Mentoring in Acute Stroke: Evaluation of an information provision strategy for stroke survivors and carers

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I certify that the work in this thesis has not previously been submitted for a degree nor has it been submitted as part of requirements for a degree except as fully acknowledged within the text.

I also certify that the thesis has been written by me. Any help that I have received in my research work and the preparation of the thesis itself has been acknowledged. In addition, I certify that all information sources and literature used are indicated in the thesis.

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ABSTRACT

Stroke survivors and their carers face a multitude of challenges. Literature suggests the need for new approaches to address an identified lack in the provision of information following discharge from hospital. This exploratory study evaluates the effects of a program using stroke survivors and their carers (defined as mentors) to provide information on available services and resources to current stroke in-patients and their carers in an acute setting. Mentoring has been successfully used in breast cancer, ischaemic heart disease and traumatic brain injury but an extensive literature search has found no evidence of evaluation of this form of intervention in acute stroke.

Using Fourth Generation Evaluation and mixed methods, data was collected from three stakeholder groups. Semi structured interviews were conducted with the inpatients and carers at 48hrs and 4 weeks post meeting the mentors. Data was transcribed and thematically analysed and the primary themes identified were: there is life after stroke, providing hope and understanding, and easing the burden of stroke. Focus groups (4) conducted with the mentors (3) and members of the Acute Stroke Team (1) were used to identify claims, concerns and issues. Mentors identified that the experience was beneficial for them and that they gained personal growth from the experience. The Acute Stroke Team identified positive aspects of the program and provided valuable input into the development of an agenda for future programs. This research confirms that mentoring can provide positive benefits for stroke survivors and their carers.

CHAPTER 1: INTRODUCTION

1.1 BACKGROUND TO THE STUDY

Stroke is a neurological event that leads to an interruption in the blood flow to the brain. The consequences may be death or permanent brain damage with associated deficits, depending on what area of the brain has been affected (Hickey, 2009). Worldwide, stroke is the second single commonest cause of death and the leading cause of disability (World Health Organization, 2003). In 2003 some 346,700 Australians had a stroke at some time in their life and with over 60,000 Australians suffering a stroke per year, the impact of this disease on society is costly physically, psychologically, socially and financially (National Stroke Foundation, 2010).

1.2 CENTRAL COAST OF NSW

Gosford Local Government Area (LGA) is located on the coast of NSW, 85km north of Sydney. It had a population of 158,157 persons according to the 2006 census with 77.8% born in Australia and 22.2% born overseas as defined by a local demographic overview (Centre for Urban and Regional Studies, 2008). A decline in population growth related to sustained low fertility rates and a decline in the mortality rate has meant an increase in life expectancy. Hence, there is a trend towards an older population. In NSW the median age of the population is 37 years and the median age in Gosford City is 40 years (Centre for Urban and Regional Studies, 2008). The Central Coast is a popular tourist attraction offering scenic landscapes and striking beaches.

It is also an affordable place to purchase a home in comparison to other areas and metropolitan resources of Sydney are still within easy reach. This makes it a popular destination for retirees who have more time to enjoy the relaxed lifestyle and scenic attractions. The census indicated that there was a significantly higher proportion of the population aged 65 years and over in the local area, with Gosford LGA having 18.2% compared to that of the rest of NSW having 13.8% (Centre for Urban and Regional Studies, 2008). As the risk of having a stroke increases with age, this places the aging population of Gosford LGA at risk (AIHW: Senes, 2006; Hickey, 2003). Around five hundred patients with a primary Diagnosis Relating Grouping (DRG) of stroke are treated at Gosford Hospital every year (Exchange, 2004).

1.3 GOSFORD LGA STROKE SERVICE

Gosford has an eight bed acute stroke unit and there is a four bed acute stroke unit at Wyong. As a Clinical Nurse Consultant for stroke at both units, I was concerned about the provision of information regarding available services and resources for stroke patients and their carers after discharge from hospital. A Stroke Folder is provided to patients and their carers. The folder contains information about stroke and its sequelae; risk factors, pathology, diagnostic tests, definitions of roles of acute stroke team members, treatment modalities, management strategies and a list of available services and resources.

The Stroke Folder, developed at a local level, is revised, then updated each year, to ensure that the information is current.

A local consumer representative and other stroke survivors and carers provide feedback on what they like about the document and any additional information they feel should be included. Carer support services have also contributed valuable information regarding care for the carers and additional services and resources available to carers that had not been included in the original folder.

It has been identified that provision of information for patients should be easily interpreted and therefore the readability of the Stroke Folder was assessed (Office of Patient Education for University of Utah Health Sciences Centre, 1997; Rodgers, Bond, & Curless, 2001). The Flesch-Kincaid Grade Level score rates text on a United States grade-school level. Hence a score of 8.0 means that an eighth grader can understand the document. Most documents, aim for a score of approximately 7.0 to 8.0. The Stroke Folder has a score of 8.0, however, an author's guide for patient education recommends that producers should aim for a sixth grade reading level (University of Utah Health Services Centre, 1997). Hinckle, Albanese and McGinty (1993) point out that readability scores only measure structural difficulties and do not take into consideration the reader's characteristics nor content organization or the conceptual difficulties of the document. As such they caution against writing solely to suit readability scores as this may alter valuable content of the text and result in a poorly written document (Hinckle, Albanese, & McGinty, 1993).

There is an audit process for the distribution of the Stroke Folder to stroke patients and their carers but not for the patient's understanding or utilisation of the resource.

Therefore, even though information provision occurs, we are uncertain if the Stroke Folder meets their needs. In fact, there needs to be clarity around what the specific needs of stroke survivors and their carers are.

In addition to the Stroke Folder, this population also has access to other information. The World Wide Web is a source of information for stroke survivors and their carers and within the Stroke Folder several web-based sources are recommended. Though the web has become a recognised source of up to date information it is not readily accessible to everyone and sites should be scrutinised in relation to accountability, readability and reliability to ensure that information is current, accurate and easily understood by the viewer (Griffen, McKenna, & Worrall, 2004).

Along with the Stroke Folder, the area health service also provides a DVD developed in conjunction with other area health services. The DVD discusses stroke recovery and life style changes to address identified risk factors. The DVD is provided free of charge, however as this is a new initiative, the distribution of the DVD by clinicians is haphazard as staff come to terms with new responsibilities in information provision. Though the DVD and the Stroke Folder are provided to patients and their carers as a means of information provision, the provision alone does not necessarily equate to greater understanding of stroke and its sequelae (Forster et al., 2005).

1.4 LOCAL SUPPORT FOR STROKE SURVIVORS AND THEIR CARERS

The Central Coast has a number of local active support groups, carer support services and the Community Stroke Support Service (now identified as part of the Community Neurological Support Service) that provide ongoing support to stroke patients and their carers after discharge from hospital. There is also provision for patients and their carers to tap into other resources such as the Commonwealth Carer Respite Service and the Stroke Recovery Association. There is concern that not all patients and carers are identifying the potential benefits of accessing these services.

In 2003, the Stroke Unit at Gosford Hospital (a tertiary teaching hospital in GLGA) enlisted the help of past stroke survivors and their carers to provide support to stroke inpatients and their carers. In one instance a past stroke survivor and carer came to the hospital as part of a promotional tour to raise awareness of stroke and met with a patient and his carer. Subsequent to discharge, the patient and carer then provided support to another patient and carer while in the acute setting. The recipients of these visits later identified the experience as being both inspirational and informative. Other research has identified positive responses from relationships such as these in stroke but these were informal long term relationships post discharge from inpatient stroke care (Roman, 2006). Support for stroke survivors and their carers extends beyond the inpatient setting and local support groups are one means of providing support in the community setting.

Working Age Group Stroke (WAGS) is a local support group for stroke survivors and their carers operating on the Central Coast. In 2005, they were involved in preliminary discussions looking at strategies to provide information and support to stroke survivors and carers within the local area. The motto of the group is "From Adversity to New Growth" which represents the philosophy that support and socialisation of stroke survivors and their carers will allow them to be better equipped for their roles within society and will enhance their recovery. With some 500 strokes treated in Gosford's tertiary-based hospital each year, there is concern that information provision may not be servicing the needs of stroke survivors and their carers within the local area. A number of local support services and resources are available but the effectiveness of making people aware of these through existing information provision is questionable.

1.5 OUTLINE OF THE THESIS

This thesis presents the results of a study evaluating a new initiative to provide information to stroke survivors and carers involving a mentor program in the acute setting of Gosford Hospital. Chapter 2 presents a review of the literature on providing information and support to stroke survivors and their carers. In Chapter 3, the mentor program is detailed. Chapter 4 details the various types of methodological approaches used in evaluation and elaborates on the type of evaluation selected for the study. Chapter 5 details the methods used to undertake the evaluation. In Chapter 6, the results of the analysis of the data are presented. Chapter 7 discusses the agenda, which is the outcome from the chosen evaluation methodology.

Finally, in Chapter 8 the significance of the results, how they compare to past research and how they may impact on the future, of information provision for stroke survivors and their carers is discussed.

CHAPTER 2:

LITERATURE REVIEW

2.1 INTRODUCTION

This chapter presents a review of the identified literature concerning the provision of information available to stroke survivors and their carers. It elaborates on past study findings and critically analyses the research methodologies and methods. The literature defines a number of standpoints including that of the stroke survivor, carer, and healthcare professionals with insight into the various approaches that have been adopted to support the multifaceted requirements in recovery after stroke (Dowswell et al., 2000). By examining the literature, strategies already studied can be explored and suggested strategies for future study can be identified.

2.2 NEEDS OF STROKE SURVIVORS AND THEIR CARERS

Survivors of stroke and their carers face a multitude of challenges including physical, psychological and social adjustment (Rittman et al., 2004). Although health professionals have a keen interest in outcome measures these measures are often defined by the professionals rather than the stroke survivors (Kersten, George, Low, Ashburn, & McLellan, 2004). In the clinical settings there is very little consideration given to identifying the social impact of stroke on stroke survivors, yet patients will identify their ability to return to meaningful activities in life as being indicative of recovery rather than their ability to master specific tasks (Dion, 2004; Kvigne, Kirkevold, & Gjengedal, 2004).

