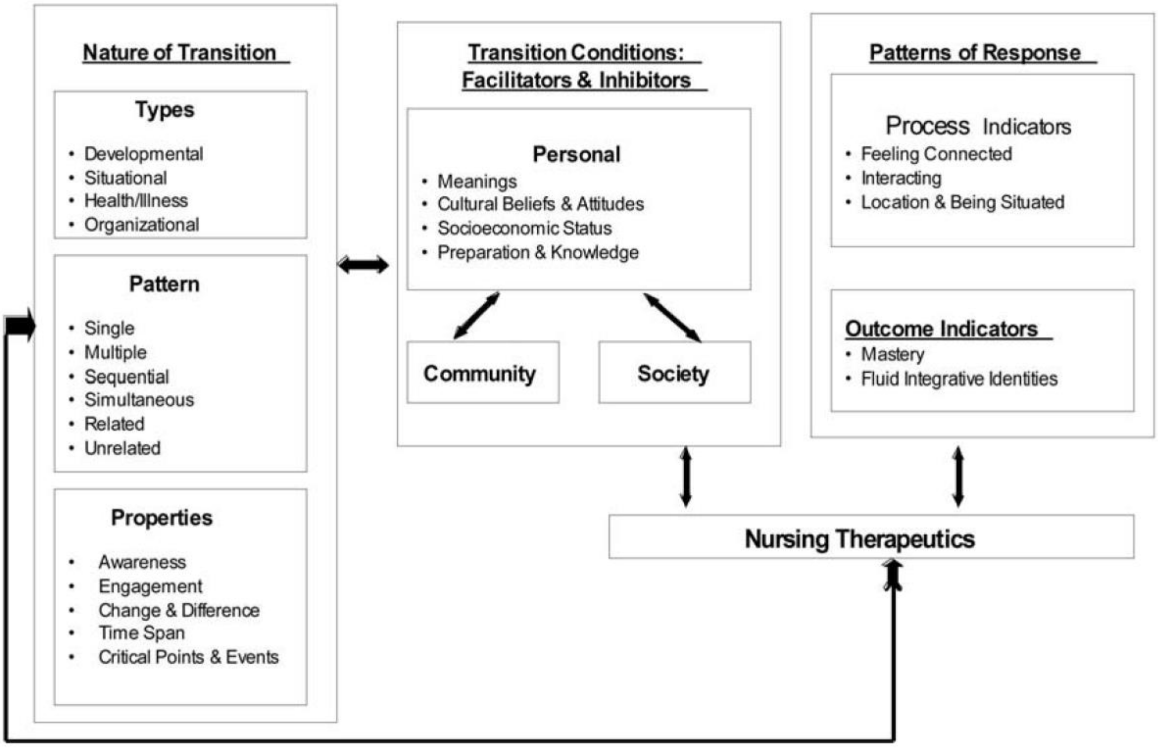
3.2.2.4 Nursing Therapeutics

Schumacher and Meleis (1994) identified three nursing interventions that are widely used during transitions. First, a transition readiness assessment is developed based on a comprehensive understanding of the individual and through multidisciplinary collaborations. Second, preparation for transition using educational interventions creates optimal conditions in transition. Sufficient time and a gradual approach to knowledge and skills-building and practice are required for adequate preparation. The third nursing therapeutic is role supplementation. As discussed above, individuals experience role and identity change during transition. For example, people with stroke may have difficulty resuming the pre-morbid role in the household, which results in role insufficiency. Role supplementation nursing interventions include role learning and clarification through a mastery of the knowledge specific to fulfilling the role, peer support, communication and social interaction (Schumacher & Meleis, 1994). During a hospital-to-home transition, the above nursing therapeutics can empower stroke dyads to prepare for the transition and gradually adapt to the new post-stroke identity.

An outline of the elements and the relationships between these elements in Meleis's transitions theory is shown in Figure 3.1.

Figure 3.1

Transition: A Middle-Range Theory (Meleis et al. 2010, p. 425)



Reprinted from *Transition: A Middle-Range Theory: Middle-Range and Situation-Specific Theories in Nursing Research and Practice* (p. 425) by Afaf Ibrahim Meleis, 2010, with permission from the Springer Publishing Company.

This theoretical framework identifies generic conditions for people undergoing transition and the nature of outcomes of the transition experience. It emphasises the interactions among the person, community and society and the conditions that enable healthy transitions. The identification of healthy transition outcomes serves as the impetus for discovering mechanisms used by people during transition that lead to positive transition experiences. The framework also provides opportunities to advance knowledge about nursing therapeutics that may facilitate successful transitions and enhance healthy coping and recovery (Meleis et al., 2000).

3.2.3 The Relevance of Meleis's Transitions Theory to the Present Study

Meleis's transitions theory has been widely used and tested in various care settings with diverse populations, including in studies on health–illness transitions, migration, motherhood and adolescence to adulthood (Meleis, 2010). In the study of health–illness-related transitions, the theory has guided a comprehensive understanding of the transition experience of relatives of older people who were admitted to a nursing home (S. Davies, 2005), of the psychosocial transition of people with stroke after hospital discharge (Rittman et al., 2007), of the experience of living with long-term conditions (Long et al., 2016) and of the caregivers of high-risk infants (Mi, 2016). In Meleis's transitions theory, the domain of 'transition conditions: facilitators and inhibitors' enhances the understanding of enablers and barriers during hospital-to-home transition and uncovers the community or societal conditions for transition (Meleis et al., 2000, p. 56). The element of 'patterns of response' also provides a theoretical foundation for a deeper insight into the outcomes of a successful transition.

3.2.3.1 Limitations of the Theory

Meleis's transitions theory is generic rather than specific to stroke transition care. The theory may not cover all stroke-specific aspects, especially the impact of post-stroke impairments. However, it is this weakness of the framework that provides the present researcher with opportunities to develop a stroke-specific transition care framework. In addition, the theory does not seem to acknowledge the interactive relationship of all stakeholders during the transition, especially health professionals. Health professionals also experience role transition, and they play a crucial role in facilitating an effective transition. Furthermore, in the global context of multidisciplinary collaboration in health care, nursing therapeutics alone may not reflect the need for interprofessional strategies to address issues during transition.

3.2.4 The Need to Adapt Meleis's Transitions Theory to the Study Context

Based on the critique of Meleis's transitions theory, the present researcher adapted this theory to address the aims of the study and to suit the study context. The elements from

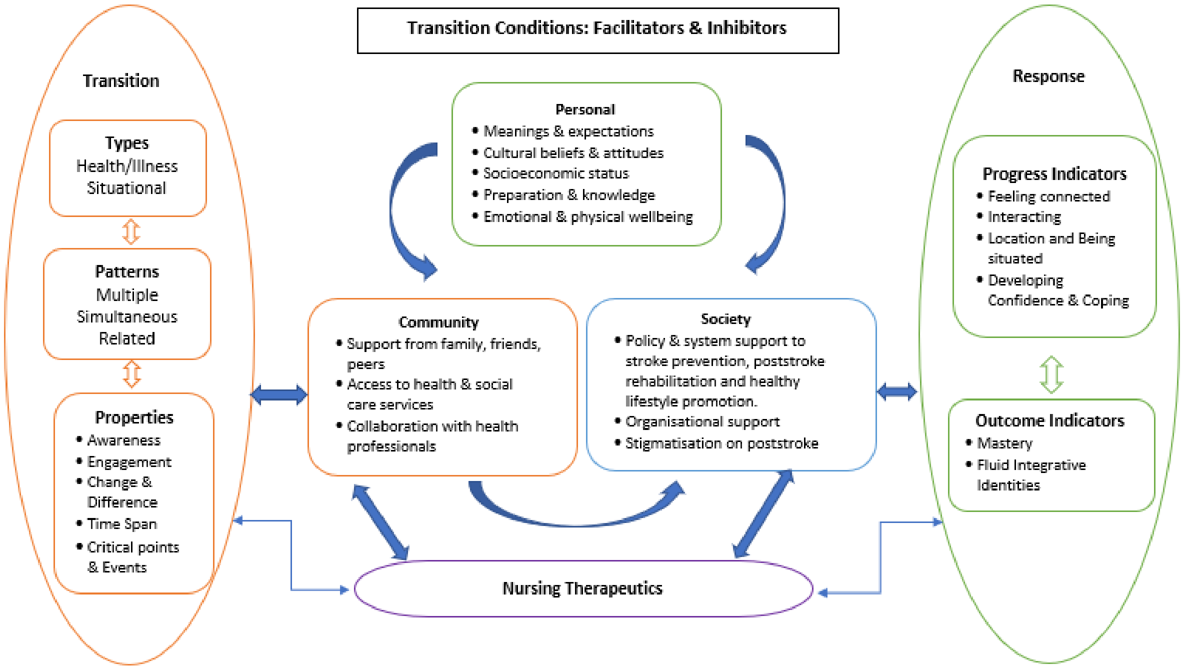
Meleis's transitions theory are shown in Figure 3.2. An explanation of these elements and relationships among these elements in the present study are discussed in the following section. It was anticipated that the findings from the study would also add new evidence to inform the further development of a framework specific to hospital-to-home transition for stroke dyads.

In the hospital-to-home transition process, stroke dyads experience multiple and complex transitions that occur simultaneously. In this post-stroke trajectory, they experience health–illness and situational transitions. With the sudden onset of stroke, the daily living functions of people with stroke and the dyads' roles in life significantly change, as do their personal identities, relationships and social networks. These related elements overlap and influence each other during the transition.

The lived experience of stroke dyads uncovers personal, community and societal conditions based on their contexts of life. The interactions of these conditions may facilitate or hinder the achievement of a healthy transition and have an impact on the outcomes of the transition. Early nursing therapeutic interventions developed through interdisciplinary collaboration help equip stroke dyads with the necessary knowledge, skills and problem-solving strategies and prepare them for the imminent hospital-to-home transition. A healthy transition is evidenced by stroke dyads' perceived capability to take charge of the post-discharge life situation, confidence in mastery of their health conditions, navigation of the health system and the ability to maintain caregiving.

Figure 3.2

Meleis's Transition Theory (Meleis, 2010, p. 425), Adapted to This Study Context



3.3 Summary

This chapter has discussed the theoretical and conceptual frameworks used in transition care studies. Meleis's transition theory presents key properties and indicators of the transition experience, which formed the foundation for developing a theoretical framework for the present study. The domains of Meleis's transitions theory served as a guide for the conduct of this study in the development of the interview guide and data analysis and, systematically, for generating comprehensive understandings of the transition experience for stroke dyads and of health professionals' perceptions.

Chapter 4: Systematic Review

4.1 Introduction

As discussed in the previous chapters, challenges and opportunities coexist during the hospital-to-home transition for stroke dyads. The integrative literature review identified a scarcity of global evidence on the care needs and expectations of health and social care in the hospital-to-home transition from the stroke dyad's point of view. Additionally, little evidence exists regarding stroke-specific transition care clinical pathways and models to enable stakeholders to work collaboratively to meet the care needs and expectations of stroke dyads. Hence, it is timely to conduct a systematic review that synthesises the qualitative studies on care needs and expectations of health and social care in the hospital-to-home transition from the perspectives of stroke dyads in a global context.

This chapter presents a published systematic review and meta-synthesis. The contribution of the first author to the paper is 70% to research design, writing and editing and 80% to data collection and analysis. The second, third and fourth authors collectively contributed 30% to research design, writing and editing and 20% to data collection and analysis.

This section presents a publication arising from this thesis that was published in the *Journal of Clinical Nursing*.

Citation: Chen, L., Xiao, L. D., Chamberlain, D., & Newman, P. (2021). Enablers and barriers in hospital to home transitional care for people with stroke and caregivers: A systematic review. *Journal of Clinical Nursing, 30*(19-20), 2786–2807. https://doi.org/10.1111/jocn.15807

This is the peer reviewed version of the following article: Enablers and barriers in hospital to home transitional care for people with stroke and caregivers: A systematic review,

4.2 Enablers and Barriers in Hospital to Home Transitional Care for People With Stroke and Caregivers: A Systematic Review

4.2.1 Abstract

Aims and objectives: To synthesise qualitative research evidence on the experience of stroke survivors and informal caregivers in hospital to home transitional care.

Background: Due to a shortened hospital stay, stroke survivors/caregivers must take over complex care on discharge from hospital to home. Gaps in the literature warrant a meta-synthesis of qualitative studies on perceived enablers and barriers during this crucial period.

Design: systematic review and meta-synthesis.

Methods: A review was guided by Enhancing Transparency in Reporting the Synthesis of Qualitative Research (ENTREQ) checklist where six databases were searched from April to June 2020 including CINAHL Plus, MEDLINE, PsycINFO, Scopus, Web of Science and ProQuest and ProQuest Dissertations and Theses. There was no date limit to the search. Selected studies were critically appraised. A thematic synthesis approach was applied.

Results: The synthesis of 29 studies identified three major findings. First, partnerships with stroke survivors/caregivers empower discharge preparation, foster competence to navigate health and social care systems and activate self-management capabilities. Second, gaps in discharge planning and the lack of timely post-discharge support contribute to unmet care needs for stroke survivors/caregivers and affects their ability to cope with poststroke changes. Third, stroke survivors/caregivers expect integrated transitional care that promotes shared decision-making and enables long-term self-management at home.

Conclusions: Hospital to home transition is a challenging period in the trajectory of poststroke rehabilitation and recovery. Further research is required to deepen understandings of all stakeholders' views and address unmet needs during transitional care.

Relevance to clinical practice: Protocols and clinical guidelines relating to discharge planning and transitional care need to be reviewed to ensure partnership approach with survivors/caregivers in the design and delivery of individualised transitional care. Stroke nurses are in a unique position to lead timely support for survivors/caregivers and to bridge service gaps in hospital to home transition care.

Keywords: Stroke survivors, transitional care, discharge, caregivers, nurses' role, care needs, meta-synthesis, qualitative research

What does this paper contribute to the wider global clinical community?

- Hospital to home transition is a critical period for stroke survivors and caregivers to develop self-management capacities and lay a solid foundation for long-term poststroke recovery and rehabilitation.
- A person-centred and partnership approach by service providers empowers stroke survivors and caregivers preparing for transitioning home from hospital. Integrated community health and social care services augment an individual's self-management capacity.
- Stroke nurses are in a unique position to lead and provide individualised stroke-specific transitional care.

4.2.2 Introduction

Stroke is a leading cause of death and adult disability worldwide (WSO, n.d.). Globally, 15 million people are diagnosed with stroke (cerebrovascular disease) every year. The overall burden of stroke is considerable and continues to increase in the context of an ageing population (C. O. Johnson et al., 2019). Most stroke survivors are discharged to home, and the hospital to home transition poses many challenges for them and family caregivers to manage care at home while engaging in rehabilitation and recovery (Lindblom et al., 2020; Reeves et al., 2019). These challenges have become more prominent in the context of shortened hospital stays and early discharge by which stroke patients and their caregivers take charge of care activities and coordinate care services instead of health professionals in hospital (Camicia et al., 2016; L. Chen et al., 2020). Although hospital to home transitional care and post-discharge care services are available in many developed nations, they are often not specific to different categories of stroke and lack standardised care components (Olson & Juengst, 2019; Wang et al., 2017) or they are fragmented, which prevents stroke survivors and caregivers from accessing (L. Chen et al., 2016; Miller et al., 2019). These situations have a negative impact on stroke survivors and caregivers achieving rehabilitation and recovery goals during their transition.

To achieve effective transition to community, the impact of stroke on the physical, psychosocial and spiritual well-being of stroke survivors and caregivers needs to be addressed (Mountain et al., 2020; Sennfält & Ullberg, 2020). The International Classification of Functioning, Disability and Health (ICF) framework developed by the WHO considers that an individual’s health condition is influenced by the interplay between functioning, personal and environmental factors (WHO, 2013). Functioning is a hypernym for functions, activities and participation. Functions denotes body function and structure. Activities refer to execution of tasks, and participation means involvement in life situations (WHO, 2013). Environmental factors are external to stroke survivors and should be considered at both micro and macro levels encompassing access to the pre-morbid home, community and workplace, and access to healthcare services and social supports (WHO, 2013). Personal factors are unique aspects of stroke survivors and caregivers including their pre-morbid relationship, past experiences with the healthcare system and coping strategies (WHO, 2013). The ICF framework was adapted in this review to explore the impact of functioning, personal and environmental factors on stroke survivors and caregivers during hospital to home transition.

Most stroke survivors live with declined functioning such as poor balance, incontinence, swallowing difficulties, visual disturbances, and psychological and cognitive disorders (Jokinen et al., 2015; Wainwright et al., 2017). Hospital readmissions are common after discharge and are associated with increased morbidity, mortality, and risk of early institutionalisation (Abreu et al., 2020; Reeves et al., 2019). Contributing factors to readmissions include falls, urinary tract infection and recurrence of stroke (Abreu et al., 2020; Kilkenny et al., 2020). These factors are preventable via person-centred discharge planning and follow-up support after discharge (Abreu et al., 2020; Lee et al., 2019).

The development of self-management capabilities is hindered by inadequate engagement in discharge planning and caregiving preparation (L. Chen et al., 2016; Miller et al., 2019). Self-management capability refers to an individual’s strategies, skills, and confidence to manage their chronic conditions and take charge of their life (Barker et al., 2018). Factors contributing to inadequate engagement in discharge planning are multifactorial and include lack of collaboration amongst multidisciplinary teams and service providers, time constraints, a lack of beds and readiness of survivors/caregivers to participate (Krishnan et al., 2019; Olson & Juengst, 2019; Waring et al., 2019). Poor engagement in the discharge planning process prevents stroke survivors and caregivers from building skills and confidence in the management of their condition and undertaking daily activities at home (Miller et al., 2019).

The WHO defines people-centred and integrated health care as an approach that considers the perspectives of individuals, families and communities which is organised around health needs and expectations rather than diseases (WHO, 2015). Based on individual needs, care services are delivered to ensure a continuum of care at different levels and sites within the health system (WHO, 2015). Whilst person-centredness is well promoted and advocated in health and social care, the design of care services is largely driven by organisational imperatives rather than helping stroke survivors and caregivers achieve individual care goals. This organisational context of care constrains health professionals' commitment to optimise care services (L. Chen et al., 2020; O'Brien et al., 2014). Discrepancies in goals are reported to inhibit partnerships and collaborations between clinicians, stroke survivors and caregivers (L. Chen et al., 2020; Krishnan et al., 2019). Stroke survivors and caregivers feel alone and abandoned after discharge due to fragmented service provision (Lindblom et al., 2020; Miller et al., 2019). When stroke survivors and caregivers are underprepared before discharge, the lack of support from health professionals further affects self-management of poststroke rehabilitation and recovery.

Studies on issues in hospital to home transitional care for stroke survivors are abundant. However, meta-synthesised research evidence about the perspectives and expectations of stroke survivors and caregivers in hospital to home transition care in the first six months post-discharge is scarce. This meta-synthesis fills this gap in the literature. Findings will inform the design of future trials of poststroke transitional care interventions, research on stroke transition specific pathways and service development.

4.2.3 Aims

The aim of this systematic review is to synthesise qualitative research evidence on the experiences and expectations of stroke survivors and informal caregivers in hospital to home transitional care.

The review questions were:

1. What are the contributing factors that enable hospital to home transitional care?
2. What are the barriers that impede hospital to home transitional care?
3. What are the expectations of stroke survivors and informal caregivers of the healthcare system and health professionals during hospital to home transition?

4.2.4 Methods

This systematic review applied a meta-synthesis approach described by Edwards and Kaimal (2016) that integrates qualitative evidence systematically and discovers novel findings that are “far removed from these findings” from the reviewed primary studies (Edwards & Kaimal, 2016; Sandelowski & Barroso, 2006, p. 18). A six step meta-synthesis framework developed by Lachal and colleagues (Lachal et al., 2017) was used. First, we defined research questions and selection criteria. Second, we selected studies that met the selection criteria. Third, we undertook quality assessment of selected studies. Fourth, we extracted data from selected studies. Fifth, we analysed data, and finally, we presented findings from data synthesis. The review reporting followed the Enhancing Transparency in Reporting the Synthesis of Qualitative Research (ENTREQ) guide (Tong et al., 2012), see Appendix 8. The review protocol was registered on PROSPERO with registration number CRD42018091345 (Appendix 9).

4.2.4.1 Search Strategy

A systematic electronic search was conducted between 9th April and 15th July 2020 for studies published in English, or with an abstract published in English, in six databases including CINAHL Plus, MEDLINE, PsycINFO, Scopus, Web of Science and ProQuest and ProQuest Dissertations and Theses. To provide a comprehensive outline of research in the studied field, there were no limitations on publication year.

The Population, Exposure and Outcome (PEO) framework guided the development of search terms (Khan, Kunz, Kleijnen, & Antes, 2003). Search terms included (P) *stroke, cerebrovascular accident, survivors, caregivers and family carers*; (E) *patient discharge, continuity of patient care, transitional care, aftercare, stroke rehabilitation, hospital to home and care coordination*; and (O) *experiences, perception, perceptive and perspective* (see Appendix 10).

Each term was entered into the databases with truncation where appropriate. All individual searches were combined into a single group using the ‘OR’ Boolean. Each group was then combined by ‘AND’ with qualitative filters indicating qualitative data collection. The final citations were saved in EndNote and screened for duplications. We also manually searched reference lists of selected studies.

4.2.4.2 Selection of Studies

An experienced librarian (PN) helped the team search databases. The screening of studies was carried out by three reviewers (LC, LX and DC) in two stages. At stage 1, the EndNote citations were shared amongst all reviewers. The primary reviewer (LC) screened each article based on title and abstract against the inclusion and exclusion criteria (Table 4.1). The other reviewers screened the titles and abstracts of half of the citations each based on the selection criteria. The review team discussed the screening results. Citations not selected by at least two reviewers were excluded from full text review but maintained for future reference. At stage 2, each reviewer independently reviewed the full text of all included articles for eligibilities. Any discrepancies were discussed until consensus was achieved.

The initial search generated 4660 articles. After removing duplicate citations, 2301 article titles and abstracts were screened. Of those, 131 full-text studies were assessed for eligibility based on the inclusion/exclusion criteria (Table 4.1). In total, 29 studies (Appendix 11) were selected for appraisal including 27 studies identified from the electronic database search and two studies identified through the manual search of reference lists (Figure 4.1).

Table 4.1

Inclusion and Exclusion Criteria

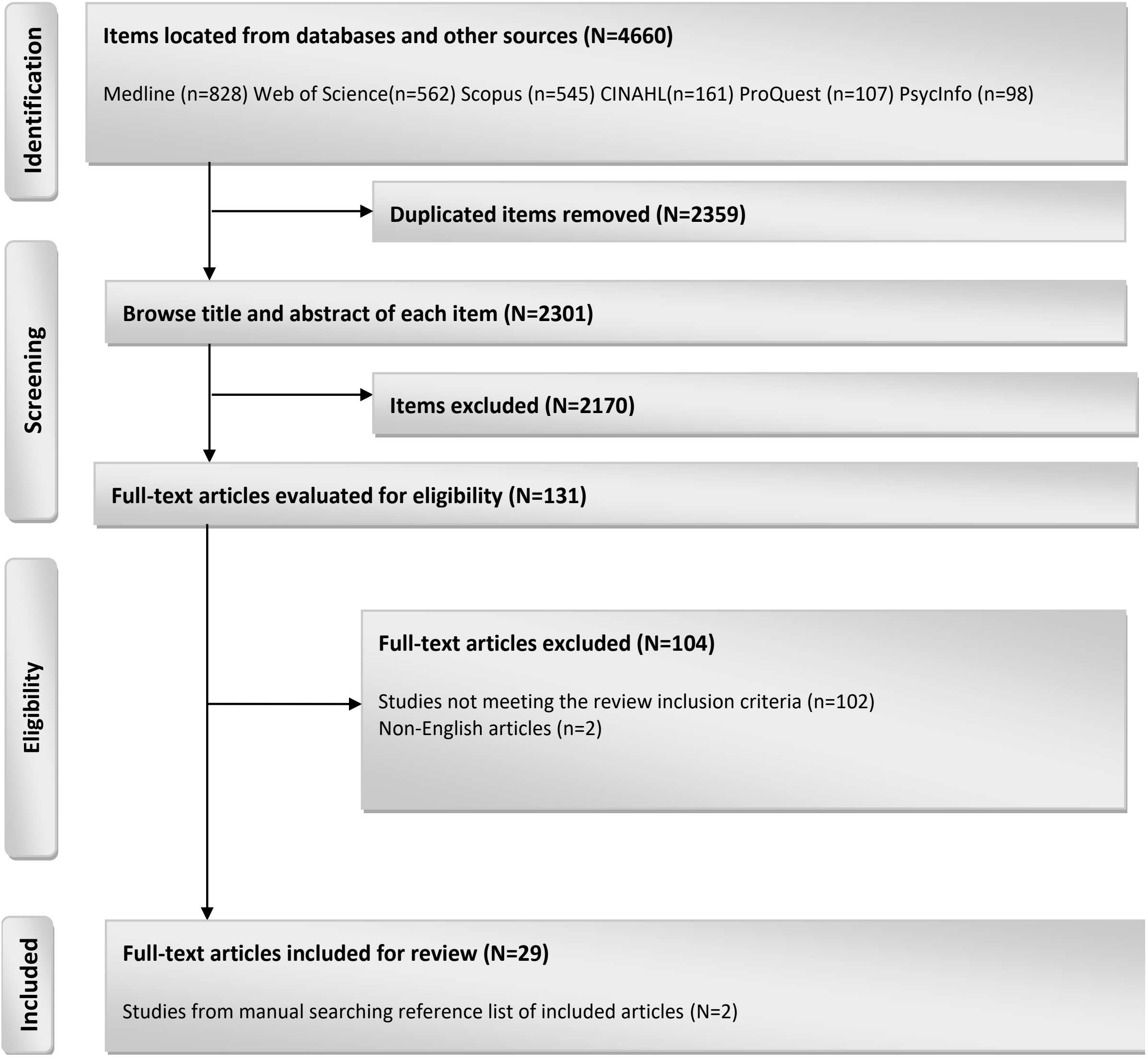
Inclusion Criteria	Exclusion Criteria
People with stroke' and family caregivers' experiences, perspectives or needs in hospital to home transition as a primary aim.	Studies examining experience poststroke long term (over 6 months after hospital discharge) needs.
Transition Period:	Studies concentrate on discharges to facilities other than home.

Inclusion Criteria	Exclusion Criteria
Preparation for discharge from hospital to home up to 6 months after hospital discharge: • The Preparation and Implementation stage of poststroke recovery trajectory defined by Time It Right framework (Cameron & Gignac 2008). • Majority of after-hospital care programs last within 6 months (Allen et al. 2014)	Studies conducted across multiple periods of stroke trajectory where the transition period cannot be separated.
People with stroke and caregivers are adult aged 18 years and above. Caregivers are defined as unpaid caregivers including spouse or partner, family members, friends, or significant others who provide physical and emotional support to people with stroke.	Studies that focus on people with stroke below 18 years old. Studies on multiple patient populations such as traumatic brain injuries, brain tumour, dementia, hip fracture where data relevant to stroke cannot be separated. Studies of multiple population e.g. health care professionals, service provider, where perspectives of people with stroke and caregivers cannot be separated.
Original studies using qualitative methods of data collection & analysis	Studies using quantitative methods or mixed methods where the qualitative data cannot be separated. Qualitative studies involving statistical data as reporting results.

Inclusion Criteria	Exclusion Criteria
	Conference proceedings, discussions, reviews or commentaries.
Published in English language	Studies published in languages other than English.

Figure 4.1

Review Flow Diagram



4.2.4.3 Quality Assessment

Quality assessment was undertaken by using the Critical Appraisal Skills Programme (CASP) tool (CASP, 2018a) (Table 4.2). The reviewers evaluated the quality of each study independently until a consensus was reached. No scores were placed during the appraisal. All studies that met the selection criteria were included as methodologically weak studies may provide novel understandings that may not be produced in methodologically strong studies (Carroll et al., 2012). Every study provided a valuable perspective to achieve the aim and objectives of this review.

Table 4.2

Critical Appraisal

Studies	**Questions***									
	Q1	**Q2**	**Q3**	**Q4**	**Q5**	**Q6**	**Q7**	**Q8**	**Q9**	**Q10**
Bakas et al. 2002	Y	Y	Y	Y	Y	?	Y	Y	Y	Y
Cameron et al. 2013	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Cobley et al. 2013	Y	Y	Y	Y	Y	?	Y	Y	Y	Y
Connolly & Mahoney 2018	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Eilersten et al. 2010	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Erikson et al. 2010	Y	Y	Y	Y	Y	?	Y	Y	Y	Y
Finch et al. 2021	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Ghazzawi et al. 2016	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Gholamzadeh et al. 2015	Y	Y	Y	Y	Y	?	Y	Y	Y	Y
Grant 1996	Y	Y	Y	Y	Y	?	Y	Y	Y	Y
Greenwood et al. 2009	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Gustafsson & Bootle 2013	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Gustafsson et al. 2014	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Lou et al. 2017	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Lutz et al. 2017	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Olofssen et al. 2005	Y	Y	Y	Y	Y	?	Y	Y	Y	Y
Pereira et al. 2021	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Pringle et al. 2013	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y

Studies	Questions*									
	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10
Rittman et al. 2004	Y	Y	Y	Y	Y	?	Y	Y	Y	Y
Rittman et al. 2007	Y	Y	Y	Y	Y	?	Y	Y	Y	Y
Sadler et al. 2014	Y	Y	Y	Y	Y	?	Y	Y	Y	Y
Timothy et al. 2016	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
C. L. Williams et al. 2005	Y	Y	Y	Y	Y	?	Y	Y	Y	Y
White et al. 2007	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
White et al. 2015	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Wottrich et al. 2012	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
S. M. Yeung et al. 2011	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
E. H. Yeung et al. 2015	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Young et al. 2014	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y

Note. Y = Yes; N = No; ? = Can't tell. Adapted from Critical Appraisal Skills Programme (CASP) (2018a), https://casp-uk.net/wp-content/uploads/2018/01/CASP-Qualitative-Checklist.pdf
* Q1: Was there a clear statement of the aims of the research?
* Q2: Is a qualitative methodology appropriate?
* Q3: Was the research design appropriate to address the aims of the research?
* Q4: Was the recruitment strategy appropriate to the aims of the research?
* Q5: Was the data collected in a way that addressed the research issue?
* Q6: Has the relationship between researcher and participants been adequately considered?
* Q7: Have ethical issues been taken into consideration?
* Q8: Was the data analysis sufficiently rigorous?
* Q9: Is there a clear statement of findings?
* Q10: How valuable is the research?

4.2.4.4 Data Extraction

This review examined the preparation and implementation stage of the poststroke recovery trajectory as defined by the Time It Right framework (Cameron & Gignac, 2008). The preparation phase refers to the stage "before patient goes home" from an acute or rehabilitation hospital. The implementation phase is the "first few months after patient returns home" (Cameron & Gignac, 2008, p. 308). Data up to six months after hospital discharge were extracted as the majority of studies on hospital to home transition reported a three to six months follow-up. Findings from the primary studies, including participants' quotations and researchers' interpretations, were extracted and organised into a data extraction form guided by Bettany-Saltikov (2012).

4.2.4.5 Data Synthesis

Thomas and Harden's approach to meta-synthesis guided the inductive thematic synthesis of data (Thomas & Harden, 2008). The synthesis involved three stages. First, after reading and re-reading full texts, we extracted data from each study relevant to the objectives of the review. We then conducted line by line coding of the extracted data and compared codes across all reviewed studies. This analytical process enabled the translation of concepts from one study to another (Thomas & Harden, 2008). Second, we assessed similarities and differences between the codes and grouped to create new codes. This step resulted in the development of descriptive themes. Third, based on the review questions, we discussed the descriptive themes (see Appendix 12 for an example) and identified analytical themes and subthemes.

We applied the GRADE-CERQual (Confidence in the Evidence from Reviews of Qualitative Research) approach (Lewin et al., 2018) to assess our confidence in the findings (Appendix 13). The CERQual provides a systematic and transparent framework to support reviewers' reflection on their confidence in each individual review finding from four perspectives: methodological limitations, coherence, adequacy of data and relevance (Lewin et al., 2018).

4.2.5 Findings

Twenty-nine studies were included in the synthesis. Sample sizes across studies ranged from 6 to 125. The total number of participants in the reviewed articles is 517 stroke survivors and 252 caregivers. Most studies were undertaken in the USA (8), with the other studies conducted in Canada (5), UK (4), Sweden (3), Australia (3), Norway, Iran, Denmark, New Zealand, Hong Kong and Portugal (1 each) (Table 2). The most common methodologies were qualitative descriptive, interpretive and grounded theory with semi-structured interviews. The review identified three higher order themes with six subthemes: 1) factors enabling transitional care (subthemes: *partnership approach to individualised* *transitional care; being prepared to navigate health and social care services and developing self-management capabilities*); 2) barriers to transitional care (subthemes: *gaps in discharge planning; factors affecting self-care at home, and inability to cope with challenges*); 3) expectations of transitional care.

A GRADE-CERQual approach to the assessment of confidence in the findings reached ‘high confidence’ in all but one subtheme (being prepared to navigate health and social care services). We agreed on ‘moderate confidence’ for this subtheme due to the low number of studies and relatively thin data (Appendix 13).

4.2.5.1 Factors Enabling Transitional Care

This review identified three key factors that enabled hospital to home transitional care for stroke survivors and caregivers: partnership approach to individualised transitional care, being prepared to navigate health and social care services and developing self-management capabilities.

Partnership approach to individualised transitional care

Stroke survivors and caregivers considered engagement in care and decision-making an essential part of discharge planning. They felt well-informed of their progress, which provided them with a sense of trust and confidence (Lou et al., 2017; Sadler et al., 2014). As a survivor stated:

> During my process of hospital stay she [partner] was there all through the time with me, so the doctor speak with her and she knows all the changes of what I’m going through and what I’m being there coping for, so she understands everything from the beginning (Sadler et al., 2014, p. 1915).

A family-centred approach to discharge planning not only empowered survivors and their families and fostered independence, but also supported family caregiving and decision-making (Cameron et al., 2013; Gustafsson & Bootle, 2013; Pereira et al., 2021; White et al., 2007). As a caregiver highlighted:

> Within the first week we had the choice of a family conference, which we elected to have. And we got all the family, and they all sat down with all the staff that … were

> involved with Catherine’s rehabilitation. And they explained what they did and what their plans were... that type of planning on behalf of the hospital is very good to give you an idea of what’s going to happen (Gustafsson & Bootle, 2013, p. 1384).

Stroke survivors valued the opportunity to practice personal care in a home environment prior to discharge as this helped them attain skills and increased confidence. This also enabled caregivers to assess caregiving capability and identify issues before their loved ones returned home (Cobley et al., 2013; Gustafsson et al., 2014). As a stroke survivor described:

> I do say that an invaluable part was coming home for the day and the weekends and the therapy in home was very much worthwhile because it gives you the confidence to do things in your own home that you don’t in the hospital (Gustafsson et al., 2014, p. 2247).

As a crucial part of poststroke rehabilitation and recovery, adequately preparing caregivers is a key element of effective transition (Cameron et al., 2013; Gustafsson & Bootle, 2013; White et al., 2007). Caregivers benefited from individualised information provision which combined verbal explanation and written material. As a caregiver praised:

> Instead of just handing me information, she sat down and went through each point even though I was so tired and I’m going to remember it so much more. When I need to, I’ll know in the sheets that she gave me where to go to look for the information (Cameron et al., 2013, p. 320).

Caregivers also valued opportunities to learn and practice caregiving skills while survivors were still in hospital. Caregivers’ training helped them build on personal care techniques and increased confidence in assisting with post-discharge rehabilitation (Cameron et al., 2013; Lutz et al., 2017; White et al., 2007). As a caregiver described:

> I worked with the nurses. When he took a shower and different things, helping to get dressed, his exercises…I practised all that before he came home…And then the two weekends that he came home…I thought that was pretty good (White et al., 2007, p. 9).

Health professionals who treated people with dignity and respect empowered survivors and caregivers and enhanced positive experiences during transition. As a survivor shared: "…was very reassuring he didn't tell me not to come [to the hospital] … and um I felt better after I spoke with him and I thought well I'll just, just wait and see if things get better" (Connolly & Mahoney, 2018, p. 3984). Health professionals' compassion and sensitivity towards survivors and caregivers further augmented post-discharge support and served as an impetus for continued participation and reintegration.

Being prepared to navigate health and social care services

Survivors and caregivers perceived that their competence in navigating complex health systems was built by health professionals. As a survivor stressed: "Transition [care team] have been terrific. Very helpful [with the] things that I can get and they've given me names of all the people I can ring who can who help me" (Gustafsson & Bootle, 2013, p. 1383). Their sense of safety was reinforced with the continuity of post-discharge follow-up services. As described by a stroke survivor: "In this process I've felt completely safe. Like, they didn't just send me home and hope for the best; I knew someone would check up on me, that I was not alone" (Lou et al., 2017, p. 305).

Early supported discharge services and community rehabilitation and social care services tailored to individual needs maintained stroke survivors' momentum for ongoing rehabilitation and helped develop self-management capabilities (Cobley et al., 2013; Gustafsson & Bootle, 2013). One stroke survivor was motivated by a therapy approach that addressed his personal goals and helped his reintegration into the community. As he stated: "The team were encouraging and motivating and would take me on a walk to make sure I could get on a bus and that I was able to cross the road, things like that" (Cobley et al., 2013, p. 753).

Developing self-management capabilities

Factors that enabled the development of self-management capabilities included positive thoughts (Connolly & Mahoney, 2018; Gustafsson & Bootle, 2013; Lou et al., 2017; Timothy et al., 2016; S. M. Yeung et al., 2011), positive self-appraisal of functional improvement and self-efficacy (Olofsson et al., 2005; Pringle et al., 2013; Sadler et al., 2014; White et al., 2007; Wottrich et al., 2012), and family and social support (Greenwood et al., 2009; Lutz et al., 2017; Rittman et al., 2007; Young et al., 2014).

Stroke survivors found it easier to accept poststroke limitations if they realised that their condition was more manageable compared to worse cases. This gave them reassurance and confidence in their capabilities to manage their own conditions: “My friends took me to a testimonial meeting with a man without limbs. Wow! I felt at peace…and positive about my life! I found courage… because I still have arms and legs” (S. M. Yeung et al., 2011, p. 2398).

Over the course of the transition, survivors gradually accepted their situation and understood that recovery is a process that takes time. Accepting that reality enables them to adapt to their new and changed role after stroke. As a survivor reflected: “Mentally, I’m alright, and going to, you know, I’ve accepted the fact that … this is what’s happened” (Timothy et al., 2016, p. 1570). Caregiver’s with a positive view of their role smoothen transition: “It brought us closer together…it’s not as sexy as it used to be, but we are still close… we help one another. I think it brings you closer, being with the person all the time” (White et al., 2007, pp. 9-10).

Survivors and caregivers developed more confidence in self-management through positive self-appraisal: “Yes, I mean I think that every time we get a little bit further away, it makes us more secure. It is like dangerous waters and we are gradually sailing out of them” (Greenwood et al., 2009, p. 1126). Caregivers’ self-efficacy, built on mastery over caregiving activities, also augments self-management. As a husband described:

> I have done so many things that I never thought that I would be able to do around the house – the banking, the shopping, the cooking, giving my wife a shower, making the bed… just something I’d never done…I’ve learned a lot of things (White et al., 2007, p. 9).

Family and social support played a critical role in assisting survivors’ early reintegration during the transition and therefore reinforced their self-management capabilities: “I’m teaching my son how to cook…him or my wife, cause neither one can cook. She can’t cook but she’ll try, so…I go in there and I guide her” (Rittman et al., 2007, p. 27). Family and social support also eases the burden on caregivers by serving as a respite to prevent caregivers’ burning out and promotes sustainability of long-term caregiving: “My neighbours said they are all going to get their schedule and make a listing and come over even if it’s for only an hour, so I can go to the grocery store” (Lutz et al., 2017, p. 884). Family support encouraged caregivers’ adjustment, sustained caregiving and expedited the return to normalcy. A caregiver stated:

> It was hard to start with but now it is sort of getting in a routine so unless suddenly something goes wrong. . .everyone has some sort of job so we all do that—the brother and sister, the other sister and my brothers (Greenwood et al., 2009, p. 1127).

4.2.5.2 Barriers to Effective Transitional Care

Three major intertwined barriers to effective transition are gaps in discharge planning, factors affecting self-care at home and inability to cope with challenges.

Gaps in discharge planning

Discrepancies between survivors and health professionals regarding discharge priorities and goals were described by stroke survivors and caregivers (Pereira et al., 2021; Sadler et al., 2014; S. M. Yeung et al., 2011). For example, a caregiver described rehabilitation activities suggested by a therapist were not accepted by the survivor due to personal preference:

> The therapist wants him to go there, to the shop. He used to enjoy being in the shop serving the public, but now she [the therapist] wants him to pack things up and transport bottles as a way of moving and he doesn’t want to (Pereira et al., 2021, p. 2904).

Some participants were exasperated when they expected a compassionate approach, but this was missing in interactions with clinicians (S. M. Yeung et al., 2011, Cobley et al., 2013, Bakas et al., 2002). They felt that clinicians often cared more about their physical than emotional needs. As a survivor complained:

> They took special care with regard to my diet and giving me my medication on time. However, they were rarely concerned with my feelings. Actually, the most important thing for a patient is words of concern (S. M. Yeung, et al., 2011 p. 2399).

A lack of engagement and being discharged with unanswered questions caused survivors and their family unnecessary anxiety and difficulties with daily care (Gholamzadeh et al., 2015; Olofsson et al., 2005; White et al., 2007). A participant shared their frustration: "When you ask a question, they do not answer. There are so many things and tips a nurse knows, which would take months for us to learn, but they did not tell us if we asked them" (Gholamzadeh, et al., 2015, p. 211).

Most caregivers are new to this role. They therefore need to have hands-on training in daily personal care activities. Inadequate preparation before discharge adds to caregivers' burden and anxiety. A caregiver shared the experience:

> Last month, the patient was discharged; it was a difficult time for us. We had lots of problems. We did not have any knowledge in this field… We did not know how to move her, how to clean her or how to put diaper on her. They didn't instruct us at the hospital… We need to know how we can help our patients with peace and comfort for both of us (Gholamzadeh et al., 2015, p. 208).

Some caregivers were not prepared for post-discharge care requirements when survivors were discharged home. They struggled to manage care activities and were left without any help. As a caregiver shared:

> Only realized how much care my father would need once he was home and no one really gave us any warning at the hospital. Even though I thought I would have help, when I really needed it, it wasn't there (White et al., 2015, p. 1095).

Factors affecting self-care at home

Survivors and caregivers are in a well-controlled environment while in hospital. Once home, stroke survivors rely on support from caregivers to maintain ADLs. Coupled with inadequate pre-discharge preparation and lack of caregivers' training, inadequate support in the community exacerbates an already challenging transition (Cameron et al., 2013; Eilertsen et al., 2010; Lutz et al., 2017; White et al., 2015; Young et al., 2014). Stroke survivors and caregivers felt that they were forgotten by the healthcare system after discharge. As one stated: "They cast us adrift, you're into the community and you're on your own" (Cameron et al., 2013, p. 320). They also experienced anxiety and uncertainty: "We felt on our own, like we had been abandoned and were so nervous and scared about everything" (White et al., 2015, p. 1096).

Survivors perceived the lack of follow up jeopardised their continued rehabilitation and reintegration. As a survivor questioned:

> They don't really help you get back into life, do they? They just sort of, you have a stroke, you have physio and that's it… it [stroke] affected my hand so obviously that was my job, so in effect: How will she move on from there? What can we do to help her get back into work? (Sadler et al., 2014, p. 1915).

There can be a significant gap between inpatient and community rehabilitation services. The considerable waiting time for community rehabilitation programs experienced by some survivors impacted on the achievement of their goals. A survivor described: "All of a sudden, it's like, "Oh, we've referred you to the hospital again to get the physio," which has took…three months. So I've had intense physio for six weeks and then, for three months, I've had nothing" (Cobley et al., 2013, p. 754).

Caregivers are imperative to support stroke survivors' continuous rehabilitation and reintegration into the community. However, some caregivers perceived being taken for granted as the home care service was never offered before discharge. A caregiver expressed her dissatisfaction: "I'm very disappointed that they didn't offer to help me, because obviously he would have had to go into a home or somewhere if I wasn't doing it" (Cobley et al., 2013, p. 754).

Financial constraints have been identified as another significant barrier during transition. Survivors and caregivers reported that poststroke disability brought an unexpected increase in daily expenses and decreased income due to unemployment (Gholamzadeh et al., 2015, Lutz et al., 2017, Young et al., 2014, White et al., 2007). A survivor stated: “Well I’m anticipating bankruptcy because I don’t see any way out of it…bills have gone unpaid simply because I don’t have the money that I had when I was working part-time” (Lutz et al., 2017, p. 885).

A lack of financial resources also compromises ongoing rehabilitation with survivors missing out on essential equipment and therapies (Bakas et al., 2002; Ghazzawi et al., 2016; Grant, 1996; Lutz et al., 2017; Sadler et al., 2014; E. H. Yeung et al., 2015). One survivor talked about giving up on buying a walking aid that could potentially improve mobility: “[The doctor] said for me to have a walking stick but my insurance ran out…I was intending to go back and get it, but I don’t have the money, $45, so I let it go” (Grant 1996, p. 897).

Financial situation is further exacerbated when survivors spend more on purchasing healthy food to make lifestyle changes to prevent secondary stroke. As a caregiver shared: “We’ve had to change the way that everybody eats because of him, that gets expensive because you’ve got to buy all this fruit now and eating healthy is expensive” (Bakas et al., 2002, p. 248).

Inability to cope with challenges

Stroke survivors’ and caregivers’ views on and the level of acceptance of poststroke physical, cognitive and emotional impairments have a significant impact on their ability to cope with poststroke disabilities and achieve community reintegration during the transition phase (Erikson et al., 2010; Finch et al., 2021; Gholamzadeh et al., 2015; Grant, 1996; Gustafsson et al., 2014; Olofsson et al., 2005; Pringle et al., 2013; Rittman et al., 2007; Timothy et al., 2016; C. L. Williams et al., 2005). Stroke survivors perceived themself as a stranger. They considered themselves as “half of a person” (C. L. Williams et al., 2005, p. 286) and that ‘it feels as if you’ve gone and somebody else is in your place’ (Timothy et al., 2016, p. 1569).

After returning to the community, survivors found it difficult to adjust to their poststroke disabilities, which caused considerable emotional distress and negative thoughts. A survivor resented:

> You're alive, but you are worthless. Alive for what? They have to feed you, bathe you… What can you say that you are doing? Living a monotonous life, like a vegetable. Sometimes it is better that they give you something that leaves you dead and it is over (Rittman et al., 2007, p. 29).

Survivors dependent on family caregivers and others to perform basic daily activities perceive themselves as a burden and "troublesome" (S. M. Yeung et al., 2011, p. 2399). One survivor viewed herself as a nuisance to her husband: "There is a lot that he (her healthy husband) is supposed to do, there's actually too much that he has to do, it does not feel quite fair, but when you can't, you can't" (Wottrich et al., 2012, p. 1221).

The difficulty of developing strategies to cope with their changed role resulted in survivors' social disengagement. One survivor described himself as being "apart" from others due to his inability to be independent, which made him think of "taking my life" (C. L. Williams et al., 2005, p. 285).

Caregivers struggled to adapt to the role. They are challenged by their own health limitations, the unexpected increase in responsibilities and personal views on poststroke life (Young et al., 2014, Gholamzadeh et al., 2015, White et al., 2007, Lutz et al., 2017, Bakas et al., 2002). Whilst having to manage their own health conditions, caring added another layer of complexity and anxiety to their lives. A survivor's wife talked about her worries: "I thought I was going to collapse physically, my knees were going on me…my back was hurting. I just thought if I collapse, what's going happen to the two of us. It's very scary" (White et al., 2007, p. 8).

When survivors return home, caregivers are faced with a sudden increase in household responsibilities that they may not have realised or been prepared for. This was described by a wife who cared for her husband on her own: "When he came home—I was reeling for weeks. My mind was just going a hundred different directions. I had no idea it was going to be as hard as it was” (Lutz et al., 2017, p. 882).

With increased responsibilities and more daily activities to perform, caregivers have less time for social interactions with others. This left them “feeling like a prisoner in your own home” (White et al., 2007, p. 8). The lack of emotional support for caregivers to develop coping strategies caused despair. As a caregiver resented: “There are things worse than death, and this is it. This is the living dead” (Young et al., 2014, p. 1896).

4.2.5.3 Expectations of Integrated Transitional Care

This review has identified stroke survivors’ and caregivers’ expectations of person-centred integrated transitional care services. Participants expressed their desire for compassionate and holistic care (Connolly & Mahoney, 2018; Gholamzadeh et al., 2015). Participants expected both their physical and psychological needs to be met. As a family suggested:

> Doctors and nurses do not care about patient’s mental status but only care about patient’s physical health, such as doing CT scan and giving them their medicines. However, the main problem of the stroke patients with functional loss is their mental status…the most important measure should be psychotherapy for both patient and family (Gholamzadeh et al., 2015 p. 212).

Survivors and caregivers considered having a central point of contact throughout their trajectory from discharge planning to transitioning home a necessity (Cobley et al., 2013, Lutz et al., 2017, White et al., 2007, White et al., 2015). During the discharge planning phase, they would have preferred a care coordinator who would talk to them regularly about their progress and keep them well-informed of what to expect next (White et al., 2007). A home visit before discharge is desirable to prepare for the reality they will face once the survivor returns home (White et al., 2015).

Most stroke survivors are unfamiliar with how the health system works. Prior to discharge, they prefer to have someone to provide information about services and benefits that they may be entitled to receive. As a survivor stated: “I thought it’d be good to talk about if you were entitled to any benefits because I've never been on the sick ever. I didn't understand any of it, we had to figure it out for ourselves" (Cobley et al., 2013, p. 755).

Participants also applauded timely follow up and support after returning home. They considered follow up and support as essential to achieving their rehabilitation goals and sustain caregiving (Cameron et al., 2013, Connolly & Mahoney, 2018, Grant, 1996, Lutz et al., 2017). A survivor longed for a follow up phone call from hospital after discharge. As she suggested: "A hospital calling to check in on you and to see how you're doing … I would have loved something like that" (Cameron et al., 2013, p. 320). Community support for survivors reassures caregivers and helps sustain caregiving. A caregiver expressed her wish: "I would have been more at ease at work if I knew a lady was here every day… just to assist her as far as going to the restroom and dressing her and making sure she is fed right" (Grant 1996, p. 897).

4.2.6 Discussion

The first six months of hospital to home transition is the most critical time for stroke survivors and caregivers to build their capability to maximise recovery, reorient to a changed life and learn to manage health conditions at home. This meta-synthesis of qualitative evidence facilitates an in-depth understanding of stroke survivors' and caregivers' perspectives on the enablers and barriers to an effective transition, and the complex interplay of poststroke functioning, environmental factors and personal factors. Findings from this review demonstrate that opportunities and challenges coexist during the transition. Effective hospital to home transition care can be achieved when health professionals utilise a partnership approach to individualised transitional care; develop stroke survivors' and caregivers' capabilities to navigate and utilise health and social care services to meet their care needs; and active self-management capabilities.

The ICF framework, underpinned by the biopsychosocial model, enabled a comprehensive analysis of the interaction between poststroke functioning and personal and environmental factors (WHO, 2013). The findings of this meta-synthesis confirm that the interplay of stroke survivors' poststroke disabilities, post-discharge support and their self-management capabilities could impede or facilitate hospital to home transition care. Multidimensional environmental factors and complex personal aspects in poststroke hospital to home transition care call for an integrated approach to care and continuity of rehabilitation processes, which are vital to maintain and foster long term self-care at home (von Koch, 2019; WHO, 2015).

Stroke triggers an inflammatory immune response and systemic immunosuppression which makes survivors susceptible to infection (Boehme et al., 2018; Pagram et al., 2017). About 30% of the stroke population develop an infection and this is one of the major causes of 30-day readmissions after discharge (Boehme et al., 2018, Pagram et al., 2017). Recurrence of stroke is another culprit behind readmissions after discharge. Approximately 65% of stroke survivors are hospitalised with secondary stroke within 12 months of the first stroke onset (Abreu et al., 2020). Providing stroke survivors and caregivers with knowledge of stroke related complications, medication management and lifestyle changes empowers them with self-management skills and proactive actions to manage risk factors and prevent adverse events. Person-centred discharge planning and transitional care coordinated by stroke nurses could reduce preventable hospitalisations resulting from complications (Condon et al., 2016; White et al., 2015).

This review demonstrated that partnerships with stroke survivors and caregivers and consistent engagement in decision-making and discharge planning processes are key factors to the success of hospital to home transitions. Due to shortened hospital stays, comprehensive discharge planning must begin early in the inpatient setting to enable preparation for transitioning to the community (Mountain et al., 2020; Olson & Juengst, 2019). Barriers to a partnership approach during discharge planning include the readiness of survivors and caregivers to participate, the lack of organisational support for health professionals and inadequate person-centredness in goal setting (Busetto et al., 2020; Connolly & Mahoney, 2018; Kable et al., 2019; Krishnan et al., 2019; Pereira et al., 2021). With mismatched care goals and priorities between health professionals and survivors/caregivers, an informed and well-planned transition is unlikely to be achieved, resulting in unmet care needs and negative impacts on the development of self-management capacities for long-term stroke management at home (Andrew et al., 2018; Hughes et al., 2020). How to collaborate with stroke survivors/caregivers and bridge these gaps in setting goals and priorities to achieve shared discharge planning are important service development areas for organisations and health professionals to explore.

Self-management refers to an individual's ability to manage a chronic condition in collaboration with the caregiver, family, community and the appropriate health professionals (Satink et al., 2016). Support from health systems and community resources is crucial to empower and enable the development and activation of self-management capabilities (Barker et al., 2018; Fryer et al., 2016). Furthermore, it is equally important for stroke survivors and caregivers to actively take part and generate ownership over the management of their condition throughout the rehabilitation and recovery process (Sadler et al., 2017; A. Taylor et al., 2019). The findings of this review confirm that self-management capacities are co-developed by survivors/caregivers and health professionals. Furthermore, the self-efficacy beliefs (or confidence in self-management) of survivors/caregivers are enhanced by their motivation to learn and commitment to take charge of care at home combined with health professionals' encouragement and feedback on performance (Dineen-Griffin et al., 2019; Pereira et al., 2021). Trustful relationships and open dialogues between stroke survivors/caregivers and health professionals motivate stroke survivors/caregivers to learn and self-manage rehabilitation and recovery at home (Osborne & Neville, 2019; Theadom et al., 2018). The activation of self-management capacities begins before discharge and is further augmented with post-discharge health and social care support in the community (Reeves et al., 2019, Mountain et al., 2020).

This review revealed that stroke survivors' and caregivers' personal attributes and contextual factors played an important role in transitional care. Regardless of stroke severity, survivors' and caregivers' introspection triggered both negative and positive thoughts about stroke, their role, relationships with family and post-discharge life (Finch et al., 2021; Hodson et al., 2019). Survivors' and caregivers' pre-stroke family dynamics, past health conditions, willingness and readiness for caregiving shaped their ability to engage and participate in rehabilitation and discharge planning, and the development of self-management capacity (L. Chen et al., 2020, Hodson et al., 2019, Osborne & Neville, 2019). Moreover, it is estimated that 40% of stroke survivors experienced cognitive impairment that had a significant impact on their self-management capability, and this is associated with a higher level of caregiver burden (Sexton et al., 2019; Wu et al., 2019). Therefore, caregivers need to be prepared with knowledge and skills to cope with cognitive impairment associated behavioural symptoms and functional decline (Rohde et al., 2019). These personal factors interplay with environmental factors, such as availability of financial support, accessibility of health and social supports, and returning to driving and work, and may contribute to readmission and early institutionalisation during the transition (Kilkenny et al., 2020; Pindus et al., 2018). Due to their close therapeutic relationships with stroke survivors/caregivers, nurse-led transitional care interventions targeting the hospital to home transition period could address some of these challenges and help sustain care at home (Condon et al., 2016; Olson & Juengst, 2019).

This review has limitations. We only included literature published in the English language. Twenty-six of the included studies were undertaken in developed countries (United Nations Department of Economic and Social Affairs, 2020). The perspectives of stroke survivors/caregivers in developing countries may resemble or differ compared to their counterparts in developed countries. The review of transitional care in developing countries/regions may further enrich understandings of the issues of concern. Additionally, the investigation timeframe was set at within six months of discharge as most transitional studies’ follow up period is three to six months. This may have impacted on the narratives as transition is a personalised experience that may extend beyond six months. Moreover, we only reached ‘moderate confidence’ in the subtheme ‘being prepared to navigate health and social care services’ due to concerns on its adequacy based on GRADE-CERQual assessment. This suggests that more primary research is needed to confirm this finding. This review will need to be updated when more original studies are available. Finally, this review only focused on the views of stroke survivors and caregivers. To generate an overall insight into challenges during the transition, future reviews need to consider perspectives of all stakeholders including health professionals and service providers. These limitations need to be considered when interpreting the findings of this review.

4.2.7 Conclusion

Through the lens of stroke survivors and caregivers, this meta-synthesis underlines challenges and opportunities in the first six months of the poststroke hospital to home transition. Findings from this review support that health professionals' partnering and engaging with stroke survivors and caregivers in individualised discharge planning facilitates self-management during their transition. Integration within multidisciplinary teams and between care service providers enables stroke survivors/caregivers to achieve care goals, develop self-management capacities and paves the way for long-term self-management. This review highlights complex and multidimensional issues in poststroke hospital to home transitional care and identifies gaps for further research.

Future research should focus on the perspectives of all stakeholders in hospital to home transitional care, especially that of health professionals, primary care providers and care service providers/organisations. Their views will deepen the understanding of issues at an organisational and systemic level. Furthermore, the unique care needs and challenges of survivors/caregivers in rural and remote regions need to be explored. Further development of stroke-transition-specific clinical pathways and care models will enhance the consistency and quality of service delivery, facilitate the integration of care services across hospital and community settings, and empower stroke survivors and caregivers to achieve and sustain long-term poststroke management at home.

4.2.8 Relevance to Clinical Practice

Protocols and clinical guidelines relating to discharge planning and transitional care support need to be reviewed to ensure partnership approach with survivors/caregivers in the design and delivery of individualised transitional care. Nurses specialised in stroke care are in a unique position to lead timely support for survivors/caregivers and to bridge service gaps in hospital to home transition care. A nurse coordinator’s role needs to be considered to ensure integrated services across care settings and service providers in transitional care. Tele-health technology needs to be established to ensure those who reside in rural and remote regions are able to receive equitable transitional care services.

This is the end of the publication.

4.3 Summary

This chapter has presented the findings of a systematic review and meta-synthesis of qualitative studies. The systematic review explored, in the global context, stroke dyads’ perceived enablers, barriers and expectations during the hospital-to-home transition. The findings highlight the desire of stroke dyads to be part of the planning for the hospital-to-home transition care. They considered that collaboration with health professionals builds their competence in navigating the healthcare system and helps foster self-management capabilities, which are essential for people with stroke to reintegrate into the community and for their caregivers to sustain long-term caregiving after they leave hospital.

The next chapter reports the methodology and methods for the qualitative study, which aimed to investigate, in an Australian context, the perspectives of people with stroke, caregivers and health professionals regarding care needs and expectations during hospital-to-home transitions.

Chapter 5: Research Methodology and Methods

5.1 Introduction

The previous chapter presented the findings from a systematic review of care needs and expectations in the hospital-to-home transition from the perspective of stroke dyads in a global context. The results highlighted the need to foster a collaborative approach to hospital-to-home transition care among all stakeholders of the stroke care chain to ensure that the care needs and expectations of stroke dyads are met. The scarcity of evidence on such a collaborative approach to transition care informed the present qualitative study. This chapter describes the study's philosophical underpinning, research methodology around Gadamer's phenomenological hermeneutics, and methods.

5.2 Aim and Objectives

The aim of the study was to explore the care needs and expectations in hospital-to-home transition care for stroke dyads in an Australian social context. The objectives were to:

1. understand the experience and perceptions of stroke dyads during the hospital-to-home transition in a global context;
2. understand stakeholders' perspectives on approaches to identifying and meeting the transition care and rehabilitation needs of people with stroke in an Australian social context.

5.3 Philosophical Perspectives of the Study

The word 'philosophy' originates from the Greek word '*phílosophía*', meaning the 'love of wisdom' and can be referred to as 'the study of the fundamental nature of knowledge, reality and existence' (Oxford Learners' Dictionaries, n.d.). Philosophy provides the principles of theoretical thinking and the philosophical underpinnings for research. It guides researchers in the design, conduct, analysis and interpretation of research and its outcomes (Moon & Blackman, 2014).

5.3.1 Paradigms in Research Design

A paradigm is a world view and a basic set of beliefs that guide the inquirer's action (Denzin & Lincoln, 2018). Major paradigms that influence research design include positivism, post-positivism, constructivism, critical theory and participatory action frameworks (Denzin & Lincoln, 2018). Each paradigm has its unique ontological, epistemological, axiological and methodological basis (Lincoln et al., 2018). They address different concerns of a study. Three paradigms are widely used in nursing research and are discussed in the following sections.

5.3.1.1 Positivism

Positivism is also called 'logical empiricism' and emphasises the rational and the scientific (Liamputtong, 2017, p. 14). Positivists view the world as a 'real reality' that can be studied and known. They assume that nature is stable and organised, that an objective reality exists and that it is separate from human observation (Lincoln et al., 2018, p. 110). Hence, positivists apply empirical tests with scientific methods to study hypotheses under carefully controlled conditions. They believe there is a real world that is driven by causes and effects (Lincoln et al., 2018).

The fundamental difference between positivism and other paradigms is its ontological perspective of 'realism' (Lincoln et al., 2018, p. 110). Positivists value objectivity as their epistemological stance. They strive to put aside personal beliefs and thoughts and avoid contamination of the studied phenomena. In the methodological dimension, positivists believe in scientific, quantitative methods with a 'gold standard' and tight control of the research situation (Lincoln et al., 2018, p. 117).

Under the same umbrella, the post-positivist paradigm evolved over time as strict positivist thinking was challenged. However, the revised post-positivists still believe that a true reality is out there. However, they are more conscious of the impossibility of total objectivity, though they continue to strive for objectivity and minimum interaction with research subjects (Lincoln et al., 2018).

Successful research guided by positivism results in replicable and objective law, which leads to generalisation. The strengths of positivism are its clarity, precision, rigour, standardisation and generalisability (Bryman, 2016; Lincoln et al., 2018). However, to remain objective, this approach does not consider the voice of participants. Only the researchers' voices are heard in the research, which denies human uniqueness and individuality (Bryman, 2016; Lincoln et al., 2018). Hence, research results may not be applicable to human beliefs, values and people's lives in different contexts and cultures.

5.3.1.2 Constructivism

Constructivism is also known as 'interpretivism' (Liamputtong, 2017, p. 13). Contrary to positivism, constructivists view reality as multiple and subjective. It is understood as a construction of individuals and is based on their beliefs and the sociocultural environment they interact with (Houser, 2015). Researchers under this paradigm believe that knowledge is co-developed and obtained through interaction between the researcher and the participants (Lincoln et al., 2018).

In the ontological dimension, interpretivists hold the world view of 'relativism'. They believe that multiple realities exist, and they depend on the individual's social and experiential situation to know the realities (Lincoln et al., 2018). Knowledge is constructed through lived experiences and interaction with others in society. To the interpretivists, produced knowledge is reflective of the reality of the participants. This ontological stance is opposite to that of the positivist (Lincoln et al., 2018).

In the epistemological dimension, interpretivists believe that new knowledge is co-constructed by the researcher and participants through interaction. The relationship between the researcher and the participants is central to new knowledge development. The main goal of inquiry based on constructivism is to inform improved practice through understanding and interpreting the meanings of phenomena (Lincoln et al., 2018). Thus, the researcher needs to actively participate in the entire research process.

The methodologies commonly used by constructivists include qualitative approaches such as phenomenology, grounded theory and case studies. Dialogue between the researcher and the participants is valued as a way to collaboratively construct a meaningful reality (Lincoln et al., 2018). Therefore, methods used to collect information include interviews, focus groups, observations and the analysis of existing texts. Evidence is generated through an inductive process. However, there are a number of limitations to using constructivism in research. Under this paradigm, information is collected through human beings as a study instrument. Human beings are intelligent and sensitive but prone to errors. Additionally, the subjective nature of constructivism may yield different conclusions by two constructivists in similar study settings and populations.

5.3.1.3 Critical Theory

Critical theory belongs to approaches within the ‘transformative paradigm’ (Polit & Beck, 2017, p. 480). In the ontological dimension, critical theorists view the world as ‘historical realism’ (Lincoln et al., 2018, p. 111). They believe that the operation of human nature in the world is based on a struggle for power. Virtual reality is shaped by social, political, cultural, economic, ethnic and gender values. Studies under this paradigm are driven by the aim to create change and benefit those oppressed by power (Lincoln et al., 2018). In the domain of epistemology, knowledge is viewed as subjective, historical consciousness and insights and developed through collaborative critical reflection with participants. It involves the self-reflective aspect of the researcher. The researcher must account for their own transformative effects to reveal changing directions and catalyse changes (Lincoln et al., 2018).

Critical researchers triangulate multiple methodologies to inform and catalyse changes. During the interactions with participants, researchers particularly focus on the expertise of participants. While carefully presenting knowledge based on their own paradigm, critical theorists remain sensitive to the views of participants (Lincoln et al., 2018).

When used in the nursing discipline, critical theory allows for the consideration of the sociocultural and political contexts of nursing care. It provides a framework for nursing research on the investigation of social inequalities related to health and the healthcare system and for transforming these situations (Mosqueda-Díaz et al., 2014). Critical ethnography is one example of critical theory's application in nursing study; it is considered suitable for health promotion research due to its focus on enabling people to have control of their own situation (Polit & Beck, 2017).

In summary, paradigms guide the design and the conduct of research. All paradigms have their strengths and weaknesses. Positivism emphasises scientific and statistical methods and the objectivity of evidence but is criticised for its ignorance of the values and beliefs of human beings. Other paradigms focus on subjectivity but are critiqued for their lack of replicability and generalisability of findings. Nevertheless, the knowledge of paradigms enables the appropriate use of a suitable methodology to achieve research goals.

5.3.2 Using Constructivism to Guide the Research Design

The design of this study is guided by constructivism. Constructivism views the existence of reality as being multiple and subjective. Reality is self-created by individuals based on their own way of thinking about life and their role in that life. The aim of an inquiry underpinned by constructivism is to understand and interpret the lived experiences of human beings (Lincoln et al., 2018).

The purpose of the present study was to explore stroke dyads' experiences, perspectives and expectations in transition care and rehabilitation. The constructivist approach helps researchers to develop in-depth insights into the experiences and perspectives of people with stroke, their caregivers and health professionals. In addition, constructivism emphasises that knowledge is co-constructed through the interaction between the researcher and participants through hermeneutical discussions (Lincoln et al., 2018). In this study, interviews with stroke dyads and focus groups with health professionals served as means to ensure sufficient dialogue and interaction between the researchers and the participants. New knowledge of transition care is gained through the interpretation of the participants' perceptions embedded in their cultural and social context (Lincoln et al., 2018).

Furthermore, the constructivist approach examines goals and knowledge to inform praxis (improved practice; Lincoln et al., 2018). One of the objectives of the present study was to develop an evidence-informed hospital-to-home transition care model and pathways to enhance collaborative and consumer-directed transition care and rehabilitation services. As a stroke rehabilitation clinician, the researcher's original intention for conducting this study was to gain a deeper understanding of the perceived issues related to stroke transition care to improve clinical practice. This feature of constructivism well serves this intention.

As discussed above, the study aimed to understand the care needs and expectations of hospital-to-home transition care for stroke dyads in the Australian social context. Qualitative research design underpinned by constructivism tends to be holistic and enables the researcher to strive for an understanding of whole phenomena. It requires the researcher to be deeply involved in the research process and to be part of the research instrument. The collection and analysis of data are concurrent, which requires the researcher to be flexible and able to adjust to new information (Polit & Beck, 2017).

