COPYRIGHT AND USE OF THIS THESIS

This thesis must be used in accordance with the provisions of the Copyright Act 1968.

Reproduction of material protected by copyright may be an infringement of copyright and copyright owners may be entitled to take legal action against persons who infringe their copyright.

Section 51 (2) of the Copyright Act permits an authorized officer of a university library or archives to provide a copy (by communication or otherwise) of an unpublished thesis kept in the library or archives, to a person who satisfies the authorized officer that he or she requires the reproduction for the purposes of research or study.

The Copyright Act grants the creator of a work a number of moral rights, specifically the right of attribution, the right against false attribution and the right of integrity.

You may infringe the author’s moral rights if you:
- fail to acknowledge the author of this thesis if you quote sections from the work
- attribute this thesis to another author
- subject this thesis to derogatory treatment which may prejudice the author’s reputation

For further information contact the University’s Director of Copyright Services

sydney.edu.au/copyright
Exploring the introduction of a Rehabilitation 'Mid-Term Report Card' in communication and education for families of stroke survivors

Yasmine Muriel LOUPIS

A thesis submitted in fulfilment of the requirements for the degree of Master of Education (Research)

Faculty of Education and Social Work
University of Sydney

March 2014
ABSTRACT

In recent years there has been greater acknowledgement of the importance of family involvement in improving outcomes for stroke survivors. Stroke rehabilitation can be an emotionally and physically draining experience, and health professionals recognise that this upheaval does not end at discharge from hospital. The researcher, a social worker in this hospital setting, conducted a literature review to gather and analyse material on the purpose and benefits of family conferences specifically for an inpatient caseload. The literature indicated that family conferences are important to the rehabilitation process, although much more can be done to ensure professionals provide the best possible care throughout the inpatient admission and on return to the community. On the whole there appears to be a need for better education and ongoing support from rehabilitation interdisciplinary teams for patients and their caregivers, and intervention should be more proactive rather than reactive to reduce strain on patients and their families. Social workers are well positioned through their skills, theoretical frameworks and approaches to determine what might be best practice for each stroke survivor and to predict practical and emotional care requirements for caregivers. This qualitative research project explored the information needs of caregivers and the trial of a new resource, a personalised ‘Mid-Term Report Card’. This report card was provided to participants half-way through the admission and contained results of assessments and therapies. Four weeks after discharge from rehabilitation each caregiver participated in a semi-structured interview with particular emphasis on the perceived benefit of provision of the report card, and the information and feedback they felt most adequately prepared them to assume their caregiving role. The study provided an opportunity to gain some preliminary insights into the caregiver experience beyond their need for information, and offers suggestions for the content of future Mid-Term Report Cards. There was clear feedback that caregivers of stroke survivors need to be supported to engage effectively with rehabilitation teams, and this study highlights the role of social work in addressing these identified areas of need.
AUTHOR’S DECLARATION

This is to certify that:

I. this thesis comprises only my original work towards the Master of Education (Research) Degree
II. due acknowledgement has been made in the text to all other materials used
III. the thesis does not exceed the word length for this degree
IV. no part of this work has been used for the award of another degree
IV. this thesis meets the requirements of the Human Research Ethics Committees of the University of Sydney and St Vincent’s Hospital Sydney for the conduct of research

Signature(s): …………………………………………………………………………………………………

Name(s): ………….. Yasmine Muriel LOUPIS …………………………….

Date: …………………27 February 2015……………………………. 
ACKNOWLEDGEMENTS

This thesis could not have been completed without the invaluable support of those who have made this journey with me. My heartfelt thanks go to:

Stroke Services NSW, The University of Sydney, St Vincent’s Hospital Sydney and the Smart Strokes Committee. Their financial assistance throughout this project in the form of scholarships, conference attendance fees and production of posters for dissemination of this information in international forums has been appreciated.

My supervisor Dr Rosalie Pockett whose ongoing guidance has been invaluable. Dr Pockett’s unwavering belief in what she considered to be a worthwhile study, and her assistance in extracting an interesting idea from a seemingly everyday occurrence, has motivated me to continue at times when I felt uninspired. She has provided interesting insights and perspectives, demonstrated an intellectual curiosity, challenged me to incorporate existing knowledge and experience into my study design, and assisted me to take my very rough idea and mould it into a manageable project worthy of a higher research degree. She encouraged me to explore the importance of my work both as a hospital clinician and an academic, as well as offering advice on transcription of interviews and relevant texts and theories that informed the study. I have appreciated Dr Pockett’s responsiveness in reading and re-reading each draft of this thesis and her generosity in starting me off on this postgraduate journey.

Associate Professor Steven Faux, Director of Rehabilitation and Pain Medicine at St Vincent’s Hospital, whose consistent enthusiasm and support since I joined the rehabilitation team at Sacred Heart inspired me to begin researching family involvement in stroke rehabilitation. His faith and respect for the social work role, particularly in stroke rehabilitation is evident in everything he does, and I thank him for challenging me to see situations from every perspective. My thanks are also extended to A/Prof Faux for his assistance in proofreading this thesis.

My colleagues at St Vincent’s Hospital. Firstly the Rehabilitation Unit’s doctors, nurses and allied health professionals for continued interest in and support of this research, and for providing feedback for the Mid-Term Report Cards. Secondly the Social Work Department including Manager Margaret Bramwell, Amy Colquhoun and Rosemary Arias for their patience and generosity in approving and supporting study leave to allow me to focus on the final chapters of this thesis, as well as for ongoing intellectual stimulation and appraisal of the literature review, plus regular supervision.

My partner and fiancée Jacob McKee-Wright for his unwavering encouragement, love and interest throughout such an enormous undertaking. His energy was infectious when mine was depleted, and his patience great when I had sacrificed both sleep and recreation to complete this project. I thank him for his proofreading efforts and for being my biggest fan.

My parents George and Maruschka Loupis who encouraged me from an early age to enquire and be passionate, sensitive to and observant of the world around me. They
continually motivate me and have been the ultimate examples of wisdom, experience and perspective. In addition to acting as sounding boards for my ideas, they have assisted in the proofreading of this thesis, and for these and many more reasons I am forever indebted.

My friends, whose understanding as I gradually withdrew from the social world and encouragement to spend time away from the computer to clear my head, have ensured I remain well-rounded and somewhat sane.

Finally I wish to express my gratitude to all the stroke survivors and caregivers who participated in and contributed to this project. Individual participant contributions cannot be acknowledged as pseudonyms have been used to ensure anonymity throughout this thesis. I acknowledge their ongoing strength, resilience and hope for those deeply affected by the sudden illness of a family member or friend. May their courage provide inspiration for all those who find themselves in disadvantaged and challenging circumstances.
TABLE OF CONTENTS

Abstract i
Author’s Declaration ii
Acknowledgements iii
Table of Contents v
Glossary of Key Terms Used vi

Chapter One Introduction
Background 1
The Sacred Heart Health Service – Rehabilitation Unit 2
Study Aims 9
Research Questions 11
Theoretical Frameworks and Approaches 11

Chapter Two Literature Review 18

Chapter Three Methodology
Recruitment 28
Mid-Term Report Card 29
Caregiver Interviews 31
Data Coding and Analysis 32
Limitations of Study 33
Ethical Considerations 34

Chapter Four Findings and Analysis
Participant Snapshot 40
Themes 43

Chapter Five Discussion and Conclusion
Implications for Social Work Practice 78
Suggestions for Mid-Term Report Card Content 80
Limitations of the Report Card 82
Implications for Future Research 84

References 86

Appendices
Appendix A: Family Conference Project Final report 90
Appendix B: Suggestions for family conferences from literature review 96
Appendix C: Interview questions and structure 97
Appendix D: Participant Snapshot 98
Appendix E: University of Sydney Ethics Approval 99
Appendix F: St Vincent’s Hospital Sydney Ethics Approval 101
Appendix G: Mid-Term Report Card Template 104
Appendix H: Participant Information Statement and Consent Form 106
GLOSSARY OF KEY TERMS USED

**Caregivers**
Family members or friends identified by patients as responsible for providing care (physical or emotional) in hospital and in the community. They are often not remunerated for this support unless receiving a Government pension for this purpose, unlike a paid care worker from an agency.

**Participants**
Caregivers who participated in the study.

**Family conference**
A meeting conducted as usual practice for stroke survivors at the Sacred Heart Health Service (SHHS) prior to discharge, but available to any rehabilitation patient on request of a team member, patient or family member. At SHHS this involves every member of a patient’s treating team (nursing, medical, allied health), in addition to the stroke survivor and any family involved or interested. Patients and families have an opportunity to meet the treating team, receive feedback specific to their progress, ask questions, and engage in problem-solving and discharge planning.

**Functional independence**
Capacity to complete tasks of daily living, with or without assistance. The FIM™ (Functional Independence Measure) is an 18-item ordinal scale used with all diagnoses within a rehabilitation population. It analyses a patient’s capacity to perform and engage in physical and cognitive tasks that are observed by the treating team, including bathing, dressing, walking, continence, memory and social interaction, and is the most widely accepted functional assessment measure in use in the rehabilitation community. A higher FIM indicates a greater functional independence, and therefore reduced reliance on caregivers both in hospital and on return to the community.

**Interdisciplinary team**
Includes all clinicians responsible for patient well-being and functioning, including doctors, nurses, physiotherapists, occupational therapists, social workers, speech pathologists, dietitians, clinical psychologists, neuropsychologists, and pharmacists. Mutual respect for defined roles exists within the interdisciplinary team and an acknowledgement that all members are working towards a common patient-centred goal.

**Thrombolysis**
The process of administering the drug rt-PA (alteplase) intravenously or interarterioly to dissolve a blood clot.
Chapter One - Introduction

Background

A stroke occurs when blood supply to the brain is interrupted, depriving cells of oxygen and nutrients (National Stroke Foundation, 2012, para. 1). This may occur because of an artery blockage (ischaemic stroke) or if an artery bursts (haemorrhagic stroke). Every stroke is different, and every person affected by a stroke will have different problems and different needs, depending on which area of the brain is affected and the severity of the stroke, as well as factors independent of the stroke such as age, general health, and co-existing illnesses. Physical deficits produced by a stroke can include difficulty moving, receiving sensory messages (such as touch, sight or smell), understanding and using language or thinking.

Regardless of whether the stroke survivor has had previous strokes, health problems or existing risks, being told a family member or friend has had a stroke can be overwhelming. A caregiver can provide physical, practical or emotional assistance after a stroke. Carers must also maintain their own health and receive relevant and detailed information about the stroke survivor's condition and prognosis to assist them in undertaking this new role. Stroke rehabilitation aims to equip stroke survivors and caregivers with feedback and involve them in therapy sessions, training of practical care requirements, goal setting and discharge planning, in order to meet their specific needs and minimise disruption to education, employment, social participation and everyday tasks. Rehabilitation can be an emotionally and physically draining experience, and health professionals recognise that this upheaval does not end at discharge from hospital.
Stroke is a significant health problem. It affects one in every six people in Australia, and 65 percent of those living with stroke also suffer a disability that impedes their ability to carry out daily activities unassisted (World Stroke Organisation, 2013, and Deloitte Access Economics, 2013, as cited in National Stroke Foundation, 2013, para. 1). Stroke poses a significant burden on patients and their families as well as on the health system and aged care services with about half of stroke survivors requiring assistance with health care, household chores, home maintenance, mobility and transport, and around one in four needing help with self-care, cognitive or emotional tasks, meal preparation and paperwork (Senes, 2006, p. ix). More than half of primary carers spent 40 hours or more each week in their caring role and for about one in four their caring responsibilities adversely affected their income (Senes, 2006, p. ix). Much of stroke research focuses on preventing and treating stroke, with comparatively little research undertaken on the ways individuals respond to strokes, and in particular the experiences of caregivers in reconstructing and managing their everyday lives once having taken on this new role. It was hoped that this new research would contribute to understandings on how individual caregivers of stroke survivors identify and manage the challenges and opportunities of life after stroke, and the ways in which health professionals may assist them in this process.

The Sacred Heart Health Service – Rehabilitation Unit

The Rehabilitation Unit of Sacred Heart Health Service (SHHS), formerly the Sacred Heart Rehabilitation Service (SHRS), is a facility of St Vincent’s Hospital in the Sydney suburb of Darlinghurst. SHHS is a sub-acute 32 bed facility providing comprehensive rehabilitation programs to assist people to achieve maximum potential physically, functionally, psychologically and cognitively when recovering
from an injury, illness or surgery. Treatment is provided through a coordinated interdisciplinary approach, with emphasis on evidence-based practice to support positive functional outcomes while reducing each patient’s hospital length of stay where possible. The SHHS consultants admit patients from the acute wards of St Vincent’s Hospital, from other hospitals around Australia, and from the community. Patients have a broad range of cultural, linguistic, education, socio-economic and ethnic backgrounds, with some being visitors to Australia at the time of illness onset, and others have travelled to Sydney for specialist surgery unavailable in their own countries. Four rehabilitation physicians provide specialised consultation in different areas of medicine including orthopaedic, geriatric, vascular/transplant and neurological. Stroke survivors make up a large proportion of the people admitted to SHHS for rehabilitation.

The importance of holistic care for patients undergoing stroke rehabilitation in sub-acute settings is becoming better recognised in both literature and clinical settings, and there is greater acknowledgement of the importance of family involvement in improving patient outcomes (National Stroke Foundation, 2010). Hospital family conferences are important and beneficial for communicating progress and therapeutic findings, and to facilitate problem solving for complex discharge planning, particularly in the stroke rehabilitation setting (see Brauer, Schmidt & Pearson, 2001; Duncan, Zorowitz, Bates, Choi, Glasberg, Graham, Katz, Lamberty & Reker, 2005; Kalra, Evans, Perez, Melbourn, Patel, Knapp & Donaldson, 2004; Louie, Liu & Man, 2009; Stein, Shafqat, Doherty, Frates & Furie, 2003). They provide an opportunity for family members to raise concerns and gain valuable feedback from the treating interdisciplinary team. They are also instrumental in future care coordination and
communication of ongoing care needs. Despite agreement that these opportunities are beneficial, there is little research or tested knowledge on the subject, specifically in the area of stroke rehabilitation (Friedemann-Sánchez, Griffin, Rettman, Rittman & Partin, 2008).

A quality improvement project on the importance of family conferences was carried out at the SHRS in 2006 and 2007 (Rollinson & Gilad, 2010). The project reviewed the effectiveness of family conferences and involved staff, patients and family members. Participants completed questionnaires before and after a family conference to examine the perceived benefit of the meeting from each perspective and to compare understanding of rehabilitation outcomes following feedback on progress, discussion with the treating team, and collaborative discharge planning. Results of this project demonstrated clear benefits of family conferences for patient and caregiver understanding of the therapy and discharge support roles of each member in the multidisciplinary team (unpublished, Appendix A).

Ideally, teamwork involves the definition of common goals and the development of a plan to which each team member makes a different but complementary contribution towards the achievement of the team’s aims (Hunt, 1979, in O’Hara & Weber, 2006, p. 13). Ovretveit (1997a, in O’Hara & Weber, 2006, pp. 230-231) distinguishes between the multidisciplinary or ‘coordinated professional team’ and the interdisciplinary or ‘collective responsibility team’, suggesting the multidisciplinary team comprises a network of professionals who deliver separately organised services, whereas the interdisciplinary team consists of a group of professionals who work closely together and take shared responsibility for their work. Within this model,
team decisions and referrals are negotiated at both a formal and an informal level, there is joint service delivery with close interaction and collaboration, roles are clearly understood and any negative use of power is challenged (Ovretveit, 1997a, in O’Hara & Weber, 2006, p233).

The SHHS employs a team of social workers to assist patients and families undergoing inpatient rehabilitation to understand and adjust to their illness in the context of their social circumstances and stressors, by working through the emotions of a diagnosis, providing counselling to facilitate and support decision-making, and planning adequate care in the community on discharge from hospital. Stroke survivors often experience extreme fatigue that can affect motivation for rehabilitation and getting back to normal. Social life and relationships, both within and outside the family are changed irrevocably. Partners and children become carers, and it can be challenging for both stroke survivors and their caregivers to maintain or develop new social relations and activities.

Social workers are essential members of this interdisciplinary hospital team, raising the awareness of other health care providers to the social and emotional aspects of a patient's illness. The researcher is one of the social workers in this team and brings to the study four years’ experience in this role including an understanding of the environment, the role of the other team members, as well as the organisational and team culture. This knowledge and experience brings an in-depth understanding to the study. As a practitioner the researcher has an interest in the outcomes of this study through an insider’s perspective on the potential benefits of such a resource for the patients and families. The social work role is pivotal in providing appropriate
and timely communication to caregivers of stroke survivors in a format that aids understanding, thereby improving rehabilitation practice and the experience of caregivers. Social workers located within this practice field bring together knowledge and frameworks that empower families through improving communication and enhancing relationships within the treating interdisciplinary team.

At the SHHS family conferences are usual practice for stroke survivors, and usually coordinated by the treating social worker. In attempting to provide information and reduce power disparities for often already distressed and vulnerable stroke survivors and family members, it is common practice for the treating social worker to provide a formal invitation to a family conference. This invitation is a simple double-sided sheet of paper that provides the details of the agreed upon family conference time, date, venue, as well as a contact person within the rehabilitation team and their phone number. The invitation provides a brief explanation of the format, agenda and reasons for a family conference, and encourages the stroke survivor and family member/s to make note of specific questions they wish to ask or comments to make during the meeting, as well as a space in which to make note of these. During the family conference the treating social worker keeps a record of the discussion, and further planning, and provides a copy to family members. This enables those attending the meeting to be fully engaged in this discussion and not distracted by the need to take notes. Family members are then encouraged to spend additional time with the social worker after the meeting to clarify understanding of the discussion and plans, as well as offered ongoing opportunities to revisit the issues and decisions documented if required later in the rehabilitation admission.
It is common for family conferences at the SHHS to run for 45 minutes or longer, and involve numerous team members including the treating consultant, medical registrar, resident medical officer, physiotherapist, occupational therapist, social worker, speech pathologist, dietitian, nurse, clinical psychologist and/or neuropsychologist. The meeting is usually chaired by the treating consultant, and information is provided by each member of the team to family members and friends present. Caregivers are then invited to enquire about specific aspects of assessments and recovery, and to be involved in a process of problem-solving and planning for the remainder of the rehabilitation admission. At SHHS family conferences are usually held in the second half of the rehabilitation admission, and are used primarily as a discharge planning tool. It is common for family members not previously involved in the stroke survivor's rehabilitation to attend these meetings, many of whom may be receiving feedback about the effects of the stroke for the first time, particularly if they are not the primary contact people liaising with the interdisciplinary team. Prior to this study many caregivers had expressed a desire to have feedback on rehabilitation progress and difficulties earlier on in the admission, although this can be difficult to obtain if they are not able to attend the ward during therapy times. Informal feedback received previously from the SHHS outpatient team suggested there have been many requests for ongoing support of caregivers of stroke survivors on leaving the hospital environment, and it is possible some of these concerns could have been addressed while still part of the inpatient service. The researcher conducted a literature review to better understand the purpose of family conferences in other hospital settings, focusing on stroke recovery, and found that these meetings alone perhaps do not meet the diverse information requirements of caregivers. It was suggested that more regular provision of feedback may be
required, and in different formats. Based on the literature review, this new study
design was developed, to investigate other methods of educating, supporting and
engaging caregivers participating in inpatient rehabilitation.