Research has shown that there are strong correlations between cognitive / physical disability, depression and health related quality of life after stroke (Haacke et al., 2006). Nevertheless, many stroke survivors who achieve high functional ability still report poor quality of life, depression and have decreased social interaction and poor self-esteem (Anderson & Marlett, 2004). The psychosocial impact of stroke on survivors is evident even 15 years post stroke (Teasdale & Engberg, 2005). Even young survivors who have good physical recovery report difficulties in returning to their premorbid social activities (Martin, Yip, Hearty, Marletta, & Hill, 2002).

The introduction of designated specialised stroke units has been associated with significant reductions in mortality, dependency and length of hospital stay (Adams et al., 2003; Collaboration, 1997; Dion, 2004; Foley, Salter, & Teasell, 2007; Stroke Unit Trialists Collaboration, 1997). Consequently, many patients are discharged directly home from the acute care setting, and are reliant on available support services within the community. There is an identified lack in the provision of information for stroke survivors and their carers following discharge from hospital (Martin et al., 2002; McKevitt, Redfern, Mold, & Wolfe, 2004; O'Connell & Baker, 2004; O'Connell et al., 2001; J Smith et al., 2008).

A systematic review of qualitative studies focusing on information provision following stroke, highlighted the need for a collaborative approach between researchers, consumers and health professionals (McKevitt et al., 2004).

One study in Seoul Korea administered a questionnaire to fifty-five patients, thirty-one doctors and fifty-seven nurses to determine ranking of importance in relation to individualised aspects of education in stroke including the following examples: possibility to cure with drug treatment; stress management; post stroke diet management; exercise and post stroke sexual activities. The study findings indicated that there were marked differences in perceived relevance of educational requirements between doctors, nurses and stroke patients and highlighted that these differing perceptions need to be considered when developing educational support (Choi-Kwon et al., 2005). As patients and carers have unique needs the education and information provision should be tailor made for the individual and not purely based on the perceptions of what is thought to be significant by healthcare professionals (Choi-Kwon et al., 2005; J Smith, Forster, & Young, 2004; Suhonen, Nenonen, Laukka, & Valimaki, 2005).

It has been suggested that health professionals should take the time to listen to the stories of those who have suffered a stroke in order to gain insight into their concerns and a greater appreciation of the ways in which they could alleviate stress (Pilkington, 1999). The literature suggests the need for varied and novel approaches when providing adequate information for stroke survivors and their carers. This would provide them with knowledge of who to turn to for assistance and what resources are available for them on discharge from the healthcare setting (McKevitt et al., 2004; O'Connell & Baker, 2004; O'Connell et al., 2001; J Smith et al., 2008; Wachters-Kaufmann, Schuling, The, & Meyboom-de Jong, 2005).

2.3 INFORMATION PROVISION RESEARCH

In the 2008 Cochrane Review of Information Provision for Stroke Patients and their Carers, of an original two hundred and twenty eight abstracts, seventeen completed trials were deemed suitable to be included in the review (J Smith et al., 2008). Many studies were excluded because they were part of a more complex rehabilitation intervention or were not randomised (J Smith et al., 2008).

The Cochrane Review included studies that provided informational booklets or leaflets, educational sessions / lectures, manuals, shared medical records or a combination of these strategies, to stroke survivors and their carers (J Smith et al., 2008). There were a number of issues identified with the review. It is difficult to compare outcomes of the various studies examined by the Cochrane Review due to the diversity in both numbers to treat and outcome tools used. There seems to be a problem identifying research where reliable and validated tools are being used consistently in the evaluation of interventional programs looking at information provision and psychosocial interventions after stroke as evidenced by a number of reviews (Brereton, Carroll, & Barnston, 2007; Forster et al., 2005; Knapp, Young, House, & Forster, 2000; J Smith et al., 2008).

Only some of the studies in the Cochrane Review revealed statistical significance in regards to information provision improving outcomes. The evidence demonstrated improved stroke survivor and carer knowledge and some reported improvement in patient satisfaction and lower scores for depression.

Those studies employing active methods of information provision rather than passive were identified as having the most impact on depression and anxiety in stroke survivors (J Smith et al., 2008).

The results of the Cochrane Review indicated that general effectiveness of information provision had not been substantially proven and even with information being provided to patients and carers this does not necessarily equate to improved outcomes (J Smith et al., 2008). The review acknowledged the need for further research and suggested that new active approaches needed to be explored but did not offer explicit suggestions on interventions or who should be responsible for them. The review also acknowledged the need for standardisation of evaluation tools (J Smith et al., 2008).

2.4 TYPES OF INFORMATION PROVISION

The majority of information provision has incorporated written information in the form of pamphlets, leaflets, fact sheets or manuals to reinforce verbal communication so that the person can seek out reinforcement or clarification of information at a time that suits them. It is recommended that any intervention strategies should be used to complement or augment the traditional verbal communication between patients, carers, families and healthcare professionals and should not be used as a replacement (Duncan et al., 2005; Toofany, 2006). Some innovative forms of information provision to facilitate education of patients and carers include CD, video, DVD and web based programs. CD, DVD and videos are often viewed as being more cost effective than traditional didactic education programs, however they are problematic in regards to their lack of interaction and inability to provide feedback (Rosen et al., 2003).

Nevertheless, there are benefits in using these mediums as they address issues of low literacy skills and visual impairment related to written material (Krouse, 2001). Web-based educational programs are another effective way of providing information and also providing the capacity for interaction but problems can exist in regards to technological literacy of the recipients (Rosen et al., 2003). There is a validated tool called the Technology Readiness Index (TRI) to assess the ability of people to utilise this strategy for information provision but then an alternative strategy would be required to accommodate people who could not utilise this approach (Rosen et al., 2003). One article suggests that the cost effectiveness of web-based programs have not yet been satisfactorily proven as a viable option to face-to-face education (Coulter & Ellins, 2007).

2.5 SUPPLEMENTED INFORMATION PROVISION

Included in an earlier Cochrane Review (Forster et al., 2005) was a study comparing the outcomes of two programs, one utilizing education only to provide stroke caregivers with information regarding stroke care. The second group was provided with both education and social work follow-up at 6 and 12 months to check on any problems they had identified and provide counselling on how these problems may be addressed. Both groups showed greater caregiver (equivalent to the Australian carer) knowledge regarding stroke care. The research showed that carers provided with follow-up by the social worker proved more effective in stabilizing family function and promoting patient adjustment, however neither the education nor the social worker follow-up influenced the use of social resources (Evans, Matlock, Bishop, Stranahan, & Pederson, 1988).

Other research sought to examine the effectiveness of providing educational sessions for stroke survivors and their carers to supplement written information aimed at improving knowledge regarding stroke and available resources (J. Smith et al., 2004). In this randomised study the control group received normal care including the availability of relevant literature and the option of input from multidisciplinary team members to answer their questions. Those in the intervention group received a specifically designed manual providing stroke information in combination with fortnightly educational meetings with a multidisciplinary team. A questionnaire was used to determine participant's knowledge of stroke and available resources, however it was suggested that the tool lacked sensitivity and reliability. The intervention group showed no statistically significant improvement in knowledge, however there were significant decreases in the stroke survivor's anxiety levels at three months ($p = 0.034$) and six months ($p = 0.021$) (J. Smith et al., 2004)

2.6 TIMING OF INFORMATION PROVISION

The time spent in the acute hospital and the months following discharge are the most significant periods for both patients and carers (King & Semik, 2006). A study undertaken in the Netherlands identified that participants wanted oral information within the first 24 hours of the person having the stroke and that this should be supplemented by written information that could be referred to later (Wachters-Kaufmann et al., 2005). This, along with the fact that many patients are being discharged from hospital earlier in response to the success of acute stroke units, suggests the need for further research and development in regards to information provision for stroke survivors and their carers early in the recovery process (Stroke Unit Trialists Collaboration, 1997).

The level of functional disability has been identified as a contributing factor to the difficulties experienced upon transition back to the home setting and the establishment of a routine was acknowledged as a major challenge for both stroke survivor and carer (Rittman et al., 2004). Even though these are demonstrations of the very people who require support, a number of issues impact upon people's knowledge and understanding of information and resources available to provide that support.

Patients and carers do not always absorb information during the early phases of stroke recovery (Wachters-Kaufmann et al., 2005). The General Practitioner (GP) was identified as the primary provider of information who was best placed to support the information provided because of the longer-term provision of care. However, there was a perceived time delay in information provided by the GP. A contributing factor to this may be delays in coordination of information between hospitals and GPs where local doctors are not alerted to the fact that their patient has had a stroke until they are discharged from the acute or rehabilitation setting (Wachters-Kaufmann et al., 2005). There are also some identified barriers with the effectiveness of communication between doctors and patients (Denham, 2008). A study by O'Connell et al. (2001) identified that General Practitioners provided much of the follow-up care, however their workload made it difficult to provide the necessary psychosocial support. The researchers concluded that support groups were valuable in such circumstances (O'Connell et al., 2001).

In light of this, it would seem pertinent for stroke survivors and their carers to be cognisant of available support groups or resources that can be accessed to provide support following discharge and to supplement the information provided by the General Practitioner.