5.4 Research Methodology

5.4.1 Overview of Qualitative Research Approaches

The history of qualitative research can be traced to the last quarter of the 19th century when the term 'ethnography' was used by anthropologists to describe the way of life of particular local groups of people living in colonial situations (Erickson, 2018, p. 38). There are five main approaches to qualitative inquiry: ethnography, phenomenology, grounded theory, narratives and case studies (Creswell, 2013). The following section focuses on the first three methodologies that have been widely used in the nursing and social sciences.

Rooted in anthropology, ethnography describes and interprets the cultural behaviours of a particular group. Ethnographers participate extensively in fieldwork and engage actively in the cultural activities of the studied group (Creswell, 2013). Ethnographers are particularly interested in information such as cultural behaviours, cultural artefacts and cultural speech. Used in health practice, ethnography helps researchers to develop an understanding of the health beliefs and behaviours of a cultural or subcultural group (Polit & Beck, 2017).

Phenomenology has its roots in both philosophy and psychology. Its focus is on an understanding of lived human experience. Phenomenological researchers describe the experiences of participants and how they experience them (Creswell, 2013). Through in-depth conversations (e.g., interviews), the researcher and the participants enter into a ‘co-participant’ relationship, which enables the researcher to enter into the world of the participant so as to obtain a more enriched understanding of their perspectives and expectations. Besides in-depth conversation, observations and introspective reflections are also data sources to gain deeper insight into the studied phenomenon (Creswell, 2013; Polit & Beck, 2017).

Grounded theory was developed in 1967 by two sociologists, Barney Glaser and Anselm Strauss (Creswell, 2013). Although grounded theorists also study people’s experiences, they attempt to understand a process or action as grounded in reality (data). The theory generated from this kind of methodology is embedded in participants’ actions and their meanings and, in return, is used to explain and anticipate human behaviours (Creswell, 2013; Polit & Beck, 2017). Data in grounded theory are sourced mainly through interviews and observation (Creswell, 2013; Polit & Beck, 2017).

All of the above approaches involve active interaction with participants to achieve research goals. The research methods shared among these research approaches include interviews and observations. In addition to these methods, ethnographers also collect data through diverse sources, including symbols and artefacts. Grounded theorists constantly compare data during the data collection process. To evolve theory, researchers using grounded theory usually go back and forth between participants and conduct new interviews (Creswell, 2013). The aim of study for these approaches is different. Grounded theory focuses on developing a new theory grounded in the collected data. Involving extensive fieldwork, the goal of ethnographers is to develop understandings of the culture of a group. Phenomenology, by contrast, strives to obtain in-depth knowledge of participants’ lived experiences and interpret what they have experienced and how they have experienced it.

Any of these three approaches could be used in this study. However, phenomenology was chosen as the most appropriate research approach to address the aim and objectives of the study. The aim of this study was not to describe cultural behaviours or generate a theory but to explore the hospital-to-home transition care experiences, needs and expectations of stroke dyads from the perspectives of stakeholders. It coincides with the inquiry aim of phenomenologists, who focus on people's lived experiences based on their individual historical, cultural and social context. Additionally, the goal of phenomenological inquiry does not stop at identification and explanation but also critiques the meanings generated from data (Crotty, 1996). Insights into the shared experiences of a particular group of people can be of great value to professionals, such as health professionals, policymakers and therapists (Creswell, 2013). One of the objectives of this study was to understand stroke dyads' transition care experiences and expectations to inform clinical practice; a phenomenological approach was well suited to achieving this objective.

5.4.2 Overview of Phenomenology

Phenomenology, developed in the early 20th century, is both a philosophy and a research methodology (Dowling, 2007). The definition of phenomenology is diverse, depending on its philosophical underpinnings. The simplest definition is that it is 'the study of things (phenomena)' (B. Taylor & Francis, 2013, p. 77). There are many types of phenomenology. Phenomenology can be classified into six types: descriptive (to accurately describe), essential (to explain essences and their relationships), phenomenology of appearance (how phenomena appear), constitutive (processes of phenomena established in humans' consciousness), reductive (suspending belief in the reality of phenomena) and hermeneutic (aims to reveal hidden meanings in phenomena; B. Taylor & Francis, 2013, p. 78). These types were established based on the inspiration of other philosophical thoughts on phenomenology. So, they are not exclusive of each other; rather, they are related (B. Taylor & Francis, 2013, p. 78). The next section discusses the key concepts of three main originators of phenomenology.

Developed by Edmund Husserl, descriptive (transcendental) phenomenology asked the question, 'What do we know as persons?', and emphasised the description of people's lives as they experience it through objectivity. The main feature of descriptive phenomenology is so-called bracketing, a process of identifying and holding aside the researcher's pre-existing beliefs and understandings of the studied phenomenon and avoiding the influence of those pre-existing beliefs on the findings of the study. Therefore, to facilitate the emergence of potentially different possibilities of understanding, Husserl advocated for an objective approach (Carpenter, 2017, p. 159; B. Taylor & Francis, 2013, p. 79).

Building on Husserl's philosophical tradition, Martin Heidegger, a student of Husserl, developed an existential-ontological hermeneutics that rejected Husserl's objectivity through bracketing. Heidegger was concerned with human existence, or '*Dasein*' ('being-in-the-world') and believed that understanding could not be separated from people's pre-cognitive awareness(B. Taylor & Francis, 2013, p. 82). In another word, understanding is connected to one's history and moves back and forth between parts and whole of experiences. Heidegger developed the concept of the hermeneutic circle to envisage a whole regarding a reality that was situated in the detailed experience of everyday existence by an individual (the parts) (B. Taylor & Francis, 2013). Researchers who follow Heidegger's approach consider their own historically situated self and bring this into their inquiry. Thus, understanding is context-based.

Hans-Georg Gadamer adopted Heidegger's view of the hermeneutic circle and further developed philosophical hermeneutics. For Gadamer, understanding is hermeneutical and historical. He emphasised that all understandings are linguistic. People engage in a conversation with their own knowledge of that encounter. This pre-knowledge needs to be acknowledged when questioning understanding (Gadamer, 1979).

With the similar aim of studying lived human experiences, the main difference between Husserl, Heidegger and Gadamer's philosophical traditions is that phenomenologists following Husserl's approach strive for objectivity in understanding. They believe in putting presuppositions in abeyance to generate new understandings, and the understandings remain at the level of describing a specific experience of a phenomenon. On the contrary, hermeneutic phenomenology values the pre-existing knowledge of the researcher, and the researcher's pre-understanding guides the development of meaningful inquiry (Carpenter, 2017).

5.4.3 Gadamer's Phenomenological Hermeneutics as a Choice for the Current Research

The term 'hermeneutics' is derived from the Greek word '*hermeneuein*', which means 'to interpret' or 'to understand' (Crotty, 1998, p. 88). In ancient Greece, this word implied 'translating' something strange that was separated in time or space to make it present and easily understandable (Crotty, 1998). It was originally used to guide scholars in interpreting biblical texts in the 17th century. Apart from its use in interpreting scripture, it was also used to study human actions to bring about understanding (Crotty, 1998).

5.4.3.1 Gadamer's Hermeneutics Circle as Applied to the Study

Gadamer claimed that understanding (interpretation) is inseparable from language and is achieved through the experience of conversation (Gadamer, 1979). He described the interpretive process as a 'hermeneutic circle', whereby the inquirer brings historical awareness (called 'prejudices' by Gadamer) and enters a questioning process with an open mind (Gadamer, 1979, pp. 235, 238). During this process, understanding emerges or 'happens' to the inquirer (Gadamer, 1979, p. 345). 'A fusion of horizons' (explained below) forms as a new understanding is established. In other words, a fusion of the past (the inquirer's presupposition) and the present (the inquirer's interpretation by reflection) develops (Gadamer, 1979, p. 273). Understanding deepens as the fusion of horizons continues.

Gadamer argued that it is impossible for interpreters to bracket their preconceived ideas or leave them in abeyance when they are engaged in the process of interpreting human actions. Gadamer (1979) emphasised prejudices ('fore-understanding') as a condition of understanding:

> The important thing is to be aware of one's own bias, so that the text may present itself in all its newness and thus be able to assert its own truth against one's own fore-meanings. (p. 238)

He believed that this was the only way by which interpreters could understand the meanings underneath the appearance of human actions.

To raise a consciousness and develop a global view of issues around post-stroke hospital-to-home transition care, the present researcher conducted an integrative literature review and a systematic review. As a stroke rehabilitation clinician, the researcher's work experience and understanding of challenges faced by stroke dyads after hospital discharge formed 'prejudices'. Maintaining consciousness of her history (pre-understanding) and being open to the meaning of the findings, results and interview excerpts ('text') of the reviewed studies, the researcher's 'own thoughts have also gone into the re-awakening of the meaning of the text' (Gadamer, 1979, p. 350), whereby they formed a 'fusion of horizon' (the pre-understanding fused with new understanding through reflection). As Gadamer (1979) emphasised:

> in fact, the horizon of the present is being continually formed, in that we have continually to test all our prejudices … Hence the horizon of the present cannot be formed without the past. (p. 273)

As the fusion of horizon continued, the hermeneutic circle widened, and the understanding of issues under study deepened.

In Phase 2 of this study, the researcher applied the hermeneutic circle to achieve an in-depth understanding of the care needs and expectations of people with stroke and their family caregivers. Bringing the understanding established from the two reviews, the researcher was engaged in long-term follow-ups with participants through two to three interviews at different time points. Interview transcripts, observation notes and semi-structured diaries completed by participants were used in the interpretation process to generate deeper insights into participants' transition care experiences. Likewise, applied to the focus groups with health professionals, the hermeneutic circle facilitates an enriched understanding of the perceptions of health professionals on care needs during the hospital-to-home transition.

5.4.3.2 The Application of Gadamer's Hermeneutic to the Study

5.4.3.2.1 The Researcher's Prejudices and Enhancing Understanding

In Gadamer's philosophical hermeneutics, prejudices are 'a judgment that is rendered before all the elements that determine a situation have been finally examined' (Gadamer, 1979, p. 240). Prejudices are shaped by traditions and play a critical role in analysing human actions because they are 'regularly greeted with current thought' and influence individual judgements (Crotty, 1998, p. 103).

As a stroke rehabilitation clinician, the researcher oversees the discharge and admission of stroke patients. It has been observed that, despite the existence of various community rehabilitation and social care services, consumer feedback indicates a breakdown of the continuity of care after people with stroke are discharged from hospital. Stroke dyads often report uncertainty about what happens and who to contact after discharge in spite of the provision of information and stroke nurse education prior to discharge. An eagerness to establish a better understanding of the issues and a passion for service quality improvement motivated the present researcher to embark on this study. This motivation served as the researcher's prejudice to initiate the inquiry. Her clinical experience and existing knowledge helped her to identify the research problem and address problems through the development of in-depth knowledge of the experience and care needs of stroke dyads.

5.4.3.2.2 Conversation/Dialogue and Relationship-Building With Participants

One of the pivotal aspects of Gadamer's hermeneutic approach is that 'language is the middle ground in which understanding and agreement concerning the object takes place between two people' (Gadamer, 1979, pp. 346–347). In Gadamer's philosophy, the inquirer and the participants do not talk at 'cross purposes' when conducting a conversation (Gadamer, 1979, p. 330). Talking at cross purposes causes misunderstanding between the inquirer and the participants. Therefore, the use of questions and answers is essential in a conversation/dialogue: 'Questions always bring out the undetermined possibilities of a thing' (Gadamer, 1979, p. 338). Therefore, when a conversation begins, neither party knows the conversation’s trajectory or where it will finally land; understanding or a failure to understand is unplanned (Gadamer, 1979).

To achieve shared understanding, Gadamer also suggested that, to conduct a conversation, ‘it requires that one does not try to out-argue the other person, but that one really considers the weight of the other’s opinion … [It is] the art of thinking that is able to strengthen what is said by referring to the object’ (Gadamer, 1979, pp. 330–331).

Gadamer considered two issues that need to be addressed during interviews and focus groups – 1) people involved in conversations are not talking at cross purposes and 2) they remain open-minded to each other’s opinion. To ensure that the researcher and participants talk at mutual purposes, an interview guide, informed by findings of the literature and systematic reviews and the existing clinical knowledge of the researcher, was developed. Semi-structured questions in the interview guide facilitated meaningful conversation between the researcher and participants, enabled participants to elaborate on their experiences and provided the researcher with the opportunity to ask probing questions to explore participants’ experiences more deeply. In this way, the researcher’s additional questions engaged with the participants’ descriptions, resulting in open-ended meanings rather than an expected gain for either the participant or the researcher.

Furthermore, during the process of interviews and focus groups, remaining open-minded, the researcher developed mutual trust and respect with participants. This allowed participants to freely express their thoughts and elaborate on their experiences. The establishment of a reciprocal relationship with participants facilitated the generation of a shared understanding. As Gadamer (1979) stressed, ‘dialectic … is the art of thinking that is able to strengthen what is said by referring to the object’ (p. 331).

5.4.3.2.3 Conditions to Reach Fusion of Horizons in the Present Study

Gadamer claimed that understanding is always the fusion of horizon between the historical horizon and the horizon of the present (Gadamer, 1979). Gadamer encouraged the inquirer to see beyond the horizon but to be limited by it. Thus, the inquirer must stand in the ‘tradition (historical horizon)’ in which human actions are rooted and ‘bring together the horizon of present (the human actions) and the horizon of the past (the tradition)' (Gadamer, 1979). The fusion of horizons is achieved through the use of language in dialogue (Gadamer, 1979).

In Gadamer's hermeneutic circle, the inquirer's prejudices (the past) constantly fuse with new knowledge (the present), obtained through an interpretation of reviewed studies interviews with participants and the inquirer's reflection. When the pre-knowledge of the inquirer agrees with the interpretation of participants, the limited, historical prejudices die away, and a genuine understanding of the studied phenomenon emerges (Gadamer, 1979). The fusion of horizons bridges the gap between the familiar and the unfamiliar: it enables the inquirer to reach a deeper understanding of either the perspectives or participants in the conversation, or both.

In the current study, the researcher stood in the 'tradition' of the socio-political-economic context of transition care in Australia. As a clinician, and through work experience in the stroke rehabilitation field and reflection on clinical practice, she developed knowledge about the Australian healthcare system, health professionals and people with stroke. With this clinical knowledge and the findings from the integrated literature and systematic reviews, the researcher developed further insights into three-tiered factors that affected the hospital-to-home transition experience of stroke dyads. These system factors, health professional factors and individual factors of stroke dyads helped the researcher reach a historical consciousness. The established historical consciousness served as prejudices for Phase 2 of the study.

5.4.3.2.4 A Holistic Understanding of Care Needs and Expectations

Gadamer believed that understanding is constantly moving from the whole to the part and back to the whole (Gadamer, 1979). The inquirer attempts to understand 'the whole through grasping its parts and comprehending the meaning of the parts divining the whole' through the hermeneutic circle (Crotty, 1998, p. 92). Gadamer suggested that 'the harmony of all the details with the whole is the criterion of correct understanding' (Gadamer, 1979, p. 259). Understanding is formed in 'ever-widening circles', created by 'constant movement and extension’, which allow the generation of new knowledge (Crotty, 1998, pp. 102–104). Hence, new knowledge forms the prejudices for another circle of interpretation.

When applied to this study, Gadamer’s concepts highlight a holistic understanding of care needs and expectations. Stroke brings enormous challenges to people with stroke and their families, including physical deficits, mental and cognitive impairment, and social and financial difficulties. When planning for hospital discharge, their physical, psychosocial and spiritual care needs and relevant services need to be considered. Consideration should be based on an assessment of their individual circumstances.

5.4.3.3 Reasons for Choosing This Methodology

The aim of this study was to explore the care needs and expectations in hospital-to-home transition care for stroke dyads in an Australian social context. Therefore, an interpretive approach, underpinned by Gadamer’s hermeneutics, was considered the most appropriate methodology to address this study’s aim and achieve its objectives.

In Gadamer’s hermeneutic circle, understanding is achieved through dialogue between the inquirer and the participants, using a question-and-answer technique. In this process, new understanding is generated through constant movement from the whole (historical context) to the part (human actions) and back to the whole, and by the fusion of the inquirer’s prejudices (the past) and newly obtained knowledge (the present) through reflection. As the circle widens, the understanding deepens (Carpenter, 2017). Different from natural science, which focuses on parts that comprise the natural world, this attention to the whole is unique to human science: ‘To understand a text bearing upon human affairs or a culture that guides human lives, one needs to be able to move dialectically between part and whole, in the mode of the hermeneutic circle’ (Crotty, 1998, p. 92).

In this study, the human interest focused on how the needs and expectations of stroke dyads in Australia regarding transition care and rehabilitation services may be better met, within the constraints of the current clinical pathway and model of care, after discharge from hospital to home and the community. New knowledge was generated by understanding the underlying meaning of stroke dyads’ perceived enablers and inhibitors during hospital-to-home transition care and of health professionals' perspectives of approaches to identify and meet the transition care and rehabilitation needs of the consumers. This knowledge enables the development of an evidence-informed hospital-to-home transition care model and pathways to enhance consumer-directed transition care and rehabilitation services.

5.4.3.4 Limitations of Gadamer's Hermeneutics

Gadamer was criticised for his embrace of tradition (Crotty, 1998). Gadamer's hermeneutics requires the inquirer to bring in their historical awareness (tradition) to the process of interpretation. Gadamer claimed that, in the process of fusion of horizons, 'those prejudices that are of a particular and limited nature die away' (Gadamer, 1979, p. 266). In other words, when the researcher brings their own presupposition of stroke transition care, some prejudices may be 'false ones by which we misunderstand' (Gadamer, 1979, p. 266). These potentially false prejudices may affect the understanding.

Gadamer claimed that 'hermeneutics surpasses methods, because it reminds us of our practical life experience and only through this awareness might the innate power of dogmatism be overcome' (Gadamer, 1976, p. 12–13, as cited in Cuff, 2019). Gadamer concentrated on the phenomenon of understanding as an event, not a method for 'objective' interpretation (Gadamer, 1979). Therefore, Gadamer did not develop concrete methods to apply his philosophy to research (Cuff, 2019). However, in critiquing Gadamer's hermeneutics, Cuff (2019) revealed that Gadamer believed methods that are in line with the principles of his philosophic hermeneutics would help interpreters to achieve an understanding of a phenomenon of interest. The researcher of the present study planned to overcome the limitations through careful inspection and reflection on her own knowledge of transition care, especially when her horizon was significantly different from that of the participants. In addition, the interview guide served as a means to enable the development of meanings and understanding from the participants' own words.

5.5 Ethical Consideration

This study was approved by the Southern Adelaide Clinical Human Research Ethics Committee (Appendix 14) prior to commencement. Based on the requirements from the committee, permissions were obtained from the head/director(s) of division/services where recruitment took place. The participant information and consent form (PICF; Appendix 15) and participant response sheet for people with stroke, their caregivers and health professionals were developed for distribution.

The PICF included a brief introduction of this study and its objectives; the participant selection criteria and justification; the contact information of the researcher, including the researcher's non-research professional role; details on the participants' rights, including voluntary participation, the right to refuse to participate or answer particular questions, freedom to withdraw from the study without prejudice, and freedom to choose the number of interviews/focus groups to attend; what the participation entailed; and how their confidentiality and anonymity would be maintained. Written informed consent was obtained from each participant prior to the interview or focus group. The consent form clarified that interviews and focus groups would be audio-recorded and, with their permission and on the condition that their identities would remain confidential, that records may be made available to other researchers.

Throughout the research, the ethical guidelines of the National Health and Medical Research Council (2018) were strictly complied with. Participants were informed that, if emotional distress occurred due to the questions asked during the interviews, they could be referred to a psychologist if deemed necessary with their consent.

Audio records and interview transcripts were maintained securely on the cloud service OneDrive at the Flinders University College of Nursing and Health Sciences. All collected data were de-identified. The transcripts of interviews and focus groups were coded so that participants' responses were de-identified. Data were analysed collectively. To further protect their identity, participants were assured that pseudonyms would be used in this thesis and all relevant publications.

5.6 Methods

This section details the study's settings, participant recruitment, data collection and analysis. The rigour of the study is discussed at the end.

5.6.1 Setting and Participant Recruitment

The study was conducted at a stroke rehabilitation ward and at the ambulatory rehabilitation service in a tertiary metropolitan public hospital in Adelaide. Stroke dyads were recruited through the stroke rehabilitation ward. Health professional participants were recruited from the stroke rehabilitation ward and the ambulatory rehabilitation service of the hospital.

5.6.1.1 Criteria for Inclusion

Setting selection criteria facilitates the identification of participants who have experienced the studied phenomenon and are able to share rich information in the area of study (Polit & Beck, 2017). Based on the aim of this study, and informed by the literature review and systematic review, inclusion criteria were developed and are listed in Table 5.1.

Table 5.1

Inclusion Criteria

Inclusion criteria	Rationale
Criteria for people with stroke	
Clinical diagnosis of stroke.	Stroke is the focus of this study.
Discharged from hospital to home, not to a facility or supported accommodation.	Hospital-to-home transition care is the scope of this study.
Discharged with further rehabilitation and community care services.	This group of people with stroke is the focus of the study.

Inclusion criteria	Rationale
MoCA: scored 20 or above. FIM: scored 4 or above in each item except Expression and Comprehension, which need to be scored 5 or above.	Including people with stroke with mild cognitive or speech impairment helps the researchers to understand the care needs of this group.
Have sufficient language and cognition to consent.	Informed consent is important for participation.
Able to communicate verbally in English before stroke.	English is the language used in this study.
Criteria for informal caregivers	
Principle informal caregivers who have daily contact with people with stroke.	Only informal caregivers who have daily contact with people with stroke are able to provide rich information.
Aged 18 or above.	A person aged 18 or above is considered an adult (ABS, 2013). Adults are the focus of the study.
Having no cognitive impairment or aphasia.	These impairments make an interview impossible.
Able to communicate in English.	English is the main language used in this study.
Criteria for health professionals	
Staff members of stroke or rehabilitation care team, not students.	Only those involved in stroke care are able to share thoughts on stroke transition care.
GPs	Inputs from GPs will enrich the understanding of stroke transition care.

Inclusion criteria	Rationale
Aged 18 and above.	A person aged 18 or above is considered an adult (ABS, 2013).
Able to communicate in English.	English is the main language used in this study.

Note. MoCa = Montreal Cognitive Assessment; FIM = Functional Independence Measure; ABS = Australian Bureau of Statistics; GP = general practitioner.

5.6.1.2 Identification and Recruitment of Potential Participants

For stroke dyad participants, potential participants were identified by ward clinicians based on the inclusion criteria. The researcher, who was the nurse unit manager of the ward but did not have a direct care relationship with the patients, approached potential participants with the recruitment poster (Appendix 16) to ascertain their intention to participate. After obtaining their intention, a research assistant (hired by the researcher and external to the ward) made an appointment and met with potential participants. This was to ensure a separation from clinical practice so that potential participants did not feel coerced to participate in the study. For people with stroke who had a caregiver, the appointment was made to meet with both. During the meeting, the research assistant provided an information pack including the PICF (Appendix 15), explained the details of the research project (including their rights to withdraw) and answered questions.

For stroke health professionals, the flyer and information pack (containing a PICF and participant response sheet) was made available in staff tea rooms and offices. Potential participants expressed their intention via email, text or phone call to the researcher. For general practitioners (GPs), information packs were posted to all GP clinics in the Southern Adelaide Region. Potential participants expressed their intention via email, text or phone call to the researcher. Upon receiving their expression of interest, the researcher screened for eligibility of participation. The researcher remained available if potential participants required further information. In this case, the researcher made appointments with the potential participants at a venue of the potential participant’s choice to explain relevant details.

5.6.1.3 Consent

For people with stroke, upon receiving instruction from the researcher, the research assistant obtained consent after a detailed explanation of the research project and an assessment of eligibility for inclusion based on cognitive assessment.

The cognitive assessment was conducted using the Montreal Cognitive Assessment (MoCA) tool (Nasreddine et al., 2005). MoCA is a widely used cognitive assessment tool to screen for mild cognitive impairment (Appendix 17). MoCA scoring is as follows: (1) 26 and above = normal cognition; (2) 25–20 = mild cognitive impairment; (3) below 20 = moderate to severe cognitive impairment (Webb et al. 2014). Participants meeting the inclusion criteria then consented to participate in the study.

In this study, speech difficulty was determined by the Functional Independence Measure (FIM; Uniform Data System for Medical Rehabilitation, 2012). The FIM is an 18-item measurement tool that explores an individual’s physical, psychological and social function (Appendix 18).

Based on the ward clinicians’ recommendation, a simplified PICF (Appendix 19) was developed and used for potential participants who required simplified text and pictures to aid understanding. The non-simplified PICF was used for all other potential participants.

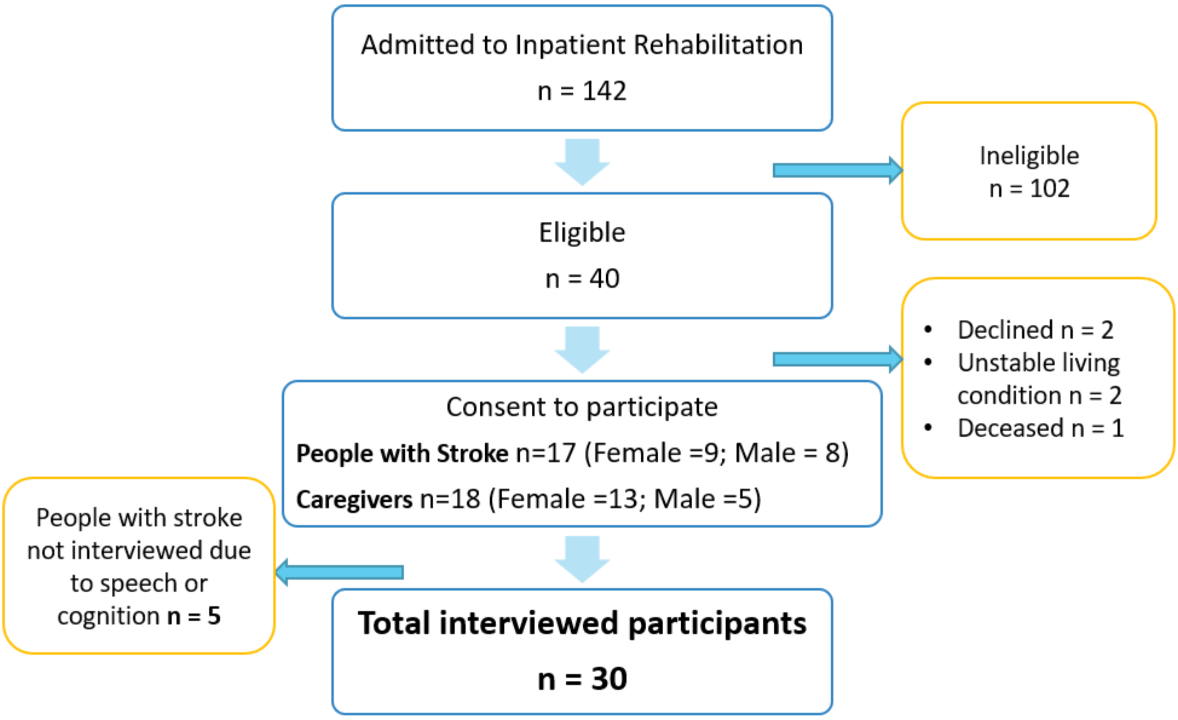
For people with stroke who had caregivers, consent was obtained from both. This was to ensure that the person with stroke was not recruited against their caregiver’s wishes. For caregivers, the research assistant obtained consent upon receiving confirmation of their intent to participate. For health professionals, the researcher obtained consent upon receiving confirmation of their intention to participate.

5.6.1.4 Sample Size

According to Creswell (2013), the sample size for phenomenological studies is 5–25. The sample size usually depends on the scope of the study questions and the sensitivity of the studied phenomenon, and the initial sample size is only an estimate rather than a fixed number (Carpenter, 2017). For qualitative studies, the richness of information supersedes the number of participants (Carpenter, 2017). It was planned for this study to recruit 15 stroke dyads (dyads comprising a person with stroke and their caregiver) for interviews. The recruitment process is illustrated in Figure 5.1. In total, 30 participants were recruited to this study: 12 dyads and six caregivers.

Figure 5.1

Recruitment Flowchart



The sample size for focus groups is dependent on the research topic and the social context of participants. Focus groups normally consist of 5–15 participants. Ideally, focus groups should include members that share similar characteristics—for example, members from the same professional group (Davidson et al., 2017). In this study, focus groups comprised health professionals from different disciplines involved in stroke care. This was because of the interprofessional approach to acute stroke and post-stroke rehabilitation. Focus groups that include multidisciplinary members help to develop a coherent as well as diverse insight into the care needs of stroke dyads during the hospital-to-home transition.

A few studies selected for the literature review (Chapter 2) included allied health team members and community service providers. These health professionals provided valuable information and their perspectives on stroke hospital-to-home transition care. However, only one study included a medical officer. In this study, health professionals included stroke care team members such as medical officers, nurses, physiotherapists, occupational therapists, speech pathologists, dietitians and social workers. Efforts were made to include medical officers due to the scarcity of data from them in the reviewed studies. Additionally, community service providers, especially GPs as the primary health practitioner in the community, have more encounters with stroke dyads after discharge. Their input may enhance the understanding of challenges regarding the continuity of transition care.

Purposive sampling was the main strategy for recruiting participants. This sampling strategy facilitates the selection of participants that benefit the study the most (Polit & Beck, 2017). Under the condition that inclusion criteria were met, snowball sampling was also used to complement the purposive sampling strategy, especially with the recruitment of health professionals. With the combination of these strategies, the planned sample size was achieved within the time constraints of the PhD program.

5.6.2 Data Collection

According to Gadamer's (1979) philosophical hermeneutics, language and dialogue are essential components for developing understanding. Thus, in-depth interviews, using a semi-structured interview guide, were used to collect data from stroke dyads.

In-depth interviewing is a well-developed method of data collection that enables researchers and participants to work together to develop an understanding of the studied phenomenon (Serry & Liamputtong, 2017). Semi-structured interviews were used as the interview framework. The interview guide (Appendix 20) provided directions for the interview but allowed some freedom for participants to express their thoughts. Compared to an informal conversational interview, where spontaneity is encouraged, and a standardised open-ended interview, which pursues asking similar questions, the semi-structured interview provided a balance that allowed some space for spontaneous thoughts and expressions in a guided condition (Serry & Liamputtong, 2017).

Face-to-face interviews were the main interviewing approach. For participants who were unable to attend face-to-face interviews, especially due to COVID-19 restrictions, telephone interviews were conducted. The limitation of telephone interviews is the lack of visual contact between interviewer and interviewee. However, collected data can still add value to a face-to-face interview data pool. Bakas et al. (2002) used telephone interviews to establish insights into the needs and concerns of stroke caregivers in the first 6 months following discharge.

People with stroke and their caregivers were interviewed separately. Family dynamics and the dyadic relationship may have become barriers for the researcher to obtain truthful information. However, if they requested to be interviewed together, their request was respected. The interview location was the participant's choice. The length of each interview was between 30 and 45 minutes. The researcher's observations and field notes were maintained to supplement interviews. The Research Assistant was only involved in the consenting with stroke dyads during the recruitment process.

A structured diary with instructions (Appendix 21) was developed for participants to take home to record activities, experiences and thoughts during the follow-up period. The diary contains a list of questions about participants' experiences/thoughts on significant events relating to their coping with post-stroke limitations, with caregiving activities and daily living activities, and how they manage other health conditions. Participants were also encouraged to record the challenges they experience when using care services. Diary entries were voluntary. The content was reviewed at the follow-up interviews. This information complemented the interview data and generated in-depth knowledge.

Transition is a continuum process, and the care needs of stroke dyads change over time. Informed by the findings of the systematic review, participants in this study were followed up from 1 month up to 6 months following discharge. Interviews were conducted at three time points—within 5 days prior to discharge and at 2–3 months and 5–6 months following discharge. The intervals allowed them to settle and progress. Participants attended 2–3 interviews at their choice.

The collection of data from health professionals was through focus groups as a first preference and one-on-one interviews if they were unable to attend focus groups. Focus groups, as a data collection method, have been widely used in the healthcare field. It is used to explore experiences, knowledge and beliefs. Focus groups enable synergy within the group and provide a collective perspective on the studied topic (Davidson et al., 2017). It can be challenging to control the dynamics of the group and monitor verbal and non-verbal responses due to the number of participants. However, careful planning and appraisal of risks in advance can minimise these challenges (Davidson et al., 2017).

In this study, it was planned to conduct 3–5 focus groups with 15–25 health professionals. The number of focus groups depends on data saturation (i.e., when no new data is being produced from subsequent groups: Davidson et al., 2017). The inclusion of multidisciplinary team members in the same focus groups may not cause heterogeneity in power relationships and social classes because all team members are working with the same goal: to ensure quality care to people with stroke. Each discipline works independently as well as collaboratively with others. So, there may not be heterogeneity in power relationships or social class within the group. Multidisciplinary participation enhances the richness of perceptions.

There have been debates on phenomenological focus groups. C. Webb and Kevern (2001) criticised the application of focus groups in phenomenological studies. They suggested that focus groups and phenomenology are methodologically incompatible in that phenomenological research pursues the essence of a phenomenon, which is achieved through an individual’s description of their lived experiences in an uncontaminated way, but focus groups, involving interactions between group members, disintegrate the totality of an individual’s lived experience that forms the foundation of phenomenological studies (B. Webb, 2002; C. Webb & Kevern, 2001).

Despite this criticism, focus groups have been used extensively as a method to collect and analyse data in phenomenological studies (Holm & Dreyer, 2018; Love et al., 2020; Robertson et al., 2019). In their research methodology discussion paper, Bradbury-

Jones et al. (2009) critiqued Webb's views from their own perspectives as researchers and that of other scholars (B. Webb, 2002). They argued that focus groups support the concept of collaboration and dialogue in phenomenological emphasis. The individual's perspectives can be preserved by allowing the individual to share their narratives with limited interruptions first, followed by other members of the group adding their insights and views to stimulate reflection and enrich the understanding of a phenomenon (Bradbury-Jones et al., 2009). They concluded that, instead of causing methodological tension, small and well-mediated focus groups complement phenomenological endeavours and that the collaboration within groups enhances the development of new insights (Bradbury-Jones et al., 2009; Nielsen et al., 2020).

A total of four focus groups for 11 stroke clinicians were conducted, with three participants in each group on average. Focus groups were facilitated by the researcher in the meeting room at the participants' workplace and lasted for 60–90 minutes. Each participant was given the opportunity to share their individual views, and this was followed by reflection and group discussions.

Other stroke clinicians (*n* = 18) had in-depth interviews due to their inability to attend focus groups. Each interview lasted 30–45 minutes. GP participants (*n* = 2) were interviewed individually in their consulting rooms.

5.6.3 Data Analysis

Data analysis is aimed at organising data and producing meaning from data (Polit & Beck, 2017). Data analysis in this study was concurrent with data collection. It was a cyclical process that allowed analysed data to inform and guide upcoming data collection so as to address issues that arose during the initial data analysis (Liamputtong & Serry, 2017).

5.6.3.1 Data Analysis Model

A three-step interactive model of data analysis was used in this study. This model included data reduction, data display and conclusion (Liamputtong & Serry, 2017).

As a crucial first step of data analysis, data reduction paves the way for deeper analysis. Audio-recorded interviews and focus groups were listened to repeatedly. Raw data from interviews and focus groups were transcribed verbatim. The preliminary analytical phase commenced at this stage, with the transcribed data transforming into initial codes, summaries and introductory themes. These initial analytic activities can be modified later as analysis further grows (Liamputtong & Serry, 2017). The transcripts were coded line by line to prepare for analytical coding—namely, focused coding (synthesis of codes), interpretive coding (categorising codes) and selective coding (identifying core themes)—as analysis deepened. This coding process allows data to be reduced and facilitates the formulation of propositions. (Liamputtong & Serry, 2017).

As the analysis continued, data display occurred because data were transformed into codes, mind maps or graphs. Conclusions were drawn from the transformed data as patterns or themes emerged. At this stage, the researcher remained open-minded and continued to draw on the analysis of upcoming collected data until enough evidence arose to verify the conclusions (Liamputtong & Serry, 2017). In the process of data analysis, a fusion of horizon occurred between the prejudice of the researcher and participants, which is in line with Gadamer's hermeneutical circle.

5.6.3.2 Data Analysis Based on Gadamerian Principles

Gadamerian philosophical hermeneutics guided a systematic approach to interpretation but did not offer specific data analysis methods (Gadamer, 1979). Inspired by a group of researchers who explored data analysis methods based on Gadamerian principles (Alsaigh & Coyne, 2019; Fleming et al., 2003), this study adapted their methods, involving five interconnected and cyclic steps to enhance interpretation and understanding. The five steps were 1) immersion in raw data; 2) understanding through line-by-line coding; 3) abstraction to identify subthemes by grouping open codes into clusters; 4) synthesis and theme development, involving a continuous moving back and forth between earlier analyses, text and literature, and across datasets to identify similarities and differences. In the process, themes were informed by, and in turn, enriched the researcher's pre-knowledge; and 5) the illumination and illustration of phenomena resulting in a reconstruction of participants' stories in their own words through linking themes and subthemes with the literature (Alsaigh &

Coyne, 2019; Fleming et al., 2003). The data analysis was closely linked to the aim and objectives of the study during the whole process. The qualitative data analysis software NVivo 12 was used to assist in coding, organising data and developing mind maps.

5.6.4 Rigour

The rigour of a qualitative study concerns the trustworthiness of the quality of its findings. The criteria established by Lincoln and Guba (1985) were used to ensure the rigour of this study. Credibility (confidence in the truth of the data) was enhanced by audio-recording and verbatim transcription of interviews and focus groups; cross-checking participants' statements and opinions during and after the study; debriefing and discussion with other research team members; and reflexivity, involving self-reflection and introspection about personal bias and every decision made (Morse, 2018; Polit & Beck, 2017).

Strategies—including maintaining a decision tree for future reference, using participants' own words to support themes and extensive discussion among the research team—were used to ensure the dependability (stability of data over time) and confirmability (originality of findings derived from participants) of data (Morse, 2018).

Qualitative studies are context-based, so findings may not be generalisable. However, they may be transferred to a similar social context. Transferability of the findings can be enhanced by citation of existing confirming research evidence from other studies to verify the interpretations and conclusions. When producing a report, the original excerpts of participants were used to enhance the understanding of readers (Morse, 2018). A reflexive journal was maintained throughout the research process to ensure the overall trustworthiness of this study. The researcher self-consciously critiqued, appraised, and evaluated how her subjectivity and context influence the research process.

5.7 Summary

The chapter has discussed Gadamer's philosophical hermeneutics as underpinning this study. Ethical considerations, methodology and methods were also described. The next chapter presents Part 1 of findings of the qualitative study on the perspectives of stroke dyads.

Chapter 6: Findings—Part 1: Outline of Findings, and Findings From the First Interviews With Stroke Dyads

6.1 Introduction

The previous chapter presented the constructivist paradigm used in the project; Gadamer's philosophical hermeneutics, which informed the methodology of this study; ethical considerations; and the methods used in the study.

This chapter, along with Chapters 7–9, presents the findings of the qualitative study of stroke dyads (Chapters 6–8) and health professionals (Chapter 9). This chapter outlines the characteristics of the participants and the themes and subthemes generated from interviews and focus groups with stroke dyads and health professionals. It presents the findings from interviews with stroke dyads within 5 days before discharge or within 2 weeks after discharge. Chapters 7 and 8 report the findings from follow-up interviews and structured diaries at 3 and 6 months after discharge for stroke dyads. Chapter 9 presents the findings from focus groups and interviews with stroke care health professionals.

6.2 Characteristics of Participants

In total, 35 stroke dyads consented to participate in the study. Interviews were conducted with 12 people with stroke and 18 caregivers; five people with stroke were unable to participate in the interviews due to cognitive and/or speech impairments. Equal numbers of male (*n* = 8) and female (*n* = 9) stroke participants were included in this study. Their ages ranged from 55 to 96 years (*M* = 74.9). Of the 17 people with stroke, 14 suffered from ischaemic stroke, and 16 had comorbidities or chronic conditions. Most of the caregivers were women (*n* = 13), and their ages ranged from 48 to 89 years (*M* = 61.5). Caregivers were spouses or ex-spouses (*n* = 11), siblings (*n* = 1) or children (*n* = 7) of the person with stroke. Of the 18 caregivers, 14 of them were co-living with the person with stroke. Table 6.1 outlines the characteristics of the stroke and caregiver participants.

In total, 31 health professionals participated in this study: rehabilitation allied health staff (*n* = 16), registered nurses (*n* = 6), service managers (*n* = 4), doctors (*n* = 3) and GPs (*n* = 2). Of the 31 health professional participants, 27 were women, and four were men, with years in profession ranging from 5 to 39 years (*M* = 13.8). The demographic information of these participants is presented in Table 6.2.

6.3 Outline of Themes and Subthemes

Seven major themes and 16 subthemes (Table 6.3) were identified in interviews with stroke dyads before hospital discharge and at 3 and 6 months after discharge from hospital. These themes represented the shared experiences of people with stroke and their caregivers during the first 6 months after discharge.

The three major themes identified from before hospital discharge revealed that similarities and differences existed between people with stroke and their caregivers in terms of their preparedness to manage post-discharge care. Stroke dyads demonstrated resilience, which was built on the same foundations, such as their positive thoughts and having the support of family and health professionals. However, they also showed psychological stress that was triggered by different factors: for example, loss of function in people with stroke and a lack of confidence from caregivers about providing home care. The findings also indicated stroke dyads’ inconsistent involvement in discharge planning, which contributed to the differences in perceived certainty about post-discharge care between people with stroke and their caregivers.

Table 6.1

Characteristics of Stroke and Caregiver Participants

Stroke patient participants									
Code	**Gender (M = 8; F = 9)**	**Age (years; *M* = 74.9)**	**Type of stroke**	**Rehabilitation length of stay (days: *M* = 28)**	**FIM score*****	**MoCA score**	**Comorbidity/chronic conditions**	**Number of interviews**	**Number of diary entries**
SS01*	M	75	Left ischaemic	23	4/4	—	Ischaemic heart disease, knee surgery	0	0
SS02	F	96	Left ischaemic	16	6/6	20/30	Hypertension, atrial fibrillation	3	7
SS03	M	64	Bilateral ischaemic	14	7/7	30/30	Ischaemic heart disease,	2	0

Stroke patient participants									
Code	**Gender (M = 8; F = 9)**	**Age (years; *M* = 74.9)**	**Type of stroke**	**Rehabilitation length of stay (days: *M* = 28)**	**FIM score*****	**MoCA score**	**Comorbidity /chronic conditions**	**Number of interviews**	**Number of diary entries**
							diabetes, cancer		
SS04	M	65	Left ischaemic	13	6/6	20/30	Renal failure on dialysis	3	0
SS05*	M	55	Bilateral ischaemic	55	1/1	—	Atrial fibrillation	0	0
SS06*	F	66	Left haemorrhagic	66	3/1	—	Stroke, hypertension, Type 2 diabetes	0	0
SS07	M	97	Left ischaemic	14	7/6	24/30	Hypertension, stroke, falls,	3	0

Stroke patient participants

Code	Gender (M = 8; F = 9)	Age (years; *M* = 74.9)	Type of stroke	Rehabilitation length of stay (days: *M* = 28)	FIM score***	MoCA score	Comorbidity /chronic conditions	Number of interviews	Number of diary entries
							Ischaemic heart disease		
SS08*	M	68	Left ischaemic	14	1/1	-	Hypertension, asthma	0	0
SS09	F	61	Left ischaemic	29	7/7	25/30	Atrial fibrillation, rheumatoid arthritis	3	4
SS10	F	77	Left ischaemic	48	7/7	24/28	Atrial fibrillation,	3	5

Stroke patient participants									
Code	**Gender (M = 8; F = 9)**	**Age (years; *M* = 74.9)**	**Type of stroke**	**Rehabilitation length of stay (days: *M* = 28)**	**FIM score*** **	**MoCA score**	**Comorbidity /chronic conditions**	**Number of interviews**	**Number of diary entries**
							stroke, cancer		
SS11	M	82	Right ischaemic	11	7/7	21/30	Nil	3	5
SS12	F	72	Left ischaemic	10	7/7	26/30	Cancer	3	0
SS13	F	83	Left ischaemic	11	7/7	24/30	Hypertension, depression	3	4
SS14*	F	91	Right ischaemic	62	4/4	—	Falls, peripheral vascular disease	0	0

Stroke patient participants									
Code	**Gender (M = 8; F = 9)**	**Age (years; *M* = 74.9)**	**Type of stroke**	**Rehabilitation length of stay (days: *M* = 28)**	**FIM score*****	**MoCA score**	**Comorbidity /chronic conditions**	**Number of interviews**	**Number of diary entries**
SS15	F	71	Left haemorrhagic	30	7/7	30/30	Hypertension, cancer, ischaemic heart disease	3	0
SS16	F	81	Left ischaemic	19	6/6	25/30	Hypertension, atrial fibrillation	3	0
SS17	M	70	Bilateral ischaemic	44	7/7	24/30	Hypertension, cancer	3	0

Stroke caregiver participants						
Code	**Gender (M = 5; F = 13)**	**Age (years; *M* = 61.5)**	**Relationship**	**Co-living**	**Number of interviews**	**Number of diary entries**
SC01	F	72	Spouse	Yes	3	0
SC02	F	65	Daughter	Yes	3	0
SC03	F	62	Spouse	Yes	3	8
SC04	F	61	Spouse	Yes	2	0
SC05	F	48	Spouse	Yes	3	0
SC06	M	68	Spouse	Yes	3	0
SC07	F	61	Daughter	No	3	0
SC08	F	64	Spouse	Yes	3	1
SC09	M	63	Brother	Yes	3	4
SC10	M	89	Spouse	Yes	3	0
SC11	F	79	Spouse	Yes	3	6
SC12	M	75	Ex-spouse	Yes	2	0
SC13	F	57	Daughter	No	3	0
SC14**	F	62	Daughter	Yes	2	0

Stroke caregiver participants						
Code	**Gender (M = 5; F = 13)**	**Age (years; *M* = 61.5)**	**Relationship**	**Co-living**	**Number of interviews**	**Number of diary entries**
SC15**	F	65	Daughter	No	2	0
SC16	M	68	Spouse	Yes	3	0
SC17	F	48	Daughter	No	3	0
SC18	F	63	Spouse	Yes	3	0

Note. M = male; F = female; SS = stroke patient; SC = stroke caregiver. MoCA = Montreal Cognitive Assessment (Nasreddine et al., 2005); FIM = Functional Independence Measure (Expression/Comprehension; Uniform Data System for Medical Rehabilitation, 2012).
* Stroke patients who were not interviewed.
**Caregiver caring for SS14. SS14 had two caregivers with one co-living providing domestic care support and the other coordinating services.
*** FIM Score Expression/Comprehension.

Table 6.2

Characteristics of Health Professional Participants

Participant group	Code	Qualification	Years in profession (*M* = 13.8)	Gender	Age range (years)
Registered nurse	NS03	Bachelor	14	Female	31–40
	NS04	Bachelor	12	Female	31–40
Allied health staff*	AH01	Bachelor	7	Female	21–30
	AH02	Bachelor	6	Female	21–30
	AH03	Bachelor	15	Male	31–40
	AH04	Bachelor	6	Female	21–30
	AH05	Bachelor	5	Female	21–30
	AH06	Master	15	Male	31–40
	AH07	Bachelor	25	Female	41–50
	AH08	Bachelor	20	Female	41–50
	AH09	Bachelor	22	Female	41–50
	DOC01	Bachelor	14	Female	31–40
Medical officer	DOC02	Bachelor	5	Female	31–40

Participant group	**Code**	**Qualification**	**Years in profession (*M* = 13.8)**	**Gender**	**Age range (years)**
	DOC03	Bachelor	9	Female	31–40
Service manager	MG01	Bachelor	16	Female	31–40
	MG02	Bachelor	20	Female	41–50
	MG03	Bachelor	15	Female	31–40
	MG04	Bachelor	28	Female	41–50
General practitioners	GP01	Bachelor	39	Male	61–70
	GP02	Bachelor	27	Male	41–50
FG01**	AH10	Bachelor	12	Female	31–40
	AH11	Bachelor	8	Female	31–40
	AH12	Bachelor	15	Female	31–40
	AH13	Bachelor	6	Female	31–40
FG02**	AH14	Bachelor	5	Female	21–30
	AH15	Bachelor	5	Female	31–40
	AH16	Bachelor	9	Female	31–40
FG03	NS01	Bachelor	20	Female	61–70

Participant group	Code	Qualification	Years in profession (M = 13.8)	Gender	Age range (years)
FG04	NS02	Bachelor	5	Female	21–30
	NS05	Bachelor	8	Female	31–40
	NS06	Bachelor	15	Female	31–40

Note. NS = registered nurse; AH = allied health; DOC = medical officer; MG = manager; GP = general practitioner; FG = focus group.

*Allied Health Staff included in interviews: Occupational therapist n=3; Physiotherapist n=2; Speech Pathologist n=2; Social Worker n=2;

**Allied Health Staff included in focus groups: Physiotherapist n=3; Speech Pathologist n=2; Pharmacist n=1; Dietitian n=1.

Major themes identified at the 3- and 6-month follow-ups after discharge indicated that people with stroke experienced setbacks in functional recovery that triggered their psychological stress, which also caused psychological stress in their caregivers. Stroke dyads continued to demonstrate resilience and coping strategies that enabled them to reconcile with their pre-stroke lives. Additionally, stroke dyads gradually developed self-management strategies through collaboration between dyadic members. The dyadic effects in dealing with challenges enabled them to transform and adapt to their post-stroke lives. Moreover, stroke dyads acknowledged the crucial role of family and friends during the hospital-to-home transition, particularly the substantial support that people with stroke received from their caregivers. Mutual support between dyadic members enhanced their transition experience.

Stroke dyads also recognised professional services as essential in supporting their transitioning home. They considered that professional support focusing on both dyadic members enabled functional improvement and psychosocial recovery during the transition. Furthermore, stroke dyads reflected on the implications of engaging both dyad members, especially caregivers, in discharge planning before returning home. They also perceived that continuity of care could be enhanced through flexible service delivery in the community to better support their transition.

Table 6.3

Major Themes and Subthemes—Perspectives From Stroke Dyads

Theme	Subtheme	Chapter presenting the findings
1. Psychological stress	**1.** 'I am looking forward to going home but feeling anxious'	Chapter 6
	2. 'Not knowing what the future holds'	
2. Resilience	**1.** 'I've come from zero to hero'	Chapter 6

Theme	Subtheme	Chapter presenting the findings
	2. ‘I look at this as a change in the road for life’	
3. Certainty and uncertainty about post-discharge care	**1.** ‘They boost you up’	Chapter 6
	2. ‘We don’t know what’s going to happen’	
4. Coping with setbacks	**1.** Processing loss and grief in people with stroke	Chapter 7
	2. Processing loss and grief in caregivers	
	3. Reconciling with resilience	
5. Role transformation	**1.** Impact of stroke-related limitations on people with stroke	Chapter 7
	2. Impact of stroke-related limitations on caregivers	
	3. Regaining control of life	
6. Transitioning with support	**1.** Support from family and friends	Chapter 8
	2. Support from health professionals	
7. Expectations in hospital-to-home transition care	**1.** Enhanced discharge planning and preparation	Chapter 8
	2. Flexibility of service provision	
	3. ‘Working towards a common goal’	

The three main themes identified from the focus groups and from interviews with health professionals (Table 6.4) revealed inadequate assessment of psychological needs for stroke dyads. The care needs assessment was largely focused on the functional needs of people with stroke, such as personal care skills and cognitive functions; a formal assessment of caregivers' care needs was lacking. Furthermore, care service delivery was constrained by the limited length of hospital stays due to bed pressures and the funding model of services. This may inhibit a dyad-centred approach to service delivery and increase stress for health professionals. However, despite these constraints, health professionals strived for excellence through their commitment to safety and quality care. Their determination and flexibility in service provision seemed to enhance the hospital-to-home transition for stroke dyads.

Table 6.4

Major Themes and Subthemes—Perspectives From Health Professionals

Theme	**Subtheme**	**Chapter presenting the findings**
1. Transition shaped by care needs assessment	**1.** 'Psychological/mental health is underplayed'	Chapter 9
	2. 'Our focus is on the patient'	
2. Transition challenged by constraints on service delivery	**1.** 'Bed pressures certainly impacts'	Chapter 9
	2. 'We're dictated by funding models'	
3. Transition enhanced by commitment to the safety of care	**1.** 'Empowering them to making decisions'	Chapter 9
	2. 'Working towards a common goal'	

6.4 Findings—Before Hospital Discharge

From the next section onwards, findings (major themes and subthemes) identified in the interviews with stroke dyads before hospital discharge are presented. These findings have been published in a peer-reviewed journal. Therefore, the presentation of findings is in a published manuscript format, as detailed in the following sections.

This section presents a publication arising from this thesis that was published in the *Journal of Advanced Nursing*.

Citation: Chen, L., Xiao, L. D., & Chamberlain, D. (2022). Exploring the shared experiences of people with stroke and caregivers in preparedness to manage post-discharge care: A hermeneutic study. *Journal of Advanced Nursing*, *78*(9), 2983–2999. https://doi.org/10.1111/jan.15275

6.5 Exploring the Shared Experiences of People With Stroke and Caregivers in Preparedness to Manage Post-Discharge Care: A Hermeneutic Study

6.5.1 Abstract

Aims and objectives: To explore the shared experiences of people with stroke and caregivers in preparedness to manage post-discharge care.

Background: People with stroke and caregivers show dyadic effects in dealing with post-discharge care challenges. However, few studies have explored their shared experiences and unique challenges for each dyadic member in preparedness to manage post-discharge care. This study addresses this research gap.

Design: An interpretive approach underpinned by Gadamer's philosophical hermeneutics.

Methods: Semi-structured interviews were conducted with people with stroke and caregivers within five days before hospital discharge (n=26) or two weeks after discharge (n=4) between July and December 2019. The study followed a five-step data analysis method aligning with Gadamerian hermeneutics. The study reporting followed the COREQ checklist.

Results: Three themes and six subthemes were identified. First, both people with stroke and caregivers experienced psychological stress, although the sources differed. Second, stroke dyads demonstrated resilience built on positive thoughts, confidence and support from family and health professionals. Third, stroke dyads exhibited different levels of certainty about post-discharge care. They desired to be equal partners in co-developing and co-implementing discharge plans.

Conclusions: Similarities and differences in perceived preparedness to manage post-discharge care existed between stroke dyadic members. A co-design approach to developing and implementing discharge plans would enhance planned post-discharge care.

Impact: Hospital to home transition is a challenging time for people with stroke and their caregivers. Understanding the shared experiences of stroke dyads in preparedness for post-discharge care enables nurses to take proactive actions to enhance managing post-discharge care. Early identification of those at risk of developing psychological stress will enable nurses to co-develop stress-coping strategies. These will have a positive influence on the dyad when facing setbacks due to stroke-related complications.

Keywords: Caregiver, discharge planning, people with stroke, dyads, qualitative research, nurse, stroke, transition care

6.5.2 Introduction

Globally, over 13 million new stroke cases occur per annum (World Stroke Organization, n.d.). With advances in stroke management, morbidity and mortality have steadily reduced, resulting in more people with stroke returning home after hospitalisation (Olson & Juengst, 2019). After discharge, they and their caregivers must take over complex care that in hospital was usually provided or coordinated by nurses. However, most are ill-prepared with insufficient knowledge and skills to effectively manage stroke-related health issues, underlying chronic diseases and engage in poststroke rehabilitation (Camicia, Lutz, Harvath & Joseph, 2021; L. Chen et al., 2021). This situation is further compounded by shortened hospital stays that challenge nurses, who usually lead the multidisciplinary team implementing discharge plans, to prepare this patient population to take over complex care within a short window of opportunity (Camicia, Lutz, Harvath & Joseph, 2021; Mountain et al., 2020). The readmission rate of people with stroke can be as high as 43% within 12 months after discharge, and most readmissions can be prevented through carefully designed discharge plans (Kilkenny et al., 2020; Sennfält & Ullberg, 2020).

Most people with stroke have functional and self-care impairments due to hemiplegia or other disabilities (C. O. Johnson et al., 2019). Therefore, they heavily rely on family caregivers to care for them post-discharge (Camicia, Lutz, Harvath & Joseph, 2021; L. Chen et al., 2020). A study by Chung et al. (2016) revealed that an interdependent relationship existed in stroke patient-caregiver dyads in which one member’s strengths in coping with poststroke health issues, for example poststroke depression, can influence the other dyad member. The dyadic effect was also reported in a systematic review and meta-analysis which found that psychoeducation interventions targeting both members can significantly improve functional independence of people with stroke and simultaneously reduce caregivers' burden in the immediate term or within one month after discharge (Mou et al., 2021). Research evidence suggests that stroke patient-caregiver dyad-centred discharge plans should be routinely developed in clinical settings to enable nurses to detect dyad strengths and promote a strength-based dyadic approach to managing poststroke care (Mou et al., 2021, Pucciarelli et al., 2021). However, few studies examined shared experiences of the dyads in preparedness to manage post-discharge care. This study addresses the gap by exploring the similarities and differences in perceived preparedness to manage post-discharge care for people with stroke and their caregivers. Findings will enable nurses and other stakeholders to identify unique challenges to each dyadic member and foster discharge plans that support them as a dyad.

6.5.3 Background

Preparedness for discharge refers to the state of being ready or willing to take over care from health providers in people with stroke and their caregivers (Camicia, Lutz, Harvath & Joseph, 2021). Patients' and caregivers' perceived preparedness for discharge is the aim of discharge planning. Discharge planning is a core component of safety and quality standards in healthcare and is best built on partnerships with patients and their caregivers to prepare them to take charge of care after discharge (Australian Commission on Safety and Quality in Health Care [ACSQHC], 2019), (Mountain et al., 2020). However, studies revealed poor discharge planning inhibited people with stroke and caregivers from preparing themselves with adequate self-management capabilities to take over hospital to home transitional care (Camicia et al., 2020; L. Chen et al., 2020). Building the required skills for people with stroke and caregivers to provide ADLs and prevent stroke-related complications (e.g., falls and pneumonia) takes time and requires hands-on practice with nurses prior to discharge (Green et al., 2021). In addition, stroke is associated with chronic health conditions, and both people with stroke and caregivers need to develop capabilities in chronic disease management, lifestyle modification, problem-solving skills, and utilisation of health care resources to manage other chronic conditions and cope with stress (Frantz et al., 2021). Patient-centred discharge planning is suggested in the hospital care standards (ACSQHC, 2019). This patient-centred approach may overlook interdependent relationships between people with stroke and caregivers (Chung et al., 2016, Mou et al., 2021); and may impede nurses from taking proactive actions to assess the strengths of people with stroke, encouraging active participation in self-care and supporting caregivers.

Studies revealed that people with stroke do not have a full understanding of the impact of stroke. Information about post-discharge services was not communicated to them at hospital discharge (L. Chen et al., 2020). Young people with stroke encountered challenges sourcing post-discharge age-appropriate support (Hersh & Armstrong, 2021; Stokman-Meiland et al., 2022). Shortened hospital stays added more challenges for nurses and multidisciplinary teams to assess and address these issues during discharge planning. Incorporating stroke patient-caregiver dyad in discharge planning that considers the dyadic effects may help nurses identify innovative solutions to address these challenges. Any solutions should be built on nurses' careful analysis of unique challenges each member face within a dyad regarding post-discharge stroke care.

Studies revealed that stroke caregivers faced enormous uncertainties about their roles and responsibilities in poststroke care (Camicia, Lutz, Harvath & Joseph, 2021; L. Chen et al., 2021). Caregivers' needs were often not assessed and met before the discharge of people with stroke from inpatient wards or rehabilitation facilities into their care at home (Camicia, Lutz, Harvath & Joseph, 2021, L. Chen et al., 2021). Caregivers' unmet care needs ranged from insufficient information on how to assume their role to a lack of basic care skills and problem solving and coping strategies in dealing with challenges arising from changed emotions, cognition and/or altered behaviours of people with stroke (Camicia, Lutz, Harvath, & Joseph, 2021). Camicia and colleagues strongly suggested that nurses use the preparedness assessment tool to explore stroke caregivers' needs and address their concerns before hospital discharge (Camicia, Lutz, Harvath & Joseph, 2021). The assessment outcomes should be interpreted in the context of an interdependent relationship within the stroke patient-caregiver dyad and consider the influence of people with stroke over caregivers.

Stroke, as a sudden adverse event or family crisis, has an enormous impact on the mental health and psychological wellbeing of people with stroke and their caregivers which weakens their active preparedness for discharge from hospital (Minshall et al., 2021). Depression and anxiety affect approximately 30% and 25% of the stroke population respectively and contribute to poor mental health and quality of life, high mortality rates and prolonged disabilities (Medeiros et al., 2020; Minshall et al., 2021). Mental stress along with stroke-related disabilities adds vulnerabilities to people with stroke developing adverse events after discharge and increasing hospital readmissions (Stein et al., 2020). Studies also indicated that caregivers experienced high-levels of emotional stress from this sudden family crisis and 40%-60% showed depression which affected their ability to undertake and sustain the caregiving role (Mou et al., 2021). Hospital readmissions can be prevented through timely detection of mental disorders, psychological and emotional stress, and individualised support for patient and caregiver populations (Denham et al., 2022; Stein et al., 2020). A study by Chung et al. (2016) suggested that strategies building on dyadic members' strengths in preventing stroke-related depression are imperative. Discharge planning provides an opportunity for nurses to initiate interventions addressing stroke-related depression within stroke dyads. However, understanding their shared experiences and unique challenges for each dyad member in preparedness for discharge is a prerequisite.

6.5.4 The Study

6.5.4.1 Aim

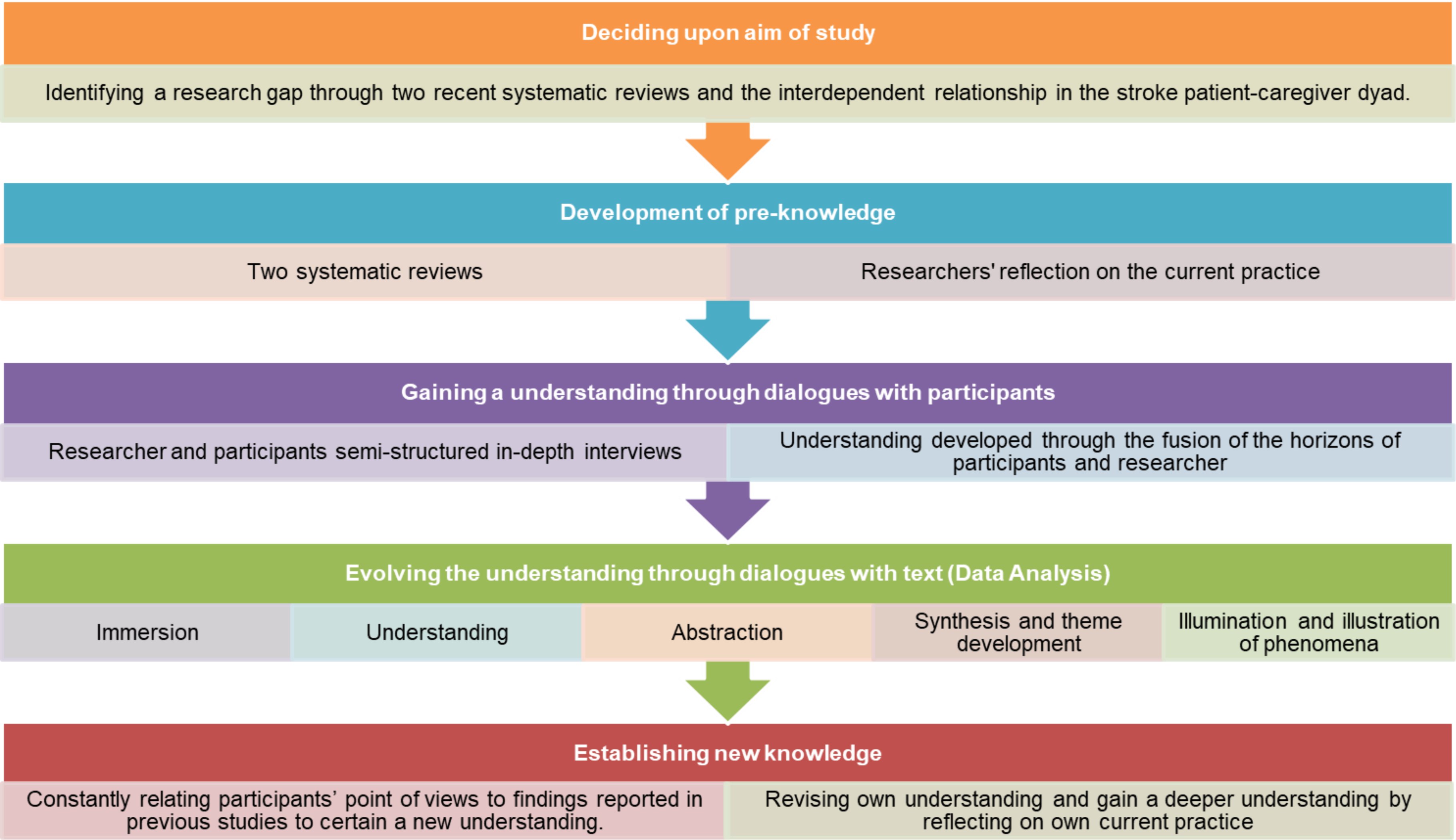
The aim of this hermeneutic study was to explore the shared experiences of people with stroke and caregivers in preparedness to manage post-discharge care. This study is part of a longitudinal study that explored hospital to home transition care for people with stroke and informal caregivers.

6.5.4.2 Design

This study applied an interpretive approach underpinned by Gadamer's philosophical hermeneutics. Gadamer described the interpretation process as a "hermeneutic circle", where the inquirer enters an interpretation process with an open mind and historical awareness of a phenomenon (pre-knowledge) (Gadamer, 1979, p 235). Gadamer emphasised that a deeper understanding can only be gained when the inquirer consciously identifies, provokes and revises their own pre-knowledge (Gadamer, 1979). Reaching a deeper understanding in a study using Gadamer's hermeneutic design has the key components shown in Figure 6.1 and detailed in the following (Alsaigh & Coyne, 2019, Fleming et al., 2003). First, the researcher needs to decide on the aim of study or develop research questions based on a research gap. In this study, we conducted two systematic reviews that helped us identify the research gap (L. Chen et al., 2020, 2021) and the interdependent relationship in the stroke patient-caregiver dyad (Chung et al., 2016, Mou et al., 2021). Second, the researcher needs to be equipped with pre-knowledge in the study field. LC currently practises in stroke care, LX and DC are experienced in chronic diseases management and nurse-led interventional study field. Our commitment to the two systematic reviews and reflections on current practice prepared us to achieve this level of pre-knowledge. Third, the researcher needs to conduct interactive dialogues with participants by which understanding is developed through fusion of the horizons of participants and the researcher. Fourth, the researcher needs to evolve their understanding through dialogues with text (transcripts and field notes) during the data analysis phase. Fifth, the researcher needs to constantly relate participants' point of views to findings reported in previous studies (historical awareness) to ascertain a new understanding generated from the dialogues with participants. In addition, the researcher needs to revise their own understanding and gain a deeper understanding (new knowledge) by reflecting on current practice including current policies and standards guiding the clinical practice individually or collectively within a team. This deeper understanding represents a shared understanding co-developed by the participants and the researcher. These key components set Gadamer's hermeneutics apart from other phenomenology methodologies (e.g., Husserl’s phenomenology) in which the researcher is required to ‘bracket’ their pre-knowledge in the research field in order to minimise the researcher’s influence on the findings (Crotty, 1998).

Figure 6.1

Research Process (Adapted From Fleming et al., 2003 and Alsaigh & Coyne, 2019)



6.5.4.3 Settings and Participants

This study is part of the first author (LC)'s PhD study and was conducted in a stroke rehabilitation unit at a tertiary care public hospital in Adelaide, South Australia. Australia has a unique hybrid health system with the foundational public health system (Medicare) complemented by private health insurance (Department of Health and Aged Care, 2019). Australians can choose to utilise Medicare or private health insurance to fund inpatient care, primary health care and community healthcare services (Department of Health and Aged Care, 2019). In South Australia, based on individual situations and age, discharge destinations include 1) home with community care services, ambulatory rehabilitation services, community transition care services or National Disability Insurance Scheme (NDIS) (for people 64 years and younger); 2) inpatient rehabilitation services, residential transition care services, or residential aged care facilities.