The SHHS is committed to research and development of its practice, particularly for
stroke survivors. There is significant support amongst medical, nursing and allied
health professionals for this study, as workers are committed to increasing their
knowledge base and further improving the reputation of the SHHS as a leading
rehabilitation provider. St Vincent’s Hospital is nationally and internationally
recognised as one of Australia’s leading hospitals, with this reputation further
enhanced by being a teaching hospital of two universities (St Vincent’s Hospital
Sydney, 2014, para. 1). The hospital is also a leader in the provision of new forms of
care and committed to serving the contemporary needs of the community. Each
discipline within the hospital is engaged in their own process of quality
improvement, encouraging innovative projects and studies designed to enhance the
service development and knowledge base for workers. Workers are regularly
encouraged to question or challenge existing practice methods and tools used to carry
out their roles, to the extent that new and innovative projects and research are
embraced. In recent years St Vincent’s and Mater Health has seen collaboration with
the Australian Catholic University Nursing Research Institute, a nursing-led but
interdisciplinary- and clinically-focused entity that prioritises outcome-oriented
research in healthcare locally and internationally. Through this partnership there
have been significant contributions to the area of stroke focusing on the experiences
of stroke survivors (St Vincent’s Hospital Sydney, 2013, para. 2). In particular, this
research has focused on implementing strict clinical protocols to ensure early
assessment of fever, blood sugar levels and safety swallowing in stroke survivors in the acute setting, as well as the importance of teamwork on the acute stroke ward in maximising outcomes (Middleton, 2012a, 2012b).

As a social worker, the researcher is interested in exploring how in this interdisciplinary setting, the rehabilitation team works to achieve its goals and how the patients’ goals are supported by this process. The study will explore the experiences of families and caregivers to inform current practices and support them in their caregiving roles. The latest National Stroke Foundation Clinical Guidelines for Stroke Management (2010, p. 41) recommend specific training should be provided to the patient and caregiver by the interdisciplinary team prior to discharge in order to improve preparation for the challenges of daily activities at home. This recommendation and the results of the literature review have informed the development of the current research.

**Study Aims**

This research included evaluation of a newly developed information and education resource for caregivers of stroke survivors undergoing inpatient rehabilitation at SHHS, the ‘Mid-Term Report Card’. The report card resource was developed by the researcher and the SHHS Director of Rehabilitation in response to outcomes and recommendations from a previously conducted literature review specifically interested in information requirements of caregivers following stroke (Loupis & Faux, 2013). It was designed to demonstrate a stroke survivor’s current capacity to promote understanding for caregivers of their progress, challenges and exercises to bring them closer to the rehabilitation process and the language used by therapists.
The purpose of this study was to invite caregivers to participate in qualitative research to collect information about how this new resource affected their self-reported rehabilitation experience and feelings of preparedness to take on this new role. In doing so it was hoped that suggestions could be developed about ways the social work service and rehabilitation service as a whole could be improved, both locally at SHHS and further afield. Of particular interest was feedback on the information requirements of caregivers upon receiving a stroke diagnosis, expectations of recovery, and involvement of families in rehabilitation activities. Considerable educational and communication opportunities were already provided for patients and caregivers (including family conferences) within the practice environment, but limited formal research existed. It was anticipated that this research would make a valuable contribution to this field and in particular the rationale for using particular assessment tools and practices over others.

In keeping with social justice principles, this study aimed to promote participation in rehabilitation for caregivers, to consider them as members of the therapeutic team in a way that had potential to reduce gaps in knowledge and power relations for those who were significantly disadvantaged and vulnerable. Social work practice values respect and recognises that people have unique and inherent worth and should be afforded the right to well-being and self-determination (AASW, 2010). Feedback was sought from participants both formally and informally, and the direct information gathered has formed the bulk of the results. With this in mind, the research methodology outlined here encouraged participants to bridge the gap between the 'treated' and the 'treating', the vulnerable and the powerful, the excluded and included, expanding choice and potential.
Research Questions

1) What information or feedback is most relevant or beneficial to families of stroke survivors through their inpatient rehabilitation admission?

2) Is there information that best encourages involvement of families and caregivers in inpatient rehabilitation therapies, retraining and discharge planning?

3) Are there elements of the ‘report card’ resource that affect compatibility between initial expectations of recovery on admission to a rehabilitation setting, and outcomes achieved at discharge?

4) Is there an indication of the optimal timing of delivery of this resource given individual needs of family members?

5) How can social work practice be improved, taking into account this new resource, feedback from caregivers and new understandings, in context of the interdisciplinary team model?

Theoretical Frameworks and Approaches

A number of key social work theories and approaches inform social work practice in hospital settings and have also informed this study. These are crisis theory, strengths-based practice and systems theory. Crisis theory, assumes that we live in a steady state, able to cope with changes in our lives. “Crises upset the steady state and provide an opportunity for developing improved skills at managing problems” (Payne, 2005, p. 97). Stroke affects individuals and families often without warning, including previously healthy people. This sudden vulnerability can upturn previously active lives and challenge coping skills. “Sudden onset is important, in that carers do not have opportunity to prepare for their roles, and neurological
impairments have psychological consequences that impact on cognition, adjustment, personality, relationships and family functioning in a more direct way than physical illness” (Lincoln, Kneebone & Macniven, 2012, p. 363). Social work intervention, according to crisis theory, strives to restore equilibrium and reduce hazardous effects of the crisis while at the same time improving a person’s capacity to cope with negative events in the future. This can take the focus of efficacy in developing new adaptive techniques, competence to utilise existing skills or obtain assistance from others, or empowerment through self-direction and adoption of new strategies. Proactive social work support and education in the context of a newly diagnosed disability and the stressful experience of hospital and rehabilitation was expected to provide patients and their caregivers with confidence and knowledge to become actively engaged in this process and to feel better prepared to take on a caregiving role.

Independence and well-being following stroke can be greatly influenced by family function (and other complicating factors such as mood, anxiety, pre-existing medical conditions), uncertainty relating to physical changes, changes to social and family roles, perceived quality of life, the suitability of the physical environment including accommodation, and the availability and certainty of ongoing financial security (National Stroke Foundation, 2010). The dominant discourse in hospital settings is that of biomedicine, in which the underlying principles of assessment and treatment assume that accurate knowledge can only be achieved through direct observation of sensory information followed by prescribed intervention and treatment (Dacher, 1995). The limitations of the biomedical framework reinforces the importance of the social work role in these settings, and their responsibility in ensuring that social
perspectives of illness and the social determinants of health are captured thorough psychosocial assessments. At St Vincent’s Hospital both in the acute stroke unit and in rehabilitation, there is a blanket social work referral for every person admitted, further affirming the complex nature of health conditions and patients that require longer hospital admissions. The biomedical perspective traditionally does not effectively incorporate psychological, psychosocial, historical, cultural or spiritual factors that may affect a person’s experience of an illness or the rehabilitation process, and their responses to it. For the purpose of this study, however, the social work role was positioned within this field, which is very much 'intervention' and 'treatment' focused. Miller and Crabtree (2003, p. 401) argue that effective clinical research involves bringing the dominant medical world and the qualitative research community “outside their walls and finding common ground and common language”. They go on to suggest that if the usually unheard voices of clients, or patients in this realm are entered into the conversation as evidence, there is capacity for the clinical research space to expand and potentially transform (Miller & Crabtree, 2003). The epistemological positioning of this study questions the underlying assumptions of the bio-psycho-social framework in which a number of these social work theories are located, in particular the assumptions concerning carer roles and behaviour, their needs and expectations, and their relationships with members of the treating team. Considering the linked concept of ontology, or the way in which reality is constructed and understood, the bio-psycho-social framework adopts a positivist perspective where actions and behaviour are explained in specifically determined and anticipated ways. In this study an interpretivist approach is used to understand the carer perspectives through their own experience of it. In particular the meanings they attributed to changes in their own lives and changes in their relationships with the
stroke survivor and those with whom they came in contact, including the treating team and service providers (D’Cruz & Jones, 2012 pp. 49-52.)

This study therefore had capacity to affect changes in standard procedures for health professionals in the area of stroke rehabilitation, in addition to enhancing the experiences of the stroke survivors and caregivers supporting them.

This study design assumed that caregivers of stroke survivors bring their own experiences, resources and strengths to the rehabilitation context. The strengths perspective described by Saleebey (2006) recognises that many people suffer great adversity but at the same time it is believed they have within them the capacity and qualities they can use to shape fulfilling lives. The strengths perspective is often utilised by social workers in these settings and concentrates on enabling individuals to articulate, and work towards, their hopes for the future, rather than seeking to remedy the problems of the past or even the present (Healy, 2005, p. 152). This approach focuses on empowerment and partnership, and when used in the rehabilitation setting there is an acknowledgement that patients and families come into the health system with capacity to learn, develop skills, and potentially benefit from early feedback and discussion of expected outcomes following a period of inpatient rehabilitation. Accordingly each situation and trajectory of recovery is treated as unique. By moving away from privileging the ‘expert’ or ‘outsider’ knowledge, we can potentially move away from traditional forms of assessment, acknowledging what people bring with them in terms of their own ‘insider’ knowledge (Béres, Bowles & Fook, 2011, p. 89). Understanding of these frameworks/perspectives and situations within a healthcare setting brings value to the dual roles of social worker and researcher.
This project acknowledged that the life and functional capacity of a person affected by stroke may never return to their previous level of independence, but with personalised and timely support, communication and education, there may be better adjustment and new ways of coping with this new situation, with a focus on quality of life and hope, rather than disillusionment and despair. A holistic approach seeks to understand the person in their social context and to promote an optimal state of physical, mental and social well-being, not merely the absence of disease (Healy, 2005, p. 25). This concept is key to social work practice, with one of the anticipated outcomes of this research being to enhance understanding amongst healthcare professionals of the uniqueness of each stroke survivor and thereby the varied support and educational needs of their caregivers. Further investigation of caregiver requirements aimed to enhance feelings of empowerment and confidence to take on this new role.

Drawing from Systems Theory (Healy, 2005, p. 143), complex systems are considered extremely sensitive to altered conditions, such that small changes at initial phases in the system’s development can lead to substantial and complex changes in the behaviour of the system. In the inpatient rehabilitation context, it can then be assumed that purposeful social work engagement and support can lead to significant benefits for patients. From this perspective the potential benefits of making slight adjustments to current hospital practice can outweigh any initial disruption to routine or cost of producing effective resources. Intervention aims to cause minimal disruption and anxiety for caregivers, while potentially contributing to positive effects on functional improvement, feelings of preparedness, and reduced carer strain. This perspective also considers the family as a unit instead of the
individual as the focus of our interventions, and assumes children are affected by everything that happens in the family, and in particular the more serious the situation, the more they will be impacted (McCue & Bonn, 1994). This model is similar to crisis theory approaches in that it assumed balance in the family is disrupted when a parental medical crisis occurs. While an ill parent requires more time and concern, the child may also be demanding and require more attention than usual (McCue & Bonn, 2003, p. 50).

“Systems focus on connections between and resources of families and groups and their effective functioning” rather than seeing the family as helping or hindering the function of improving the health or well-being of the individual patient (Payne, 2005, p. 143). At the SHHS families and caregivers of stroke survivors are involved in care and decisions as much as possible, often being reassured that they are themselves members of the interdisciplinary team and therefore part of the ‘bigger picture’. Positive results are more likely when caregivers feel they are included, empowered and respected in collaboration with hospital staff (Brauer, Schmidt & Pearson, 2001, p. 91). Social workers in this setting are often used as trouble-shooters and problem solvers, encouraging accountability and integrity among health professionals, including those at a management level, reminding them of social obligations, patient rights, and ethical practice (Browne, 2001, p. 108). Involvement of caregivers in a qualitative research project aimed to encourage feedback on rehabilitation assessments and progress, as well as provide meaningful representation and analysis of a new resource that could be used to shape future healthcare based on a tested model and open dialogue.
Social workers in healthcare settings are well positioned to analyse existing practices and tools with relevance to social outcomes, drawing on their extensive understanding of biomedical terminology. This enables them to link perspectives and discourses for the benefit of patients and their families, and to use their interpersonal skills in interpreting and mitigating as much as possible the hospital environment, often taken for granted by those who work in it. This knowledge, according to Healy (2005, p. 19) can enable social workers to critically analyse their practice contexts and to identify opportunities to use dominant discourses for achieving positive outcomes for service users. This has potential for creating knowledge, understanding how people connect to social structure and power operations (Béres, Bowles & Fook, 2011, p. 90). The resource proposed here used terminology that is rarely found outside of the rehabilitation environment, although with an interdisciplinary approach and encouragement of a close collaboration between health professionals and caregivers, there was an opportunity to enhance understanding and thereby reduce existing power disparities.

It was hoped families would also develop a greater understanding through this process of their own capacities and future challenges, and be more confident in discussions with health professionals using this terminology. Feedback from participants about their experience would enable aspects of the service to be improved with an emphasis on collaboration in the rehabilitation process. They would ideally feel encouraged to help guide the rehabilitation process and provide regular feedback to the treating team about their experience and difficulties throughout the admission, exercising their right to self-advocacy and improving feelings of empowerment, thereby resuming the role of experts in their own lives.
Chapter Two – Literature Review

A systematic literature review on family conferences in stroke rehabilitation was undertaken by the researcher prior to commencing this university study (Loupis & Faux, 2013). The review gathered and analysed published material on the purpose and benefits of family conferences, including evaluation of their structure and effectiveness in providing information and feedback to families of stroke survivors. Guiding the review were questions around whether family conferences are effective in communicating information and feedback from interdisciplinary teams to stroke patients and their families, and ways in which the effectiveness of family conferences may be optimised. This review aimed to integrate and analyse current knowledge on family conferences in the inpatient stroke rehabilitation setting.

The literature review identified some key themes in providing a context for the development of the research questions for this current study. It has been presented in poster format at the 2011 Australasian Nursing and Allied Health Stroke Conference held at Surfers Paradise and the 2012 World Congress on NeuroRehabilitation held in Melbourne, and was published in the *Journal of Stroke and Cerebrovascular Diseases* online in January 2013 and August in print.

The 23 articles included in this study made specific reference to family conferences in clinical practice, identified stroke rehabilitation as the primary research area, made reference to the inpatient rehabilitation experience rather than outpatient or community approaches, and provided guidelines for clinical practice. They also provided suggestions for alternative support systems for stroke survivors and
caregivers, and referred to an interdisciplinary approach to rehabilitation. The articles demonstrated commonalities in themes and ideas.

Some authors suggest that patients and families have additional education and support needs beyond what is already provided (National Stroke Foundation, 2010; Duncan, Zorowitz, Bates, Choi, Glasberg, Graham, Katz, Lamberty & Reker, 2005, p. e103; Fronek, 2008, p. 28; Louie, Liu & Man, 2009, p. 195; Brereton, Carroll & Barnston, 2007, p. 868; Clark, Rubenach & Winsor, 2003, p. 704; Bhogal, Teasell, Foley & Speechley, 2003, p. 115; Smith, Forster, House, Knapp, Wright & Young, 2008, p. 2; Hill, 2005, p. 24; Pierce, Finn & Steiner, 2004, p. 14). One study found that information packages alone are not generally associated with improved outcomes, and that additional social support interventions such as active education and counselling were associated with improved patient and caregiver outcomes, as caring for stroke survivors in the community often has a dramatic effect on family functioning and caregiver burden (Bhogal et al., 2003, p. 115). This raises the question, then, about what information is required, what type of support is beneficial at that stage in recovery, and who should be providing this?

The National Stroke Foundation guidelines recommend specific training should be provided to the patient and caregiver by the interdisciplinary team prior to discharge in order to improve preparation for the challenges of daily activities at home (2010, p. 6). A Cochrane review of effective information provision following stroke examined randomised trials in which the intervention group of stroke patients or caregivers were provided with a course of lectures (Smith et al., 2008, p. 11). Results indicated reduced depression when provided with additional information
about severity of stroke, therapeutic interventions, and expected outcomes, as well as feedback opportunities. With the provision of additional information, perceived caregiver burden also significantly reduced and quality of life of stroke survivors and caregivers significantly improved when reviewed at three and twelve months following discharge (Smith et al., 2008, p. 9). Providing active problem solving intervention and educational resources as preventative measures resulted in fewer incidents of depression and anxiety among caregivers and enhanced knowledge, compared with control groups (National Stroke Foundation, 2010, p. 6; Kautz & Van Horn, 2009, p. 168; Brauer, Schmidt & Pearson, 2001, p. 91; Bhogal et al., 2003, p. 115; King, Hartke & Denby, 2007, p. 68). This would suggest that providing education and information to stroke survivors and caregivers in a clear and succinct way may improve understanding of the impact of the illness, thereby improving understanding of a stroke survivor’s abilities and difficulties.

Stein, Shafqat, Doherty, Frates & Furie (2003, p. 173) suggested that caregivers with better understanding of a stroke survivor’s functional capacity may have increased potential to make accurate predictions around recovery, and therefore may experience less stress than those without this information. Studies demonstrated that family support is associated with progressive improvement for rehabilitation patients (both physically and psychologically), and greater communication as an interdisciplinary team with caregivers can reduce psychological stress and facilitate better adjustment to an illness or disability, thereby improving quality of life and long-term outcomes (Hudson, Quinn, O’Hanlon & Aranda, 2008; Griffith, Brosnan, Lacey, Keeling & Wilkinson, 2004, p. 578; Louie et al., 2009, p. 195; Kautz & Van Horn, 2009, p. 169). It can be equally assumed that understanding of a poor
prognosis could lead to heightened levels of stress, although the emphasis here is on providing caregivers with as much information as possible early on in the stroke recovery to afford them time to absorb the feedback and reflect on the implications this might have on their independence and lifestyle. There is a significant role to play here for social workers in supporting a caregiver following diagnosis, particularly around advice, advocacy and service coordination.