2.7 CARERS' NEEDS

Carers may also feel that they have insufficient knowledge of available services to assist them to adequately prepare for their future in caring for a stroke survivor (O'Connell et al., 2001). Some carers feel that their capacity to assume this role is taken for granted by health professionals and that there is little consultation in relation to their coping abilities (L. Smith, Lawrence, Kerr, Langhorne, & Lees, 2004). One study undertaken in Adelaide looked at the outcomes for stroke survivors and their carers who were involved in accelerated hospital discharge with home based rehabilitation (Hackett, Vandal, Anderson, & Rubenach, 2002). Though this study did not address information provision, it did examine the outcomes of accelerated discharge on stroke patients and their carers. At one-year follow-up, it was identified that there was a negative variation in the mental health scores for carers in the intervention group as opposed to the control group. The researchers noted that this may have been incidental and commented that the results were to be interpreted cautiously. They advised that further research was needed in the area of carer outcomes (Hackett et al., 2002)

In one study an intervention group received a specifically designed manual providing stroke information in combination with fortnightly educational meetings with a multidisciplinary team (J. Smith et al., 2004).

The study results indicated that the intervention group were more likely to seek out external services. This may have been because the intervention group had a higher incidence of total anterior circulation syndromes, which are high severity strokes equating to greater disability (Hickey, 2003, 2009). The carers of patients who have had such strokes, would require greater support and hence were more likely to seek out services (Rittman et al., 2004). This was not clearly indicated in the research as a reason for the intervention group seeking out services. Rather, the study acknowledged that the greater access of services by the intervention group might have occurred because of the availability of a reference source in the provided manual. In relation to the unchanged knowledge of stroke between the intervention and control groups, the study did recognise bias relating to the input of the multidisciplinary team with the control group and the impetus of this group to seek out information of their own accord (J. Smith et al., 2004).

O'Connell and Baker's (2004) study identified a need for information and education to support the role of a new carer for a stroke survivor. The lack of training and preparedness for the care-giving role for stroke survivors has been well documented including a randomised control trial (Kalra et al., 2004) and a systematic review (Brereton et al., 2007). A number of studies identified the crucial role of carers to support the stroke survivor's recovery (Brereton et al., 2007; Kalra et al., 2004; Larson et al., 2005; O'Connell & Baker, 2004). As some 146,400 stroke survivors in Australia are left with disability as a result of stroke (AIHW: Senes, 2006) there is potentially a large number of Australian carers in need of support.

A trial program using experienced carers to mentor new stroke carers was recommended in one study (O'Connell & Baker, 2004). The researchers hypothesised that the use of mentors to provide information to stroke survivors and their carers in the acute setting would have a positive outcome. The researchers suggested that this type of initiative could address the following issues:

- The time constraints of healthcare workers in providing for education and informational needs of stroke carers in a relaxed manner
- Socialisation, in providing stroke survivors and their carers with the opportunity to talk to people who have undertaken a similar journey to their own
- Finally, the provision of information from people who can personally identify with needs that stroke survivors and their carers may have.

2.8 MENTORING

The origins of mentoring come from Greek mythology. In the Odyssey, Homer wrote of Odysseus, called to fight in the Trojan Wars, who left his palace and son Telemachus in the care of his old friend Mentor, the son of Alcumus. Athena the Goddess of Wisdom would disguise herself as Mentor in her meetings with Telemachus and she encouraged Telemachus to go in search of his father. Telemachus would later go on to become the King of Ithaca (Hayes, 2005; *The Odyssey by Homer*, 2003; Schapira, Kalet, Sxhwartz, & Gerrity, 1992; J. Smith et al., 2004).

The term mentor is sometimes used interchangeably with peer support (Hibbard et al., 2002). Much of the literature refers to mentoring as a long term relationship fostering knowledge and personal growth (Fawcett, 2002; Hayes, 2005; Lister, 2004; Tracey & Nicholl, 2006). The term "mentor" is more succinctly defined in the Oxford Dictionary (2005, p315) as an “experienced and trusted advisor”.

Hibbard (2002) identified the following mentoring characteristics:

- Willingness to provide time and energy
- Motivation to help others and give something back
- Personal adjustment to the lived experience of the condition
- Insight into their own strengths and personal limitations
- No current serious psychiatric medical problems
- Empathy and the ability to listen and refrain from imposing personal views or opinions (Hibbard et al., 2002).

Mentoring programs have been found to be effective in providing information and support to patients with a number of other health conditions including breast cancer, traumatic brain injury (TBI) and ischaemic heart disease (Coull, Taylor, Elton, Murdoch, & Hargreaves, 2004; Greiger, Mullen, Sloman, Edgerton, & Petitti, 2000; Hibbard et al., 2002). Though these studies all explored a strategy of mentoring in one capacity or another, they employed different outcome measures, making comparison of the outcomes difficult. Nevertheless, these studies do indicate that such an approach can have a positive outcome in diverse patient populations.

In fact research has identified that stroke survivors who have mentored people following discharge from hospital have positively impacted on the recovery of the recipient (Roman, 2006).

In the breast cancer study, the purpose was to evaluate the patient's level of satisfaction with their care. One aspect of care was the use of mentors (Greiger et al., 2000). The findings of the study indicated that the participants of the intervention group rated their level of satisfaction with the care provided higher than the control group (Greiger et al., 2000). The preliminary findings for the mentees of a traumatic brain injury study indicated that the mentor program increased knowledge of TBI, improved quality of life and general outlook and enhanced the ability to cope with depression (Hibbard et al., 2002). The Braveheart Project investigated the impact of mentoring on modifying risk factors associated with ischaemic heart disease and also the impact of the strategy on physical and psychosocial wellbeing (Coull et al., 2004). The study findings indicated that mentoring was feasible, practical and inclusive and produced positive influences on physical activity, diet and utilization of health resources.

Mentoring has also been successfully adopted as a strategy to provide guidance and support to healthcare professionals (Hayes, 2005; Lister, 2004; Tracey & Nicholl, 2006). In fact, many of the benefits achieved from this form of support are universal. The scope of mentoring can also span across diverse age groups as there are currently over one hundred registered youth mentoring programs in Australia (National Youth Mentoring Partnership, 2008).

As with other forms of mentoring it is the mentor's willingness to share knowledge and experience that allows a program to generate success (Tracey & Nicholl, 2006). Nevertheless, it is important to remember the purpose behind mentoring and the importance of selection of appropriate people for the task (Fawcett, 2002; Hibbard et al., 2002). The relationship should be one that is mutually beneficial for both the mentor and the mentee. The benefits of mentoring should work both ways with mentors gaining just as much insight and reward from undertaking the role as those whom they are endeavouring to mentor (Hibbard et al., 2002; Lister, 2004).

Some articles made reference to the destructiveness that can occur from a "toxic" mentor and acknowledged the importance of screening those who adopt the mentoring role (Feldman, 1999 ; Tracey & Nicholl, 2006). There are clearly defined characteristics that should be able to be demonstrated by mentors including: patience, enthusiasm, knowledge, a sense of humour and respect (Fawcett, 2002). Weil (2001) highlighted that mentoring should be voluntary and that there can be ramifications arising from having a forced relationship. The suggestion of a choice of mentor is posed in a number of articles particularly in relation to professional mentoring programs (Hayes, 2005; Tabbron, Macaulay, & Cook, 1997). Another consideration is that there may need to be financial support to run a mentoring program. An estimated $100 000 was attributed to the cost of running the breast cancer mentoring program out of two proposed sites (Greiger et al., 2000).

Much of the expense was attributed to a project coordinator's salary but incidental cost associated with written information, phone calls, allocated space and supplies for the coordinator and expenses associated with future training of mentors were also factored in (Greiger et al., 2000).

2.9 CONCLUSION

The literature reveals the need to research alternative ways of providing information to stroke survivors and their carers about available services and resources that can be accessed after discharge from hospital. It is suggested that healthcare workers should be actively seeking past consumers' input into providing a better service and should include them in the processes required in developing it (Forster et al., 2005). By utilising consumers to recognise the issues that a stroke survivor and their family will encounter you are incorporating the very people who have been through the experience. The experiences of past sufferers are now being recognised by health professionals and researchers for their ability to contribute to the care needs of new sufferers (Sylvain & Talbot, 2002).

An identified deficit in the provision of information and support for stroke survivors and their carers suggests researching varied and novel approaches to address this need. Some strategies that have been implemented or trialled throughout the literature have been evaluated using various quantitative tools, however there is concern that valuable data may be lost in a tool that does not address the specific issues that existed for the participants or is not sensitive enough to register a variation in response.

The literature also highlights that diverse quantitative outcome measures do not allow for comparison between the outcomes of various strategies. Qualitative studies afford the opportunity to gain valuable insight into the intricate and often subtle meanings behind what people say (Pennebaker, 2007). Qualitative research can provide insight into not only the success or failure of an intervention strategy but may also provide direction regarding appropriate quantitative tools for future research.

Mentoring to provide information and support to survivors and carers has proven successful in breast cancer, traumatic brain injury and ischaemic heart disease. At the inception of the program an extensive literature search through Ovid (1982-January 2006), Medline (1982-January 2006) and CINAHL (1982-JanuaryWeek 4 2006) did not reveal any research detailing the evaluation of this as a strategy for information provision for stroke survivors and carers in the acute stroke setting. Hence, this study will seek to investigate the potential of mentoring as a strategy for acute stroke. Preparation for the mentors was necessary prior to implementing the study and chapter three shall highlight some of this preparation.

CHAPTER 3: THE MENTOR PROGRAM

The literature review revealed the need for further study regarding information provision for stroke survivors and their carers. At Gosford Hospital, past stroke survivors/carers would be enlisted to provide this information and would be known as stroke mentors. In order to assist the mentors to provide information to the stroke inpatients and their carers it was essential to provide training, knowledge, skills and resources. This chapter will detail the preparation undertaken prior to the mentors' initiation into the acute hospital setting.

3.1 OVERVIEW OF THE MENTOR PROGRAM

As indicated in Chapter One, on two occasions past stroke survivors/carers had informally been utilised to offer support to inpatients and their carers in the acute setting. It was postulated that a more formal program would offer a unique means of making stroke survivors and their carers aware of what services and resources they could access after discharge from the inpatient healthcare setting. The mentors would complement the existing information and support offered in the acute setting. Mentors would provide unique insight to inpatients/carers regarding their own experiences and coping mechanisms and make them aware of what resources were available to them on discharge. This would afford the inpatients and their carers the opportunity to discuss concerns with someone who had first hand experience of stroke and its sequelae.