The rehabilitation unit where this study was conducted is led by an interprofessional team. Discharge education and information provision occurs throughout the admission with particular focus on developing a post-discharge plan two to three days before discharge. Discharge planning usually entails activities with people with stroke and their caregivers including goal setting, caregiver training, education, home visits and family meetings. A patient's target length of stay is assessed based on the rehabilitation outcomes measure – Functional Independence Measure (FIM) on admission (Uniform Data System for Medical Rehabilitation, 2012). However, their actual length of stay and discharge destination depends on individual factors, such as severity of stroke deficits and caregiver availability and capacity, and availability of community rehabilitation and care services etc.

Participants were selected based on the inclusion criteria (see Table 5.1). The criterion sampling enabled identification and selection of information-rich participants relevant to this study (Polit & Beck, 2012). Recruitment occurred between July and December 2019. During this period, there were 142 stroke admissions to the unit. Based on the inclusion criteria, unit clinicians recommended potential participants. LC, who is the Nurse Manager of this unit but does not have a direct care relationship with patients, initially approached potential participants to determine their interest. If interested, a Research Assistant provided and explained the participant information sheet and consent form. Among 22 eligible people with stroke-caregiver dyads, two declined, two were excluded due to unstable living conditions and one deceased. In total, 17 people with stroke-caregiver dyads were invited to the study and one person with stroke had two caregivers, making a total of 35 potential participants. However, five people with stroke were unable to participate in an interview due to moderate to severe cognitive and/or speech impairment. Therefore, only 30 of them participated in interviews. The mean length of stay of people with stroke in the rehabilitation unit was 28 days. All people with stroke were discharged home into the care of their family with community support.

6.5.4.4 Data Collection

We developed separate semi-structured interview questions for people with stroke and caregivers (see Table 6.5). These interview questions were developed based on the research aim, the findings of literature reviews and previous studies on stroke rehabilitation and hospital to home transition care (L. Chen et al., 2016, 2021). These questions served as a prompt for people with stroke and caregivers to share their point of views regarding preparedness to manage post-discharge care. The interviews reported here are the first round of interviews in a longitudinal study with follow up interviews occurring three and six months after returning home.

LC collected data through face-to-face semi-structured interviews with participants. People with stroke and caregivers were interviewed separately except people with mild cognitive impairment (n=3) who were interviewed with their caregiver to cross check the narratives. Of 30 participants, 26 participants including those with cognitive impairment were interviewed 24 to 48 hours before discharge except one dyad who was interviewed 48 hours beforehand. Due to the participant’s deteriorating medical condition, discharge was subsequently postponed until three days after the interview. Two dyads were interviewed within two weeks after discharge due to time constraints before discharge. Participants chose an interview time and venue. The average time of each interview was 30 minutes and was audio-recorded and transcribed verbatim for analysis.

Table 6.5

Interview Guide

Participants	**Stroke Patients**	**Stroke Caregivers**
Question 1	How have you been since the stroke? • How have you been dealing with the fact that you had a stroke? • How do you think your family cope with what happened?	How have you been since the stroke of your relative? • How have you been coping with the fact that your relative had a stroke? • How do you think your relative is dealing with what happened?
Question 2	Now you are going home soon, please tell me about your rehabilitation experience. • How prepared do you think you are for returning home?	Now your relative is going home soon, please tell me about your thoughts on the caregiving role. • How prepared do you think you are for supporting your relative at home?
Question 3	What are your expectations after returning home? • Expectations on your rehabilitation/recovery. • Expectations on community health and social care services.	What are your expectations after your relative returns home? • Expectations on the relative’s rehabilitation/recovery. • Expectations on the support services.

6.5.4.5 Ethical Considerations

This study was approved by the the Southern Adelaide Clinical Human Research Ethics Committee (Approval No. 39.19). Participants received a detailed explanation of the study and participation was voluntary. Participants were informed of strategies to ensure confidentiality and their freedom to participate or withdraw from the study. They provided informed consent before the interview. Deidentified data were stored on a secure university cloud drive.

6.5.4.6 Data Analysis

Gadamer advocated a systematic approach to achieve a deeper understanding although he did not offer a detailed data analysis method (Gadamer, 1979). Subsequently, a group of researchers explored directions for undertaking data analysis (Alsaigh & Coyne, 2019, Fleming et al., 2003). We have adapted these methods and detailed our dialogues with text (transcripts and field notes) in the five interrelated and cyclical steps outlined below to enrich understanding. Nvivo 12 software was used to assist with data analysis.

Step 1: Immersion. Interviews were transcribed verbatim and read repeatedly while listening to the original record to immerse researchers in the raw data. From this an understanding of the whole text was obtained, which influenced understandings of other parts of the text. At this step, text was encountered with anticipation developed through our pre-knowledge.

Step 2: Understanding. Every single sentence of the text (the part) was examined carefully to expose its meanings and identify first order (participant) constructs. This was achieved with line-by-line coding in NVIVO. Open codes were developed by LC to represent participants' ideas (their horizon).

Step 3: Abstraction. The researchers identified subthemes by grouping open codes into clusters and labelling each cluster based on the meaning. Regular team discussions were conducted to elaborate potential subthemes based on their relevance to the aim of the study and the researchers' pre-knowledge. The subthemes represented the researchers' horizon.

Step 4: Synthesis and theme development. Subthemes were grouped into themes through elaboration and clarification on the relationship between subthemes and themes (see Table 6.6). This involved continuous moving back and forth between the literature, our earlier analysis and the text, and across people with stroke and caregiver datasets to identify similarities and differences. Moving from parts to the whole and back again is known as the rhythm of Gadamer's hermeneutic circle. In this process, themes were informed by and in turn enhanced researchers' pre-knowledge. From this process, interpretations on the perceived preparedness of people with stroke and their caregivers to manage post-discharge care, and the differences between them evolved.

Step 5: Illumination and illustration of phenomena. The researchers linked the literature to the themes and subthemes derived from the entire dataset. Based on the themes, subthemes and their interrelationships, the team reconstructed the perceived preparedness to manage post-discharge care for people with stroke and caregivers using their own words and highlighted key findings from the data. In this process, the research team examined the quality of stories to ensure the constructed stories reflected participants' perceptions and their voices were represented in the findings.

Through dialogues with the text, our pre-knowledge changed through data collection and interpretation. The team met and discussed these changes to facilitate the hermeneutic circle process (Fleming et al., 2003).

Table 6.6

Interpretation Process Exemplar

Transcripts	Coding	Grouping and summarising coding	Sub-theme	Theme
Out of here being symbolic. I've done well, and I'm on my way again (SS17).	SS17Co1: Out of hospital a great achievement SS17Co2: Satisfied with recovery SS17Co3: Ready for a new journey after discharge	**Focusing on capabilities** SS09Co1: Clear about limitations and solution SS11Co1: Accepted	"I've come from zero to hero."	Resilience

Transcripts	Coding	Grouping and summarising coding	Sub-theme	Theme
I've come from zero to hero. A fortnight ago, I couldn't sit up in bed. [Now] I can walk some distance independently (SS03).	SS03Co1: Consider recovery a great success SS03Co2: Significant achievement in 2 weeks	poststroke impairment SS11Co2: Observed stroke patients in worse conditions SS11Co3: Satisfied with remaining physical functions SS13Co1: Observed other stroke patients' disabilities SS13Co3: Appreciate remaining body functions **Positive thoughts about recovery** SS17Co1: Out of hospital a great achievement SS17Co2: Satisfied with recovery SS03Co1: Consider recovery a great success SS03Co2: Significant achievement in 2 weeks SS13Co2: Felt lucky having mild stroke **Hope for future**		
I just know that I have to be careful and go slowly. All those things I'm not terribly good at but I'll try. My brother will fix the shopping and I will do the cooking. And we'll go back to how we were before (SS09).	SS09Co1: Clear about limitations and solution SS09Co2: Plan to continue progress SS09Co3: Clear plan with caregiver SS09Co4: Confidence to resuming pre-stroke life			
I saw the awful disabilities that had happened to them, and I saw this man and he was just so badly stricken with his stroke that it really upset me … And it made me realise how lucky I was that I had just had a minor stroke, was still able to think and feel (SS13).	SS13Co1: Observed other stroke patients' disabilities SS13Co2: Felt lucky having mild stroke SS13Co3: Appreciate remaining body functions			
After really accepting that I had a stroke, I understand I'm not going to get back to where I was and things	SS11Co1: Accepted poststroke impairment SS11Co2: Observed stroke patients in worse conditions			

Transcripts	Coding	Grouping and summarising coding	Sub-theme	Theme
will be all slower… And I see around here a lot of people are far worse and I'm certainly happy with my physical side of things in many ways (SS11).	SS11Co3: Satisfied with remaining physical functions	SS09Co2: Plan to continue progress SS09Co3: Clear plan with caregiver SS09Co4: Confidence to resuming pre-stroke life SS17Co3: Ready for a new journey after discharge **Coping through internal strength** SC11Co1: Natural ability to manage crisis SC11 Co2: Calm personality to manage unexpected situations SC08Co1: Personality to look at positives SC08Co4: Past life experience facilitate acceptance of stroke SC01Co1: Activated coping strategies **Coping through positive thoughts and preparation**		
I do have the facility and I've already had it. When there's a drama, I gone dead calm and deal with it. [It is] my personality' (SC11).	SC11Co1: Natural ability to manage crisis SC11 Co2: Calm personality to manage unexpected situations		"I look at this as a change in the road for life."	
I face things front-on, so this is what it is, look at the positives. I 've got him and he's lucky…the family's lucky. We don't look at this as a disability, I look at this as a change in the road for life. All my life and we've had a lot of ups and downs…I just accept it and work from there (SC08).	SC08Co1: Personality to look at positives SC08Co2: Felt lucky husband still alive SC08Co3: Interpret stroke as a change rather than a disability SC08Co4: Past life experience facilitate acceptance of stroke			
I'm as prepared as I can be for what's going to come, but I really don't know what's going to come. I think it's just	SC14Co1: Prepared for uncertainties SC14Co3: Pre-empted to face ups and downs			

Transcripts	Coding	Grouping and summarising coding	Sub-theme	Theme
going to be again a rollercoaster for some time to come (SC14).		SC08Co2: Felt lucky husband still alive SC08Co3: Interpret stroke as a change rather than a disability SC14Co1: Prepared for uncertainties SC14Co3: Pre-empted to face ups and downs SC01Co2: Coping strategies to alleviate stress		
So, I have done a lot of mindfulness practice and that has been hugely beneficial. And I would really recommend that there is support for people in that area to learn – to be able to manage their anxiety or anything that might come up (SC01).	SC01Co1: Activated coping strategies SC01Co2: Coping strategies to alleviate stress			

Note. SS = people with stroke; SC = stroke caregiver; Co = code.

6.5.4.7 Rigour

We applied the criteria established by Lincoln and Guba (1985) to ensure rigour of this study. Credibility was enhanced by audio-recording interviews and transcribing verbatim, crosschecking statements with participants during interviews and debriefing and discussion among the research team (Morse, 2018). Strategies applied to fulfil dependability and confirmability of data included maintaining a decision trail, using participants’ own words to support themes and extensive research team discussions (Morse, 2018). During data analysis, LC maintained a research journal in which the research team’s reflections and discussions were recorded. This practice also enhanced dependability and confirmability of data. Transferability of the findings was enhanced by citation of existing research evidence to verify interpretations and conclusions. When reporting, original excerpts from participant interviews were used to enhance readers’ understanding (Morse, 2018). A reflexive journal was maintained throughout the research process to enhance the overall trustworthiness of this study. Study reporting followed the Consolidated Criteria for Reporting Qualitative Research (COREQ) checklist (Tong et al., 2007) (see Appendix 22).

6.5.5 Findings

In total, 17 stroke dyads were invited to the study and interviews were conducted with 12 people with stroke and 18 caregivers only as five people with stroke were unable to participate due to cognitive and/or speech impairments. Table 6.1 outlines participants' characteristics. Three main themes with two subthemes under each theme presented perceived preparedness of people with stroke and caregivers in managing post-discharge care. First, both people with stroke and caregivers showed psychological stress that may affect them to take over complex post-discharge care. The causes and triggers contributing to the stress differed and required nurses and the multidisciplinary team to consider individualised discharge planning. Second, despite the stroke crisis in the family, both people with stroke and caregivers demonstrated similar resilience that might enable dyadic effects to overcome challenges and stress arising from post-discharge care. Third, perceived certainty about post-discharge care and rehabilitation differed between people with stroke and caregivers. Most people with stroke were certain about post-discharge rehabilitation due to considerable support they received from nurses and therapists during the hospitalisation. However, most caregivers exhibited uncertainty due to lack of engagement in discharge planning. Both people with stroke and caregivers expected to co-develop and co-implement discharge plans to meet their concerns regarding post-discharge recovery and care. These themes are detailed in the follows and additional information regarding findings is presented in Appendix 23.

Theme 1: Psychological stress

Before discharge, both people with stroke and their caregivers exhibited psychological stress resulting from the unexpected and overwhelming nature of the stroke. The origins seemed to differ between them. People with stroke were anxious about stroke-related loss of functions whereas caregivers expressed uncertainty about their caregiving role and the impact of the stroke on their future lives. Understanding the dyads' psychological stress and different causes would facilitate the assessment of risks and development of dyad-focused discharge plans by nurses and the multidisciplinary team.

Subtheme 1.1: "I am looking forward to going home but feeling anxious."

People with stroke expressed psychological and emotional stress arising from the onset of stroke. Stress seemed to affect their mental strength to deal with anxiety about returning home.

The loss of functions seemed to have caused anxiety. A person with stroke described his impairments in calculation and writing: "It is frustrating. I'm annoyed about it, and I wrote this morning, well a page in the notebook…it probably took me half an hour to write, and I made some mistakes" (SS11). The loss of functions triggered various psychological and emotional reactions, for example, frustration, depression, fear and worry in people with stroke. Inability to walk safely was distressing to people with stroke, but it also seemed to form a major part of their rehabilitation goals as a person with stroke stressed:

> A big focus for me was the walking part because that was quite devastating to find that you'd stand up and you couldn't put any weight on the left hand side. And when I started using the walker, it was kind of very stilted… it became I suppose a focal point for me to actually keep doing that (SS12).

People with stroke were challenged with the unexpected and overwhelming nature of stroke-associated functional impairments and the detrimental impact on their lives. They would benefit from professional counselling that helped them develop positive thoughts, a critical indicator of psychological preparedness to self-manage post-discharge care.

They were also concerned about the consequences of stroke on their health after discharge: "[I feel] a bit depressed, worried about having another one [stroke] and not going back to my previous life. Worried about my independence" (SS09). In this case, psychological stress was triggered by the lack of knowledge about preventing a second stroke. Discharge planning that incorporates self-care education would relieve people with stroke from this stress. Another person with stroke resonated her anxiety about imminent discharge:

> I am looking forward to going home but, at the same time, I'm also feeling anxious about my level of functioning in the home situation…what impact it's going to have on me and how is it going to perhaps affect me emotionally as well (SS12).

Findings indicated people with stroke were psychologically unprepared to self-manage care after discharge. Early detection of psychological stress via assessment and individualised interventions could support them to better cope with stress before discharge. Findings also indicated the need to integrate psychological counselling into post-discharge care services.

Subtheme 1.2: "Not knowing what the future holds."

This subtheme revealed various sources that triggered psychological stress for caregivers. Caregivers perceived that they were assigned to the caregiving role and expected to take over complex poststroke care while still affected emotionally by the vivid memory of stroke onset and facing potential financial impacts. They were unconfident about providing home care and unclear about the post-discharge plan.

Stroke suddenly changed the lives of caregivers. Remembering events at the onset of stroke continued to emotionally impact caregivers, which heightened their anxiety as a caregiver recalled: "I worry about him at home. I've been the one that's found him on the floor. And I worry about that [another stroke] … and falling again" (SC18). Another caregiver described: "The initial shock was terrible because we nearly lost him…it seemed unreal, but gradually, I know from the moment he had the stroke my life will change, so will his" (SC08).

The emotional trauma challenged caregivers to have the mental strength to take over care and assume their role in hospital to home transition. The need for sufficient time to be mentally prepared to take charge of care at home was mentioned by a caregiver interviewed on the day of her husband's discharge: "It's been difficult…Just running everywhere, making sure that everything's okay when he comes home. I'm usually very organised… things have sort of gone a bit haywire. I lost my keys, forget my phone" (SC18). The psychological and emotional distress of caregivers may be underestimated due to the focus on people with stroke, rather than their caregivers, during hospital stays. An assessment of caregivers' psychological health would help identify their needs and facilitate early interventions. Caregivers may need additional support during the transition in order to be mentally stable to take over care of the stroke patient.

Stroke can have a negative impact on family income, especially when the people with stroke were the main breadwinner. In such a circumstance, financial stress becomes another source of mental stress for caregivers:

> Well because XX [the husband] was the main breadwinner we've got a mortgage, young family, kids in school, I needed to stabilise my work... But I've cut back one day so I'm three days a week, but I need to build back up to doing just so that we can pay off our [bills] (SC05).

Caregivers were anxious before discharge because they were unsure what the future would hold and whether they would have sufficient capacity to provide care. A wife described her concerns about providing care at home:

> I do [worry] because he's not always easy to tell to slow down, and we'll stress at each other over those things. And just not knowing what the future holds, how I can care for him and help him better... [I feel] really stressed, depressed, just generally a lot of sadness because of not knowing what the future holds for him. Just coping, coping not as good as I used to be (SC03).

In this case, caregivers may benefit from an assessment on their preparedness for the caregiving role and a psychological consultation to alleviate anxiety and other mental health issues.

Findings demonstrated that various sources may contribute to caregivers' mental stress during hospital to home transition. Their perceived preparedness for providing care depended on their mental status and pre-discharge support received to help stabilise this.

Theme 2: Resilience

In this study, both people with stroke and caregivers demonstrated resilience despite the devastating outcomes of stroke. Their resilience was built on the same foundations such as positive thoughts and appraisal of their situation. Resilience of people with stroke was enhanced by their functional achievements and family support, whereas caregivers' resilience was built on their internal strength, past life experience and pre-existing coping strategies. Insights into the mechanisms underlying resilience would guide nurses and rehabilitation clinicians in tailoring interventions that address the needs of both people with stroke and caregivers from individual and dyadic perspectives.

Subtheme 2.1: "I've come from zero to hero."

This subtheme demonstrates resilience and acceptance of stroke-related limitations for people with stroke despite a great sense of loss of functions. The source of their resilience came from their positive thoughts, positive appraisal of attaining rehabilitation goals and family support.

By focusing on their functional capabilities and comparing themselves with worse cases, people with stroke generated positive thoughts about their recovery as they stated:

> After really accepting that I had a stroke, I understand I'm not going to get back to where I was and things will be all slower… And I see around here a lot of people are far worse and I'm certainly happy with my physical side of things in many ways (SS11).

> I saw the awful disabilities that had happened to them, and I saw this man and he was just so badly stricken with his stroke that it really upset me … And it made me realise how lucky I was that I had just had a minor stroke, was still able to think and feel (SS13).

Acceptance of stroke-related functional impairments seemed to enhance optimism for people with stroke about their ability, rather than their disability. Recognising these positive thoughts may help nurses to activate and motivate people with stroke to self-manage their chronic conditions and rehabilitation.

People with stroke who viewed discharge from hospital as a huge milestone reinforced their resilience: “Out of here being symbolic. I’ve done well, and I’m on my way again” (SS17). The same attitude was echoed by another participant: “I’ve come from zero to hero. A fortnight ago, I couldn’t sit up in bed. [Now] I can walk some distance independently” (SS03). Their positive appraisal of recovery may activate and motivate them to self-manage care after discharge and engage in further rehabilitation.

People with stroke appeared prepared to overcome challenges ahead: “I’m just so looking forward to going home. I am probably going to make mistakes, but I’ve got things organised” (SS15). Support from families also enhanced resilience:

> I just know that I have to be careful and go slowly. All those things I’m not terribly good at but I’ll try. My brother will fix the shopping and I will do the cooking. And we’ll go back to how we were before (SS09).

The findings highlighted that resilience is a crucial personal attribute that could enable self-management of care after discharge. Through discharge planning, nurses and rehabilitation health professionals can enhance resilience in people with stroke by engaging them in self-assessing their abilities to manage their conditions and by providing resources to support self-management in the community setting.

Subtheme 2.2: “I look at this as a change in the road for life.”

Caregivers demonstrated resilience and revealed mechanisms to manage change including their personality, past life experiences, views about life and death, and strategies previously used to alleviate stress. These helped them face the sudden onset of stroke and perceived challenges after discharge.

Caregivers discussed how the coping strategies that came naturally as part of their personality had helped them respond to the stroke event. A caregiver linked her personality with coping mechanisms: “I do have the facility and I’ve already had it. When there’s a drama, I gone dead calm and deal with it. [It is] my personality” (SC11).

The combination of a positive outlook and past life experiences seemed to have further strengthened caregivers' perceived capacity to manage the uncertainties and challenges ahead of them. A wife's statement represented:

> I face things front-on, so this is what it is, look at the positives. I 've got him and he's lucky…the family's lucky. We don't look at this as a disability, we look at this as a change in the road for life. All my life and we've had a lot of ups and downs…I just accept it and work from there (SC08).

Past work experience and prior knowledge about the healthcare system alleviated anxiety and made it easier for caregivers to coordinate care. As a caregiver shared:

> My job is working with people that live at home with disabilities. So, it's more setting up rosters and doing care plans and working with the NDIS [National Disability Insurance Scheme]. So, I have set up support for XX [the husband] with the NDIS just for when I'm working (SC05).

Caregivers' openness towards life and death facilitated the development of resilience and enabled them to embrace adversity with courage and an open mind as a caregiver described their advanced care planning:

> We've talked about death and dying, we're very straight forward about the future. We've got things in place with the family and with our executor as to what we want and we both realise he's 82, I'm nearly 80 that our life is coming towards the end (SC11).

Caregivers who showed resilience might be better prepared to overcome challenges and stress they may face after discharge. A couple of caregivers shared their thoughts:

> I'm as prepared as I can be for what's going to come, but I really don't know what's going to come. I think it's just going to be again a rollercoaster for some time to come (SC14).

> So, I have done a lot of mindfulness practice and that has been hugely beneficial. And I would really recommend that there is support for people in that area to learn – to be able to manage their anxiety or anything that might come up (SC01).

Caregivers’ resilience activated their coping mechanisms. Resilience may enhance caregivers’ capability to support people with stroke and overcome challenges ahead in hospital to home transition.

Theme 3: Certainty and uncertainty about post-discharge care

This theme highlighted the perceived certainty about post-discharge care and rehabilitation differed between people with stroke and caregivers. People with stroke had more interactions with nurses and other health professionals to discuss their post-discharge rehabilitation. Therefore, they showed a sense of certainty about post-discharge rehabilitation plan and implementation. In contrast, caregivers perceived uncertainty about post-discharge care due to lack of clarity about post-discharge support services and the exclusion from discharge planning. The findings are detailed in the following subthemes.

Subtheme 3.1: “They boost you up.”

Setting clear and realistic goals with rehabilitation therapists for continued rehabilitation at home gave participants hope of returning to norm after discharge. Several people with stroke shared their views on what they planned to achieve at home: “I think probably a week, 10 days, I’ll be managing to walk…There are stairs at home, well I won’t be able to do those yet … but I think eventually I’ll be able to do all those things” (SS15); “I’d like to be able to strive to get back to a normal life. I’m hopeful that given a week at home, I can push a vacuum around…” (SS03).

Interventions tailored to individuals and positive feedback from nurses and therapists while in the rehabilitation unit improved adherence to rehabilitation programs during the hospital stay and further enhanced self-determination of people with stroke to succeed at home. Tailored rehabilitation was built on partnerships with nurses and other health professionals. A couple of participants’ comments exemplified:

> They [nurses and therapists] know where I’m comfortable to work within that risk parameter, but if they weren’t as professional, I may be nervous and not as willing to undertake those next exercises. And they encourage you all the time that makes me feel like to do more (SS17).

> [They] explain what was happening all the time. They [nurses] have given me a lot of confidence. They said: 'Oh, you're wonderful. You did it all really well'. So apart from the actual showing you how to do things, they boost you up (SS15).

These examples showed a true partnership approach between people with stroke and health professionals in co-developing and co-implementing discharge plans. This cooperative approach may have helped improve health professionals' knowledge about care needs and facilitated shared decision-making.

Awareness of the continuum of rehabilitation and care services available after discharge seemed to reassure people with stroke that support to manage poststroke recovery and care at home was available. A participant shared his experience of how a well-organised post-discharge rehabilitation plan increased his self-confidence: "I am confident, I'm not intimidated or nervous by it, rehab will go on but in a different way, from the home and visits from here. So, I'll still get that support, I'm just thrilled to be going home" (SS17).

However, the lack of a clear rehabilitation plan after discharge was also reported: "I don't know exactly what the services are at this stage" (SS11). Another person with stroke echoed: "I believe that I'll be getting some in-home rehab and that's one of the things. The other things are sort of not specifically sure in the home situation" (SS12). These contrasting findings highlighted the significance of information sharing to enhance preparedness of people with stroke for discharge. A clear follow-up plan increases confidence as well as supporting self-management capabilities at home.

Findings indicated that people with stroke demonstrated determination for transition through their hope for rehabilitation. Nurses and the interprofessional team who used a co-develop approach enhanced sense of certainty, confidence, motivation and preparedness for discharge in people with stroke.

Subtheme 3.2: "We don't know what's going to happen."

Different from perception of people with stroke, caregivers demonstrated uncertainty about post-discharge care due to lack of opportunities to engage in discharge planning with nurses and other health professionals. Some caregivers perceived that they were not fully engaged in developing and implementing discharge plans. As the handover of care neared, they expected health professionals to treat them as an equal partner and help them to build capabilities to take over care at home.

Caregivers were unsure what to expect and felt things would be out of their control. A mother of three young children discussed her uncertainty about rehabilitation and associated outcomes at the point of discharge:

> No, I just know that really there can't be expectations because we don't know what's going to [happen] – my commitment is only to put the work in, to put the therapies in place, that's what I requested from all of them [service providers] to give me as much as we can with therapy … but you know we'll just keep strengthening him and see what we can glean out of it (SC05).

In this case, education about post-discharge care for the caregiver was much needed to activate and empower them to work with health professionals as an equal partner in developing and implementing discharge plans.

Caregivers desired to be fully informed of the post-discharge rehabilitation plan. However, approaching discharge that information could be unclear. A wife expressed her concerns on the day of discharge:

> I don't know what to expect. I believe someone came and spoke to XX [the husband]. But he's not reliable [due to memory issues]. And here we are going home. I'd like to know who I'm expecting to come into my home, how often. Now because of Christmas it's not going to happen. So, it's just bad luck that you've got the public holidays (SC18).

This case revealed the lack of a consistent partnership approach by health professionals to co-developing post-discharge plans with caregivers. It also indicated the lack of information provision about stroke-related community resources. Together, these situations triggered additional psychological stress for this caregiver that affected her confidence and preparedness to manage post-discharge care.

Caregivers continued to cope with life changing situations caused by the stroke crisis in the family. Hence, they might be unavailable for meetings scheduled by discharge nurses and the interprofessional team. As a daughter complained: “It was a little bit disappointing because we had phone calls about that we all get together and have a chat about Mum. And it just never happened” (SC13). This example reveals the difficulties in engaging all family members in discharge planning during a short hospital stay. More realistic strategies that enable family members to engage in discharge planning, for example publicly available education programs for family members and meeting with the family soon after discharge, may be needed.

A husband who has cared for his wife for the past 30 years echoed: “But also not knowing on the support side what’s available, what’s going to be available. It really was a matter of trying to get information from XX [an organisation] (SC06)”. This case indicates that people with prior long-term experience in the caregiver role still feel a lack of capability to navigate information about stroke-related post-discharge care. The need for additional caregiver education about post-discharge care is evident.

In contrast, some caregivers perceived that they were included in the decision-making and planning process, and they benefited from these activities. Caregivers commended their interactions with the interprofessional team that prepared them to care for their mother after discharge: “[We have been] totally involved and where we’ve thought that we haven’t had an answer quickly enough, we’ve rung; so, there was a time where somebody didn’t get back to us and we followed it up straight away (SC 14 & 15)”. This case supports the dyad-centred discharge planning that may be enhanced with two-way communication and collaboration between caregivers and discharge nurses or other health professionals.

The availability of timely access to rehabilitation team support after discharge improved caregivers’ perceived ability to assume their role. As a wife who would be caring for her husband with cognitive impairments specified: “I also feel confident – I am being told all the time that I can access support here, ask any questions. That will be important for anything that comes up” (SC01).

Compared to people with stroke, caregivers may have limited time capacity to discuss their concerns with discharge nurses and other health professionals. This may impact their participation in discharge planning. Innovations such as video/tele discharge planning conferences could improve communication and information-sharing. Discharge nurses’ collaborative approach could also help maintain an open dialogue with caregivers. Caregivers’ desires to co-develop and co-implement discharge plans with discharge nurses and other health professionals were evident.

6.5.6 Discussion

The use of Gadamerian philosophical hermeneutics (Gadamer, 1979) enabled us to holistically interpret the shared experiences of people with stroke and their caregivers regarding perceived preparedness to manage post-discharge care. The interpretation of findings has been further enhanced through the first author’s reflections on her own practice as an experienced stroke nurse. Our study revealed that perceived preparedness of people with stroke and caregivers in managing post-discharge care is influenced by their psychological and emotional status, resilience and the level of engagement in discharge planning. The findings indicated that the event of returning home triggered distinct feelings in people with stroke and caregivers. Returning home after stroke was celebrated as a significant milestone in the poststroke trajectory by both. However, compared to people with stroke, caregivers demonstrated feelings of profound uncertainty about their role and how to take over care after hospital discharge.

In this study, people with stroke and caregivers were to experience transition from professional care in hospital to self-management at home. Transition can be defined as “a passage from one life phase, condition, or status to another” (Chick & Meleis, 1986, p. 239). Meleis transition theory described personal, community and societal transition conditions that could facilitate or hinder the transition (Meleis, 2010). In ‘personal conditions’, Meleis discussed that a wide range of emotions, especially stress and emotional distress, are common during the transition. The level of comfort with changes in the body influences well-being during the transition (Meleis, 2010).

Aligning with Meleis transition theory, our findings demonstrated that people with stroke and caregivers experienced different psychological stressors in the lead up to discharge. Psychological stress for people with stroke seemed to be related to the loss of function, worries about prognosis and future independence. Whereas caregivers' emotional stress appeared to be triggered by lack of knowledge and confidence about their caregiving role and unclear post-discharge plans. Psychological and emotional stress have detrimental impacts on caregivers' preparedness to manage post-discharge care, suggesting the need to provide them with psychological counselling services in the poststroke trajectory. However, discharge plans largely focus on physical and cognitive functions of people with stroke with substantially less attention to psychological and emotional stress (Hughes & Cummings, 2020; Stroke Foundation, 2019b). A recent stroke services audit revealed that only 56% of people with stroke had a mood assessment and only 37% of audited hospitals provided psychology services (Stroke Foundation, 2019a). Nurses leading discharge planning in a multidisciplinary team need to initiate and coordinate psychological counselling services. Considering the dyadic effects in poststroke depression prevention reported by Chung et al (2016), assessments of dyadic members' characteristics relevant to depression prevention, such as self-esteem and optimism, need to be undertaken and development of interpersonal skills that foster positive dyadic effects on preventing and coping with depression need to be incorporated into psychological counselling services to increase perceived preparedness for discharge.

Findings revealed uncertainty as a common psychological stressor for both people with stroke and caregivers. Uncertainty in illness refers to the inability to determine the meaning of illness-related events or accurately predict outcomes (Mishel, 1990). As found in this and previous studies, uncertainty could be heightened by a lack of information and the unpredictability of poststroke outcomes (Ramazanu et al., 2021). In the reconceptualisation of uncertainty in illness theory, Mishel (1990) advocated that uncertainty could become an opportunity for the individual to reconstruct a new view of life by developing a probabilistic thinking on uncertainty. Probabilistic thinking considers uncertainty as natural and part of reality (Mishel, 1990). By assessing their learning needs and implementing tailored health education for stroke dyads, nurses can help people with stroke and caregivers to maintain probabilistic thinking and manage uncertainty (Ashcraft et al., 2021). Providing dyads with evidence-based information on poststroke functional ability improvement rates and the reduction and/or prevention rates of stroke-related complications, medication side effects, acute episodes of chronic diseases and secondary stroke will not only reduce uncertainty-induced psychological stress, but also motivate dyads to actively participate in and take responsibility for post-discharge care. A nurse-led intervention encompassing informational support, shared decision making, and practical skills showed preliminary benefits for stroke couples to cope with uncertainty (Ramazanu et al., 2021).

Up to 56 % of people with stroke also live with one or more chronic diseases (e.g., hypertension, diabetes) and the stroke recurrence rate one year after the first-ever stroke can be as high as 25% in stroke survivors (Feigin et al., 2022; Lin et al., 2021). While an inpatient, nurses spend far more time with people with stroke than other health professionals. Nurses are therefore well-positioned to identify high-risk patients and enhance the dyad's preparedness to manage stroke-related complications, pre-existing comorbidities and secondary stroke prevention through health education. Health education interventions empower dyads at home to proactively monitor stroke risk factors, take action to stabilise chronic conditions and seek timely medical advice. Adequate discharge preparation, structured post-discharge follow-up and early evaluation by specialist nurses could reduce unplanned hospital admissions due to complications (Lin et al., 2022; Pugh et al., 2022).

Our study confirmed previous studies that people with stroke and caregivers are not consistently engaged in discharge planning although they have strong desires to be equal partners (L. Chen et al., 2021; Krishnan et al., 2019). Co-design in healthcare is defined as a partnership between patients, their family/caregivers and health service providers to develop a person-centred care plan/intervention with the aim of achieving better outcomes or improved efficiency (Ward et al., 2018). Engaging people with stroke and their caregivers in co-designing poststroke care leads to better care outcomes (Jones et al., 2020; Lobo et al., 2021). Increased understanding of stroke dyads interdependent nature in post-discharge care would encourage stroke nurses to lead the revision of conventional practice in discharge planning and advocate for a co-design approach. Any innovative discharge planning practice needs to engage both people with stroke and caregivers in assessment and care plans that address the dyads mutual concerns as well as acknowledging individual needs (Mou et al., 2021).

6.5.6.1 Limitations

This study has limitations. The findings may not be generalisable due to the nature of the hermeneutic study, which is built on specific social and cultural contexts, but they may be transferrable to similar social contexts. Additionally, some participants with stroke in this study had mild cognitive impairment. Findings do not represent those with moderate to severe cognitive impairment. Moreover, the recall bias may impact on narratives from two dyads interviewed after discharge. Furthermore, dyadic relationship may influence narratives of dyads interviewed together. Finally, this study excluded non-English speakers and findings may not represent the perceptions of those from ethnic minority groups.

6.5.7 Conclusion

This study developed new knowledge on the shared experience, similarities and differences of perceived preparedness to manage post-discharge stroke care between people with stroke and caregivers. The use of Gadamer’s philosophical hermeneutics enabled us to reach new insights into the co-existence of psychological stress and resilience, sense of certainty and uncertainty in people with stroke and caregivers and the different factors that contributed to these conditions in the dyadic members. The research methodology also enabled us to explore the expectations of the stroke dyads for co-developing and co-implementing discharge plans to meet their care and information provision needs.

Findings strongly suggest the review and revision of conventional discharge planning guidelines in a healthcare system using a co-design approach by inviting stroke dyads to participate in the process. Any innovative discharge planning practices for these populations should address dyad concerns and consider dyadic effects in health promotion and post-discharge stroke care while acknowledging individual needs of people with stroke and their caregivers. Stroke nurses and nurse practitioners are in an ideal position to lead and coordinate a multidisciplinary team to implement discharge planning. A stroke nurse coordinator’s role should be developed to facilitate early identification of high-risk patients with multiple chronic conditions, support stroke patient-caregiver dyads to navigate the complex healthcare system through the continuum of hospital to home transition and achieve stabilisation of home care.

Anonymised Conflict of Interest Statement

No conflict of interest has been declared by the authors.

This is the end of the publication.

6.6 Summary

This chapter has outlined the demographic characteristics of the stroke dyads and health professionals who participated in the study and has outlined the major themes identified from interviews with the former and focus groups with the latter. In addition, this chapter detailed the findings generated from the interviews with stroke dyads before hospital discharge.

The first set of interviews of this longitudinal study explored the shared experiences of stroke dyads in terms of their preparedness for managing post-discharge care. The findings highlighted the unique challenges that people with stroke and their caregivers experienced individually and as a dyad before transitioning home from hospital. Their perceived preparedness in managing post-discharge care was affected by their psychological and emotional status, resilience and level of engagement in discharge planning. People with stroke and their caregivers manifested distinct feelings about returning home from hospital. Although they both viewed homecoming as a significant success in post-stroke recovery, caregivers perceived, in comparison to people with stroke, profound uncertainty as to how to assume the caregiving role.

The next two chapters (Chapters 7 and 8) report findings from the interviews of dyads at 3 and 6 months following hospital discharge.

Chapter 7: Findings—Part 2: Themes From the Follow-Up Interviews With Stroke Dyads

7.1 Introduction

As discussed in the previous chapter, people with stroke and their caregivers experienced significant challenges before discharge both individually and dyadically. Despite their optimism about returning home from hospital, they experienced psychological stress. People with stroke were frustrated about their loss of function and were worried about the prognosis and future independence, whereas caregivers perceived insufficient time to take on the caregiving role. Caregivers also doubted their capabilities to manage post-stroke care at home.

The dyads were followed up for 6 months after discharge. They were encouraged to record their experiences in managing care at home using a structured diary (see Appendix 21) and to participate in interviews at 3 and 6 months after discharge. The findings about their experiences in hospital-to-home transition care are reported in this chapter and the next chapter. The findings include four major themes and 10 subthemes (Table 7.1). This chapter reports the first two major themes: coping with setbacks and role transformation. The other two main themes—transitioning with support and expectations in hospital-to-home transition care—are reported in the next chapter.

Table 7.1

Major Themes and Subthemes in Chapters 7 and 8

Theme	Subtheme	Chapter
4. Coping with setbacks	**1.** Processing loss and grief in people with stroke	Chapter 7
	2. Processing loss and grief in caregivers	

Theme	Subtheme	Chapter
	3. Reconciling with resilience	
5. Role transformation	**1.** Impact of stroke-related limitations on people with stroke	Chapter 7
	2. Impact of stroke-related limitations on caregivers	
	3. Regaining control of life	
6. Transitioning with support	**1.** Support from family and friends	Chapter 8
	2. Support from health professionals	
7. Expectations in hospital-to-home transition care	**1.** Enhanced discharge planning and preparation	Chapter 8
	2. Flexibility of service provision	

The findings represented participants' experiences individually and dyadically regarding the challenges they encountered, efforts they made and support they received from family and those in the community when managing care at home after hospital discharge. The findings revealed new understandings of both positive and negative dyadic effects between people with stroke and their caregivers in home care settings after discharge from hospital. Dyadic members demonstrated various strategies for coping with setbacks and adapting to changes in their lives.

These findings were supported by data collected from interviews and structured diaries at two time points: 3 and 6 months after hospital discharge. The codes SS and SC are used to indicate quotations from a person with stroke and the stroke caregiver, respectively. The codes T1 and T2 are used to indicate quotations from interviews at 3 and 6 months following discharge, respectively.

7.2 Theme 4: Coping With Setbacks in Home Care

The full impact of stroke-related impairments on everyday life only became clear to stroke participants on their return home. Home was a very different environment from the carefully controlled and well-supported hospital environment. This theme reflects participants’ perceptions of the impact of stroke on their psychological wellbeing and the resilience they demonstrated in reconciling and moving forwards with the changes in their lives in the 6 months after hospital discharge. Subtheme 1 revealed that people with stroke experienced setbacks in functional recovery that triggered their psychological stress. Subtheme 2 highlighted that psychological stress in people with stroke triggered psychological stress in their caregivers. Stroke dyads demonstrated resilience and coping strategies that enabled them to reconcile with and adapt to their pre-stroke lives.

7.2.1 Subtheme 1: Processing Loss and Grief in People With Stroke

Unlike the anticipation of getting on with a life at home that stroke participants perceived before hospital discharge (Chapter 6), participants were disappointed by the fact that their expected functional improvement did not occur. They further experienced a profound sense of loss and grief in the home care environment that had a negative impact on their psychological wellbeing. However, they rarely mentioned the impact that caregivers and health professionals had on them when dealing with the setbacks. The findings are detailed in the following sections.

Participants felt a sense of setback when they did not achieve the recovery goals they had set before discharge: ‘I thought I’d come home and 3 or 4 weeks I’d be doing everything normally. But it hasn’t happened that way now’ (SS02, T2). The setbacks triggered their frustration throughout the transitional care period: ‘What I find a little bit frustrating is I expected to get to continue on another curve [of improvement]. But it’s flattened out and nothing much has changed’ (SS07, T2). The setbacks to recovery also contributed to their grief on the loss of independence brought about by stroke: ‘It’s pretty hard to take that independency away from me that all that’s gone now to a degree because I can’t drive anymore’ (SS04, T1). The loss of independence also contributed to the perception of the loss of their usual role and responsibilities in a family: ‘I’ve suddenly felt outside my family. I’m not important to anyone anymore’ (SS04, T1). Without proper interaction, situations like this would result in a sense of loneliness in their own family for people with stroke, although they might have had family members around them. Loneliness in people with stroke not only affected their mental health but also that of their caregivers due to the dyadic effects. Therefore, the need to prepare caregivers to engage their care recipients in meaningful activities in the family is evident for hospital-to-home transition care.

Stroke participants also shared their emotional reactions towards the setbacks in post-stroke recovery. These included feelings of resentment and fear, being teary and having negative thoughts about their future. For example, one participant felt that ‘the living situation is worse because I get angry quickly … I get emotional, teary … Just a thought. My grandson’s in Grade 3. Am I going to see him when he is in Grade 4?’ (SS08, T2). Some participants described their fear of having another stroke: ‘I’m afraid to get into my bed again because that’s where the stroke happened. I sleep in the lounge chair every night, which is not really the best thing to do’ (SS05, T1). This case revealed a possible lack of knowledge in preventing secondary stroke that resulted in behavioural changes in people with stroke. Preparing people with stroke with knowledge about stroke prevention in the transitional care period is a way to reduce their psychological stress and change their behaviour while engaging them in self-care. Such an education strategy would reduce burdens for caregivers, considering the dyadic effects.

It was evident that unrealistic recovery goals contributed to the feeling of setbacks and triggered psychological stress in people with stroke in the first 6 months after returning home. Such situations underscored the need to support people with stroke to develop achievable and realistic recovery goals throughout the transitional care period. Considering the dyadic effects, caregivers also need to be included in the discussions of the recovery goals to foster their positive impact on the care recipients.

7.2.2 Subtheme 2: Processing Loss and Grief in Caregivers

Caregivers also experienced setbacks in taking on the caregiving role. Returning home after stroke seemed to have provided caregivers something to look forward to (Chapter 6). However, when faced with the changes in a real-life situation, caregivers were overwhelmed and did not seem to find hope and positivity in their situation. They experienced loss and grief due to their loved ones' health conditions and the changes in the lives in the family. One caregiver revealed her sense of loss and grief at the 3-month interview:

> His speech was shocking, his cognitive skills were very bad. So, I was living with half a shell of a man, which it becomes very, very stressful because you've lost your partner, your confidant, your husband, your friend, it's all gone, and you have to adjust to that. That's very, very difficult. (SC08, T1)

After hospital discharge, caregivers were faced with not only practical care activities but also significant psychological adjustment to develop strategies for living with their loved ones with stroke-related impairments, especially cognitive and speech deficits. It cannot be overemphasised that service providers need to continue to monitor caregivers' care needs and identify psychological needs timely after discharge from hospital so that rehabilitation teams and community service providers can continue addressing these concerns and develop a care plan specific to individual life situations.

The sense of loss was particularly significant in couples who used to work closely in everyday life before the stroke. Grief, to an extent, seemed to have left caregivers in despair, as one young caregiver shared: 'I do grieve the fact that XX [husband] has changed so much. Because we used to have lots of talks and conversations. I want to have hope, but it's quite hard; I do feel quite alone at times' (SC05, T1). In this case, tailored interventions to address the psychological care needs of caregivers would be warranted for community care providers when developing care plans for people with stroke. Counselling services may improve the feeling of helplessness and further support the development of resilience.

The unpreparedness to assume the caregiver role before hospital discharge also contributed to the feeling of setbacks, loss and grief that had a negative impact on the psychological wellbeing of caregivers in the follow-up period. At the 3-month follow-up, their stress seemed to present in the form of anger and resentment when talking about the changes in their life since their loved ones returned home. This was reflected in a wife's explanation of her mental state: 'I just felt he [husband] consumes me. I have no time for myself … I struggled with resentment of my own emotions. Just the guilt I felt the whole time. I thought one time if he died it would be better' (SC03, T1). The caregivers' psychological and emotional distress seemed to be intensified after taking over care from professionals. Caregivers would benefit from a thorough review of their psychosocial needs by community service providers so that a tailored plan targeting each caregiver's specific circumstances could be put in place to provide emotional support and address some concerns that might not have been identified before hospital discharge.

At the 6-month follow-up point, people with stroke demonstrated functional improvements, including in cognition and speech. While functional improvement signified a milestone for people with stroke, the anxiety and fear that came with it complicated the transition for caregivers. One wife described mixed feelings regarding her husband's improved cognition:

> XX [husband]'s brain function has improved. But with that, his cognitive understanding of where he's at has made him quite depressed. He feels anxious that he's never going to get better. He's scared that this family is going to abandon him when I had to work extra hours and gradually back to normal working hours. So, that was very stressful. (SC05, T2)

In this case, the dyadic effect was evident. The mental state of people with stroke triggered psychological stress for caregivers. Understanding such dyadic effects would help nurses and other stroke care professionals to better support caregivers and those they care for.

As demonstrated in these findings, stroke-related disabilities in people with stroke appeared to be a significant impact on their caregivers' psychological stress. However, people with stroke rarely described the impact of their caregivers' psychological stress on them. Interventions in hospital and continued psychological support in the community for caregivers would not only empower them to cope with stress but also help their care recipients to deal with setbacks and the sense of loss and grief.

7.2.3 Subtheme 3: Reconciling With Resilience

Despite setbacks and the sense of loss and grief, stroke dyads seemed to actively seek strategies individually and dyadically to cope with stress, manage their negative feelings and work with stroke-related limitations. It was evident that time and functional improvement for people with stroke had helped with the adaptation process. Furthermore, participants perceived dyadic effects in the psychological adaptation process in the home care setting, as detailed in the following sections.

7.2.3.1 Resilience in people with stroke

Most stroke participants demonstrated resilience, which was evidenced by their acceptance of and positive thoughts about stroke-related changes and their determination to find ways to resume everyday life activities. While adapting to changes, participants persevered with strategies that could help them move forward. One participant expressed his gratitude that he was 'lucky to be still alive and can still participate' (SS04, T1). This was echoed by another participant, despite his disappointment regarding his progress 6 months after discharge: 'It is not changing; I got to live with it. It is not ideal, but I can walk. Well, I see people that are in wheelchairs or people who can't move legs and say to myself, I'm lucky' (SS07, T2).

People with stroke demonstrated an ability to identify positivity when faced with challenges. In the process of working together with them to achieve their rehabilitation goals, recognition and encouragement from health professionals may support the cultivation of positive thoughts.

Participants discussed the positive thoughts that enabled them to accept stroke-related limitations and adjust to these changes. One participant with memory issues stated, ‘some things I just keep forgotten. In the long run I thought I’m better off just being cheerful and getting on with it. And I’m not feeling sorry for myself and negotiating everything if it comes up’ (SS10, T2). Other participants reconciled themselves with their limitations. The statement from a participant who was living with stroke-related fatigue and sensation changes exemplified this: ‘I think probably more coming to terms with the fact that this is what it’s like … the level of getting better is probably very little increase; however, the acceptance of it being as it is, is probably more accepted’ (SS08, T2). Reconciliation with stroke-related physical and emotional limitations seemed to help participants leave behind the stroke event and approach the post-stroke adjustment realistically.

With time, participants developed strategies that enabled them to acknowledge limitations while focusing on what they could do. One participant discussed how he had to adapt to balance and dexterity issues: ‘I won’t say I have adapted. I’m still adapting and adjusting. I am looking at my improvement is that I can work the heights and multitask’ (SS02, T2). Similarly, when reflecting on what made him persevere and move forward in spite of stroke-related limitations, one participant identified silver linings in the midst of adversity: ‘But my life has changed because I don’t want to go back to the old [unhealthy] life. People saying now how much weight I’ve lost … Recovery from stroke had also shown me a way that I could be healthier’ (SS12, T2).

Over time, people with stroke demonstrated resilience in the presence of challenges brought on by stroke through reappraising their functions, reinforcing positive thoughts, reconciling with limitations and identifying positivity out of negative situations. Resilience enabled people with stroke to focus on the priorities in the transition and attempt to resume pre-stroke life. These findings may inspire health professionals to consider strategies to instil hope and provide support, validation and guidance in their interactions with people with stroke to activate and enhance their self-management capabilities.

7.2.3.2 Resilience in caregivers

Caregivers also demonstrated resilience and talked about strategies to help them reconcile with their changed lives. Their resilience seemed to be enhanced with time, the functional improvement of their loved ones, spiritual beliefs and past life experiences. Three months after hospital discharge, caregivers expressed their gradual acceptance of a changed post-stroke life. They identified even the smallest functional improvement in their loved ones, which played a part in their acceptance. As one wife shared:

> It’s only just now you accept what’s happened … You do accept because my husband will never speak like he did, but his speech is getting better, and he can have a little conversation … The grieving and acceptance is better as he’s getting better. (SC08, T1)

The findings implied that both people with stroke and their caregivers have positive dyadic effects in their approach to managing stroke-related limitations and enhancing resilience.

The approach to the changed life, coupled with past life experience, helped caregivers to cope with the challenges during the hospital-to-home transition: ‘My life has not always been easy. So that’s why I am accepting. I look at my life now, it’s not bad, but it’s different. And I’m just going to live a little bit of a quieter life’ (SC08, T2). In this case, life experience and personal value seemed to act as sources of strength to enhance caregivers’ resilience, which gave them the courage to continue to support their loved ones. A lack of this may hinder an adjustment and return to pre-stroke life for the dyads.

Some caregivers had not quite accepted the changes yet, even at the 6-month follow-up. However, they exhibited the ability to live with uncertainty and ‘just expecting the unexpected’ (SC06, T1) and move on with life. As one caregiver’s statement represents:

> I have not completely accepted [stroke]. I am wanting him back to the way he was. And I’ve got to keep saying the same when he wants more of my time: ‘You’ve got to do that [exercises]’ … My mind is at the painting while listening to him talking about cars. That’s just something that I’ve got to live with. (SC11, T2)

Viewing uncertainty as part of life may symbolise caregivers’ ability to live with it. As presented in this case, caregivers seemed to have developed strategies to balance their own needs and those of their loved ones. These strategies may enable them to continue supporting people with stroke and become new ways to adapt to stroke-related limitations and better sustain the caregiving role.

During the first 6 months following hospital discharge, caregivers were in the process of adapting to their changed lives and reconciling the present with the pre-stroke life. With time and functional improvement in their loved ones, they developed coping strategies and enhanced resilience to face the challenges. Positive dyadic effects were evident in the enhanced resilience in stroke dyads and functional improvements in people with stroke. These findings encourage stroke nurses and rehabilitation teams to formulate interventions targeting individuals’ specific life situations, to guide them in balancing expectations and the capacity to optimise their relationship, and to strengthen the adaptation.

7.3 Theme 5: Role Transformation

This theme focuses on stroke participants’ self-management development with the support from their caregivers and on caregivers’ evolving ability to build capabilities in collaboration with people with stroke despite being confronted with physical, communication and cognitive limitations and psychological distress. The dyadic effects in dealing with challenges enabled them to transform and adapt to their post-stroke lives. Stroke participants demonstrated their ability to accept stroke-related limitations, create new ways to work with these limitations, and regain a sense of control of health, wellbeing and social integration. Stroke caregivers appeared to be in the process of gradually transforming and settling into a new role in the family and community. They also discussed what could have been done to support the development of self-management and caregiving capabilities.

7.3.1 Subtheme 1: Impact of Stroke-Related Limitations on People With Stroke

This subtheme illustrates the challenges related to various stroke-related limitations experienced by people with stroke, especially at the early stage of returning home. Prior to hospital discharge (Chapter 6), they might have already expected a different life after stroke. However, it was when they encountered these differences in real-life daily activities that they realised the implications of these limitations.

When they first came home, some stroke participants perceived home as a strange place and experienced distinctive differences between their expectations of their functioning and their actual status in the home environment. A participant described her feeling when she first arrived home after a long hospital admission: ‘You think, if I get home, everything is going to be normal, but it’s a bit of a shock when you get home and discover that you can’t move around like before, you can’t do the things like before’ (SS06, T1). The unexpected nature of stroke, functional impairments and length of hospital stay complicated transitioning home for people with stroke. A health-professional-supported home visit, with trials of daily activities in the home environment before discharge from hospital, may help put in place some strategies and alleviate anxiety and frustration at the initial homecoming stage.

Stroke participants experienced difficulties affecting their participation in daily activities. For example, a woman who was independent with ADLs found her ‘energy level gets smashed’ (SS08, T1); she had to break down her tasks, and everything became slower. Another participant was ‘very depressed and unhappy’ (SS05, T1) that she needed antidepressants to continue participation in telerehabilitation at home. Stroke participants would benefit from education about stroke-related complications and the implications for their daily activities. Strategies such as energy conservation and managing negative emotions may foster the development of self-management capabilities.

Stroke participants were not only confronted with the impact of these limitations in self-care activities, but they also expressed concerns about the impact of stroke on their caregivers. Their concerns extended over the 6 months after hospital discharge. One stroke participant emphasised the need for support for caregivers: ‘Me coming home was an enormous challenge and burden for her [wife]. While the focus was on me, she probably needed emotional support. Some support on really what is the impact to the partner when the patient comes home’ (SS12, T2). This case implied that a stroke participant’s perception of their caregiver’s emotional distress and caregiving burden being ignored by health professionals could distract those people with stroke from concentrating on developing self-management capabilities during the transition. This highlights the interdependence within a stroke dyad and the possible dyadic effects that could promote or hinder the progression of regaining control of life.

Resuming driving was an important symbol of regaining control of post-stroke life. Several stroke participants expressed their frustration at the prolonged and seemingly incomprehensible assessment process to regain their driver’s license. They understood the need to suspend their license after stroke, but they did not seem to know the assessment process and felt they were expecting the unexpected in the process. A participant’s statement represented this: ‘The issue is that you are not kept informed what’s going on. It’s just like the process of getting a license again. The process was unknown to me … I know the principle, but nobody told us that’ (SS07, T2). Stroke participants’ experiences indicated a lack of adequate information provision before hospital discharge. Comprehensive processes, like the assessment for a driver’s license, should be explained with a step-by-step guide that considers an individual’s stroke-related limitations. This may alleviate stress when people with stroke need to face it in the community.

Perceived stroke-related limitations and their impact on the life of people with stroke was complex. Physical and psychological impairments limited their participation in self-care and home-based rehabilitation programs. Before they returned home, people with stroke were probably mentally unprepared as to the extent of the impact of these limitations on their life, especially the impact on their caregivers. The perceived unmet emotional needs of stroke caregivers may hinder the concentration of people with stroke on developing self-management capacities. The in-depth insights of health professionals into the complexity of the perception of people with stroke can help in developing strategies for discharge planning and for the process of delivering home-based or community rehabilitation programs.

7.3.2 Subtheme 2: Impact of Stroke-Related Limitations on Caregivers

People with stroke returned home with varied levels of physical, emotional and cognitive limitations that caregivers must manage together with them. Caregivers revealed inadequate knowledge and skills to deal with these limitations, which placed people with stroke at risk of adverse events, such as rehospitalisation, and placed caregivers at risk of mental stress. For example, a caregiver brother was concerned about stroke-related incontinence that was neither managed before hospital discharge nor reviewed in the community. He felt helpless because he was unable to support his sister: ‘Since she’s had the stroke, she is suffering from incontinence. No one has done anything about it, which I find it frustrating. Because she’s got it and cannot control it, she suffers from depression so badly. Nobody’s helping her’ (SC10, T2). This case demonstrated that a stroke participant’s physical limitations and mental state could negatively affect the caregiver’s caregiving experience. Understanding the interdependent interaction within a stroke dyad and the factors contributing to positive or negative dyadic effects would inspire stroke nurses and rehabilitation teams to co-develop care plans that can be implemented in the community and promote self-management for both people with stroke and their caregivers.

This sense of unpreparedness was echoed by another caregiver caring for her mother, who was on a modified diet:

> We found it very hard when Mum first came home because she was on a soft moist diet. The speech pathologist went through what Mum could and couldn’t have. But Mum didn’t know what to have, so it was a lot for us to work out what she can eat. (SC02, T1)

This demonstrated a lack of effective pre-discharge preparation for both people with stroke and their caregivers regarding the knowledge about stroke complications and the management of these complications. They might have received education and training on caregiving, but the evaluation of effectiveness seemed opaque. Gaps in assessment and communication between care settings were evident, which highlighted the significance of a holistic approach from nurses and rehabilitation clinicians to care needs identification and intervention before hospital discharge.

Apart from dealing with visible stroke-related limitations for people with stroke, such as walking and speech difficulties, incontinence and the requirement for a modified diet, caregivers were also faced with challenges from invisible limitations, such as fatigue, emotional lability, memory issues and behavioural changes for people with stroke. A wife caregiver shared her struggle with her husband's memory impairment:

> I've really struggled with the fact that his [husband] memory has interrupted his ability to see how he's improving … He doesn't see the whole idea of being dependent and me offering my observations and giving him feedback—and so we've had to work through a lot of things but having the counselling once a week has really helped. (SC01, T1)

Since the onset of stroke and before hospital discharge, caregivers might have expected difficulties managing stroke-related limitations. These limitations only became more prominent and posed challenges when they were manifested in real-life situations. As applauded by the caregiver in the above example, counselling services were essential for supporting caregivers in managing their own emotions and in developing strategies to cope with the changed cognitive state of people with stroke. Psychological support in the community may also help prevent caregivers from burnout.

Intimacy and sexuality form an important part of quality of life. Satisfaction in intimate relationships may be impacted by stroke-related sequelae. This seemed to have complicated an already challenging transition time for caregivers, as one wife expressed: 'Everything was breaking down. His confidence took a real blow. Life now is pretty sexless—we had a fairly healthy sex life before. We were very confident with each other. He's just lost that. He's a lot less patient' (SC03, T1). Stroke dyads may experience relationship challenges due to a changed level of intimacy caused by stroke-related limitations. In this case, the interdependence within the dyad may create unhealthy dyadic coping that challenges the dyad's adjustment to their changed roles in their relationship. This suggests that there is a need to include topics about post-stroke intimacy and dyadic relationships in discharge planning and stroke education so that stroke dyads understand the potential impacts of stroke on their relationships and can co-develop interventions to prevent deterioration and enhance their relationships.

All caregivers in this study talked about how busy they became after stroke throughout the whole hospital-to-home transition period, especially at the early stage of the transition. They had to juggle different roles and multiple tasks to maintain some pre-existing routines and to motivate people with stroke to continue with rehabilitation activities. A couple of caregivers described the situation at different time points:

> First 6 weeks I think—there's been shifts and changes. Initially, it was just really hard work. I felt like I was battling against time the whole time because I wanted time for XX [husband] to practice those things that are difficult for him to do, such as processing information. (SC01, T1)
>
> Life has picked up a much faster pace. Because XX [husband] has increased the amount of therapy. He's going to hydro three times a week, gym four times a week. He's got appointments. It's been hard just juggling these. And on top of that, I've got teenagers. (SC05, T2)

Findings demonstrated that some care needs may be addressed before discharge through education and hands-on caregiver training. Other care needs may emerge and change with time during the transition. Closing the gaps in care needs identification and support between the hospital and the community may be achieved through the early engagement of caregivers with discharge planning in the hospital setting and continued involvement with community service providers. It was clear in the findings that, despite the stress, caregivers were able to find ways to adapt to the changed life. Support and guidance from nurses and other health professionals may ease the intensity of care during the transition.

Echoing people with stroke, at the 6-month follow-up point, caregivers expressed different views about post-stroke progress in people with stroke and their adaptation approaches. Six months after hospital discharge, people with stroke made further progress in functional abilities. The progress seemed to have slowed down and plateaued to a level that both people with stroke and their caregivers had to face and accept. One wife expressed her concerns regarding her husband's mental state: 'XX [husband] hasn't really gone forward, and things have been fairly flat. He's very keen to be independent. But he's not independent' (SC11, T2). With functional improvement in people with stroke, stroke dyads may have established daily routines and resumed some pre-stroke activities, but the feeling of helplessness continued to confront caregivers, as one wife shared: 'So, my life is back. But I haven't got a partner I had before stroke. The responsibility is yours. That's the transition that takes time. It comes with anger, sorrow, grieving because that word "carer", I don't like it' (SC08, T2).

The journey to manage stroke-related limitations for caregivers was filled with strength, resilience, stress and sadness. Caregivers had to manage their own feelings as well as be the resource person for people with stroke to encourage and motivate them through the transition. Understanding the differences in managing stroke-related challenges for stroke dyads would encourage nurses and other health professionals to shift focus from functional recovery in people with stroke to an encompassing view of the transition for the dyad. Health professionals' appreciation of dyadic effects in dyads' coping with the changed life would enhance their engagement with stroke dyads, treating them as a unit of care so that outcomes of both dyad members could be optimised during the transition.

7.3.3 Subtheme 3: Regaining Control of Life

This subtheme presents the strategies that stroke dyads developed to meet the challenges of stroke-related limitations and changed roles over time. Dyads were in the process of balancing expectations and capacities and had achieved different levels of adaptation. Positive dyadic effects between stroke dyad members were reflected in their ability to work together and achieve functional improvement.

With time, stroke participants developed their own strategies to enable pre-stroke activities. As one participant indicated, 'the best physio I've had is actually coming home'

(SS02, T1). He shared his experience of working out specific ways to complete a task: ‘Picking up an electric drill, I have to think through new processes because previously I’d just pick it up and drill. Now I have to put my body behind the drill because I don’t have the strength and dexterity’ (SS02, T1). Finding alternative ways to accommodate stroke-related limitations signified the development of self-management and adaptation.

To achieve their goals of resuming pre-stroke activities, participants not only tried different ways to adjust, but they also explored and sourced services that met their own needs. One participant shared her story of finding a neurophysiotherapist who made a difference to her physical improvement:

> I did get to see my first good physiotherapist 3 weeks ago. That has made a great difference. It was very hard finding one … Now I can climb up and down extremely steep stairs at home, which is a real landmark for me. (SS10, T2)

The initiatives from people with stroke to find services customised to their individual needs reflected their progress in post-stroke adaptation and the beginning of taking responsibility for their own health.

At the 6-month interview, a majority of participants described their physical and cognitive improvement and increased confidence in performing pre-stroke activities: ‘My hand was not working well. Now it is fairly normal. My memory is much better—I am not mixed up with appointments anymore. I had trouble banking on that computer initially. I could do that right now’ (SS05, T2). This case demonstrated that people with stroke developed confidence from re-evaluating their recovery over time, which enhanced their resilience and acted as an impetus for further rehabilitation. However, their progress and increased confidence may not have been possible without the support from their caregivers. One stroke participant attributed his post-stroke improvement to his own efforts and support from his wife:

> My wellbeing is still very high. With the support from XX [wife], I maintain exercise regime in my room. I am walking longer distances now with assistance from family.

> There has been some development with my vision. XX [wife] and I are positive about the way things are. (SS12, T2)

This example indicated that functional improvement and resilience in people with stroke would facilitate stroke dyads' reconciliation with stroke-related changes and the resumption of pre-stroke life. Positive dyadic effects between dyadic members could foster optimism and strengthen dyadic coping in the recovery process.

As summarised by a participant who returned to work after discharge, resuming pre-stroke activities was viewed as a significant achievement during the transition: 'I went from probably being very dependent on the great help I got there [workplace] to having to look around for and try and find other ways of doing things' (SS10, T2). It symbolised a new chapter in their lives as well as facilitating regaining control of their lives.

Findings showed that, with time, people with stroke adapted to the changed life during the transition. Acknowledging their emotional stress and physical and cognitive limitations, they focused on managing and learning how to live with the consequences of stroke, gaining confidence from improvements and maintaining optimism even when challenged with discrepancies between their desired functional gains and reality. Positive dyadic effects demonstrated during the recovery process seemed to have augmented their adaptation.

Caregiver participants reported that they assumed the caregiving role regardless of their different views about the changed role in life and their relationship with the person with stroke. Time, functional improvement in people with stroke, and improved caregiving skills seemed to have helped caregivers transform and increase their strength to look beyond the current situation.

Caregivers' views about their changed role were related to the type of stroke-related impairment in people with stroke. Caregivers for people with stroke who had cognitive or speech impairment and changed behaviours seemed to struggle with the caregiving role even 6 months after discharge. A wife who cared for her husband with significant communication deficits shared her struggles in the adaptation process:

> I am a lucky carer. He could live on his own: just need somebody to come in every day to make sure everything was okay. But becoming a carer made me feel not good at all in the beginning because when you become a carer, you're totally responsible. When you have a partner, you share. So, all of a sudden, you can't share. (SC08, T2)

However, for people with stroke who had physical impairments with no or mild speech and cognitive deficits, caregivers seemed to have experienced positive dyadic effects and found it rewarding to care for their loved one, as shared by one husband:

> It has been tiring and demanding, but it's also been very rewarding. I can see every day she makes progress. Every day she can do some little thing that she couldn't do the day before. She's been really focused and determined to get well. (SC16, T1)

Echoing the above spousal caregiver's experience, non-spousal caregivers also expressed their positive views about becoming a caregiver, as one daughter caregiver commented: 'Well, it's better in one way because I was lonely and on my own as well, and it's given me a purpose and given me things to do for my dad, and I don't mind' (SC07, T1).

Caregivers' perspectives on their changed role seemed to be associated with the status of the person with stroke. Understanding dyadic interdependence in stroke dyads and incorporating dyadic perspectives in support services design may facilitate the hospital-to-home transition.

Regardless of their views, all caregivers demonstrated the ability to renegotiate the new role with a changed mindset and through working together with the person with stroke. Over time, caregivers developed coping strategies: for example, doing exercises for physical fitness, taking up hobbies and chatting with friends. A couple of caregivers who looked after their spouses with memory and communication deficits shared how they managed to cope with all the changes:

> I think generally I'm coping. I'm really grateful that I've used meditation and done a lot of personal growth work, especially in a time of crisis. It's basically breathing and

> centring and letting go and practising mindfulness techniques … and I suppose because of this and also my attitude has supported me. (SC01, T1)

> I have got a theory that if I can do something about a problem, I do it. If I can't, I've got a rubbish bin over my shoulder, and I throw it in the rubbish bin and don't worry about it anymore. So, I have been just going along with the changes. (SC11, T2)

Caregivers' experiences in handling crises in the past seemed to have sustained them in the stroke event. They seemed to be able to utilise resources to develop and enhance resilience to ease the adjustment process. Listening to and understanding caregivers' sources of strength and pre-existing coping mechanisms would assist nurses and the stroke team in creating interventions to instil positivity and hope during the transition, which may have a far-reaching impact on caregivers' ability to sustain long-term care.

When people with stroke and their caregivers worked in partnership, the positive outcomes of their partnership not only encouraged both but also promoted their ability to return to pre-stroke life. One husband caregiver shared their achievement:

> We've gotten deep into the garden down quite a steep path. I just stand there in case she stumbles so I can catch her. We think it's better for her to do it herself … Except those stairs, there's almost nothing around the house that she used to do that she can't do now. So, I'm sure that's been a great boost to the morale of us. (SC16, T1)

Positive dyadic effects were evident when people with stroke and their caregivers worked together to achieve mutual goals, which seemed to have strengthened their relationship, deepened interactions and enhanced dyadic coping.