A common theme of the articles reviewed was that much of family involvement that occurs in rehabilitation is reactive rather than proactive. This indicates clinicians spend much of their time responding to specific issues or crises rather than addressing concerns pre-emptively to prevent miscommunication or distress. Often patients and caregivers are not provided with necessary information about the patient’s condition and progress, and the caregiver does not always understand the purpose of stroke rehabilitation and its role specifically in relation to the person receiving care (Louie et al., 2009, p. 192; Hill, 2005, p. 21). Although health professionals are expected to ‘have all the answers’ or are perceived to be the experts, when it comes to illnesses and effective methods of overcoming these, it may assist caregivers to receive information about the particular assessments and tools used to support stroke survivors to return to independence, so that they can understand more about the process, and the rationale for using certain strategies over others, thereby enhancing knowledge and reducing uncertainty. Power disparities in family conference settings, such as an unwelcoming environment or differences in knowledge of stroke rehabilitation and projected outcomes, can influence confidence and capacity for the patient and caregivers to participate.
Most authors agree that family conferences are time-consuming for the interdisciplinary team and families involved, and therefore strategies to encourage better time management were suggested. Donnelly, Carter-Anand, Gilligan, Mehigan & O’Neil (2008, p. 7) describe family conferences as successful when their purpose has been effectively communicated, good time management has been utilised, and all participants are involved in the decision-making process. Hansen, Cornish & Kayser (1998, p. 61) agree that greater clarification of the agenda of each family conference is beneficial, and that additional smaller meetings to the larger family conference (held either before or after, and usually with a social worker) would provide more regular problem-solving opportunities, again promoting the preventative approach. Here social work intervention is highlighted for its capacity to assist stroke survivors and their caregivers in preparing for discharge, and because social workers have an appreciation of the social, financial and emotional context of each caregiver, they may also be able to identify and respond to sources of conflict and carer strain. At the SHHS it is expected that the social workers will play a significant role in each family conference, including negotiating a time and day that is appropriate for the rehabilitation team and the family, providing an invitation to family members and discussing the purpose and agenda of the meeting, taking notes during the meeting to provide to families for later reference, as well as providing emotional and practical support for the remainder of the admission.

There is some debate in the literature as to when information and rehabilitation feedback should be provided to caregivers. Eight articles made suggestions for the most beneficial and appropriate timing of family conferences throughout patient admission (National Stroke Foundation, 2010, p. 8; Duncan et al., 2005, p. e106;
Providing information regarding long-term prognosis shortly after admission to rehabilitation may be difficult and fraught with inaccuracy, as participation in rehabilitation, natural recovery and efficacy of high intensity therapy are yet to be tested. Given the time taken to plan, facilitate and assist with resulting concerns or the ‘aftermath’ from a family conference, for most inpatient rehabilitation facilities it is not realistic to hold numerous family conferences for the same person. The literature therefore would suggest that health professionals must be creative and resourceful in their information provision, to allow more regular updates and feedback to be provided to caregivers.

Caregivers assume their role suddenly and most families of patients undergoing physical rehabilitation are subject to a great deal of stress, largely relating to lack of information and carer burden (Louie et al., 2009, pp. 194-195). Rates of depression and anxiety amongst caregivers are often high, and health professionals (and in particular social workers) are ideally positioned to monitor this and develop strategies to decrease strain where possible (Duncan et al., 2005, p. e106; Brauer et al., 2001, p. 90; Hill, 2005, p. 24; King et al., 2007, p. 68). The National Stroke Foundation and Amador et al (2010, p. 8; 2007, pp. 129-131) recommend patients and caregivers be provided the opportunity to be involved in discharge planning.
where needs can be identified, goals devised and plans specified, serving to increase satisfaction with the care provided, as well as increase feelings of preparedness. It is important to be mindful, of competing demands on family members throughout inpatient rehabilitation, and that some caregivers may not be able to become involved in everyday ward activities or goal setting or discharge planning. Social workers in these instances may act as negotiators, allowing a dialogue to develop between caregivers and the rehabilitation team, to ensure that those not able to participate physically on the ward may still have input into care planning and skill development.

Donnelly et al (2008, p. 10) suggest that professionals providing direct care require better education themselves to consider appropriate approaches to improving participation and engagement in practical and social activities. Quality assurance data from the SHHS (Rollinson & Gilad, 2010) indicate that a proportion of health professionals in interdisciplinary teams working in stroke rehabilitation do not receive formal training to conduct family conferences and many express anxieties about ensuring they run well, particularly as the decision making process, discharge planning outcomes and levels of satisfaction can be variable. There appeared to be a clear need for best practice guidelines to alleviate stress on caregivers and patients, provide information regarding stroke rehabilitation and make plans regarding discharge. From this review, a best practice guideline for family conferences during stroke rehabilitation was proposed that may minimise carer burden and stress and optimise patient engagement with the discharge planning process and successful community reintegration (Appendix B, cited in Loupis & Faux, 2013, p. 892).
The authors cited in the literature review agree that family conferences are important to the rehabilitation process, although much more can be done to ensure professionals provide the best possible care throughout the inpatient admission and on return to the community. The articles highlight that more personalised and concise information, delivered in a timely fashion, and with a more preventative approach, could promote better short- and long-term outcomes. Patients and their families may benefit from closer involvement in discharge planning to reduce caregiver burden and stress. Other interventions such as a social work consultation, appointment of a contact person in the treating team to provide feedback on rehabilitation progress, the provision of written and/or electronic information on the roles of assessment, timetabling and expectations of stroke rehabilitation may assist in reducing caregiver and patient anxiety early in the stroke rehabilitation process. The literature review informed the current research design and questions by providing a picture of current gaps in practice and knowledge, as well as suggestions of the types of changes that could be implemented to improve understanding and confidence of caregivers. This new research has taken a creative approach to informing caregivers of stroke survivors, attempting to further engage them with the rehabilitation process and therapies, through a central contact person and single resource.
Chapter Three - Methodology

This study used a qualitative approach to research that lends itself more readily to exploration of participants’ experiences and enhances the richness of the feedback available through interviews. Qualitative research can be defined by its methods and its grounding in methodological assumptions. Rolfe (2006, in Porter, 2007, p. 80) suggests qualitative research uses verbal and textual data and interpretivism and constructivism assumptions in contrast to quantitative research that relates to numerical data and realist or positivist assumptions. An interpretivist approach to data analysis using thematic and inductive approaches supported the epistemological positioning of the study enabling a richer understanding of participants’ experiences.

In designing this qualitative study there was a conscious attempt to minimise opportunities for reactivity and bias on the part of both the researcher and participants, and in turn enhancing the trustworthiness of the design and analysis. One strategy used here was that of prolonged engagement, as described by Lietz, Langer & Furman (2006, p. 441), who suggested a number of methods a researcher may engage in order to describe research findings in a way that authentically represents the meanings expressed by the participants. The idea of prolonged engagement stems from anthropological fieldwork and assumes that engaging in prolonged interventions with participants may increase rapport, thereby encouraging participants to be more open in their interactions with the researcher (Padgett, 1998, in Lietz et al., 2006, p. 453). From a social constructivist approach, there was opportunity for participant responses to be richly descriptive, with their own language used to express their reality (Teater, 2014, p. 78).
Engaging in strategies that seek to build rigor in qualitative research is unlikely to negatively affect the creativity or flexibility of a study, rather this allows participants’ perceptions and experiences to be placed at the highest priority. The researcher is interested in how people make sense of their experience in the rehabilitation context, and therefore data can be gathered to build further concepts and theories through observation. Social workers are responsible for bringing awareness to new perspectives, and in order to do this, they must incorporate strategies into every intervention that will allow management of threats to trustworthiness (Lietz et al., 2006, p. 456). One strategy may be reflecting on the ways in which training and experience as social workers and assumptions brought with us to a particular situation, may lead to approaching a scenario in a specific way or to misinterpret the meaning behind caregiver feedback or responses. This is fundamental to qualitative research in that it is expected that meaning is socially constructed by individuals in interaction with their world (Carey, 2012, p. 75). Reality is not the fixed, single, agreed upon, or measurable phenomenon that it is assumed to be in positivist, quantitative research (Merriam, 2002, p. 3).

A study design was developed to fit the underlying research questions and logic, while articulating the specific purpose and aims of the study. In keeping with a qualitative approach, the study did not begin with an hypothesis to test, but with something that is not yet well understood, in this case a desire to understand how certain events affect individuals and how they make sense of them, acknowledging that people are active participants in developing their knowledge of the world (Teater, 2012, p. 77). There were no statistical inferences made about the characteristics of this stroke population, but instead this research was designed with
the aim of gaining insight into social processes and the rationality underpinning certain actions and events (Alaszewski, Alaszewski, Potter, Penhale & Billings, 2003, p. 11). The research design, methods, data collection and analysis were made transparent at each stage of this study and with approval of and in accordance with the ethics requirements. Completion of this thesis aimed to maximise accessibility for health care professionals in carrying out their work with stroke survivors and their families.

**Recruitment**

Ethics approval for this study was received from the University of Sydney on December 11 2012 and from St Vincent’s Hospital on February 8 2013. For this study caregivers of all patients admitted to SHHS following stroke were provided with a Participant Information Sheet by the treating nurse following the initial social work intervention and assessment. Social Work assessments ordinarily are conducted with stroke survivors themselves within two working days of their admission to the rehabilitation unit, although the caregiver in some instances was not approached until two or three days after this, and only once consent to contact a caregiver or person responsible was provided by the stroke survivor. The researcher identified caregivers for potential participation with the nursing staff, after which caregivers were invited to join the study by contacting the researcher directly or their nurse, with an emphasis on voluntary recruitment. Participation of up to 10 caregivers was considered possible within the time frame allocated. Recruitment began in February 2013, with the last participant recruited in September 2013. For caregivers to be eligible for inclusion in this study, the stroke survivors must have been transferred to rehabilitation directly from another acute hospital following
stroke (that is, not admitted from the community for assistance related to a previous stroke). The type of stroke suffered was not considered important for this study. Demographic data (such as participants' age, gender, ethnicity, site and size of stroke, co-morbidities, medications and acute interventions including thrombolysis) was obtained to provide a contextual snapshot of participants and the stroke survivors for whom they were caregivers.

**Mid-Term Report Card**

Ten participants were provided with a personalised ‘Mid-Term Report Card’ by the treating social worker half-way through their rehabilitation admission as estimated by the Australian National Sub-Acute and Non Acute Patient, or AN-SNAP, classification (The Australian Health Services Research Institute, 2012), based on functional capacity on admission to the ward. The report card template was edited by the researcher with information provided by each stroke survivor’s treating team and included details of balance assessments such as the Berg Balance scale (Berg, Wood-Dauphinee, Williams & Maki, 1992), muscle strength (manual muscle testing), mood and anxiety (Depression Anxiety and Stress Scale, Lovibond & Lovibond, 1996), activities of daily living and the Functional Independence Measure (Wright, 2000), continence, cognition and any other relevant medical progress. All measures and comments on the report card were explained in simple terms with the aim of providing meaningful feedback. If necessary, the report cards could have been translated into languages other than English, however none of the participants in this study required language assistance.
Family conferences were also held for participating families towards the end of the admission if requested by either family members or the treating team, in keeping with usual practice. Participants were encouraged to discuss concerns and comments with the relevant therapists throughout the remainder of the admission. As the social worker assigned to all but one of these stroke survivors, the researcher also provided regular informal updates to the study participants following weekly case conferences with the rehabilitation team, in keeping with the usual method of support.

The sample size was small and not necessarily representative of a general caregiver population, although sufficient for this study in which we were more interested in understanding the social reality or interpretation (finding the meaning that participants ascribe to their situations), than recognising patterns in behaviour or results. Alston and Bowles (2002, p. 87) suggest a small sample size is “useful and justifiable when the researcher is seeking information in a new area and targets subjects or cases who typify the issue to be studied”. The sample was intended to reflect the issues being investigated from the caregiver perspective, and therefore a convenience/availability sample determined by access and availability was considered appropriate. Due to time limitations related to completing the Master of Education (Research) degree, this study focused on the experiences of caregivers only. It may be possible for future studies to include the perceptions and narratives of stroke survivors themselves. This new research was not aimed purely at exploring current practice and increasing knowledge and understanding, but with implementing a new tool and gathering feedback on its effect and capacity to support caregivers participating in stroke rehabilitation, potentially bringing about change in communities and programs.
Caregiver Interviews

Four weeks after discharge from SHHS each caregiver participated in an interview with the researcher, by which time the clinical relationship had concluded. While all participants were invited to attend a face-to-face interview, only one participant, who lived close to the hospital, attended the rehabilitation ward in person, while the remaining nine participants preferred to be interviewed by telephone. Eight of the caregivers lived in Sydney, but not close to Darlinghurst, while the remaining participant lived on the South Coast of NSW, and therefore having the capacity for telephone interviewing for geographically scattered participants was an advantage. Literature on telephone interviewing suggests that when the interviewer is unknown, respondents are less likely to be cooperative (Howard, Meade, Booth & Whall, 1988, p. 45). In this study all participants were familiar with the researcher from the stroke survivor’s inpatient rehabilitation admission and this reduced any potential negative affect. It also aided the other difficulty in telephone interviewing which is the inability of the researcher to observe non-verbal communication. To address this difficulty the researcher conducting the interviews gave greater attention to language and expression and included clarifying questions to elicit and ensure that meaning was understood. The advantages of telephone interviewing may include the participant not reacting to environmental stimuli (by returning to the rehabilitation ward, a potential source of negative emotions), and while the researcher was explicit about the interview being recorded, the actual recording was not visible, and therefore participants may have felt less threatened or intimidated (Ibsen & Ballweg, 1974, p. 185). The semi-structured interviews were in keeping with the bottom-up approach to this study, and the questions related to the overall research questions (Alston & Bowles, 2003). Particular emphasis was placed on the perceived benefit
of provision of the report card, and feedback from caregivers regarding the
information and feedback they felt most adequately prepared them to assume their
caregiving role. The interviews involved the same set of key topics for discussion, in
addition to suggestions for probes or prompts and summary techniques to ensure
understanding of what has been said (Appendix C).

Interviews were recorded using a Digital Voice Recorder and transcribed by the
researcher. Transcripts were then analysed to examine the perceptions of the
participants and how they gave meaning to their experiences. Liamputtong (2009)
asserts that it also provides opportunities for the researcher to probe and explore
concerns and experiences in greater depth, and to clarify responses immediately.
This is evident in the differences in interview length, with the sessions lasting
between 25 and 60 minutes each.

**Data Coding and Analysis**

Data from ten interviews were analysed drawing on thematic networks as described
by Attride-Stirling (2001). This is a way of organising a thematic analysis of the
interview data. “Thematic analyses seek to unearth the themes salient in a text at
different levels, and thematic networks aim to facilitate the structuring and depiction
of these themes” (Attride-Stirling, 2001, p. 387). A coding framework was first
devised using participants' own language, and text dissected on the basis of the
theoretical interest guiding the research questions or issues arising in the text itself.
Abstract themes were then identified, refined and arranged (Attride-Stirling, 2001, p.
392). Interviews were interpreted through identification of patterns, trends and
explanations, leading to conclusions which could be tested through more data
collection, reduction, organisation and interpretation, until no more new insights or information could be generated.

In the process of uncovering the themes, concepts, patterns and structures that arose in the participant interviews, the researcher could then return to the original research questions to explore the existing organisational practices and analyse these new experiences in order to share new perspectives and possibilities and make a useful contribution to the knowledge in this field. Attride-Stirling (2001, p. 403) suggests “the value of qualitative research lies in its exploratory and explanatory power, prospects that are unachievable without methodological rigour at all stages of the research process – from design, to field work, to analysis.” To this end, returning to the original research questions and the theoretical perspectives guiding these, new arguments could be presented grounded in the patterns emerging in the exploration of the interviews.

**Limitations of Study**

It was not assumed that all participants would view all of the information and measurements on the report card as important or noteworthy. This resource was intended only as a guide, and it was expected that families would use this as a communication tool for discussing other concerns. Participants were given the opportunity to discuss additional concerns or outcomes throughout the remainder of the rehabilitation admission and at the family conference prior to discharge. The literature review summarised in chapter two indicates that some information does not become relevant or cannot be absorbed until after discharge from hospital, and therefore this written feedback may prove useful upon return to the community.
Ethical Considerations

Caregivers were invited to participate in the research through provision of verbal and written information about the study in plain language to enable them to provide informed consent. The expected outcomes and potential risks and benefits of taking part were transparent at each stage in order to promote informed decision making. In order to reduce the risk of coercion it was made clear to caregivers that if they declined to participate, they would not be disadvantaged in any way, and the stroke survivor would continue to receive care as usual by the SHHS interdisciplinary team. During the recruitment period there were 15 caregivers identified as being appropriate participants in the study. All were approached and provided with the introductory letter, the Participant Information Sheet and a verbal explanation of what the research would involve. Ten caregivers agreed to participate. The researcher was at all times mindful of ensuring the professional integrity of the study and a responsible use of power was maintained with vulnerable participants. This study design anticipated that stroke survivors and their caregivers would benefit from access to this additional resource, and it was not expected that this would cause any further harm or distress, although inclusion and continued participation in the study needed to be a voluntary decision. The semi-structured interviews were conducted following the conclusion of inpatient treatment and included key themes to be explored with allowances for more in-depth prompts depending on the participants’ responses. The researcher was clear about the purpose of the interviews and communicated that responses would in no way affect the care the caregiver or the stroke survivor received.
As the researcher is also a clinician in this research field, there is an inherent overlap between the two roles. This can be viewed as both a strength and a limitation of the study design. As a strength qualitative research requires interpretative and explorative tools in order to create methods, guidelines and techniques, as well as “for the exchange of ideas, concepts and experiences” (Attride-Stirling, 2001, p. 403). Without a thorough understanding of the rehabilitation environment and without the existence of professional relationships between the researcher and the medical, nursing and allied health workers on this ward, the researcher would likely not have capacity to gather as much detailed information about each stroke survivor and their progress as would be required for the Mid-Term Report Cards. The process of obtaining this information requires an understanding and trust between the researcher and the workers that this method of communication, which essentially exposes the everyday practice and impressions of health professionals for a vulnerable group of patients, has potential to improve outcomes for not only the current stroke survivors but also future rehabilitation inpatients. As a limitation in the study design, participants who may have wished to discuss their interactions with the social worker as a member of the interdisciplinary team may have felt constrained to do so. However overall the study was considered to contain low to minimal risks for participants and these issues could be accommodated in the provision of additional independent social work support for participants negotiated by the researcher if required.