3.2 MENTOR PREPARATION

A formalised curriculum was developed to ensure that the mentors received the appropriate training prior to undertaking the role. An outline of what was included can be seen in Appendix 1. The curriculum was based on strategies for adult education and mentoring programs identified through the literature (Caffarella, 1994; Coulter & Ellins, 2007; Fawcett, 2002; Feldman, 1999; Freire, 1993; Tabbron et al., 1997; Tracey & Nicholl, 2006; Weil, 2001). The education program addressed pertinent issues such as communication, privacy, confidentiality and occupational health and safety.

As successful communication is required to undertake the mentoring role, the mentors were trained in effective listening, non verbal communication, and ways of initiating conversations with others (Hibbard et al., 2002). Role-plays were undertaken and if mentors wanted to practice their skills, an opportunity was provided to speak to some inpatients. This aided the mentors in building their confidence.

The area health service required assurance of the suitability of anyone engaging in volunteer work at the hospital and the mentors, as volunteers, had to complete the necessary paperwork and training. The manager of volunteer services at the hospital assisted the mentors with paperwork for criminal record checks and trained the mentors in occupational health and safety, confidentiality, privacy and dress requirements.

It was important for the mentors to have a clear understanding of boundaries to comply with both volunteer and occupational health and safety standards of the area health service to protect and ensure safety of the patients and the mentors. Volunteer parking swipe cards were supplied to ensure that no added burden was placed upon the mentors regarding parking at the hospital.

The program included appropriate discussion to ensure that information provided to the patient and their carer would not contravene or contradict the instructions given by medical, nursing or allied health staff. The mentors were expected to help the inpatient stroke survivors/carers to identify whom to approach within the multidisciplinary team to answer individual concerns. Introductions to members of the multidisciplinary acute stroke team were undertaken during the program.

The educational sessions took place over several weeks with on average one session a week each session lasting for around two hours. These sessions were organised based on availability of the mentors and were usually organised in the morning so that parking was at a premium being outside standard visiting hours. If a mentor was unable to attend a planned education session then a separate time was organised for them to attend an individual session.

The preparation of the mentors did require review to ensure all considerations were addressed. Summative evaluation with objective based review using a five point Likert Scale was used to determine if the objectives of the mentors' education were achieved (Caffarella, 1994).

Evaluation took place at the end of each session on a purposely-designed evaluation sheet and collation occurred straight after each session so that any necessary changes to the program could be organised rapidly. In response to the evaluation, an additional session was added to the five-day program to address the confidence of the mentors through role-plays.

3.3 IMPLEMENTATION OF THE MENTOR PROGRAM

To promote awareness of the mentors a number of strategies were implemented. A poster with pictures of each of the mentors and their first names resided on the ward to improve staff familiarity and aid in identification. Mentors were provided with badges to identify them to patients and to ward staff. Identification badges were also a requirement of volunteer services and the mentor's first name was included on the badge to help people address them by name rather than role. Mentors were also required to sign on/off and provide an emergency contact number, in order to adhere to safety requirements in case of an adverse event. Raising awareness of the mentors on the ward aimed to prompt members of the Acute Stroke Team (AST) to consider the mentors for patients on the ward.

A timetable of when the mentors would be available to come in and meet with a stroke inpatient /carer was also developed. As there were only 10 mentors, it was important to make the most of their availability with minimum pressure or disruption to their lives. It was agreed that mentors would be given at least 48 hours notice before a scheduled meeting with the stroke inpatient/carer.

The timetable also indicated rest periods so that mentors were aware of this and could factor this into their visit.

3.4 SUPPORT FOR THE MENTORS

Even though the mentors were already part of a local support group with previously established relationships and support networks it was important that the mentors felt supported in their roles. Contact details were given to the mentors in case they needed clarification, advice or to discuss anything regarding the program. A diary was supplied to the mentors to allow them to record the mentoring encounter at a time most convenient to them, providing them with the opportunity to reflect on and keep a record of the experience.

The mentor group were familiarised with a number of available services. These included the Community Stroke Support Service, an outpatient service offering support and education to people who have experienced stroke and the Carer Support Service, which is a hospital based program that provides resources highlighting available support for carers within the community. The mentors were introduced to members of the AST and were given a tour of the ward and introduced to nursing staff.

In addition to the education, mentors were given the necessary resources to support their learning. A booklet was developed based on an original document developed by the National Stroke Foundation and Hunter Area Health Service for a community based support program. This booklet was locally adapted and included the rights and responsibilities of people undertaking the role of mentor.

It provided helpful hints regarding communication strategies and advice to the mentors on how to look after themselves. The book defined the boundaries including those pertaining to occupational health and safety as well as those dealing with confidentiality and privacy. Section three of the booklet included a list of all of the health professionals that may be involved in the care of a stroke patient with particular reference to members of the AST. This would aid the mentor in determining the most appropriate person that they could suggest the inpatient or carer seek advice from in the event that specific questions were raised that required healthcare input.

The mentors received a copy of the Stroke Folder supplied to stroke patients during the course of their stay in the acute setting. This is an existing document aimed at providing information to stroke survivors and their families regarding available services and resources. The folder contains information about stroke, the stroke team, available resources and a multitude of additional information that a stroke survivor or their carer may require. The mentors used this resource as a conversation piece during their meeting with the inpatient and / or carer.

3.5 MATCHING THE MENTORS TO INPATIENTS AND CARERS

Hayes (2005) pointed out that mentees within a program for nurse practitioners developed anxiety when they did not have input into the selection of a mentor but were designated a mentor by the faculty. Nevertheless, it is impractical to suggest that the participants of this program would be capable of selecting an appropriate mentor.

In order to assist in addressing this issue, a teleform (see Appendix 2) was used to collect profiles of mentors, inpatients and carers including age, type of stroke, hobbies and interests so that they could be matched to one another.

Preliminary interviews with inpatient stroke survivors/carers were also used to aid in matching the mentor's characteristics with the needs of the recipients. At this interview, the following questions were asked:

1. Do you feel that you would benefit from talking to someone who has experienced stroke or cared for someone who has had a stroke? (They were identified as mentors at this time).
2. What type of information would you like from someone undertaking this role?
3. Do you have any doubts or reservations in undertaking discussions with a mentor?
4. When do you feel would be the best time to talk to someone mentoring?
5. Are there any specific requirements you have concerning selection of a mentor?

On the basis of the demographic information and the responses of the stroke inpatient/carer they were matched to the profile of a mentor. Mentors were then contacted, depending on their availability, to coordinate a meeting with the stroke survivor inpatient/carer.

Only one scheduled meeting between mentor and stroke inpatient/carer occurred in the acute setting. Both parties could negotiate additional contact depending on mentor availability and agreement.

During the interactions the mentors introduced inpatient stroke survivors/carers to the stroke folder (a resource currently distributed to inpatients) to raise awareness of available services, acted as a referral agent for support groups and provided supportive discussion based on personal experience. Healthcare specific questions were referred onto the members of the Acute Stroke Team for follow up.

Interviews used to aid in matching the mentors with the stroke inpatients/carers provided some valuable insight into the inpatient and carer participants. From this information, twelve of the participants were confident that they would gain something from the experience of talking with a mentor. Five had past family experience of stroke and two had been traumatic experiences. Three of the participants had had previous stroke and two were outside the local demographic area. Most participants identified that they were seeking something from the experience. The specific requirements in regards to selection of a mentor were limited to age and ability to understand any accents that the mentors may have. This could relate to the fact that a number of health professionals working in the area were from various nationalities and some patients had expressed concern over the fact that they had difficulties in understanding some of the accents during healthcare consultation.

Due to the early discharge of many stroke patients from the acute setting it was often necessary to organise the mentor visit as soon as possible but with interviews with the patients and their carers and 48 hours notice required to coordinate the mentors, the sessions often took place just prior to discharge.

The interaction between the mentor and inpatient stroke survivor or inpatient carer was anticipated to last for approximately 30 minutes, however there proved to be great variance in this, as illustrated in Table 3.1.

TABLE 3.1 NUMBER AND LENGTH OF INTERVIEWS

Number of Visits	23
Average	60 minutes
Standard deviation	31.2 minutes
Median	50 minutes
Shortest time	25 minutes
Longest time	160 minutes

3.6 SUMMARY

This chapter outlined the preparation mentors were required to complete prior to entering the acute setting to provide information and support to inpatient stroke survivors/carers. There was a need for formal evaluation of the mentor program to determine worth and to ensure no negative consequences to inpatient stroke survivors/carers, mentors or members of the AST. To initiate the evaluation the following research questions were formulated:

- "What are the experiences of stroke patients and their carers in the acute setting who participate in a support program using past stroke survivors and their carers as mentors?"
- "What are the experiences of mentors who participate in a support program for stroke survivors and their carers in the acute setting?"
- "What are the experiences of an acute stroke team involved in a support program for stroke survivors and their carers in the acute setting?"

The following chapters will detail the formal evaluation of an acute stroke mentoring program.

CHAPTER 4: METHODOLOGY

4.1 INTRODUCTION

The previous chapters have provided insight into the environment of enquiry and a detailed literature review regarding information provision for stroke survivors and their carers. The literature review also provided insight into examples of how mentoring, an approach to address information provision has been applied in other situations.

In order to evaluate the mentor program, various forms of enquiry were explored to identify the most appropriate methodological approach to answer the research questions identified in Chapter 3. The different paradigms of enquiry will be explored including the positivist, interpretive or constructivist and critical. A summary of the history of evaluation will be provided and a discussion on the evolution and use of evaluation in healthcare. The strengths and weaknesses associated with evaluation methodology will be presented and finally, the evaluation methodology selected for this study will be discussed.