Caregivers reflected on the fact that the first few weeks of hospital discharge were much busier compared to the stages after that. Over time, they started to look into their own health and wellbeing:

> It was getting me down about trying to get the housework done. Now I've realised that if it doesn't get done, don't worry about it. I'm not so hard on myself anymore.

> You learnt along the way. We'll just have to accept how you are and what you can do. (SC18, T1)

Caregivers were in the process of balancing their capacity and expectations of how their life should be. Shifting the focus to people with stroke alone, to the realisation of caregivers' own wellbeing may pave ways for caregivers' transformation during the transition.

All caregivers who participated in both the 3- and 6-month interviews expressed their hope and determination to move forwards to a better future. Despite the uncertainty, they began to think about plans for the future or about strategies to sustain their life for the long term. A couple of wives shared their visions:

> I said to him, getting away, that's something we've got to work together to sort out. We just got to try and find a happy medium so I can do what I want to do, and he can do what he wants to do. (SC03, T2)
>
> I'm just trying to look at strategies going forward and not using the kids as my means because they'll burn out too. I am going to meet with the support coordinator to see if there are some other things that she would suggest making it work a little bit better. (SC05, T1)

Findings revealed that becoming a caregiver was a huge adjustment for relatives of people with stroke. Losing their identity in the family relationship, taking over full household responsibility and assuming the new role of caring for and motivating people with stroke—for caregivers, these all required both psychological and physical adaptation. Depending on individual circumstances, and at different stages of the hospital-to-home transition, caregivers began to adapt and regain control of their lives over time. Understanding the unique challenges of stroke caregivers and dyadic effects derived from dyadic interactions would enable stroke care providers to co-develop interventions with stroke dyads to strengthen caregivers' ability to adjust and ease the adaptation process.

7.4 Summary

Stroke dyads shared their experiences and views about the process of adapting to the changed life after hospital discharge. This chapter presented two themes and six subthemes focusing on the psychosocial and physical challenges encountered after hospital discharge and the efforts made to find ways to adapt to these changes. Over time, stroke dyads reflected on the impact of stroke; they moved on from the negative thoughts and initial shock when they first returned home. Additionally, interdependent interactions within stroke dyads produced dyadic effects that were closely associated with functional and psychological adjustment of the dyads and their capabilities for partnership to overcome everyday challenges.

One-way dyadic influence was observed in this study, in that caregivers' psychological stress seemed to be affected by the physical, mental and relationship status of the person with stroke, whereas the person with stroke rarely mentioned the caregivers' influence on them regarding psychological stress. Furthermore, they were at different levels in terms of regaining a sense of control through facing limitations with resilience, negotiating daily activities with self-developed strategies, and balancing capacities and expectations. Moreover, while both experienced a huge adaptation, people with stroke seemed to focus more on their physical recovery, while caregivers seemed to perceive the complex losses and reconciliation journey for achieving the adaptation.

The next chapter (Chapter 8) offers the perspectives of stroke dyads regarding support during the hospital-to-home transition and their expectations of post-stroke services during the transition.

CHAPTER 8: Findings—Part 3: Themes From the Follow-Up Interviews With Stroke Dyads (Continued)

8.1 Introduction

As discussed in the previous chapter, this study identified four major themes in relation to the experiences of stroke dyads in the 3- and 6-month follow-ups after hospital discharge. These themes are coping with setbacks, role transformation, transitioning with support, and expectations in hospital-to-home transition care. The first two themes (Themes 4 and 5) were presented in the previous chapter (Chapter 7); this chapter presents the last two themes (Themes 6 and 7). Both themes include subthemes, as shown in Table 8.1.

Table 8.1

Major Themes and Subthemes in Chapter 8

Theme	Subtheme
6. Transitioning with support	**1.** Support from family and friends
	2. Support from health professionals
7. Expectations in hospital-to-home transition care	**1.** Enhancement of discharge planning and preparation
	2. Flexibility of service provision

8.2 Theme 6: Transition With Support

Both people with stroke and their caregivers acknowledged that they were unable to achieve rehabilitation goals and adapt to the changed lives without support from family, friends and health professionals. Subtheme 1 revealed the indispensable role of family and friends throughout the hospital-to-home transition journey for stroke dyads, especially the considerable support people with stroke received from their caregivers. Positive effects arising from the support between dyadic members were identified. Subtheme 2 detailed participants' perceptions about professional service provision that either enhanced or could work better to facilitate their transition.

8.2.1 Subtheme 1: Support From Family and Friends

All stroke participants perceived the critical role their families and friends, especially caregivers, played in supporting them to adapt to living with stroke-related disabilities at home in the first 6 months after hospital discharge. Positive dyadic effects arising from perceived support between the dyadic members fostered transitional care. However, caregivers were in the midst of developing their caregiving capability, and the support they received from other family members varied in the early stage of homecoming. Stroke dyads also received support from those in their social network, including friends, neighbours and colleagues, which had a positive impact on their recovery experiences and enabled them to cope with stress and self-care despite living with stroke-related disabilities. In addition, adequate community resources enhanced their transition experiences.

The support from caregivers and other family members encouraged people with stroke to improve self-management, as one stroke participant emphasised:

> I love my wife and kids. I really understand more now post-stroke. XX [wife] is always there. My son and daughter drop in frequently … They really inspire me. It's almost the case I owe them that I go in to work through this and come out on the other side. I am well on my way to doing that. (SS12, T2)

It is evident that perceived support from the caregiver and other family members motivated the person with stroke to achieve his rehabilitation goals and to adapt to stroke-related disabilities. The findings also indicated that stroke caregivers and other family members, as a care unit, played a critical role in supporting people with stroke.

Diary and interview data from participants revealed positive dyadic effects arising from caring, understanding and encouragement within the dyad. For example, a stroke participant reflected on the support from his wife in the diary at different time points. At Week 1 post-discharge, he wrote, 'XX [wife] is very understanding of my limitations. But she allows me to try things out' (Diary SS02, T1); At Week 2, he described, 'I am starting to do small things in the kitchen. XX [wife] does not have to provide personal care now' (Diary SS02, T1). At the last interview, he said, 'I sometimes need motivation to do things. XX [wife] tries different ways to help me with this' (SS02, T2). Likewise, his wife was also inspired by his improvement, as the wife wrote in the diary at Week 4, 'I can see good and positive changes happening. I'm happy because he is not so negative' (Diary SC03 [wife of SS02], T1). These examples indicated that the dyad had a mutual understanding of stroke-related limitations and self-management goals. Moreover, they also demonstrated partnership in post-stroke recovery and care, which benefited their wellbeing.

However, each family is unique. Some participants perceived less support at the early stage of returning home than they had expected, for various reasons (e.g., the caregiver's advanced age). A stroke participant shared her perspectives on family support when she needed it the most upon arriving home from hospital. Her elderly husband caregiver was only able to provide minimal assistance, and there was no active home care service at the time:

> My family have been lovely, but I think once you leave hospital, they think you're better [and do not need help] … XX [husband] can't help much. I don't like to press the family; I know they're busy. My daughter works, and my daughter-in-law has also got her mother living next door, can't do [much for me]. (SS06, T1)

This case highlighted the significance of caregiver capacity assessment before hospital discharge. In some family situations, both the primary caregiver and other family members should be engaged in discharge planning to activate family support for stroke dyads during the transition.

People with stroke highly regarded the support from caregivers during the transition. They suggested that it is particularly important for health professionals to understand caregivers' needs and their preferred approach to address these needs during the transition:

> I was prepared for that [discharge] physically … [but] we are not prepared as patient, partner and even other members of the family … challenges and responsibilities all of a sudden bestowed upon my wife, particularly she is employed … There were

> probably small incidents where we weren't all on the same page, and that can affect me as patient, and could also affect my principal carer. (SS12, T2)

Findings indicated that support from caregivers is imperative for people with stroke to cope with challenges in their reintegration into the community. However, other family members also play important roles in supporting stroke dyads in the transition. Perceived unpreparedness for stroke dyads and their family seemed to have intensified psychological stress for stroke dyads. Engaging all key family members, including principal caregivers, in care planning and decision-making before hospital discharge appeared to be essential to empower caregivers and other family members to appropriately support people with stroke.

Stroke caregivers in this study highlighted the support they received from people with stroke and other family members that was essential for alleviating stress and strengthening their caregiving capabilities during the transition. One caregiver, who cared for her husband with cognitive impairment, talked about the support from family that enabled her to sustain caregiving: 'I feel like I've been blessed with the people around me. When I am getting up towards a bit of overwhelm maybe, they come along and just take off things that they can, which have been really good' (SC01, T1). Another husband caregiver concurred and expressed his gratitude for the support he received from his wife (the person with stroke) and son:

> She [wife] has never complained or been self-pitying. She's just focused on what the next step is ahead. Our son has also been splendid. He came over here from XX [city] and helped me a lot … I'm optimistic. I hope and expect her [wife] to be with us for a good number of years. (SC16, T1)

As described in this example, optimism demonstrated by people with stroke, coupled with support from family and friends, seemed to have cultivated hope, strengthened caregiving capability and enhanced resilience in caregivers. This case also demonstrated positive dyadic effects in the dyad.

Caregivers also revealed that their ability to cope with daily activities and caregiving during the transition was impossible without support from friends, neighbours and employers. They identified that ‘neighbours are wonderful and have walked the dog for us’ (SC16, T1) and that friends had been ‘fantastic. From that point of view, we’ve had really good support’ (SC06, T1). For caregivers who were still in the workforce, their employers also played an important role in supporting them in coping with the changes: ‘I’m very tired, but coping. I think I have a very strong faith, along with the workplace that’s very supportive’ (SC05, T2).

The experiences described by the caregivers above indicated that the support from social networks helped them adapt to the new norm. The physical and emotional support not only helped alleviate some of the caregiving burden but also enhanced caregivers’ resilience. Support from family and social networks enabled stroke dyads to cope with challenges and setbacks during the transition. It served as a protective barrier against threats to their wellbeing. Health professionals’ knowledge of pre-stroke family dynamics, social support networks, the family’s caregiving capabilities and potential dyadic effects would prompt a tailored care plan to support stroke dyads through the hospital-to-home transition.

8.2.2 Subtheme 2: Support From Health Professionals

Recovery from neurological injury following stroke is complex and influenced by individual situations. This requires stroke care service providers and health professionals to work collaboratively to apply collective knowledge and specialist skills for the benefit of stroke dyads. Stroke dyads perceived that support that focused on both dyadic members facilitated effective functional improvements for people with stroke and enabled psychosocial recovery for both of the dyad’s members in the transition period.

All participants commended the support from health professionals who enabled the person with stroke to achieve goals of resuming pre-stroke daily activities and facilitated caregivers’ adaptation. Compared to their perceptions at the initial homecoming stage, stroke participants gradually adapted to the ‘new’ home environment and daily activities at home. They perceived that they were ‘getting more confident and much stronger’ (SS09, T1) and continued rehabilitation helped them regain functions and maintain motivation: ‘I’m basically pretty lazy anyway, what I could've done extra on my own, I never did. I just did my exercises with them [therapists on iPad]. It got me to the stage where I could walk without the frame' (SS05, T1).

Rehabilitation was imperative in the first 6 months after hospital discharge. It not only helped improve physical functions, but it also strengthened and maintained participants' motivation to move on with their lives. Suspension of planned rehabilitation due to the global coronavirus pandemic clearly affected participants' desires for continued functional improvement: 'I'd been to the hospital [day rehabilitation centre]. I really came out with strength and determination. Then it was COVID. The rehab was deferred. I was a bit low; it was frustrating that I was marking time' (SS12, T2). This example indicated the need for innovation in community rehabilitation service delivery. Telehealth may have filled in the gaps during the pandemic by improving the accessibility of rehabilitation services and continuity of quality care for stroke dyads.

Stroke caregivers echoed stroke participants' positive views about health professionals who provided post-discharge rehabilitation programs. They considered that the continuity of rehabilitation motivated them: 'It gave her [person with stroke] some confidence to get up and go around and doing things she had to do, and I felt so relieved' (SC17, T2). Post-discharge rehabilitation follow-up also reassured caregivers:

> I think when you're in the carer role … initially it's kind of a scary outlook. These services help you in a lot of ways with that. They help balance your crazy thoughts at that time and offer those things that help settle you in that way, which I think is worth gold. (SC02, T2)

Continued engagement with caregivers after discharge and stroke participants' increased confidence and functional recovery seemed to have strengthened caregiving capabilities and promoted their adaptation during the transition.

In addition to the benefits brought by post-discharge rehabilitation programs, participants also discussed the support they received from community care services. The continuity of these care services enabled stroke dyads to focus on functional improvement, psychological adjustment and self-management capability development. One stroke participant, who had carer responsibility for her daughter who had disability, commended the support she received from the service provider for her daughter:

> When I was in hospital, they [service provider] put in extra support for XX [daughter]. Initially, when I came home from hospital, they actually came on Saturday/Sunday as well just to make sure I was okay to handle things … now I'm at a stage to cut back. However, I could always call on them to help out again. (SS08, T1)

This case revealed that individualised care services and flexibility with service delivery offered reassurance as well as alleviated anxiety for people with stroke in case their health condition changed.

Continuity of community care services for people with stroke after completion of rehabilitation programs seemed to have also supported caregivers and enhanced their sense of certainty. One caregiver expressed his satisfaction:

> [Rehabilitation therapists] were terrific. Then they handed us over to XX [community care service] … They made regular phone calls to see how things are going … it makes me feel we're in control of the situation; we're not waiting for something to happen unexpectedly. (SC06, T2)

Participants' experiences indicated that community care services played a crucial role in supporting stroke dyads through this challenging transition period. These services enabled stroke dyads to adapt to the changed life at their own pace and enhanced their self-management capabilities to improve independence and resume pre-stroke life.

When discussing service delivery, stroke dyads acknowledged the essential role health professionals played throughout their post-stroke recovery journey, especially during the hospital-to-home transition. Stroke participants were inspired by health professionals during therapy interactions. They commended the tailored approach of health professionals that carried them through the transition and helped them increase confidence and gradually resume meaningful activities and reintegrate into the community. One stroke participant shared how the physiotherapist from the home rehabilitation service supported her to achieve her goals:

> I said to him [physiotherapist], ‘I want to get on the bus and go up to the city’. So, at the last session, we walked up to the bus stop, got on the bus, went to the city, and caught the bus back. We were really pleased that I’d really achieved what I wanted to do. (SS09, T1)

This participant’s experience exemplified the positive outcomes generated through collaborative efforts between health professionals and people with stroke. Health professionals’ partnership approach to service delivery appeared to have promoted a return to pre-stroke daily routines for people with stroke that helped improve their physical and psychological wellbeing.

Stroke participants’ positive perspectives resulting from their interactions with health professionals were also reflected at the completion of a service program. Appropriate preparation focusing on developing self-management helped to maintain motivation for rehabilitation:

> I knew it was time to move on. XX [therapist] and I discussed what I supposed to do when that rehab [program] stopped. He pointed out the benefits of continuing exercise. And the responsibility was shifting to me to maintain the programs. It, in a way, was a turning point. He also provided me with paperwork on organisations and some physios contact. (SS12, T1)

This example augmented the significance of self-management development guided by health professionals. Encouraging people with stroke to take an active role in their own rehabilitation seemed to motivate people with stroke and strengthen their self-management.

Caregivers’ perceived engagement in the hospital-to-home transition process appeared to have increased their confidence to take over care from health professionals. One caregiver, caring for her husband with speech and cognitive impairment, described, ‘they [rehabilitation professionals] were trying to give strategies to me to support XX [husband] at home. I felt respected and felt like I was an important part. There was a sharing of information and collaboration' (SC01, T1). A focus by health professionals on caregiving capacity development would facilitate problem-solving during the transition and potentially improve caregiving sustainability.

Health professionals' compassionate approach in their interaction with stroke dyads was described by caregivers as 'encouraging that instilled confidence and helped him [husband with stroke] improve so much' (SC18, T1). Moreover, caregivers viewed the provision of tailored information by health professionals as educational in that it 'answered all of my questions about what's available and gave us tremendous information of things that we didn't know' (SC06, T1).

These caregiver perceptions further highlighted the benefits of stroke-dyad-focused care provision, which could potentially motivate stroke dyads, improve their physical and psychological wellbeing and enhance the hospital-to-home transition.

However, contrary to the above, participants also discussed what could have been done to facilitate their transition and areas for improvement to enable the building of self-management capabilities. One stroke participant, who was involved in telerehabilitation after discharge decided to cancel the rehabilitation service, described her interactions with the therapist:

> She [therapist] didn't really give me any exercises on iPad after the first session. She rang once again and said 'why can't you come down to the hospital'? I said I live in the hills and can't drive yet. She didn't ring again. I just didn't get any physio at all. And I really still needed it badly. (SS10, T1)

It was evident in this case that a partnership approach by health professionals would promote service utilisation. Assessment and knowledge of the specific situation of people with stroke would facilitate individualised rehabilitation intervention for them.

People with stroke who participated in rehabilitation programs aimed to achieve their personal goals. They perceived that, when rehabilitative interventions were delivered in a one-fits-all approach, the intervention was ineffective and resulted in frustration. A participant with reading and writing difficulties perceived that he was asked to read the same article many times and write three main points over the 6 weeks of the program without receiving feedback on what he wrote: ‘I didn’t initially but tried to mention at the end. I think they understood what I was saying … but one of them even said “No, got to tick this box”. So, I thought this is just a ticking box exercise’ (SS07, T1).

Participants’ experiences emphasised the person-centredness and shared goals of service delivery. The approach and attitude of health professionals seemed to decide the level of engagement of people with stroke. The perceived box-ticking approach did not consider the differences of the individual and their needs. Declining therapy participation during the transition may affect the motivation of people with stroke and jeopardise the building of self-management capabilities.

Differences regarding perceived challenges working with health professionals existed between people with stroke and their caregivers. Difficulties experienced by people with stroke seemed to be associated with post-stroke rehabilitation therapy. For caregivers, when working with health professionals, their perceived challenges appeared to be related to information provision and the flexibility of service provision. Caregivers appreciated post-discharge support but found that ‘we just got so much information. We understand that they [therapists] had a lot to do in a short time. But to try and process it all was really tricky for us’ (SC02, T1). Information provision based on health professionals’ workload rather than stroke dyads’ needs and capacity may create stress and confusion for stroke dyads due to information overload. This not only defeats the purpose of building self-management capacity but may also intensify caregiver distress.

During the transition, caregivers experienced different levels of flexibility in service delivery, ranging from positive experiences—‘they really give you the opportunity to make a time that you’re available’ (SC02, T1)—to less positive ones —‘I don’t think in the whole process that people understand just what’s involved from the carers’ perspective. For example, they would just expect you to be there the next day for an appointment’ (SC05, T2). Caregivers’ distinct experiences indicated inconsistent post-discharge service delivery.

A person-centred service delivery model appeared to ease anxiety and stress during the transition.

Findings highlighted that post-discharge rehabilitation and community care services were essential to enable the hospital-to-home transition for stroke dyads. Participants identified health professionals' central and critical role in supporting stroke dyads during the transition. The person-centred approach strengthened the confidence of stroke dyads and guided them to grow and accomplish taking over care from health professionals. Positive interactions with health professionals seemed to encourage and motivate people with stroke and enable caregivers to develop self-management capabilities. This further emphasised the significance of health professionals' involvement in the transformation of stroke dyads during the transition.

8.3 Theme 7: Expectations in Hospital-to-Home Transition Care

Reflecting on their hospital-to-home transition journey, study participants identified what could have been done to make their transition better. Subtheme 1 highlighted the significance of engaging both people with stroke and their caregivers, though especially caregivers, in the discharge planning process before returning home. It also highlighted that continuity of care could be enhanced by stroke-specific services, especially for those residing in regional areas. Subtheme 2 detailed the expectations of stroke dyads on the flexibility of service delivery in the community that could better support stroke dyads, especially caregivers, during the transition.

8.3.1 Subtheme 1: Enhancement of Discharge Planning and Preparation

After stroke dyads arrived home, they started to identify issues that could have been addressed before hospital discharge. They recognised that adequate preparation before discharge, with continued rehabilitation and care services, were essential to support their post-stroke adaptation and transformation. Participants discussed strategies that could better support them in coping with the transition, including information provision and self-care and caregiving skills-building.

Stroke dyads expressed their preference for engaging in the discharge planning process so that they could feel prepared and informed for homecoming. They recognised that a lack of involvement could have a negative impact on their ability to adapt to stroke-related consequences. One stroke participant, who had continence issues complained, 'I'm just disappointed that I've been left with it [incontinence]. I don't understand why. I'm quite devastated. I was hardly at all [involved in discharge planning]. The [rehabilitation] goals weren't done until the day before I left the hospital' (SS05, T1). From the caregivers' perspective, involvement in discharge planning would help them organise life and prepare for the arrival of their loved ones. However, some caregivers were not adequately prepared with personal care skills. One caregiver, who needed to help her husband with personal care, stated, 'no, I did not have training. You just do it. I just accepted it and did it. We had a seat in the shower. So, it's just all been about him' (SC18, T1).

These examples reinforced that stroke dyads' full engagement in their own care and skills-building for ADLs were essential parts of discharge planning. Training and practising these activities, guided by health professionals, seemed to empower stroke dyads and ease some uncertainties after they returned to the community. This had a significant impact on their perceived capabilities to self-manage daily life situations.

Some stroke caregivers for people who had long hospital stays suggested that a meeting with the rehabilitation team at the early stage of admission and before discharge would have made them feel more engaged because 'after these meetings in the beginning, as time goes by, you sort of left to your own bosses and you just don't have that contact [with the team]' (SC18, T2). A second family meeting 'just gives a sense of what everybody thought was beyond the hospital and what to do to prepare for the coming discharge' (SC14 & 15, T2). Caregivers also indicated that family meetings on the day of discharge would not work because 'at the time you're trying to get them out [of hospital], you don't always think of the questions to ask' (SC02, T2).

The above suggestions illustrated the timing and format of communication and involvement in discharge preparation that could improve stroke dyads' transition experience.

Their suggestions further emphasised that discharge plans should be based on individual situations and tailored to specific needs—for example, people with long hospital stays may require comprehensive preparation before discharge.

Participants also highlighted that the content of information, and the approach to delivery, could be improved before hospital discharge, which may alleviate their sense of uncertainty. They desired a clear rehabilitation plan after discharge as well as a clear explanation of the person-specific challenges that they may face after returning home:

> I just think there's not enough time or written material available to just spell out, 'hey, when the patient gets home, you're going to be confronted with this, this and this. You'll be [with] home rehab and then you're back in the day rehab'. So, I think that can be modified and inclusive, certainly more inclusive of the carer, the wife. (SS12, T1)

Conversely, some caregivers were overwhelmed by the quantity of information they received before discharge. As one caregiver, looking after her mother with swallowing difficulty, stated, 'it was good that they all came and spoke to us. But some of that food thing, which I find overwhelming. Maybe that's just a personal thing for me' (SC02, T2).

Findings revealed the unique information needs of stroke dyads that could be influenced by stroke-related impairments, the family situation or the caregiver's capacity to digest information. Insights into their preferred approach to information-sharing may guide health professionals to improve collaboration with stroke dyads in planning and preparing for discharge.

This subtheme reinforced the significance of health professionals' partnership during the post-stroke recovery journey for stroke dyads. Findings stressed stroke-dyad-centred discharge planning, self-management capability-building and information-sharing that could play essential roles in enhancing stroke dyads' hospital-to-home transition.

8.3.2 Subtheme 2: Flexibility of Service Delivery

During the first 6 months after hospital discharge, stroke dyads seemed to mainly focus on maintaining existing functions and making continuous improvements. However, some participants perceived receiving inadequate rehabilitation and care services due to the unavailability of services at their residential address and the inflexible design of available services. Challenges arising from the inadequacies of services were perceived as barriers to a smooth hospital-to-home transition.

Participants who lived in regional areas considered themselves to be disadvantaged in accessing community services and follow-up rehabilitation programs after they completed formal post-discharge programs due to their location. The lack of stroke-specific services and support groups in regional suburbs seemed to have posed great barriers for them to make further progress in achieving their goals. One stroke participant discussed his desire to continue improving his speech and writing: 'There is nothing [services] around this area. The system seems to be all geared to metropolitan area' (SS07, T2). Another participant echoed the lack of community and rehabilitation services in regional areas: 'There wasn't community help or rehab here. I am still classified as city living. But when I spoke to XX [service provider], they said I am too far out. Not living close to town has made a big difference' (SS10, T2).

The findings unveiled gaps between hospital and home that may hinder the process of adjusting to stroke-related impairments and the desire to make further functional improvements for people with stroke during the transition. It was evident that participants expected service integration between hospital and the community and expected stroke-specific services to be available in all residential locations after they completed formal rehabilitation.

Stroke dyads who had access to rehabilitation and care services perceived being overwhelmed by the approach of service delivery. Some felt the 'seamless' home rehabilitation service was 'far too early for anyone. We checked out of the hospital at 10 to 12; we had the first home visit at 12:30. You need to come home to settle first and not to have these visits' (SC08, T1). Additionally, the long waiting list for care services left stroke dyads, especially caregivers, devastated: 'she [wife] is qualified for a Level 4 [care package] and there is probably a 2–3 year waiting list. But we need it now! … Even for a Level 2 in the meantime, the waiting list is 6–12 months!' (SC06, T1). Furthermore, due to the timeframe of programs, stroke dyads felt overloaded: 'they [therapists] tried to integrate Mum into the home in those 2 weeks. It was a lot of effort for us. Mum found it hard' (SC02, T1). Moreover, some caregivers commented on the available rehabilitation interventions for people with stroke that 'could improve physical side. But very little on the mental side' (SC06, T2).

Findings call for service design and delivery to be flexible and to target individualised needs. Balancing service providers' imperatives and the capacity of care recipients may enable stroke dyads to maximise the benefits of care services at their own pace.

The majority of participants in this study desired a contact person after discharge. Some preferred an in-person visit; others preferred at least phone calls, emails or a contact number that they could call when needed. They perceived a contact person would be 'just to reassure you that you're doing the right to follow you in the right path' (SS06, T2), and 'if you're caring for somebody, sometimes you have a bit of self-doubt, or you need to discuss a change in something, you need that sounding board and somebody to talk about it' (SC02, T1).

Findings unfolded the complexity of post-stroke rehabilitation and care services in the community pertaining to the availability, accessibility and flexibility of these services and their impact on stroke dyads' hospital-to-home transition experience. It cannot be overemphasised that service providers' service design and delivery must be customised to individuals' life situations and care needs. Stroke dyads' expectations imply the need for a co-design approach in service development.

8.4 Summary

Stroke dyads reflected on the support they received during the transition that either empowered or negatively affected their adaptation to post-stroke life and their expectations of service provision. This chapter has presented two themes and four subthemes detailing the essential support stroke dyads received from family, friends, neighbours and employers.

Dyadic effects were evident between stroke dyad members supporting each other, generating positive perceptions of physical and psychological wellbeing. Furthermore, professional support from service providers facilitated their transition through collaboration and partnership. Moreover, stroke dyads identified issues during the transition that could be improved to strengthen their adaptation. They expected enhanced engagement in discharge planning and preparation and flexible service provision that considered their individual life circumstances and specific care needs.

The next chapter (Chapter 9) presents the perspectives of stroke health professionals regarding the hospital-to-home transition for stroke dyads.

Chapter 9: Findings—Part 4: Themes From Focus Groups and Interviews With Health Professionals

9.1 Introduction

The previous three chapters presented seven major themes pertinent to the hospital-to-home transition experience of stroke dyads. Themes identified before hospital discharge were psychological stress, resilience, and certainty and uncertainty about post-discharge care. Themes identified from the 3- and 6-month follow-ups after discharge were coping with setbacks, role transformation, transition with support, and expectations of hospital-to-home transition care. In the early stage of the transition, stroke dyads experienced psychological stress pertaining to stroke-related physical and cognitive limitations. However, with time and support, they gradually adapted to the changes and began to resume pre-stroke life.

This chapter presents findings from focus groups and interviews with stroke rehabilitation health professionals on factors affecting hospital-to-home transition care for stroke dyads. Participants in this study were recruited from both the inpatient rehabilitation wards and ambulatory services, including home-based and centre-based rehabilitation services. In total, 31 health professionals participated in this study, including rehabilitation allied health staff (*n* = 16), registered nurses (*n* = 6), service managers (*n* = 4), doctors (*n* = 3) and GPs (*n* = 2). The demographic information of participants is presented in Table 6.2 (Chapter 6).

Data analysis of interviews and focus groups identified three major themes: (1) transition shaped by care needs assessment, (2) transition challenged by constraints on service delivery and (3) transition enhanced by a commitment to the safety of care. These themes and their subthemes are listed in Table 9.1.

Table 9.1

Major Themes and Subthemes in Chapter 9

Theme	Subtheme
1. Transition shaped by care needs assessment	**1.** ‘Psychological/mental health is underplayed’
	2. ‘Our focus is on the patient’
2. Transition challenged by constraints on service delivery	**1.** ‘Bed pressures certainly impacts’
	2. ‘We are dictated by funding models’
3. Transition enhanced by commitment to the safety of care	**1.** ‘Empowering them to making decisions’
	2. ‘Working towards a common goal’

9.2 Theme 1: Transition Shaped by Care Needs Assessment

Health professionals perceived stroke care needs assessment as the foundation of a rehabilitation program that helped realistic goal-setting for rehabilitation, determined the length of stay for people with stroke in the program and identified the support that was needed for stroke dyads on the completion of the program. However, rehabilitation care needs assessment mainly focused on the physical and cognitive functions of people with stroke. Psychological needs assessment was largely overlooked (Subtheme 1). Moreover, the assessment only focused on people with stroke. Caregivers’ involvement in the assessment was lacking (Subtheme 2). These subthemes are detailed below.

9.2.1 Subtheme 1: ‘Psychological/Mental Health is Underplayed’

Participants described care needs assessment based on the physical and cognitive functions of people with stroke. For example, on admission to a rehabilitation program, care needs for people with stroke were identified ‘by different members of the team depending on what they’ve been focusing on’ (DOC02). The initial assessment focused on the level of function ‘so that we [clinicians] can determine how long they will need the program for. And it’s also a way of informing us how much they will be gaining at the end of their rehab program’ (DOC01). Rehabilitation goals were set based on these discipline-based assessments. Goals were discussed in team meetings throughout the life of the rehabilitation program. When preparing for discharge from hospital, care needs were unpacked based on ‘how much physical assistance they are going to need … showering … home modification … then as a team, problem-solving, how to best support the client and carer to transition into the community’ (MG01).

These examples demonstrated that health professionals prioritised rehabilitation to improve the functional recovery of people with stroke. There seemed to be a limited focus on the assessment of psychological needs for people with stroke: ‘the emotional side, perhaps we don’t address that as well as we could. Clinical psychology is an area that we’re struggling with. We’ve got quite low FTE [working hours] and patients’ feedback that they’d like more emotional support’ (MG01). Even when psychological health for people with stroke was assessed and addressed during inpatient stay, this may not have been carried out in primary care, as a medical officer reported:

> Psychological/mental health is underplayed in our medical model, where we focus on physical health. We have psychologists coming to review patients, but they don’t attend team discussion … All our summaries and handovers to GP, other services are generally about the physical and cognitive recovery, not so much about coping and psychological … If it’s something mild [psychologically], we won’t necessarily pick it up (DOC02).

The unmet psychological care needs were also observed by nurses at the stroke follow-up outpatient clinics: ‘When it comes to the questions around mood, I’d say roughly 40% of patients say they have been down. It’s not something they come out straight away; you have to really dive into that’ (NS06, FG04).

Health professionals’ perceptions of factors affecting care needs assessment for people with stroke revealed gaps in meeting the psychological needs of people with stroke. With the trend of shortened hospital stays, psychological needs might have to be managed in the community setting after hospital discharge. Identifying and effectively communicating these needs to the next service may address the psychological and emotional support needs for stroke dyads.

Additionally, the focus on physical recovery seemed to be driven by the decision of hospital discharge. Participants indicated that ‘the challenge is particularly when someone can walk, and physically their care needs aren’t great. Often there’s a big push to get someone home. [For those with] cognition or even communication [deficits], sometimes it is hard to advocate’ (AH01). Health professionals’ perceptions suggested that people with stroke who had fewer physical impairments but had cognitive and/or speech impairment might be disadvantaged in hospital discharge decision-making, which was based on physical functioning. People with stroke and with cognitive and/or speech impairment and their caregivers might encounter more challenges in coping with these types of stroke-related disabilities during the transition if they missed rehabilitation as inpatients before hospital discharge.

Although health professionals perceived that cognitive or speech impairment were significant components of post-stroke rehabilitation, they showed limitations in advocating for stroke patients with these impairments due to system pressure on discharging patients. Health professionals also perceived that mental health and psychological wellbeing played crucial roles in post-stroke transition. However, they had limited time and resources to facilitate the early identification and treatment of psychological health issues for both people with stroke and their caregivers.

9.2.2 Subtheme 2: ‘Our Focus is on the Patient’

All participants discussed the significance of care needs assessment to enable discharge planning and the transfer of care for stroke dyads. However, throughout the continuum of hospital-to-home transition and at different care settings (inpatient and in the community), health professionals mainly assessed care needs for people with stroke, and caregivers’ needs and the dyadic effects were not formally assessed:

> Obviously, the patient is the primary focus. (MG02)

> It’s mainly if the caregiver coping or not coping … It’s more are they able to take care of the patient, and do they need more support? But I think our focus is on the patient, and we often expect the caregiver to just do everything we’re recommending. (DOC02)

Additionally, caregiver care needs assessments were ‘more just informally discussing what their capacity is and what their concerns are’ (AH07). Caregivers’ needs were largely around the hands-on care activities for people with stroke, as revealed in a focus group: ‘In the interdisciplinary assessment tools that we use, there are questions around their [people with stroke] care needs. So how they manage showering, dressing, shopping, transport … And that encompasses the carer’ (AH14, FG02).

Moreover, caregivers’ care needs may be identified shortly before discharge from the services. For example, ‘sometimes those [care needs] conversations come up when we start talking about discharge. You suddenly get that response: “If this is coming to an end, where am I going to get my respite? Where am I going to get …” ’ (AH11, FG01). In some cases, ‘when we’re going to discharge the patient in a few days, then we say, oh, they [patient and carer] haven’t had carer training’ (DOC03).

Furthermore, caregivers’ psychological and emotional stress was largely ignored during hospital stays despite being viewed as crucial care partners in the National Safety and Quality Health Service Standards. One inpatient clinician indicated, ‘I think carers aren’t coping well at all. It’s quite sad that we haven’t probably identified upset in a carer’ (AH08).

Findings indicated that, as a member of stroke dyad, caregivers’ care needs were not formally assessed. As stroke affects both people with stroke and their caregivers, early identification of caregivers’ specific needs would facilitate discharge planning and enhance stroke dyads’ preparedness for the transition.

Care needs assessment is an essential part of discharge planning. Findings revealed the need to include both people with stroke and their caregivers in the assessment and to meet their needs accordingly as a dyad and as individuals. Moreover, the identification of psychological and mental health issues of both people with stroke and their caregivers would support intervention plans and enhance their transition experience.

9.3 Theme 2: Transition Challenged by Constraints on Service Delivery

This theme focused on the challenges that health professionals encountered in supporting stroke dyads during the hospital-to-home transition. Health professionals perceived that shortened hospital stays only provided a narrow window of opportunity for them to support stroke dyads in the discharge planning process, which might affect the stroke dyads' preparedness for the hospital-to-home transition. The shortened length of stays could also create increased workload and additional stress for health professionals (Subtheme 1). Furthermore, gaps existed in service accessibility for stroke participants who resided in non-metropolitan suburbs. Community care services with a specific cutoff age (65 years old) may contribute to the mismatch between stroke dyads' care needs and available community care services for them (Subtheme 2). These subthemes are presented in the following sections.

9.3.1 Subtheme 1: 'Bed Pressures Certainly Impacts'

Health professionals identified that hospital length of stays and the support from community rehabilitation services affected them in setting out and implementing the rehabilitation goals of people with stroke. For example, discharging home early with support from community rehabilitation services was viewed as beneficial because 'if someone doesn't have significant deficits from stroke, sometimes it's better for them to go home so that they don't become institutionalised but get the opportunity to be in their own environment that might actually enhance their recovery' (AH01). Moreover, regarding services meeting targeted length of hospital stays in the healthcare system, health professionals perceived that:

> We are accountable to improving patient outcomes … to maximise function and support a safe discharge home. But there's also accountability around funding … Our

> service is funded on a length-of-stay target. We do need to look at meeting those targets. (AH06)

And safety for discharge was a key consideration, as one manager indicated:

> The longer we keep them [patients] in hospital, they are more likely to develop complications or become less confident about returning home … we need to make room for the patients coming through the door. But also, if they're not able to safely be home, then they're only going to be readmitted, which doesn't help the system. So those targets just give us a reference point when we're setting goals with patients and their family. (MG01)

Health professionals' perceptions about the length of hospital stay targets indicated that they needed to initiate early discharge for people with stroke if it was safe for them. Meanwhile, health professionals needed to set rehabilitation goals for stroke dyads at the point of discharge, which may need further adjustments after discharge. Such a situation required health professionals to partner with stroke dyads to set up follow-up rehabilitation goals that were based on their needs and preferences during the hospital-to-home transition period.

Participants also recognised that longer inpatient stays may provide more chances for rehabilitation therapists to support people with stroke and to further improve stroke-related limitations before returning home. However, due to hospital bed pressures, they were at times discharged earlier than desired, as one therapist stated:

> Bed pressures certainly impact. For those people that can walk and got someone at home with them. But got cognitive changes … if we had kept them, we could have made them more independent from a cognitive perspective. But the fact that they are supported at home and safe with their mobility, then it's unfortunately less of a priority. (AH02)

Shortened hospital stays could also affect the delivery of community rehabilitation services. People with stroke may be discharged too soon to be ready for community rehabilitation, as discussed in one focus group:

> Patients may get discharged potentially early, and they might not be as suitable [for community rehabilitation]. So, the amount of intervention that you can provide is limited because they are still acute, not feeling very well [for rehabilitation]. (AH14, FG02)

Findings demonstrated that shortened hospital stays have a significant impact on the ongoing care people with stroke after discharge. Shortened hospital stays might have contributed to inadequate education and discharge preparation for stroke dyads, which may in turn compromise their continued rehabilitation and recovery at home. The feedback at the stroke follow-up outpatient clinic reflected the potential risks, as one clinician stated: 'I think it's mainly anxiety. So, they go home, they're not sure about what appointment they need to attend, when they leave hospital, they're not clear of a contact person' (NS05, FG04).

Health professionals perceived that they were sometimes unable to provide support for stroke dyads within a limited timeframe 'Quite often we've got an agenda and things that we need to look at. And giving that time for people to have more open discussions, I think, is few and far between sometimes because we've got such a schedule' (AH02). Additionally, the perceived high workload due to quick hospital bed turnover seemed to have prevented therapists from providing rehabilitation interventions needed for people with stroke, as one therapist reported: 'Workloads are really high. I think we are more heading towards acute-based therapy model than rehab model. We probably would be building therapeutic relationships. But for the acute, you're kind of in and out. You don't build those' (AH09). Furthermore, shortened hospital stays created additional stress to everyday practice for clinicians, as one medical officer shared:

> You'd like to have a bit more time to work this patient out. So, you got that additional stress … You constantly have patients in the back of your mind, we'd like to know how they're going now or whether we'd done enough for them. That's probably slightly higher with a higher turnover in shorter stays. (DOC03)

Findings revealed that hospital bed pressures and shortened hospital stays may have contributed to inadequate preparedness for discharge in stroke dyads. However, some people with stroke may benefit from short hospital stays with enhanced recovery in their home setting, subject to their safety at home, their family support and continuity of community rehabilitation. For health professionals, working within the constraints of shortened hospital stays may challenge them with increased workload and additional stress. These challenges could prompt care services designers to reflect and develop strategies to support health professionals and improve service sustainability.

9.3.2 Subtheme 2: 'We're Dictated by Funding Models'

Community care services facilitate continuity of care after hospital discharge, support continued rehabilitation and help meet the care needs of stroke dyads. However, health professionals identified gaps associated with community care services that may pose barriers to meeting the specific needs of people with stroke at different ages.

While inpatient and ambulatory rehabilitation services (home rehabilitation and centre-based rehabilitation services) are not age-based, there is a cutoff age for other hospital-to-home transition services and community support services: 'People over 65 get aged-care services while those under 65 get disability care services. Unless people have support in the community to help them, it could be quite challenging finding those services' (AH07). Although community-based care services were consumer-directed, some stroke dyads may not be ready to navigate the system:

> All of the services now are supposed to be consumer-directed, which is great. But it presents huge challenges for people who can't manage to navigate through the system. We have to try and do a lot of that for them whilst they're on the program during that short period of time. But, sometimes, we just don't know what happens to them after that. (MG02)

Findings indicated the need to prepare stroke dyads to master consumer-directed aged-care or disability care services so that they were empowered to identify care services to meet their specific care needs. Findings also implied the potential risk of unmet care needs within the limited length of stay in a community rehabilitation program.

Another challenge brought by age-oriented service design was that the services may not have met the specific care needs of individuals when their lifestyle did not fit the age group, as discussed in a focus group:

> I’ve got a 66-year-old who really live like 40-year-old. So just because of their age, they are set into this funding, which means they get next to nothing going forward. But if they were 50, they get XXXX [a disability service] and could have a lot more. So, I think that age [cutoff] makes it difficult sometimes. (AH14, FG02)

Findings suggested that care services considering both the age and specific needs of individuals may provide more opportunities for people with stroke to reintegrate into the community and manage care for the long term. This lack of person-centredness may generate additional challenges to the transition for stroke dyads.

To reduce hospital length of stays, people who were deemed unsafe to return home with ambulatory rehabilitation services sometimes had to be moved across different interim inpatient services while waiting for community support at home. One therapist shared her concerns about these interim services:

> In my opinion, the kind of waiting between services and programs is not always an effective way of doing things. Some patients are quite frustrated about having to go to a queue and move across [different interim inpatient services] … By that time, they’ve spoken to five different therapists and the risk of miscommunication, handover breakdown … and I’d question mental health wise how those people actually coping, being waiting for so long for services. (AH01)

Long waits for community support services and moving between different settings could jeopardise post-stroke recovery and increase the risk of psychological distress for people with stroke and their families. It may also increase the risk of institutionalisation and reduce people’s confidence to return home.

Health professionals perceived that people living in non-metropolitan suburbs might be disadvantaged due to the lack of services, especially stroke-specific services, in these suburbs, as discussed in one focus group:

> I think in metro, it’s probably easier to be referred to services that specialise in adult rehab. But as you get further out, there’s not the luxury of that, and you’re referring to a generalist service. Some sites have rehab, but they might not be stroke-specific. (AH16, FG02)

Stroke-specific rehabilitative interventions are essential to maximise functional gains for people with stroke during the first 6 months after stroke. Their recovery may be compromised without these interventions. Lacking services in non-metropolitan areas could create barriers to continuity of care after completion of time-limited post-discharge rehabilitation programs.

Participants expressed their expectations of service integration and flexibility in service provision that could enhance transition and continuity of care. For example, before hospital discharge, ‘it’d be helpful for us [home-based rehabilitation therapists] to come up here [ward] first, meet them to get a sense of strategies for discharge’ (AH02). Participants perceived that, if therapists from inpatient and ambulatory rehabilitation services had time to meet people with stroke so that ‘there is a clear communication of expectations and differences in the programs … that might help to ease any anxiety about the transition … some greater transparency or communication at that point would be great’ (AH05). Suggestions from health professionals highlighted the potential benefits of integration between services before hospital discharge to alleviate the anxiety heightened by hospital discharge for stroke dyads, and the integration may also improve communication between services and facilitate the development of individualised care plans.

Health professionals from the ambulatory rehabilitation services particularly conveyed their expectations of flexibility in providing home-based and centre-based rehabilitation services. Due to funding models, two services were operated independently, which meant that, when people with stroke received the home-based service, they could not access the centre-based service until they were referred to the service after completing the home-based service. However, in reality, people with stroke may benefit from both services at the same time to better achieve their goals, as a service manager advocated:

> Ideally, home rehab and day rehab would almost merge, and patients would get whatever they needed, wherever they needed it … Transitioning from a team on the ward and then to home rehab and then to day rehab would be very confusing [for patients]. A lot of duplication, handover … Unfortunately, we're a bit dictated by funding models. (MG04)

Shifting between multiple services or programs may increase the risk of communication breakdown and compromise individualised care delivery. Instead of funding-based services delivery, care-needs-oriented services delivery may better meet individuals' specific care needs and ease the stress of navigating a complex health system for stroke dyads.

Additionally, the flexibility of service delivery seemed to be constrained by service design. For example, the home-based rehabilitation service was designed as 'service where somebody gets a service everyday … it's a hospital substitution and replicates what happens on an inpatient ward … Seeing a patient two or three times a week doesn't feel like an intensive program for people to meet their goals' (MG02). Some people with stroke may not be able to tolerate the intensity of the program. However, they would still benefit from the home-based program, as one therapist expected:

> More complex patients would probably benefit from more therapy in their own home and community setting. Say getting back to shopping or go on public transport … they [patients] generally don't have the time to do that. So, having that sort of support for a little bit longer would probably make that transition from hospital a bit smoother and make sure that they're getting back to all those meaningful activities rather than just surviving. (AH07)

Findings suggested that providing a tailored rehabilitation service to people with stroke is a way to help them overcome challenges during the hospital-to-home transition. Supporting people with stroke to resume meaningful activities would promote community reintegration and caregiving sustainability.

This theme revealed that shortened hospital stays may affect preparation for the hospital-to-home transition for stroke dyads. It may also increase the workload and stress for health professionals. Findings highlighted the need for a co-design approach to care service development, which reflects a true partnership with stroke dyads and may strengthen their self-management capabilities.

9.4 Theme 3: Transition Enhanced by Commitment to the Safety of Care

Despite the challenges in supporting people with stroke during the hospital-to-home transition, health professionals demonstrated their commitment to safe discharges from their services and identified strategies to enhance safety after discharge. Safety enhancement strategies were implemented during discharge planning and in the process of supporting stroke dyads navigating the complex health system (Subtheme 1). Collaboration of health professionals within and across services enabled enhanced safety and supported continuity of care (Subtheme 2). Details of both subthemes are presented below.

9.4.1 Subtheme 1: ‘Empowering Them to Making Decisions’

In the context of shortened hospital stays for people with stroke, health professionals remained proactive in discharge planning in that they ‘should be thinking about discharge planning as soon as we’re assessing and admitting patients. We need to identify discharge barriers early in the stay as a team’ (AH06). Health professionals tried to ‘be flexible and available to answer any questions from family’ (DOC03). They also tried to involve stroke dyads in discharge planning at the early stage of admission as they believed this approach would ‘empower them [caregivers] to making decisions and feeling comfortable saying they’re taking on extra care burden and that they’ve got some support for that’ (DOC03). To improve caregivers’ engagement, health professionals would invite them to therapy sessions. For example, speech pathologists would invite caregivers to ‘communication partner training in aphasia [communication disorder] because, when they go, it’s the family that are communicating with the patient’ (AH09). Additionally, caregiver training was arranged in a way to save caregivers’ time and accommodate their specific situations where possible. For example, for a person with cognitive impairment, therapists organised ‘a well-rounded [caregiver] education session with physio, speech pathologist and occupational therapist so that they [caregivers] didn’t have to come in more than once’ (AH02).

Other strategies to involve caregivers and family in discharge planning in the inpatient setting included encouraging ‘family to take their loved ones home or out in community, come back and let us know how is going’ (AH08), inviting caregivers to ‘stay overnight in hospital, so they can get a better idea of how much assistance is required … or goes on overnight leave for carer to carry out all the duties. Then they come back and give us some feedback’ (NS01, FG03).

Despite the challenges with shortened hospital stays, health professionals demonstrated endeavours and flexibility to partner with stroke dyads. These efforts reflected health professionals’ dedication and determination to support a safe hospital-to-home transition for stroke dyads.

Regardless of service settings, all participants considered safety as ‘first and foremost’ (AH07) in discharge planning process, and ‘if they’re physically at risk of, say, fall because they didn’t have the right equipment yet, even we’re getting pushed [due to bed pressures], we wouldn’t send them home’ (MG02). Additionally, ambulatory rehabilitation services had implemented strategies to fill in the gaps for the next services. For example, when the next service provider was unknown, ‘to bridge that gap, I just gave my email address to the patient’s partner to email me and let me know [the provider] so I can [handover]’ (AH11, FG01). Similarly, when the next service could not take over the care, the ambulatory services extended the length of the program to fill in the gaps: ‘in some cases, we go over our length of stay to bridge a gap … we can advocate for patients, so they don’t miss out on any therapy … it’s always what’s best for the patient’ (AH14, FG02). Furthermore, to meet the specific needs of people with stroke, sometimes a check-in service after completion of a program would be in place to support the transition:

> When there’s ones that we are feeling like there’s a particular space that is standing out, what we’ve sometimes done, like we’ve finished this 6-week [program], but let’s

> just checking in a week's time by a telerehab and to see how that's going, especially [for] the return-to-work ones (AH13, FG01).

These examples highlighted that health professionals were enabled to be flexible in service provision to enhance safety of care. Health professionals attributed this enablement to the safety culture at the workplace:

> I do feel we are very lucky that executive in this division and leaders on the wards do genuinely care about the patients' wellbeing and outcomes. And I think there is a recognition that, yes, we need to try and make room for the patients coming through the door. But, if we do that at the expense of patients who are not able to safely be home, system-wide [it] doesn't help. (MG01)

Findings revealed health professionals' commitment to partnership with and their advocacy for stroke dyads to enhance safety and quality of care. A focus on safety, driven by strong leadership, seemed to foster a positive safety culture and enable health professionals to empower stroke dyads to take over care and be supported during the transition.

9.4.2 Subtheme 2: 'Working Towards a Common Goal'

All participants identified that effective communication among multidisciplinary team members and between services was key to supporting the hospital-to-home transition for stroke dyads. As nursing leaders described, 'we're all kept on the same page … we all have our own roles, but we're working towards a common goal, which is the best, focused outcome for patients' (NS01, FG03). The benefit of the interdisciplinary approach was that 'everyone having an input towards what the patient requires, and what their level of functioning is and working towards that effective discharge with the patient or their family' (DOC01). Additionally, efficient communication among team members may have also helped fill in gaps between hospital and home, as one therapist discussed:

> Sometimes even when they're coming from an inpatient [rehab] ward, it could only be quite a short stay there. And staffing issues mean that potentially they've ever been seen a couple of times from XX [therapy] perspective. So, it's through [setting] goals

> and lots of multi-D discussion in our team that helps with discharge planning. (AH16, FG02)

Effective communication and an interdisciplinary approach to service delivery and discharge planning facilitated shared visions on care planning in a multidisciplinary team. It may also enhance the quality and safety of the transition and strengthen continuity of care for stroke dyads.

Participants also highlighted the support among team members that fostered collaboration: ‘Some people in the team feel burdened, especially after a prolonged busy period … It’s very challenging. But they support each other very well. We try to do things to lighten the load and lighten the mood and help each other’ (MG02). Furthermore, trust and confidence in the expertise of colleagues seemed to enhance safety and continuity of care:

> We have good communication avenues between us [inpatient and ambulatory services] to support discharge, flagging any issues that perhaps we couldn’t manage in an inpatient setting … I think it’s because the staff move around that provides them with a better understanding of what each service can provide and how we best tackle that transition. (AH05)

In contrast, when referring to external services, health professionals may not have had the same level of confidence:

> We feel the most comfortable transitioning those dysphagic patients if we know where they’re going, the home rehabs or day rehabs because there’s the feedback, and you know they’re getting the service. The ones like XX [community service] where you don’t have that feedback. (AH09)

Health professionals’ perceptions indicated that communication and trust built on understanding among team members were important elements to promote team collaboration regardless of the care setting. The findings also suggested that collaboration of service providers in the chain of stroke care could potentially enhance the transition experience of stroke dyads.

To enable reflective practice and further improve the quality of care, participants expressed their expectations of feedback from stroke dyads. One therapist suggested:

> I think it is so important to get that patient feedback in a meaningful way … that's the really challenging thing for someone to negotiate a system after they've left here … If we don't really get that feedback, we just don't know how to change our practice or reflect more on our practice. (AH01)

Reflective practice supports continuous quality improvement. A feedback system would strengthen the partnership between health professionals and stroke dyads to enhance their experience in the hospital-to-home transition.

Findings suggested that effective communication and collaboration between health professionals would enable safe and quality care and improve outcomes during the hospital-to-home transition for stroke dyads. Health professionals and service providers would benefit from a system established to receive feedback and to evaluate the effectiveness of discharge planning and continuity of care.

9.5 Summary

Stroke rehabilitation health professionals reflected on the challenges and opportunities in the first 6 months of hospital-to-home transition for stroke dyads. This chapter has presented three themes and six subthemes. Involving both people with stroke and their caregivers in the assessment was essential to enable an individualised approach to care planning as a dyad and as individual dyadic members. Additionally, focusing mainly on the functional recovery of people with stroke may overlook their psychological needs and caregivers' pivotal role in the rehabilitation of people with stroke during the transition. Moreover, health professionals' commitment to safety and continuity of care was evident despite the challenges they encountered, such as shortened hospital stays and limited resources. Their dedication and collaboration were considered paramount to enhancing the transition experience of stroke dyads.

The next chapter (Chapter 10) explains the significance of the findings and new knowledge generated from this study.

Chapter 10: Discussion

10.1 Introduction

The previous four chapters presented 10 major themes and multiple subthemes regarding hospital-to-home transition care from the perspectives of stroke dyads and health professionals. The experience of stroke dyads was explored across the time period from before hospital discharge to 6 months after returning home. Seven themes identified for stroke dyads were (1) psychological stress, (2) resilience, (3) certainty and uncertainty about post-discharge care, (4) coping with setbacks, (5) role transformation, (6) transition with support and (7) expectations in hospital-to-home transition care. Interviews and focus groups with health professionals from inpatient and ambulatory rehabilitation settings generated three major themes: (1) transition shaped by care needs assessment, (2) transition challenged by constraints on service delivery and (3) transition enhanced by commitment to the safety of care.

Gadamer’s (1979) philosophical hermeneutics was used in this qualitative study. This methodology enabled the researcher, who has extensive experience in stroke care, to bring her pre-understandings of factors influencing hospital-to-home transition care for stroke dyads to the interactions with participants during the interviews and focus groups to achieve rich data for analysis. The researcher also experienced numerous hermeneutic circles during the interpretation of data (Gadamer, 1979). The interpretation and reflection processes in the hermeneutic circles helped the researcher to reach a new understanding and generate new knowledge pertinent to hospital-to-home transition. Gadamer’s philosophical hermeneutics also enabled the researcher to link study findings to the socio-political-economic context to achieve a historical consciousness about stakeholders’ views of factors affecting the hospital-to-home transition in the current health and social care system in South Australia. This chapter presents a discussion of the main findings and relates the findings to similar studies in a global context.

The discussion is organised in four sections: (1) balancing functional rehabilitation and psychological support, (2) understanding dyadic interdependence to promote dyad-centredness in healthcare, (3) the role of health professionals in enhancing hospital-to-home transition and (4) enriching Meleis's transitions theory.

10.2 Balancing Functional Rehabilitation and Psychological Support

The study's findings shed light on the coexistence of psychological stress and coping with resilience in stroke dyads during the hospital-to-home transition. However, the findings suggest that their psychological needs could be addressed more appropriately during this critical period. Participants highlighted several contributing factors that hindered the provision of appropriate psychological support, including a function-oriented rehabilitation service that concentrated on functional recovery over emotional wellbeing, limited access to psychological/counselling support and a lack of awareness among stroke dyads about their psychological wellbeing and its impact on a healthy recovery transition. These findings offer a novel perspective on the care needs of stroke dyads across the transition process, highlighting the need for a more comprehensive and integrated approach to care that prioritises the psychological wellbeing of stroke dyads alongside their physical health.

Psychological stress refers to the negative emotional status of an individual when they perceive a lack of resources to cope with a real or imagined threat (Gyawali et al., 2020; Monroe & Slavich, 2016). The present study concurs with previous findings that both people with stroke and their caregivers experience psychological stress during the hospital-to-home transition (L. Chen et al., 2022; Lin et al., 2022). They presented fear, frustration and uncertainty before hospital discharge, and their stress continued through the hospital-to-home transition (Lin et al., 2022; L. Chen et al., 2022). Psychological stress, if left unaddressed, may cause increased bone marrow activity and arterial inflammation, leading to intensified amygdala activity, which is associated with recurrent stroke (Booth et al., 2015; Tawakol et al., 2017). Studies have also highlighted the psychological sequelae of stroke leading to mental health issues such as depression and anxiety, which accounts for approximately 30% and 25% of the stroke population, respectively (Dos Santos et al., 2018; Rhudy et al., 2020).

The present study reveals that sources of stress for caregivers differed from those experienced by people with stroke. For people with stroke, their psychological distress and sense of achievement were closely associated with their functional recovery. For caregivers, their psychological wellbeing was not only affected by stroke-related limitations in people with stroke but also by the changed relationship and their adaptation to the caregiving role. An interesting finding in the present study was that people with stroke rarely described the impact of caregivers' psychological stress on them. They attributed their progress to the support from their caregivers. The findings suggest that caregivers might have hidden their emotions and put aside their own needs because the main focus of life during the transition was to support the person with stroke with progressing in functional recovery and resuming their pre-stroke lifestyle (Bucki et al., 2019; Quinn et al., 2014). By hiding their true feelings, caregivers might be misinterpreted as if they were effectively coping with the transition. This could increase the risk of vulnerability in coping during the transition (Quinn et al., 2014). Insights into stroke dyadic differences and their psychological trajectory are of paramount significance for stroke nurses to identify stroke dyads at high risk of developing psychological distress and to create tailored interventions to enhance continuity of care during the transition.

The findings of this study parallel with other studies that have shown that post-stroke rehabilitation mainly focuses on functional recovery with limited emphasis on psychological recovery or support in hospital and community settings (Hughes & Cummings, 2020; K. F. Liu et al., 2022). Such a practice disregards the association between psychological stress, low resilience and poor post-stroke outcomes in people with stroke (Gyawali et al., 2020; Ianni et al., 2022). In a stroke services audit, approximately 44% of people with stroke did not have a mood assessment and as much as 63% of audited hospitals did not provide psychology services (Stroke Foundation, 2019a). Additionally, caregivers' preparedness for the caregiving role is significant for a positive hospital-to-home transition (Camicia, Lutz, Harvath & Joseph, 2021; Pucciarelli et al., 2021). A formal caregivers' needs assessment, including psychological assessment, is lacking. In their study of challenges to stroke caregivers' resilience, Qureshi et al. (2022) suggested that caregivers need to be engaged in care planning and that their needs assessment would enable person-centred planning.

Functional recovery after stroke refers to the recovery of cognitive and motor impairment affecting ADLs such as mobility, shower, feeding and toileting (Branco et al., 2019; Grefkes & Fink, 2020). Psychological wellbeing in stroke dyads and functional recovery in people with stroke are positively correlated (Ezema et al., 2019; Perna & Harik, 2020). Therefore, psychological support for stroke dyads should be viewed as an equally important care element as functional recovery during the post-stroke trajectory. Psychological symptoms may be hidden and may not be readily observable by therapists during therapy interactions (Perna & Harik, 2020; Vlachos et al., 2021). Stroke nurses providing 24-hour care are well poised to assess and identify stroke dyads at risk of developing psychological symptoms and to work collaboratively with the interdisciplinary team to develop a care plan tailored to an individual's specific situations. Shifting the mindset of health professionals from a focus on the physical health (i.e., functional recovery) of people with stroke to both physical and mental health (i.e., psychological wellbeing) in both dyad members may potentially improve the hospital-to-home transition experience and stroke outcomes (Meyers et al., 2020; Qureshi et al., 2022).

The American Psychology Association (APA) defines resilience as 'the process and outcome of successfully adapting to difficult or challenging life experiences, especially through mental, emotional, and behavioural flexibility and adjustment to external and internal demands' (APA, 2023). When applying this definition to the stroke population, resilience refers to a person's ability to cope with adversity in life, adapt to changed situations and engage in meaningful activities to maintain quality of life (Gibbs et al., 2020; Zapater-Fajarí et al., 2021). Resilience can be influenced by an individual's views about and engagement with the world, the availability and quality of social resources, and coping strategies (APA, 2023). This individual attributor has been found to protect stroke dyads against mental health issues and predict quality of life after stroke (Kim et al., 2019; Z. Liu et al., 2021). The findings of the present study align with previous studies that show that stroke dyads demonstrate coping with resilience, drawing on their past life experiences, functional improvement in people with stroke, and the support from family, friends and health professionals despite the stress they face (L. Chen et al., 2020; Pereira et al., 2021). They were able to identify positivity, adapt to changes and regain health, wellbeing and social integration in the continuum of the transition (L. Chen et al., 2020; Pereira et al., 2021). Therefore, support from nurses and rehabilitation clinicians to build and enhance resilience should be incorporated into post-stroke rehabilitation. Recent studies have highlighted some preliminary benefits of psychoeducational interventions to enhance caregivers' resilience and the importance of understanding the predictors of differing levels of resilience before designing interventions (Qureshi et al., 2022; W. Zhang et al., 2020).

Functional recovery and psychological wellbeing are two core elements in post-stroke rehabilitation for stroke dyads. They are interrelated and contribute to stroke dyads' reconciliation and regaining control of health, wellbeing and social integration during the hospital-to-home transition (Baker et al., 2018; Pereira et al., 2021). They also influence the sustainability of caregiving and the self-management of stroke-related health issues at home (Baker et al., 2018; Pereira et al., 2021). Stroke care stakeholders' perceptions of the equal importance of functional recovery and psychological wellbeing in stroke dyads is crucial for designing and funding stroke care services. Perna and Harik (2020) have suggested that psychology services are embedded in stroke care to enable a focus on psychological wellbeing and to help optimise rehabilitation outcomes in the continuum of hospital-to-home transition care. With the opportunity to work with stroke dyads closely during their post-stroke journey, stroke care nurses are ideally positioned to assess the psychological needs and resilience of stroke dyads, develop tailored strategies in collaboration with the interdisciplinary team and reinforce these strategies in their daily encounters with stroke dyads (Diaz et al., 2020; Le Danseur, 2020).

10.3 Understanding Dyadic Interdependence to Promote Dyad-Centredness in Healthcare

Consistent with previous studies, the findings of this study highlight dyadic effects between stroke dyad members that either facilitate or hinder their hospital-to-home transition (Bakas et al., 2022; Pucciarelli et al., 2021). In this study, positive dyadic effects were evident between dyadic members in supporting each other, demonstrating positive coping resilience and positive views when facing uncertainty. The level of physical, cognitive and functional ability, and resilience in people with stroke either enhanced or challenged their caregiver's confidence in caregiving and the psychological distress those caregivers experienced. Likewise, support from caregivers motivated people with stroke to continue their rehabilitation and reintegration into the community. It was evident that caring, understanding and encouragement within the dyads could produce positive outcomes.

A caregiver and a care recipient form a caregiving dyad (Ferraris et al., 2022). Previous studies on patient–caregiver dyads living with chronic conditions, such as stroke, cancer and cardiac diseases, have suggested dyadic interdependence. In other words, a caregiver and a care recipient share a mutual experience in the adaptation process of a health condition, and their wellbeing is interconnected (Badr et al., 2019; Bakas et al., 2022; Ferraris et al., 2022). The concept of interdependence originated from the theory of interdependence developed by Kelley and Thibaut (1978). They suggested that interpersonal relationships are shaped through interpersonal interdependence, which is the process whereby interacting people affect one another in the context of a specific interdependence situation (Rusbult & Van Lange, 2008). Stroke affects caregiving dyads as a unit, which results in dyadic members affecting each other regarding their health, wellbeing and social integration (Ferraris et al., 2022; Welten et al., 2023).

Stroke dyads experience relationship challenges, such as perceived power imbalance, difficulties adjusting to changed identities as care recipient and caregiver, and incongruent views about the physical and cognitive capabilities of people with stroke

(Hodson et al., 2019; McCarthy et al., 2021). These interpersonal relationship challenges may increase the risk of psychological distress in stroke dyads. Previous studies have revealed that dyadic effects have a vital role to play in the physical, psychological and quality-of-life outcomes for both spousal and non-spousal dyads (Ferraris et al., 2022; Pucciarelli et al., 2021).

Caregiving dyads in this study comprised couples (*n* = 11), parent and adult child (*n* = 6) and sibling (*n* = 1) dyads. Regardless of their relationship, this study found that stroke dyads experienced and navigated the hospital-to-home transition together. Their shared understanding of stroke and its impact, and mutual support, as well as support from health professionals and from their social networks, enabled their community reintegration. The present study accords with previous stroke dyadic studies. Pereira et al. (2021) revealed that mutual goals and priorities between people with stroke and their caregivers facilitated their regaining control of life after hospital discharge. A systematic review and meta-analysis by Pucciarelli et al. (2021) agreed that stroke dyadic educational intervention studies generated improved outcomes on functional independence and psychosocial distress for stroke dyads. These positive findings from previous studies (Pucciarelli et al., 2021; Pereira et al., 2021) are promising and support a dyad-centred approach for enhancing stroke dyads’ hospital-to-home transition.

The present study adds new knowledge to the existing literature in that, apart from rehabilitative interventions delivered by health professionals, people with stroke in this study attributed their psychological and functional recovery to the positive influence that caregivers had on them during the transition. In their view, caregivers had not only taken on household responsibilities that were shared by both before the stroke but also provided strong support, encouragement and navigated the transition with them. Contrastingly, caregivers discussed the negative impact of psychological distress, behaviour changes and functional limitations in people with stroke on them and the psychological adjustment they had to make. Ample studies have revealed challenges experienced by stroke caregivers, including unpreparedness for the new role, changed family relationships, physical and mental caregiving burden, and stress (Achilike et al., 2020; Kazemi et al., 2021). The present study suggests that caregivers may have put on a brave face and tried to be strong for their loved ones because the focus of post-stroke recovery during the transition was on the functional recovery of the person with stroke (Hughes & Cummings, 2020; Bucki et al., 2019). This approach to coping may overwhelm caregivers and add extra burden to the already challenging situation. Previous studies explored the use of caregiver assessment tools to understand caregiver’s preparedness for care and their prioritised needs from a caregiver’s perspective (Camicia et al., 2023; Toye et al., 2016). Researchers found that preparing caregivers for their role is pivotal to home care sustainability and caregivers’ long-term health and well-being (Camicia et al., 2023; Toye et al., 2016). Findings of this study support a comprehensive caregiver preparedness and support needs assessment before hospital discharge and at key timepoints in the continuum of hospital-to-home transition such as before separation from care services and when health condition of care recipient changes.

Camicia et al. (2022) advocated for a family-integrated care model for caregivers of patients in the rehabilitation inpatient setting. The family-integrated care model acknowledges the interdependence of the caregiver and care-recipient dyad and provides an avenue to build caregivers’ confidence through comprehensive assessment and targeted strategies. Recognising dyadic interdependence and taking a dyad-centred approach have implications for health professionals’ engagement with stroke dyads in the hospital-to-home transition. A dyad-centred approach enables health professionals to consider the stroke dyad as a unit and to integrate the dyad into all aspects of their care. This approach would enhance the development of tailored plans that consider the needs and preferences of caregivers as well as care recipients (see Family Integrated Care, http://familyintegratedcare.com/).

Person-centred care is widely recognised as a foundation for safe, high-quality health care (ACSQHC, 2021). The WHO describes people-centred health services as an approach that responds to the needs, preferences and values of individuals, families and communities in humane and holistic ways and through education and support to promote their participation in their own care (WHO, 2015). This care approach, focusing on people rather than disease. is described in the National Standards for Quality and Safety in Healthcare in Australia (ACSQHC, 2021). Findings from the present study support a person-centred approach but also advocates for dyad-centredness in stroke care, emphasising the equal importance of partnering with stroke dyads in all facets of care.