Abraham and Purkayastha (2012, p. 133) on translating knowledge to practice, suggested:
Altering what is to be known, and how one should alter practices based on this knowledge – especially the new indicators, or practices of data gathering and dissemination – brings less visible groups and their knowledge ‘to the table,’ in new configurations, to alter, in turn, power imbalances, and work toward achieving social justice and social change.

It was expected that this research will only strengthen existing professional relationships and commitment, and assist in reducing perceived or real power imbalances by encouraging closer interaction with healthcare professionals and a greater understanding of stroke recovery and the caregiving role as it relates to each individual.

Data gathered during the course of the interviews was not intended to provide explanations of certain phenomena or generalisations of these findings to larger stroke survivor or caregiver populations. The flexible research design had the capacity to maintain trustworthiness of the study and analysis by allowing the researcher’s existing knowledge of the environment and potential participants to inform the methodology and research questions. In this research context the researcher could reflect on existing literature and her own practice in order to help make meaning of practice methods and reconnect with what seems most important (Béres, Bowles & Fook, 2011, p. 82). This reflexivity of research design refers to a circular relationship between influence and feedback. That is to say, examination of current practice in this clinical area has the capacity to affect the way the researcher conducts the interviews, collects the data and analyses results and themes (Béres, Bowles & Fook, 2011, p. 84). Reflexivity was also important for the researcher to ensure the integrity of the epistemological positioning of the study given that it was
being conducted within a setting where competing perspectives were dominant. Adopting a reflexive stance enabled the differing knowledge frameworks to be considered through a more critical lens.

At the same time, understanding reflexivity in this context further highlights the need for qualitative research methods in this clinical area, where outcomes and experiences can be so variable. This research design encouraged participants to make meaning from their experience, tell their story, and reflect through their own narrative (Béres, Bowles & Fook, 2011, p. 83-4). For participants discussing difficult topics such as grief and loss, time was available during and following the interviews to debrief and offer information or education on additional resources. This flexibility was beneficial for maintaining rapport and ensuring the caregivers were supported and engaged at every stage of the study.

The interview questions were the same for all participants and additional prompting questions were used to ensure there remained a logical flow to each interview. Throughout the stages of research design, recruitment, provision of the information resource, interviews and analysis, reflexivity was supported through research supervision and regular opportunities to discuss the process and findings. In addition, the researcher’s exposure to professional and social scenarios throughout the completion of this thesis, for example discussion of this study at international conferences, hospital research forums, staff meetings, and with friends and family, enhanced opportunities to locate the research in different contexts, and influence the way data was collected and interpreted through a process of self-reflection.
Clear delineations needed to be made between the dual roles of social worker and researcher, as the researcher's clinical caseload included most of these participants. The involvement of the social worker as a researcher was sequential in that it occurred after the discharge of the patient and family from the service. A positive aspect of the researcher working within this setting is that during interviews certain concepts and tools to be discussed were familiar, and the participants could be assured interviewer understanding without the need for further explanation. If at any stage there may have been indication that the researcher role was impacting on clinical duties, or that participants were uncomfortable with the duality of roles necessary for this study to be successfully carried out, there was capacity within the existing clinical social work team at SHHS to provide a backup or clinical replacement for the duration of the research, although this was not a concern at any stage of the study.

The research project was supervised by Dr Rosalie Pockett at The University of Sydney with additional support provided by Associate Professor Steven Faux, Director of the Rehabilitation Service at SHHS and co-author of the literature review. This diversity of professional background in the supporting roles provided different and valuable perspectives on developing interview questions and the report card resource. According to Liamputtong (2009), researchers bring with them distinct positions and personal perspectives into the research process which cannot be ignored, and reflexivity acknowledges that researchers play a key role in shaping and analysis of findings. “The resulting discourse between the perspectives and experiences of the researcher will make research more meaningful” (Liamputtong, 2009, p. 25). Kemmis and McTaggart (2003) argue that change is inevitable in the
study of practice, and reflexivity seeks to understand the mutuality and relationship between the individual, the social, objective versus subjective. Through a dynamic process of reflection and self-reflection, practitioners are engaged in a process of learning from action and history through research (Kemmis & McTaggart, 2003, pp. 354-355).
Chapter Four – Findings and Analysis

Participant Snapshot

In Australia the average age of stroke onset is 72 years, and about 85 percent of people who suffer a stroke are over the age of 65 (National Stroke Foundation, 2013a, p. 10). There are about 25 percent more males living with stroke in Australia than females (National Stroke Foundation, 2013a, p. 39). The prevalence of stroke in men increases markedly with age from 50 to 54 years, while for women stroke prevalence increases from age 65 to 69 (Senes, 2006, p. 17). In this study however an equal proportion of stroke survivors were male and female, and the average age of stroke survivors was 57 years (Appendix D). The ages of stroke survivors in this study ranged from 41 to 71, all below the national average. One possible explanation for this difference is that many of the stroke survivors admitted to the rehabilitation ward between February and September of 2013 presented to hospital with a stroke that was a side-effect of another illness. In these cases the stroke survivor experienced premature onset of many of the risk factors for stroke such as high blood pressure, irregular heart beat or weakness in the blood vessel walls. The SHHS is situated nearby a specialist geriatric rehabilitation hospital. It is therefore possible that a proportion of the stroke survivors over the age of 65 presenting to St Vincent’s Hospital may have been transferred to this hospital for inpatient rehabilitation instead of the SHHS.

In the last 12 months 80 percent of stroke survivors admitted to SHHS for rehabilitation had suffered an uncomplicated stroke, whereas only 20 percent had suffered a stroke following another event or procedure. The stroke survivor
population for this study is quite unusual in that only 50 percent of participating caregivers supported a person who was transferred to SHHS following a stroke in the absence of any other condition. One stroke survivor was admitted following a fall related to existing Parkinson’s Disease and reduced mobility, one suffered a stroke following a heart transplant, and two suffered strokes following removal of brain tumours.

In this study, two stroke survivors had dependent children and were aged 41 and 42. One had two children aged six and nine years of age, and the other had four children ranging from five to 13 years. Fifty percent of stroke survivors in this study were still working at the time of illness. Of those not working, three were over 65 years of age, and the other was 42 years of age and was caring for her children full-time. All but two of the caregiver participants were still working at the time of the stroke, and six caregivers were married to or partnered with the stroke survivor and living together. The remaining caregivers were an ex-wife, mother-in-law, a friend and a neighbour. In the largest study of stroke incidences on the east coast of Australia, more than half of co-resident primary carers of people with stroke and disability spent 40 hours or more per week in their caring role, and the majority of caregivers in paid employment did not change their working arrangements to accommodate their carer role (Thrift, Dewey, Macdonell, McNeil & Donnan, 2000, as cited in Senes, 2006, p. 32).

All but one of the stroke survivors in this study had progressed well enough in rehabilitation to return home with support. This person required full time supervision and assistance as he was impulsive and considered a significant falls risk.
He was unable to feed himself or tend to his personal hygiene, and required administration of specialised medicine for a previous condition that he could not manage himself. He required placement in a high level residential care facility and as there were no suitable vacancies at the time of discharge at any facilities in his local area he was placed in a care facility away from his family and friends. Two of his friends, who previously were quite active in his care and monitoring at home, participated in this study. Six male and four female caregivers made up this participant population.

The average admission length at SHHS for stroke rehabilitation is three weeks. On admission to the rehabilitation unit stroke survivors and caregivers are advised of this, but are informed that the length of stay is dependent on each person continuing to demonstrate functional improvements and benefiting from the inpatient environment. Each week during the interdisciplinary team meetings there is discussion around a stroke survivor’s projected remaining time as an inpatient, and this is normally conveyed to the stroke survivor and their caregiver to provide as much time as possible to plan the discharge from hospital. For this study, the lengths of stay in rehabilitation ranged from ten days to 14 weeks, and the average time spent as an inpatient for the eight stroke survivors was six weeks, which is double the average, indicating the severity of these strokes and impact on ability to complete everyday tasks. This figure is representative of the medical complications experienced by the stroke survivors, the capacity to return home given requirements for home modifications and significant support services to be implemented, and in one scenario, finding a residential care facility that was willing to accept a person with complex care needs and to be trained in administering a particular drug for
management of Parkinson’s Disease. For many of the study participants, ongoing social work involvement was provided to support the caregivers in managing carer stress, financial issues, developing coping strategies and problem solving around home and community environments, and access to support services, as well as organising family meetings. It is possible that caregivers spending a longer period of time in the inpatient rehabilitation environment than the average may have had more time to adjust to the enormity and implications of a new disability, and to prepare for their caregiving role.

**Themes**

A number of themes emerged from the interviews as key points concerning the caregivers’ rehabilitation experience and interpretation of the information presented to them on the stroke survivor’s progress. These key points were then further categorised into their own groupings, based on an emergence of discursive and conceptual themes common across the interviewees and based on the research questions. Each of the ten caregivers was assigned an identifying number (P1, P2 and so on) based on the order in which the interviews took place. These themes are as follows:

- Specific information prompted further questioning among caregivers, in addition to encouraging engagement and sharing of new knowledge
- Having information from the treating team through the Mid-Term Report Card improved caregivers’ understanding of stroke and rehabilitation, and improved their expectations of stroke recovery
- Previous exposure to stroke or the rehabilitation setting aided caregiver adjustment and increased confidence to participate in ward activities
• Some caregivers received inconsistent or inaccurate feedback throughout the hospital admission, resulting in significant negative financial distress for them and the stroke survivor

• Caregivers adjusted to the challenges of changed lifestyles and daily schedules, and quickly adopted a supporting role

• Improved engagement of caregivers with the rehabilitation process led to learning of new devices, tools and skill development

• The caregivers were vulnerable and needed access to support, information and understanding from the rehabilitation team

• Caregivers had additional information requirements beyond the Mid-Term Report Card and what is normally offered by the SHHS rehabilitation team

Each theme will be discussed individually.

**Specific information prompted further questioning among caregivers, in addition to encouraging engagement and sharing of new knowledge.**

Prior to receiving the Mid-Term Report Card, P1 suggested he needed to often make inferences from what was said to him by the rehabilitation team, from which time he felt he had more concrete and structured feedback which was relevant to him and the stroke survivor. He added “I think that comes back to personality a lot. They are conveying the same thing, just in a different manner”. P2 reported receiving written feedback from each of the different treating therapists all in one place was beneficial, and provided a good understanding of his wife’s current capacities and difficulties, or the “state of play”. P2 and P4 mentioned they received regular feedback of their wives’ progress by email from the social worker which was also useful as it could provide a reference and comparison point for all information collectively and be
referred to at other times during the rehabilitation admission. P5 stated that the report card provided the opportunity to receive small amounts of feedback from each member of the rehabilitation team, and that “they just told me exactly what was wrong with her”. P9 suggested the report card enabled him to further understand his friend’s situation and potential inability to return to independent living, while P9 stated “I already knew, I could see the situation he was in, and of course with the report it just made me realise that that’s how it is, you know”. P3 believed the report card:

was excellent, because it puts us in the picture with what was happening for her as a whole person … people who have a loved one who’s very ill, they’re just, they’re in the clouds, they don’t know what’s going on, especially if they’ve got no medical knowledge, and they’re upset anyway. And if they’ve got clear guidelines as to what’s happening and what they’ve planned to do next time, and what they’re going to do, what kind of therapy they’re going to implement after that particular stage that the patient’s at, it just would bring the families more into the picture.

Caregivers were motivated to observe the rehabilitation process, to ask questions of health professionals in order to better understand the purpose of the exercises the stroke survivors were engaged in, and to witness their progress. P4 reported he had approached many of the rehabilitation team members to enquire about his wife’s progress throughout her recovery, stating “in my case, I actually got everything from the horse’s mouth, so to speak”. Similarly, P8 advised he was motivated to assist in therapy sessions where possible: “as you know, I did get to see her in OT, and I did get to see her in physio. I was like, around her doing as much as I could to help them
out”. P9 indicated that by attending therapy sessions he could understand the relevance of the particular exercises to his friend’s recovery: “it seemed to flow along quite nicely, and I was more or less getting update reports from anybody that I could catch.” He “was following it all the way through, watching and listening to what all the staff in there were saying too. I actually sat in on quite a few lessons with him and learnt what they are actually teaching him, and he’s still doing that now.” P2, P6 and P9 felt that receiving this information resource encouraged them to ask additional questions of the rehabilitation team throughout the remainder of the hospital admission, with P2 adding “we asked a lot of questions around, well can she continue to do the speech therapy when she’s at home even if she’s done, you know an hour this morning?”

Most participants felt encouraged by seeing the stroke survivor’s gradual functional improvements and receiving positive feedback from family and friends, and many were involved in continuing therapy at home. P4 felt that despite being a difficult time for them, he could look back on rehabilitation as a positive experience as he and the stroke survivor were looked after so well by the team. P5 advised during the interview that he had difficulty with some of the language used in the report card, and therefore there will need to be more emphasis placed on ensuring the feedback is easy to understand. P6 advised she felt able to interact with the rehabilitation team as needed “and you didn’t feel as though you were too embarrassed or scared to ask a question. So I felt very comfortable.” P9 reported “everybody there was more than helpful to give that information too on [his] progress.”
Caregivers expressed differing opinions on the most beneficial time to receive rehabilitation feedback, although the majority suggested having an information resource during admission prompted closer engagement in the remainder of the hospital stay. Many suggested that half-way through a stroke survivor’s rehabilitation admission is an ideal time to receive this information. P1, P4, P5 and P9 felt as though this timing was appropriate in terms of having enough insight into the effects of the stroke to make predictions for recovery, and they could see a logical flow in the rehabilitation process through this feedback. P6 and P8 suggested they would have been too overwhelmed earlier in the admission to comprehend this feedback, and that they needed to focus on progress one day at a time. In reference to the report card, P6 claimed “if I’d been given it at the beginning [of the rehabilitation admission] I would have thought ‘what the hell’s this? You know, come on, give me a break’!” This suggests that caregivers may be preoccupied with other matters and still experiencing shock at the beginning of rehabilitation that they may not be capable of absorbing the information. P1 believed his partner would have needed to reach a certain stage in his recovery before there would be anything worth reporting, and to maintain realistic expectations. P5 agreed, stating “you really can’t give a good assessment if you’re going to do it earlier.” This correlated with findings from the literature review (Loupis & Faux, 2013), which suggest providing this feedback and predictions for recovery shortly after admission may be fraught with inaccuracy, given limited time to complete thorough rehabilitation assessments, commencing therapeutic interventions and allowing for natural recovery. In addition, P8 made reference to the benefit of receiving the report card prior to a family conference, held later in the admission, reporting it “sets you up for what’s going to happen in the family conference.”
Some participants suggested they would have preferred to receive updates more regularly. P7 felt she would have benefited from an update on her ex-husband’s medical and mobility status when he first arrived on the ward, including expectations of practical abilities, in addition to regular updates throughout the admission. P2, P3 and P7 believed more regular updates, even weekly, would be beneficial for tracking progress, to have a comparison of goals and achievements from week to week. All of these participants received informal updates from the social worker at least on a weekly basis throughout the rehabilitation admission, and they felt this assisted in their understanding of the recovery trajectory.

Improved understanding of the stroke survivor’s abilities, difficulties and therapies they were involved in, provided confidence to some caregivers to explain stroke and its effects to family and friends, and in many cases the information resource was used as a communication tool with other health professionals on discharge. P2, P3, P5, P6 and P9 mentioned that they used the report card to facilitate further discussion with family members and medical professionals once out of the hospital system. P5 and P9 gave copies of the report to other family members and the stroke survivors’ family doctors, and P5 suggested there were a couple of items of feedback on the report card that he didn’t agree with, which is why he took this to his doctor of many years, “which was good, you know, it gave us something to discuss”. P6 took the report card to the next appointment with their neurosurgeon, and felt that having this information from the report card and the opportunity to discuss aspects of recovery with the rehabilitation team has “made me quite knowledgeable to think I can actually explain to people what’s happened. Which I think is fantastic. You know, I think gosh I’m quite knowledgeable now!” She reported that she felt inclined to
share this feedback with the neurosurgeon because “by now you understand and you’ve got a few more questions to ask, because obviously you’ve had a few more weeks of having it with you.” In this situation the caregiver had seemed to have gained some power and control over the situation through increased information and understanding.

**Having information from the treating team through the Mid-Term Report Card improved caregivers’ understanding of stroke and rehabilitation, and improved their expectations of stroke recovery.**

Caregivers were able to create a clearer and more holistic interpretation of the stroke survivor’s capacity in context of the therapy they were engaged in and in comparison with others undergoing rehabilitation. Most participants indicated that the report card put them in the picture, as part of the team, and allowed them to understand their stroke recovery holistically, not just using a medical framework. P1 noted that he received small amounts of information along the way, although he “got big bits of the puzzle with the report card.” P2 and P3 suggested that having additional explanations of conditions (for instance symptoms of aphasia, difficulty comprehending and producing language, and how it specifically manifested for a certain individual) and both frequency and intensity of therapy from different team members, assisted with putting together a clear picture in their heads to aid their understanding. P3 noted that each experience of stroke recovery is individual, and compared her daughter-in-law, the stroke survivor, to her cousin who had also recently suffered a stroke, and who was unfortunately incapacitated to the point where he required full time nursing care in a residential facility. She described her daughter-in-law as “lucky”, despite ongoing deficits, in the context of this. P6
reportedly felt fortunate that her husband was independent with his personal care and mobility, despite fatiguing easily. P8 suggested he was able to use the feedback provided to him, in addition to what he had observed on the ward, to develop his own understanding of his wife’s condition and potential recovery: “we could see what her goals were, you could see what the team’s goals were, and you know it was approaching an end goal.”