4.2 OVERVIEW OF THE PARADIGMS OF ENQUIRY

Selecting a research methodology is directly related to the questions being asked (Glanz, Rimer, & Viswanath, 2008; Mukoma & Flisher, 2004). In this study the research questions were:

- "What are the experiences of stroke patients and their carers in the acute setting who participate in a support program using past stroke survivors and their carers as mentors?"

- "What are the experiences of mentors who participate in a support program for stroke survivors and their carers in the acute setting?"
- "What are the experiences of an acute stroke team involved in a support program for stroke survivors and their carers in the acute setting?"

There are three predominant philosophical paradigms of enquiry: the positivist (also known as scientific enquiry), the interpretive (also referred to as naturalistic or constructivist enquiry) and the critical stance (sometimes referred to as critical social theory) (Crookes & Davies, 2004; Guba & Lincoln, 1989). It has been suggested that positivist enquiry is aligned to objectivity, interpretive enquiry is aligned to idealism and critical enquiry is aligned to realism (Titchen, 1995). These paradigms, though distinct in their research approaches, are not exclusively unique in their application and evaluators may choose to alternate or mix approaches as the need arises (Guba & Lincoln, 1989). It has been argued that to exclusively declare one paradigm as holding more weight than the other would negate from the advancements achieved through the scientific paradigm and suggest that there is no truth in interpretive or critical paradigms (Clark, 1998).

4.2.1 POSITIVIST ENQUIRY

Universal laws that ensure both objectivity and neutrality ground the positivist paradigm.

This form of enquiry has its roots in the scientific world and some proponents of this stance profess that it is the only true form of research and believe that unless the method of data collection and analysis is substantiated by quantitative tools or statistical analysis, then the quality is thought to be second rate (Holloway & Wheeler, 2002). The purists of this paradigm will suggest that any deviation away from the positivist approach would only serve to taint the enquiry but many of the social researchers recognised changes occurring in society and with these changes came questions that could not always be answered by the positivist approach.

Kuhn (1970) identified some of the major flaws arising from such a constrictive paradigm, with subjects recognised as a whole but not as individuals and outcomes measured for the collective. In the positivist paradigm the researcher stands apart from the research to ensure true objectivity (Crookes & Davies, 2004). Quantitative research has a strong place in society but it is not able to examine the participant's views within the context they occur (Holloway & Wheeler, 2002).

The types of evaluation attributed to this paradigm include first, second and third generation evaluation (Guba & Lincoln, 1989). First generation evaluation relies on measurement and would not be a suitable form of evaluation for this study as it would not allow a detailed exploration of the participant's experiences and "what to measure" is essentially unknown (Guba & Lincoln, 1981, 1989; Koch, 2000).

Second generation evaluation looks at measurable objectives that direct the focus of the evaluation in regards to a specific goal or outcome. This limits the investigative enquiry and the opportunity to explore responses in far greater detail; in essence it places guide rails or barriers on exploring responses of participants (Guba & Lincoln, 1981). This would not be a suitable form of evaluation for this study because although the program is designed for information provision for inpatient stroke survivors/carers, familiarity with what information is significant to the participants is largely unknown.

Third generation evaluation is embedded in judgment by the evaluators and is reliant on a comparison between issues or items much like a fine cheese is judged against others at a show (Guba & Lincoln, 1981, 1989; Koch, 2000). This form of evaluation requires comparative evaluands, and as discussed in the literature review, the intervention requiring evaluation, has not been studied in this context.

The methodological stance of virtually every first, second or third generation evaluation models is grounded in the positivist or scientific paradigm (Guba & Lincoln, 1989). This form of enquiry would not be suitable to answer the research questions posed in this study because what to measure is not yet clear. No identified measurement tool would effectively evaluate all aspects of the program and no means of comparison are available because no previous studies of this intervention in this population have been undertaken.

4.2.2 INTERPRETIVE, NATURALISTIC OR CONSTRUCTIVIST PARADIGM

The interpretive, naturalistic or constructivist paradigm was largely adopted by philosophers, anthropologists and historians. This approach focuses on the interpretative comprehension of humans within their environments and the held belief that empathetic understanding was the true mechanism of finding the answers surrounding enquiry emanating from the social sciences (Guba & Lincoln, 1981, 1989; Holloway & Wheeler, 2002). This approach is often under scrutiny because it relies on interpretation of the data and 'true' positivists would argue as to the accuracy and objectivity of the interpretation. In qualitative evaluation one of the issues any enquirer is faced with is that they do have an impact on outcomes and that they are an integral part of whatever is being investigated, and in light of this they must reflect upon their own impact on the evaluative process (Holloway & Wheeler, 2002). Fourth generation evaluation resides within the constructivist paradigm (Guba & Lincoln, 1989).

The interpretive, naturalistic or constructivist paradigm maintains that participants present differing points of view regarding a particular phenomenon because responses are largely influenced by past experience and personal beliefs and as such differing realities can exist for people when faced with the same occurrence. By examining the individual experiences the researcher is not limited to categorising responses into a survey or predetermined value judgement (Crookes & Davies, 2004; Sankar, Golin, Simoni, Luborsky, & Pearson, 2006). Proponents of interpretive enquiry suggest that this offers a far more expansive view of responses to the research question, however this factor makes such enquiry challenging.

This form of enquiry generates a large amount of data requiring analysis and interpretation to allow for meaningful representation of participants' responses. In order to address issues around bias, reliability and truthfulness of the enquiry there must be strict adherence to the guidelines or rules affirming a chosen methodology and the methods used (Crookes & Davies, 2004; Lacey & Luff, 2001).

4.2.3 CRITICAL PARADIGM

Critical theory is similar to the interpretive paradigm, however, even though this form of enquiry recognises the uniqueness and individuality of responses from those who have experience, the purpose and motivation of the researcher and indeed the research question itself, is what separates this paradigm from the others. Critical theorists aim to bring about social change through empowering the very subjects of enquiry, to initiate the change. This methodology focuses on correcting social injustices by empowering the impoverished or oppressed (Burns & Grove, 2005; Freire, 1993; Saddler, 2006). In this form of enquiry the researcher is actually considered to be the change agent or facilitator and the research itself stems from an identified imbalance of power that suggests the need for empowerment of a disenfranchised group (Crookes & Davies, 2004). This type of design gives control over the focus of enquiry, how it is studied and the recipients of the results (Burns & Grove, 2005). Evaluation within this context cannot be clearly defined with standard measurement tools rather it looks at social injustices and requires dialogue to identify and adapt for transformative action to take place within a group or community in which the social injustices exist (Potvin, Gendron, Bilodeau, & Chabot, 2005).

4.3 EVALUATION

Evaluation, used throughout history to determine the efficacy and worth of various programs and interventions (Owen & Rogers, 1999), has been closely linked to the development of the social sciences (Hulshof, Verbeek, Van Dijk, Van Der Weide, & Braam, 1999). However, House (1993) proclaimed that the principles and intellectual skills of evaluation far predated the social sciences and looks to philosophers and the meta-theory obtained from educational researchers, as the true roots of evaluation.

Michael Scriven (1972) identified the need for evaluation to encompass aims and components of the interventions and how they relate; what exactly is happening; how the intervention performs over time; opportunities for improvement and the ability to replicate the success of the intervention in other areas. Patton focused on the purpose of the evaluation rather than the data analysis when he defined evaluation, stating that evaluation was a means of not only determining worth but also providing direction for future development of the programs or initiatives being evaluated (Patton, 1997). Even beyond this, evaluators are now expected to negotiate and plan the evaluation, ensure dissemination of findings, ensure that ethical and social codes of conduct are adhered to and work interactively and internally with clients to realize effectual change (Owen & Rogers, 1999).

4.4 HEALTHCARE EVALUATION

Much healthcare research tends to focus on the health of the population or patient, targeting death, disease, disability, discomfort and dissatisfaction.

As healthcare has developed so have the markers used to define the characteristics of health, including functional ability, overall wellbeing, satisfaction in care provision, understanding and knowledge, general quality of life, life skills and behavioural adjustment (Hulshof et al., 1999; Owen & Rogers, 1999). Healthcare specific evaluation predominantly explored the effectiveness of a change initiative in regards to health and its efficiency, looking at the cost in relation to the outcome; acceptability which refers to the social and professional satisfaction with the initiative and whether the program achieves its stated aims or objectives (Hulshof et al., 1999). Consideration must also be given to the cost of the evaluation itself and the potential burden that the process of evaluation may place upon participants (Glanz et al., 2008).

Evaluation in nursing research since the early 1990's has lead to an expansion in the use of qualitative approaches to enquiry (Swenson, 1991). The nursing profession realises that many of the questions posed by the profession could not be answered through use of the positivist paradigm. This led to an exploration of alternative approaches to research and the emergence of such collaborative approaches as participatory action research and fourth generation evaluation.

Evaluation is a fundamental means of determining credibility and trust in establishing change in modern society. It is used to determine the effectiveness of reorganization, restructuring, modification, transformation and alteration that comes about through development (Segerholm, 2003). It is not always easy to quantify the impact of change and it would be a pointless endeavour to apply a strategy unless believed that there could be some worth attached to it, but negative outcomes may outweigh the potential worth of the strategy.

Through a process of evaluation, outcomes can be scrutinised and, provided the evaluation is rigorously approached, gather valuable information as a basis for decision making (Lee, Cheng, & St Leger, 2005).

Considering the various methodologies, the positivist paradigm is too focused and restrictive to answer the research questions and social injustice is not what motivates the study, therefore it is not a critical enquiry. The study sits within an interpretive or constructivist paradigm whereby seeking to construct a picture of the experience of participants in the study at this particular place in time. Fourth Generation Evaluation sits within the constructivist paradigm.