The present study, along with existing research evidence, highlights the crucial and indispensable role of caregivers in hospital-to-home transition for people with stroke (Camicia et al., 2023; Pont et al., 2020). A co-designing approach to developing care plans and incorporating their situation-specific priorities in care design empowers stroke dyads to develop self-management capabilities, which has a far-reaching impact on long-term care in the community (Jones et al., 2020; Lobo et al., 2021). Acknowledging the benefits of person-centred care principles in dyad-centredness, the present study recognises the challenges in the operationalisation of this approach in clinical practice. Byrne et al. (2020) have argued that person-centred care would require organisational culture development to facilitate implementation. This involves policy, funding and education to align the concepts and principles with reality (Byrne, Baldwin & Harvey, 2020; McCormack & McCance, 2017).

Valuing interdependence within stroke dyadic members provides a way for stroke care health professionals to shift their mentality from stroke-patient-centredness to stroke-dyad-centredness to enhance their engagement with both members of the stroke dyad in goal-setting, care plan development and discharge planning. Preliminary positive outcomes on functional recovery in people with stroke, self-management capabilities and psychosocial adaptation in stroke caregivers offer opportunities for further research on dyadic interventions during the hospital-to-home transition with the aim of enhancing self-management and caregiving sustainability in the long term (Bannon et al., 2020; Pucciarelli et al., 2021). The implementation of person-centredness in stroke-dyad-centred care calls for healthcare policymakers, leaders of healthcare organisations and frontline health professionals to work in collaboration to create a culture of enabling the dyad-centred approach in clinical practice (Byrne, Baldwin & Harvey, 2020; McCormack & McCance, 2017).

10.4 The Role of Health Professionals in Enhancing the Hospital-to-Home Transition

Post-stroke recovery and an individual’s response to treatment, therapy and care is highly complex and variable (Bishop et al., 2021; Kyle et al., 2020). The present study reveals the intertwined challenges at the systemic, organisational and professional levels, including funding model constraints on service provision, imbalances between service demand and the care needs of stroke dyads, and discrepancies in priorities between stroke dyads and health professionals. These challenges may impede authentic partnerships between health professionals and stroke dyads. However, the present study also highlights the significant role that health professionals played in supporting stroke dyads transitioning through their stroke journey from an inpatient setting to the community. The interdisciplinary team approach, safety culture and team resilience enhanced the safety and continuity of care during the hospital-to-home transition for stroke dyads.

Stroke rehabilitation refers to a proactive, person-centred and goal-oriented process, with interventions designed to maximise function and reduce limitations for people with stroke in interacting with their environment (Stroke Foundation, 2022; WHO, 2021). Aligning with the *Clinical Guidelines for Stroke Management* (Stroke Foundation, 2022), rehabilitation is provided by specialised interdisciplinary health professionals throughout the stroke care continuum (Stroke Foundation, 2022). Coordinated interdisciplinary teamwork has enabled improvements in stroke care and supported stroke dyads to achieve their goals of maximising recovery and reintegration into the community (Franz et al., 2020; Kyle et al., 2020). Nevertheless, in parallel with previous studies, the present study reveals that funding, service design and availability, the trend of time-limited rehabilitation services and the lack of specialist health professionals challenged the interdisciplinary team to support stroke dyads through the hospital-to-home transition (Kyle et al., 2020; L. Chen et al., 2020). Kyle et al.

(2020) have suggested health and social care system reform to foster an environment that empowers stroke care health professionals to provide person-centred care for stroke dyads.

Working within the constraints of the above challenges, health professionals in this study demonstrated flexibility and determination to enhance the safety of care. Safety culture was evident in the findings. Patient safety culture is related to organisational culture and refers to ‘a pattern of individual and organisational behaviour, based upon shared beliefs and values that continuously seeks to minimise patient harm, which may result from the process of care delivery’ (ACSQHC, n.d.-a). Patient safety culture is fostered through shared perceptions of the importance of safety at all levels, constructive communication and mutual trust (ACSQHC, n.d.-a; Hessels et al., 2019). The present study supports previous studies that show that patient safety is a priority in care service delivery among interdisciplinary stroke care teams and is supported by leadership, transparency, communication, effective collaboration and mutual goals in the care team (Berry et al., 2020; Vaughn et al., 2019).

Team resilience refers to the collective capacity of all team members to respond well to change, pressure and disruption (Hartwig et al., 2020). Team resilience emerged from the present study as an important element for positively influencing health professionals’ partnership and collaboration with stroke dyads in the face of constraints on service delivery (e.g., time constraints on health professionals in a busy clinical setting). In the present study, support from leaders, trust, clear communication and peer support among team members contributed to team resilience-building, team collaboration and enhanced team capability for partnering with stroke dyads in the hospital-to-home transition. With challenges in clinical practice, such as the demand for quality improvement and the rising cost of the health system (Department of Health and Aged Care, 2019; Kyle et al., 2020), resilience in health professionals in the workplace may provide an avenue for reducing psychological risks and promoting wellbeing in health professionals (Hartmann et al., 2020; Kuntz, 2021). Kuntz (2021) advocated for promoting resilience through clear organisational communications, peer and leadership support, flexibility, role clarity and quality teamwork (Kuntz, 2021).

The present study also revealed that nursing participants seem to have limited input into their role of supporting stroke dyads during the transition. This finding parallels with previous studies that showed that nurses' contributions to patients' care experience were not fully recognised by patients and their families or identified by nurses (L. Chen et al., 2016; Godsey et al., 2020; Landis et al., 2020). Globally, nurses make up the largest healthcare workforce in the healthcare system (AIHW, 2022b; World Health Organization, 2022b). Despite their professional qualifications and unique value to care services, nurses remain undervalued and unrecognised for their contributions to the healthcare system (Landis et al., 2020; Godsey et al., 2020). Landis et al. (2020) argued that nurses are viewed by patients and other health professionals in terms of the 'visible' work they do, such as caring for basic needs and psychomotor skills for performing nursing tasks. The 'visible' work is seen as less valuable compared to that of other health professionals, such as physicians and physiotherapists. The 'invisible' work—such as patient advocacy, nursing leadership and time spent with patients and family to build rapport—is not fully recognised in patients' care experiences (Landis et al., 2020). From nurses' perspectives, Godsey et al. (2020) suggested improving the nursing professional identity; nursing education needs to focus on both technical proficiency and soft skills such as communication, critical thinking, decision-making and coordinating care in a multidisciplinary team. Health organisations need to develop nursing leadership development pathways and enhance nursing involvement in decision-making (Godsey et al., 2020).

'Stroke nurse liaison', 'coordinator' or 'navigator' are terms that have been used interchangeably to describe the role of advanced practice nurses to coordinate stroke care, facilitate discharge planning, provide education and promote service development (Camicia, Lutz, Summers et al., 2021; Purvis et al., 2021). This specialised stroke nurse's role is gaining international recognition and has been recommended by the National Acute Stroke Services Framework in Australia (Camicia, Lutz, Summers et al., 2021; Stroke Foundation, 2019a). However, challenges in implementing this role have been identified, including insufficient time to perform the role, a lack of role clarity and inequality in job classification, limited funds to enable professional development, and inadequate orientation to the role (Purvis et al., 2022). To address these challenges and ensure the sustainability of this role, healthcare organisations need to conduct comprehensive reviews, establish systems to overcome barriers and allocate adequate resources (Camicia, Lutz, Summers et al., 2021; Purvis et al., 2022).

Health professionals play essential roles in post-stroke rehabilitation and hospital-to-home transition for stroke dyads. Despite the challenges they face in the reality of time-limited care services and inflexible funding models, health professionals demonstrate a resilience that is strongly influenced by patient safety culture in the workplace and strengthened through flexibility, consistent goals of the team, leadership and peer support. Team resilience enables health professionals to collaborate with stroke dyads to develop self-management capabilities and regain health, wellbeing and social integration during the hospital-to-home transition, despite challenges they may encounter in the ever-changing healthcare system. Stroke care nurses are in a unique position to lead and facilitate safe, effective and efficient care transitions for stroke dyads (Camicia, Lutz, Summers et al., 2021).

10.5 Enriching Meleis's Transitions Theory

In this study, the concepts in Meleis's transition theory (Meleis et al., 2000) that emphasise the nature of transition, transition conditions (facilitators and inhibitors) and patterns of response informed the analysis and interpretation of the potential factors affecting hospital-to-home transition care for stroke dyads (Chapter 3). Findings from this study enrich Meleis's transition theory through the perspective of stroke-specific transition care, as discussed in the following sections.

10.5.1 Nature of Transitions

10.5.1.1 Types and Patterns of Transitions

Stroke attacks the brain and instantly changes people's lives. Transitioning from hospital to home is considered the most challenging period for stroke dyads and their families. This transition is complex and multidimensional, affecting not only people with stroke but also their immediate families and social networks. Stroke dyads' hospital-to-home transitions are interwoven into a pattern of health–illness and situational transition. These include, for example, the transition from health to life-threatening illness (stroke), survival to recovery, independence to dependence, well-controlled hospital environment to the home environment with uncertainty, employment to unemployment, and from shared family roles to caregiving and care-receiving roles.

10.5.1.2 Transitional Properties

Three critical time points emerged during the hospital-to-home transition in this study: (1) during the hospital stay, (2) arriving home and during formal rehabilitation programs and (3) after separation from formal rehabilitation programs and during community dwelling. The transition brings changes and also results in changes. Changes emerge in the transition over time (Meleis et al., 2000). In this study, before hospital discharge, some participants with stroke viewed post-stroke impairments as temporary and anticipated significant improvement after returning home. They struggled to accept the reality of having to live with these impairments even at 6 months after hospital discharge. The perception of setbacks experienced by stroke dyads reflected the fact that the transition was a nonlinear process. Therefore, a thorough assessment of care needs at different key time points is warranted.

A stroke dyad's level of awareness of transition influences their level of engagement in the transition process (Meleis et al., 2000). For example, when experiencing challenges upon arriving home, some caregivers in the study realised the inadequate preparation they had before hospital discharge. Insights into a stroke dyad's awareness of transition and the level of preparedness would empower health professionals to better engage them in the discharge planning process.

10.5.2 Transition Conditions

Transition conditions either facilitate or inhibit the transition and encompass personal conditions (e.g., meanings, preparation and knowledge, and expectations), community conditions (e.g., social support and access to community supports) and societal conditions (e.g., stigmatisation or marginalisation; Meleis et al., 2000). These transition conditions intersect to influence the transition outcomes.

10.5.2.1 Personal Conditions

This study reveals that a stroke dyad's individual and dyadic personal conditions contribute to their transition experience. For example, both psychological distress and resilience emerged as attributes that could either enhance or challenge the transition. Sources for psychological distress and positive coping resilience differed between stroke dyad members. The study uncovered an inadequate assessment and exploration of these personal conditions before hospital discharge. Another example is caregivers' preparation for managing post-stroke complications, especially cognitive or speech impairment. Despite the information received before hospital discharge, the perceived challenges coming with the management of these impairments were beyond the capability of some caregivers at the early stage of the transition. An understanding of individual and dyadic personal conditions for stroke dyads would empower nurses and other health professionals to proactively identify care needs and mobilise the stroke dyad's inner resources, such as resilience and motivation, which contribute to a healthy transition.

10.5.2.2 Community Conditions

The social network served as a positive community condition for this study's participants, especially stroke caregivers. Emotional support and physical help from family, friends and neighbours seemed to have alleviated psychological distress and enhanced resilience for stroke dyads. Additionally, information-sharing and education on available community resources influenced stroke dyads' perceived confidence in self-management. For example, perceived support from health professionals was experienced by participants who had written the information and contact details of available stroke-specific community services. Moreover, the availability and accessibility of community rehabilitation services and peer support groups contributed to participants' transition experience. For example, people living in regional areas perceived challenges in seeking appropriate services to support their ongoing rehabilitation needs after separation from formal rehabilitation services. Participants living in regional areas may be disadvantaged in accessing peer support groups due to the absence of groups in their region.

10.5.2.3 System Conditions

Meleis et al. (2000) described the third transition condition as societal conditions, such as social stigmatisation or marginalisation, which were not revealed in this study. Instead, participants experienced positive outcomes through the collaboration between stroke dyads and health professionals, and they also suggested improvements that could enhance stroke dyads’ transition experiences and rehabilitation outcomes. All of these were rooted in the healthcare organisations and the healthcare system. For example, a focus on both dyadic members in assessing care needs, providing education and information, and engaging in decision-making and planning supported a proactive dyad-centred approach to care delivery and better targeted specific dyadic and individual needs. Additionally, a patient safety culture, supported by positive organisational leadership within the organisations, fostered clinical reflection and continuous quality improvement. Moreover, flexible funding models would potentially strengthen the integration of stakeholders on the stroke care chain to support the realisation of stroke dyads receiving the right service at the right time and in their preferred settings. Finally, as novices to the complex healthcare system, stroke dyads would benefit from a stroke nurse navigator to guide them in navigating the system, which would ease the psychological stress experienced by stroke dyads, especially the caregivers.

10.5.3 Patterns of Response

Meleis et al. (2000) presented patterns of response in process and outcome indicators and considered these indicators to be interlinked. Transition is a temporal process, and people in transition experience changes over time. Therefore, it is important to identify process indicators in the transition that either direct towards a healthy transition (referring to people feeling connected, positive intradyadic interactions, developed confidence and skills, and settling in the new role/situation) or to vulnerability and risk. Early assessment and intervention facilitate healthy outcomes (Meleis et al., 2000).

10.5.3.1 Process Indicators

In this study, several process indicators emerged. For example, both psychological distress and resilience were experienced by stroke dyads in the continuum of the transition. People with stroke and their caregivers differed in the sources and outcomes of these indicators. Psychological distress and resilience for people with stroke were related to their functional recovery. They experienced setbacks at the early stage of returning home but regained confidence and strengthened resilience with time, functional recovery and stabilisation, and support from their caregivers and health professionals. In contrast, caregivers experienced initial anxiety and distress before hospital discharge and at the early stage of returning home. The distress was balanced at the later stage of the transition, with resilience enhanced by learning to manage post-stroke complications, by support from social networks and health professionals, and by the improvement of functional recovery of their loved ones. Nurses and other health professionals would benefit from an understanding of these process indicators when interacting with stroke dyads in daily encounters. Knowledge of stroke dyads' direction of transition in the transition process enables early interventions to promote a healthy transition.

10.5.3.2 Outcome Indicators

Meleis's transition theory outlines two healthy transition outcome indicators: (1) mastery of new skills to manage the transition and (2) development of a fluid yet integrative identity, and these may be indicators for the completion of a healthy transition (Meleis et al., 2000). Meleis et al. (2000) suggested that process and outcome indicators overlap and also cautioned on the flexibility and variability in determining the completion of a transition (Meleis et al., 2000).

In this study, at the later stage of the transition (3–6 months after hospital discharge), stroke dyads were at different levels of reintegration into the community. All participants gradually resumed some pre-stroke activities. After completion of formal rehabilitation programs, some participants learned to seek stroke-specific therapies to stabilise or further enhance the regained functions. Participants also expressed gaining confidence and described developing their own strategies for solving problems in ADLs. These are positive outcome indicators for self-management and community reintegration. Regarding developing an integrative identity, some participants in this study, especially caregivers, struggled to situate themselves in the changed relationship, which was evidenced by their perceived challenges in accepting the lost functions and adapting to the caregiving role. This may suggest that an integrative role was yet to be established. Therefore, the conclusion of hospital-to-home transition may not be determined because they were still in the process of adaptation and transformation, which is a subjective process.

10.5.4 Nursing Therapeutics

Meleis's transitions theory highlights the importance of nursing therapeutics that recognise the complexity and multidimensionality of transitions, with a focus on preventing unhealthy transitions and promoting perceived wellbeing (Meleis et al., 2000). However, the findings of this study suggest that an interprofessional approach is necessary to facilitate the transition process. Understanding the perspectives of all stakeholders involved in the transition and recognising the dynamic and reciprocal nature of the relationships between stroke dyads and other stakeholders can empower interprofessional stroke teams to develop nurse-led interdisciplinary interventions that are tailored to each individual's unique situation and transition experience (Naylor et al., 2020; Ramsay et al., 2014).

Following discharge, people with stroke in this study accessed community-based rehabilitation and care services, such as home or centre-based rehabilitation, telerehabilitation or household support services. Despite receiving support from health and social care organisations, participants expressed a desire for a central contact person to support them in navigating the complex health and social care system and addressing any queries that might arise during the transition. The participants identified nurses as suitable candidates for this role, given that care coordination is a crucial nursing competency that encompasses patient advocacy, education and the facilitation of care transitions (Camicia, Lutz, Summers et al., 2021; Nursing and Midwifery Board, 2016).

Meleis's transitions theory served as a valuable foundation for the researcher's exploration of hospital-to-home transition care for stroke dyads. However, it is important to acknowledge that Meleis's framework is generic in nature and lacks consideration for the intricate and dynamic nature of the relationship between people with stroke and their caregivers. Additionally, it overlooks the importance of involving multiple stakeholders in the transition process. To address these limitations, it is essential to integrate stroke-specific elements, such as stroke-dyad-centredness and the contemporary model of care that emphasises interprofessional collaboration. By incorporating these aspects, the framework can better capture the unique challenges faced by stroke dyads during their hospital-to-home transition. A stroke-specific hospital-to-home transition care framework would not only deepen our understanding of stroke dyads' experiences but also facilitate the development of effective strategies to enhance transition care. To address these gaps, the next chapter presents a novel stroke-specific transition care framework, inspired by the findings of this study and supported by evidence from prior research.

10.6 Summary

This chapter has discussed the complexity and multidimensionality of hospital-to-home transition care for stroke dyads, considering the perspectives of both stroke dyads and health professionals. The focus on physical functions in post-stroke recovery neglects the psychosocial needs of stroke dyads and overlooks the negative impact of the caregiving role on caregivers' mental health during the transition. Dyadic interdependence within stroke dyads can either facilitate or challenge the transition process. Moreover, a workplace culture that prioritises safety and resilience strengthens the commitment of interprofessional teams to provide safe and quality care. Stroke dyads would benefit from the guidance of a stroke nurse coordinator/navigator throughout the transition. These findings enrich Meleis's transitions theory by incorporating stroke-specific elements and highlight the need for a stroke-specific dyad-centred hospital-to-home transition care framework, which is detailed in the next chapter.

Chapter 11: Proposing a Novel Stroke-Specific Hospital-to-Home Transition Care Framework

11.1 Introduction

Chapter 10 discussed the interwoven factors that shaped the transition experiences of stroke dyads. The study reveals that caregivers tend to prioritise providing physical and psychological support to people with stroke while overlooking their own health and care needs. Such a situation compromises caregivers' psychological wellbeing and can potentially affect their self-management and caregiving capabilities. This finding highlights the importance of a dyad-centred approach to assessing care needs and planning care throughout the transition period. Furthermore, this study underscores the significance of workplace safety culture and the resilience of interprofessional teams in enhancing transition care.

To facilitate the transition, the presence of a stroke nurse coordinator/navigator is proposed to guide stroke dyads through the complexities of the healthcare system. Building upon the research evidence from this study and previous research, a novel stroke-specific hospital-to-home transition care framework (hereafter, 'the framework') is proposed. The key components of the framework are illustrated in Figure 11.1 and elaborated in the subsequent sections.

11.2 Overview of the Framework

The purpose of the framework is to engage stakeholders in planning future service development to improve stroke dyads' experience in hospital-to-home transition. The framework emphasises gaps in the transition process, opportunities to bridge the gaps and stroke-nurse-navigator-enabled interprofessional collaboration and partnership with stroke dyads during the transition. The framework consists of two interconnected components: (1) the stroke-specific hospital-to-home transition care foundation, and (2) stroke-nurse-navigator-enabled hospital-to-home transition care in the three key phases—during the hospital stay, arriving home and during formal rehabilitation programs, and after separation from formal rehabilitation programs and during community dwelling.

11.3 The Stroke-Specific Transition Care Foundation

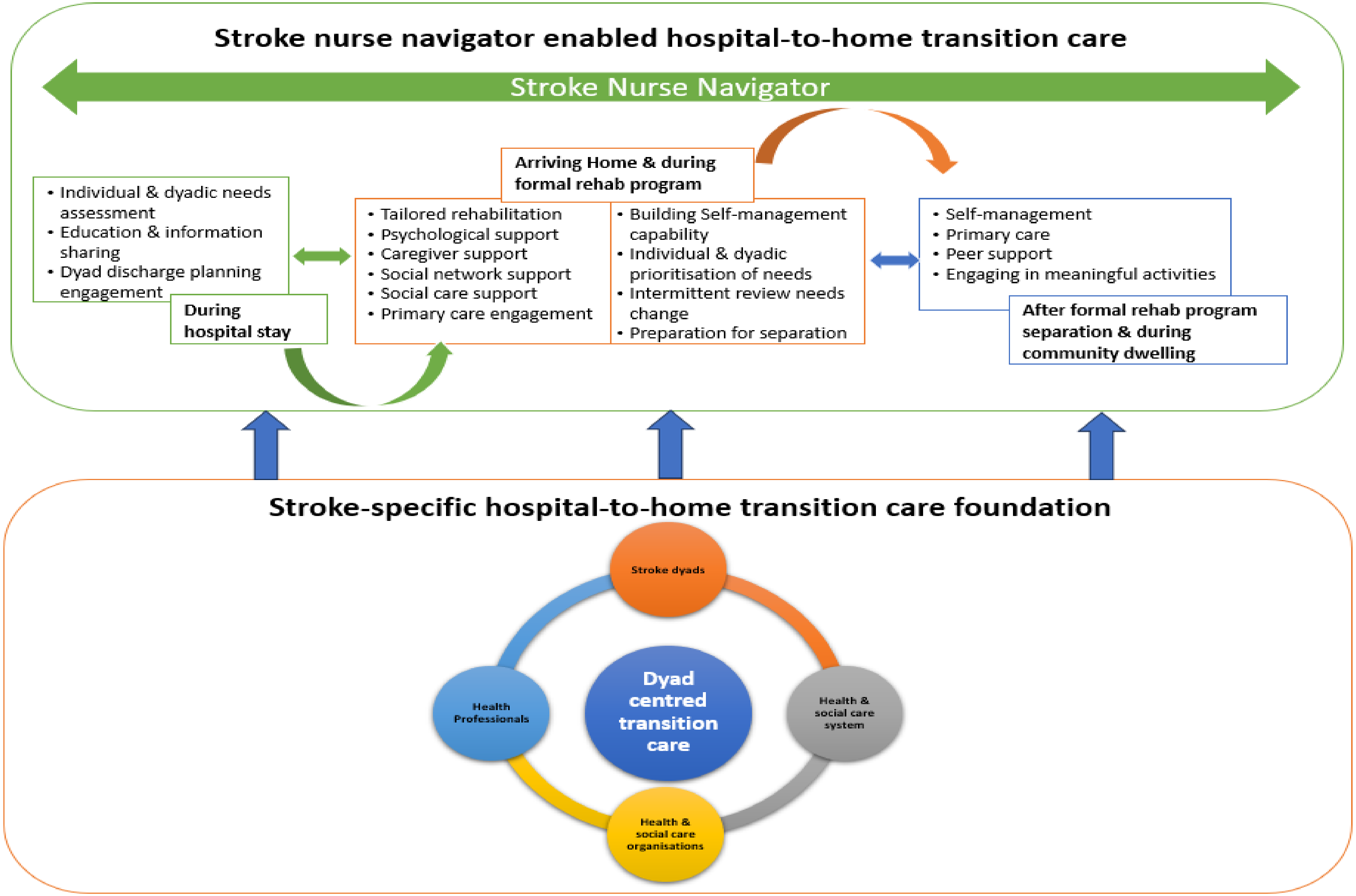
The foundation emphasises the collaboration and partnerships among stakeholders in transition care, including but not limited to the health and social care systems, health and social care organisations (facilities), health and social care professionals, and stroke dyads in the health and social care systems. The stroke dyads' care needs during the transition are the central focus in the foundation. Each stakeholder plays individual and collaborative roles throughout the transition process. The foundation highlights the need for stroke care stakeholders to work together by implementing strategies that support the stroke-nurse-navigator-enabled hospital-to-home transition care.

11.3.1 Health and Social Care Systems

The health and social care system (hereafter, 'health system') plays a crucial role in meeting people's individual needs by providing safe, effective, accessible and appropriate treatment and services (AIHW, 2022a). Australia has a unique hybrid health system (hospital and community services) that combines public and private components, with Medicare serving as the foundation and supplemented by private health insurance. Eligible individuals in Australia can access government-subsidised health services either free of charge or at a low cost (Department of Health and Aged Care, 2019).

Figure 11.1

Proposed Stroke-Specific Hospital-to-Home Transition Care Framework


Stroke nurse navigator enabled hospital-to-home transition care
Stroke Nurse Navigator
• Individual & dyadic needs assessment
• Education & information sharing
• Dyad discharge planning engagement
During hospital stay
Arriving Home & during formal rehab program
• Tailored rehabilitation
• Psychological support
• Caregiver support
• Social network support
• Social care support
• Primary care engagement
• Building Self-management capability
• Individual & dyadic prioritisation of needs
• Intermittent review needs change
• Preparation for separation
• Self-management
• Primary care
• Peer support
• Engaging in meaningful activities
After formal rehab program separation & during community dwelling
Stroke-specific hospital-to-home transition care foundation
Stroke dyads
Health Professionals
Dyad centred transition care
Health & social care system
Health & social care organisations

Stroke dyads use a range of rehabilitation and social care services to support the rehabilitation and community living of people with stroke after hospital discharge. These include hospital outreach services provided in homes, day hospitals or community centres; telehealth options; as well as social care services offered by community aged-care and disability care providers. Community services are typically organised based on age criteria, with government-subsidised aged-care services for people aged 65 years and over (or 50 and over for Aboriginal and Torres Strait Islander people). Disability services are primarily designed for individuals below this age threshold (My Aged Care, n.d.). However, the findings of this study align with the report of the Royal Commission into Aged Care Quality and Safety (2021), which highlighted the inequitable access to disability services for people above the age of 65, who do not meet the eligibility criteria for services such as the NDIS. The participants in this study emphasised the importance of service development based on individual needs rather than age, as it would significantly enhance transition experiences for stroke dyads.

The study's findings indicate the need for investment in psychology and mental health care resources, particularly in rural and remote areas, to enhance timely access to services and address existing gaps (Kable et al., 2019; Prior et al., 2023). The Australian National Stroke Audit (Stroke Foundation, 2020a) revealed that about 31% of rehabilitation services lack access to clinical psychologists or neuropsychologists, despite over 65% of community-dwelling people with stroke reporting unmet psychological needs within 2.5 years after stroke (Tjokrowijoto et al., 2023). Another study exploring health professionals' views on mental health services gaps in Australia advocated for system reforms and increased investment in mental health services to meet the growing demand (Petrie et al., 2021).

The expectations expressed by stroke dyads in this study call for a flexible and proactive health system to empower them to take an active role in their own care. Policy and financial innovations and reforms are necessary to enable stroke dyads to choose their preferred care facilities and providers, timings and settings for care services. Such reforms are particularly crucial for stroke caregivers, who play a vital role in supporting the sustainability of the health system (Kokorelias et al., 2020). Quality improvement in care services resulting from health system reforms would foster greater engagement of stroke caregivers in care planning, enhance their transition experiences and strengthen sustainable caregiving for people with stroke in the community (Kokorelias et al., 2020; Lobo et al., 2021).

11.3.2 Health and Social Care Organisations (Facilities)

Health and social care organisations encompass a diverse range of public and private entities responsible for delivering health and social care services (AIHW, 2022a). Ensuring safety and quality in healthcare is a collective responsibility that relies on effective governance and management processes and the establishment of systems within these organisations (ACSQHC, n.d.-b). To provide safe and high-quality care in partnership with consumers, health and social care organisations must establish robust governance systems and implement strategies that foster a culture of safety and engage health professionals through leadership, communication and collaboration (ACSQHC, n.d.-b).

‘Culture’, within an organisation, refers to the shared values and beliefs among different occupational groups, which manifest in the common patterns of behaviour sustained through rituals, ceremonies and rewards of everyday organisational practices (H. T. O. Davies & Mannion, 2013). Leadership, workforce wellbeing and engagement, team coherence, and transparency are key factors that contribute to sustaining a culture of safety and high-quality care, ultimately improving the overall quality of healthcare within health organisations (Mannion & Davies, 2018; Tate et al., 2023). A study by Tate et al. (2023) emphasised the critical role of complementary and relationship-focused leadership styles and cultures in hospitals, highlighting their effect on quality care improvement and patient outcomes.

The findings of the present study reinforce the idea that health and social care organisations need to prioritise patient safety culture, emphasise organisational leadership and governance, and foster team resilience. By cultivating a culture of safety and high-quality care, these organisations can promote dyad-centredness, equity, integration and effectiveness in the provision of care services during hospital-to-home transition care. This entails an enabling environment wherein health professionals, especially stroke nurse navigators, feel empowered to collaborate, communicate effectively and contribute their expertise, ultimately resulting in improved outcomes and experiences for stroke dyads during the transition between different care settings (Adeoye et al., 2019; Lip et al., 2022).

11.3.3 Health and Social Care Professionals

Health and social care professionals involved in post-stroke care have a vital role in supporting stroke dyads throughout the hospital-to-home transition. They work closely with stroke dyads by assessing and understanding the care needs and priorities of stroke dyads; implementing and evaluating fundamentals of care and evidence-based rehabilitation interventions; and providing emotional support (Jarva et al., 2021; Theadom et al., 2018). However, the findings of this study suggest that health and social care professionals can further enhance their partnership and collaboration with stroke dyads by developing knowledge about dyadic interdependence and its effect on stroke dyads during the transition. Incorporating this kind of knowledge into their practice would allow health professionals to better assess the care needs, goals and preferences of stroke dyads; co-develop and implement discharge plans; and proactively address their physical and psychosocial care needs. By understanding the dynamics of dyadic interdependence, professionals can cultivate resilience within stroke dyads and enable them to explore meaningful activities that lead to a purposeful life, regardless of the post-stroke disabilities experienced by the person with stroke.

Furthermore, in this study, despite physical and psychological challenges faced by the stroke dyads during the transition, they demonstrated resilience and the ability to reconcile with the changes and move forward with their changed lives. By adopting a partnership approach to care provision, health professionals can further cultivate resilience and strengthen dyadic coping in the transition period. This collaborative approach fosters a sense of empowerment, trust and shared responsibility, ultimately leading to improved outcomes and a more positive hospital-to-home transition experience for stroke dyads (ACSQHC, n.d.-b).

Collaboration among professionals across disciplines, organisations and care settings is widely recognised as a crucial strategy to enhance person-centred care, improve patient and system outcomes and prevent silos in care delivery (McLaney et al., 2022; Rawlinson et al., 2021). The WHO defines interprofessional collaboration as the collective practice of multiple health workers from different professional backgrounds working together with patients, families, carers and communities to deliver the highest quality of care across settings (WHO, 2010). The core competencies of interprofessional collaboration encompass fostering a culture of mutual respect, trust and shared decision-making among professionals; valuing the expertise of others to assess and address healthcare needs; facilitating interprofessional communication; and strengthening teamwork to plan, deliver and evaluate safe, timely, effective and equitable healthcare services (Interprofessional Education Collaborative, 2016).

To facilitate interprofessional collaboration, health systems and organisations should establish mechanisms to optimise funding that supports collaborative practice. This can involve allocating resources specifically for interprofessional teamwork, such as dedicated time for team meetings, training programs and shared decision-making processes. Additionally, creating an enabling environment to promote a culture of caring relationships among team members is crucial. This can be achieved by fostering open and respectful communication, promoting a sense of psychological safety and encouraging collaboration and mutual support within the team. Professional development opportunities should be provided to enhance knowledge and skills related to collaborative practice, ensuring that professionals are equipped with the necessary competencies to effectively work together across disciplines. The clear delineation of roles and responsibilities is essential to facilitate interprofessional communication and coordination, minimising confusion and enhancing the efficiency and effectiveness of care delivery (Ansa et al., 2020; Rawlinson et al., 2021; H. Wei et al., 2020).

By embracing authentic partnership and collaboration, health professionals can break down the silos in care delivery and create a more integrated and dyad-centred approach to stroke transition care. This collaborative approach enhances continuity of care, reduces fragmentation, avoids duplication of services and ultimately improves the overall experience and outcomes for stroke dyads (Ansa et al., 2020; H. Wei et al., 2020). However, implementing interprofessional collaboration in daily clinical practice comes with challenges that require further research to establish insights into barriers and facilitators to interprofessional collaboration, inform the development of effective communication and coordination strategies, and promote a culture of collaboration within and across health organisations (Didier et al., 2020; Schot et al., 2020).

11.3.4 Stroke Dyads

Stroke dyads are at the core of this framework’s foundation. Stroke dyads play a critical role in their own recovery and care planning. The study’s findings emphasise their active involvement and desire to participate in their care, fostering a sense of ownership and empowerment throughout the hospital-to-home transition. They seek a collaborative relationship with health professionals, aiming for shared decision-making and the co-development of care plans.

In the present study, stroke dyads recognised the importance of addressing both physical and psychological care needs during the transition. While the physical rehabilitation of people with stroke is often a primary focus, the study revealed the significance of attending to the psychological wellbeing of both the person with stroke and their caregiver. Health professionals need to recognise the emotional and mental strain experienced by caregivers and provide appropriate support and resources to strengthen caregiving support systems.

Moreover, this study underscores the notion that stroke dyads’ care needs evolve over the course of the transition. As dyads navigate different stages and face various challenges, it is crucial for health professionals to regularly reassess and evaluate the dyads’ changing care needs. Staying attuned to these evolving needs will enable health professionals to collaborate with stroke dyads to adjust care plans accordingly and ensure their needs are met effectively. In addition, actively engaging in ongoing communication with the dyads will inform health professionals of strategies for fostering a strong partnership with stroke dyads and promoting a dyad-centred and responsive approach to care planning.

Peer support plays an important role in supporting stroke dyads and is recommended by the *Clinical Guidelines for Stroke Management* as a means of promoting community participation and reintegration (Stroke Foundation, 2023). During the transition, health professionals should provide stroke dyads with information about peer support in the community, particularly before their separation from formal services (Stroke Foundation, 2023). Connecting with peer support allows dyads to share experiences, receive mutual support, overcome social isolation and enhance their problem-solving skills and functional capabilities (Clark et al., 2020; May et al., 2023). Peer support can be delivered individually or in group settings, offering potential benefits such as reduced psychological stress and improved self-management capabilities for the dyads (Clark et al., 2020; May et al., 2023).

Collaboration among all stroke care stakeholders is the cornerstone for successful hospital-to-home transition care for stroke dyads. This involves a stroke-dyad-centred approach, co-created goals and appropriate support from the health system. Active participation and shared decision-making between stroke dyads and health professionals are key to ensuring that care plans are tailored to the dyads' specific needs. By actively involving stroke dyads in the care planning process, their preferences and priorities can be integrated, leading to a more personalised and effective transition experience.

11.4 The Stroke-Nurse-Navigator-Enabled Hospital-to-Home Transition

This framework emphasises the need to enhance the role of the stroke nurse navigator in the hospital-to-home transition care period, as detailed in the following sections.

11.4.1 The Role of Stroke Nurse Navigator

The study's findings highlight the value of dedicated stroke nurse navigators (hereafter, 'navigators') in supporting stroke dyads throughout their journey from inpatient settings to the community. These specialised stroke nurses, practising at an advanced level, play a crucial role in facilitating and managing care transitions, which leads to improved continuity of care, reduced service fragmentation, enhanced quality of care for stroke dyads and decreased hospital readmissions (Byrne, Hegney et al., 2020; Camicia, Lutz, Summers et al., 2021). While the role of nurse navigators was initially introduced in the United States to address gaps in oncology care (Freeman, 2006), it has also been implemented internationally, including in Australia, to benefit people with chronic conditions, including stroke, and strengthen comprehensive support (Byrne, Hegney et al., 2020; Deen et al., 2016).

In Australia, the role of stroke clinical coordinator, also known as a stroke liaison officer or stroke facilitator, has been established as an integral part of stroke care and is recommended in the National Acute Stroke Services Framework (Purvis et al., 2018; Stroke Foundation, 2019a). Stroke coordinators fulfil various responsibilities across different settings, including stroke units in acute hospitals and community settings. These responsibilities encompass facilitating the patient journey from the emergency department to discharge, discharge planning, patient and professional education, and service development (Purvis et al., 2021). Previous studies have demonstrated that the implementation of the stroke coordinator role is associated with reduced hospital length of stay and the delivery of evidence-based care in hospitals with a stroke unit (Purvis et al., 2018), as well as improved quality of care during the hospital-to-home transition (Miller et al., 2019). However, the coordinator role in these studies focused either on the acute post-stroke phase in the hospital (Purvis et al., 2018) or the post-discharge phase in the community (Miller et al., 2019). In contrast, the present study advocates for the role of a navigator to follow-up with stroke dyads throughout the entire hospital-to-home transition continuum (Camicia, Lutz, Summers et al., 2021).

In 2016, Queensland Health introduced nurse navigators as a team of advanced practice registered nurses responsible for delivering comprehensive clinical care to patients with complex health conditions, including stroke (Queensland Health, 2019). The nurse navigators’ role is guided by key principles that include establishing partnerships, coordinating consumer-centred care, facilitating system improvement and enhancing consumer outcomes (Queensland Health, 2019). The use of nurse navigators has demonstrated positive outcomes, such as reducing unplanned 30-day readmissions, improving post-discharge compliance and enhancing the quality of life for stroke dyads (Deen et al., 2016; Hudson et al., 2019; Jun-O’Connell et al., 2023). Nevertheless, in contrast to previous studies, the present study revealed the importance of stroke navigators collaborating with stroke dyads throughout the entire hospital-to-home transition and offering opportunities for stroke dyads to navigate back to the healthcare system when needed (Camicia, Lutz, Summers et al., 2021). This approach may open up a new avenue for addressing long-term care needs and better sustaining community-dwelling for stroke dyads (Scrivener et al., 2022).

To effectively support stroke dyads during the hospital-to-home transition, navigators should possess knowledge about the health systems, available resources and care services, relevant organisations, and professionals involved in post-stroke care. They should also understand dyadic interactions within stroke dyads, including their unique care needs, preferences and factors influencing their recovery and rehabilitation goals. Navigators must demonstrate proficiency in providing comprehensive support to stroke dyads, including resource and service navigation, emotional and psychological assistance, education, and coordination of services. Their interventions should aim to alleviate the stress and uncertainty associated with the transition back to home and community settings (Byrne, Hegney et al., 2020; Camicia et al., 2020).

Furthermore, navigators need to facilitate effective communication within the stroke team and across disciplines, organisations and care settings. It is crucial to rigorously evaluate the role of stroke navigators in terms of stroke dyads’ overall transition experience, improving health outcomes and reducing hospital readmissions and healthcare costs (Mitchell et al., 2022; Mora et al., 2017). To ensure the presence of knowledgeable and skilled stroke navigators, governments at the federal or state levels need to fund their position in the healthcare system. Moreover, nursing professional bodies (e.g., the Australasian Rehabilitation Nurses' Association and Acute Stroke Education Network) will need to advocate for the establishment of stroke navigators in the healthcare system. In addition, healthcare organisations need to create the position and work with nursing education providers to co-design and co-produce competent navigators using flexible, ongoing, work-integrated learning approaches or micro-credential courses based on navigators' learning needs and experiences (Desmarchelier & Cary, 2022; Karlsson et al., 2022; Purvis et al., 2022).

11.4.2 Key Transition Phases

The framework introduces a novel approach with three key transition phases derived from the findings of this study. While previous studies have examined the experiences of stroke dyads during the hospital-to-home transition period, they have not identified pivotal turning points that influence stroke dyads' care needs and progression throughout the transition, particularly the key point of arriving home (Connolly & Mahoney, 2018; Kable et al., 2019; Pereira et al., 2021). The key phases identified in this study were (1) during the hospital stay, (2) arriving home and during formal rehabilitation programs, and (3) after separation from formal rehabilitation programs.

11.4.2.1 During the Hospital Stay

The present study, along with other abundant research evidence, has demonstrated that preparation before hospital discharge and active engagement of stroke dyads in discharge planning significantly affects their ability to manage care at home, particularly for stroke caregivers who assume their role within a short timeframe (Camicia et al., 2022; L. Chen et al., 2022). The present study revealed the interdependence between stroke dyad members, highlighting the need for comprehensive care needs assessments for both the person with stroke and the caregiver. It is important to recognise that, while individuals with stroke may regain independence in walking and self-care, they may struggle with sharing household tasks with their caregivers. Consequently, caregivers often face unexpected burdens and stress after hospital discharge (L. Chen et al., 2022; Camicia et al., 2022). A dyad-centred approach to care needs assessment becomes crucial, enabling the stroke care team to provide tailored education, share relevant information and resources, and address stroke dyads’ specific needs within their unique life situations. This approach enhances engagement in discharge planning, thereby paving the way for the transition journey after leaving hospital.

Navigators play a vital role in collaboration with interdisciplinary teams at stroke units and rehabilitation wards to ensure coordinated care. They achieve this by maintaining effective and efficient communication, actively participating in dyadic care needs assessment, promoting stroke education, providing emotional support and facilitating the transition from the acute setting to rehabilitation. Prior to hospital discharge, navigators contribute to discharge planning by fostering dyadic engagement in the process. This includes facilitating knowledge and skills preparation, particularly for caregivers and collaborating with inpatient and post-discharge service providers to ensure the implementation of discharge plans that are tailored to the needs and preferences of stroke dyads.

11.4.2.2 Arriving Home and During Formal Rehabilitation Programs

The present study highlights the period immediately after arriving home as the most vulnerable phase for stroke dyads. This period refers to the first few weeks following arrival home, during which this study’s participants experienced a stark contrast between the controlled hospital environment and the new post-stroke and post-hospitalisation home environment. To mitigate challenges during this phase, it is beneficial for individuals with stroke to familiarise themselves with the home environment before hospital discharge through overnight stays or day visits at home (Camicia et al., 2014; L. Chen et al., 2020). This practice enables stroke dyads, particularly those with lengthy hospital stays, to identify potential issues; facilitates clear goal-setting during inpatient rehabilitation; and addresses any concerns proactively.

Furthermore, service delivery should allow for flexibility, giving stroke dyads sufficient time to settle into their home environment before community-based rehabilitation and care services commence. While seamless service delivery aims to bridge the gap between hospital and home, it is essential to negotiate service arrangements based on each individual’s specific needs to ensure proper alignment. Mismatches between provided services and actual care needs can intensify the challenges faced by stroke dyads upon returning home. Therefore, in addition to tailored rehabilitation programs for individuals with stroke, it is imperative that there is psychosocial support for caregivers, social care support to alleviate caregiving burden and support from social networks. The stroke care team should also engage with the primary care team in the community to explore alternatives, such as peer support groups, that could help establish a support system for those with limited social networks.

Before separation from formal rehabilitation services, healthcare professionals need to build confidence for the dyads in navigating the healthcare system, developing self-management capabilities and adapting to post-stroke limitations in daily life. It is crucial to engage in dyadic assessments, preparing stroke dyads for separation by facilitating goal-setting, trialling meaningful activities and sharing information about available community resources, stroke-specific rehabilitation programs, social care support and peer support groups. Additionally, informing stroke dyads about pathways to refer back to formal rehabilitation services when needed enhances ongoing support.

During this phase of the transition, navigators maintain regular contact with stroke dyads through various means, such as phone calls, telehealth technology or home visits, depending on the specific needs of the dyads. In the present study, participants expressed their expectation for stroke navigators to serve as the central point of contact, allowing them to share their concerns, discuss their thoughts about their own health and seek feedback on their future plans. Navigators also play a crucial role in assisting stroke dyads in developing self-management capabilities. This includes helping them devise strategies to enhance resilience and psychological wellbeing, acquiring knowledge about the healthcare and social care systems, identifying available support services, and establishing meaningful connections with community peer support groups or individuals. Additionally, stroke navigators maintain collaborative relationships with community rehabilitation, primary care, and social care teams to effectively address any challenges that may arise during the transition phase.

11.4.2.3 After Separation From Formal Rehabilitation Services and During Community Dwelling

In the present study, it was observed that, 6 months after hospital discharge, the majority of participants had completed formal rehabilitation programs, with or without follow-up community rehabilitation services, except for one participant. The participants expressed an expectation for a gradual decrease in the intensity of rehabilitation therapies over an extended period rather than a sudden cessation at a specific point. Previous research has indicated that post-stroke functional improvement may slow down or plateau after 6 months from the onset of stroke (Grefkes & Fink, 2020; Scrivener et al., 2022). However, it is important to note that a significant number of individuals experience deterioration over time and continue to live with higher levels of disability (Scrivener et al., 2022). This is further compounded by the presence of comorbidities, such as cardiac diseases and diabetes, which can further complicate community living and adversely impact the quality of life for stroke dyads (Scrivener et al., 2022).

To continue the support for stroke dyads in the chronic phase of the stroke trajectory, the healthcare system needs to reform and ensure ongoing access to disability services for stroke dyads, irrespective of their age, to address their care needs and support their community dwelling (Scrivener et al., 2022). Navigators play a key role as intermediaries between stroke dyads and the healthcare system. They provide support to stroke dyads, facilitating connections with peer support groups, community health and social care teams, and primary care providers when the need arises. It is essential to recognise that there should be no time limit for follow-up, and navigators should be a government-subsidised, needs-driven and self-referred service available to stroke dyads. However, it is important to acknowledge that the role of navigators alone cannot fully address the complex care needs of stroke dyads without the support of health systems. Collaborative efforts between navigators and other healthcare providers are necessary to provide comprehensive and holistic care for stroke dyads in the long term.

11.5 Summary

This chapter has discussed the proposed stroke transition care framework. The proposed framework offers a novel perspective on the hospital-to-home transition for stroke dyads, highlighting the crucial role of navigators in supporting them throughout the entire stroke trajectory. It emphasises the unique needs and necessary support at various phases of the transition, which have a significant influence on the transition experience and long-term outcomes for stroke dyads. The presentation of this framework aims to inspire meaningful discussions among stroke care stakeholders about the importance of the hospital-to-home transition and its profound impact on the ability of stroke dyads to live and thrive in the community over the long term.

The next chapter reviews the research findings, identifies study limitations, draws conclusions from the study, makes recommendations for stroke hospital-to-home transition care and discusses the implications of the findings for clinical practice and future research.

Chapter 12: Conclusion

12.1 Introduction

This two-phase qualitative study has effectively achieved its aim of exploring the care needs and expectations of stroke dyads during the hospital-to-home transition, as perceived by both stroke dyads and health professionals, in the Australian social context. The study built upon the evidence generated by a comprehensive systematic review and meta-synthesis of qualitative studies and employed Gadamer's philosophical hermeneutics to guide data collection, analysis and interpretation (Gadamer, 1979). Meleis's middle-range transition theory (Meleis et al., 2000) was also used to comprehend the complexity and multidimensionality of the transition and to aid the generation of a transition care framework. The study's findings and proposed framework offer a novel perspective on post-stroke transition care that emphasises the dyadic interdependence of caregivers and care recipients, as well as the importance of interprofessional team culture and resilience. This final chapter critically evaluates the limitations of the study; outlines implications and recommendations for practice, policy, and future research; and provides a reflective account of the researcher's experience.

12.2 Limitations

The study has several limitations that need to be acknowledged. First, the generalisability and replicability of the findings may be limited due to recruitment from a single rehabilitation centre and the exclusion of non-English speakers. Moreover, the study's hermeneutic approach is rooted in specific social and cultural contexts, which may limit the transferability of the findings to other contexts. However, the existing literature supports the study, suggesting that the findings may be transferable to similar social contexts. Furthermore, the researcher acknowledges that no participants from Aboriginal or Torres Strait Islander backgrounds or culturally and linguistically diverse backgrounds expressed interest in participating in the study. Therefore, the findings may not represent the perspectives of these minority ethnic groups and should be interpreted accordingly.

Second, the study's sample only included participants with mild cognitive or speech impairment. Thus, the findings may not reflect the experiences of those with moderate to severe cognitive or speech impairment. Moreover, recall bias may have affected the narratives of two dyads whose first interview occurred within 2 weeks after hospital discharge. Additionally, three participants with mild cognitive impairment and their caregivers were interviewed together to cross-check the narratives, which may have suppressed free discussions from each side due to family dynamics. However, the same interviewer conducted all the interviews, which helped to achieve a level of internal consistency.

Third, the study only managed to recruit two GPs, which may limit the understanding of stroke dyads' transition experience from the perspectives of primary care teams, including community care service providers. Future research could incorporate this consideration. Furthermore, health professional participants were colleagues of the interviewer, which may have influenced the full expression of participants' thoughts. Therefore, this needs to be considered when interpreting the findings.

12.3 Summary of the Study

Stroke is a sudden brain injury that leads to long-term physical, psychological and cognitive sequelae (Grefkes & Fink, 2020; Scrivener et al., 2022). As stroke management advances, more people are surviving stroke and returning home from the hospital, where they are supported by caregivers while living with disabilities (Stroke Foundation, 2022; Zimmerman et al., 2021). The hospital-to-home transition (hereafter, 'transition') poses significant challenges for stroke dyads to navigate complex care needs and face the global trend of shortened hospital stays (Camicia, Lutz, Harvath & Joseph, 2021; L. Chen et al., 2020). Despite the demonstrated dyadic interdependence during the transition, there is a lack of research exploring the individual and dyadic care needs and expectations of stroke dyads.

Phase 1 of this research project involved a systematic review and meta-synthesis of qualitative studies with the primary aim of examining the experiences and care needs of stroke dyads during the transition. This meta-synthesis revealed various enablers and barriers in transition care. Health professionals' partnerships with stroke dyads facilitated discharge preparation and helped stroke dyads build self-management capabilities and competence in navigating health systems. Stroke dyads attributed their unmet care needs to inadequate discharge planning and post-discharge support, which adversely affected their ability to cope with post-stroke changes. Moreover, stroke dyads emphasised the need for integrated transitional care that promotes partnership and shared decision-making and empowers long-term self-management at home. These findings, encompassing a global perspective, offered a comprehensive understanding of stroke dyads' experiences, needs and expectations during transition, which paved the way for Phase 2 of this research project.

Theories and concepts applied to transition care for stroke dyads were analysed to identify a suitable theoretical framework to inform this study. The middle-range transitions theory developed by Meleis et al. (2000) was viewed as relevant to this study. Meleis's transition theory has been widely used and tested in various care settings with diverse populations. Acknowledging engagement, change, time and critical points as key properties of transition, the theory emphasises the dynamic interactions among the person, community and society, as well as the role of nursing therapeutics in facilitating healthy transition. The concepts outlined in Meleis's transition theory informed the analysis and interpretation of potential factors influencing the transition for stroke dyads in this study.

Gadamer's (1979) philosophical hermeneutics guided the qualitative study in Phase 2 of this project. Central to Gadamer's hermeneutics is a linguistically mediated dialogical approach that encourages the engagement of the researcher in the interpretation process and is referred to as a hermeneutic circle. A deeper understanding (new knowledge) of the studied subject is achieved through the cyclical fusion of horizons between the researcher's pre-knowledge (the past) and study participants' perspectives (the present). In this process, the researcher maintains an open mind and consciously identifies, provokes, and revises the pre-knowledge (Gadamer, 1979). Gadamer’s hermeneutics guided the researcher to design this study, collect and interpret data, and formulate the findings.

Phase 2 was a longitudinal qualitative study that took place in a tertiary public hospital in Adelaide, South Australia. Thirty people—people with stroke and their caregivers—had face-to-face interviews separately before hospital discharge and at 3 and/or 6 months after discharge. In addition, 31 health professionals participated in the study through face-to-face interviews or focus groups.

The study’s findings highlight the complexity and multidimensionality of the transition for stroke dyads. Participants viewed that psychological care for stroke dyads could be further enhanced by health professionals’ equal attention to both functional recovery and psychological care needs for stroke dyads. Additionally, stroke dyads’ perceived dyadic interdependence positively impacted their adaptation to challenging situations. Caregivers played a vital role in psychological support for people with stroke, but such a role was not fully recognised nor supported in the healthcare system. Moreover, stroke dyads expected enhanced engagement and shared decision-making in discharge planning and needs-driven service provision. Furthermore, health professionals believed that their commitment to safe and quality care was enhanced by the workplace safety culture that was fostered through leadership and team resilience.

The findings of this study led to the proposal of an innovative transition care framework. The foundation of the framework is the partnership and collaboration among various stakeholders: health systems, healthcare organisations, health professionals and stroke dyads. Built on this foundation is navigator-enabled dyad-centred transition care at three key phases: (1) during the hospital stay, (2) arriving home and during formal rehabilitation programs, and (3) after separation from formal rehabilitation programs and during community dwelling. This novel transition care framework has implications for clinical practice and future research.

12.4 Implications

Findings of the longitudinal qualitative study on the transition for stroke dyads have implications for policy development, health organisations, health professional education and future research. The implications are discussed in this section.

12.4.1 Implications for Policy Development

Despite advancements in stroke management, stroke dyads in Australia face challenges in accessing equitable and timely best-practice stroke and rehabilitation services, especially in rural and regional areas (Royal Commission into Aged Care Quality and Safety, 2021; Stroke Foundation, 2019a, 2022). Policy development and resource allocation are needed to address these challenges and to support stroke dyads during the transition. The findings of this study have implications for policies and resources to enhance the health, wellbeing and social integration of stroke dyads.

12.4.1.1 Implication for Policy Development to Remove Age Threshold of Disability Services for Equal Access

Stroke dyads residing in the community have ongoing needs related to physical functioning and psychosocial wellbeing, which are crucial for maintaining their independent living (Guo et al., 2021; Scrivener et al., 2022). *Australia's Disability Strategies 2021–2031* also emphasises the importance of ensuring that individuals with disabilities have access to necessary support (National Disability Insurance Agency, 2021). However, both the findings of this study and the existing research highlight inequitable access to disability services for people with stroke aged 65 and above, who constitute 71% of the stroke population (AIHW, 2023; Royal Commission into Aged Care Quality and Safety, 2021; Scrivener et al., 2022).

Currently, discrepancies exist between the services available under the NDIS and those provided through the aged-care system, with significantly higher funding allocated to the NDIS (Royal Commission into Aged Care Quality and Safety, 2021). Research evidence emphasises the need for the government to review existing disability care and aged-care policies and eliminate the age threshold for these services. This policy change would ensure that stroke dyads have access to services that align with their specific needs and life circumstances, regardless of their age.

12.4.1.2 Implication for Policy Development to Increase Funding in Psychological Resources for Enhanced Post-stroke Psychological Wellbeing

Research evidence highlights the significant impact of psychological wellbeing on rehabilitation outcomes for stroke dyads (Ezema et al., 2019; Perna & Harik, 2020). The importance of providing psychological support to stroke dyads is also emphasised in Australia's National Rehabilitation Stroke Services Framework (Stroke Foundation, 2022). However, the findings of this study indicate that there is a shortage of psychological resources in both hospital and community settings, resulting in unmet psychological care needs during the transition for stroke dyads. Therefore, adequate funding and allocation of resources are needed to establish a robust workforce capable of meeting the psychological care needs of stroke dyads, including those in rural and regional areas. Policy reforms, by investing in and expanding psychological resources, can bridge the existing gap in care and promote optimal psychological support for stroke dyads throughout their transition journey.

12.4.1.3 Implication for Policy to Invest in the Evidence-Based Nurse-Led Transition Care Services

The present study proposed a framework that holds significant implications for clinical practice. This framework presents an opportunity to establish strong connections between acute care, rehabilitation, primary care and community services to address the care needs of stroke dyads during the transition phase and to address existing gaps after formal rehabilitation programs. In the current healthcare system, the collaboration across care settings and care facilities is lacking, and stroke dyads have limited opportunities to be reassessed and referred for care services they need (Stroke Foundation, 2021).

The proposed role of navigator has the potential to bridge these gaps by serving as a central point of communication and engagement. The navigator would identify the care needs of stroke dyads, facilitate appropriate referrals to services at the right time and in the right setting, collaborate with interdisciplinary teams to solve problems, and provide opportunities for stroke dyads to access rehabilitation services when required. Investment in research is necessary to test the feasibility, effectiveness and potential cost-effectiveness of a navigator model of care as shown in the proposed framework.

Allocating resources and funding to develop the role of navigators would greatly benefit stroke dyads as they navigate transition. It would enhance their ability and independence to cope with the challenges of the transition, improve their quality of life and support their long-term community living. Investment in evidence-based nurse-led transition care services has the potential to transform the care experiences of stroke dyads, ensuring they receive comprehensive and coordinated care throughout their transition journey.

12.4.2 Implications for Health Organisations

Health organisations play a crucial role in delivering safe, high-quality and consumer-centred care (ACSQHC, 2021). The study's findings underscore the importance of a workplace safety culture and team resilience in enhancing care for stroke dyads during the transition. These implications are crucial for health organisations as they strive to improve the quality of care provided during this process.

12.4.2.1 Implication for Staff Wellbeing Focus to Enable Team Resilience Development

The study's findings highlight the importance of team resilience in fostering collaboration and partnership with stroke dyads during the transition. Health professionals often encounter numerous challenges in their daily clinical practice, including time pressure and staffing shortages. However, the study demonstrated that team resilience was nurtured through several factors, including effective leadership, open and transparent communication, trust among team members, and the presence of peer support networks. By prioritising staff wellbeing, organisations can contribute to the development of team resilience and enhance the ability of health professionals to cope with the challenges they face in daily practice (Mills et al., 2020; Wald, 2020).

Organisations can support staff wellbeing by implementing strategies such as promoting self-care and stress management, fostering a culture of support and collaboration, and providing resources for professional development. Strong leadership is crucial for creating a positive work environment that values staff wellbeing. Leaders should actively engage with their teams, promote open communication, recognise and address concerns, and provide opportunities for feedback and reflection. (Mills et al., 2020; Wald, 2020).

12.4.2.2 Implication for Support to Develop and Sustain the Role of Stroke Nurse Navigators

The role of navigator emerged from the study’s findings to enhance care transitions by supporting stroke dyads to build capacities for decision-making and self-management as they transition through the post-stroke trajectory. The nurse navigator is an established role in cancer care, primary health care and the management of chronic conditions. The role has generated positive outcomes by providing timely and culturally appropriate guidance and support and improving service integration (Byrne, Hegney et al., 2020; McMurray & Cooper, 2017). However, previous studies have identified barriers to implementing the nurse navigator’s role. The challenges included role confusion, inadequate resources to support the role (e.g., insufficient time to perform the role), inconsistent methods for orientation and role implementation, and a lack of professional development opportunities (Cantril et al., 2019; Purvis et al., 2022).

Healthcare organisations should collaborate with education providers to develop tailored education modules or micro-credential courses for navigators. These programs should address their learning needs and experiences, equipping them with the necessary clinical skills and understanding of healthcare systems and available services for stroke dyads. Clear role descriptions, well-structured orientation and continuous professional development opportunities are essential. Additionally, careful evaluation of the navigator’s role is crucial to ensure sufficient resources, such as time and staffing, to support their responsibilities. Workforce estimation should be aligned with individual needs and evidence-based interventions rather than a fixed staff-to-patient ratio (Stroke Foundation, 2022).

12.4.3 Implications for Health Professionals

Interdisciplinary teams, including nurses and other health professionals, play a pivotal role in the post-stroke trajectory of stroke dyads by partnering with them to set individualised goals and engage in decision-making and care planning. The findings of this study have important implications for nurses and other health professionals to enhance their collaboration with stroke dyads through dyad-centred approaches and holistic care needs assessments.

12.4.3.1 Implication for Nursing Profession to Recognise Core Competencies in Stroke Transition Care

The findings of this study shed light on the under-recognised and under-identified role of nurses in transition care for stroke dyads. To bridge this gap, it is crucial for nurses to identify and embrace their core competencies in this area. Patient education, care coordination and advocacy, counselling and emotional support, and leadership are integral nursing competencies that should be recognised and prioritised (Nursing and Midwifery Board, 2016).

Nurses need to be empowered with the knowledge and skills necessary to implement dyad-centred care and strengthen their partnership with stroke dyads. This includes a deep understanding of the physical and psychological needs of both people with stroke and their caregivers during the transition. Nursing education programs should prioritise enhancing competencies such as effective communication, conflict resolution, critical thinking and care coordination within interdisciplinary teams, enabling nurses to apply these skills in clinical practice (Godsey et al., 2020).

Healthcare organisations also play a vital role in supporting the nursing profession in stroke transition care. They should develop nursing leadership advancement pathways and provide opportunities for nurses to actively participate in health policy decision-making. By empowering nurses and recognising their expertise, organisations can create an environment that fosters professional growth and enhances the impact of nursing in stroke care (Godsey et al., 2020; Hajizadeh et al., 2021).

12.4.3.2 Implication for Health Professionals to Strengthen Partnership With Stroke Dyads

This study highlights the significance of the partnership between health professionals and stroke dyads in facilitating the transition. However, the study's findings also indicate that this partnership could be further strengthened through the adoption of dyad-centred approaches by health professionals, addressing both the physical and psychological care needs of stroke dyads equally.

Health professionals should develop insights into the significant role of psychological wellbeing in the transition for stroke dyads, particularly in relation to caregivers' psychological wellbeing. The study's findings reveal that caregivers often conceal their emotional stress to support people with stroke during the transition. Therefore, routine clinical practice should include psychological assessments for caregivers to raise awareness of their psychological care needs. By doing so, appropriate support can be provided throughout the entire post-stroke journey, with special attention given to the transition.

Stroke caregivers are vital partners in stroke care, and their involvement is invaluable for health professionals when devising tailored care plans to support post-stroke recovery. Health professionals should systematically assess caregivers to identify any risks they may face in their caregiving role and to determine the necessary support required to sustain their caregiving efforts (Camicia et al., 2022). The positive outcomes observed in this study further underscore the notion that stroke affects not only the person with stroke but also their caregivers and family members. Therefore, it is crucial for health professionals to implement dyad-centred approaches to foster authentic partnerships during the transition period. Additionally, when establishing workforces for stroke care services, health organisations should consider evidence-based practices and the specific care needs of stroke dyads, rather than solely focusing on staffing numbers, to promote dyad-centred practice (Stroke Foundation, 2022).

12.4.4 Implications for Future Research and Education

The study introduces a nurse-led framework for stroke-specific transition care, offering potential avenues for future research to investigate its implementation. Additionally, the study's findings underscore the need for enhancements in healthcare education.

12.4.4.1 Implications for Future Research

The participant sample in this study consisted solely of English-speaking Australian Caucasians. To expand the scope of knowledge in post-stroke transition care, future research should aim to include perspectives from Aboriginal or Torres Strait Islander people, as well as those from culturally and linguistically diverse populations. Incorporating their experiences and expectations would enrich our understanding of stroke transition care and contribute to the development of culturally sensitive stroke care services.

Furthermore, this study proposes the role of navigators as leaders of interdisciplinary teams to facilitate post-stroke transition care. To advance this concept, future research could focus on the development of their role in working with stroke dyads, employing a co-design approach. Additionally, pilot studies could be conducted to assess the effectiveness of nurse-led transition care interventions, incorporating health economics to evaluate their cost-effectiveness and feasibility for implementation in clinical practice. Moreover, employing a knowledge translation approach would be valuable in conducting trials of the intervention and guiding the implementation of interventions within larger stroke populations.

12.4.4.2 Implications for Healthcare Education

To enhance the continuous professional development of navigators, tailored micro-credential courses at a post-graduate level would be beneficial (Desmarchelier & Cary, 2022; Karlsson et al., 2022). Additionally, for undergraduate education, it is recommended to provide equal emphasis on both technical nursing skills and interprofessional skills, including communication, critical thinking and care coordination within interdisciplinary teams. Equipping nursing graduates with these skills before entering the workforce is crucial (Godsey et al., 2020).

In the context of an increasingly complex healthcare system, it is essential to integrate interprofessional education into undergraduate programs for all healthcare professionals. This approach fosters collaboration among professionals from various disciplines and breaks down silos. Ultimately, such interprofessional collaboration can significantly enhance health outcomes (van Diggele et al., 2020).

12.5 Reflection

As a nurse unit manager actively involved in the rehabilitation journey and discharge planning for stroke dyads in an inpatient setting, this study has provided the researcher with a valuable opportunity to gain profound insights into the complex and multifaceted nature of transition care for stroke dyads. Reflecting on the study's findings has prompted the researcher to examine her own clinical practice and to take proactive steps towards developing strategies for quality improvement and effecting positive changes.

The study's findings have empowered the researcher to initiate quality improvement within the inpatient rehabilitation setting. Specifically, these initiatives aim to enhance continence management and promote better information-sharing regarding post-stroke intimacy and sexuality for stroke dyads. Additionally, the findings have inspired the formation of a stroke lived-experience peer support team dedicated to improving emotional support for stroke dyads within the inpatient setting.

Moreover, the framework proposed in this study has motivated the researcher to pursue new research endeavours. These research projects will focus on the development and implementation of the navigator role within a clinical context, employing co-design and knowledge translation approaches.

Upon reflecting on the journey of this study, the researcher realised that Gadamer's philosophical hermeneutics was the most suitable methodology. This approach allowed the researcher to incorporate her pre-knowledge of transition care into the interpretation process, known as the hermeneutic circle. The researcher's pre-knowledge was acquired through her extensive experience in stroke care clinical practice, self-reflection on current practices and dedication to two systematic reviews (L. Chen et al., 2020, 2021).

Furthermore, an understanding was cultivated and evolved through a fusion of horizons, achieved through dialogues between the participants and the researcher during the data collection phase, as well as dialogues between the textual data (transcripts and field notes) and the researcher during the data analysis phase. In the interpretation process, the researcher consistently connected participants’ perspectives with findings from previous studies (historical awareness) to validate newly generated understandings arising from the dialogues.

Additionally, the researcher refined her pre-knowledge and developed new insights by reflecting on policies and standards that guide current clinical practices. This deeper understanding of post-stroke transition care emerged through a collaborative process between the participants and the researcher, with knowledge being co-developed through their mutual engagement.

12.6 Conclusion

The transition period for stroke dyads poses significant challenges and can be overwhelming, especially with shortened hospital stays. The study’s findings shed light on both the hindrances and facilitators encountered during this transition from the perspectives of stroke dyads and health professionals.

First, enhancing the rehabilitation experience and preparation for hospital discharge requires a comprehensive approach that addresses both the physical and psychological care needs of stroke dyads. Caregivers’ needs should be thoroughly assessed to ensure their wellbeing is considered alongside the needs of people with stroke.

Second, recognising the interdependence within stroke dyads can inspire health professionals to adopt a dyad-centred approach, fostering a strong partnership with stroke dyads and involving them in their own care planning.

Third, safety culture, team resilience and interprofessional collaboration play crucial roles in facilitating the continuity of care and enhancing the transition for stroke dyads.

Furthermore, the proposed stroke transition care framework, which incorporates the role of navigators, offers a promising avenue for improving post-stroke transition care. The study’s findings have implications for policy development, health organisations and health professionals. This study has also informed future research to improve care across different settings and service providers for stroke dyads.