This concept of comparison with other stroke survivors is interesting in the context of progressing the realisation amongst caregivers of the impact the stroke has had on their lives and how this is likely to continue impacting on them as they take on this caring role. It may therefore be worthwhile offering a comparison between the stroke survivor’s results in standardised testing and the larger population of stroke survivors, providing caregivers with an understanding of their position within the stroke recovery spectrum. There is a sense among some caregivers that the situation could have been worse (that is, that the stroke could have caused more damage, or the stroke survivor may not have been deemed appropriate for rehabilitation by the consultants), while others ask themselves ‘why me’? Rehabilitation for many is a turning point, and the social work role here is important in assisting a caregiver through this life-altering stage and the crisis that is occurring. Following a medical event such as a stroke, a number of losses may be experienced for example, loss of functioning such as speech or physical abilities, independence, lifestyle, and future plans. A study by Dowswell, Lawler, Dowswell, Young, Forster & Hearn (2000, in Alaszewski et al., 2003, p. 4) investigating recovery from stroke, found that people measured recovery in terms of their pre-stroke stroke lives and had to adjust to accepting that they will never be the same. From a crisis theory perspective, these
participant responses may be indicative of caregivers’ attempts to reflect on their losses, appreciate the remaining capacities of the stroke survivors, and begin to develop new priorities and goals.

Caregivers developed a greater understanding of the effects of stroke, the efforts required to regain everyday functional capacity, and the time-frames required with rehabilitation as the admission progressed. Expectations seemed to improve in line with increased knowledge of potential physical gains and awareness of safety concerns, although this also brings anxiety around demands of the caring role and amount of assistance or supervision required by the stroke survivor. Feedback from participants indicates that the information presented in the report card improved expectations of progress and understanding of assessments used in rehabilitation to judge capacity and difficulty, as well as improving overall knowledge of stroke and the role of stroke rehabilitation. P3 reported that caregivers “are upset anyway, and if they’ve got clear guidelines as to what they’ve planned to do next time, and what they’re going to do, it just would bring the families more into the picture.” This indicates that greater communication initiated by the rehabilitation team could further encourage participation for some caregivers. P1 and P9 believed they had a good understanding from the time of admission in rehabilitation that the stroke survivor would need to work hard in order to return as close to “normal” as possible.

Two participants had very limited understanding of rehabilitation and strokes in general, which affected their expectations of recovery. P5 advised “I just thought rehab was just, you know, like getting her back to work full-time type of thing”, while P9 stated “I didn’t know how long it would take. What I’ve learnt, I suppose
in one sense, it’s a matter of time if they do fully recover from it”, and the occupational therapist “explained a lot to us on the process with [the stroke survivor] with the stroke issue, the progress he might make, what to look out for and what may happen in the future, and I know he’s showing progress.” It is at this point that caregivers begin to consider changes that may be needed (such as home modifications and equipment), community services required, inconvenience to schedules and lifestyle, and expenses relating to therapy provision. Social workers can assist caregivers to express and adjust to feelings of carer burden and high expectations, and can provide information and referral to appropriate services.

All participants agreed that feedback in the report card about safety considerations and warning signs following stroke and on return to the community (for instance capacity to drive, or tendency to fall), were particularly useful, as this provided them with something to be mindful of on discharge from rehabilitation and assisted in preparing them to provide appropriate care at home. P1 believed the most valuable information for him was making obvious the areas where his partner was doing well, and the areas where he was likely to experience difficulty, as he felt this gave him “something to work with and from”. He did admit to experiencing heightened feelings of anxiety on discharge from hospital (based on feedback from the rehabilitation team regarding risk of falling) until his partner’s balance and mobility had improved, and he was concerned particularly about safety in the shower and outdoors on uneven surfaces. This theme has been explored in previous studies on spousal caregivers of stroke survivors, suggesting fear of falling has the potential to hinder improvements in mobility as some caregivers impose activity restrictions in an attempt to reduce the incidence of falls, resulting in muscular decline and
deconditioning (see Dever Fitzgerald, Hadjistavropoulos & MacNab, 2009, p. 466; Kelley, Graham & Braswell Christy, 2010, p. 244; Lincoln, Kneebone, Macniven & Morris, 2012, pp. 349-361). P6 felt that because she had received feedback on her husband’s risk of falling she was more aware of trip hazards and taking safety measures such as holding on to rails while using stairs, although she did not feel additional anxiety around this. Similarly P9 used this feedback to increase his friend’s opportunities for exercise, just being mindful of safety requirements: “and now I use the [safety] belt on him, and all I’m doing really is just in case he falls”.

Previous exposure to stroke or the rehabilitation setting aided caregiver adjustment and increased confidence to participate in ward activities.

Caregivers bring with them a wealth of knowledge, skills and experiences that may assist them and the stroke survivor to adjust to a new disability. Many of the caregivers had previous health related knowledge and experience, or experience as a caregiver, which they believed was an advantage in navigating the rehabilitation system and understanding the potential effects of stroke. P3 had worked for many years as a nurse, and felt that she had a good understanding of the trajectory of recovery, and was able to utilise her skills and knowledge to assist her daughter-in-law through a difficult period. This participant stated she was prepared to take on this caregiving role until she was no longer needed. P4 had previously cared for his ex-wife prior to her death, and his mother-in-law before that and felt prepared for the caring role because of this experience, but acknowledged that each situation will understandably be quite different. This participant also had a family history of stroke, Parkinson’s Disease, dementia and lung problems. P8 has worked as a nurse in the areas of cardiology and neurosciences, and stated “I had an understanding of
stroke, as you know, as I’m in the medical field. But for a bloke on the street with no medical knowledge, [the report card] is quite informative with the nursing, and with the OTs and with physio it was just like, you know, very open book, very informative”. P9 advised “I’ve done this before for my daughter, it’s something I do not mind doing for a human being.” He also mentioned he had friends who had passed away on the palliative care ward, in the same building as the rehabilitation unit, and his mother was a volunteer in palliative care when she was younger. He indicated that having previous exposure to the SHHS environment resulted in increased confidence for him to engage in rehabilitation, as he felt comfortable visiting. These comments would suggest that a combination of experience, knowledge and new information and education could assist with adjustment and confidence to provide support following stroke.

P7 had recently spent time in hospital and rehabilitation after suffering a broken ankle, and she felt she had a good understanding of the process and timing involved in her former husband’s recovery, although this particular caregiver was noted to have expectations that were not congruent with the stroke survivor’s eventual recovery and capacity. P10, despite having limited previous knowledge of strokes, felt that she was able to assume the caregiver role easily for her good friend, saying “it’s like you’ve gotta nurse your, your mum or your sister or your father, it’s the same thing. Automatically it becomes natural, whatever you are doing.” Regardless of previous knowledge of stroke or rehabilitation, and previous caring experience, these caregivers indicated that receiving information in the form of the mid-term report card provided an indication of the expectations or care provision, and helped prepare them psychologically for this role. It also suggests that many caregivers
come to a hospital environment possessing useful life skills that can be translated to the rehabilitation context.

Caregivers with previous exposure to rehabilitation, stroke, St Vincent’s Hospital or a caring role seemed to approach recovery in a more practical manner and adjust more easily, while those without this knowledge or with few expectations experienced significant shock. P1, P5, P6, P9 and P10 mentioned that prior to this recent illness, they had little or no understanding of stroke and rehabilitation to prepare them for this experience, and they certainly felt they learned a great deal from the process. P1 advised “we had had two friends who had had strokes, but we weren’t close friends. We didn’t go into the exact nature of the stroke.” P5 and P6 mentioned that their only previous knowledge of strokes was “just what you see on TV”, with P6 adding “if they’re raising money for something”, indicating that it may have also been beneficial to provide information to these caregivers about the type of stroke and area of damage sustained. This also suggests, however, that caregivers may have unhelpful and inaccurate understandings of stroke based on media dramatisations, further reinforcing the importance of personalised and meaningful feedback for each caregiver. P8 suggested that because of the magnitude of his wife’s stroke, they were unable to prepare physically or psychologically for recovery, as her prognosis for walking and managing personal care activities independently was very poor, and they had no indication of the time various goals might take to achieve. “It was quite a severe stroke. For her it was just like one day at a time”. P9 reported “I have seen people walking around, the after-effects of the stroke. But for me personally, I learnt a lot about what a stroke can cause. It’s a big new, a big new ball game for me to see a person in that condition after having that type of stroke”. P10 found her friend in
his home on the morning of his stroke, and advised she had little exposure to stroke and what it can do. She had not considered her friend could be injured so badly and have such significant deficits from his stroke, and “that’s why it was all a shock to me.” She continued on to say “he was on the floor in the kitchen. Oh my god when I saw him. Yeah, it was a bit of a shock, I had a shock. I had to go and call the neighbour because I couldn’t cope. I couldn’t do anything, what could I have done? I mean I’ve already done more than what I should.”

Some caregivers received inconsistent or inaccurate feedback throughout the hospital admission, resulting in significant negative financial distress for them and the stroke survivor.

P4 was reportedly advised by a doctor in the stroke unit of St Vincent’s Hospital that his wife could expect to achieve a full recovery of her leg and “about 14 percent use of her right arm” without any indication of how the doctor had arrived at this conclusion. This further enforces the medicalisation of stroke and rehabilitation, where feedback on a technical assessment of the stroke survivor’s recovery is often provided with no indication of what this assessment may mean in terms of day-to-day abilities and care requirements. It also highlights the importance of health professionals providing accurate information rather than attempting to provide predictions that will be potentially misleading or provide false hope. Some caregivers felt as though it would have been better in their cases to receive less information rather than incorrect feedback or suggestions. Many participants advised they were concerned about the stroke survivor being able to return to work and driving. P7 was upset that her ex-husband had been recently encouraged to contact a government-funded rehabilitation provider to assist him in returning to work,
whereas another doctor had earlier advised him he could return to his previous employment four weeks after his stroke. “[He] will be back at work in four weeks, was what she said to me, and I remember thinking at the time ‘I don’t think so’”.

She reported she needs to declare him bankrupt because she has been unable to obtain a medical certificate that would provide a prognosis of capacity to return to work within the next three months, and therefore he could not claim on his income protection insurance. She suggested there was no mention while he was in rehabilitation about capacity to return to driving, which she felt would have dramatically increased his chance of returning to work as well as his freedom and self-confidence. P5, P6, P7 and P8 on the other hand had already had discussions with their families, the stroke survivor and the therapists while in hospital about potentially needing to retire from employment early. At four weeks after leaving rehabilitation, these caregivers seemed to be more accepting of the new disability and had been able to begin assisting the stroke survivor in planning for the future. This would suggest that discussions around returning to previous activity levels would be beneficial earlier in the rehabilitation process in order to assist the stroke survivor and their caregiver in preparing for the worst case scenario. P5, P7, P8, P9 and P10 mentioned the financial difficulties they and the stroke survivor had experienced following hospitalisation, including inability to return to work and extensive medical bills.

P7 felt frustrated with the inconsistency in the feedback she received from earlier in the hospitalisation to later on in rehabilitation and in hindsight feels the situation could have been dealt with quite differently, and her expectations for full recovery on discharge may therefore have not been as high. She said “he’s made a small
improvement with his arm, but not enough. Not for a man who’s 55. Now I know that his arm may never come back.” P4, P5, P7, P8, P9 and P10 noted a reduction in frequency and intensity of outpatient therapy or access to Government-subsidised therapy on leaving inpatient rehabilitation. They were reportedly advised this would be the case prior to discharge from hospital, but nonetheless were hoping there would be some capacity to continue with the same services that the stroke survivors were offered as inpatients. P8 explained that “the only problem is with the outpatient, it’s not as full on as it was at Sacred Heart”. Similarly P9 reported “the trouble is, once you leave a rehabilitation unit, and in [his] case where he had to move on to a nursing home, it’s just not there. The facilities are just not there now”. “What was said to us” he continued, is “if [he] shows improvement, if he keeps on showing improvement well, they’ll more or less keep on working on him. It just could have gone a little bit further, you know”. P9 agreed, saying “I would have liked to have seen [him] stay there a bit longer because I could see the progress that he was making”. Most participants felt that the inpatient phase of rehabilitation was not long enough, and therefore were disappointed when they were faced with discharge dates.

As health professionals it seems important to balance provision of hope and realistic information about demands of and limited time within a hospital system with finite or limited resources as there is likely increased risk of negatively affecting stroke survivor or caregiver mood when expectations are not met. Many caregivers find they have not had sufficient time to grieve or adjust to the reality of what has happened to their friend or family member, and being provided with a discharge date
as dictated by the medical team can produce anxiety and panic around managing at home.

**Caregivers adjusted to the challenges of changed lifestyles and daily schedules, and quickly adopted a supporting role.**

Caregivers demonstrated resilience through such activities as managing busy schedules, new symptoms and frustrations, and swiftly adopting a caring, supportive role, but often require assistance to access ongoing services and supports. Most caregivers believed it was made clear to them the impact of stroke on particular areas on the body based on the areas of damage in the brain. Many received what they believed to be vital information including rates of stroke survivor fatigue following stroke, and as such they felt better equipped to manage these symptoms and to schedule in regular rest breaks. Most were willing to put their regular activities or responsibilities on hold as much as possible to be physically and emotionally available for the stroke survivor. Studies that focus on how vulnerable individuals and their carers cope have found that carers have active and creative strategies for managing everyday life (Pound, Gompertz & Ebrahim, 1999, in Alaszewski et al., 2003, p. 2). P1 reported he “didn’t need to be encouraged at all. I wanted to do that [participate] for him to see him well again. I couldn’t wait to help him get better”. P4 felt that he was able to assist by visiting the hospital and taking his wife off the ward for coffee or a meal: “so that broke up her day a bit, made it more tolerable … I think it improved her state of mind.” P5 saw his role as mainly one of support, reassurance and positive motivation for his wife, and said “it’s going to take time, you know, just take one step at a time, that’s what I keep telling her.” P6 reported feeling prepared towards the end of the rehabilitation admission to take on the
caregiving role, despite not really knowing what to expect. “No, I didn’t have a clue. But you know, because I’m a housewife and sort of the old-fashioned one, I just accepted it.”

P3 suggested she was made aware of potential signs that the stroke survivor may be having another event or a serious enough symptom to call for medical assistance, but had felt capable of differentiating between a “headache” and a life-threatening complaint. “For the first few days she came home, you know, she was very, very tired and she was having a sleep during the day.” P6 was mindful of the importance of keeping her husband engaged in a routine once at home and to monitor his energy levels, while P3 noted that she understood the recovery would not happen overnight, and the road to recovery was a long one, with an uncertain end. P9 felt proud to be able to provide support to his friend, and that many others are not as fortunate. He said “to stop him from getting a bit depressed, that was one of the main reasons that I was in there so often helping him out. There’s other people up there that don’t have anybody at all, and that’s the sad point about it isn’t it? They don’t have other people around.”

Many of the participants mentioned the demands the stroke has had on their families and schedules. P8 reportedly spends most of his time dividing time between work, caring for their children, taking them to school, and taking his wife to outpatient therapy sessions. He stated that he knew having his wife return home from rehabilitation was always going to be difficult, but that they have managed to develop a routine that works for all family members. “Yeah we manage it, we’re coping, it’s an ongoing … she has her days. She’s still up, she’s still down, you
know. We just get through it.” He mentioned they have a community service visiting every day for an hour to assist with household tasks, which allows him to have a break from this responsibility. He suggested he needed to find a fine balance at home of encouraging his wife to complete as many tasks around the home as she could manage safely, while also being mindful of her limitations. He said “now that she’s home there’s the frustrations of, you know I’m home, and I still can’t do stuff around the house … but you try not to make her feel like she’s any different, although she knows she is, because she can’t do as much as she had hoped to.”

In the study of stroke incidence on the east coast of Australia the effect of caring responsibilities on stroke survivor and primary caregiver relationships was examined (Thrift et al, 2000, as cited in Senes, 2006, p. 32). For co-resident primary carers of people with stroke and disability, 21 percent reported a strain in their relationship (Senes, 2006, p. 35). In this current research no caregivers mentioned a negative effect on their existing relationship, and two indicated their relationships with their spouse had actually deepened through this experience. P5 suggested “she’s more affectionate, because she realised she could have died” while P8 advised “we were always close, and it has brought us even closer together I think. Being there for her is the main thing that she wanted. She was scared, and I had to be strong for her, and being strong for the family as well.” This would suggest there is a role for social workers in providing additional support to caregivers, who are likely to feel pressure to seem as though they are managing the physical and emotional demands of caring for the stroke survivor, when they may benefit from counselling and practical support. Where possible within rehabilitation centres, it may therefore be beneficial for social workers to provide a service for checking in with caregivers and
monitoring their mood and the impact of the caring role on their lives and schedules following discharge from hospital.

Following discharge from hospital, the caregivers have remained hopeful of recovery, feel better able to manage difficulties in the future, and feel better prepared psychologically to take on the caregiving role. On the whole, participants were able to reflect positively on their experience of rehabilitation, and felt that four weeks following discharge from hospital, they were much more hopeful, as the stroke survivor’s functional recovery had exceeded their initial expectations. P1 felt that participating in his partner’s stroke recovery equipped him with skills and confidence to deal with future mishaps and stressors, and certainly made him stronger emotionally. P3 maintained hope that her daughter-in-law would continue to progress well, stating “we keep positive, and I can see a light at the end of the tunnel. I don’t know how long it will be, but I can see it.” P6, P9 and P10 placed emphasis on smaller achievements and gradual improvements that were realistic within a shorter time-frame, that this allowed them to gain perspective on the bigger picture and feel as though there remains direction in the outpatient rehabilitation services. P9 stated that “overall I can see the ongoing improvement with [him] on a steady basis and that’s why I’m holding out hope that one day he may be able to get back home and live some sort of normal life.” Caregivers who had been able to accept that their lives had undergone significant change and that their friend or family member may never return to previous roles, employment or thinking abilities, seemed to have a more positive outlook and acceptance of their new lives, and took it upon themselves to set smaller goals in partnership with the stroke survivor. It is clear that a stroke is a major life event or defining moment for individuals who have
experienced them. Caregivers will often need to rethink who they are and what they want out of life. Alaszewski et al suggest that “rehabilitation is a complex journey in which individuals set their own goals and explore, often slowly and painstakingly, ways and strategies for achieving them” (2003, p. 3).

**Improved engagement of caregivers with the rehabilitation process led to learning of new devices, tools and skill development.**

Caregivers participating in stroke rehabilitation experienced a significant learning curve and in so expressed improved capacities in coping better with adversity. P1 felt that the experience and knowledge he gained throughout the rehabilitation admission was invaluable, and that he would have been “flying blind” without some indication of progress from the treating team. “Who knows what’s around the next corner, but it does make you a bit stronger to go through something like this, and you definitely learn a bit”. P9 suggested “it was a big eye opener for me, and a big learning curve too.”, and P10 spoke of the satisfaction gained from being able to assist her friend: “I learnt a fair bit, how to take good care of a person, you know, it’s a satisfaction that you get.” The participants indicated they had gone through a transition period of something they weren’t prepared for, but believed that four weeks following discharge they could reflect on how much had already been achieved, and felt confident to continue this caring role.