4.5 FOURTH GENERATION ANALYSIS

Fourth Generation Evaluation (FGE) is defined as being constructivist, whereby data collection and analysis takes place within the constructivist paradigm including the ontological and epistemological perspectives (Guba & Lincoln, 1989). Guba and Lincoln (1989) identify the constructivist belief systems as relativist ontology where multiple constructs of reality may exist unguided by natural laws. Where truth is defined as the amount and quality of the information and the way in which this information is interpreted and used to form either single or multiple constructions that are supported by general consensus (Guba & Lincoln, 1989). The epistemological stance of the constructivist paradigms according to Guba and Lincoln is monistic (a viewpoint that reduces all phenomena to one principle), subjectivist epistemology that claims:

> "An inquirer and the inquired-into are interlocked in such a way that the findings of an investigation are the literal creation of the inquiry process" (Guba & Lincoln, 1989 p. 84).

FGE is a joint collaborative process not unlike participatory action research except that the agenda is shaped by claims, concerns and issues (Schneider, Elliott, Beanland, LoBiondo-Wood, & Haber, 2003). Clifford and Clark (2004) claim that action research differs from evaluation because they state it is specifically aimed at instigating change whereas evaluation research aims at determining the value or worth of a program. Nevertheless, FGE is not merely aimed at determining worth it is also used to inform future change and development (Guba & Lincoln, 1989).

Involving stakeholders in evaluation can improve acceptance of the initiative under investigation, increase the likelihood of acceptance of recommendations stemming from the research and enhance the likelihood of ongoing monitoring (Mukoma & Flisher, 2004). This collaborative approach to evaluation also promotes empowerment of the identified stakeholders as the views of all participants are explored and valued for their contribution to the enquiry process (Liburd, 2010; Patton, 2002).

There can be inconsistencies in the levels of power in the identified stakeholders and it is the role of the evaluator to act as mediator in the process of negotiation and the evaluator and the stakeholders can then become the agents of change (Swenson, 1991).

FGE recognises the fact that the researcher is in essence part of the construct developed and that credibility of the evaluation is ensured through the very enquiry and the rigorous systematic approach to its application (Guba & Lincoln, 1989).

The FGE methodology is identified as hermeneutic where views are presented, critiqued, examined in greater depth and then synthesised into a didactic discourse until final consensus is reached of the constructs that have been developed (Guba & Lincoln, 1989). During the process of evaluation data is categorised into claims, considered positive assertions; concerns, which are viewed as negative assertions; and issues, which are things that can be reasonably 'agreed to be disagreed on' (Guba & Lincoln, 1989; Koch, 2000). Once claims, concerns and issues have been identified, they can be categorised and synthesized into an agenda where concerns and issues can be addressed.

This form of evaluation has been used extensively by Koch (1994, 1996, 2000) and Koch, Webb and Williams (1995). However, it was not widely used by other nursing researchers until 1995 when its popularity as a chosen form of evaluation increased in nursing research (Glendon, 2003; Lundgren et al., 2000; Sylvain & Talbot, 2002; Watson, Turnbull, & Mills, 2002). This form of evaluation is defined as empowering because the identified stakeholders are allowed a voice (Guba & Lincoln, 1989; Koch, 1994, 1996, 2000; Koch, Webb, & Williams, 1995; Lundgren et al., 2000; Walker & Dewar, 2000).

Some have identified difficulties in the application of FGE arising from the variance in power held by various stakeholders and the engagement of stakeholders with prolonged exposure at the site of enquiry. Lengthy negotiations can be difficult for people who are time precious in their roles (Lai, 1991). Furthermore, it can be difficult for the evaluator to engage stakeholders and to effect negotiation. Where engagement of the stakeholders is secured and their commitment to the evaluation process strong, then this form of negotiation can set the stage for an enlightening and productive means of evaluation. A lot of work was undertaken in preparing the mentors and members of the acute stroke team were supportive of the multidisciplinary approach to providing information to stroke survivors/carers. FGE was considered an appropriate method of evaluation for answering the research questions posed in this study.

4.6 SUMMARY

In summary, the constructivist paradigm allows the emergence of all the stakeholder perspectives through interpretive comprehension of how the experience was for these participants at this place in time. The unique approach of identifying claims, concerns and issues offered by FGE allows for a clear means of identifying and presenting the keys aspects of the evaluative process and sets the stage for the development of an agenda from the negotiation. Fourth generation evaluation has not been extensively used in nursing research but its popularity is growing. Though this form of evaluation may not be suitable for all, it is certainly appropriate to the research questions in this enquiry. The inclusion of stakeholders in a collaborative approach to evaluation fits in with the multidisciplinary approach to stroke care.

The environment in which the enquiry is to take place has a philosophy that supports the views of others as being significant and valued. Therefore, fourth generation evaluation was selected to evaluate the program and answer the research questions. The following chapter details the methods used to undertake this enquiry.

CHAPTER 5: METHOD

In Chapter Five the design of the study used to answer the research questions is presented. The recruitment methods adopted to enlist key stakeholder participation and eligibility criteria are detailed, along with a description of the study setting. This chapter includes explanation and justification of the data collection methods, the approach to data analysis, and an explanation of how the trustworthiness of the study was maintained. Ethical issues of consent, confidentiality and protection of the participant's rights are also discussed.

5.1 RESEARCH QUESTIONS

The aim of the study was to evaluate the introduction of a mentoring program designed to provide support and information to stroke survivors and carers in the acute setting. To construct a picture of the experiences of all stakeholders the following research questions were developed:

1) What are the experiences of stroke patients and their carers in the acute setting who participate in a support program using past stroke survivors and their carers as mentors?

2) What are the experiences of mentors who participate in a support program for stroke survivors and their carers in the acute setting?

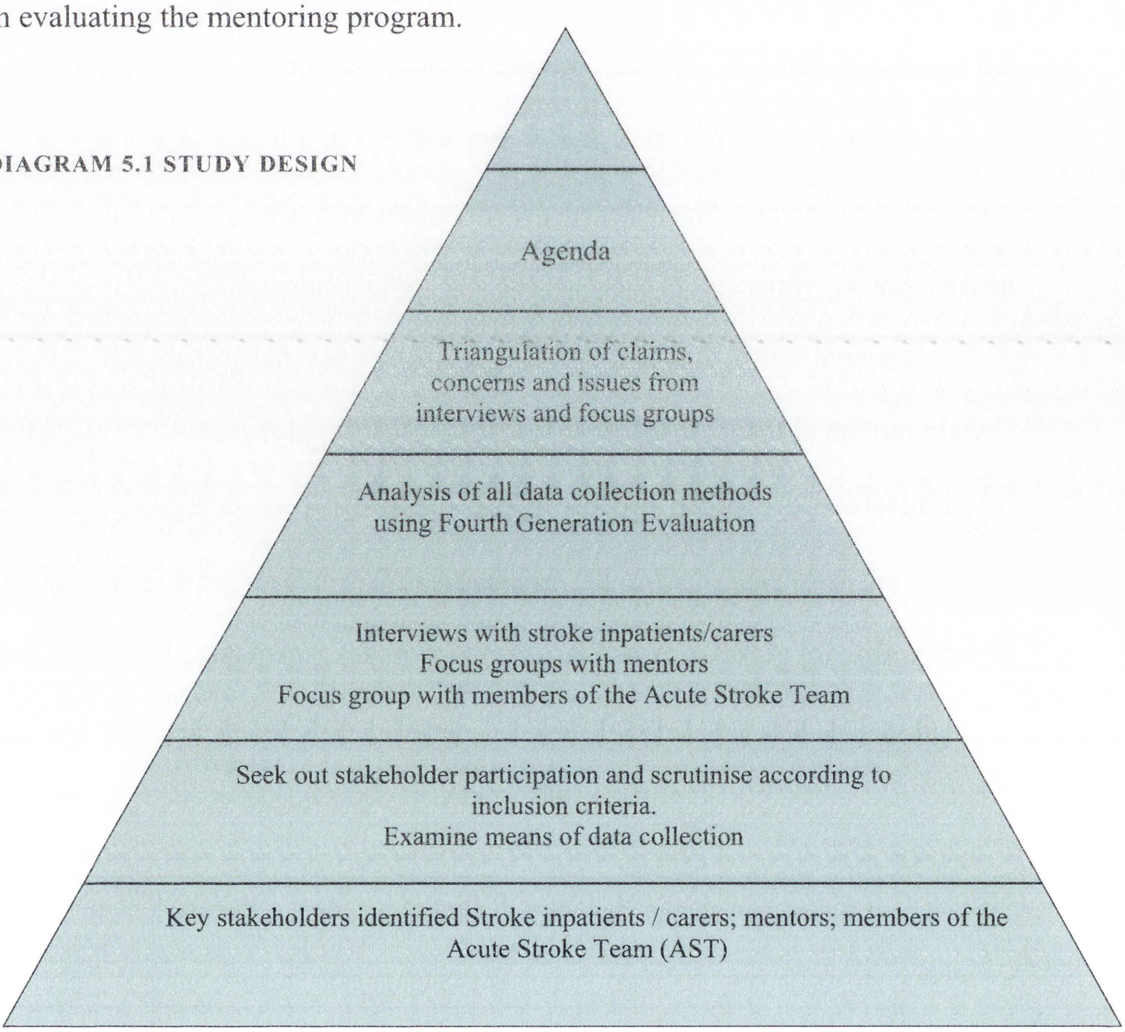
3) What are the experiences of an acute stroke team involved in a support program for stroke survivors and their carers in an acute setting using mentors?

5.2 STUDY DESIGN

The study took place within a primary referral hospital in a 32-bed acute neurology ward that incorporates an eight-bed acute stroke unit. In order to evaluate the Mentor Program (MP) from the perspective of its participants, a research design was selected that would allow all key stakeholders to be involved. This was important to ensure that all aspects of the MP experience were included. Consequently, a qualitative descriptive design using Fourth Generation Evaluation (FGE) was selected.

Diagram 5.1 illustrates the study design and how the experiences of the key stakeholders will be drawn together to provide the claims, concerns and issues in evaluating the mentoring program.