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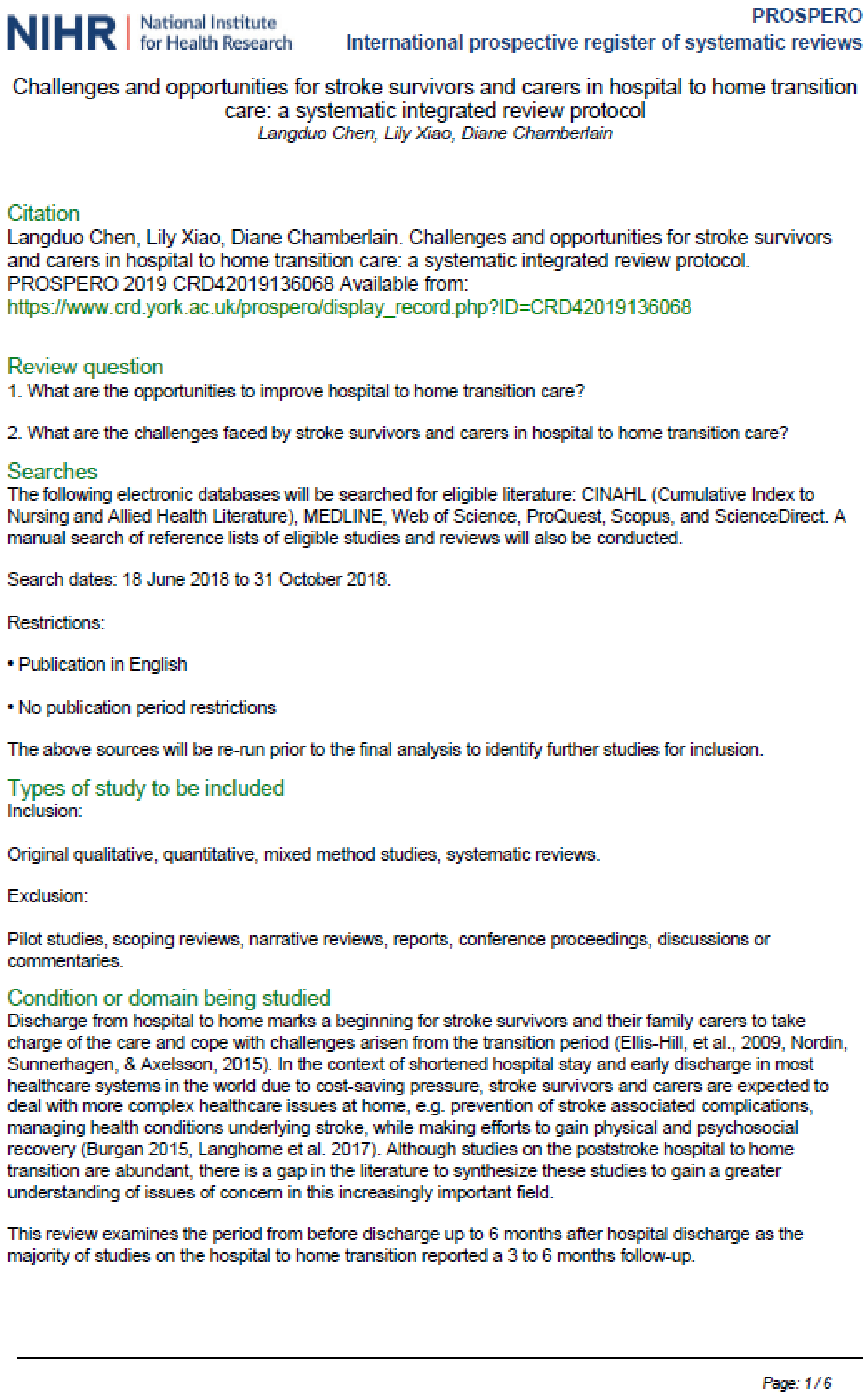
Appendices

Appendix 1: Published Integrative Review Protocol



NIHR | National Institute for Health Research

PROSPERO
International prospective register of systematic reviews

Challenges and opportunities for stroke survivors and carers in hospital to home transition care: a systematic integrated review protocol

Langduo Chen, Lily Xiao, Diane Chamberlain

Citation

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Review question

1. What are the opportunities to improve hospital to home transition care?

2. What are the challenges faced by stroke survivors and carers in hospital to home transition care?

Searches

The following electronic databases will be searched for eligible literature: CINAHL (Cumulative Index to Nursing and Allied Health Literature), MEDLINE, Web of Science, ProQuest, Scopus, and ScienceDirect. A manual search of reference lists of eligible studies and reviews will also be conducted.

Search dates: 18 June 2018 to 31 October 2018.

Restrictions:

- Publication in English

- No publication period restrictions

The above sources will be re-run prior to the final analysis to identify further studies for inclusion.

Types of study to be included

Inclusion:

Original qualitative, quantitative, mixed method studies, systematic reviews.

Exclusion:

Pilot studies, scoping reviews, narrative reviews, reports, conference proceedings, discussions or commentaries.

Condition or domain being studied

Discharge from hospital to home marks a beginning for stroke survivors and their family carers to take charge of the care and cope with challenges arisen from the transition period (Ellis-Hill, et al., 2009, Nordin, Sunnerhagen, & Axelsson, 2015). In the context of shortened hospital stay and early discharge in most healthcare systems in the world due to cost-saving pressure, stroke survivors and carers are expected to deal with more complex healthcare issues at home, e.g. prevention of stroke associated complications, managing health conditions underlying stroke, while making efforts to gain physical and psychosocial recovery (Burgan 2015, Langhorne et al. 2017). Although studies on the poststroke hospital to home transition are abundant, there is a gap in the literature to synthesize these studies to gain a greater understanding of issues of concern in this increasingly important field.

This review examines the period from before discharge up to 6 months after hospital discharge as the majority of studies on the hospital to home transition reported a 3 to 6 months follow-up.

Reference:

Langhorne, P., Baylan, S., & Early Supported Discharge Trialists. (2017). Early supported discharge services for people with acute stroke (Review). Cochrane Database of Systematic Reviews(7).

Participants/population

Inclusion:

- Adult stroke survivors aged 18 years and above.

- Carers: Carers are defined as unpaid carers including spouse or partner, family members, friends, or significant others who provide physical and emotional support to stroke survivors.

- Healthcare professionals: multidisciplinary stroke care team members and community service providers.

Exclusion:

- Stroke survivors younger than 18 years old.

- Multiple patient populations including brain tumour, traumatic brain injury, other neurological condition and/or other

diagnoses where stroke specific data cannot be separated.

Intervention(s), exposure(s)

Inclusion:

Studies that explored the experience, care needs, expectations of stroke survivors, their carers and healthcare professionals during the hospital to home transition or a transition facilitating intervention up to 6 months after discharge.

Exclusion:

- Studies that examined

• Poststroke long term experiences and needs (over 6 months after hospital discharge).

• Discharges to facilities other than home.

- Studies conducted across multiple periods of stroke trajectory where the hospital to home care transition period cannot be separated.

Comparator(s)/control

Not applicable

Context

Studies in hospital on patient wards, outpatient clinics, in community.

Main outcome(s)

The primary outcomes are (1) professional practices, services, care approaches, care models, self-care, patient/carer educations and resources that enabled the hospital to home transition and resulted in positive outcomes of post stroke recovery and rehabilitation: (2) factors that impeded the hospital to home transition and contributed to poor care outcomes.

* Measures of effect

This review examines the period from before discharge up to 6 months after hospital discharge as the majority of studies on the hospital to home transition reported a 3 to 6 months follow-up.

Additional outcome(s)

None.

* Measures of effect

Not applicable.

Data extraction (selection and coding)

Study Selection:

The screening process will be carried out by three reviewers.

Stage 1

Using EndNote, the initial citations will be shared amongst reviewers. Reviewer 1 will screen each article based on the title and abstracts against the inclusion and exclusion criteria. The rest of the reviewers will screen the title and abstracts of half of the citations. The screening results will be compared, and any disagreements will be resolved through discussions in regular team meetings. Citations that are not selected by two reviewers will be excluded for full-text review.

Stage 2

Reviewer 1 will source full text and save PDF versions into EndNote database from the title and abstracts screening process. Each full text of all included articles will be reviewed by two reviewers independently. Any discrepancies will be discussed and resolved in team meetings. All decisions will be recorded in EndNote.

Data Extraction:

- Data that will be extracted from study documents include information about the study, study design, methodology, participant demographics, main findings, limitations, and implications.

- Interview excerpts will be extracted from qualitative studies for analysis.

- The text-in-context method developed by Sandelowski and associates (2013) will be applied to extract data from the quantitative, mixed-method and systematic review studies. Data extraction form will be used to transform quantitative data into context-preserved restatements of findings (Sandelowski, Leeman, Knafl, & Crandell, 2013).

- Reviewer 1 will extract data. Reviewer 2 and 3 will review half of the extracted data.

- Any discrepancies will be discussed and resolved in team meetings. A third party will be involved to solve disagreement if required.
- Original study authors will be contacted for missing data or clarification of data details.
- The software NVivo 11 will be used to record and manage data extraction.

Risk of bias (quality) assessment

Critical Appraisal Skills Programme (CASP) tools (CASP 2018) will be used to evaluate the qualitative studies, randomised controlled trials and systematic reviews. Quality of the cross-sectional and descriptive quantitative studies will be assessed with a set of questions developed by Büttner and Muller (2015) for appraising epidemiological studies. The mixed method study will be appraised by using the 'Mixed Methods Appraisal Tool (MMAT) -Version 2011' developed by Pluye and colleagues (2011). All studies that meet the inclusion criteria will be included disregarding the study quality as methodologically weak studies may provide novel understandings that may not be produced in methodologically strong studies (Carroll et al. 2012).

References:

Büttner, P., & Muller, R. (2015). Epidemiology (2nd ed.). England, UK: Oxford University Press.

Carroll, C, Booth, A, and Lloyd-Jones, M 2012, 'Should we exclude inadequately reported studies from qualitative systematic reviews? An evaluation of sensitivity analyses in two case study reviews', Qualitative Health Research, vol. 22, no. 10, pp. 1425-34.

Pluye, P., Robert, E., Cargo, M., Bartlett, G., O'cathain, A., Griffiths, F., . . . Rousseau, M. (2011). Proposal: A mixed methods appraisal tool for systematic mixed studies reviews. Retrieved from http://mixedmethodsappraisaltoolpublic.pbworks.com/w/file/fetch/84371689/MMAT%202011%20criteria%20and%20tutorial%202011-06-29updated2014.08.21.pdf

Strategy for data synthesis

Synthesis of data will be conducted based on the integrated design described by Sandelowski, Voils, and Barroso (2006). Qualitative and quantitative data are viewed as being able to be transformed into each other and generate findings to serve the same study purpose. The aim of data analysis is to translate findings so they can be combined to answer the same research questions (Sandelowski, et al., 2006). Underpinned by the principles of this synthesis design and based on the review questions, data will be highlighted in different colours and categorised into challenges and opportunities. Under these two categories, data for the first 6 months post-discharge will be compared constantly within the same category and across categories to identify relevant findings.

Reference:

Sandelowski, M., Voils, C. I., & Barroso, J. (2006). Defining and designing mixed research synthesis studies. Research in the schools: a nationally refereed journal sponsored by the Mid-South Educational Research Association and the University of Alabama, 13(1), 29-40.

Analysis of subgroups or subsets

Not planned.

Contact details for further information

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Assistant/Associate Professor Diane Chamberlain. Flinders University of South Australia

Type and method of review
Systematic review

Anticipated or actual start date
10 July 2018

Anticipated completion date
30 June 2019

Funding sources/sponsors
None

Conflicts of interest

Language
English

Country
Australia

Stage of review
Review Ongoing

Subject index terms status
Subject indexing assigned by CRD

Subject index terms
Caregivers; Hospitals; Humans; Stroke; Survivors; Transitional Care

Date of registration in PROSPERO
23 July 2019

Date of publication of this version
23 July 2019

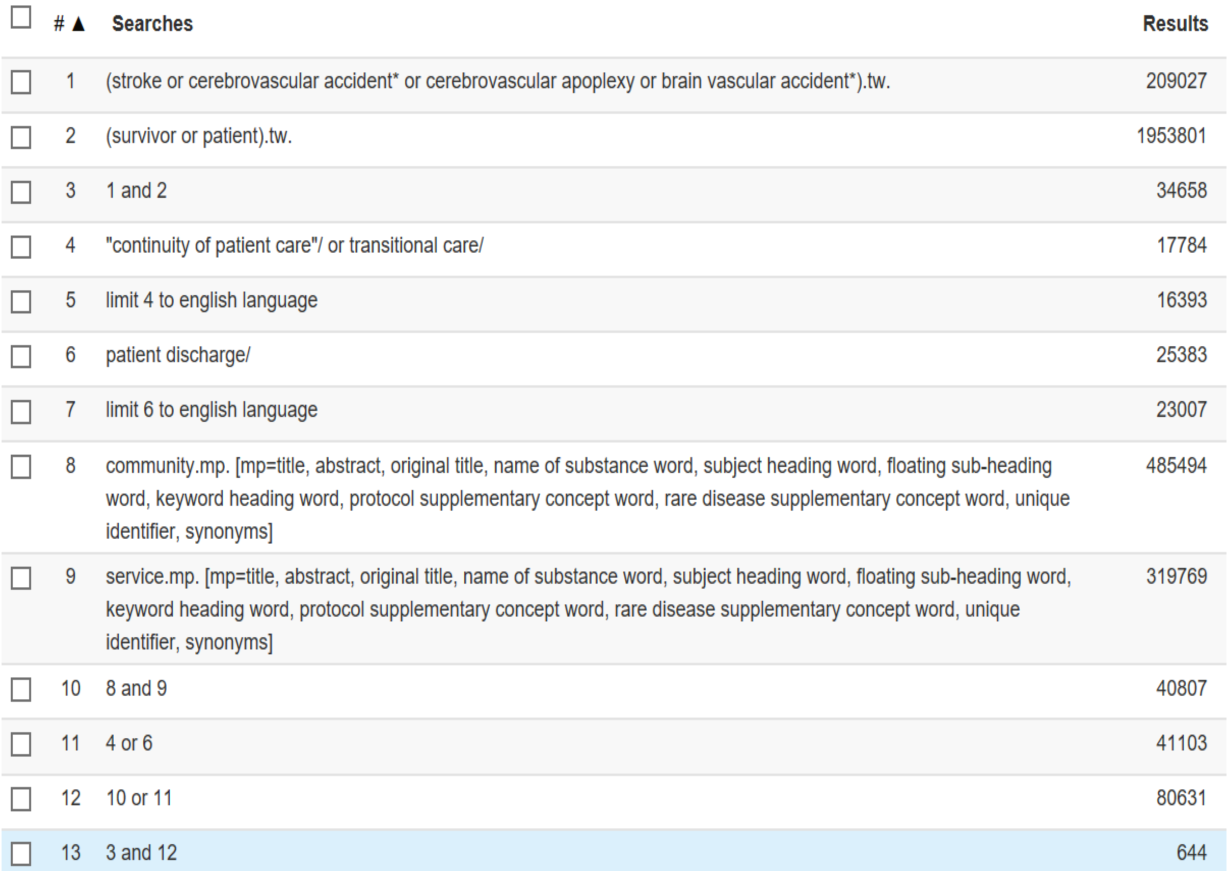
Details of any existing review of the same topic by the same authors

Stage of review at time of this submission

Stage	**Started**	**Completed**
Preliminary searches	Yes	No
Piloting of the study selection process	Yes	No
Formal screening of search results against eligibility criteria	Yes	No
Data extraction	Yes	No
Risk of bias (quality) assessment	Yes	No
Data analysis	Yes	No

Versions
23 July 2019

Appendix 2: Medline Search Strategy



☐	# ▲	Searches	Results
☐	1	(stroke or cerebrovascular accident* or cerebrovascular apoplexy or brain vascular accident*).tw.	209027
☐	2	(survivor or patient).tw.	1953801
☐	3	1 and 2	34658
☐	4	"continuity of patient care"/ or transitional care/	17784
☐	5	limit 4 to english language	16393
☐	6	patient discharge/	25383
☐	7	limit 6 to english language	23007
☐	8	community.mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]	485494
☐	9	service.mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]	319769
☐	10	8 and 9	40807
☐	11	4 or 6	41103
☐	12	10 or 11	80631
☐	13	3 and 12	644

Appendix 3: Summary of Selected Studies

No.	Author and year	Aim/objective	Sample and setting	Methodology and methods	Main findings	Limitations and rigour/validity	Significance to the review
1	Almborg et al., 2008 *Sweden*	To describe stroke patients' perceptions of their participation in the discharge planning process and identify correlates of perceived participation	Consecutive sampling In a hospital in Southern Sweden 188 stroke patients	Quantitative Questionnaire via interview 2–3 weeks after discharge Exploratory factor analysis Prospective, descriptive cross-sectional study	• Most satisfied with information related to illness, medication & rehabilitation. • Poorly involved in medical treatment decision-making, goal-setting and evaluation of needs. • Younger patients perceived higher participation than older patients—may be older patients wanted HCP to take initiatives. • Patients with shorter hospital stay were more satisfied. • Patients with high-level dependency perceived poorer participation than those with low-level dependency.	• The exclusion of patients with aphasia or moderate to severe cognitive impairment • Single unit	Understanding of stroke patients' participation and factors influencing the participation helps clinicians to facilitate a more person-centred discharge planning.
2	Almborg et al., 2009 *Sweden*	To describe relatives' perception of participation in discharge planning of patients with stroke To identify the association between patient characteristics and relatives' perceptions Participation	Consecutive sampling In a hospital in Southern Sweden 152 relatives of stroke patients	Quantitative Questionnaire via interview 2–3 weeks after discharge Multiple regression models Prospective, descriptive cross-sectional study	• Most relatives did not receive sufficient information on stroke, medication, rehabilitation, care and community support. • 80% of them perceived no participation particularly in goal-setting and identification of care needs. • Longer hospital stay, higher educated and female patients and relatives were associated with higher participation.	• Single unit	Understanding of relatives' participation and factors influencing the participation helps clinicians to facilitate a more person-centred discharge planning.
3	Bakas et al., 2002 *USA*	To determine the self-reported needs and concerns of family caregivers of stroke survivors soon after discharge to the home setting	Convenience sampling An outpatient neurology clinic in an inner-city hospital in a large Midwestern city of the USA. 14 family caregivers of stroke survivors	Qualitative Telephone interviews within 6 months after discharge Using a pre-determined code list to identify categories of interview data	Information: • need to be better educated with stroke signs and symptoms, and management of complications. To meet this need, a network of support groups sessions facilitated by professionals was needed prior to discharge. Emotions and behaviours: • need help in providing emotional support and managing behavioural problems manifested by the stroke survivor. Physical care:	• All participants are female caregivers; male caregivers may have different needs and concerns • Stroke severity was not assessed—may affect the findings	Understanding the needs and concerns of stroke family caregivers in transition from hospital to home helps professionals better identify caregiver needs so interventions could be in place before discharge. The findings could serve as a guide to

No.	Author and year	Aim/objective	Sample and setting	Methodology and methods	Main findings	Limitations and rigour/validity	Significance to the review
					• concerns about medication management, motivating survivor, proper diet, fall prevention. Instrumental care: • managing finances, providing transportation, finding respite care. Personal response to caregiving: • managing own emotions, adapting to changed social life, own health challenges; those were ignored by professionals.		develop tailored educational activities before discharge to enable a smooth transition home.
4	Cameron et.al., 2014 *Canada*	To explore stroke survivors', caregivers', and professionals' perceptions of Weekend Pass (WP, weekend stay at home) offered during inpatient rehabilitation and its role in facilitating the transition	Purposive Sampling First interview 16 patients & 15 caregivers Second interview 11 patients & 11 caregivers 20 HCP: three focus groups & one interview A rehabilitation facility in a large urban centre in Canada	Qualitative Descriptive First interview during the week following the first WP. Second interview 4 weeks post-discharge. Three focus groups or an in-depth interview with HCP.	Preparing for patients to be safe at home: • Professionals discussed & assessed patient readiness including home assessment • patients/carers desired to be better prepared with expectations for WP and training of family • Professionals' insufficient time to train and discuss. Gaining insight through WP: • provides insight into ability of care needs. • informs future inpatient therapy sessions. • Professionals' caseload and work hours limited ability to interact with caregivers who work. Need to develop a formal procedure when returning from WP. Emotional context of WP.	• Exclusion of non-English speakers • Single site • Absence of physician's views	WP has therapeutic value—guides inpatient rehabilitation after WP. Highlighted emotional support needed in the process. WP helps stroke survivors and family manage most challenges in transition care.
5	Chouliara et al., 2014 *UK*	To explore professionals' perspectives of ESD service	Purposive sampling 35 professionals Two ESD services in the East Midlands of UK	Qualitative Cross-sectional Semi-structured interviews	Facilitators: • specific and flexible eligibility criteria • the systems needed to be reflective of individuality of each case • flexibility of the length of the intervention • the support of rehabilitation assistants to sustain the service • collaborative links with other services by staff rotations across services, participation in meetings and common training events. Challenges: • lack of clarity regarding the referral decision-making process	• Nature of qualitative study—not generalisable • The findings only reflected service provision in urban and semi-urban setting	The findings highlighted the contribution of ESD service to early transition home for stroke patients. Further exploration was warranted to evaluate strategies aiming to improve interactions between professionals in different settings to ensure a seamless transition.

No.	Author and year	Aim/objective	Sample and setting	Methodology and methods	Main findings	Limitations and rigour/validity	Significance to the review
					• fragmented stroke care pathway—(1) the process of securing social care input was delayed; (2) lack of specialist community services that could respond to the needs of more disabled patients. • duplication of assessments across services. Perceived impact of Early Supported Discharge: • reduction of the length of hospital stay without compromising the intensity of rehabilitation input • contributed (bridging) to the improvement of collaboration between the acute and community stroke services. • ESD was intensive, stroke-specific and patient-centred intervention • emotional issues could be addressed timely • smoother transition to home.		
6	Cobley et al., 2013 *UK*	To investigate patients' and carers' experiences of ESD services	Purposive sampling 27 stroke patients and 15 carers Community stroke services in Nottinghamshire, UK	Qualitative Semi-structured interviews	• Limited support in dealing with carer strain. • Lack of education and training of carers. • Inadequate provision and delivery of stroke-related information. • Disjointed transition between ESD and ongoing rehabilitation services. • Patients and carers were satisfied with home-based rehabilitation.	• Participants' reports open to biases related to self-evaluation • Majority of carers were female • Participants' willingness to provide feedback may lead to exaggerated and inaccurate descriptions • Design did not allow capturing changes over time	The study provided unique insights into patients' and carers' experiences of ESD services. It highlighted areas for service development and provision.
7	Ellis-Hill et al., 2010 *UK*	To develop the understanding of what constitutes a 'good' or 'poor' experience in relation to the transition from	Purposive sampling 20 stroke survivors and 13 carers within 1 month of being discharged from hospital following a stroke	Qualitative Semi-structured interviews	• Stroke survivors' recovery changes over time. • Provision of services need to be based on the stroke survivors' and health providers' shared models of recovery. • Communication of discharge plans was critical in hospital-to-home transition.	• Only mobility was explored in-depth. Lack of in-depth analysis of other stroke-related changes • Exclusion of people with severe	The findings provide some understanding of stroke survivors' and carers' needs when discharged from hospital to home. The researchers' recommendation may

No.	Author and year	Aim/objective	Sample and setting	Methodology and methods	Main findings	Limitations and rigour/validity	Significance to the review
		hospital to home following a stroke	Participants were recruited from an acute stroke ward in the district general hospital		• Understanding of patients' model of recovery revealed expectations and training needs of carers. • Many patients were discharged with unanswered questions about stroke.	communication or cognitive deficit • Single-site study	inform the discharge planning process.
8	Greenwood et al., 2009 *UK*	To investigate the experiences of informal carers of stroke survivors in the first 3 months after discharge	Purposive sample 31 stroke caregivers 3 months after discharge	Qualitative ethnography In-depth interviews at three time points—prior to discharge and 1 month and 3 months post-discharge	• New carers were struggling to provide home care in early stage of home care after discharge • Established carer were more confident in coping with home care • Unreliable services Coping strategies: • establishing routines • focusing on the present reduced uncertainty • relying on established coping skills • identifying positive aspects of caregiving • different views on future care for stroke survivors.	• Only followed up to 3 months after discharge • Survivors' present may have impacted on the openness of caregivers during interviews • The research setting was an ethnically diverse area in London	Caregivers' experiences changed over time during the transition. Findings have implications for assessment and support provision. Differences between new caregivers and established caregivers help clinicians to develop more individualised interventions.
9	Gustafsson & Bootle, 2013 *Australia*	To explore and contrast the transition to home experience of stroke survivors and their carers during discharge and first month at home	Purposive sampling 5 first-time stroke patients 5 carers Recruited from a major metropolitan hospital in Queensland	Descriptive qualitative design Semi-structured interviews	• Inability to participate in meaningful activities during inpatient rehabilitation may have prevented adaptation and recovery. • Weekend leave, overnight leave and family meetings were identified as positive strategies for hospital-to-home transition care. • Lack of information on a contact person when having questions after discharge (unclear, check and change) • Carers needs more support due to change of role. • Uncertainty about ongoing care after completion of rehabilitation program.	• Small sample size • Recruitment from one single site • Study designs did not allow investigation of changes over time	Useful insights gained from this study are important to inform further research to explore alternate approaches for rehabilitation service delivery and transition to home.
10	Grant et al., 2006 *USA*	To identify problems and associated feelings experienced by family caregivers of stroke survivors during the second and	Purposive sampling 22 family caregivers assigned to the intervention group of an RCT: 1 week post-discharge, 3-hour home visit with training on the use of a positive	Descriptive quantitative Data form and biweekly telephone contacts	Week 6: • concerns about safety—falls • issues with managing personal care • issues with managing emotional, cognitive and behavioural changes • felt unsure, scared, helpless, frustrated. Week 8:	• Small sample size • Recruitment of participants from an intervention group of an RCT • Stroke survivors with moderate level of disability	The findings help development of interventions targeting specific issues at varied time frames and involving both consumers and professionals.

No.	Author and year	Aim/objective	Sample and setting	Methodology and methods	Main findings	Limitations and rigour/validity	Significance to the review
		third month after discharge from a rehabilitation facility to home	problem orientation and problem-solving skills		• same issues as Week 6; 50% felt to be able to manage better. Difficulties in managing symptoms. Week 10: • same issues as Week 8, significantly more positive and able to manage issues as survivors become more independent • more evident of issues with finances and tenuous family and social relationships. Week 12: • same issues as Week 10; continued to be positive towards management • caregivers were able to establish realistic goals for self to participate in social activities and for the care of the stroke survivors • acknowledged that cognitive and behavioural issues may be long-term.	• Lack of data analysis details	
11	Hall et al., 2012 *Australia*	To explore the transition experiences of individuals with non-traumatic brain injury using mixed-methods approach	Using maximum of variation sampling *N* = 6 Acquired Brain Injury (Subarachnoid Haemorrhage & stroke)	Qualitative: in-depth interview 6 months after discharge Quantitative: self-reported questionnaires Assessment prior to hospital discharge and 6 months after discharge	Qualitative findings: • changes in role performance and relationships; tapering off social relationships • inadequate support due to distance, time and pre-injury family relationships • participants were satisfied with hospital extended post-discharge services • lack of support groups, long waiting between reviews in the community • difficulties in navigating healthcare system—unaware of available services, confused about process, unsure how to use information • people in the community lacked understanding of brain injury Quantitative findings at 6 months: • psychosocial integration remained the same for half of participants • functional ability also remained the same for half of participants • emotional function remained the same for most participants • improved perceived health status for most participants.	• Sample representation: 4 SAH due to aneurysm • Single site • Single time point for interviews	Findings provide evidence for clinical practice and service development.

No.	Author and year	Aim/objective	Sample and setting	Methodology and methods	Main findings	Limitations and rigour/validity	Significance to the review
12	Langhorne et al., 2017 *UK*	To establish if ESD services can result in a better patient recovery and if they are as acceptable and affordable as usual services	17 RCTs from countries—Canada, Australia, India, Thailand, Norway, Portugal, Ireland, Denmark, UK and Sweden. 2422 participants (moderate degree of disability) ESD team—multi-D coordination—including at least physiotherapist, OT, doctor and speech therapist; nurses not always included No ESD team—no multi-D coordination	Systematic review	• Reduced the length of hospital stay by 6 days in the ESD group compared to the usual care group • Reduced death or institutional care in the ESD group compared to the usual care group • Small improvement of ADLs in the intervention group compared to the usual care group • More satisfaction with services in the ESD group compared to the usual care group • Greatest reduction of death and dependency was identified in the coordinated ESD team with case manager in subgroup analyses • Cost of ESD was a reduction to a moderate increase	• Insufficient information for 3 studies • Missing data for small amount of patients • Systematic review authors being authors of individual trials	Effectiveness of ESD services was delivered by multi-D team (including Nurses). The identification of multi-D-team-involved services warrants further trial targeting stroke population with moderate level of disability.
13	Lou et al., 2017 *Denmark*	To investigate how mild stroke patients and their partners experience and manage everyday life in the context of ESD	Purposive sample *N* = 40 (22 stroke survivors, 18 partners) Central Denmark region	Qualitative 3–6 weeks after stroke onset	Theme 1—Home as a healing place: • minority of participants felt inadequate information on their condition • coming home was a relief and as own space compared to structured day in hospital • ESD services supported a safe transition. Theme 2—Flow of everyday life: • physical and cognitive impairment impact on daily activity for some • collaboration between stroke survivors and their partners maintains flow of daily life • patients with chronic illnesses adjusted better due to experience with healthcare system • uncertainty—e.g. recognition of symptoms of another stroke. Theme 3—Professional safety net: • home a better arena for rehabilitation • satisfied with quality of ESD—safe and highly accessible • ESD did not focus on goal of returning to work.	• Recruitment via ESD team—unsure consistency of criteria and total recruitment • Interviewing survivor and caregiver as a dyad together—potential under-report of issues • Relatively optimistic responses to outcomes shortly after discharge • Responses to longer time (i.e. after completion of ESD remain unknown. Homogeneous sample	ESD services are a valuable solution for mild stroke survivors who return home after discharge from hospital. ESD could be trialled in a broader region.

No.	Author and year	Aim/objective	Sample and setting	Methodology and methods	Main findings	Limitations and rigour/validity	Significance to the review
14	Nordin et al., 2015 *Sweden*	To describe patients' expectations of coming home very early after stroke with support and rehabilitation at home	10 participants from the intervention group in an RCT project	Descriptive qualitative Interviews 0–5 days before discharge (after rehab goal-setting was agreed)	• Mixed feelings about coming home—fear, insecurity, important milestone of recovery. • Participants had confidence of support to gain independence from the team. • Expectation that the visits from the team would reduce participants' insecurity. • Unrealistically high expectation of functional status.	• Small sample size • Single site • Shorter interviews with three participants, two interviews before setting rehab goals—may affect the description of experience	Implications for clinical practice: • exploring patients' expectations prior to discharge may help professionals and stroke survivors/carers to set agreed and realistic goals for recovery and rehabilitation. • identify issues that might compromise the transition; • Building on the trust and partnership to achieve the goals.
15	O'Brien et al., 2014 *Australia*	Explore HCP perceptions of stroke carer roles and support needs; Examine carer needs across the stroke care trajectory to assist with the development of an OHP to support carers	Purposive sampling 23 professionals who represented a range of disciplines An Australian metropolitan public health service 4 clinical settings—acute care, rehabilitation, transitional care and community rehabilitation	Focus group—dual-moderated focus groups approach	• Support for carers was crucial, especially during hospital-to-home transition. • The role of HCP and carer changes over time. • Professionals' role in supporting carer may be challenged by workload. • Carers devote to the role rather than asking for help. Challenge for carer to access support. • Timing and volume of information provision was a challenge to HCP. • Carers experience loss and financial disadvantage.	• Single site • Only included perception from professionals	Informing development of OHP. Training professionals with OHP may improve consistency in the provision of carer support across stroke pathways.
16	Perry & Middleton, 2011 *Australia*	To advance understanding of stroke caregiving in Australia	Convenience sampling Acute stroke patients from two hospitals in two Australian states—Sydney (New South Wales) and Brisbane (Queensland)	Quantitative Descriptive with survey instruments through interviews at 1 and 3 months follow-up after discharge	• Inadequate preparation for discharge. • Lack of information provision. • Lack of involvement in discharge arrangements. • Services were least satisfactory where they were most needed.	• Small sample size • Assessment at different time post-discharge—i.e. assessment at one site was later than the other • Lack of validity of assessment tools	The findings of this study provide insights into current issues with informal stroke caregiving in Australia. It may help formulate consumer-guided questions for future research.

No.	Author and year	Aim/objective	Sample and setting	Methodology and methods	Main findings	Limitations and rigour/validity	Significance to the review
			32 patient–carer dyads				
17	Pringle et al., 2008 *UK*	To understand the experiences of stroke patients and their carers during the early days following discharge from hospital	28 articles 943 participants References examined for the first month after discharge home	Systematic review 26 qualitative studies 1 quantitative 1 mixed-method	- Little evidence available on early discharge experience, especially in the UK. - Younger stroke patients' and carers' needs are neglected. However, young and the old shared many similar experiences. First month at home was most distressful time. - Few studies made reference to the time of discharge home. Most studies excluded aphasic patients.	- Heterogeneity of original studies	The issues stroke patients and carers described during their early days at home will inform the preparation for discharge. More focused follow-up services to meet individual needs in the community are needed.
18	Pringle et al., 2013 *UK*	To investigate and improve understanding of the experiences of patients and their carers during the first month at home following discharge from hospital	12 patient/carer dyads Setting—local hospital ward. Other information unclear	Qualitative Interpretive phenomenology analysis Double hermeneutic process In-depth interviews and self-reported diaries	Revisioning: - 1 month post-discharge a dynamic time - altered concept of image and identity - loss and grief - lack of information—needs unpredictable while in hospital. Reconnecting: - family and social support - regaining control and exit sick role. Revisiting: - reflection on previous life - recounting stroke event.	- Small sample size - Localised nature of study	Understanding of patient/carer experience will benefit advance planning and preparatory training from health professionals to assist with psychosocial transitions. Early identification of dysfunction may lead to fewer negative outcomes.
19	Rittman et al., 2007 *USA*	To describe three domains of psychosocial experiences of stroke survivors during the first months following discharge for acute stroke	125 stroke survivors and caregivers	Qualitative Semi-structured interviews and field observations during home visits at 1 month post-discharge	- The experiences are characterised by a process of adapting to changes in sense of self, connections with other and community participation. - All participants, regardless of their functional assessment scores, could benefit from interventions that prepare them to manage multiple psychosocial changes during the transition.	- Limited sample—veterans	Given that the transition period is a time of adjustment, interventions are needed to support stroke survivors and their caregivers. The result also highlighted importance to assess and match the level of support with the needs of stroke survivors.
20	Shyu et al., 2008 *Taiwan*	To examine the effects of a discharge planning program that targets preparation of	158 older stroke patients and their caregivers from four homogeneous neurological wards of a 3,000-bed	Quantitative Randomised experimental design A nurse-directed, family-oriented,	- Experimental group showed significantly better discharge preparation, greater satisfaction with meeting discharge needs. - No significant difference was found between caregiver groups in perceived balance of competing needs.	- Attrition of 26.8% - Lack of baseline data for some assessment - The risk of contamination between control and	This caregiver-oriented discharge planning program, with its emphasis on individualised health education and home visits following

No.	Author and year	Aim/objective	Sample and setting	Methodology and methods	Main findings	Limitations and rigour/validity	Significance to the review
		family caregivers, in Taiwan	medical centre in northern Taiwan	discharge-intervention program Three assessments—within 3 days of admission, before discharge, 1 month after discharge		experimental groups because of randomisation within the same hospital • Lack of blinded assessment may affect quality of assessment by professionals.	discharge may improve caregivers' preparation and the satisfaction of their needs during the discharge transition. It warrants a larger scale of research to further examine the effectiveness of the program.
21	Simeone et al., 2015 *Italy*	To describe the experience of stroke survivors 3 months after being discharged home from rehabilitation hospitals	Purposive sampling From a longitudinal study 15: Rome = 13; Naples = 2 Stroke patients	Qualitative phenomenology	• Deeply change lives • Vivid memory of acute phase of stroke • Slowed lives • Relief after recovering from stroke • Being a burden to family members	• Mostly male patients • Mostly independent patients	Understanding of stroke patients early discharge experience helps HCP reflect on how to deliver person-centred care.
22	Wong & Yeung, 2015 *Hong Kong*	To test the effectiveness of a nurse-led transitional care program	Purposive sampling From three regional hospitals within the same cluster in Hong Kong 54 each in controlled and intervention group	Quantitative RCT Follow-up at 4 and 8 weeks	• The intervention group had significantly higher quality of life and satisfaction in interpersonal skills and health advice. • The intervention group had significantly less depressive symptoms and emergency department visit. • The ADL performance was better for the intervention group.	• Single region • Missing values replaced by group means • Only followed up for 8 weeks	The effectiveness of this nurse-led transition care intervention warrants further research and clinical trial to see the effect for the transition period up to 6 months. The findings confirmed that nurses are in the appropriate position to lead and coordinate transition care programs.
23	Wood et al., 2010 *Canada*	To examine the process of community reintegration after stroke for their perspective	Purposive sampling *N* = 10 (four women, six men) 2 rehabilitation units	Qualitative Grounded theory Interviews Observational field notes Total of 46 interviews at pre-discharge and 2 weeks, 3 months, 6 months and 1 year post-discharge	• Community reintegration was a process of transitioning through a series of goals. • Early stage of discharge home was overwhelming from appointments, family and HCP visits. • Decreased confidence due to altered physical ability and dependence on others—e.g. driving, ADLs. • 3 months onwards after discharge, participants adjusted expectations and participated more meaningful activities in the community.	• Sample was from a sub cohort of a larger trial • Participants had high functioning • Exclusion of aphasic and cognitive impaired	Understanding of the process of community reintegration helps clinicians to address the importance of creating balance between capacity and expectations by setting realistic and attainable goals. Peer support groups may also benefit stroke

No.	Author and year	Aim/objective	Sample and setting	Methodology and methods	Main findings	Limitations and rigour/validity	Significance to the review
							patients' social reintegration.
24	Wottrich et al., 2012 *Sweden*	To investigate how stroke survivors describe their expectations when they were discharged from rehabilitation ward and during the first 3 months at home	Purposive sampling 5 stroke survivors From two rehabilitation centres in Stockholm, Sweden	Qualitative Semi-structured interview	Prior to discharge: • home practice before discharge was beneficial for transition. • physical training plan was important to maintain hope for recovery. 2–4 weeks after discharge • adjustment and waiting for recovery • dissatisfied with reduced physical training • physical and psychological deterioration. 3–4 months after discharge: • acceptance • disappointment about physical training • concern about new stroke • lower expectations to self and others • strong desire for independence.	• Small sample size • Exclusion of people with aphasia and dementia • Setting is limited to two rehabilitation centres in the same region; hence, limits generalisability	Understanding of stroke survivors' experience during rehabilitation process may contribute to improved quality of care via more realistic goal-setting, discussion of prognosis prior to discharge and home practice before returning home.
25	Young et al., 2014 *USA*	To understand the needs of spousal caregivers of stroke survivors during the transition from rehabilitation to home	Purposive sampling 14 spousal caregivers of first-time stroke survivors 2 inpatient rehabilitation facilities in the USA	Qualitative Grounded theory	• Caregiver unprepared, unclear caregiving expectations. • Beneficial to conduct a caregiver assessment at an early stage of rehabilitation. • A health professional to assist, advocate tailored to needs of caregivers may smooth transition. • Making transitional plan to address post-discharge care needs. • Home-based family counselling service may help develop coping skills in transition.	• Options given to spouses to be interviewed together or separately.	The result demonstrates research and practice gaps in improving post-rehabilitation outcomes. A comprehensive assessment of caregivers may provide a solid base for a discharge plan that reflects assessment findings. Further research should focus on the development of a caregiver assessment protocol.

Note. HCP = healthcare professional/provider; USA = United States of America; WP = weekend pass; UK = United Kingdom; ESD = early supported discharge.; RCT = randomised controlled trial; OT = occupational therapist; OHP = optimal health program; ADL = activity of daily living.

Appendix 4: Quality Appraisal of Reviewed Studies

Appendix 4a: Evaluation of Qualitative Studies Included for Review

Study	**Question***									
	Q1	**Q2**	**Q3**	**Q4**	**Q5**	**Q6**	**Q7**	**Q8**	**Q9**	**Q10**
Bakas et al., 2002	Y	Y	Y	Y	Y	?	Y	Y	Y	Y
Cameron et al., 2014	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Chouliara et al., 2014	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Cobley et al., 2013	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Ellis-Hill et al., 2009	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Greenwood et al., 2009	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Gustafsson & Bootle, 2013	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Lou et al., 2017	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Nordin et al., 2015	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
O'Brian et al., 2014	Y	Y	Y	Y	Y	?	Y	Y	Y	Y
Pringle et al., 2013	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Rittman et al., 2007	Y	Y	Y	Y	Y	?	Y	Y	Y	Y
Simeone et al., 2015	Y	Y	Y	Y	Y	?	Y	Y	Y	Y
Wood et al., 2010	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Wottrich et al., 2012	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Young et al., 2014	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y

Note. Y = yes; N = no; ? = cannot tell. Adapted from: Critical Appraisal Skills Programme. (2018a). *CASP qualitative checklist*. https://casp-uk.net/wp-content/uploads/2018/01/CASP-Qualitative-Checklist.pdf

*Q1: Was there a clear statement of the aims of the research?
*Q2: Is a qualitative methodology appropriate?
*Q3: Was the research design appropriate to address the aims of the research?
*Q4: Was the recruitment strategy appropriate to the aims of the research?
*Q5: Was the data collected in a way that addressed the research issue?
*Q6: Has the relationship between the researcher and participants been adequately considered?
*Q7: Have ethical issues been taken into consideration?
*Q8: Was the data analysis sufficiently rigorous?
*Q9: Is there a clear statement of findings?
*Q10: How valuable is the research?

Appendix 4b: Evaluation of Randomised Controlled Trials Included for Review

Study	**Question***										
	Q1	**Q2**	**Q3**	**Q4**	**Q5**	**Q6**	**Q7**	**Q8**	**Q9**	**Q10**	**Q11**
Shyu et al., 2008	Y	Y	Y	?	Y	Y	Y	Y	Y	?	Y
Wong & Yeung, 2015	Y	Y	Y	Y	Y	Y	Y	?	?	Y	Y

Note. Y = yes; N = no; ? = cannot tell. Adapted from: Critical Appraisal Skills Programme. (2018b). *CASP randomised controlled trial checklist*. https://casp-uk.net/wp-content/uploads/2018/03/CASP-Randomised-Controlled-Trial-Checklist-Download.pdf
*Q1 Did the trial address a clearly focused issue?
*Q2 Was the assignment of patients to treatments randomised?
*Q3 Were all of the patients who entered the trial properly accounted for at its conclusion?
*Q4 Were patients, health workers and study personnel ‘blind’ to treatment?
*Q5 Were the groups similar at the start of the trial?
*Q6 Aside from the experimental intervention, were the groups treated equally?
*Q7 How large was the treatment effect? Is the primary outcome clearly specified?
*Q8 How precise was the estimate of the treatment effect?
*Q9 Can the results be applied to the local population or in your context?
*Q10 Were all clinically important outcomes considered?
*Q11 Are the benefits worth the harms and costs?

Appendix 4c: Evaluation of Systematic Reviews Included for Review

Study	**Question***									
	Q1	**Q2**	**Q3**	**Q4**	**Q5**	**Q6**	**Q7**	**Q8**	**Q9**	**Q10**
Langhorne et al., 2017	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Pringle et al., 2008	Y	Y	Y	Y	?	?	?	Y	N	?

Note. Y = yes; N = no; ? = cannot tell. Adapted from: Critical Appraisal Skills Programme. (2018c). *CASP systematic review checklist*. https://casp-uk.net/wp-content/uploads/2018/03/CASP-Systematic-Review-Checklist-Download.pdf
*Q1 Did the review address a clearly focused question?
*Q2 Did the authors look for the right type of papers?
*Q3 Do you think all the important, relevant studies were included?
*Q4 Did the review’s authors do enough to assess the quality of the included studies?
*Q5 If the results of the review have been combined, was it reasonable to do so?
*Q6 What are the overall results of the review?
*Q7 How precise are the results?
*Q8 Can the results be applied to the local population?
*Q9 Were all important outcomes considered?
*Q10 Are the benefits worth the harms and costs?

Appendix 4d: Evaluation of Quantitative Studies Included for Review

Study	Question*								
	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9
Almborg et al., 2008	Y	Y	Y	Y	Y	Y	Y	Y	?
Almborg et al., 2009	Y	Y	Y	Y	Y	Y	Y	Y	?
Grant et al., 2006	Y	Y	Y	Y	N	N	?	N	?
Perry & Middleton, 2011	Y	Y	Y	Y	Y	Y	Y	Y	Y

Note. Y = yes; N = no; P = partly; ? = unclear. Adapted from a set of questions developed by Büttner and Muller (2015) to assess epidemiological studies.
*Q1 Was the research question clearly stated?
*Q2 Was the design clearly reported?
*Q3 Was the design appropriate for the purpose of the study?
*Q4 Was the sample described in detail?
*Q5 Did the sample represent the target population?
*Q6 Was the outcome assessed with a validated tool?
*Q7 Was confounding bias controlled in the study?
*Q8 Were the main results presented in a statistically appropriate way?
*Q9 Does the study add to the question of causality between study factor and outcome?

Appendix 4e: Evaluation of the Mixed Method Study Included for Review

Study	Question*					Qualitative				Quantitative			
	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10	Q11	Q12	Q13
Hall et al., 2012	Y	Y	Y	Y	?	Y	Y	Y	?	Y	Y	Y	Y

Note. Y = yes; N = no; ? = cannot tell. Adapted from: Pluye, P., Robert, E., Cargo, M., Bartlett, G., O'Cathain, A., Griffiths, F., Boardman, F., Gagnon, M.P., & Rousseau, M.C. (2011). Proposal: A mixed methods appraisal tool for systematic mixed studies reviews. Retrieved on September 3,2023 from http://mixedmethodsappraisaltoolpublic.pbworks.com Archived by WebCite® at http://www.webcitation.org/5tTRTc9yJ
*Q1 Is there a clear mixed methods question (or objective)?
*Q2 Do the collected data allow address the research question (objective)?
*Q3 Is the mixed methods research design relevant to address the qualitative and quantitative research questions (or objectives)?
*Q4 Is the integration of qualitative and quantitative data (or results) relevant to address the research question (objective)?
*Q5 Is appropriate consideration given to the limitations associated with this integration, e.g., the divergence of qualitative and quantitative data (or results) in a triangulation design?
*Q6 Are the sources of qualitative data (archives, documents, informants, observations) relevant to address the research question (objective)?
*Q7 Is the process for analysing qualitative data relevant to address the research question (objective)?
*Q8 Is appropriate consideration given to how findings relate to the context, e.g., the setting in which the data were collected?
*Q9 Is appropriate consideration given to how findings relate to researchers' influence, e.g., through their interactions with participants?
*Q10 Is the sampling strategy relevant to address the quantitative research question (quantitative aspect of the mixed methods question)?
*Q11 Is the sample representative of the population understudy?
*Q12 Are measurements appropriate (clear origin, or validity known, or standard instrument)?

*Q13 Is there an acceptable response rate (60% or above)?

Appendix 5: Exemplar—Data Extraction by Rule of Thumb for Anchoring Text to Context in Restatements of Findings (Sandelowski et al., 2013, p. 1432)

Shyu, Chen, Chen, Wang & Shao (2008). A family caregiver-oriented discharge planning program for older stroke patients and their family caregivers (nursing intervention)

Sample

- 65–95 years stroke patients from Northern Taiwan who were discharged to home and screened as high-risk patients requiring discharge planning services.
- 18–85-year-old family caregivers who were primarily responsible for providing direct care to or supervising the care of the patient.

Source of information

- Caregivers

Time

Perceived balance between competing needs measured one month after discharge indicated no significant difference between the two groups. The competing needs were moderately well-balanced, with the experimental group slightly better than the control group.

Findings

Program: 1) needs assessment; 2) individualised health information 4–5 times at bedside based on needs assessment; 3) assess competing needs. Consult with caregivers before discharge on handling competing needs (together with bedside health information); 4) consult by telephone within one week; visit at home within one week and at one month after discharge to support including demonstration of skills and problem-solve.

Caregiver preparation evaluation before discharge

- Nurse evaluated: both groups before program moderately prepared, after program significantly improved. Experimental group slightly better than the control.
- Self-evaluated before discharge: experimental group significantly improved than the control.

Caregiver satisfaction with discharge needs being met

- Experimental group: moderately satisfied before discharge, significantly improved one month after discharge.
- Control group: mildly satisfied before discharge, significantly improved one month after discharge.
- Experimental group had a significantly higher satisfaction score than the control group on month after discharge.

Perceived balance between competing needs

Assessment only at one month after discharge. No significant difference between groups.

Appendix 6: Themes With Direct Participant Quotations

Theme 1. Health and social care systems factors		
Subtheme 1. Enhanced transition care via well-coordinated services		
Quotations	‘[The specialist service played a critical role in] bridging a big part of the gap in community-based rehabilitation [and it is] what sets the service aside from other community services.’	Chouliara et al., 2014, p. 374
	‘In this process I’ve felt completely safe. Like, they didn’t just send me home and hope for the best; I knew someone would check up on me, that I was not alone.’	Lou et al., 2017, p. 306
	‘When people get home, they realise what they can do and what they can’t do, their limitations, and they realise, okay, this is what I need to work on.’	Cameron et al., 2014, p. 861
Subtheme 2. Compromised transition due to silos in service provision		
Quotations	‘I felt like I was a little old Eskimo woman that they put on this ice block, chopped it off and sailed it out into the middle of the ocean.’	Young et al., 2014, p. 1895
	‘Yes. I mean, with hindsight, it would obviously have been better for me to stay in C [place] because I would have had access to getting physio every day, but I realise that they need the beds. I ‘m not saying they were trying to get rid of me, they weren’t.’	Ellis-Hill et al., 2009, p. 67
	‘Cos I said, you know, “it’s been over a week now” and I feel it’s really bad that he’s had nothing, professionally, only what I’ve been doing at home, nothing professionally, and I think it should be ongoing because he’s very positive about the future and, um, you know, this is not helping.’	Ellis-Hill et al., 2009, p. 68
	‘all of a sudden it’s like, “Oh, we’ve referred you to the hospital again to get the physio”, which has took, like three months. So I’ve had intense physio for six weeks and then, for three months, I’ve had nothing.’	Cobley et al., 2013, p. 754
	‘There is dependence and reliance, which is difficult to navigate, mainly because people need long-term support and we are the end of the line as community rehabilitation. Especially discharge conversation. “Yeah but where are we going? We still need support with this.” There is still much more improvement to make, which is right but there no one else.’	O’Brien et al., 2014, p. 425
Theme 2. Health professionals and stroke survivors/caregivers engagement factors		
Subtheme 1. Tailored transition built on partnership with consumers		
Quotations	‘it’s never just one of us that is addressing the problem, if the whole team works together … brainstorm together … with the family member and the patient—we can come up with hopefully the best ideas, the best solutions possible.’	Cameron et al., 2014, p. 860

	‘It is less about a body in a bed that needs a bit of fixing; to me, it feels more of a holistic service; just being in people’s houses, seeing what problems they actually have and adapting the service around that.’	Chouliara et al., 2014, p. 375
	‘[they] learned that both the caregiver and survivor were important in the caregiving process and ways to take care of both… that there were people who cared about them and made them realise that they, as well as the stroke survivor, were important, which made them feel good.’	Grant et al., 2006, p. 72
	‘I think a lot of what we do in terms of carers is subtle supportive counselling … just trying to have an understanding to know what it might be like to walk in their shoes.’	O’Brien et al., 2014, p. 427
Subtheme 2. The lack of individualised support for clients		
Quotations	‘I would like to give more time to families but feel constrained by my workload for the shift and sometimes you see husbands or wives, or carers and you know in your heart they are finding things difficult and this is very hard and I feel it is part of my work.’	O’Brien et al., 2014, p. 425
	‘If you’ve got any questions … you could ask them [the Early Supported Discharge team after discharge], whereas when you’re in a hospital, I feel that I can’t take up the people’s time because they haven’t really got time.’	Cobley et al., 2013, p. 753
	‘Er … the uncertainty. Even now I’m not sure whether one should expect another stroke … the biggest problem is not knowing what the future holds … No they haven’t [talked about that]. I haven’t asked. Perhaps that’s the reason they haven’t mentioned it. Perhaps they feel that I’m quite lucid and comfortable with it, but I do feel a little bit uncertain.’	Ellis-Hill et al., 2009, p. 68
	‘I don’t think they told me anything. I was just left out in the cold … I didn’t have a clue what was going on.’	Cobley et al., 2013, p. 754
	‘His depression … I just don’t know what to do. I cannot cope because I don’t know what to do to stop it. When he is continuously crying, it can be really wearing because you are helpless.’	
	‘They just don’t know—that is what is quite scary, it is the unknown. You just don’t know what it is going to be like in a year’s time … because … everybody is just so different.’	Greenwood et al., 2009, p. 1125
	‘I wasn’t physically shown the best way to support him … it was all trial and error.’	Cobley et al., 2013, p. 754
	‘because [they are just] saying I can come home and do 90 percent of what I used to be able to, but they haven’t actually assessed that I can do it.’	Gustafsson & Bootle, 2013, p. 1383

Theme 3. Stroke survivors/caregivers self-management capability factors		
Subtheme 1. Resilience as a key indicator of a smooth transition		
Quotations	‘There is one lady that she has a stroke before Mum and she hasn’t gained any physical movement at all … I think with Mum—well, I think she has improved a lot anyway.’	Greenwood et al., 2009, p. 1128
	‘I was in hospital with people that were really bad, that couldn’t walk properly, couldn’t dress … I could have been so much worse. And each day when I see a slight improvement, and I do every day, I’m so thankful.’	Pringle et al., 2013, p. 1995
	‘One thing that—whatever happens, I always say that it is best. Better. God never wants to harm you, it is your destiny. And there is something always positive—good.’	Greenwood et al., 2009, p. 1129
	‘I’ve always been Catholic. I’ve always believed in God. So that’s, I’m sure there’s a reason for all this.’	Rittman et al., 2007, p. 25
	‘Yeah, that is one thing, giving them hope, that’s one thing we are really good at as a team we never, never extinguish hope. It may look bleak, but we never extinguish that hope.’	O’Brien et al., 2014, p. 427
	‘My hope is to recover to my previous level, to be able to walk as well as before and to use the arm, to get as close as possible to where I was before, preferably all the way there. I’m not sure if it’s going to be possible, it’s just training.’	Wottrich et al., 2012, p. 1220
	‘She’s (her daughter) got bad behavioural problems … (laughs) It sounds very throw away but it’s just … Yes … it’s a stroke … it’s nothing really.’	Greenwood et al., 2009, p. 1126
	‘I didn’t have to figure out anything because we had taken care of her mother for 17 years with a stroke. And so, I more or less knew what we had to do.’	Young et al., 2014, p. 1897
	‘It was a bit difficult at first with everything new, but it gets better and better, one enjoys being at home more now than one did when one left hospital.’	Wottrich et al., 2012, p. 1222
	‘You try to provide education and strategies for communication at home and provide examples to support someone to be independent in the community and at home.’	O’Brien et al., 2014, p. 426
	‘We have learnt from last time. Umm P doesn’t have a lot of trousers with buttons now. It is more jogging bottoms. He doesn’t have a lot of shirts with buttons because he had difficulty fastening buttons. To give him his independence, we have altered all that so that he can still dress himself and he doesn’t rely on me.’	Greenwood et al., 2009, p. 1128
	‘When it comes to social events and going out I have to thank my friend because she drives and the same thing with my son … it’s encouraging that these people are around me.’	Wood et al., 2010, p. 1051

Subtheme 2. Sense of loss and burdensome on others		
Quotations	‘I have lost this person, who is this new person who I have to take care of? I have lost my husband and I don’t know who it is.’	O’Brien et al., 2014, p. 427
	‘I feel I’ve got a different man home than he was before he had the stroke, because before he was a very well educated man, and although we tended to make decisions together, I always took his lead … and now he’s not—he’s not even interested in anything.’	Pringle et al., 2013, p. 1995
	‘I’ve always been independent//so it is a completely new situation and I can’t know how it is going to be//it might be great, or it can go badly.’	Nordin et al., 2015, p. 5
	‘Even people that have minimal physical impairments can be really anxious because their whole life has changed.’	Chouliara et al., 2014, p. 375
	‘I think the support around the emotional journey, [for] both client and families, is a big gap because if we had access to psychology or counselling, we could start educating about stroke … offering what they need as things change such as adjusting to their emotions.’	O’Brien et al., 2014, p. 245
	‘it took me a long time to buy into the rehab therapist … being pleased with small little gains and I tried to look at it from their point [of view]. They know nothing about him. They do not see him until the first day he is here. So that is the history they have of him, so every little thing that he does that gets better they see as great progress. It’s very difficult [when they didn’t know the way he was before the stroke.’	Young et al., 2014, p. 1898
	‘the 24/7 care gave her a ‘whole different perspective’ about how difficult caregiving was.’	Young et al., 2014, p. 1897
	‘The financial disadvantage of the client is the biggest hurdle … if you have a family that can buy a lifting machine and a special bed and employ a physio, so they can get a better outcome, they have the potential to have a better outcome than those who are lower socioeconomic.’	O’Brien et al., 2014, p. 426
	‘Here we are getting her better and then, boom, we’ll run out of money, and our social system encourages you to confine them into a nursing home and that will kill her.’	Bakas et al., 2002, p. 248
	‘… pressured to take the patient home despite feeling unprepared.’	Young et al., 2014, p. 1895
	‘Carers have their issues before the person had their stroke and it pushes them to the limit of what their capacity is. They might not have been managing with what they had before, and this comes and just tops it off.’	O’Brien et al., 2014, p. 427
	‘it’s really, really dependent on the family and … I don’t want to say their level of involvement, but their readiness to be involved … in this stage … a lot of families are really overwhelmed … it is not that they don’t want to help, it’s just that they can’t kind of get their heads around helping.’	Cameron et al., 2014, p. 860

	‘I’ve hurt my back … I will do this until the day that we finally both crash to the floor or I break a hip, or he breaks a rib. Then we will both end up in a nursing home together … there are things worse than death, and this is it. This is the living dead. You’re looking at us right here, he and I.’	Young et al., 2014, p. 1896
	‘I don’t wanna be a burden to anybody else … Now I can’t seem to get out and do what I wanna do … it’s depressing … All of a sudden find out that you can’t do much of anything, you gotta depend on people.’	Rittman et al., 2007, p. 27
	‘Do you see the condition in which I put my son? I forced my son to bounce among work, home, his family, and me. My son seems like a yo-yo attached to the rope running back and forth, poor man!’	Simeone et al., 2015, p. 166

Appendix 7: PRISMA (Preferred Reporting of Items for Systematic Reviews and Meta-Analysis) Statement

Section/topic	#	Checklist item	Reported in manuscript page #
TITLE			
Title	1	Identify the report as a systematic review, meta-analysis, or both.	1
		ABSTRACT	
Structured summary	2	Provide a structured summary including, as applicable: background; objectives; data sources; study eligibility criteria, participants, and interventions; study appraisal and synthesis methods; results; limitations; conclusions and implications of key findings; systematic review registration number.	1–3
		INTRODUCTION	
Rationale	3	Describe the rationale for the review in the context of what is already known.	3–6
Objectives	4	Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS).	7
		METHODS	
Protocol and registration	5	Indicate if a review protocol exists, if and where it can be accessed (e.g., Web address), and, if available, provide registration information, including registration number.	7
Eligibility criteria	6	Specify study characteristics (e.g., PICOS, length of follow-up) and report characteristics (e.g., years considered, language, publication status) used as criteria for eligibility, giving rationale.	7–8, Supp file S2
Information sources	7	Describe all information sources (e.g., databases with dates of coverage, contact with study authors to identify additional studies) in the search and date last searched.	7–8
Search	8	Present the full electronic search strategy for at least one database, including any limits used, such that it could be repeated.	Supp file S1
Study selection	9	State the process for selecting studies (i.e., screening, eligibility, included in a systematic review, and, if applicable, included in the meta-analysis).	8, Figure 1
Data collection process	10	Describe the method of data extraction from reports (e.g., piloted forms, independently, in duplicate) and any processes for obtaining and confirming data from investigators.	9
Data items	11	List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made.	9, Supp file S5
Risk of bias in individual studies	12	Describe methods used for assessing risk of bias of individual studies (including specification of whether this was done at the study or outcome level), and how this information is to be used in any data synthesis.	8, Supp file S4

Section/topic	#	Checklist item	Reported in manuscript page #
Summary measures	13	State the principal summary measures (e.g., risk ratio, difference in means).	Table 1 & Supp file S3
Synthesis of results	14	Describe the methods of handling data and combining results of studies, if done, including measures of consistency (e.g., I^2) for each meta-analysis.	9, Supp file S6
Risk of bias across studies	15	Specify any assessment of risk of bias that may affect the cumulative evidence (e.g., publication bias, selective reporting within studies).	8, Supp file S4
Additional analyses	16	Describe methods of additional analyses (e.g., sensitivity or subgroup analyses, meta-regression), if done, indicating which were pre-specified.	NA
		RESULTS	
Study selection	17	Give numbers of studies screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally with a flow diagram.	Figure 1
Study characteristics	18	For each study, present characteristics for which data were extracted (e.g., study size, PICOS, follow-up period) and provide the citations.	Table 1, Supp file S3
Risk of bias within studies	19	Present data on risk of bias of each study and, if available, any outcome level assessment (see item 12).	8, Supp file S4
Results of individual studies	20	For all outcomes considered (benefits or harms), present, for each study: (a) simple summary data for each intervention group (b) effect estimates and confidence intervals, ideally with a forest plot.	NA
Synthesis of results	21	Present results of each meta-analysis done, including confidence intervals and measures of consistency.	9–18
Risk of bias across studies	22	Present results of any assessment of risk of bias across studies (see Item 15).	8, 21, Supp file S4
Additional analysis	23	Give results of additional analyses, if done (e.g., sensitivity or subgroup analyses, meta-regression [see Item 16]).	NA
		DISCUSSION	
Summary of evidence	24	Summarise the main findings, including the strength of evidence for each main outcome; consider their relevance to key groups (e.g., healthcare providers, users, and policymakers).	18–22, Figure 2
Limitations	25	Discuss limitations at study and outcome level (e.g., risk of bias) and at review level (e.g., incomplete retrieval of identified research, reporting bias).	21
Conclusions	26	Provide a general interpretation of the results in the context of other evidence, and implications for future research.	22
		FUNDING	

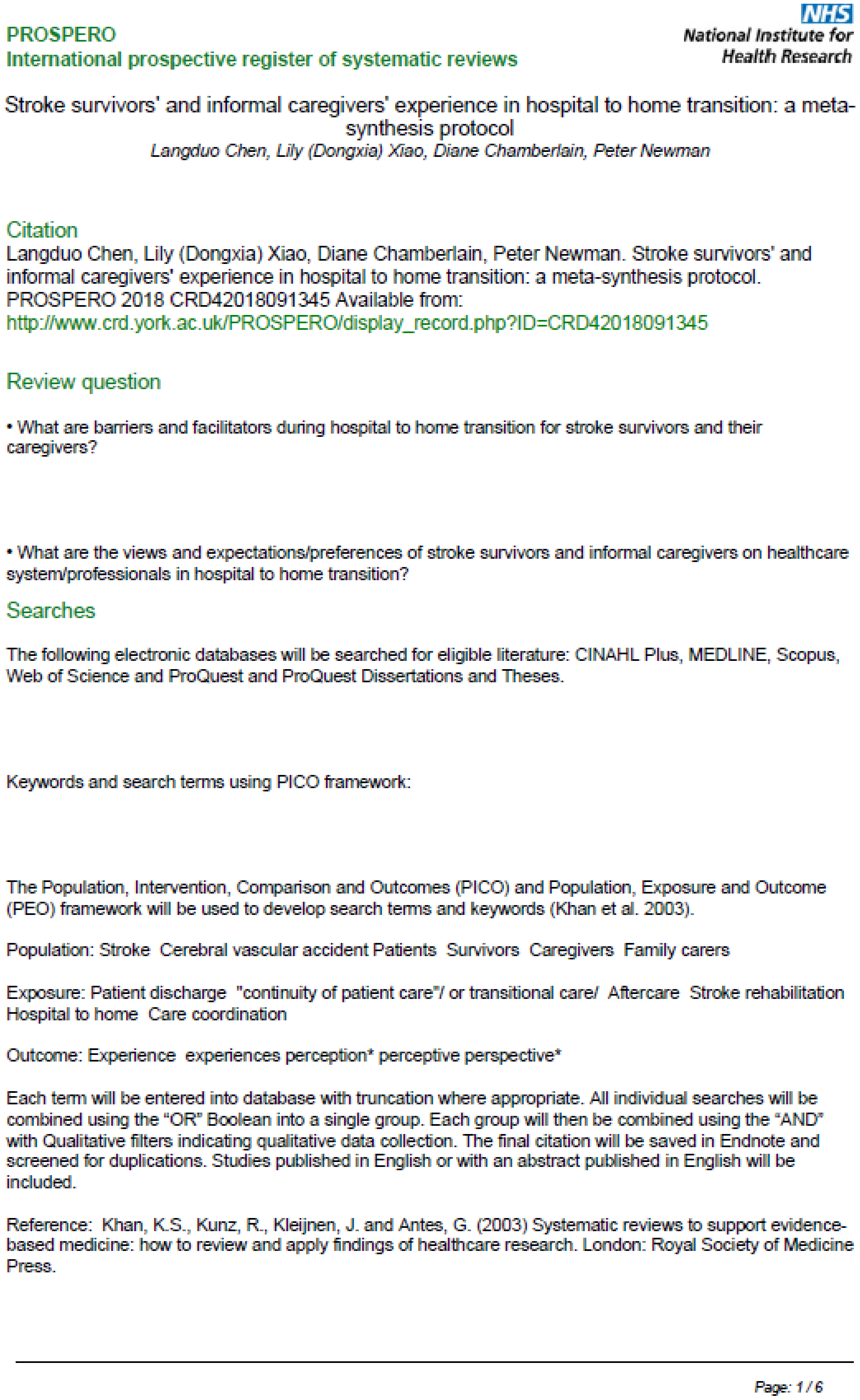
Section/topic	#	Checklist item	Reported in manuscript page #
Funding	27	Describe sources of funding for the systematic review and other support (e.g., supply of data); role of funders for the systematic review.	Title Page

Appendix 8: ENTREQ (Enhancing Transparency in Reporting the Synthesis of Qualitative Research) Statement

No.	Checklist items	Guide and description	Page no. in manuscript
1	Aim	State the research question the synthesis addresses.	1, 6
2	Synthesis methodology	Identify the synthesis methodology or theoretical framework that underpins the synthesis and describe the rationale for the choice of methodology.	6, 7
3	Approach to searching	Indicate whether the search was pre-planned (comprehensive search strategies to seek all available studies) or iterative (to seek all available concepts until they theoretical saturation is achieved).	7
4	Inclusion criteria	Specify the inclusion/exclusion criteria (e.g. in terms of population, language, year limits, type of publication, study type).	7,8 Table 1
5	Data sources	Describe the information sources used (e.g. electronic databases (MEDLINE, EMBASE, CINAHL, psycINFO, Econlit), grey literature databases (digital thesis, policy reports), relevant organisational websites, experts, information specialists, generic web searches (Google Scholar) hand searching, reference lists) and when the searches conducted; provide the rationale for using the data sources.	1, 7
6	Electronic Search strategy	Describe the literature search (e.g. provide electronic search strategies with population terms, clinical or health topic terms, experiential or social phenomena related terms, filters for qualitative research, and search limits).	7
7	Study screening methods	Describe the process of study screening and sifting (e.g. title, abstract and full text review, number of independent reviewers who screened studies).	7, 8
8	Study characteristics	Present the characteristics of the included studies (e.g. year of publication, country, population, number of participants, data collection, methodology, analysis, research questions).	10, Table 2,
9	Study selection results	Identify the number of studies screened and provide reasons for study exclusion (e.g. for comprehensive searching, provide numbers of studies screened and reasons for exclusion indicated in a figure/flowchart; for iterative searching describe reasons for study exclusion and inclusion based on modifications to the research question and/or contribution to theory development).	8, Figure 1
10	Rationale for appraisal	Describe the rationale and approach used to appraise the included studies or selected findings (e.g. assessment of conduct (validity and robustness), assessment of reporting (transparency), assessment of content and utility of the findings).	8, Table 3
11	Appraisal items	State the tools, frameworks and criteria used to appraise the studies or selected findings (e.g. Existing tools: CASP, QARI, COREQ; reviewer developed tools; describe the domains assessed: research team, study design, data analysis and interpretations, reporting).	8, Table 3

No.	Checklist items	Guide and description	Page no. in manuscript
12	Appraisal process	Indicate whether the appraisal was conducted independently by more than one reviewer and if consensus was required.	8
13	Appraisal results	Present results of the quality assessment and indicate which articles, if any, were weighted/excluded based on the assessment and give the rationale.	8, Table 3
14	Data extraction	Indicate which sections of the primary studies were analysed and how were the data extracted from the primary studies? (e.g. all text under the headings ‘results /conclusions’ were extracted electronically and entered into a computer software).	8, 9
15	Software	State the computer software used, if any.	EndNote
16	Number of reviewers	Identify who was involved in coding and analysis.	7–9
17	Coding	Describe the process for coding data (e.g. line-by-line coding to search for concepts).	9
18	Study comparison	Describe how were comparisons made within and across studies (e.g. subsequent studies were coded into pre-existing concepts, and new concepts were created when deemed necessary).	9, Appendix 1
19	Derivation of themes	Explain whether the process of deriving the themes or constructs was inductive or deductive.	9
20	Quotations	Provide quotations from the primary studies to illustrate themes/constructs, and identify whether the quotations were participant quotations of the author’s interpretation.	11–22
21	Synthesis output	Present rich, compelling and useful results that go beyond a summary of the primary studies (e.g. new interpretation, models of evidence, conceptual models, analytical framework, development of a new theory or construct).	11–22, Table 4

Appendix 9: Published Systematic Review Protocol



PROSPERO
International prospective register of systematic reviews

NHS
National Institute for
Health Research

Stroke survivors' and informal caregivers' experience in hospital to home transition: a meta-synthesis protocol

Langduo Chen, Lily (Dongxia) Xiao, Diane Chamberlain, Peter Newman

Citation

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http://www.crd.york.ac.uk/PROSPERO/display_record.php?ID=CRD42018091345

Review question

• What are barriers and facilitators during hospital to home transition for stroke survivors and their caregivers?