Caregivers spending a larger amount of time on the rehabilitation ward participating in activities, therapies, education and planning, may develop necessary tools and better awareness of the daily challenges of living in the community following stroke. Caregivers reportedly understood the importance of becoming involved in the stroke
recovery, allowing the rehabilitation team, where possible and appropriate, to provide further education and training in preparation for discharge from hospital. P2 reported “we were there to support her, to understand the sort of programs that she’s working on, and so that we can then carry that forward as much as possible.” P3 felt encouraged to participate in therapy sessions on the ward, requesting guidance around intensity of treatment and what to be aware of, and preparation for discharge by taking overnight leave while still an inpatient, allowing troubleshooting and further advice and planning with the inpatient team. “I spoke with the speech therapist on the ward, and she gave me some pages of exercises for [her] to do, and we did that on the weekends that she came home, but she got tired very easily.” While on overnight leave, P3 “realised she was having a panic attack, I just put her into bed with me and she was fine, she calmed down.” P4 felt privileged that he was allowed to “participate in things as they happened.”

P6 believed that being able to visit her husband each day and becoming involved in therapy exercises and recovery resulted in greater awareness of his capabilities, and knowledge that he should be supervised outdoors. She felt that receiving detailed feedback on her husband’s progress in rehabilitation prompted her to spend more time on the hospital ward to understand a little more about the process and the goals that were set for each week, and helping with exercises set by the speech pathologists. In relation to her education and learning experience, she added “you can go away and just think about it for a little bit. Because then a lot of the information that you’ve had comes back.” This correlates with the literature review findings, particularly the Bhogal et al (2003) experience that active education and counselling measures were associated with improved caregiver outcomes, and is in
accordance with the NSF guidelines (2010, p. 41) that recommend specific training be provided to caregivers during the inpatient rehabilitation admission in order to improve preparation for assisting with daily care activities and the challenges that lay ahead. Based on findings of the literature review and findings of this study, personalised and concise feedback with a more preventative focus may promote better outcomes, and providing support to caregivers and developing their skills and capacity may assist in preparing them for discharge from hospital.

Many participants felt that they were able to take on a supporting role to assist with recovery, including assisting with daily care tasks on the ward. P9 stated “I watch a lot and I listen a lot, and I have gained a hell of a lot on how to handle [him] I suppose. I did push [him] a bit because I know his capabilities.” All participants apart from P7 were provided education on use of electronic devices to assist with muscle recovery, encouraged the stroke survivor to mobilise on the ward more regularly and provided hands-on support to facilitate this, as often there were not enough staff members around to provide this practice outside of scheduled therapy sessions. Participants would regularly request guidance from the therapists to assist with being more involved in the recovery process, and would be on the rehabilitation ward regularly in order to gain feedback from the treating team and gain a therapeutic rapport with them. In a rehabilitation environment that places importance on collaborative team models, this is likely to further aid interventions, as each member of the interdisciplinary team may gain further insight into the needs and potential contributions of the caregivers and stroke survivors they are supporting.
The caregivers were vulnerable and needed access to support, information and understanding from the rehabilitation team.

Caregivers can feel overwhelmed and vulnerable following stroke and may benefit from closer involvement in the rehabilitation process, goal setting and decision-making. Overall, participants communicated a need to be brought into the picture by members of the rehabilitation treating team, as they are already distressed and vulnerable, and without clear guidelines, goals and implementation strategies, they feel disconnected from the process. P6 suggested that earlier in the hospital admission she was not able to take in information as easily. “Well in emergency I don’t think you’re in a state of mind to really understand. You know, you just go oh yes, oh yes, OK, oh, right”. She believed the report card feedback was informative for a person who previously had little understanding of stroke or its affects, “because we were so new to everything [the report] was just wonderful, really putting in the information as to what was happening.” P10 felt comforted and motivated by her friend’s progress in rehabilitation, particularly given the traumatic way in which her experience of hospital began. “I felt good because I’ve been feeling guilty for a while, with the fall and everything. I used to blame myself. Oh my god. So every time I feel a bit better because he’s improving.”

P6, P7 and P9 reported experiencing caregiver fatigue and stress. P6 stated “the day just goes so quickly. It’s unbelievable. And I think you hardly get anything done, it’s exhausting, and sometimes when we both go to bed at 8:30, I think ‘this is ridiculous’!” P9 added “it can be a bit tiring of course, there’s no doubting that. But overall, no it’s a pleasure to help.” Social workers in rehabilitation are well-positioned to monitor caregiver stress, particularly using thorough psychosocial
assessments and close ongoing support, and in some cases may have capacity and resources within facilities to run carer support groups. Literature exploring support groups specifically for caregivers of stroke survivors, report that the most beneficial aspects of the groups were feeling supported by others in the same situation and offering support in return, having time away from their caring responsibilities and feeling more confident about their own situations (Morris & Morris, 2012, p. 347; Williams, 2012, p. 24).

Caregivers are affected by emotional and practical demands on family, and these demands during rehabilitation can limit a caregiver’s ability to be present and fully engage in the process. Caregivers were also mindful of stroke survivor fatigue, mood disturbance and reduced motivation to complete tasks. Most participants communicated the demands the illness and hospitalisation had had on their families and relationships, which could sometimes feel overwhelming. P2, P3, P5, P7 and P8 were engaged in full-time employment and unable to visit as regularly as they had wanted to, and P3 was also responsible for caring for her grandchildren and could not attend the rehabilitation ward during therapy times. P5 was overwhelmed by the stroke and ongoing rehabilitation to the point where he intentionally limited his visits the rehabilitation ward because he felt exhausted, and believed it would be better for his wife’s concentration if he was not around during therapy times. He spoke of the change their family and relationship had undergone through the recovery process:

“Your world gets turned upside down straight away. When you find out she’s in hospital you think ‘oh well, after a few weeks everything should be back to normal’ but it’s not, and it never will be. We’re still hoping she’ll make a full recovery. Our lives have
changed completely now. Like she’s changed, her personality has
changed completely. It’s like she’s a different person.”

For the six months that his wife was hospitalised, P8’s two young children lived with
friends who had children of their own of a similar age, and on weekends they were
cared for by grandparents, to allow him to continue working and to visit hospital
after work each day. For these six months their children had to attend a different
school so as not to interrupt the schedule of the family that was caring for them.

P5 described his wife’s reduced mood and motivation for therapy at home despite
encouragement. He said “I’ve tried to get her to do things on the computer but she’s
just not interested.” P7 also experienced her ex-husband’s reduced motivation and
partly associated this with his slow recovery and partly with a history of depression
in context of recent unemployment and ongoing financial and functional uncertainty.
She said “he comes to me over the weekend, and he doesn’t do any of his exercises,
despite me saying you should do them.” This participant communicated significant
anger towards the rehabilitation service and the hospital in general, as she felt she
was provided misleading information and false hope regarding his potential for
recovery and time required, and she also believed he was discharged from hospital
prematurely and without adequate follow-up support. Many participants found that
once outside of the hospital system, they experienced difficulty making connections
with medical specialists and organising follow-up care through community services.
P2 had needed to schedule further tests and appointments, but feels he did not receive
enough information on discharge when his wife left hospital to do so. P4 suggested
discharge from rehab was “very hit and miss … disjointed” and “the time frame
changed rapidly and often” suggesting he felt unprepared both practically and
psychologically for his wife to return home. P5 who had a low level of literacy, received a letter in the mail advising his wife had been placed on a waiting list, but he did not understand for what. “Since she’s left hospital it’s virtually dropped to a full stop. Yeah, nothing’s happening at the moment.” Rehabilitation teams and particularly social workers are conscious of pre-existing family dynamics, difficulty of other family members to adjust to a new diagnosis or disability, and the need to offer appropriate support to a primary caregiver. Caregivers come to the hospital environment with different expectations, some more realistic than others, and the social work role here is crucial in educating interdisciplinary teams in acknowledging, respecting, and responding to these complex concerns that can potentially affect a stroke survivor’s recovery.

**Caregivers had additional information requirements beyond the Mid-Term Report Card and what is normally offered by the SHHS rehabilitation team.**

Participants regularly sought additional information and feedback, and were particularly interested in how the stroke survivor was progressing in comparison to others, any ongoing medical requirements and risks they may have needed to be aware of. P7 felt that the report card did not aid her understanding of her ex-husband’s likely progress and recovery. She advised it “didn’t tell me anything that I hadn’t been able to observe myself”, but that for those who may not have been as present on the ward or as observant, the information would have been very helpful. Many participants suggested they had additional information requirements beyond the feedback provided in the report cards, and often would seek out regular feedback from individual therapists to piece together a better understanding of the stroke survivor’s recovery. P2, P3 and P7 suggested it may also be helpful to indicate what
results or achievements could be expected, or would be considered normal for a similar stroke survivor at that stage in their recovery, so that they could judge whether the stroke survivor was progressing within the timeframe initially outlined. P2 also proposed each task highlighted in the report card could receive a rating from the therapist out of ten, provided the ratings were standardised and not subjective, possibly providing further insight into areas of difficulty.

P2, P4 and P7 felt they received a lack of information from the medical teams at all stages of the hospital admission, and would have liked more information included in the report card about the stroke survivor’s prognosis for recovery and likelihood of further stroke, for instance. A previous study looking at emotional strain in caring for stroke survivors, indicated that many caregivers remain “worried about the care recipient having another stroke” (see Pierce, Finn & Steiner, 2004, p. 14). P4 attended a family conference at which no doctor attended, leaving many medical questions remaining unanswered on discharge. P2 suggested that future caregivers may benefit from being able to schedule a time to speak with the medical team, and to have questions prepared prior to the meeting. This participant noted that he could not have possibly had a thorough understanding of his wife’s condition or prognosis during the inpatient rehabilitation stay as there was an ongoing evolution of understanding while the medical knowledge itself was improving with new diagnoses or theories of causality. P1 felt there was a tendency at times among staff members to be careful about the feedback they provided, but they would have liked to receive more concrete information in the early stages of admission, not just offers of encouragement. P7 suggested she received very limited feedback from all teams within the hospital, with the exception of the social worker, from the time her ex-
husband was admitted. She said that she struggled to receive information despite making an effort to speak with the relevant teams, and “we just watched [him] deteriorate, no one was listening, nobody talked to me. The whole thing I thought was a bloody disaster.” She suggested that most of the information she received was from her ex-husband himself. “What there was, was a complete lack of communication, from anyone other than yourself about what was going on and what sort of prognosis we could expect.”
Chapter Five – Discussion and Conclusion

This study began with some key questions about the information needs of caregivers based on what was known in the literature so far. It is understood that family conferences provide opportunities for caregivers to receive information and feedback on a stroke survivor’s progress and to be engaged in future planning, however this study aimed to explore an alternative method of communicating and educating caregivers during the inpatient rehabilitation admission. This resource, the Mid-Term Report Card, was evaluated and found to be a useful tool in supporting the information needs of caregivers. Although the study was primarily about the usefulness of this resource to caregivers, it also provided an opportunity to gain some preliminary insights into the caregiver experience beyond their need for information. In addition, the major findings of this study challenge some of the current thinking about the importance of family conferences and their timing.

This research firstly set out to explore whether there was specific information or feedback that was most relevant or beneficial to these families of stroke survivors through their inpatient rehabilitation admission. Feedback from the research participants suggests that provision of written, specific information in one place may assist caregivers of stroke survivors to better understand the impact of the illness on each person half-way through inpatient rehabilitation. Having the opportunity to discuss rehabilitation progress, capabilities and goal setting to family, friends and other health professionals provides some caregivers with confidence and a feeling of empowerment.
Very often in a hospital environment there will be limited warning for a caregiver of the planned date of discharge, and this was evident in the experiences of some participants. Particularly given a caregiver’s vulnerability, providing as much notice as possible of an expected discharge date will assist in planning the stroke survivor’s return to the community. Many study participants felt that the stroke survivor was discharged from hospital prematurely and without adequate follow-up support. These caregivers communicated disappointment when faced with discharge dates and believed the stroke survivor could have benefited from additional therapy and that they themselves required additional preparation time. Understandably what is considered ‘enough time’ will be different for all team members and families, although clearer communication of the expected time in rehabilitation and earlier planning of support services and appointments following discharge, is likely to assist caregivers in planning for their future role.

Analysis of the individual responses and themes suggest that there was a desire for additional medical feedback and caregivers had additional queries that went unanswered, particularly around prognosis and ongoing risk factors. Caregivers looked to the rehabilitation team for results and news of progress and health professionals must be mindful of the implications of providing false hope. Caregivers indicated they did not want to receive information that seemed more appealing if it was not realistic, just for the sake of not providing negative feedback or potentially distressing news. It is therefore essential that caregivers receive concise written information about rehabilitation progress, goals, medical feedback and discharge plans that portray a realistic image of the stroke survivor’s abilities and difficulties in language that is easy to understand.
The second research question explored whether there was information that best encouraged involvement of families and caregivers in inpatient rehabilitation therapies, retraining and discharge planning. There was clear feedback that caregivers felt the need to be supported in order to engage effectively with rehabilitation teams and maintain motivation for the stroke survivor, and this may be facilitated through provision of easy to understand and readily available information. Caregivers communicated a sense of pride and achievement in their role supporting a friend or family member through stroke rehabilitation, although often in a hospital situation they will need to seek some sort of authorisation or permission to be actively involved. For the most part caregivers were enthusiastic about being involved in rehabilitation, and all participants indicated they required direct and concise feedback so that they could better prepare, encourage and support the stroke survivor. The dominant biomedical discourse of a hospital does not traditionally incorporate a person’s own experience of stroke and particularly not the effect on a family member, in their method of responding to this illness. This study highlights these unheard perspectives and their importance in stroke recovery.

In keeping with systems theory, it seems in the best interests of the entire rehabilitation team to support caregivers and other family members throughout the admission as this is likely to improve the outcomes for the stroke survivors also. A more preventative focus could promote better outcomes, and there should be emphasis among rehabilitation teams on providing support to caregivers and developing their skills and capacity in preparation for discharge from hospital. The National Stroke Foundation (2010, p. 41) recommended in its latest clinical guidelines for stroke management, that relevant and specific training be provided to
caregivers of stroke survivors, and this study found that providing this report card resource and encouraging further engagement with the interdisciplinary team is likely to have enhanced the capacity of the participants to manage the challenges of living in the community on discharge from hospital. This new research may allow clinicians and managers to transform clinical spaces from within, in an effort to improve outcomes, further understanding and reduce barriers. Feedback from these study participants demonstrates that interdisciplinary teams can support families to become engaged in rehabilitation activities and training to prepare for assuming the caregiver role on discharge from hospital.

The third research question guiding this study looked at whether there were elements of the Mid-Term Report Card that affected compatibility between initial expectations of recovery on admission to a rehabilitation setting, and outcomes achieved at discharge from hospital. Feedback from participants indicated that the information provided on the Mid-Term Report Cards must be as clear and accurate as possible to avoid misunderstandings and clarify the interdisciplinary team’s expectations for recovery. Most caregivers indicated they required more medical information throughout the hospital admission, and therefore social workers can encourage the rehabilitation medical team to be responsive to these needs. For instance a doctor might attempt to speak with a caregiver while attending the ward, or to contact them by telephone if there is any significant feedback to provide or information required. Caregivers can also be encouraged to attend medical ward rounds in rehabilitation in order to provide an open forum for further discussion. Providing these opportunities may prevent unnecessary concern and confusion later in the hospital admission.
For many participants the Mid-Term Report Card brought together an understanding about the therapy the stroke survivor was engaged in and the safety concerns the rehabilitation team felt were necessary to communicate, which was one of the aims of this study. In this way the resource appeared to promote engagement and provide realistic observations around the purpose of the exercises for that person, and that the stroke survivor was continuing to experience difficulty with certain activities of daily living. This assisted the caregivers to adjust to a new disability but also for some caused concern regarding significant changes, and new responsibilities. Caregivers reportedly benefited from clear explanations of the process and progress of rehabilitation, including team assessments, professional opinions and the need for goal setting or further discussion with the stroke survivor’s family. One of the elements of the report card that most affected compatibility between expectations of recovery on admission to rehabilitation and actual outcomes on discharge was that of safety, in particular balance and risk of falling, most likely because of the implicated requirement for the caregiver to provide more hands-on support with daily tasks.

There remains a need to ensure ongoing support from the entire interdisciplinary team particularly if the feedback to be provided may be concerning for the caregiver. Offering practical suggestions for the caregiver regarding areas of concern such as fear of falling may be particularly beneficial. This study has made a number of suggestions for future practice, and in particular the social work role can take into account this feedback from caregivers, incorporate these new understandings, and strive to promote a rehabilitation environment that is considerate of, and responsive to, individual needs and requirements of caregivers. In particular, social workers can use their skills and knowledge to better engage families in stroke rehabilitation.
identify potential areas of concern prior to these developing into larger problems, and support caregivers to navigate hospital systems in a way that promotes empowerment, collaboration and self-determination.

The fourth research question asked whether there is an indication of the optimal timing of delivery of this resource given individual needs of family members. Based on the findings presented here there was no clear consensus among caregivers of the optimum time to receive feedback on the stroke survivor’s progress. Proactive and regular feedback from the rehabilitation team however may better assist caregivers to prepare for their caregiving role, and the inpatient experience is facilitated and supported by accessible, clear information given in a supportive way.

Throughout a hospital admission there can be numerous opportunities for, and methods of feedback, although there may be benefit in having a standardised response and resource to provide to caregivers of stroke survivors, in addition to regular interventions. There certainly remains a place for family conferences in stroke rehabilitation, although participant responses suggest that receiving feedback on the rehabilitation progress earlier in the admission, and prior to a family conference, assists with caregiver preparation for these discussions practically and psychologically. In the same way, it may also enhance these opportunities, since the time spent together with the rehabilitation team can be more productive if caregivers are better informed, and the discussion could be more collaborative.
Implications for Social Work Practice

Lastly, this research aimed to explore the ways in which social work practice might be improved, taking into account this new resource, feedback from caregivers and new understandings, in the context of an interdisciplinary team model. A key part of the social work role is to clarify a caregiver’s understanding of the feedback received, aiming at supporting this transition and adjustment period to assist in facilitating timely discharge planning. Being afforded opportunities to seek feedback from and discuss concerns with medical and allied health teams throughout a hospital admission may improve understanding of the illness and recovery, enhance feedback mechanisms such as family conferences, while reassuring and improving confidence for caregivers. This study has highlighted the pivotal role social workers hold in providing appropriate and timely communication in a format that aids understanding.