DIAGRAM 5.1 STUDY DESIGN



5.3 RECRUITMENT OF PARTICIPANTS

The key stakeholders were identified as the stroke inpatients/carers, the mentors and the members of the AST. In this section, the recruitment of the participants (key stakeholders) including the eligibility criteria to participate in the evaluation is described,

5.3.1 INPATIENT STROKE SURVIVORS AND CARERS

Though it is difficult to assess the exact number of participants that should be included in an explorative descriptive study, the numbers are traditionally small. This is because such studies generally require in-depth data collection and analysis and it is therefore necessary to consider the time required to achieve the sample and undertake the study (Brink & Wood, 2001). An article by Nixon and Wild (2008) claimed that data saturation is generally achieved by ten interviews in patient reported outcome studies. For the purpose of this study, twenty patient and/or carer participants were selected to ensure that data saturation was achieved. If both a stroke survivor and their carer participated in the program they would count as one participant to ensure enough patients (considered the primary end-point) to achieve data saturation. In order to maximise the recruitment of participants, members of the AST were asked to identify suitable patients who met the selection criteria. This would also help engage health professionals in the mentoring experience (Morse, 2005).

Eligibility criteria for the stroke inpatients and/or their carers included:

- Ability to speak English
- Aged 18 to 75 years
- A confirmed diagnosis of stroke for the inpatient
- Carers must be responsible for someone with a confirmed diagnosis of stroke
- Patient is medically stable and cognitively able to participate

These criteria were identified as significant so that the stroke inpatient could respond to the interview questions. The age criterion was selected based on the increased incidence of catastrophic complications and co-morbidities amongst those aged more than 75 years (IPART, 2010). The demographics of the setting reflect that the area has a predominantly English speaking population and the design of the study did not accommodate non- English speaking participants.

5.3.2 THE MENTORS

Ten members of a local support group volunteered to be mentors and subsequently agreed to be involved in the evaluation of the program. All mentors met the following eligibility criteria: The eligibility criteria for the mentors included:

- Over the age of 18
- Previous personal experience with stroke either as a survivor or carer
- Ability to speak English

These criteria were selected to ensure that the mentors were old enough to consent to all of the requirements of participating in the mentoring program and the study and to confirm that they had firsthand experience of stroke either as a survivor or as a carer. Again, to participate in the data collection the mentors needed to speak English.

5.3.3 ACUTE STROKE TEAM (AST)

Preliminary discussions with members of the AST including staff from medical, nursing, physiotherapy, speech pathology, occupational therapy, social work and nutrition were held during regular scheduled meetings. The only eligibility criteria for this group were that they were members of the Gosford AST who were willing to participate.

5.4 REASONS FOR NOT PARTICIPATING IN THE STUDY

The recruitment of inpatient stroke survivors and carers took place between November 2006 and August 2007. Even with some five hundred stroke patients discharged from the hospital each year, it took some time to recruit. This was in part due to the criteria, most specifically age as illustrated in Table 5.1, which shows the number of patients and the specific reason they were not included in the study.

TABLE 5.1 NUMBERS AND REASONS FOR EXCLUSION FROM THE STUDY

Criteria	Number (N)
Age >Than 75 Years	230
Medically Unstable	47
Non-Stroke	45
Unable to recruit prior to discharge	27

Cognitive Impairment	25
Dysphasia	18
Declined to participate	13
Non English Speaking	1

5.5 ETHICS, CONSENT AND CONFIDENTIALITY

Ethical approval for this research was granted through the Central Coast Health Service Ethics Committee and the University of Technology, Sydney Human Research Ethics Committee.

Information was provided to the participants through either an information sheet for stroke inpatients/carers (see Appendix 3) or PowerPoint presentation for mentors and members of the Acute stroke Team. Written consent was obtained and all participants were instructed that they could withdraw from the study at any time without repercussion or explanation.

All data collection was coded to ensure the confidentiality of the participants. Excel spread sheets were used to track the codes and these codes were used to identify all word based transcriptions. The transcribed data was stored in a locked filing cabinet in a locked office. This information is to remain securely stored for 7 years and if no longer required will then be appropriately disposed of.

As a Clinical Nurse Consultant for stroke working in the area health service, I would at times have contact with stroke inpatients/carers participating in the program but often times it was during recruitment that my first introduction with stroke inpatients/carers took place.

I had direct contact with the mentors and members of the AST. In order to limit any bias that may arise from familiarity with the mentors and members of the AST, the focus groups were undertaken by an external facilitator.

5.6 DATA COLLECTION

The data collection methods adopted for this study included semi-structured interviews and focus groups. Both approaches allowed for exploration of the different claims, concerns and issues of the participants (Guba & Lincoln, 1989). Semi-structured interviews were the chosen method of data collection for the stroke inpatients and their carers in order to allow them to speak freely in a one on one situation. This would also accommodate the fact that stroke inpatients/carers were recruited at various times. Personal interviews allow people to speak freely but they also generate a lot of data. This data was transcribed to allow for data analysis.

Focus groups were chosen for the mentors and separate focus groups were held for the members of the AST. Each of these teams was familiar with the other members of their group and it allowed for ease of data collection. As previously mentioned the focus groups were conducted by an external facilitator who had been instructed about the purpose of the research and the chosen method of evaluation. It is important for the facilitator to have a clear understanding of the aims of the research and be skilled at making the group feel at ease during the discussions (Lane, McKenna, Ryan, & Fleming, 2001; Richards & Morse, 2007). The use of an external facilitator was aimed at reducing bias.

A research assistant captured the identified claims, concerns and issues on butchers' paper and the sessions were video recorded so the data could be reviewed during analysis. All identified claims, concerns and issues were taken back to the mentors and members of the AST to confirm that all the data had been captured and correctly interpreted. It was important to ensure that all participants in the focus groups were given the opportunity to put forward their point of view. Ensuring this occurred was a responsibility of the external facilitator.

5.6.1 INPATIENT STROKE SURVIVOR AND CARER INTERVIEWS

Data collection for the evaluation of the program from the stroke inpatients and their carers involved two interviews. This strategy enabled research question 1 to be addressed. The first interview took place within forty-eight hours of meeting the mentor and centred on their experience of the meeting.

The first interview was structure around the following questions

1. Describe how you feel that the discussion with the mentor went?
2. Was the time for the discussion adequate for your needs?
3. Do you feel that the discussion was helpful to your needs?
4. Are there any concerns you have with regards to the discussion?
5. Do you feel that anything could have made the discussion more beneficial for your needs?

These questions were selected as they directed the participant to explore their perception of the experience of the MP, incorporating claims, concerns and issues.

The participants were encouraged to consider anything that could have improved the experience. The interviews were largely conducted at the bedside as indicated in Table 5.2.

TABLE 5.2 SETTING OF MENTOR VISIT

Participant	Number (N)	Location of Interaction with Mentor
Stroke survivor + carer (stroke inpatients with carers were counted as n = 1 but interviews were undertaken separately)	N = 3	Bedside
Stroke survivor without carer	N = 16	Bedside
Carer only	N =1	Private Room

Final interviews were conducted either in person or by telephone one-month following the in-patient stroke survivor/carer meeting with the mentor. The interview focused on their experience of the program after discharge. It was anticipated that at this time, the patient would have been discharged from the acute or rehabilitation setting. The following five questions were asked:

1. What do you remember about the discussion or discussions that you had with your mentor?
2. Do you feel that the mentoring program was beneficial for you?
3. At this stage, have you identified any new issues that you feel could have been addressed in the mentoring program?
4. Would you recommend the mentoring program to other people?

5. Have there been any negative issues that you identified with the mentoring program?

These questions were selected as they would identify if the experience had been memorable for the participant and if the discussion had been meaningful for them after discharge. It is following discharge that stroke survivors and/or carers will identify issues from their stroke that may not have been apparent in the acute or rehabilitation setting (Vanhook, 2009).

If both a stroke survivor and the carer were involved in the research, then each were interviewed separately to allow for freedom of expression regarding private or sensitive issues. All interviews were recorded using audio and digital recording devices either in person, if the patient was still an inpatient, or using a hands free phone if the patient was discharged. Interviews were undertaken in a private area where possible to ensure confidentiality of the information. A secretary who worked at the hospital was employed to transcribe the interviews. Even though two types of recording device were used, one lot of datum was unable to be accurately transcribed because the quality of the sound was poor. It was thought that this may have been due to an issue with the volume or location of the devices during the interview. Therefore the final number of interviews transcribed for analysis was forty five.

5.6.2 MENTOR FOCUS GROUPS

In order to determine the experience of the mentors, three focus groups were undertaken. As previously mentioned the mentors received a diary to document the details of their experience as mentors.

As there was an anticipated time delay between the meeting with the stroke inpatient/carer and the first focus group the diaries provided to the mentors were useful aides for recollecting their experience.
By diarising their experience they were able to refer to their writings to refresh their memories and provide a much more accurate and meaningful account (Burns & Grove, 2005). The diaries were not collected as part of data collection and the mentors had been given strict instruction that no identifying personal details regarding the inpatient stroke survivors or their carers were to be recorded in them.

All the mentors attended three focus groups (each lasting approximately 2 hours). At the end of the second session the group felt that they had reached data saturation and the subsequent meeting of the group involved presentation of the identified claims, concerns and issues so that analysis of the data could be confirmed as being a true and accurate account of the discussions. The interaction within a focus group revealed valuable data that would be difficult to obtain in a one-on-one interview. By doing this as a group it was a more relaxed atmosphere for the participants and allowed simultaneous data collection from a number of participants (Kitzinger, 1995).

The focus groups for the mentors took place in a private room within the hospital. An external facilitator was consistently used to run the focus groups to reduce any bias that may arise if the researcher had facilitated (Burns & Grove, 2005; Krueger & Casey, 2000). The facilitator, recommended by other researchers within the area health service had been extensively employed by the service.