• What are the views and expectations/preferences of stroke survivors and informal caregivers on healthcare system/professionals in hospital to home transition?

Searches

The following electronic databases will be searched for eligible literature: CINAHL Plus, MEDLINE, Scopus, Web of Science and ProQuest and ProQuest Dissertations and Theses.

Keywords and search terms using PICO framework:

The Population, Intervention, Comparison and Outcomes (PICO) and Population, Exposure and Outcome (PEO) framework will be used to develop search terms and keywords (Khan et al. 2003).

Population: Stroke Cerebral vascular accident Patients Survivors Caregivers Family carers

Exposure: Patient discharge "continuity of patient care"/ or transitional care/ Aftercare Stroke rehabilitation Hospital to home Care coordination

Outcome: Experience experiences perception* perceptive perspective*

Each term will be entered into database with truncation where appropriate. All individual searches will be combined using the "OR" Boolean into a single group. Each group will then be combined using the "AND" with Qualitative filters indicating qualitative data collection. The final citation will be saved in Endnote and screened for duplications. Studies published in English or with an abstract published in English will be included.

Reference: Khan, K.S., Kunz, R., Kleijnen, J. and Antes, G. (2003) Systematic reviews to support evidence-based medicine: how to review and apply findings of healthcare research. London: Royal Society of Medicine Press.

Types of study to be included

Inclusion:

Qualitative original studies published in English (including qualitative data from mixed methods studies) focusing on the experiences of the hospital to home transition period, self-care or self-management approaches and expectations of improved care services that enable hospital to home transition care.

Exclusion:

Studies using quantitative methods or mixed methods where the qualitative data cannot be separated. Qualitative studies involving statistical data as reporting results. Conference proceedings, discussions, reviews or commentaries.

Condition or domain being studied

Hospital to home transition (the transition) is the most stressful period for stroke survivors and their informal caregivers. The widely reported challenges and difficulties for stroke survivors include self-care deficits, complications associated with stroke related functional declines and risk factors, isolation, depression, cognitive and personality changes (Rittman et al. 2007, Langhorne, Bernhardt and Kwakkel 2011). The widely reported challenges for caregivers are lack of information, resources, knowledge, skills and confidence to manage care at home and to coordinate required treatment, rehabilitation and various care services. They experience high levels of caregiving burden and burnout (Greenwood and McKenzie 2010, Grant et al. 2014). It is evident that personal coping skills, service providers' factors and the health care system factors contribute to these undesirable situations that stroke survivors and their caregivers encounter during hospital to home transition (Wissle et al. 2013, Chen et al. 2016).

This review examines the Preparation and Implementation stage of post stroke recovery trajectory defined by the 'Time It Right' framework (Cameron and Gignac 2008). Data up to 6 months after hospital discharge will be analysed as majority of studies on hospital to home transition reported a 3 to 6 month follow-up.

References:

Cameron, JI and Gignac, MA 2008, '"Timing It Right": A conceptual framework for addressing the support needs of family caregivers to stroke survivors from the hospital to the home', Patient education and counselling, vol. 70, no. 3, pp. 305-14.

Chen, L, Xiao, LD and De Bellis, A 2016, 'First?time stroke survivors and caregivers' perceptions of being engaged in rehabilitation', Journal of Advanced Nursing, vol. 72, no. 1, pp. 73-84.

Grant, J, Hunt, C and Steadman, L 2014, 'Common caregivers issues and nursing interventions after a stroke', Stroke, vol. 45, pp. e151-e3.

Participants/population

Inclusion:

- Adult stroke survivors and informal caregivers aged 18 years and above.

- Informal caregivers are defined as unpaid caregivers including spouse or partner, family members, friends, or significant others who provide physical and emotional support to stroke survivors.

Exclusion:

- Studies that focus on stroke survivors less than 18 years old.

- Studies on multiple patient populations such as traumatic brain injuries, brain tumour, dementia, hip fracture where data relevant to stroke cannot be separated.

- Studies of multiple populations e.g. health care professionals, service provider, where perspectives of stroke survivors and caregivers cannot be separated.

Intervention(s), exposure(s)

Inclusion:

Studies that explore the impact and perceptions of stroke, the experience of stroke survivors and family caregivers, perspectives or needs in hospital to home transition up to 6 months after hospital discharge.

Exclusion:

Studies examining post stroke long term experiences and needs (over 6 months after hospital discharge). Studies on discharges to facilities other than home. Studies conducted across multiple period of stroke trajectory where the transition period cannot be separated.

Comparator(s)/control

Not applicable

Context

Studies in hospital on patient wards, outpatient clinics, in community.

Main outcome(s)

The primary outcomes are qualitatively derived experiences and needs of stroke survivors and informal caregivers in hospital to home transition.

Timing and effect measures

This review examines the Preparation and Implementation stage of post stroke recovery trajectory defined by the 'Time It Right' framework (Cameron and Gignac 2008). Data up to 6 months after hospital discharge will be analysed as majority of studies on hospital to home transition reported a 3 to 6 month follow-up.

Reference:

Cameron, JI and Gignac, MA 2008, '"Timing It Right": A conceptual framework for addressing the support needs of family caregivers to stroke survivors from the hospital to the home', Patient education and counselling, vol. 70, no. 3, pp. 305-14.

Additional outcome(s)

The secondary outcomes are the views and expectations/preferences of stroke survivors and informal caregivers on healthcare system/professionals in hospital to home transition.

Timing and effect measures

Same as the Primary outcome(s).

Data extraction (selection and coding)

The screening process for the review will be carried out by three reviewers in 2 stages. The citations will be distributed in the following manner:

- Reviewer 1 (primary reviewer) will review each citation.

- Each articles is independently reviewed by two reviewers.

Stage 1: Screening based on title and abstract

Using EndNote, the initial citations will be shared amongst reviewers. Reviewer 1 will screen each article based on title and abstract against the inclusion and exclusion criteria. The rest of reviewers will screen title and abstract of half of the citations based on the inclusion and exclusion criteria. The screening results will be discussed and citations not selected by two reviewers will be excluded for full text review and maintained for future reference. The included citations will be reviewed in stage 2.

Stage 2 Full text review

Reviewer 1 will source full text and save PDF versions into EndNote database from the title and abstract screening process. Each reviewer will independently review full text of all included articles. Any discrepancies will be discussed and resolved until consensus is achieved.

Data will be extracted from the studies selected for inclusion following the data extraction methods developed by Bettany-Saltikov (2012).

Reference:

Bettany-Saltikov, J 2012, How to do a systematic literature review in nursing: a step-by-step guide, McGraw-Hill Education (UK).

Risk of bias (quality) assessment

The rigour of the qualitative studies will be appraised using the CERQual approach (Confidence in the Evidence from Reviews of Qualitative Research) (Lewin et al. 2015). Studies will be reviewed by three independent review authors. The CERQual approach consists of 4 components:

1. Methodological limitations refers to any problems in the design or conduct of the included primary studies. The Critical Appraisal Skills Programme checklist (CASP) (2017) will be used as a tool to evaluate the methodological strengths and weaknesses of the primary studies.

2. Relevance is considered as the extent to which the evidence of the primary studies is aligned with the context of the review question. This includes study population, phenomenon of interest, setting and time frame.

3. Coherence assesses the confidence in the study findings. Whether or not these findings are well grounded in the data and provide explanation to support the pattern found in these data.

4. Adequacy can be defined as richness and quantity of data supporting a finding.

The quality assessment in this review serves to offer further insights into the contribution of the included studies at the later stage of the review (Carroll and Booth 2015). All studies that meet the inclusion criteria will be included disregarding the study quality as methodologically weak studies may provide novel understandings that may not be produced in methodologically strong studies (Carroll et al. 2012).

Reference:

Carroll, C, Booth, A and Lloyd-Jones, M 2012, 'Should we exclude inadequately reported studies from qualitative systematic reviews? An evaluation of sensitivity analyses in two case study reviews', Qualitative Health Research, vol. 22, no. 10, pp. 1425-34.

Carroll, C and Booth, A 2015, 'Quality assessment of qualitative evidence for systematic review and synthesis: Is it meaningful, and if so, how should it be performed?', Research synthesis methods, vol. 6, no.

2, pp. 149-54.

Lewin, S., Glenton, C., Munthe-Kaas, H., Carlsen, B., Colvin, C.J., Gülmezoglu, M., Noyes, J., Booth, A., Garside, R. and Rashidian, A. (2015) Using Qualitative Evidence in Decision Making for Health and Social Interventions: An Approach to Assess Confidence in Findings from Qualitative Evidence Syntheses (GRADE-CERQual). PLOS Medicine, 12(10), e1001895.

Strategy for data synthesis

The qualitative studies will be analysed using Thomas and Hare's approach to metasynthesis (Thomas and Hare, 2008). This involves 3 steps:

Step 1: Free line-by-line coding of findings of primary studies to enable "Translation" of concepts from one study to another.

Step 2: Developing descriptive themes by grouping similarities and differences between the codes and creating new codes.

Step 3: Generating analytical themes based on review questions.

Reference:

Thomas, J and Harden, A 2008, 'Methods for the thematic synthesis of qualitative research in systematic reviews', BMC medical research methodology, vol. 8, no. 1, p. 45.

Analysis of subgroups or subsets

Not planned

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Review_Ongoing

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Subject indexing assigned by CRD

Subject index terms
Caregivers; Hospitals; Humans; Stroke; Survivors

Date of registration in PROSPERO
21 March 2018

Date of publication of this version
21 March 2018

Details of any existing review of the same topic by the same authors
Not applicable

Stage of review at time of this submission

Stage	**Started**	Completed
Preliminary searches	Yes	Yes
Piloting of the study selection process	Yes	Yes
Formal screening of search results against eligibility criteria	Yes	Yes
Data extraction	No	No
Risk of bias (quality) assessment	No	No
Data analysis	No	No

Versions
21 March 2018

Appendix 10: Search Strategies

Medline

Ovid MEDLINE(R) Epub Ahead of Print, In-Process & Other Non-Indexed Citations, Ovid MEDLINE(R) Daily, Ovid MEDLINE and Versions(R)

#	Search
1	exp Stroke/
2	(stroke or cerebrovascular accident* or cerebrovascular apoplexy or brain vascular accident*).tw.
3	1 or 2
4	"continuity of patient care"/ or transitional care/
5	Stroke Rehabilitation/
6	aftercare/
7	patient discharge/
8	Patient Education as Topic/
9	(transition* or aftercare or aftercare or discharge plan* or (patient* adj2 discharg*) or (care adj2 coordinat*) or continuity of care or (discharg* adj3 folllow-up*) or (patient* adj2 educat*) or rehabilitation).tw.
10	or/4-9
11	Independent Living/
12	(home or homes or (independent* adj2 living) or communit*).tw.
13	11 or 12
14	interviews as topic/ or focus groups/ or narration/ or qualitative research/
15	((semi-structured or semistructured or unstructured or informal or "in-depth" or indepth or "face-to-face" or structured or guide? or group*) adj3 (discussion* or questionnaire*)).tw.
16	(Interview* or focus group*).tw.

#	Search
17	((context* or semantic or content) adj2 analys*).tw.
18	(narrat* or qualitative* or ethnograph* or phenomenolog* or hermeneutic*).tw.
19	((personal* or patient* or inpatient* or participant* or lived) adj2 (experience or experiences or perception* or perceptive or perspective*)).tw.
20	or/14-19
21	3 and 10 and 13 and 20

CINAHL Database

S1	(MH "Stroke+")
S2	TI (stroke or cerebrovascular accident* or cerebrovascular apoplexy or brain vascular accident*)
S3	S1 OR S2
S4	(MH "Continuity of Patient Care") OR (MH "Transitional Care")
S5	(MH "Rehabilitation")
S6	(MH "After Care")
S7	(MH "Patient Discharge")
S8	(MH "Patient Education")
S9	(MH "Discharge Planning") OR (MH "Patient Discharge Education")
S10	TI ((transition* or aftercare or aftercare or "discharge plan*" or (patient* N2 discharg*) or (care N2 coordinat*) or "continuity of care" or (discharg* N3 folllow-up*) or (patient* N2 educat*) or rehabilitation)) OR AB ((transition* or aftercare or aftercare or "discharge plan*" or (patient* N2 discharg*) or (care N2 coordinat*) or "continuity of care" or (discharg* N3 folllow-up*) or (patient* N2 educat*) or rehabilitation))
S11	S4 OR S5 OR S6 OR S7 OR S8 OR S9 OR S10
S12	(MH "Community Living+")

S13	TI ((home or homes or (independent* N2 living) or communit*)) OR AB ((home or homes or (independent* N2 living) or communit*))
S14	S12 OR S13
S15	(MH "Interviews+") OR (MH "Focus Groups") OR (MH "Narratives") OR (MH "Qualitative Studies+")
S16	TI ((("semi-structured" or semistructured or unstructured or informal or "in-depth" or indepth or "face-to-face" or structured or guide? or group*) N3 (discussion* or questionnaire*))) OR AB ((("semi-structured" or semistructured or unstructured or informal or "in-depth" or indepth or "face-to-face" or structured or guide? or group*) N3 (discussion* or questionnaire*)))
S17	TI ((Interview* or focus group*)) OR AB ((Interview* or focus group*))
S18	TI (. ((context* or semantic or content) N2 analys*)) OR AB (. ((context* or semantic or content) N2 analys*))
S19	TI ((narrat* or qualitative* or ethnograph* or phenomenolog* or hermeneutic*)) OR AB ((narrat* or qualitative* or ethnograph* or phenomenolog* or hermeneutic*))
S20	TI (((personal* or patient* or inpatient* or participant* or lived) N2 (experience or experiences or perception* or perceptive or perspective*))) OR AB (((personal* or patient* or inpatient* or participant* or lived) N2 (experience or experiences or perception* or perceptive or perspective*)))
S21	S15 OR S16 OR S17 OR S18 OR S19 OR S20
S22	S3 AND S11 AND S14 AND S21

PsycINFO

#	Search
1	Cerebrovascular Accidents/ or exp Cerebral Ischemia/ or Cerebral Hemorrhage/
2	(stroke or cerebrovascular accident* or cerebrovascular apoplexy or brain vascular accident*).tw.

#	**Search**
3	1 or 2
4	Continuum of Care/
5	Rehabilitation/
6	aftercare/
7	hospital discharge/ or discharge planning/
8	Client Education/
9	(transition* or aftercare or aftercare or discharge plan* or (patient* adj2 discharg*) or (care adj2 coordinat*) or continuity of care or (discharg* adj3 folllow-up*) or (patient* adj2 educat*) or rehabilitation).tw.
10	or/4-9
11	Self-Care Skills/
12	(home or homes or (independent* adj2 living) or communit*).tw.
13	11 or 12
14	interviews/ or interviewing/ or narratives/ or qualitative research/
15	((semi-structured or semistructured or unstructured or informal or "in-depth" or indepth or "face-to-face" or structured or guide? or group*) adj3 (discussion* or questionnaire*)).tw.
16	(Interview* or focus group*).tw.
17	((context* or semantic or content) adj2 analys*).tw.
18	(narrat* or qualitative* or ethnograph* or phenomenolog* or hermeneutic*).tw.
19	((personal* or patient* or inpatient* or participant* or lived) adj2 (experience or experiences or perception* or perceptive or perspective*)).tw.
20	or/14-19
21	3 and 10 and 13 and 20

Scopus

(TITLE-ABS-KEY (({stroke} OR "cerebrovascular accident*" OR "cerebrovascular apoplexy" OR "brain vascular accident*"))) AND (TITLE-ABS-KEY ((transition* OR aftercare OR aftercare OR "discharge plan*" OR (patient* W/2 discharg*) OR (care W/2 coordinat*) OR "continuity of care" OR (discharg* W/3 folllow-up*) OR (patient* W/2 educat*) OR rehabilitation))) AND (TITLE-ABS-KEY ((home OR homes OR (independent* W/2 living) OR communit*))) AND (((TITLE-ABS-KEY ((interview* OR focus AND group*)) OR TITLE-ABS-KEY (((context* OR semantic OR content) W/2 analys*)) OR TITLE-ABS-KEY ((narrat* OR qualitative* OR ethnograph* OR phenomenolog* OR hermeneutic*)) OR TITLE-ABS-KEY (((personal* OR patient* OR inpatient* OR participant* OR lived) W/2 (experience OR experiences OR perception* OR perceptive OR perspective*))))) OR (TITLE-ABS-KEY ((("semi-structured" OR semistructured OR unstructured OR informal OR "in-depth" OR indepth OR "face-to-face" OR structured OR guide? OR group*) W/3 (discussion* OR questionnaire*)))))

Web of Science

TS=(("stroke" OR "cerebrovascular accident*" OR "cerebrovascular apoplexy" OR "brain vascular accident*")) AND TS=((transition* OR aftercare OR aftercare OR "discharge plan*" OR (patient* NEAR/2 discharg*) OR (care NEAR/2 coordinat*) OR "continuity of care" OR (discharg* NEAR/3 folllow-up*) OR (patient* NEAR/2 educat*) OR rehabilitation)) AND TS=((home OR homes OR (independent* NEAR/2 living) OR communit*)) AND TS=((("semi-structured" OR semistructured OR unstructured OR informal OR "in-depth" OR indepth OR "face-to-face" OR structured OR guide? OR group*) NEAR/3 (discussion* OR questionnaire*)) OR (Interview* OR focus group*) OR ((context* OR semantic OR content) NEAR/2 analys*) OR (narrat* OR qualitative* OR ethnograph* OR phenomenolog* OR hermeneutic*) OR ((personal* OR patient* OR inpatient* OR participant* OR lived) NEAR/2 (experience OR experiences OR perception* OR perceptive OR perspective*)))

ProQuest

all("stroke" OR "cerebrovascular accident*" OR "cerebrovascular apoplexy" OR "brain vascular accident*") AND all(transition* OR aftercare OR aftercare OR "discharge plan*" OR (patient* NEAR/2 discharg*) OR (care NEAR/2 coordinat*) OR "continuity of care" OR (discharg* NEAR/3 folllow-up*) OR (patient* NEAR/2 educat*) OR rehabilitation) AND all(home OR homes OR (independent* NEAR/2 living) OR communit*) AND all((("semi-structured" OR semistructured OR unstructured OR informal OR "in-depth" OR indepth OR "face-to-face" OR structured OR guide? OR group*) NEAR/3 (discussion* OR questionnaire*)) OR Interview* OR focus group* OR ((context* OR semantic OR content) NEAR/2 analys*) OR narrat* OR qualitative* OR ethnograph* OR phenomenolog* OR hermeneutic* OR ((personal* OR patient* OR inpatient* OR participant* OR lived) NEAR/2 (experience OR experiences OR perception* OR perceptive OR perspective*)))

Appendix 11: Summary of Reviewed Studies

Author and year	Aim/objective	Sample and setting	Time post-discharge	Methodology and methods	Summary of findings
1. Bakas et al., 2002 *USA*	To determine the self-reported needs and concerns of family caregivers of stroke survivors soon after discharge to home.	*N* = 14 stroke family carers discharged from hospital wards. An outpatient neurology clinic	Within 6 months	• Telephone interviews • Using a pre-determined code list to identify categories	• Preparation required before discharge on management of stroke complications. • Caregivers' emotions and needs ignored by healthcare professionals.
2. Cameron et al., 2013 Canada	Using Time It Right framework to determine stroke caregivers' needs, how these needs change over time and the support received.	*N* = 38 (24 caregivers, 14 health professionals) Inpatient rehab centre & community programs	1 month to 1 year	• Face-to-face or phone interviews • Qualitative framework analysis	• More information needs at preparation and implementation phase. Needs change over time. • Caregivers need to be involved in inpatient rehab phase. Support from health professionals needed after discharge.
3. Cobley et al., 2013 UK	To investigate patients' and carers' experiences of ESD services.	*N* = 42 (27 stroke patients and 15 carers) Two stroke units	*M* = 69.5 ± 40.5 days.	• Face-to-face semi-structured interviews • Thematic analysis	• Lack of education and support for carers. • Disjointed transition between ESD and ongoing rehabilitation services. • Home-based rehabilitation satisfactory.
4. Connolly & Mahoney, 2018 USA	To investigate the experiences of ischaemic stroke survivors during the first 4 weeks after discharge home directly from the hospital.	*N* = 31 Two general medical and surgical neurological wards	Within 4 weeks	• Exploratory descriptive design • Semi-structured phone interviews • Qualitative analysis	• A journey to new self hindered by lack of preparation, delayed follow-up services. • A cohesive plan developed with survivors facilitated adjustment. • Personal views of situation decided adjustment.
5. Eilersten et al., 2010 *Norway*	To examine older women's experience and the characteristics of their recovery process during the first 2 years post-stroke.	*N* = 6 Two stroke units	0–24 months	• Gadamer's phenomenological hermeneutics • In-depth interviews	• Transition home = taking on more responsibilities as more demanding than anticipated. • Difficulty functioning in home environment. • Loss of ability to perform pre-morbid activities = loss of value and meaning.
6. Erikson et al., 2010 *Sweden*	To investigate the meaning of acting with others in different places during the first year of rehabilitation after stroke.	*N* = 9 A rehabilitation department	1, 3, 6, 12 months	• Grounded theory • Interviews	• Unable to gain understanding from friends during social interaction. • Sensed to be a burden to family and caregiver. • Establishment of sense of belonging through engaging with others.
7. Finch et al., 2021 *Australia*	To explore how people with minor stroke make sense of the stroke in the first weeks following hospital discharge to home.	*N* = 17 A hospital	*M* = 17 days	• Qualitative descriptive approach • Semi-structured interviews • Content analysis	• Post-stroke symptoms continued but not knowing how to follow up as hospital clinicians deemed no need for further treatment. • Minor stroke impacted on social participation and personal relationships.
8. Ghazzawi et al., 2016 *Canada*	To explore family carers' perceptions of navigating the stroke rehab system in transition from rehab facility to home.	*N* = 14 An outpatient rehabilitation facility	4–12 weeks	• Qualitative exploratory design • Interviews • Inductive content analysis	• Carers forced to become system navigator due to non-linear and dynamic nature of stroke rehab system. • Challenges included own health, insufficient information, unavailability of services and financial constraint.

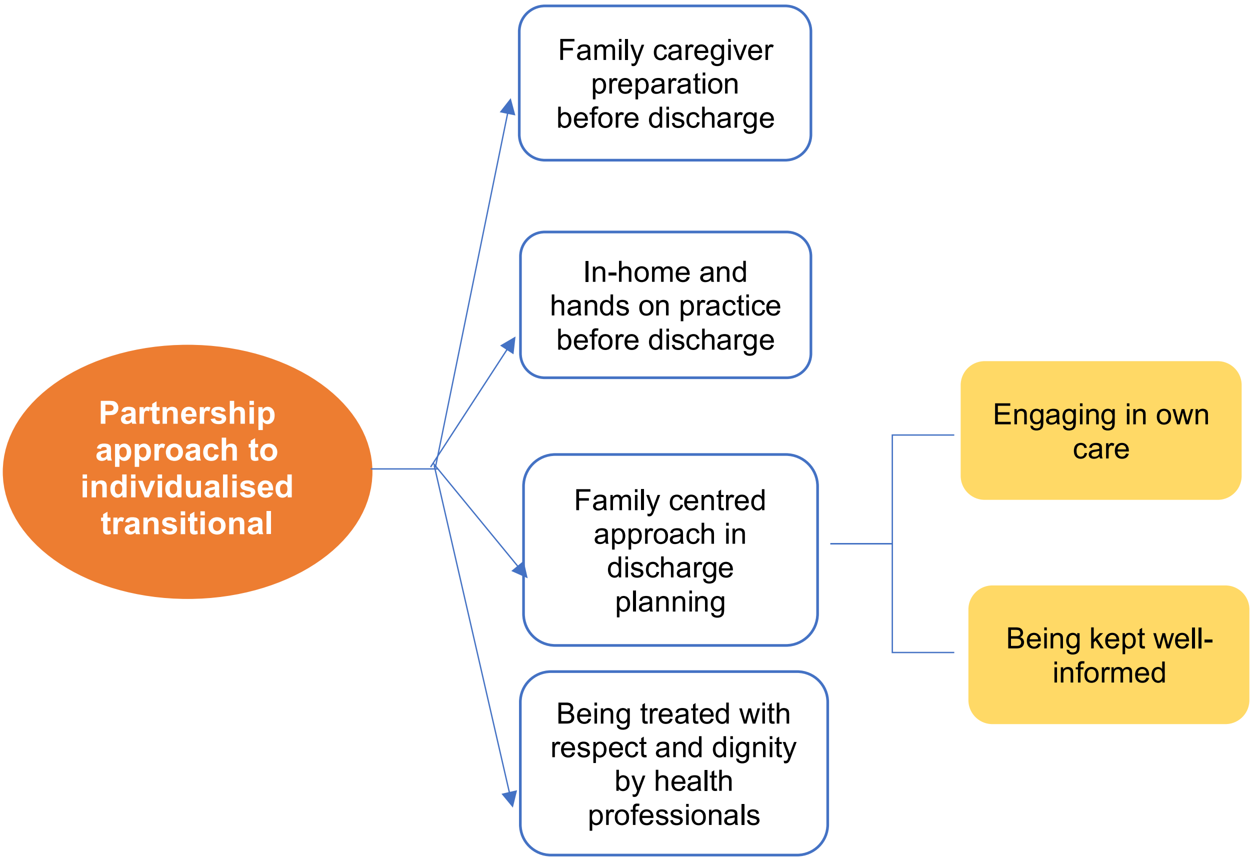
Author and year	Aim/objective	Sample and setting	Time post-discharge	Methodology and methods	Summary of findings
9. Gholamzadeh et al., 2015 *Iran*	To explore the supportive needs, concerns and coping behaviours of daughter and daughter-in-law caregivers of stroke survivors.	*N* = 17 Two large university hospitals	1 month	• Semi-structured interviews & focus groups • Content & thematic analysis	• Inadequate preparation before discharge on carer skills and management of stroke complications. • Early discharge complicated with lack of follow-up and unavailability of community support services. • Carers coped by spiritual emotion-focused strategies.
10. Grant, 1996 *USA*	To explore home care problems experienced by stroke survivors and their family caregivers after discharge home.	*N* = 20 (10 dyads) Rehabilitation ward Outpatient clinic	Within 4 months of stroke onset	• Interviews • Constant comparative method	• Loss of survivors' familiar identity. • Struggling with personal care activities, mainly depending on carers. • Difficulty obtaining support, especially emotional, financial support and community services.
11. Greenwood et al., 2009 *UK*	To investigate the experiences of informal carers of stroke survivors in the first 3 months after discharge.	*N* = 31 Rehabilitation Units	3 months	• Ethnography • Interviews before discharge, 1 and 3 months post-discharge • Thematic analysis	• New carers struggled with care at early stage while established carers more confident. • Community services delivery unreliable. • Coping strategies included establishing routines, focusing on the present, identifying positives.
12. Gustafsson & Bootle, 2013 *Australia*	To explore and contrast the transition to home experience of stroke survivors and their carers during discharge and first month at home.	*N* = 10 (5 dyads) An inpatient rehab unit	1 month	• Descriptive qualitative design • Semi-structured interviews • Thematic analysis	• Weekend & overnight leave and family meetings as positive strategies for the transition care. • Lack of information on a contact person after discharge. Carers needs more support due to changes. • Uncertainty about ongoing care after rehab program.
13. Gustafsson et al., 2014 *Australia*	To investigate experiences and expectations of stroke survivors in hospital-to-home transition and after participating in inpatient outreach program.	*N* = 7 An inpatient rehab unit	4–6 weeks	• Descriptive qualitative design • Interviews • Thematic analysis	• Therapy at home before discharge (outreach program)—very positive in preparation for discharge. • Inadequate communication on rationale for therapy. • Community support and services helped finding alternative way of living for some participants.
14. Lou et al., 2017 *Denmark*	To investigate how mild stroke patients' and their partners' experience and manage life in a context of ESD.	*N* = 40 (22 survivors, 18 partners) Stroke units	3–6 weeks after stroke onset	• Semi-structured interviews • Thematic analysis	• ESD services supported a safe transition—safe and highly accessible. • ESD did not focus on goals of returning home. • Patients with chronic illnesses adjusted better due to experience with healthcare system.
15. Lutz et al., 2017 *USA*	To develop a theoretical framework for improving stroke caregiver readiness that is grounded in the experiences of stroke family caregivers.	*N* = 40 Two inpatient rehabilitation facilities	1–6 months	• Grounded theory • Interviews • Dimensional analysis and constant comparative method	• Consider contextual factors in getting carers ready. • Risk assessment including survivors' functional status, carers' capacity and commitment. • Before discharge identify gaps and problem-solve. • Planning for self-care to enhance sustainability.
16. Olofsson et al., 2005 *Sweden*	To understand stroke patients' experiences and needs in their journey from falling ill to discharge and after discharge.	*N* = 9 (5 survivors, 4 carers) Stroke centre	Within 4 months of hospital admission	• Face-to-face interviews • Content analysis	• Inconsistent involvement in discharge planning and information provision. • Uncertainty on the function and organisation of care. • Wish for support from healthcare services.

Author and year	Aim/objective	Sample and setting	Time post-discharge	Methodology and methods	Summary of findings
17. Pereira et al., 2021 *Portugal*	To understand how stroke survivors and carers adapt over time, and how health professionals support transition to home.	*N* = 18 (8 survivors, 10 carers) (Health professionals' views were excluded from this review) Hospital and rehabilitation unit	1 & 6 months	• Prospective qualitative approach • Interviews	• Family-centred team approach to manage challenges in rehabilitation and adaptation process. • Interest from health professionals helped adaptation. • Differences in expectations and collaboration between survivors/family and health professionals.
18. Pringle et al., 2013 *UK*	To investigate the experiences of patients and their carers during the first month after discharge from hospital.	*N* = 24 (12 dyads) Stroke unit	1 month	• Interpretive phenomenology • In-depth interviews and self-reported diaries • Thematic analysis	• One month post-discharge a dynamic time. • Loss and grief over altered concept of identity. • Lack of information—needs unpredictable while in hospital. • Family and social support key to reconnect with life.
19. Rittman et al., 2004 *USA*	To describe dimensions of the experience of time during hospital-to-home transition.	*N* = 96 Inpatient ward	1 month	• Grounded theory • Semi-structured interviews and field observation • Constant comparative analysis	• Challenges during transition included change of role, disruption of daily routines. • Griefs on loss of old self and pre-morbid roles. • The transition is a multidimensional, not only adjusting to impairments.
20. Rittman et al., 2007 *USA*	To describe three domains of psychosocial experiences of stroke survivors during the first months following discharge for acute stroke.	*N* = 125 Inpatient ward	1 month	Semi-structured interviews and field observations	• Psychological experience is a process of adapting to changes in self and community participation. • Participants could benefit from interventions that prepare them to manage psychosocial changes. • Depression is related to low community participation.
21. Sadler et al., 2014 *UK*	To investigate younger stroke survivors' experiences in navigating stroke care, and in adjusting to life after stroke.	*N* = 31 A population-based stroke register and a tertiary rehabilitation unit	6 weeks and 28 months after stroke onset	• Semi-structured interviews • Thematic analysis	• Stroke has significant impact on finance. • Mismatch between patients' expectation and community service provider's focus and capacity. • Inadequate involvement in care before discharge. • Lack of vocational support to return to work.
22. Timothy et al., 2016 *New Zealand*	To explore embodiment and stroke through understanding of participants' bodily experience and how this related to their lived following discharge from hospital.	*N* = 7 Stroke rehabilitation ward	1 month	• Grounded theory • Semi-structured interviews	• Loss of freedom linked to loss of pre-morbid body performance. • Confusion resulted from mismatch of embodied experience and self-identity. • Positive attitude help anchor to a more personally acceptable embodied experience.
23. C. L. Williams et al., 2005 *USA*	To explore the emotional experience of veterans following hospitalisation for stroke.	*N* = 51 Medical centres	1 month	• Structured interview schedule, field notes and observation	• <u>Non-depressed participants:</u> Facing adversity with strength; Finding meaning in a setback; Staying present; Hope for the future. • <u>Depressed participants:</u> Taking in multiple losses; Battling a new reality; Preparing for the worst.

Author and year	Aim/objective	Sample and setting	Time post-discharge	Methodology and methods	Summary of findings
24. White et al., 2007 *Canada*	To explore the perceptions of stroke carers on barriers and facilitators to undertaking the caregiving role, particularly as related to healthcare system.	*N* = 14 Acute hospitals	50% < 6 months 50% > 1 year	• Interviews and focus group • Content analysis	• Barriers: limited involvement in discharge planning process; insufficient skills preparation; lack of community support; negative lifestyle changes. • Facilitators: coordinated care; integration of changes to daily life; mastery of caregiving skills; accessible community resources.
25. White et al., 2015 *Canada*	To describe the perspectives of older stroke survivors and caregivers related to a readmission after stroke.	*N* = 20 Acute hospitals	2 weeks	• Descriptive qualitative design • Interviews with medical records review	• Inconsistency in preparation before discharge. • Inadequate information provision e.g. medications. • Lack of post-discharge follow-up. • Inconsistency in community care planning. • Financial and social support constraints.
26. Wottrich et al., 2012 *Sweden*	To investigate stroke survivors' expectations after being discharged from rehabilitation ward and during the first 3 months at home.	*N* = 5 Two rehabilitation centres	3–4 months	• Semi-structured interview • Content analysis	• Home practice before discharge beneficial. • 2–4 weeks: Adjustment and waiting for recovery; physical and psychological deterioration. • 3–4 months: Acceptance with lower expectations to self and others; strong desire for independence.
27. Yeung et al., 2011 *Hong Kong*	To explore the phenomenon of concerns as experienced by Chinese stroke survivors during hospitalisation and in transition to home.	*N* = 15 Two stroke wards	1 week	• Phenomenological design • Semi-structured interviews • Thematic analysis	• Focus of holistic concerns different hospital vs. home. • Feeling of a burden to family. • Social disengagement due to post-stroke changes. • Needs physical as well as social, psychological and spiritual support. • Inadequate provision of information.
28. Yeung et al., 2015 *Canada*	To investigate experiences of Chinese stroke survivors and family caregivers as they return to community living.	*N* = 18 A rehabilitation centre	Average 6 months	• Interviews • Framework analysis (Time It Right framework)	• Information and training needs highest during rehabilitation and returning to community phase esp. social support and long-term plan. • Limited educational resources in Chinese language. • Inadequate pre-discharge education.
29. Young et al., 2014 *USA*	To understand the needs of spousal caregivers of stroke survivors during the transition from rehabilitation to home.	*N* = 14 Two inpatient rehabilitation facilities	3–6 months	• Grounded theory • Semi-structured interviews • Dimensional constant comparative analysis	• Carers unprepared with clear caregiving expectations. • Beneficial to conduct a caregiver assessment at early stage of rehabilitation. • A health professional to assist, advocate tailored to needs of caregivers may smooth transition. • Home-based family counselling service may help develop coping skills in transition.

Note. USA = United States of America; ESD = early supported discharge.

Appendix 12: Developing Descriptive Themes Example



Appendix 13: CERQual Evidence Profile

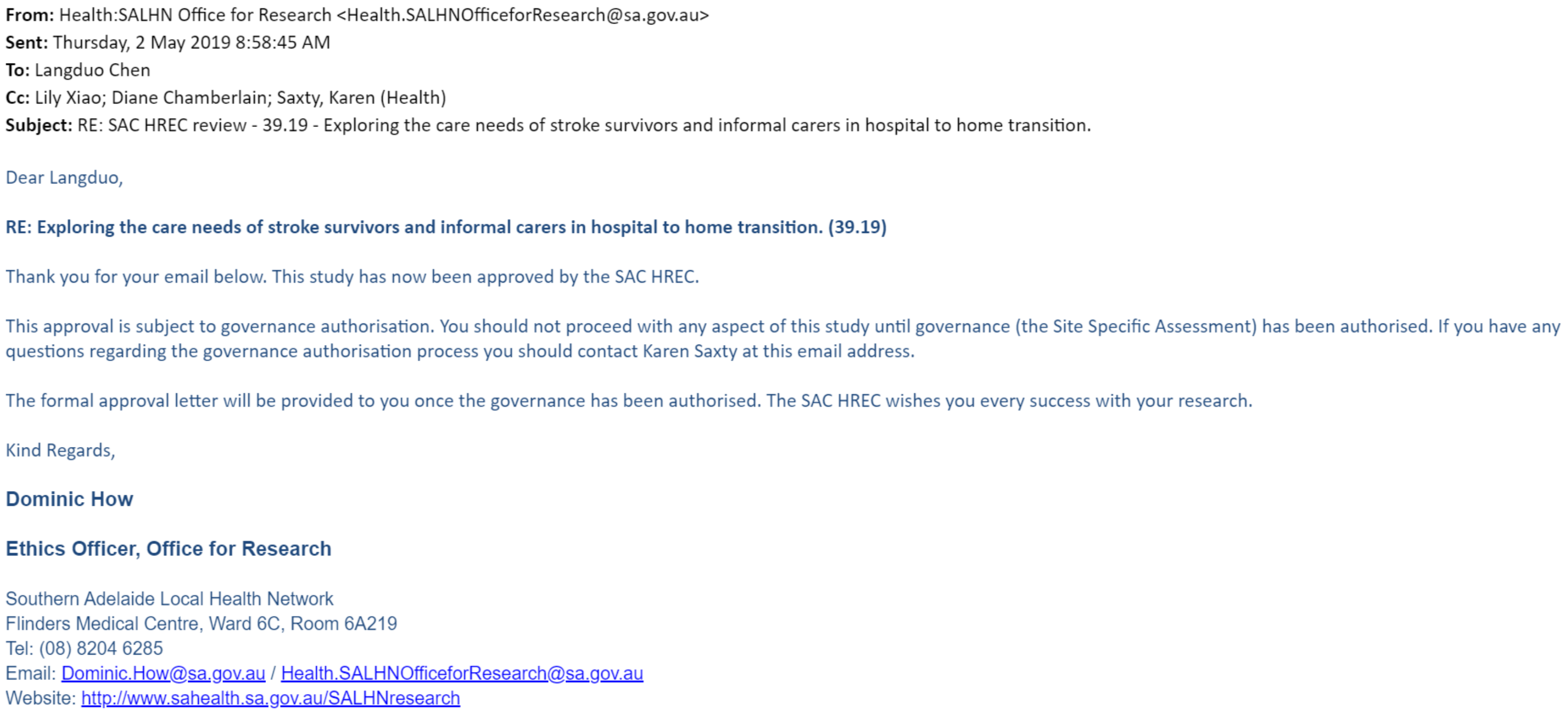
Summary of review findings	**Studies contributing to the review finding**	**Methodological limitations**	**Coherence**	**Adequacy**	**Relevance**	**CERQual assessment of confidence in the evidence**	**Explanation of CERQual assessment**
Factors enabling transitional care							
Partnership approach to individualised transitional care Stroke survivors and caregivers considered engaging in own care as an essential part of the discharge planning. They valued health professionals' compassionate care and family-oriented approach, which enhanced their experience during the transition. Being able to practice in home environment prior to discharge and caregivers' building of care skills empowered them with self-management capabilities.	2–4, 12–15, 17, 20, 21, 24, 25	No or very minor concerns (Ten studies with no or very minor concerns and two study with minor concern on unclear reflexivity (3,20))	No or very minor concerns	No or very minor concerns	No or very minor concerns (Nine studies with direct relevance; three studies with indirect relevance (2,13,25))	High confidence	Twelve studies with no or very minor concerns about methodological limitations, coherence, adequacy and relevance.
Being prepared to navigate health and social care services Stroke survivors and caregivers perceived that having a contact person after discharge that can offer help, continuity of rehabilitation and community support services generated sense of safety and facilitated post-discharge rehabilitation.	3, 4, 13, 15, 25	No or very minor concerns (Four studies with no or very minor concerns and one study with minor concern on unclear reflexivity (3))	No or very minor concerns	Moderate concerns (Only five studies contributed to this review finding with relatively thin data)	No or very minor concerns	Moderate confidence	Five studies with no or very minor concerns about methodological limitations, coherence and relevance, moderate concerns on adequacy.

Summary of review findings	Studies contributing to the review finding	Methodological limitations	Coherence	Adequacy	Relevance	CERQual assessment of confidence in the evidence	Explanation of CERQual assessment
Developing self-management capabilities Positive thoughts, positive self-appraisal of functional improvement and self-efficacy, and family and social support contributed to the development of self-management capabilities for stroke survivors and caregivers.	4, 11, 12, 14–17, 20–22, 26, 27, 29	No or very minor concerns (Ten studies with no or very minor concerns and three studies with minor concern on unclear reflexivity (16, 20, 21))	No or very minor concerns	No or very minor concerns	No or very minor concerns (Twelve studies with direct relevance, one study with indirect relevance (16))	High confidence	Thirteen studies with no or very minor concerns about methodological limitations, coherence, adequacy and relevance.
Barriers to effective transitional care							
Gaps in discharge planning Stroke survivors and caregivers identified gaps in the discharge planning process including discrepancies in goals of care between survivors and health professionals, emotional needs negligence, disengaging survivors and caregivers in discharge preparation. These gaps hindered a satisfactory transition.	1, 3, 4, 9, 16, 17, 21, 24, 25, 27	Minor concerns (Six studies have no or very minor concerns of methodological limitations. Four studies have minor concerns on reflexivity (1,9,16,21))	No or very minor concerns	No or very minor concerns	No or very minor concerns about relevance (Seven studies with direct relevance. Three studies with indirect relevance (3,16,27))	High confidence	Ten studies with no or minor concerns about coherence, adequacy and relevance. Five studies have no or very minor concerns of methodological limitations. Four studies have minor concerns on methodological limitations.

Summary of review findings	Studies contributing to the review finding	Methodological limitations	Coherence	Adequacy	Relevance	CERQual assessment of confidence in the evidence	Explanation of CERQual assessment
Factors affecting self-care at home Stroke survivors' self-care capability was inhibited by discontinuation of support in community, lack of post-discharge follow-up, and significant gaps between inpatient and community rehabilitation services. Caregivers found themselves in an unexpected challenging situation due to inadequate preparation before discharge. Financial constraints impacted on their ability to achieve rehabilitation goals.	1–3, 5, 8–10, 15, 19, 21, 24, 25, 28, 29	Minor concerns (Eight studies have no or very minor concerns of methodological limitations. Six studies have minor concerns on reflexivity (1,8–10, 19, 21))	No or very minor concerns	No or very minor concerns	No or very minor concerns about relevance (Ten studies with direct relevance. Four studies with indirect relevance (3,5,19,25))	High confidence	Fourteen studies have no or very minor concerns about coherence, adequacy and relevance. Eight studies have no or very minor concerns on methodological limitations. Six studies have minor concerns on methodological limitations.
Inability to cope with challenges Stroke survivors' inability to accept the post-stroke impairments prevented them from developing coping strategies, which resulted in social disengagement. Caregivers struggled to cope with increased responsibilities and providing care while managing own health conditions. Lack of social interaction and emotional support added burden to the already challenging caregiving situation.	1, 6, 7, 9, 10, 13, 14, 15,18, 20, 22–24, 26, 27, 29	Minor concerns (Nine studies have no or very minor concerns. Seven studies have minor concerns on reflexivity (1,6,9,10,16,20, 23))	No or very minor concerns	No or very minor concerns	No or very minor concerns	High confidence	Sixteen studies with no or very minor concerns on coherence, adequacy and relevance. Nine studies have no or very minor concerns on methodological limitations. Seven studies have minor concerns on

Summary of review findings	**Studies contributing to the review finding**	**Methodological limitations**	**Coherence**	**Adequacy**	**Relevance**	**CERQual assessment of confidence in the evidence**	**Explanation of CERQual assessment**
							methodological limitations.
Expectation of integrated transitional care Stroke survivors and caregivers desired a person-centred integrated transitional care encompassing compassionate and holistic care approach from health professionals and adequate information provision before discharge, especially about their condition and the healthcare system. They also expected a central point of contract after discharge to help and problem-solve. Timely post-discharge follow-up and community support services would benefit achievement of rehabilitation goals.	2–4, 9, 10, 15, 24, 25	No or very minor concerns (Six studies have no or very minor concerns. Two studies have minor concerns on reflexivity (9,10))	No or very minor concerns	No or very minor concerns	No or very minor concerns	High confidence	Six studies have no or very minor concerns on methodological limitations, coherence, relevance and adequacy. Two studies have minor concerns on methodological limitations.

Appendix 14: Authorisation Letter From the Southern Adelaide Local Health Network Ethics Committee



From: Health:SALHN Office for Research <Health.SALHNOfficeforResearch@sa.gov.au>
Sent: Thursday, 2 May 2019 8:58:45 AM
To: Langduo Chen
Cc: Lily Xiao; Diane Chamberlain; Saxty, Karen (Health)
Subject: RE: SAC HREC review - 39.19 - Exploring the care needs of stroke survivors and informal carers in hospital to home transition.

Dear Langduo,

RE: Exploring the care needs of stroke survivors and informal carers in hospital to home transition. (39.19)

Thank you for your email below. This study has now been approved by the SAC HREC.

This approval is subject to governance authorisation. You should not proceed with any aspect of this study until governance (the Site Specific Assessment) has been authorised. If you have any questions regarding the governance authorisation process you should contact Karen Saxty at this email address.

The formal approval letter will be provided to you once the governance has been authorised. The SAC HREC wishes you every success with your research.

Kind Regards,

Dominic How

Ethics Officer, Office for Research

Southern Adelaide Local Health Network
Flinders Medical Centre, Ward 6C, Room 6A219
Tel: (08) 8204 6285
Email: Dominic.How@sa.gov.au / Health.SALHNOfficeforResearch@sa.gov.au
Website: http://www.sahealth.sa.gov.au/SALHNresearch

To: Lily Xiao <lily.xiao@flinders.edu.au>; Prendergast, Justin (Health) <Justin.Prendergast@sa.gov.au>
Subject: 39.19 authorisation letter

Good morning

The SSA form for the application **39.19** has been authorised and the project may now commence.

Thank you

Dani Eley
Administration Officer
Executive Assistant | Paula Davies, Director Research Operations

Southern Adelaide Local Health Network
Flinders Medical Centre, Ward 6C, Room 6A219
Phone: 8204 6453 | Email: Danielle.eley@sa.gov.au / health.SALHNOfficeforResearch@sa.gov.au
Website: http://www.sahealth.sa.gov.au/SALHNresearch

Monday to Friday 800 – 1600

The Office for Research is keen to work with researchers and we have organised education initiatives each week at FMC (Level 6, Room 6A219). We run a drop in advisory clinic session Wednesday 9am – 11am but we are happy to discuss any concern you may have relating to new or ongoing research at any stage via ***Health.SALHNOfficeforResearch@sa.gov.au*** *or 8204 6453. We also can provide tailored team training sessions by appointment.*

Appendix 15: Participant Information and Consent Form

Participant Information Sheet/Consent Form

(Stroke survivors)

Title	Exploring the care needs of stroke survivors and informal carers in hospital to home transition
Short Title	Stroke hospital to home transition
Coordinating Principal Investigator/ Principal Investigator	Professor Lily Xiao
Associate Investigator(s)	Langduo Chen, A/Professor Diane Chamberlain
Location	Flinders Medical Centre

Part 1 What does my participation involve?

1. Introduction

You are invited to participate in a research project to investigate the care needs and the approaches to meeting the care needs of stroke survivors and their informal carers during the first 6 months after discharge from hospital to home. Stroke survivors in this study are defined as stroke patients who are 18 years and older and are discharged to home with ongoing rehabilitation and community support services after hospital stay. Participants in the study are required to use English in interviews and diary entry to share their experience. This Participant Information Sheet/Consent Form tells you about the study. It explains the activities involved. Knowing what is involved will help you decide if you want to participate in the research project.

Please read this information carefully. Ask questions about the project that you do not understand or want to know more about. Before deciding whether to take part, you might want to talk about it with a relative and friend.

Participation in this research is voluntary. If you do not wish to take part, you do not have to.

If you decide to take part in the research, you will be asked to sign the consent section.

By signing it you are telling us that you:

- Understand what you have read;
- Consent to take part in the research;
- Consent to the use of your personal and health information as described.

You will be given a copy of this Participant Information and Consent Form to keep.

2. What is the purpose of this research?

The aim of this research is to explore the care needs and the approaches to meeting the care needs for stroke survivors and their informal carers during hospital to home transition. The first 6 months after discharge from hospital is the most stressful period for stroke survivors and their informal carers. They usually face enormous challenges to adapt to their home care environments for continuing recovery after discharge. They also encounter great difficulties in identifying suitable rehabilitation and care services. Findings of this research will inform the improvement of transition care services for stroke survivors and their informal carers.

The results of this research will be used by the researcher Langduo Chen to obtain a *PhD in Nursing* degree.

3. What does participation in this research involve?

You are invited to participate in 2-3 times of a face to face, 30-45 minutes interview with the researcher at those time periods: prior to discharge, 3 months and 6 months after returning home from hospital. The interview will occur at a venue of your choice. Hospital to home transition is a continuum process and care needs of stroke survivors and carers change over time. Interviews at different time points help the researchers to identify these changes. Each interview will be audio recorded for data analysis. You are also required to take a structured diary at home and record key activities/challenges they face during the follow up period. The consent form will be signed before you participate in this research. The interview will be guided by the overarching question ‘what was it like to be discharged from hospital after stroke’. The interviews provide you with an opportunity to tell your experience, care needs and expectations of health and social care system during hospital to home transition. You have the rights to refuse or withdraw from the research at any stage. You also have the right to refuse to answer any questions.

The interview will be audio recorded and later transcribed word by word by the researcher. You will be given the opportunity to edit your response before data analysis if you wish to do so. All records containing personal information will remain confidential and no information which could lead to your identification will be released, except as required by law. Data will be stored at the university’s computer and protected by a password to ensure security. On the completion of the research, you will receive a written summary of research findings.

If you decide to take part in the research project, you will first be contacted by a researcher to make an appointment with you before discharge. The Researcher will conduct a cognitive function assessment for you to determine if you are eligible to take part. The assessment will take about 10 minutes to complete. Based on the assessment outcome, the researcher will discuss with you if you are eligible to take part in the project.

This research project has been designed to make sure the researchers interpret the results in a fair and appropriate way and avoids researchers or participants jumping to conclusions.

There are no costs associated with participating in this research project, nor will you be paid. However, you will be reimbursed for any reasonable travel and parking expenses associated with the research project visit. Participant who completes at least 2 times of interviews and diary entries will receive a $50 complementary Woolworth gift card.

4. Other relevant information about the research project

This research is part of a PhD study for the PhD candidate, Ms Langduo Chen at Flinders University, South Australia. The research project will be conducted at Flinders Medical Centre. Langduo will undertake interviews with stroke survivors and their informal carers.

5. Do I have to take part in this research project?

Participation in this research is voluntary. You do not have to if you do not wish to take part. If you decide to take part and later change your mind, you are free to withdraw from the research at any stage.

Your decision whether to take part or not to take part, or to take part and then withdraw, will not affect your routine care, your relationship with professional staff or your relationship with Flinders Medical Centre.

There are a few ways to express your interest.

- When approached for expression of intention, you can verbally inform the researcher your intention to participate. A Research Assistant will make an appointment with you for further discussion.
- You can fill in and return the response slip in a prepaid envelope and post to the researcher.
- You can text message or ring the researcher (Ms Langduo Chen, phone number: 08 8404 2062) to express your interest in participation.
- You can email the researcher to express your interest in participation (Ms Langduo Chen, email: langduo.chen@flinders.edu.au)

On receipt of your response, the researcher will contact you to confirm your participation. More detailed information related to the research will be explained to you by the Research Assistant if you would like to know. If you do decide to take part, you will be given this Participant Information and Consent Form to sign and you will be given a copy to keep.

6. What are the possible benefits of taking part?

We cannot guarantee or promise that you will receive any benefits from this research. You will be reimbursed for any reasonable travel and parking expenses associated with the research project visit. Participant who completes at least 2 times of interviews and diary data entries will receive a $50 complementary Woolworth gift card.

Your participation will be a valuable addition to our research and findings could lead to greater understanding of the care needs and expectations during hospital to home transition after stroke. The findings will assist health professionals and health/social care service providers to improve transition care services. The findings will also inform staff education and training associated with transition care for stroke survivors.

7. What are the possible risks and disadvantages of taking part?

There are no foreseen risks associated with the research. You may feel that some of the questions we ask are stressful or upsetting. If you do not wish to answer a question, you may skip it and go to the next question, or you may stop immediately. If you become upset or distressed as a result of your participation in the research project, upon your request and permission, the research team will be able to arrange for counselling or other appropriate support. Any counselling or support will be provided by qualified staff who are not members of the research team. This counselling will be provided free of charge.

8. What if I withdraw from this research project?

If you do consent to participate, you may withdraw at any time. If you decide to withdraw from the project, please notify Langduo Chen before you withdraw. Langduo will inform you if there are any special requirements linked to withdrawing. If you do withdraw, you will be asked to complete and sign a ‘Withdrawal of Consent’ form; this will be provided to you by the research team.

If you decide to leave the research project, the researchers will not collect additional personal information from you, although personal information already collected will be retained to ensure that the results of the research project can be measured properly and to comply with law. You should be aware that data collected up to the time you withdraw will form part of the research project results. If you do not want your data to be included, you must tell the researchers when you withdraw from the research project.

9. Could this research project be stopped unexpectedly?

This research project may be stopped unexpectedly for a variety of reasons. These may include reasons such as the PhD student researcher stops the PhD study. You will be advised if this occurs.

10. What happens when the research project ends?

After the research project is completed, a summary of the global findings will be sent to you by email or posting to you with your permission.

Part 2 How is the research project being conducted?

11. What will happen to information about me?

By signing the consent form you agree to the study team to accessing health records in this research project. By signing the consent form you also consent to the research team collecting and using personal information about you for the research project. Any information obtained in connection with this research project that can identify you will remain confidential and you will not be individually identifiable in the resulting report and thesis. Any information provided by you will be collected in a de-identifiable form. Therefore, the data will not be linked to the individual or organisation. Data collected through this research will be stored in a locked cabinet in the researcher's office and electronic data will be kept on Flinders University computer server, which is password protected. All study-related data will only be accessible to the researchers. All data will be retained for fifteen years, and then it will be destroyed. Your information will only be used for the purpose of this research project and it will only be disclosed with your permission, except as required by law. The personal information that the research team collects and uses is your age, gender, education level, diagnosis, functional impairment scores, admission and discharge date, community rehabilitation services you receive.

Information about your diagnosis, type of stroke and functional impairment may be obtained from your health records held at this hospital for the purpose of this research. By signing the consent form you agree to the research team accessing health records if they are relevant to your participation in this research project.

It is anticipated that the results of this research will be published and/or presented in a variety of forums. In any publication and/or presentation, information will be provided in such a way that you cannot be identified, except with your permission. All collected data will be de-identified. The transcripts of interviews and focus groups will be coded so participants' responses are de-identified. Data will be analysed collectively. Pseudonyms will be used in the PhD thesis and all relevant publications.

In accordance with relevant Australian privacy and other relevant laws, you have the right to request access to the information about you that is collected and stored by the research team. You also have the right to request that any information with which you disagree be corrected. Please inform the research team member named at the end of this document if you would like to access your information.

Any information obtained for the purpose of this research project that can identify you will be treated as confidential and securely stored. It will be disclosed only with your permission, or as required by law.

12. Complaints and compensation

There is no foreseen adverse event and outcomes associated with your participation in this project. If you suffer any distress or psychological injury as a result of this research project, you should contract the research team as soon as possible. You will be assisted with arranging appropriate treatment and support. The complaints contact is

Position	Asst. Director, Office for Research
Telephone	8204 6453
Email	Health.SALHNofficeforresearch@sa.gov.au

13. Who is organising and funding the research

As part of the PhD study, this research project is being conducted by the PhD candidature Langduo Chen and the PhD student supervisors.

14. Who has reviewed the research project?

All research in Australia involving humans is reviewed by an independent group of people called the Human Research Ethics Committee (HREC). The ethical aspects of this research have been approved by the Southern Adelaide Clinical Human Research Ethics Committee (SAC HREC).

This research will be carried out according to the National Statement on Ethical Conduct in Human Research (2007 updated 2018). This statement has been developed to protect the interests of people who agree to participate in human research studies.

15. Further information and who to contact

If you have any complaints about any aspect of the project, the way it is being conducted or any questions about being a research participant in general, then you may contact:

Reviewing HREC approving this research and HREC Executive Officer details

Reviewing HREC name	Southern Adelaide Clinical
Position	Executive Officer
Telephone	8204 6453
Email	Health.SALHNofficeforresearch@sa.gov.au

Local HREC Office contact (Single Site -Research Governance Officer)

Position	Research Governance Officer
Telephone	8204 6453
Email	Health.SALHNofficeforresearch@sa.gov.au

Thank you for taking the time to read this information sheet and we hope that you will accept our invitation to be involved.

For further information or questions, please contact:

Name:	Langduo Chen
Phone:	08 8404 2062
Email:	Langduo.chen@flinders.edu.au

Consent Form

Title	Exploring the care needs of stroke survivors and informal carers in hospital to home transition
Short Title	Stroke hospital to home transition
Coordinating Principal Investigator/ Principal Investigator	A/Professor Lily Xiao
Associate Investigator(s)	Langduo Chen, A/Professor Diane Chamberlain
Location	Flinders Medical Centre

Declaration by Participant

I (being over the age of 18 years) have read the Participant Information Sheet or someone has read it to me in a language that I understand.

I understand the purposes, procedures and risks of the research described in the project.

I have had an opportunity to ask questions and I am satisfied with the answers I have received.

I freely agree to participate in this research project as described and understand that I am free to withdraw at any time during the project without affecting my future care.

I freely agree to audio recording of my information and participation.

I give permission for health professionals and hospitals to release information to the principle investigator and associate investigators concerning my disease for the purposes of this research. I understand that such information will remain confidential.

I understand that I will be given a signed copy of this document to keep.

I am aware that I should retain a copy of the Information Sheet and Consent Form for future reference.

I have had an opportunity to ask questions and I am satisfied with the answers I have received.

I understand that:

- I may not directly benefit from taking part in this research.
- I am free to withdraw from the research at any time and am free to decline to answer particular questions.

- While the information gained in this study will be published as explained, I will not be identified, and individual information will remain confidential.
- Whether I participate or not, or withdraw after participating, it will have no effect on any treatment or service that is being provided to me.
- I may ask that the recording/observation be stopped at any time, and that I may withdraw at any time from the session or the research without disadvantage.

Name of Participant (please print)____

Signature ______________________ Date ______________________

Name of Participant's Carer (please print)_____________________________________

Signature ______________________ Date ______________________

Declaration by Researcher†

I have given a verbal explanation of the research, its procedures and risks and I believe that the participant has understood that explanation.

Name of Researcher (please print)____

Signature ______________________ Date ______________________

† An appropriately qualified member of the research team must provide the explanation of, and information concerning, the research project.

Note: All parties signing the consent section must date their own signature.

Response Slip

I………………………. (name) would like to participate in the research.

Please contact me on…………………….……………………. (phone No.)

or Email…………………………………………………

Alternatively, you can text message or ring the researcher (Ms Langduo Chen, phone number: 08 8404 2062) or email the researcher to express your interest in participating (Ms Langduo Chen, email: langduo.chen@flinders.edu.au).

Form for Withdrawal of Participation

Title	Exploring the care needs of stroke survivors and informal carers in hospital to home transition
Short Title	Stroke hospital to home transition
Coordinating Principal Investigator/ Principal Investigator	A/Professor Lily Xiao
Associate Investigator(s)	Langduo Chen, A/Professor Diane Chamberlain
Location	Flinders Medical Centre

Declaration by Participant

I wish to withdraw from participation in the above research project and understand that such withdrawal will not affect my routine care, or my relationships with the researchers or Flinders Medical Centre.

Name of Participant (please print)____

Signature ______________________ Date ______________________

In the event that the participant's decision to withdraw is communicated verbally, the Senior Researcher must provide a description of the circumstances below.

Declaration by Researcher†

I have given a verbal explanation of the research, its procedures and risks and I believe that the participant has understood that explanation.

Name of Researcher (please print)____

Signature ______________________ Date ______________________

† An appropriately qualified member of the research team must provide the explanation of, and information concerning, the research project.

Note: All parties signing the consent section must date their own signature.

Participant Information Sheet/Consent Form

(Stroke carers)

Title	Exploring the care needs of stroke survivors and informal carers in hospital to home transition
Short Title	Stroke hospital to home transition
Coordinating Principal Investigator/ Principal Investigator	Professor Lily Xiao
Associate Investigator(s)	Langduo Chen, A/Professor Diane Chamberlain
Location	Flinders Medical Centre

Part 1 What does my participation involve?

1. Introduction

You are invited to participate in a research project to investigate the care needs and the approaches to meeting the care needs of stroke survivors and their informal carers during the first 6 months after discharge from hospital to home. Informal carers of stroke survivors are persons who are 18 years and older, principal carers who have daily contact with stroke survivors. Participants in the study are required to use English in interviews and diary entry to share their experience. This Participant Information Sheet/Consent Form tells you about the study. It explains the activities involved. Knowing what is involved will help you decide if you want to participate in the research project.

Please read this information carefully. Ask questions about the project that you do not understand or want to know more about. Before deciding whether to take part, you might want to talk about it with a relative and friend.

Participation in this research is voluntary. If you do not wish to take part, you do not have to.

If you decide to take part in the research, you will be asked to sign the consent section.

By signing it you are telling us that you:

- Understand what you have read;
- Consent to take part in the research;
- Consent to the use of your personal and health information as described.

You will be given a copy of this Participant Information and Consent Form to keep.

2. What is the purpose of this research?

The aim of this research is to explore the care needs and the approaches to meeting the care need for stroke survivors and their informal carers during hospital to home transition. The first 6 months after discharge from hospital is the most stressful period for stroke survivors and their informal carers. They usually face enormous challenges to adapt to their home care environments for continuing recovery after discharge. They also encounter great difficulties in identifying suitable rehabilitation and care services. Findings of this research will inform the improvement of transition care services for stroke survivors and their informal carers.

The results of this research will be used by the researcher Langduo Chen to obtain a *PhD in Nursing* degree.

3. What does participation in this research involve?

You are invited to participate in 2-3 times of a face to face, 30-45 minutes interview with the researcher at those time periods: prior to discharge, 3 months, 6 months after returning home from hospital. The interview will occur at a venue of your choice. Hospital to home transition is a continuum process and care needs of stroke survivors and carers change over time. Interviews at different time points help the researchers to identify these changes. Each interview will be audio recorded for data analysis. The participant is also required to take a structured diary at home and record key activities/challenges they face during the follow up period. The consent form will be signed before you participate in this research. The interview will be guided by the overarching question 'what was it like to be discharged from hospital after stroke'. The interviews provide you with an opportunity to tell your experience, care needs and expectations of health and social care system during hospital to home transition. You have the rights to refuse or withdraw from the research at any stage. You also have the right to refuse to answer any questions.

The interview will be audio recorded and later transcribed word by word by the researcher. You will be given the opportunity to edit your response before data analysis if you wish to do so. All records containing personal information will remain confidential and no information which could lead to your identification will be released, except as required by law. Data will be stored at the university's computer and protected by a password to ensure security. On the completion of the research, you will receive a written summary of research findings.

If you decide to take part in the research project, you will firstly be contacted by a researcher to make an appointment with you before the discharge of your relative. The research will ask about your age, relevant information about relation with your relative, discharge date and community rehabilitation services that your relative will receive after discharge. Answering these questions will take approximately 5-10 minutes. Based on the assessment outcome, the researcher will discuss with you if you are eligible to take part in the project.

This research project has been designed to make sure the researchers interpret the results in a fair and appropriate way and avoids study researchers or participants jumping to conclusions.

There are no costs associated with participating in this research project, nor will you be paid. However, you will be reimbursed for any reasonable travel and parking associated with the research project visit. Participant who completes at least 2 times of interviews and diary entry will receive a $50 complementary Woolworth gift card.

4. Other relevant information about the research project

This research is part of a PhD study for the PhD student, Ms. Langduo Chen at Flinders University, South Australia. The research project will be conducted at Flinders Medical Centre. Langduo will undertake interviews with stroke survivors and their informal carers.

5. Do I have to take part in this research project?

Participation in this research is voluntary. You do not have to if you do not wish to take part. If you decide to take part and later change your mind, you are free to withdraw from the research at any stage.

Your decision whether to take part or not to take part, or to take part and then withdraw, will not affect your routine care, your relationship with professional staff or your relationship with Flinders Medical Centre.

There are a few ways to express your interest.

- When approached for expression of intention, you can verbally inform the researcher your intention to participate. A Research Assistant will make an appointment with you for further discussion.
- You can fill in and return the response slip in a prepaid envelope and post to the researcher.
- You can text message or ring the researcher (Ms Langduo Chen, phone number: 08 8404 2062) to express your interest in participation.
- You can email the researcher to express your interest in participation (Ms Langduo Chen, email: langduo.chen@flinders.edu.au)

On receipt of your response, the researcher will contact you to confirm your participation. More detailed information related to the research will be explained to you by the researcher if you would like to know. If you do decide to take part, you will be given this Participant Information and Consent Form to sign and you will be given a copy to keep.

6. What are the possible benefits of taking part?

We cannot guarantee or promise that you will receive any benefits from this research. You will be reimbursed for any reasonable travel and parking associated with the research project visit. Participant who completes at least 2 times of interviews and diary entry will receive a $50 complementary Woolworth gift card.

Your participation will be a valuable addition to our research and findings could lead to greater understanding of the care needs and expectations during hospital to home transition after stroke. The findings will assist health professionals and health/social care service providers to improve transition care services. The findings will also inform staff education and training associated with transition care for stroke survivors.

7. What are the possible risks and disadvantages of taking part?

There are no foreseen risks associated with the research. You may feel that some of the questions we ask are stressful or upsetting. If you do not wish to answer a question, you may skip it and go to the next question, or you may stop immediately. If you become upset or distressed as a result of your participation in the research project, upon your request and permission, the research team will be able to arrange for counselling or other appropriate support. Any counselling or support will be provided by qualified staff who are not members of the research team. This counselling will be provided free of charge.

8. What if I withdraw from this research project?

If you do consent to participate, you may withdraw at any time. If you decide to withdraw from the project, please notify Langduo Chen before you withdraw. Langduo will inform you if there are any special requirements linked to withdrawing. If you do withdraw, you will be asked to complete and sign a ‘Withdrawal of Consent’ form; this will be provided to you by the research team.

If you decide to leave the research project, the researchers will not collect additional personal information from you, although personal information already collected will be retained to ensure that the results of the research project can be measured properly and to comply with law. You should be aware that data collected up to the time you withdraw will form part of the research project results. If you do not want your data to be included, you must tell the researchers when you withdraw from the research project.

9. Could this research project be stopped unexpectedly?

This research project may be stopped unexpectedly for a variety of reasons. These may include reasons such as the PhD student researcher stops the PhD study. You will be advised if this occurs.

10. What happens when the research project ends?

After the research project is completed, a summary of the global findings will be sent to you by email or posting to you with your permission.

Part 2 How is the research project being conducted?