The social work role plays a large part in clarifying rehabilitation goals and plans, although this approach would not be possible without contribution from the entire interdisciplinary team. For many people stroke recovery is a very new situation and health professionals should not assume caregivers will understand the hospital system or their rights. Social workers can take on the role of family liaison and attempt to break down this barrier to ensure that caregivers have access to the information and support they require. From a crisis perspective, social workers are instrumental in assisting caregivers to realise or develop new techniques and competencies in preparing practically and psychologically for their new role. Inadequate grieving can affect a caregiver’s capacity to adjust to this new illness and acceptance of their role. Each situation must be considered independently, and social workers can assist caregivers to reframe their despair and anxieties to more practical
reflection on quality of life and development of new interests based on changed physical or cognitive abilities.

Caregivers must be recognised as part of a larger system, affected by external influences and competing demands. Half of the caregivers experienced financial difficulties following the stroke, including a cancelled holiday, specialist appointments, not being able to return to work, cost of scans, outpatient therapy, having to rent out one stroke survivor’s home to pay for extra therapy, not being able to access Centrelink’s Disability Support Pension because of their husband’s income, and having a Centrelink Carers Allowance terminated because the stroke survivor needed to enter a residential care facility. Being aware of the social and legal implications of stroke can assist the rehabilitation team in responding appropriately to caregiver concerns and planning appropriate services, equipment, modifications and ongoing healthcare. In addition, social workers can identify barriers to participation and help empower caregivers by introducing them to the healthcare system as contributors and not consumers or customers of a medical environment. From their position within this healthcare team, social workers play a significant role in advocating for stroke survivor and caregiver needs, and on behalf of all who find themselves part of this system due to illness or injury.

This study recognises that caregivers are the experts in their own lives, and the interdisciplinary team is only part of these lives for a brief moment. Social workers find ways to have a substantial and beneficial impact on this experience, and it is this determination that ensures our profession continues to grow and that we develop new skills and knowledge. In the area of stroke rehabilitation an effective clinician is one
who embraces challenges and has a thirst for knowledge and deeper understanding of the ways people overcome difficulties and their interpretations and experiences of this. Social workers are creative in suggesting there may be different perspectives to those we taught or developed, and their role is to support these caregivers who have entered the hospital environment at the height of vulnerability, in new and inclusive ways. Social workers are also well positioned to provide education to health professionals on the information, education and support needs of caregivers following stroke, which can aid understanding and lead to more efficient and appropriate support. Hospital social workers could benefit from professional development opportunities that aim to update their skills and knowledge around the needs of caregivers. It is also be beneficial to prepare social work students for employment in a health-related field to allow an element of their university courses to include study of the effect of sudden illness and disability on caregivers and family members.

**Suggestions for Mid-Term Report Card Content**

The research findings indicate key content for future versions of the Mid-Term Report Card that could be simple to edit and implement within rehabilitation settings. It is suggested that the report cards include information and feedback on the following items, and caregivers should be encouraged to use this to better engage with the therapeutic process and the rehabilitation team:

- Medical information including test results and any ongoing concerns, as well as changes in medications
- Areas where the stroke survivor has made improvements
• Areas where the stroke survivor is continuing to experience difficulties, including safety concerns

• An indication of whether progress so far is above what was originally expected, or slower than expected, and suggestions as to why this might be the case

• An indication of the progress the stroke survivor might expect to see in the near future

• Therapy sessions and exercises being completed

• Devices and machines used in therapy and their purpose

• Indication of whether personal goal setting or a family conference is recommended

• Expected date of discharge from rehabilitation

It is possible that future versions of the Mid-Term Report Card could include some aspect of the benchmarking mentioned earlier, however it will be important to ensure the reports are individualised. This is essential particularly as each stroke survivor will be affected differently depending on pre-existing health status, site and severity of stroke, as well as age and immediacy of presentation to hospital, and would be likely to respond to similar exercises or approaches in unique ways. The report card was designed to provide caregivers with a snapshot of the stroke survivor’s progress in the first stages of rehabilitation, as well as a clear indication of their current abilities and difficulties.
Limitations of the Report Card

In evaluating this new resource, the findings demonstrate needs of the participants that were separate to the report card, and therefore there were both clear benefits and limitations to receiving this resource. Although the Mid-Term Report Card can be a helpful tool this study demonstrates the need for a number of other changes that would improve the overall experience for caregivers, many of which have a direct bearing on the social work role. While useful for some, this resource may not address the identified needs of all caregivers. The report card can be considered one ingredient of good communication and ongoing support for caregivers from the entire rehabilitation team, and many other questions are likely to arise from this feedback.

This study design was informed by a proposition that participant caregivers would offer their own experiences, strengths and resources to rehabilitation. Caregivers displayed increased confidence in the challenge of the supporting role particularly if they had previous experience of stroke or a healthcare setting while for those without this experience adjustment took longer. This may indicate that caregivers without prior knowledge or understanding of the healthcare system or of the potential effects of stroke could require additional encouragement and support from social workers and the entire rehabilitation team to assist them in taking advantage of the inpatient services and knowledge base.

Despite being provided with an estimated date of discharge from inpatient rehabilitation at an early stage in the recovery process, some caregivers underestimated the time required for recovery, expected the stroke survivor’s
disabilities would resolve completely, and believed the intensity and frequency of therapy received would remain following discharge from hospital. It appears that caregivers would benefit from earlier clarification by the interdisciplinary team of expected length of stay in the rehabilitation unit and what is considered a plateau in functional improvement for the purposes of making this decision. Who then should be responsible for providing this information? Should there be a designated rehabilitation contact person assigned for each stroke survivor as suggested earlier? This may be beneficial for the purpose of acting as a bridge or liaison, gathering feedback from interdisciplinary team meetings and relaying these messages to a caregiver, who could then in turn make further enquiries. The difficulty with this scenario, often occurring in rehabilitation at SHHS and reflected in the research findings, is that many caregiver questions relate to medical or therapeutic interventions, which the social worker will not be able to answer without an allowance of additional time to consult the team. This process can be demanding for therapists who are focused on helping the stroke survivors achieve maximum outcomes in the limited time available to them as inpatients. For many health professionals, taking the time to explain what they do and why, as well as the purpose of each exercise and expected results, may be considered more time-consuming by them. However, feedback from this study suggests finding ways of integrating this feedback and ongoing support is valuable for caregivers and may prevent problems later in the hospital admission and on return to the community.

There are plans underway at SHHS to develop a handbook for inpatient rehabilitation that will provide information about the hospital stay, and allow space for handouts, exercise sheets and additional notes regarding services and appointments for follow-
up. This type of resource may assist caregivers, particularly those new to a hospital setting, by having all the rehabilitation details in one place that can be referred to at a later stage. It could also encourage the stroke survivor, if capable, to keep track of supports and services they might need to access, and possibly feel more engaged in the process. With or without an inpatient handbook, social workers could assist caregivers to plan ahead prior to leaving hospital, by ensuring they understand what is required and provide the relevant contact details to make appointments. In addition, future versions of the report card could offer a measure of perceived carer strain either from the ward social worker or psychologist, to encourage further awareness, discussion and support around the physical and emotional demands of caring for the stroke survivor.

Implications for Future Research

This preliminary study lends itself to a larger in-depth study on the social effects of stroke, the role of caregivers and the engagement of stroke survivors and caregivers with the health system. In particular, key areas of insight that could be studied in future research include adjustment to the stroke diagnosis and new caregiver role, the need for ongoing rehabilitation engagement beyond the inpatient admission, and the social disruption of a stroke.

Adjustment to a new illness, responsibilities and changes in lifestyle requires time and consideration of individualised approaches, which cannot be prescribed or thoroughly studied in a fixed inpatient admission. Future research projects involving the Mid-Term Report Card could investigate the effect of continued contact and support with caregivers of stroke survivors following receipt of a report card and
again on discharge from hospital. In many hospital settings this is not possible, particularly at SHHS where there is currently no funding for a researcher or an outpatient social work role, but perhaps in the future given additional funding and resources this could be realistic. Where possible within rehabilitation centres, it may be beneficial for social workers to provide a service for checking in with caregivers and monitoring their mood and the impact of the caring role on their lives and schedules following discharge from hospital.

It may be possible for future research projects to investigate the impact of an information resource such as the Mid-Term Report Card, and other rehabilitation interventions, on the experiences of stroke survivors themselves. As many stroke survivors experience residual cognitive or language difficulties, it may not be possible to include them in such studies, although feedback from those stroke survivors capable of communicating effectively and engaging in research may provide a valuable contribution to clinician and researcher understanding of the stroke experience. Several study participants identified the impact of the stroke on their lives. Of significant concern was the social disruption that occurred, including effects on employment, financial security and family relationships, and these issues may be addressed in further research projects.
References


facilities. *Gerontology, 55*, 460-467


Oxford University Press
Appendix A: Family Conference Project Final Report


Williams, R. (2012). Setting up a support group for carers of stroke survivors. *Nursing Older People, 24*(1), 22-24

Family Conference Project

EQuIP criteria 4th Edition

1.1.2 Care is planned and delivered in partnership with the consumer / patient and when relevant, the carer, to achieve the best possible outcomes.

BACKGROUND/INTRODUCTION

- The Sacred Heart Rehabilitation Service provides a multi-disciplinary Family Conference for patients with multiple medical conditions, high care needs or complex discharge plans.
- Families and patients are formally invited to attend a conference and are encouraged to prepare questions for the Rehabilitation team.
- Each discipline’s representative provides patients and their families with specific assessment information about the patient’s rehabilitation and post discharge needs. Families and patients are given the opportunity to question all of the patient’s medical and therapeutic professionals.
- Patients and families are provided with discipline specific recommendations for on-going rehabilitation and care.
- The conference provides the opportunity for patients, their carers and families and the Rehabilitation team to determine the most appropriate discharge plan.

Aim/Expected Outcome

- To formalise the process of family conferences at Sacred Heart Rehabilitation Service into a procedure.
- To establish whether family conferences actually improve the patient’s and family’s understanding of their condition and discharge arrangements.

Definitions

Family conference is “a meeting which involves a number of family members the patient and hospital personnel in discussions concerning the patient illness, treatment and plans for their discharge or their care outside of the hospital” (Hansen, Cornish & Kayser 1998)

Literature review

There is very little literature about family conferences to guide practice. Hansen, Cornish & Kayser (1998)
METHODOLOGY

Plan/Do

To establish a consistent procedure for the identification of the requirement to have a family conference.

1. Trigger project (see appendix 1 for trigger for family conference) identified criteria for those families that would benefit from a family conference.
2. Review the process of informing attendees for the conference, including meeting time and changes to meeting times. Implementation of a contact person for each patient and the utilisation of a Multi-disciplinary team communication book.

Undertake a review of the effectiveness of Family conferences and the debriefing process following a family conference.

Include:

- Attendance of staff and families.
- Timing and punctuality
- Role of the attendees
- Information provided
- Record sheet.
- Debriefing process

■ Over the course of 2006 and 2007, all the participates involved in a Rehabilitation Family Conference including; therapist, medical, nursing and allied health staff, patients, families and carers, were asked to completed a questionnaire (see appendix 2) both prior to and after the conference. which asked for their views about the effectiveness of the conference and specifically if they felt the conference assisted or exacerbated any conflict between the family or patient’s planned discharge arrangements and the rehabilitation team’s recommendations

■ The questionnaire for families and patients (see appendix 3) consisted of 10 items seeking responses to issues such as the timing, format and structure of the conference, as well as the effectiveness of each disciplines contribution to the conference and patient’s and family’s overall confidence in managing after discharge.

■ 58 patient and family questionnaires were complete and 164 staff questionnaires were completed. These questionnaires were collated and analysed to provide the following results.
Results

See appendix 4 for data results.

Summary of Results: Patients and families responses

- Patients and families overall report a high rate of satisfaction with the information provided to them at their family conference.
- 87% reported they had a good understanding of their or their relatives disability,
- 98% reported they had a good understanding of their or their relatives rehabilitation program and
- 95% reported that they understood and agreed with their or their relatives discharge plans and ongoing care needs.
- Patients and families reported a high level of understanding of the specific recommendations and assessment information provided by each discipline. Percentage of the time families and patients reported a good understanding of information given were:
  - Occupational Therapy 100%
  - Physiotherapy 98%
  - Medical 98%
  - Social Work 97%
  - Nursing 97%
  - Speech Pathology 97%
  - Psychology 93%
  - Other 95%
- Patients and carers reported a moderate to high degree of confidence in the areas of patient’s progress and carer support.
- 72% of patients and families believed they or their relative were making good progress in rehabilitation, and
- 86% of carers agreed that they felt they had been given appropriate advise and support.
- A high degree of satisfaction was reported from patients and families regarding the timing format and structure of the Family Conference, however slightly less than half of all conferences were reported to have started approximately 10 minutes later than the time on the patient and family’s invitation.
- 79% felt the timing of the family conference was appropriate.
- 93% noted that they had been given a formal invitation and patient and relative questions form.
- 55% of conferences started at the agreed time.

Summary of Results: Staff responses

- Overall staff reported a high degree of approval about the effectiveness, timing and outcomes of family conferences.
- 84% of staff agreed that the Conference was necessary and useful.
- 87% of responses noted that the conference had achieved an agreement between the rehabilitation team and the patient and their families about the patients rehabilitation goals, and
Appendix A: Family Conference Project Final Report

- 78% of responses indicated that the conference had resolved an agreed discharge plan for the patient.
- Staff predictions about the likelihood that the conference could cause conflict or distress to patients and families proved less accurate.
- 21% of staff responses predicted that the conference would be likely to generate conflict either between the team and the family or patient, or between family members, where as 80% of responses provided after the conference indicated the conference had caused conflict.
- 50% of staff responses predicted that the conference would cause distress or anguish to patients or families, however 74% of responses provided after the conference reported that the conference had caused distress or anguish to patients and families.
- Staff indicated that they personally felt distressed following a family conference 10% of the time.
- Staff indicated that they generally felt the Family Conference timing, format and structure was useful.
- 94% of staff responses indicated that the timing of the family conference was appropriate.
- 74% of responses noted that the staff member felt they had significant advice and information to share with patients and families.
- 70% of responses indicated that staff felt the information they provided had been understood by patients and families.
- 88% of staff felt that the staff only, pre-conference meeting had been useful to them in planning their contribution to the Family Conference.

Discussion

- A significant criticism of the rehabilitation Family conference related to the late start of the meeting, with about half of all conferences commencing at least 10 minutes late. A greater need for punctuality by staff attending the meeting is recommended.
- Staff members, patients and families all reported a high degree of satisfaction with the timing and structure of the Family Conference. Consequently it is advisable that the Rehabilitation team maintain the current family conference structure and plan to hold conferences at an appropriate time that is not too early or late in the admission. It would seem that approximately one to two weeks prior to discharge is the preferred time for a family Conference.
- Greater recognition of the likelihood that a Family Conference will generate some degree of conflict between parties and that it also may lead to patients and family members becoming distressed needs to be factored into the conference planning process.
- Pre and post conference counselling to be offered to patients and families to assist in managing feelings of distress and anguish generated by the Family Conference.
Study/Evaluation

Refer back to the aim/expected outcomes and background.
Did it achieve the improvement it set out to achieve?
What was achieved?

Achieved Outcome:
This project has evidence of the usefulness and benefits of family conferences for the patient and families’ understanding of the roles of each member of the Rehabilitation Multidisciplinary team in the provision of therapy and discharge planning.

Act
There is a procedure (appendix 5) to ensure a consistent approach to conducting family conferences for a reliable equitable outcome for all patients and families receiving Rehabilitation.

Considerations for the future
Patients and families are satisfied with the structure of the family conferences however there remain recommendations for further improvements these include:
- punctuality arriving for the family conference.
- consideration and anticipation of the distress that families experience to be incorporated into the conduction of the family conference. This includes the requirement for all members of the treating team to be present at the family conference.