11. What will happen to information about me?

By signing the consent form you consent to the research team collecting and using personal information about you for the research project. Any information obtained in connection with this research project that can identify you will remain confidential and you will not be individually identifiable in the resulting report and thesis. Any information provided by you will be collected in a de-identifiable form. Therefore, the data will not be linked to the individual or organisation. Data collected through this research will be stored in a locked cabinet in the researcher's office and electronic data will be kept on Flinders University computer server, which is password protected. All study-related data will only be accessible to the researchers. All data will be retained for fifteen years, and then it will be destroyed. Your information will only be used for the purpose of this research project and it will only be disclosed with your permission, except as required by law. The personal information that the research team collects and uses is your age, gender, education level, diagnosis, functional impairment, discharge date, community rehabilitation services you receive.

Information about your diagnosis, type of stroke and functional impairment may be obtained from your health records held at this hospital for the purpose of this research. By signing the consent form you agree to the research team accessing health records if they are relevant to your participation in this research project.

It is anticipated that the results of this research will be published and/or presented in a variety of forums. In any publication and/or presentation, information will be provided in such a way that you cannot be identified, except with your permission. All collected data will be de-identified. The transcripts of interviews and focus groups will be coded so participants' responses are de-identified. Data will be analysed collectively. Pseudonyms will be used in the PhD thesis and all relevant publications.

In accordance with relevant Australian privacy and other relevant laws, you have the right to request access to the information about you that is collected and stored by the research team. You also have the right to request that any information with which you disagree be corrected. Please inform the research team member named at the end of this document if you would like to access your information.

Any information obtained for the purpose of this research project that can identify you will be treated as confidential and securely stored. It will be disclosed only with your permission, or as required by law.

12. Complaints and compensation

There is no foreseen adverse event and outcomes associated with your participation in this project. If you suffer any distress or psychological injury as a result of this research project, you should contract the research team as soon as possible. You will be assisted with arranging appropriate treatment and support. The complaints contact is

Position	Asst. Director, Office for Research
Telephone	8204 6453
Email	Health.SALHNOfficeforResearch@sa.gov.au.

13. Who is organising and funding the research

As part of the PhD study, this research project is being conducted by Langduo Chen and the PhD student supervisors.

14. Who has reviewed the research project?

All research in Australia involving humans is reviewed by an independent group of people called the Human Research Ethics Committee (HREC). The ethical aspects of this research have been approved by the Southern Adelaide Clinical Human Research Ethics Committee (SAC HREC).

This research will be carried out according to the National Statement on Ethical Conduct in Human Research (2007 updated 2018). This statement has been developed to protect the interests of people who agree to participate in human research studies.

15. Further information and who to contact

If you have any complaints about any aspect of the project, the way it is being conducted or any questions about being a research participant in general, then you may contact:

Reviewing HREC approving this research and HREC Executive Officer details

Reviewing HREC name	Southern Adelaide Clinical
Position	Executive Officer
Telephone	8204 6453

Email	Health.SALHNofficeforresearch@sa.gov.au

Local HREC Office contact (Single Site -Research Governance Officer)

Position	Research Governance Officer
Telephone	8204 6453
Email	Health.SALHNofficeforresearch@sa.gov.au

Thank you for taking the time to read this information sheet and we hope that you will accept our invitation to be involved.

For further information or questions, please contact:

Name:	Langduo Chen
Phone:	08 8404 2062
Email:	Langduo.chen@flinders.edu.au

Consent Form

Title	Exploring the care needs of stroke survivors and informal carers in hospital to home transition
Short Title	Stroke hospital to home transition
Coordinating Principal Investigator/ Principal Investigator	A/Professor Lily Xiao
Associate Investigator(s)	Langduo Chen, A/Professor Diane Chamberlain
Location	Flinders Medical Centre

Declaration by Participant

I (being over the age of 18 years) have read the Participant Information Sheet or someone has read it to me in a language that I understand.

I understand the purposes, procedures and risks of the research described in the project.

I have had an opportunity to ask questions and I am satisfied with the answers I have received.

I freely agree to participate in this research project as described and understand that I am free to withdraw at any time during the project without affecting my future care.

I freely agree to audio recording of my information and participation.

I give permission for health professionals and hospitals to release information to the principle investigator and associate investigators concerning my disease for the purposes of this research. I understand that such information will remain confidential.

I understand that I will be given a signed copy of this document to keep.

I am aware that I should retain a copy of the Information Sheet and Consent Form for future reference.

I have had an opportunity to ask questions and I am satisfied with the answers I have received.

I understand that:

- I may not directly benefit from taking part in this research.
- I am free to withdraw from the research at any time and am free to decline to answer particular questions.

- While the information gained in this study will be published as explained, I will not be identified, and individual information will remain confidential.
- Whether I participate or not, or withdraw after participating, it will have no effect on any treatment or service that is being provided to me.
- I may ask that the recording/observation be stopped at any time, and that I may withdraw at any time from the session or the research without disadvantage.

Name of Participant (please print)____

Signature ______________________ Date ______________________

Declaration by Researcher†

I have given a verbal explanation of the research, its procedures and risks and I believe that the participant has understood that explanation.

Name of Researcher (please print)____

Signature ______________________ Date ______________________

† An appropriately qualified member of the research team must provide the explanation of, and information concerning, the research project.

Note: All parties signing the consent section must date their own signature.

Response Slip

I………………………. (name) would like to participate in the research.

Please contact me on……………….……………………………. (phone No.)

or Email…………………………………………………

Alternatively, you can text message or ring the researcher (Ms Langduo Chen, phone number: 08 8404 2062) or email the researcher to express your interest in participating (Ms Langduo Chen, email: langduo.chen@flin**ders.edu.au).**

Form for Withdrawal of Participation

Title	Exploring the care needs of stroke survivors and informal carers in hospital to home transition
Short Title	Stroke hospital to home transition
Coordinating Principal Investigator/ Principal Investigator	A/Professor Lily Xiao
Associate Investigator(s)	Langduo Chen, A/Professor Diane Chamberlain
Location	Flinders Medical Centre

Declaration by Participant

I wish to withdraw from participation in the above research project and understand that such withdrawal will not affect my routine care, or my relationships with the researchers or Flinders Medical Centre.

Name of Participant (please print)____

Signature ______________________ Date ______________________

In the event that the participant’s decision to withdraw is communicated verbally, the Senior Researcher must provide a description of the circumstances below.

Declaration by Researcher†

I have given a verbal explanation of the research, its procedures and risks and I believe that the participant has understood that explanation.

Name of Researcher (please print)____

Signature ______________________ Date ______________________

† An appropriately qualified member of the research team must provide the explanation of, and information concerning, the research project.

Note: All parties signing the consent section must date their own signature.

Participant Information Sheet/Consent Form

(Health professionals)

Title	Exploring the care needs of stroke survivors and informal carers in hospital to home transition
Short Title	Hospital to home transition for stroke survivors
Coordinating Principal Investigator/ Principal Investigator	Professor Lily Xiao
Associate Investigator(s) *(if required by institution)*	Langduo Chen, A/Professor Diane Chamberlain
Location	Flinders Medical Centre

Part 1 What does my participation involve?

1. Introduction

You are invited to participate in a research project to investigate the care needs and the approaches to meeting the care need of stroke survivors and their informal carers during the first 6 months after discharge from hospital to home. Health professionals in this study are defined as staff members of stroke/rehabilitation care team (not students) and General Practitioners (GPs) who are older than 18 years and are involved in the care of stroke patients. This Participant Information Sheet/Consent Form tells you about the study. It explains the activities involved. Knowing what is involved will help you decide if you want to participate in the research project.

Please read this information carefully. Ask questions about the project that you do not understand or want to know more about. Before deciding whether to take part, you might want to talk about it with a relative, friend or your colleague.

Participation in this research is voluntary. If you do not wish to take part, you do not have to.

If you decide to take part in the research, you will be asked to sign the consent section.

By signing it you are telling us that you:

- Understand what you have read;
- Consent to take part in the research;
- Consent to the use of your personal information as described.

You will be given a copy of this Participant Information and Consent Form to keep.

2. What is the purpose of this research?

The aim of this research is to explore the care needs and the approaches to meeting the care need for stroke survivors and their informal carers during hospital to home transition. The first 6 months after discharge from hospital is the most stressful period for stroke survivors and their informal carers. They usually face enormous challenges to adapt to their home care environments for continuing recovery after discharge. They also encounter great difficulties in identifying suitable rehabilitation and care services. Increased knowledge on their care needs will inform changes to transition care for these populations.

Findings of this research will inform the development of a transition care model and pathway to provide better patient centred care for stroke survivors and their informal carers.

The results of this research will be used by the researcher Langduo Chen to obtain a *PhD in Nursing* degree.

3. What does participation in this research involve?

You are invited to participate in one of the 3-5 focus groups lasting about 60-90 minutes. If you are unable to attend focus groups, you will be invited to a one on one, face to face interview lasting about 45 to 60 minutes. General practitioners will participate in a face to face, 45-60 minutes interview with the researcher. The focus groups/interview will occur in a meeting room at participants' workplace. Each focus group/interview will be audio recorded for data analysis. You will be asked to sign a consent form before you participate in this research. The focus group/interview will be guided by the overarching question 'what are the approaches to identifying and meeting transition care needs of the stroke survivors and their informal carers'. The focus group/interview provides you with an opportunity to share your thoughts, ideas and experience in the care of stroke survivors and their carers during hospital to home transition. You have the rights to refuse or withdraw from the research at any stage. You also have the right to refuse to answer any questions.

The interview will be audio recorded and later transcribed word by word by the researcher. You will be given the opportunity to read your response before data analysis if you wish to do so. All records containing personal information will remain confidential and no information which could lead to your identification will be released, except as required by law. Data will be stored at the university's computer and protected by a password to ensure security. On the completion of the research, you will receive a written summary of research findings.

If you decide to take part in the research project, you will first be contacted by the researcher, Langduo Chen, asking about your age, occupation and experience in stroke care. This will determine if you are eligible to take part. Answering these questions will take approximately 5-10 minutes. If the screening questions shows that you meet the requirements, then you will be able to participate in the research project.

This research project has been designed to make sure the researchers interpret the results in a fair and appropriate way and avoids study researchers or participants jumping to conclusions.

There are no costs associated with participating in this research project, nor will you be paid. However, you will be reimbursed for any reasonable travel and parking associated with the research project visit.

4. Other relevant information about the research project

This research is part of a PhD study for the PhD candidate, Langduo Chen at Flinders University, Australia. The research project will be conducted at Flinders Medical Centre. Langduo will undertake interviews with stroke survivors and their informal carers as well as the General Practitioners. She will also facilitate focus groups for stroke health professionals.

5. Do I have to take part in this research project?

Participation in this research is voluntary. You do not have to if you do not wish to take part. If you decide to take part and later change your mind, you are free to withdraw from the research at any stage.

Your decision whether to take part or not to take part, or to take part and then withdraw, will not affect your employment status.

There are a few ways to express your interest.

- You can fill in and return the response slip in a prepaid envelope and post to the researcher.
- You can text message or ring the researcher (Ms Langduo Chen, phone number: 08 8404 2062) to express your interest in participation.
- You can email the researcher to express your interest in participation (Ms Langduo Chen, email: langduo.chen@flinders.edu.au)

On receipt of your response, the researcher will contact you to confirm your participation. More detailed information related to the research will be explained to you by the researcher if you would like to know. If you do decide to take part, you will be given this Participant Information and Consent Form to sign and you will be given a copy to keep.

6. What are the possible benefits of taking part?

We cannot guarantee or promise that you will receive any benefits from this research. However, your participation will be a valuable addition to our research and findings could lead to greater understanding of the care needs and how to meet the care needs during hospital to home transition after stroke. The evidence will assist the development of a transition care model and pathway that will be beneficial for stroke survivors and their carers. The result will also inform staff development and training in stroke care.

7. What are the possible risks and disadvantages of taking part?

There are no foreseen risks associated with the research. You may feel that some of the questions we ask are stressful or upsetting. If you do not wish to answer a question, you may skip it and go to the next question, or you may stop immediately. Whilst all care will be taken to maintain privacy and confidentiality, you may experience uncomfortable if one of the group members were to repeat things said in a confidential group meeting. If you become upset or distressed as a result of your participation in the research project, the research team will be able to arrange for counselling or other appropriate support. Any counselling or support will be provided by qualified staff who are not members of the research team. This counselling will be provided free of charge.

8. What if I withdraw from this research project?

If you do consent to participate, you may withdraw at any time. If you decide to withdraw from the project, please notify Langduo Chen before you withdraw. Langduo will inform you if there are any special requirements linked to withdrawing.

If you decide to leave the research project, the researchers will not collect additional personal information from you, although personal information already collected will be retained to ensure that the results of the research project can be measured properly and to comply with law. You should be aware that data collected up to the time you withdraw will form part of the research project results. If you do not want your data to be included, you must tell the researchers when you withdraw from the research project.

9. Could this research project be stopped unexpectedly?

This research project may be stopped unexpectedly for a variety of reasons. These may include reasons such as the PhD student researcher stops the PhD study. You will be advised if this occurs.

10. What happens when the research project ends?

After the research project is completed, a summary of the global findings will be sent to you by email or posting to you with your permission.

Part 2 How is the research project being conducted?

11. What will happen to information about me?

By signing the consent form you consent to the research team collecting and using personal information about you for the research project. Any information obtained in connection with this research project that can identify you will remain confidential and you will not be individually identifiable in the resulting report and thesis. Any information provided by you will be collected in a de-identifiable form. Therefore, the data will not be linked to the individual or organisation. Data collected through this research will be stored in a locked cabinet in the researcher's office and electronic data will be kept on Flinders University computer server, which is password protected. All study-related data will only be accessible to the researchers. All data will be retained for fifteen years, and then it will be destroyed. Your information will only be used for the purpose of this research project and it will only be disclosed with your permission, except as required by law. The personal information that the research team collects and uses is your age, gender, education level, occupation, length of time in the position.

It is anticipated that the results of this research will be published and/or presented in a variety of forums. In any publication and/or presentation, information will be provided in such a way that you cannot be identified, except with your permission. All collected data will be de-identified. The transcripts of interviews and focus groups will be coded so participants' responses are de-identified. Data will be analysed collectively. Pseudonyms will be used in the PhD thesis and all relevant publications.

In accordance with relevant Australian privacy and other relevant laws, you have the right to request access to the information about you that is collected and stored by the research team. You also have the right to request that any information with which you disagree be corrected. Please inform the research team member named at the end of this document if you would like to access your information.

Any information obtained for the purpose of this research project that can identify you will be treated as confidential and securely stored. It will be disclosed only with your permission, or as required by law.

12. Complaints and compensation

There is no foreseen adverse event and outcomes associated with your participation in this project. If you suffer any distress or psychological injury as a result of this research project, you should contract the research team as soon as possible. You will be assisted with arranging appropriate treatment and support. The complaints contact is

Position	Asst. Director, Office for Research
Telephone	8204 6453
Email	Health.SALHNofficeforresearch@sa.gov.au

13. Who is organising and funding the research

As part of the PhD study, this research project is being conducted by Langduo Chen and the PhD student supervisors.

14. Who has reviewed the research project?

All research in Australia involving humans is reviewed by an independent group of people called the Human Research Ethics Committee (HREC). The ethical aspects of this research have been approved by the Southern Adelaide Clinical Human Research Ethics Committee (SAC HREC).

This research will be carried out according to the National Statement on Ethical Conduct in Human Research (2007 updated 2018). This statement has been developed to protect the interests of people who agree to participate in human research studies.

15. Further information and who to contact

If you have any complaints about any aspect of the project, the way it is being conducted or any questions about being a research participant in general, then you may contact:

Reviewing HREC approving this research and HREC Executive Officer details

Reviewing HREC name	Southern Adelaide Clinical
Position	Executive Officer
Telephone	8204 6453
Email	Health.SALHNofficeforresearch@sa.gov.au

Local HREC Office contact (Single Site -Research Governance Officer)

Position	Research Governance Officer
Telephone	8204 6453
Email	Health.SALHNofficeforresearch@sa.gov.au

Thank you for taking the time to read this information sheet and we hope that you will accept our invitation to be involved.

For further information or questions, please contact:

Name:	Langduo Chen
Phone:	08 8404 2062
Email:	Langduo.chen@flinders.edu.au

Consent Form

Title	Exploring the care needs of stroke survivors and informal carers in hospital to home transition
Short Title	Stroke hospital to home transition
Coordinating Principal Investigator/ Principal Investigator	A/Professor Lily Xiao
Associate Investigator(s)	Langduo Chen, A/Professor Diane Chamberlain
Location	Flinders Medical Centre

Declaration by Participant

I (being over the age of 18 years) have read the Participant Information Sheet or someone has read it to me in a language that I understand.

I understand the purposes, procedures and risks of the research described in the project.

I have had an opportunity to ask questions and I am satisfied with the answers I have received.

I freely agree to participate in this research project as described and understand that I am free to withdraw at any time during the project without affecting my work.

I freely agree to audio recording of my information and participation.

I understand that I will be given a signed copy of this document to keep.

I am aware that I should retain a copy of the Information Sheet and Consent Form for future reference.

I have had an opportunity to ask questions and I am satisfied with the answers I have received.

I understand that:

- I may not directly benefit from taking part in this research.
- I am free to withdraw from the research at any time and am free to decline to answer particular questions.
- While the information gained in this study will be published as explained, I will not be identified, and individual information will remain confidential.
- Whether I participate or not, or withdraw after participating, it will have no effect on my work.

- I may ask that the recording/observation be stopped at any time, and that I may withdraw at any time from the session or the research without disadvantage.

Name of Participant (please print)____

Signature ______________________ Date ______________________

Declaration by Researcher†

I have given a verbal explanation of the research, its procedures and risks and I believe that the participant has understood that explanation.

Name of Researcher (please print)____

Signature ______________________ Date ______________________

† An appropriately qualified member of the research team must provide the explanation of, and information concerning, the research project.

Note: All parties signing the consent section must date their own signature.

Response Slip

I………………………. (name) would like to participate in the research.

Please contact me on………………..……………………………. (phone No.)

or Email…………………………………………………

Alternatively, you can text message or ring the researcher (Ms Langduo Chen, phone number: 08 8404 2062) or email the researcher to express your interest in participating (Ms Langduo Chen, email: langduo.chen@flinders.edu.au).

Form for Withdrawal of Participation

Title	Exploring the care needs of stroke survivors and informal carers in hospital to home transition
Short Title	Stroke hospital to home transition
Coordinating Principal Investigator/ Principal Investigator	A/Professor Lily Xiao
Associate Investigator(s)	Langduo Chen, A/Professor Diane Chamberlain
Location	Flinders Medical Centre

Declaration by Participant

I wish to withdraw from participation in the above research project and understand that such withdrawal will not affect my routine care, or my relationships with the researchers or Flinders Medical Centre.

Name of Participant (please print)____

Signature ______________________ Date ______________________

In the event that the participant's decision to withdraw is communicated verbally, the Senior Researcher must provide a description of the circumstances below.

Declaration by Researcher[†]

I have given a verbal explanation of the research, its procedures and risks and I believe that the participant has understood that explanation.

Name of Researcher (please print)____

Signature ______________________ Date ______________________

† An appropriately qualified member of the research team must provide the explanation of, and information concerning, the research project.

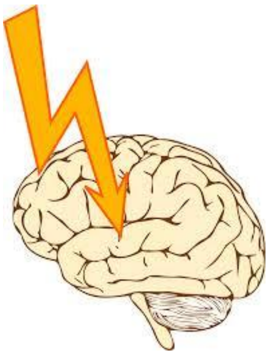
Note: All parties signing the consent section must date their own signature.

Appendix 16: Recruitment Poster

Recruitment poster for stroke survivor and carer participants

Participants wanted for study on Stroke

We are undertaking a study to explore care needs of persons with stroke and their family carers during hospital to home transition in South Australia.



You and your family carer are invited to the study if you/your relative:

- Are aged ≥18 years
- Have diagnosed with stroke
- Discharge home

Activities involved in participation:

- Prior to consent, potential stroke survivor participant will need to undergo a 10- minute cognitive assessment. A decision on inclusion or exclusion of participation will be based on the assessment outcome.
- Take part in 2-3 times of a 30-45 minutes interview within 6 months of discharge
- Use a diary designed by the researchers to record your experiences during the 6-month transition care period.

If you are interested in participating, please fill in and return the response slip to a survey drop box in your ward/clinics. The researcher will contact you shortly to explain more details of the study and sign a consent form with you.

The project has been approved by the *Southern Adelaide Clinical Human Research Ethics Committee (SAC HREC).*

RESPONSE SLIP

Name______

Contact Number

____

Name______

Contact Number

____

Name_____

Contact Number

____

Name______

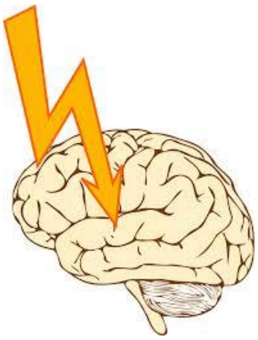
Contact Number

____

Recruitment poster for health professional participants

Participants wanted for study on Stroke

We are undertaking a research study to explore care needs of persons with stroke and their unpaid carers during hospital to home transition in South Australia.



You are invited to the study if you:

- Have worked with people with stroke and their informal carers

Activities involved in participation:

- 60 to 90 minutes focus group ONCE only

If you are interested in participating, please fill in and return the response slip to a survey drop box in your work place. The researcher will contact you shortly to explain more details of the study and sign a consent form with you.

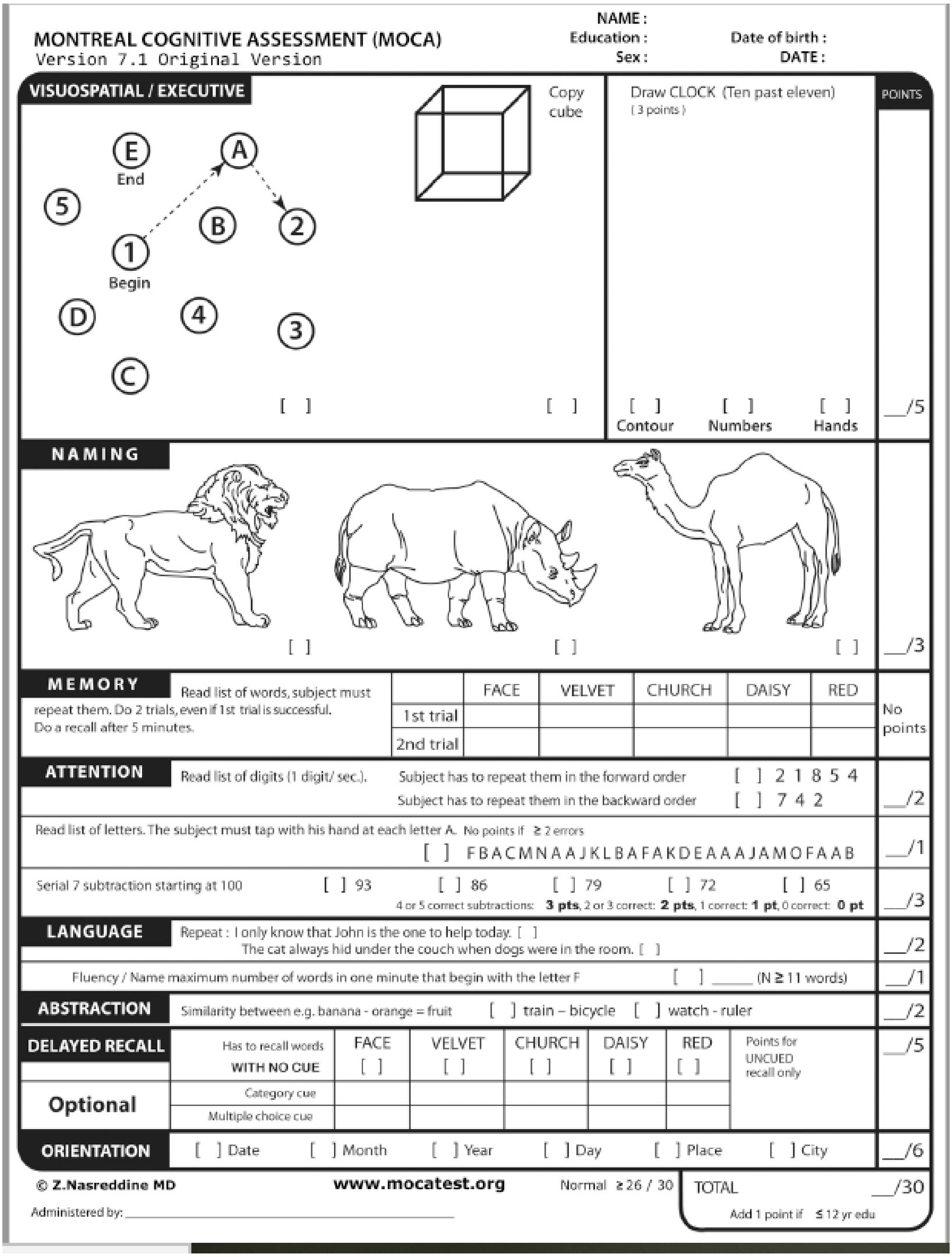
The project has been approved by the

Southern Adelaide Clinical Human Research Ethics Committee (SAC HREC).

RESPONSE SLIP

Name__________ _	**Name__________ _**	**Name__________ _**	**Name__________ _**
Contact Number ______________	**Contact Number** ______________	**Contact Number** ______________	**Contact Number** ______________

Appendix 17: Montreal Cognitive Assessment



MONTREAL COGNITIVE ASSESSMENT (MOCA)
Version 7.1 Original Version

NAME :
Education :
Sex :
Date of birth :
DATE :

		POINTS
VISUOSPATIAL / EXECUTIVE	[ ] Copy cube [ ] Draw CLOCK (Ten past eleven) (3 points) [ ] Contour [ ] Numbers [ ] Hands	___/5
NAMING	[ ] [ ] [ ]	___/3

MEMORY Read list of words, subject must repeat them. Do 2 trials, even if 1st trial is successful. Do a recall after 5 minutes.

	FACE	VELVET	CHURCH	DAISY	RED	
1st trial						No points
2nd trial						

ATTENTION	Read list of digits (1 digit/ sec.). Subject has to repeat them in the forward order [ ] 2 1 8 5 4 Subject has to repeat them in the backward order [ ] 7 4 2	___/2
	Read list of letters. The subject must tap with his hand at each letter A. No points if ≥ 2 errors [ ] FBACMNAAJKLBAFAKDEAAAJAMOFAAB	___/1
	Serial 7 subtraction starting at 100 [ ] 93 [ ] 86 [ ] 79 [ ] 72 [ ] 65 4 or 5 correct subtractions: **3 pts**, 2 or 3 correct: **2 pts**, 1 correct: **1 pt**, 0 correct: **0 pt**	___/3
LANGUAGE	Repeat : I only know that John is the one to help today. [ ] The cat always hid under the couch when dogs were in the room. [ ]	___/2
	Fluency / Name maximum number of words in one minute that begin with the letter F [ ] _____ (N ≥ 11 words)	___/1
ABSTRACTION	Similarity between e.g. banana - orange = fruit [ ] train – bicycle [ ] watch - ruler	___/2

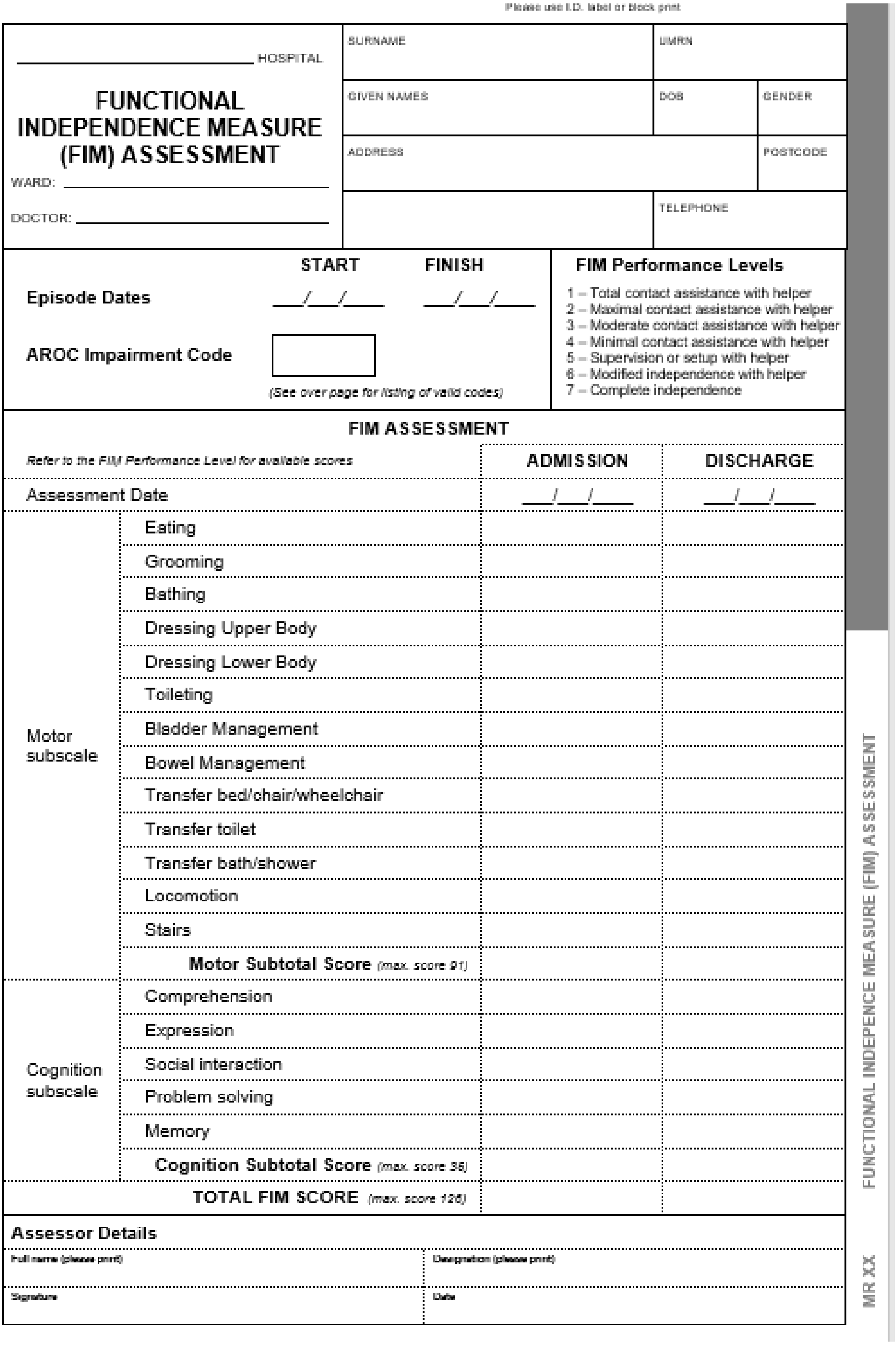
		FACE	VELVET	CHURCH	DAISY	RED		
DELAYED RECALL	Has to recall words **WITH NO CUE**	[ ]	[ ]	[ ]	[ ]	[ ]	Points for UNCUED recall only	___/5
Optional	Category cue							
	Multiple choice cue							

ORIENTATION	[ ] Date [ ] Month [ ] Year [ ] Day [ ] Place [ ] City	___/6

© Z.Nasreddine MD **www.mocatest.org** Normal ≥26 / 30 TOTAL ___/30
Add 1 point if ≤ 12 yr edu

Administered by: ______________________________

Appendix 18: Functional Independence Measure



Please use I.D. label or block print

____________________ HOSPITAL

FUNCTIONAL INDEPENDENCE MEASURE (FIM) ASSESSMENT

WARD: ____________________

DOCTOR: ____________________

SURNAME	UMRN	
GIVEN NAMES	DOB	GENDER
ADDRESS		POSTCODE
	TELEPHONE	

	START	FINISH
Episode Dates	___/___/____	___/___/____
AROC Impairment Code	☐	

(See over page for listing of valid codes)

FIM Performance Levels

1 – Total contact assistance with helper
2 – Maximal contact assistance with helper
3 – Moderate contact assistance with helper
4 – Minimal contact assistance with helper
5 – Supervision or setup with helper
6 – Modified independence with helper
7 – Complete independence

FIM ASSESSMENT

Refer to the FIM Performance Level for available scores		**ADMISSION**	**DISCHARGE**
Assessment Date		___/___/____	___/___/____
Motor subscale	Eating		
	Grooming		
	Bathing		
	Dressing Upper Body		
	Dressing Lower Body		
	Toileting		
	Bladder Management		
	Bowel Management		
	Transfer bed/chair/wheelchair		
	Transfer toilet		
	Transfer bath/shower		
	Locomotion		
	Stairs		
	Motor Subtotal Score *(max. score 91)*		
Cognition subscale	Comprehension		
	Expression		
	Social interaction		
	Problem solving		
	Memory		
	Cognition Subtotal Score *(max. score 35)*		
TOTAL FIM SCORE *(max. score 126)*			

Assessor Details

Full name (please print)	Designation (please print)
Signature	Date

FUNCTIONAL INDEPENCE MEASURE (FIM) ASSESSMENT

MR XX

AUSTRALIASIAN REHABILITATION OUTCOMES CENTRE IMPAIRMENT CODES VERSION 2

STROKE

Haemorrhagic

1.11	Left body involvement (right brain)
1.12	Right body involvement (left brain
1.13	Bilateral involvement
1.14	No paresis
1.19	Other stroke

Ischaemic

1.21	Left body involvement (right brain)
1.22	Right body involvement (left brain)
1.23	Bilateral involvement
1.24	No paresis
1.29	Other stroke

BRAIN DYSFUNCTION

Non-traumatic

2.11	Sub-arachnoid haemorrhage
2.12	Anoxic brain damage
2.13	Other non-traumatic brain dysfunction

Traumatic

2.21	Open injury
2.22	Closed injury

NEUROLOGICAL CONDITIONS

3.1	Multiple Sclerosis
3.2	Parkinsonism
3.3	Polyneuropathy
3.4	Guillain-Barre
3.5	Cerebral Palsy
3.8	Neuromuscular disorders
3.9	Other neurological disorders

SPINAL CORD DYSFUNCTION

Non traumatic

4.111	Paraplegia, incomplete
4.112	Paraplegia, complete
4.1211	Quadriplegia, incomplete C1-4
4.1212	Quadriplegia, incomplete C5-8
4.1221	Quadriplegia, complete C1-4
4.1222	Quadriplegia, complete C5-8
4.13	Other non-traumatic spinal cord dysfunction

Traumatic

4.211	Paraplegia, incomplete
4.212	Paraplegia, complete
4.2211	Quadriplegia, incomplete C1-4
4.2212	Quadriplegia, incomplete C5-8
4.2221	Quadriplegia, complete C1-4
4.2222	Quadriplegia, complete C5-8
4.23	Other traumatic spinal cord dysfunction

AMPUTATION OF LIMB

Not resulting from trauma

5.11	Single upper above elbow
5.12	Single upper below elbow
5.13	Single lower above knee (includes through knee)
5.14	Single lower below knee
5.15	Double lower above keen (includes through knee)
5.16	Double lower above/below knee
5.17	Double lower below knee
5.18	Partial foot (single or double)
5.19	Other amputation not from trauma

Resulting from trauma

5.21	Single upper above elbow
5.22	Single upper below elbow
5.23	Single lower above knee (includes through knee)
5.24	Single lower below knee
5.25	Double lower above knee (includes through knee)
5.26	Double lower above/below knee
5.27	Double lower below knee
5.28	Partial foot (single or double)
5.29	Other amputation from trauma

ARTHRITIS

6.1	Rheumatoid arthritis
6.2	Osteoarthritis
6.9	Other arthritis

PAIN SYNDROMES

7.1	Neck pain
7.2	Back pain
7.3	Extremity pain
7.4	Headache (includes migraine)
7.5	Multi-site pain
7.9	Other pain (includes abdominal/chest wall)

ORTHOAPEDIC CONDITIONS

Fractures (includes dislocation)

8.111	Fracture of hip, unilateral (includes #NOF)
8.112	Fracture of hip, bilateral (includes #NOF)
8.12	Fracture of shaft of femur
8.13	Fracture of pelvis
8.141	Fracture of knee
8.142	Fracture of lower leg, ankle, foot
8.15	Fracture of upper limb
8.16	Fracture of spine
8.17	Fracture of multiple sites
8.19	Other orthopaedic fracture

Post orthopaedic surgery

8.211	Unilateral hip replacement
8.212	Bilateral hip replacement
8.221	Unilateral knee replacement
8.222	Bilateral knee replacement
8.231	Knee and hip replacement same side
8.232	Knee and hip replacement different sides
8.24	Shoulder replacement or repair
8.25	Post spinal surgery
8.26	Other orthopaedic surgery

SOFT TISSUE INJURY

8.3	Soft tissue injury

CARDIAC

9.1	Following recent onset of new cardiac impairment
9.2	Chronic cardiac insufficiency
9.3	Heart and heart/lung transplant

PULMONARY

10.1	Chronic obstructive pulmonary disease
10.2	Lung transplant
10.9	Other pulmonary

BURNS

11	Burns

CONGENITAL DEFORMITIES

12.1	Spina bifida
12.9	Other congenital deformity

OTHER DISABLING IMPAIRMENTS

13.1	Lymphoedema
13.3	Conversion disorder
13.9	Other disabling impairments that cannot be classified into a specific group

MAJOR MULTIPLE TRAUMA

14.1	Brain + spinal cord injury
14.2	Brain + multiple fracture/amputation
14.3	Spinal cord + multi fracture/amputation
14.9	Other multiple trauma

DEVELOPMENT DISABILITIES

15.1	Developmental disabilities (excludes cerebral palsy)

RE-CONDITIONING/RESTORATIVE

16.1	Re-conditioning following surgery
16.2	Re-conditional following medical illness
16.3	Cancer rehabilitation

Appendix 19: Simplified Participant Information and Consent Form

Government
of South Australia
SA Health

Flinders
UNIVERSITY
College of Nursing
& Health Sciences

Information Sheet

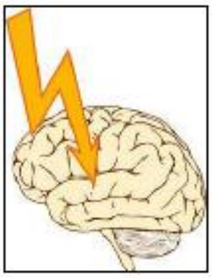
Title: Care needs of stroke survivors and carers in hospital to home transition

Main researcher: Ms. Langduo Chen

You are invited to take part in research.

What is this project about?

Stroke changes people's **life.**



It affects **you and your family.**

Returning home from hospital can be a very **hard** time.

We want to know **your experience.**

What do I need to do?

You will need to have a **cognition assessment.**

You will need to **sign a consent form.**

You will be **asked** for your **personal information**.

- Age
- Occupation
- Health information

You will need to attend **2-3 times** of **interviews** and each interview will take about **30 to 45 minutes**.

- Before discharge
- 3 months after discharge
- 6 months after discharge

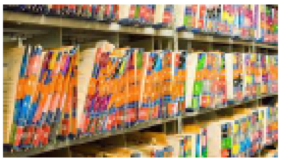
Where will I need to go?

The **interview** takes place at a **location of your choice.**

What will happen to the information I give?

- You will be **audio recorded**.

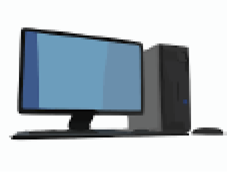
- **We** will need to **read** your **medical notes.**



- We will **keep the information** you give us and recordings at **The Flinders University of South Australia.**

- All information will be **kept safely.**

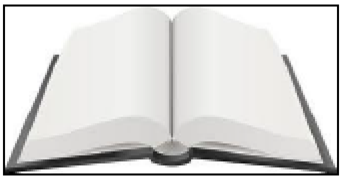
- All information will be **confidential.**



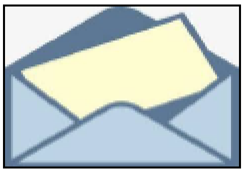
- To **protect your privacy**, all information about you will be **labelled** with **a code number**.

What will happen to the information I give?

- The results may appear in **journal publications** and **conference presentations.**



- **Your identity** in publications will be **kept private**.
- We will send all participants a **summary of the results**.



How long will you keep my information for after the project is completed?

- All your information from the study will be stored securely for **15 years.**

Are there any risks?

- There is **no danger** in doing this research.

Are there any benefits?

- We are doing this study to learn how to improve health services for people with stroke.
- It **might not help you** right now**.**

What if I decide I do not want to be involved?

- You **do not have to participate**. It is **your choice**.
- You can start participating and then **change your mind**.
- You can **ask questions** at any time.
- Saying no **will not affect** your **relationship** with **staff** at Flinders Medical Centre.
- You **can stop** at **any time**.

To stop doing the research contact:

Ms. Langduo Chen

☎ Phone: 08 8404 2062

🖥 Email: Langduo.chen@flinders.edu.au

Who has approved this research?

- This study has been **approved** by the Southern Adelaide Clinical Human Research **Ethics Committees**.

What if I have a complaint?

- If you would like to speak to an officer of the Committee **not involved in the study**, you may contact:

The Ethics Officer at the Ethics Committee

☎ 8204 6453

🖥 Health.SALHNofficeforresearch@sa.gov.au

What if I have more questions?

Please contact:

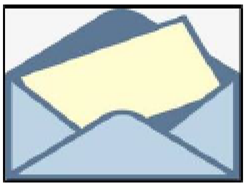
Ms. Langduo Chen

☎ Phone: 08 8404 2062

Email: Langduo.chen@flinders.edu.au

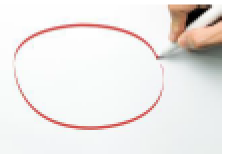
How can I find out the results of the study

- We can **mail** our **findings** out to you.



- Do you want us to **email** our **findings** to you?

  (Please circle)



Yes ✓

No ✗

Government of South Australia
SA Health

Flinders UNIVERSITY
College of Nursing & Health Sciences

Consent Form

Title: **Care needs of stroke survivors and carers in hospital to home transition**

Main researcher: **Ms. Langduo Chen**

☎ Phone: 08 8404 2062.

Email: Langduo.chen@flinders.edu.au

*(Please **circle**)*

I have **read**  and **understood** the **information sheet.**

👍 **Yes**

I have had time to **think**  about the information and ask **questions**.

👍 **Yes**

I am **happy**  with the **answers.**

👍 **Yes**

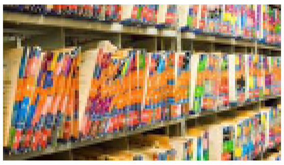
I understand that I can **stop** at any time.

I do **not** have to **give a reason**. 👍 **Yes**

I will answer **questions** about my experience and thoughts.

👍 **Yes**

I will allow researchers to look at my medical notes.



👍 **Yes**

I will take part in **2-3 interviews** about my experience. 👍 **Yes**

I will **allow** the interview to be **audio-recorded** and typed up.

👍 **Yes**

I understand that people will be told about the study but

my name will **never** be **used.** 👍 **Yes**

I will allow **the information** I supply to be used **anonymously** in journal **publications** and **conference** presentations.

👍 **Yes**

I would like to **see** the **results** of the study when it is completed.

👍 **Yes**

Name of Participant (please print)

____

Signature ________________ Date ________________

Name of Participant's Carer (please print)

____

Signature ________________ Date ________________

Declaration by Researcher†

I have given a verbal explanation of the research, its procedures and risks and I believe that the participant has understood that explanation.

Name of Researcher (please print)

____

Signature ______________ Date ______________

† An appropriately qualified member of the research team must provide the explanation of, and information concerning, the research project.

Note: All parties signing the consent section must date their own signature.

Appendix 20: Interview Guide

Appendix 20a: Interview Guide Before Hospital Discharge (the First Interview)

Question	Stroke patient	Stroke caregiver
Question 1	How have you been since the stroke? • How have you been dealing with the fact that you had a stroke? • How do you think your family cope with what happened?	How have you been since the stroke of your relative? • How have you been coping with the fact that your relative had a stroke? • How do you think your relative is dealing with what happened?
Question 2	Now you are going home soon, please tell me about your rehabilitation experience. • How prepared do you think you are for returning home?	Now your relative is going home soon, please tell me about your thoughts on the caregiving role. • How prepared do you think you are for supporting your relative at home?
Question 3	What are your expectations after returning home? • Expectations on your rehabilitation/recovery. • Expectations on community health and social care services.	What are your expectations after your relative returns home? • Expectations on the relative’s rehabilitation/recovery. • Expectations on the support services.

Appendix 20b: Interview Guide After Hospital Discharge (the Second and Third Interviews)

Interview guide for stroke survivors (2nd interview)

The following questions will serve as a guide in the interview. Questions may be asked in a different order or some omitted or added, depending on the participants' responses.

1. Could you please tell me your experience in the preparation for discharge?
    - Level of involvement?
    - Information/training received?
    - Practice sufficient for home?
2. What were your expectations in discharge preparation? Any suggestions?
3. Now you have come home, how do you feel being at home after stroke? Can you please tell me a typical day? How do you manage daily activities?
    - Meaning of home
    - Differences comparing to life before
    - Strategies to manage daily activities
4. What health and social care services do you receive after discharge from hospital?
5. How have these care services helped you to recover at home?
6. What changes regarding your recovery and health have you experienced since your discharge from hospital?
    - Examples of the progress of recovery that you are satisfied with
    - Examples of the progress of recovery that you are not satisfied with
    - Thoughts and ideas about health and social care that may help you to achieve your goal for recovery
7. Is there anything else that you would like to talk about and add?
8. Is there anything that you have talked about that you would like me not to include in my research report?

Interview guide for stroke survivors (3rd interview)

1. How have you been since our last meeting?
    - Health condition
    - Hospital visit
    - Issues and concerns
2. Now you have come home for XX weeks. Tell me about a typical day? How do you manage daily activities?
3. How has your life changed since the last meeting?
    - Relationship with your family/carer/friends
    - How the changes impacted on the recovery
4. What do you think about the community support/rehabilitation you received?
    - Helped or hindered you to adapt to the new life after stroke
    - Suggestions
5. What changes in health and social care do you want to see in order to help you to achieve the heist level of recovery and adapt to the new life after stroke?
    - Process of discharge from hospital
    - Health professionals
    - Health and social care system
6. Is there anything else that you would like to talk about and add?
7. Is there anything that you have talked about that you would like me not to include in my research report?

Interview guide for caregivers (2nd Interview)

1. Please tell me about your experience in the preparation for discharge.
    - Level of involvement
    - Training/skills building
    - Practice sufficient?
    - What helped/didn't?
2. Now your relative has come home, would you please tell me how you feel being at home? Describe a typical day? How do you manage daily activities?
    - Differences comparing to life before
    - Strategies to manage daily activities
    - Relaxing and have time for yourself
3. What commitment you have made in order to support your relative to go through rehabilitation after discharge from hospital? How have these commitments impacted on your life?
    - Physical e.g. manual handling
    - Mental e.g. emotional support to persist
    - Financial e.g. giving up work or reducing working hours
    - Time e.g. how many hours per day or per week
4. Please tell me about the support and services your relative received after discharge?
    - Source of information
    - Knowledge of all available services
    - Helped transition home?
5. Is there anything else that you would like to talk about and add?
6. Is there anything that you have talked about that you would like me not to include in my research report?

Interview guide for caregivers (3rd Interview)

1. How have you been since our last meeting?
   - Health condition
   - Hospital visit
   - Issues and concerns
2. Now your relative have come home for XX weeks, could you please tell me how you feel being at home? Describe a typical day? How do you manage daily activities?
3. How has your life changed since the last meeting?
   - Relationship with your family/carer
   - How the changes impacted on the recovery
4. How have your relationship with your relative changed? How have these changes impacted on your life?
5. What do you think about the support/rehabilitation your relative received after discharge?
   - Impact on your life style/employment
   - Helped/hindered transition home
   - Care needs met?
6. What changes do you want to see in order to make the process of discharging home easier?
   - Discharge planning process
   - Health professionals
   - Health care system
7. Is there anything else that you would like to talk about and add?
8. Is there anything that you have talked about that you would like me not to include in my research report?

Appendix 20c: Interview Guide for General Practitioners

General question: full name, years of experience, experience with stroke population.

The following questions will serve as a guide in the interview. Questions may be asked in a different order or some omitted or added, depending on the participants' responses.

1. Could you please talk about your involvement in the care of stroke survivors?
2. What are your thoughts on factors that facilitate the continuity of care for stroke survivors after discharge from hospital?
3. What are your thoughts on factors that impede the continuity of care for stroke survivors after discharge from hospital?
4. What are your expectations of the discharging hospital? What recommendations do you have?
5. What community rehabilitation services and supports do you know that are available for stroke survivors and their informal carers? From which sources you have obtained the information?
6. What community rehabilitation services and supports do you usually refer the stroke survivors to? How well do these services support them? Please provide some examples.
7. What challenges do you face when caring for stroke survivors and working with their informal carers? Any recommendations on how to better manage these challenges?
8. What changes do you want to see regarding the process of discharging from hospital?
9. What changes do you want to see for the health care and social care system to support stroke survivors and their carers during hospital to home transition?

10 Is there anything else that you would like to talk about and add?

11 Is there anything that you have talked about that you would like me not to include in my research report?

Appendix 20d: Focus Group and Interview Guide

Focus Group and interview Guide

Generic Questions

1. What are your involvements in the care of stroke survivors?
2. What strategies do you usually use to identify care needs for stroke survivors during hospital to home transition? Are those strategies workable? Examples?
3. What strategies do you usually use to identify the need to prepare carers to care for stroke survivors prior to discharge? Are those strategies workable? Examples?
4. What do you do to ensure that the transition care and rehabilitation needs for stroke survivors are met? Examples?
5. What impact do the early discharge and shortened hospital stay have on the hospital to home transition for stroke survivors and their family?
6. What are the factors contributing to the implementation of effective discharge planning? Examples especially for patients with cognitive impairment?
7. What are system factors that enable or impede the continuity of health care and social care services in hospital to home transition?
    - Examples
    - What could be done better?

Discipline-specific questions

Social worker

For young stroke survivors (<65 years, <45 years Aboriginal population), what factors facilitate or impede a smooth transition? Examples?

Physiotherapist/Occupational therapist

What are the differences in discharge preparation approaches between young and old stroke survivors?

Speech pathologist

For survivors with speech and swallowing impairment, what factors facilitate or impede a smooth transition? Examples?

Medical and Nursing

What are the challenges in secondary prevention? Examples?

For survivors with continence issues, what are strategies to ensure continuity of care at home?

Appendix 21: Structured Diary

Structured Diary Entry Guide for Person with Stroke

The following tables will serve as a guide for your diary entry. There is no restriction on writing or recording more or less; depending on your choice.

Name: (Option)…………… Code Number (for researchers to enter):……….. Date……………

Your experience	Your experiences, thoughts and comments on the **Significant Events**
In coping with physical difficulties	
In coping with other health problems	
With your family carers	
In the use of care services	
In engaging support group	
Any difficulties you encounter and how you cope with the difficulties	

Structured Diary Entry Guide for Caregiver of Person with Stroke

The following tables will serve as a guide for your diary entry. There is no restriction on writing or recording more or less; depending on your choice.

Name: (Option)…………… Code Number (for researchers to enter):……….. Date……………

Your experience	Your experiences, thoughts and comments on the **Significant Events**
In coping with post stroke difficulties	
In coping with other health problems	
With your own health problems	
In coping with caregiving	
In daily activities	
In the use of care services	
In engaging support group	
Any difficulties you encounter and how you cope with the difficulties	

Appendix 22: COREQ (COnsolidated Criteria for REporting Qualitative Research) Checklist

Topic	Item	Guide question/descriptions	Reported in manuscript on page no.
Domain 1: Research team and reflexivity			
Personal characteristics			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	10
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	9
Occupation	3	What was their occupation at the time of the study?	10
Gender	4	Was the researcher male or female?	NA
Experience and training	5	What experience or training did the researcher have?	9
Relationship with participants			
Relationship established	6	Was a relationship established prior to study commencement?	10
Participant knowledge of the interviewer	7	What did the participants know about the Researcher? e.g. personal goals, reasons for doing the research	10—stated in participant information sheet
Interviewer characteristics	8	What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	10
Domain 2: Study design			
Theoretical framework			
Methodological orientation and theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	7–13
Participant selection			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	9, Table 1
Method of approach	11	How were participants Approached? e.g. face to face, telephone, mail, email	9–10
Sample size	12	How many participants were in the study?	10
Non-participation	13	How many people refused to participate or dropped out? Reasons?	10
Setting			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	9, 10
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	10
Description of sample	16	What are the important characteristics of The sample? e.g. demographic data, date	Table 4

Topic	Item	Guide question/descriptions	Reported in manuscript on page no.
Data collection			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	10, Table 2
Repeat interviews	18	Were repeat interviews carried out? If yes, how many?	NA
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	10–11
Field notes	20	Were field notes made during and/or after the interview or focus group?	8, 11
Duration	21	What was the duration of the interviews or focus group?	11
Data saturation	22	Was data saturation discussed?	NA
Transcripts returned	23	Were transcripts returned to participants for comment and/or correction?	NA, statements cross-checked during interview
Domain 3: Analysis and findings			
Data analysis			
Number of data coders	24	How many data coders coded the data?	12
Description of coding tree	25	Did authors provide a description of the coding tree?	Table 3
Derivation of themes	26	Were themes identified in advance or derived from the data?	11–12
Software	27	What software, if applicable, was used to manage the data?	11
Participant checking	28	Did participants provide feedback on the findings?	NA
Reporting			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation Identified? e.g. participant number	14–26
Data and finding consistent	30	Was there consistency between the data presented and the findings?	14–26 SuppInfo Table 2
Clarity of major themes	31	Were major themes clearly presented in the findings?	14–26
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	14–26

Adapted from: Tong, A., Sainsbury, P., Craig, J. (2007). Consolidated criteria for reporting qualitative research (COREQ): A 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*, *19*(6), 349–357. https://doi.org/10.1093/intqhc/mzm042

Appendix 23: Themes With Quotations

Theme	Subtheme	Direct quotation
Psychological stress	‘I am looking forward to going home but feeling anxious’	The, the only thing I have to be just mindful of is my, probably my physical strength. I don’t have as much physical strength as I used to. (SS03) [I feel] a bit depressed, worried about having another one [stroke]. And not going back to my previous life. Worried about my independence yeah … Just as I said just a bit fearful of the future, I guess. Who knows what it will bring. (SS09) It is frustrating, I’m annoyed about it and I wrote this morning well a page in the notebook … it probably took me half an hour to write and I made some mistakes, which I corrected in it. (SS11) I am looking forward to going home because this a fairly lengthy time to be in hospital but at the same time, I’m also feeling anxious about my level of functioning in the home situation to see what I can do, what I can’t do, what impact it’s going to have on me and how is it going to perhaps affect me emotionally as well? Because all those things that under normal circumstances you take for granted, suddenly it’s a bit like having electricity on in the house where you just switch it on, take it as a given thing that it’s there. As soon as the power gets switched off, you think no electricity. (SS12) A big focus for me was the walking part because that was quite devastating to find that you’d stand up and you couldn’t put any weight on the left hand side. And when I started using the walker, it was kind of very stilted … it became I suppose a focal point for me to actually keep doing that. (SS12)
	‘Not knowing what the future holds’	Well, I think mainly I mean if his needs are ongoing as far as not being able to stay at home by himself, that will create a whole new set of issues, and at the moment I am willing to support his needs 24/7 simply because he is mobile. So the main concern I think might be down the track as far as getting some sort of assistance for me to be able to leave the home at times. (SC01) My blood pressures up. Look one of—one of the—one of the I guess the fall—some of the fall out of—of I do [worry] because he’s not always easy to tell him to slow down, and we’ll stress at each other over those things. And just not knowing what the future holds, how I can care for him and help him better. (SC06)

Theme	Subtheme	Direct quotation
		[I feel] really stressed, depressed, just, just generally a lot of sadness because of not knowing what the future holds for him. Just coping, coping not as good as I used to be. (SC03) I do [worry] because he's not always easy to tell to slow down, and we'll stress at each other over those things. And just not knowing what the future holds, how I can care for him and help him better … [I feel] really stressed, depressed, just generally a lot of sadness because of not knowing what the future holds for him. Just coping, coping not as good as I used to be. (SC03) No, I just know that really there can't be expectations because we don't know what it's going to—my commitments only to put the work in, to put the therapies in place, that's what I requested from all of them to give me as much as we can with therapy because he's so young and because obviously the boys expect him to be playing soccer with them and doing stuff and so but you know we'll just keep strengthening him and see what we can glean out of it, but they're very excited, they want me to pick them up because Dad's coming home. (SC05) And the 20-year-old was XX's [husband's] apprentice for 5 years, so XX [husband] worked for himself so as the main breadwinner of the family and we found him unconscious the morning my son went to write his final exam, so it's been quite emotional, quite difficult for the family to work through because it was quite traumatic. (SC05) Well it's been 12 weeks of coming in and out of hospital with four children, so juggling family/work and home and hospital, it's been tricky. So it's been hard and emotionally it's been hard especially because the children are quite—well, two of the children are quite young. (SC05) Well because XX [the husband] was the main breadwinner we've got a mortgage, young family, kids in school, I needed to stabilise my work … But I've cut back one day so I'm 3 days a week, but I need to build back up to doing just so that we can pay off our [bills]. (SC05) The initial shock was terrible- Because we nearly lost him, it was really bad. Unreal—it seemed unreal, but gradually, I know from the moment he had the stroke, my life will change, so will his. (SC08) When I knew that Mum had had—she had two mini strokes and yeah it was quite upsetting and then yeah to see her in the hospital as well was sad yeah. (SC13) I mean to see her like this after being so well for 91 years and not having any sicknesses or anything and then to see her have to go through something like this, it has been pretty stressful

Theme	Subtheme	Direct quotation
		and you do have your ups and downs, but I’m so glad now that she seems to be on the road. (SC14) It’s been difficult … Just running everywhere, making sure that everything’s okay when he comes home. I’m usually very organised … things have sort gone a bit haywire. I lose my keys, forget my phone … I don’t know what to expect. I believe someone … spoke to XX [the husband]. But he’s not reliable. Here we are we’re going home. I’d like to know who I’m expecting to come into my home, how often. (SC18) I worry about him at home. I’ve been the one that’s found him on the floor. And I worry about that [another stroke] … and falling again. (SC18)
Resilience	‘I’ve come from zero to hero’	I—I can accept that with the major stroke I have, there might be some limitations … If you could say, I’ve come from zero to hero … a fortnight ago … I couldn’t sit up in bed. I was in XX [acute ward], And physios came and tried to sit my up in bed, and I couldn’t do it. So, I’ve gone from that to walking, with a frame. I can walk some distance independently … You know, I mean I was—I quite surprised myself, yesterday I actually put sneakers on, and I was able to tie the shoelaces. And to me, I know some adults that still can’t …—they still can’t tie their shoelaces. (SS03) I’m reasonably confident. I just know that I have to be careful and go slowly, be sensible. All those things I’m not terribly good at but I’ll try … my brother will fix the shopping and I will do the cooking. And we’ll go back to how we were before. (SS09) After really accepting that I had a stroke and, and it seemed to be a slow improvement, most days going forward. But I, I appreciate I understand, at least I believe I’m not going to get back to where I was, and things will be all slower … I can live with my calculation ability and I think I can live with my speech it’s not the best but it could be far worse … And I see around here a lot of people are far worse and I’m certainly happy with my physical side of things in many ways. (SS11) I wouldn’t say that it’s nice to sort of be face with things like that but I think you start to adjust your way of thinking a little bit to—and you’ve got to—to try to use those things. (SS12) I saw the awful disabilities that had happened to them and I saw this man and he was just so badly stricken with his stroke … And it made me realise how lucky I was that I had just had a minor stroke, was still able to think and feel … (SS13)

Theme	Subtheme	Direct quotation
		Well I'm just so looking forward to going home. And sleeping in my own bed and doing stuff for myself when I want to do it and I'm, I'm probably going to make mistakes but I've got things organised, I've got a cleaner organised, my driver's license, which is my lifeline, is being organised. And that's really great because I live on top of a ridge, in a bushfire prone area and I'm right on the top. So either way it's very steep going down. In the hills at Bridgewater I don't have footpaths, streetlights or any of those sophisticated things, and driving and being able to get my license back is an absolutely wonderful, it's a God send. (SS15) I think my objective up there [acute ward] was to walk out of here one day cured or fit and well and able to walk. See the significance on able to walk, I guess I'm gauging my wellbeing and mobility through being able to walk and out of here being symbolic with, hey I've done well, I've recovered from potentially a very dangerous incident or event and I'm on my way again. (SS17)
	'I look at this as a change in the road for life'	I have done a lot of mindfulness practice in the past and that has been hugely beneficial. And I would really recommend that there is support for people in that area to learn—to be able to manage their anxiety or anything that might come up. (SC01) My job is working with people that live at home with disabilities. So, it's more setting up rosters and doing care plans and working with the NDIS. So, I have set up support for XX [the husband] with the NDIS just for when I'm working. (SC05) I face things front-on, so this is what it is, look at the positives. I've got him and he's lucky and I'm lucky, the family's lucky. So we don't look at this as a disability, we look at this as a change in the road for life. That's all it is. All my life and we've had a lot of ups and downs … Business, financial, but you've got to look at the positives. I just accept it and work from there and try and make my husband's life through speech therapy and us working at home as best as he can get it, and that's the goal. (SC08) I am as prepared—I've been prepared the whole time he's been in care. Well now, I can't tell you how prepared. I'm a strong person, I think I can manage, in fact, I'm positive, I know I can manage, but I'm sure there would be times where I would feel a little bit angry because my life has changed. (SC08) I do have the facility and I've already had it, when there's a drama, I gone dead calm and deal with it. My personality, yes. (SC11)

Theme	Subtheme	Direct quotation
		Yeah, that's alright; I mean we've talked about dying, we're very straight forward about the future, we've talked about death and we say death and dying. We've got things in place with the family and with our executor as to what we want and we both realise he's 82, I'm nearly 80 that our life is coming towards the end. We're not going to live forever, no one does. (SC11) [when we feel stressed] we talk a lot, spend time with friends because my son and close friends are still in Melbourne, I'm on the phone a lot, I read, I go walking and I sleep; I suppose they're the things that I've been trying to do. (SC14) But we are both in our 70s. We're quite realistic about the—the reality of mortality. But there's no reason why she can't have a good quality of life, and enjoy life for the foreseeable future. And that's what my expectations are. (SC16)
Certainty and uncertainty about post-discharge care	'They boost you up': certainty about post-discharge rehabilitation	But I'd like to be able to strive to get back to a normal life … I'm hopeful that given a week at home, I can push a vacuum around. We've got a Dyson vacuum; very lightweight. (SS03) I don't know exactly what the services are at this stage. (SS11) I believe that I'll be getting some in-home rehab and that's one of the things. The other things are sort of not specifically sure in the home situation. (SS12) Well to start with the physios showed me how to put, how to walk what it was like, even though I had to hang onto things all the time and then they worked on my balance and they worked on my walking and coordination and getting those neural pathways back. And explaining what was happening all the time, and so they've taught me a lot of the things I need to know. And it's been terrific and they've given me a lot of confidence too, that I could do it … Because they said, 'Oh you're wonderful you did it all really well'. And so apart from the actual showing you how to do things, they boost you up and so do the nurses. (SS15) But I think probably week, 10 days I'll be managing to walk, my works nearly finished for this year. So I don't know if I'll get to my studio because there's also big stairs there. There are stairs at home, well I won't be able to do those yet because they're extremely steep, but I think eventually I'll be able to do all those things. (SS15) Well just their expertise, it can be no, no more complicated than someone holding me down in the gym, while I'm trying to develop a balance, improve balance. So there's the expertise, they know where I'm comfortable to work within that risk parameter but if they weren't as professional I may be nervous and not as willing to undertake that next exercise. My walking or

Theme	Subtheme	Direct quotation
		my mobility has improved from a walking frame to a mobile walking frame and now it’s a walking stick and I even suggest I’m not far off just walking naturally. And that’s all been with their guidance, so I think that answers your question. (SS17) I’m confident, I’m not intimidated or nervous by it, rehab will go on but in a different way from the home and visits from here. So I’ll still get that support, but I’m just thrilled to be going home, particularly Christmas season. And I was informed by the doctor here that the best thing I could do had, them having observed my progress, was to go home into the work environment—sorry the home environment where improvement should be more pronounced. So of course, I would do it. (SS17)
	‘We don’t know what’s going to happen’: uncertainty about post-discharge care	I also feel confident—I am being told all the time that I can access support here, ask any questions. That will be important for anything that comes up. (SC01) and I asked him to do a family meeting, so we had a family meeting to discuss with the children what Michael’s needs would be at home and how he would be different. And that they understand that he can’t come back in the same capacity and that they need to be looking out for him, so that was a very beneficial meeting. (SC05) No, I just know that really there can’t be expectations because we don’t know what’s going to [happen]—my commitment is only to put the work in, to put the therapies in place, that’s what I requested from all of them [service providers] to give me as much as we can with therapy … but you know we’ll just keep strengthening him and see what we can glean out of it. (SC05) The past few weeks is it not knowing what the future holds of course. But also not knowing on the support side what’s available, what’s going to be available. It—it really was a matter of trying to get information from My Aged Care. (SC06) Okay well we had a lot of phone calls from the hospital just to say that Mum would be coming home on this date and that we were expected to go up there as a family but that didn’t happen. Then I don’t know it just never came about so Mum was just discharged and when I rang she’d already left. Well it was a little bit disappointing because you know we had all the phone calls about we were going to do—go to the hospital and all get together and have a chat about Mum and it just never happened and then she was discharged so that side of it didn’t happen. (SC13) Totally and where we’ve thought that we haven’t had an answer quickly enough, we’ve rung; so there was a time where somebody didn’t get back to us and so we followed it up straight away.

Theme	Subtheme	Direct quotation
		So no, totally involved and as I said, we've pushed a little bit where we've felt that we haven't had an answer quickly enough. So yeah and I don't think that's going to change, I think we'll be totally involved because at the end of the 12 weeks there has to be something as well, so we'll keep pushing. (SC14) As prepared as I can be because it's a bit unknown. I think we've now got a reasonable amount of stuff in the house and we've got RDNS coming today, so once I get to know who those people are going to be and how we're going to then work together in the house I think I'll be a lot calmer; so today there's a little bit of trepidation, but then I'm a person that kind of just keeps going with the flow, so we get the next group of people and we'll learn how to deal with the next group of people and work out how it's going to be at home. I think it's going to be great; I've always said I thought Mum would heal sooner at home than in this environment and I think the couple of days we've had her home on leave has demonstrated that. So I'm really—I'm as prepared as I can be for what's going to come, but I really don't know what's going to come. I think there are going to be days where we're at each other's throats and I think there'll be days that will just be bliss, I think it's just going to be again, a rollercoaster for some time to come. (SC14) Well I don't know too much about the details. I understand we're going to receive recommendations about grips for the shower, etc. And the sooner that happens the better, because until I know what's required, I can't do anything about it. It has been explained to XX [wife] that there are various forms of assistance available. And she has much more detail—knowledge with that than I do. I'm going to be spending as much time with her as I can. (SC16) I came in on Friday to talk to the social worker, she wasn't here. So then I asked the desk, I said look I don't know what's happening with rehab next week. I don't know what to expect. And she said oh I'll get somebody here at 3:30 to talk to you. I come back and I didn't speak to anybody. I believe someone came and spoke to Ian. But he's not reliable, yeah he's not reliable to tell me exactly what is being said, yeah. So I think there's been a bit of a problem there yeah. And here we are we're going home. And I'm hoping to talk to somebody today. Well there's nobody—I thought there would be another family meeting, I thought. That's why I wanted to talk to the social worker on Friday, but she's not here. So therefore I suppose it's because of Christmas, and people are not around, so yeah. (SC18) About the rehab. Well I've got no idea. It's just the OTs that have said oh yes you'll have this, and you'll have that. But no—I believe I'm going to get a pack with some notes in. I'd like to

Theme	Subtheme	Direct quotation
		know who I'm expecting to come into my home, how often. And now because of Christmas it's not going to happen Wednesday, and Thursday on public holidays. Or the week after it's not going to happen on the public holiday. I did ask do we get an extension of the time for them to come. No, you don't. So it's just bad luck that you've got the public holidays in there. But I'd just like to know what is set up. I don't want to feel—and I worry about his new medication, I want to talk to the pharmacist and get the list. (SC18)

Note. SS = person with stroke; SC = stroke caregiver; NDIS = National Disability Insurance Scheme; RDNS = Royal District Nursing Service; OT = occupational therapi