References
(Hansen, Cornish & Kayser 1998)

Appendices
Appendix 1 – Triggers for Family conference
Appendix 2 – rehab staff questionnaire pre & post family conference
Appendix 3 – family & patients questionnaire pre & post family conference
Appendix 4 – results of the questionnaires
Appendix 5 – procedure
Table 2. *Essential ingredients for effective family conferences*

<table>
<thead>
<tr>
<th>Essential ingredient</th>
<th>Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>Effective communication of meeting purpose to patients and caregivers</td>
<td>Held in a comfortable environment that allows for effective communication and contact, reducing power disparities</td>
</tr>
<tr>
<td>Meeting agenda aligned between patients, caregivers and staff, agreed upon prior</td>
<td>Held at a time suitable for most people involved, not just the treating team</td>
</tr>
<tr>
<td>Held in a comfortable environment that allows for effective communication and contact, reducing power disparities</td>
<td>Employment of good time management to enhance overall satisfaction with the process</td>
</tr>
<tr>
<td>Held in a comfortable environment that allows for effective communication and contact, reducing power disparities</td>
<td>Open acknowledgement that patients and caregivers have taken time out of their own schedules to attend</td>
</tr>
<tr>
<td>Prior discussion between caregivers and the multidisciplinary team (pre-meetings) of rehabilitation progress and patient’s functional capacity to ensure adequate opportunities for education provision and proactive use of the meeting time</td>
<td>Active problem-solving, decision-making and discharge planning from all participants for the benefit of the stroke survivor, and to reduce feelings of despair and carer burden following a prognosis</td>
</tr>
<tr>
<td>Prior discussion between caregivers and the multidisciplinary team (pre-meetings) of rehabilitation progress and patient’s functional capacity to ensure adequate opportunities for education provision and proactive use of the meeting time</td>
<td>Held prior to discharge when rehabilitation outcomes and available support systems/services can be thoroughly discussed</td>
</tr>
</tbody>
</table>

(Loupis & Faux, 2013, p. 892)
Appendix C: Interview questions and structure

Guide for Semi-structured interviews with participating caregivers
Mid-Term Report Card project

Introduction and general questions to establish rapport.
Specific questions and prompts for interviewer:

1) Can you tell me about the information you received about _____ 's progress while in rehab?
   - aspects of rehabilitation received feedback on
   - information in writing

2) What was your understanding of _____ 's illness prior to coming to rehab?
   - knowledge of strokes in general, knowledge of rehab

3) This study involved providing you with a report card with specific feedback on rehab progress and assessments. Can you tell me anything about the report card?
   - most memorable aspect
   - understanding of information presented
   - discussion with treating team and outcomes of this

4) If you were back in that moment, given what you know now, would you change anything about the report card?
   - other information useful
   - better time to provide this information
   - able to make sense of the information at that stage

5) What can you tell me about your role in _____ 's rehabilitation?
   - encouraged to participate
   - activity involved in (eg goal setting, family conference, personal care retraining)
   - understanding of different therapeutic roles
   - effect of this on carer and on _____ 's progress

6) What were your feelings or thoughts on discharge in terms of knowing what to expect?
   - skills or knowledge gained
   - role of rehab team in this
   - prepared to take on the caring role
   - difference in expectations or feelings than on arrival to rehab

7) Since _______ left rehab, have you made use of any community support services?
   - names/types of services
   - referral source

8) Is there anything else you would like to tell me about your experience over the last few weeks?
<table>
<thead>
<tr>
<th>Participant Number</th>
<th>Age of Stroke Survivor</th>
<th>Cause of Stroke</th>
<th>Children of Stroke Survivor</th>
<th>Length of Rehabilitation Admission</th>
<th>Caregiver Gender</th>
<th>Caregiver Relationship</th>
<th>Caregiver Paid Employment</th>
<th>Discharge Destination</th>
</tr>
</thead>
<tbody>
<tr>
<td>P1</td>
<td>71</td>
<td>Uncomplicated</td>
<td>No</td>
<td>10 days</td>
<td>Male</td>
<td>Partner</td>
<td>Yes</td>
<td>Home</td>
</tr>
<tr>
<td>P2</td>
<td>42</td>
<td>Removal of brain tumour</td>
<td>Yes, dependent</td>
<td>18 days</td>
<td>Male</td>
<td>Husband</td>
<td>Yes</td>
<td>Home</td>
</tr>
<tr>
<td>P3</td>
<td>42</td>
<td>Removal of brain tumour</td>
<td>Yes, dependent</td>
<td>18 days</td>
<td>Female</td>
<td>Mother-in-law</td>
<td>Yes</td>
<td>Home</td>
</tr>
<tr>
<td>P4</td>
<td>66</td>
<td>Uncomplicated</td>
<td>Yes, adult</td>
<td>63 days</td>
<td>Male</td>
<td>Husband</td>
<td>No</td>
<td>Home</td>
</tr>
<tr>
<td>P5</td>
<td>58</td>
<td>Uncomplicated</td>
<td>Yes, adult</td>
<td>22 days</td>
<td>Male</td>
<td>Husband</td>
<td>Yes</td>
<td>Home</td>
</tr>
<tr>
<td>P6</td>
<td>59</td>
<td>Removal of brain tumour</td>
<td>Yes, adult</td>
<td>10 days</td>
<td>Female</td>
<td>Wife</td>
<td>Yes</td>
<td>Home</td>
</tr>
<tr>
<td>P7</td>
<td>59</td>
<td>Uncomplicated</td>
<td>No</td>
<td>45 days</td>
<td>Female</td>
<td>Ex-wife</td>
<td>Yes</td>
<td>Home</td>
</tr>
<tr>
<td>P8</td>
<td>41</td>
<td>Heart transplant</td>
<td>Yes, dependent</td>
<td>97 days</td>
<td>Male</td>
<td>Husband</td>
<td>Yes</td>
<td>Home</td>
</tr>
<tr>
<td>P9</td>
<td>64</td>
<td>Following fall</td>
<td>No</td>
<td>76 days</td>
<td>Male</td>
<td>Friend</td>
<td>No</td>
<td>Residential care</td>
</tr>
<tr>
<td>P10</td>
<td>64</td>
<td>Following fall</td>
<td>No</td>
<td>76 days</td>
<td>Female</td>
<td>Friend</td>
<td>No</td>
<td>Residential care</td>
</tr>
</tbody>
</table>
Appendix E: University of Sydney Ethics Approval

Ref: [MF/KFG]

13 December 2012

Dr Rosalie Pockett  
Faculty of Education & Social Work  
The University of Sydney  
Email: rosalie.pockett@sydney.edu.au

Dear Dr Pockett,

Thank you for your submission on 6 December 2012 addressing comments made to you by the Human Research Ethics Committee (HREC).

I am pleased to inform you that the matters now addressed are in line with the requirements outlined by the protocol entitled “Exploring the introduction of a Rehabilitation ‘MidTerm Report Card’ in communication and education for families of stroke survivors” has been approved.

Details of the approval are as follows:

Protocol No.: 2012/2798 (old ref: 15609)  
Approval Date: 11 December 2012  
First Annual Report Due: 11 December 2013  
Authorised Personnel: Dr Rosalie Pockett Miss Yasmine Loupis AVProf Steven Faux

Documents Approved:

<table>
<thead>
<tr>
<th>Document</th>
<th>Version Number</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Introduction Letter</td>
<td>Version 1</td>
<td>October 2012</td>
</tr>
<tr>
<td>Participant Information Statement</td>
<td>Version 2</td>
<td>December 2012</td>
</tr>
<tr>
<td>Participant Consent Form</td>
<td>Version 1</td>
<td>October 2012</td>
</tr>
<tr>
<td>Guide for Semi-Structured Interviews</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mid-Term Report Card</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

HREC approval is valid for four (4) years from the approval date stated in this letter and is granted pending the following conditions being met:

**Special Conditions of Approval**

- The researchers are to ensure appropriate approvals (ethics/governance) are obtained from St Vincent’s Hospital for the conduct of this study on their premises.
Appendix E: University of Sydney Ethics Approval

**Conditions of Approval**

- Continuing compliance with the National Statement on Ethical Conduct in Research Involving Humans.
- Provision of an annual report on this research to the Human Research Ethics Committee from the approval date and at the completion of the study. Failure to submit reports will result in withdrawal of ethics approval for the project.
- All serious and unexpected adverse events should be reported to the HREC within 72 hours.
- All unforeseen events that might affect continued ethical acceptability of the project should be reported to the HREC as soon as possible.
- Any changes to the protocol including changes to research personnel must be approved by the HREC by submitting a Modification Form before the research project can proceed.

**Chief Investigator / Supervisor’s responsibilities:**

1. You must retain copies of all signed Consent Forms (if applicable) and provide these to the HREC on request.
2. It is your responsibility to provide a copy of this letter to any internal/external granting agencies if requested.

Please do not hesitate to contact Research Integrity (Human Ethics) should you require further information or clarification.

Yours sincerely

[Signature]

Dr Margaret Faedo
Manager, Human Ethics
*On behalf of the HREC*

cc: Yasmine Loupis
yloupis@sydney.edu.au

This HREC is constituted and operates in accordance with the National Health and Medical Research Council’s (NHMRC) National Statement on Ethical Conduct in Human Research (2007), NHMRC and Universities Australia Australian Code for the Responsible Conduct of Research (2007) and the CPMP/ICH Note for Guidance on Good Clinical Practice.
Appendix F: St Vincent’s Hospital Sydney Ethics Approval

8 February 2013

A/P Prof Steven Faux
Level 3
Sacred Heart Rehabilitation Service
St Vincent’s Hospital
Darlinghurst NSW 2010

Dear Steven

SVH File Number: 13/020
Project Title: Exploring the introduction of a Rehabilitation ‘Mid-Term Report Card’ in communication and education for families of stroke survivors.
(HREC Reference Number: LNR/13/SVH/222)

Thank you for submitting the above project for review. Based on the information you have provided and in accordance with the NHMRC National Statement 2007 and NSW Health Policy Directive PD2010_055 Ethical and Scientific Review of Human Research in NSW Public Health Organisations, this project has been assessed as low/negligible risk and is therefore exempt from full HREC review.

This HREC has been accredited by NSW Ministry of Health as a Lead HREC under the model for single ethical and scientific review and Certified by the NHMRC under the National model for Harmonisation of Multicentre Ethical Review (HoMER). This lead HREC is constituted and operates in accordance with the National Health and Medical Research Council’s National Statement on Ethical Conduct in Human Research and the GMP/VICH Note for Guidance on Good Clinical Practice. No HREC members with a conflict of interest were present for review of this project.

I am pleased to advise that the HREC Executive at a meeting on 5 February 2013 has granted ethical and scientific approval of the above single centre project.

You are reminded that this letter constitutes ETHICAL and SCIENTIFIC approval only. You must not commence this research project at a site until a completed Site Specific Assessment Form and associated documentation have been submitted to the site Research Governance Officer and Authorised. A copy of this letter must be forwarded to all site investigators for submission to the relevant Research Governance Officer.

The project is approved to be conducted at St Vincent’s Hospital Sydney.

If a new site(s) is to be added please inform the HREC in writing and submit a Site Specific Assessment Form (SSA) to the Research Governance Officer at the new site.

The following documents have been approved:

- Participant Information Sheet and Consent Form Version 3 dated January 2013
- Mid-Term Report Card Version 2 dated January 2013

The Low and Negligible Risk Research Form (LNRF) reviewed by the HREC was LNRF AU/6/2980117.

Please note the following conditions of approval:

- HREC approval is valid for 5 years from the date of the HREC Executive Committee meeting and expires on 5 February 2018. The Co-ordinating Investigator is required to notify the HREC 6 months prior to this date if the project is expected to extend beyond the original approval date at which time the HREC will advise of the requirements for ongoing approval of the study.

Continuing the Mission of the Sisters of Charity

101
• The Co-ordinating Investigator will provide an annual progress report beginning in February 2014, to the HREC as well as a final study report at the completion of the project in the specified format.

• The Co-ordinating Investigator will immediately report anything which might warrant review of ethical approval of the project in the specified format, including unforeseen events that might affect continued ethical acceptability of the project and any complaints made by participants regarding the conduct of the project.

• Proposed changes to the research protocol, conduct of the research, or length of approval will be provided to the HREC Executive for review, in the specified format.

• The HREC Executive will be notified, giving reasons, if the project is discontinued before the expected date of completion.

• Projects that are undertaken by Investigators holding an academic appointment (including conjoint appointments) or by students as part of a University course are also required to contact the relevant University HREC to seek advice from the University regarding their requirements.

Should you have any queries about your project please contact the Research Office, Tel: 8382-2075, email research@stvincents.com.au. The HREC Terms of Reference, Standard Operating Procedures, National Statement on Ethical Conduct in Human Research (2007) and the CPMP/ICH Note for Guidance on Good Clinical Practice and standard forms are available on the Research Office website: www.stvincents.com.au/researchoffice or internal at http://research/stvincents.com.au/researchoffice

Please quote SVH File Number 13020 in all correspondence.

The HREC wishes you every success in your research.

Yours sincerely

Maria Mury
Acting HREC Executive Officer
Research Office
L6 deLacy Building

CC: Yasmine Loupls
Trim File Ref: D/2013/6929
Appendix F: St Vincent’s Hospital Sydney Ethics Approval

St Vincent’s Hospital

11 February 2013

A/Prof Steven Faux
Level 3
Sacred Heart Rehabilitation Service
St Vincent’s Hospital
Darlinghurst NSW 2010

Dear Steven

SVH File Number: 13/020

Project Title: Exploring the introduction of a Rehabilitation ‘Mid-Term Report Card’ in communication and education for families of stroke survivors.

(HREC Reference Number: LNR/13/SVH/22) (LNRSSA/13/SVH/36)

Thank you for submitting a Low and Negligible Risk Research Site Specific Assessment (LNR SSA) form for site authorisation of this project. I am pleased to advise that the Research Governance Officer on 8 February 2013 has granted authorisation for the above Low and Negligible Risk Research Project to be conducted at St Vincent’s Hospital.

The version of the LNR SSA reviewed by SVH RGO was: XAU7/F8B019.

Please Note: Site authorisation will cease on the date of HREC expiry (5 February 2018).

The following conditions apply to this research project. These are additional to those conditions imposed by the Human Research Ethics Committee that granted ethical approval:

1. Proposed amendments to the research protocol or conduct of the research which may affect the ethical acceptability of the project, and are submitted to the lead HREC for review, are copied to the Research Governance Officer.

2. Proposed amendments to the research protocol or conduct of the research which may affect the ongoing site acceptability of the project are to be submitted to the Research Governance Officer.

3. Projects that are undertaken by investigators holding an academic appointment (including conjoint appointments) or by students as part of a University course are also required to notify the relevant University HREC.


Yours sincerely

Julie Charlton
Research Governance Officer
Research Office

CC: Yasmine Loupis
TRM Record Number: D2013/8005

Continuing the Mission of the Sisters of Charity
The ‘Mid-Term Report Card’ project is an initiative of SHRS and forms the basis of a Masters Degree at The University of Sydney.

You are encouraged to use the feedback and information presented in this report card to familiarise yourself with the terminology and assessment tools used in rehab, and to facilitate discussion with the individual therapists.

This project is supported by members of the therapeutic rehabilitation team, including medical, nursing and Allied Health staff. If you have questions or concerns about the study itself or your involvement, please discuss these with the researcher, Yasmine Loupis (8382 9320 or yloupis@stvincents.com.au)

Rehabilitation

Mid-Term Report Card

This report card provides feedback and scores on standard rehabilitation testing, with a short explanation of their meaning.
<table>
<thead>
<tr>
<th>Category</th>
<th>Score</th>
<th>Meaning</th>
<th>Provided by __________ (position)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Berg Balance</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Manual Muscle Testing</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mood</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Activities of Daily Living</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cognition</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Continence</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mobility</td>
<td>Transfers</td>
<td></td>
<td>Walking</td>
</tr>
<tr>
<td>Speech and Swallowing</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
The 'Mid-Term Report Card' Project

PARTICIPANT INFORMATION STATEMENT AND CONSENT FORM

(1) What is the study about?

You are invited to participate in a study of a new resource in the form of a 'report card' that aims to provide rehabilitation feedback to caregivers of stroke survivors halfway through their admission. We hope that providing this feedback will encourage you to engage in further discussion with rehabilitation therapists, nurses and doctors, will enhance participation during family conferences, and reduce feelings of stress and carer burden following the rehabilitation patient’s discharge from the facility.

(2) Who is carrying out the study?

The study is being conducted by Yasmine Loupis and will form the basis for the degree of Master of Education (Research) at The University of Sydney under the supervision of Dr Rosalie Pockett, Senior Lecturer at the School of Social Work and Policy Studies, and A/Prof Steven Faux, Director of Rehabilitation and Pain Medicine at St Vincent’s Hospital.

(3) What does the study involve?

This study involves you, as a caregiver, in the trial of a new information resource (the 'Mid-Term Report Card') at the Sacred Heart Rehabilitation Service (SHRS) and a follow-up interview (with audio recording) following (name of patient)’s discharge from hospital to discover in reflection, from your perspective, the effect of the information presented in this 'Report Card' on the remainder of the rehabilitation admission and your feelings of preparedness on leaving our facility.

You will be invited to attend an interview at the SHRS at a mutually convenient time, to seek your feedback on the information you receive from the inpatient rehabilitation team (including this new resource), and on your knowledge of strokes prior to this recent illness. If you are unable to return to the hospital, a telephone interview can be arranged. We will also ask you about your experiences in the rehabilitation journey, your feelings and concerns on discharge from the service, and whether you have been able to utilise available community support services following discharge.

It is not anticipated that participation in this study would cause you harm. However if you experience distress for any reason, the SHRS will provide social work and clinical psychology support as necessary.

(4) How much time will the study take?

It is expected that participation in the study will require a minimum of one hour of your time (15 minutes for a brief explanation of the report card results and 45 minutes for the follow-up interview). Additional time may be spent with individual therapists discussing results and feedback as desired.
(5) Can I withdraw from the study?

Being in this study is completely voluntary - you are not under any obligation to consent and - if you do consent - you can withdraw at any time without affecting your relationship with The University of Sydney or St Vincent's Hospital.

You may stop the interview at any time if you do not wish to continue, in which case the audio recording will be erased and the information provided will not be included in the study.

(6) Will anyone else know the results?

All aspects of the study, including results, will be strictly confidential and only the researchers will have access to information on participants. A report of the study may be submitted for publication, but individual participants will not be identifiable in such a report.

(7) Will the study benefit me?

Involvement in the study will provide you with an opportunity to discuss the information you receive while the person you are caring for is participating in stroke rehabilitation and your experience of this process.

(8) Can I tell other people about the study?

Your treating clinicians including medical, nursing and allied health support workers will be aware of your participation as they will assist in preparation of the report cards and respond to ongoing information and education needs. You are encouraged to be discrete about your participation when speaking with other patients and caregivers, although this knowledge is not expected to disadvantage you in any way. Clinicians will not disclose the identity of participants to other patients or caregivers.

(9) What if I require further information about the study or my involvement in it?

When you have read this information, Yasmine Loupis will discuss it with you further, answer any questions you may have, and obtain your consent (see following pages). If you would like to know more at any stage, please feel free to contact Yasmine on 8382 9320 or by email at yloupis@stvincentshospital.com.au, or A/Prof Faux (details on page 1 of this sheet).

(10) What if I have a complaint or any concerns?

Any person with concerns or complaints about the conduct of a research study can contact the St Vincent's Hospital Research Office on 8382 2075 (Telephone), +61 2 8382 3667 (Facsimile) or research@stvincentshospital.com.au (Email) and quote reference LNR/13/SVH/22.

This information sheet is for you to keep
PARTICIPANT CONSENT

I, [PRINT NAME], give consent to my participation in the 'Mid-Term Report Card' research project.

In giving my consent I acknowledge that:

1) The procedures required for the project and the time involved have been explained to me, and any questions I have about the project have been answered to my satisfaction.

2) I have read the Participant Information Statement and have been given the opportunity to discuss the information and my involvement in the project with the researcher(s).

3) I understand that participating in this study is completely voluntary – I am not under any obligation to consent.

4) I understand that my involvement is strictly confidential. I understand that any research data gathered from the results of the study may be published however no information about me will be used in any way that is identifiable.

5) I understand that I can withdraw from the study at any time without affecting my relationship with the researcher(s), St Vincent’s Hospital (including the Sacred Heart Rehabilitation Service) or the University of Sydney now or in the future.

6) I understand that I can stop the interview at any time if I do not wish to continue, the audio recording will be erased and the information provided will not be included in the study.

7) I consent to:

   - Audio-recorded interviews [ ] YES [ ] NO
   - Receiving Feedback [ ] YES [ ] NO

If you answered YES to the “Receiving Feedback” question, please provide your details i.e. mailing address, email address.

Feedback Option

[ ] Address: ________________________________

[ ] Email: ________________________________

The 'Mid-Term Report Card' Project
Version 3, January 2013

Page 3

108
<table>
<thead>
<tr>
<th>Name of Participant</th>
<th>Signature of Participant</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Name of Witness to Participant</th>
<th>Signature of Witness</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Name of Investigator</th>
<th>Signature of Investigator</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>