Preliminary discussions with the facilitator included a background to the study, identification of those who would be participating in the focus groups, questions that were aimed at stimulating discussion around the evaluation and the requirements of FGE in evaluating the MP. The facilitator was paid from the funding obtained for the study.

The focus groups allowed for an open forum of discussion to validate, contest or explore in greater depth identified claims, concerns and issues from the perspective of these stakeholders (Kitzinger, 1995; Lane et al., 2001). As the mentors were already familiar with one another through their membership of a local support group and through their participation as mentors, there was ease with group discussions. The ten participants of the group was consistent with that recommended to provide good group dynamics, six to ten (Crabtree & Miller, 2004).

The following questions were used to facilitate the discussion in the focus group:

1. What are you thoughts on the MP?
2. Did you identify any positive aspects of the MP?
3. Did you identify any negative aspects of the MP?
4. Is there anything you feel should be changed about the MP?
5. Is there anything else you wish to discuss about the MP?

Once the group felt that they had exhausted all aspects of one of the questions the facilitator would move to the next question.

At anytime, the group could return to a particular response for either further discussion or clarification.

Along with the video recording of the focus group, a research assistant helped by transcribing chains of discussion onto butcher's paper for future analysis, allowing the facilitator greater opportunity to concentrate on the discussion. The mentors consented to the focus groups being video recorded which allowed the researcher to observe group dynamics (Richards & Morse, 2007). Videotaping provided the context of the focus group discussion and assisted in ensuring the trustworthiness of the data analysis (Burns & Grove, 2005).

5.6.3 ACUTE STROKE TEAM (AST) FOCUS GROUP

In order to evaluate the MP from the AST's perspective, a focus group with the facilitator was arranged. The focus group provided the AST with the opportunity to express their experienced claims, concerns and issues. A preset meeting time where all of the members of this team met, was forfeited to allow for the focus group at a time that was convenient for all AST members. At the time of the focus group the speech pathologist had left and a replacement had yet to be employed. The other members of the team who did participate included a neurologist, three nursing staff and a social worker, nutritionist, physiotherapist and occupational therapist. The group agreed to both audio and visual recording of the session.

The various health disciplines were able to provide a diverse perspective and unique threads to the discussion.

As part of a multidisciplinary team that has a good working relationship, each of the participants was afforded the opportunity to voice their experience of the program with ease, an observation that was confirmed on the video.

Once the discussion around claims was exhausted the facilitator then moved the group onto exploring concerns or negative assertions and finally any issues.

At a subsequent meeting, the group confirmed they had identified all of the claims, concerns and issues and that no further focus group was required. The need for only one focus group was not surprising, as this group of stakeholders had limited roles in the MP.

5.7 DATA ANALYSIS

All forms of data collection including audio/video recordings, butchers paper and transcriptions were reviewed, as they were collected. This allowed for immersion in the data and allowed for rapid detection of any problems arising from the data collection such as inaudible recordings, which did occur in one instance. The following sections detail the process of data analysis.

5.7.1 INTERVIEW DATA

The verbatim transcriptions of the interviews with the stroke inpatients/carers were first coded using coloured markers to highlight chains of discussion that were linked or identified as meaning units (Graneheim & Lundman, 2004). These highlighted sections or quotes were then extracted from the transcripts and entered into an excel spreadsheet.

From these quotes, word reduction was undertaken and the significant content of the quote was extracted and placed in the next column of the spreadsheet. Rows were then sorted to allow for the development of codes which linked groups of content that had shared commonality (Graneheim & Lundman, 2004).

From the meaning units, word reduction and codes underlying meanings were interpreted and provided sub-themes, which were then subject to further interpretation and scrutiny to construct themes. This abstraction of data allowed the material to be summarised and for meaning to be interpreted in the context of the research (Harwood & Hutchinson, 2009). The themes were then sorted to identify if they were claims, concerns or issues in line with FGE (Guba & Lincoln, 1989).

5.7.2 FOCUS GROUP DATA

The data obtained from the focus groups, including transcriptions collected by the research assistant, and subsequent information obtained from review of the video recordings, were placed onto an excel spreadsheet. Common meaning units were identified and word reduction lead to the formation of categories and finally themes. Common meaning units are those sections of data that are linked or have a common thread. These sections of data were then reduced down to the essence of what they were identifying. It is these common threads that come together in their extracted form to formulate categories (Graneheim & Lundman, 2004). These categories were taken back to the focus groups for confirmation that the interpretation had been an accurate account of the experience of both the mentors and the AST.

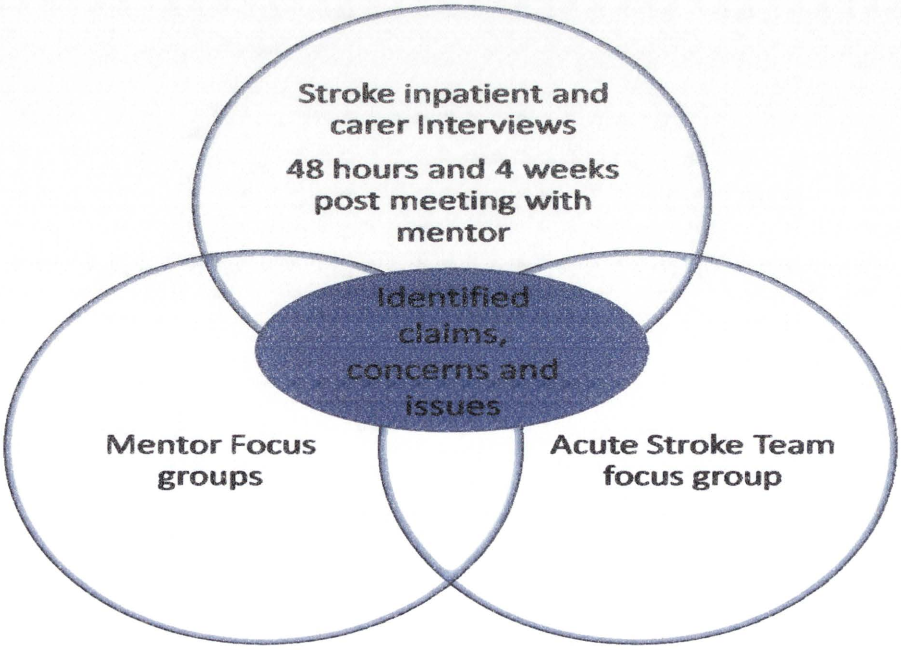
5.7.3 DATA TRIANGULATION

Qualitative and quantitative data are often combined in research to provide a greater richness and validity to the research findings (Burns & Grove, 2005).

There is far less evidence of the implications of combining data collection within the same methodological framework than across the qualitative and quantitative boundaries and this may be due in part to the belief that combining data analysis across different research paradigms holds more challenges (Barbour, 1998). Nevertheless, there are considerations required to ensure the trustworthiness of the analysis.

FGE seeks to provide input from all stakeholders the primary focus is collaboration and unification for the purpose of determining worth and developing an agenda (Guba & Lincoln, 1989). This data source triangulation is aimed at providing differing views of the same evaluand to contribute to the credibility of the findings (Lambert & Loiselle, 2008). The primary claims, concerns and issues extracted from the interviews and focus groups were available to answer each of the individual research questions and these responses were then combined to formulate the outcome of the evaluation and an agenda for future development if necessary. Diagram 5.2 illustrates how these responses were integrated.

DIAGRAM 5.2 TRIANGULATION OF DATA SOURCES



5.8 TRUSTWORTHINESS OF THE STUDY

The goal of qualitative research is accurate representation of the participants' experiences. It is the credibility, dependability, transferability and confirmability that are the operational techniques that ensure that qualitative research will be accepted (Crookes & Davies, 2004).

As identified by Guba and Lincoln (1989) the main criteria for ensuring credibility in Fourth Generation Evaluation (FGE) are prolonged engagement at the site of enquiry, persistent observation and peer debriefing. In qualitative data collection not all cases will align with identified categories but when categories have been identified and are supported by a number of participants then this provides confidence in the results (Guba & Lincoln, 1989).

A review of data that is not supported by a number of participants is called negative case analysis which can also add weight to the credibility (Guba & Lincoln, 1989). A process check by the research supervisors provides progressive subjectivity of the data analysis to ensure that the researcher was not imposing any preconceptions of outcomes of the research into the research analysis. This section discusses how these elements were applied in the study.

Prolonged engagement at the site of enquiry enables the enquirer to become immersed in the data collection and to recognise the context in which it is delivered. The researcher was employed as the Clinical Nurse Consultant (CNC) for stroke within the setting and the research assistant was a registered nurse.

Direct contact with the participants of the study and electronic recording of all of the data allowed for persistent review of the data within the context it was collected (Guba & Lincoln, 1989).

Peer debriefing by research colleagues provided an objective party to critique and challenge the findings and provide counsel to the evaluator (Guba & Lincoln, 1989). Negative case analysis was also included to show that only those themes supported by a number of participants have been included in the final results (Guba & Lincoln, 1989).

Peer debriefing by other research colleagues also provided progressive subjectivity whereby a process check is undertaken of the data analysis to ensure that the researcher was not imposing any preconceptions of outcomes of the research, into the research analysis and the research supervisors were able to provide guidance in the rigour of the research (Guba & Lincoln, 1989).

As the researcher is also the CNC within the AST and in a position of authority, it was important that I did not attend the focus groups. Consequently, an external facilitator was employed to reduce the possibility of researcher influence/bias.

Member checks, whereby the stakeholders have the right to confirm or reject the construction arising from the analysis were undertaken with the focus groups to ensure that the identified claims, concerns and issues were a true and accurate account (Lacey & Luff, 2001). A process check of the analysis of the interviews was also undertaken by a peer to ensure that the investigator had introduced no preconceived suggestion.

Data being sought from three different sources also supports rigour, by seeking responses from more than just a single entity and it gives weight to the evaluation (Lacey & Luff, 2001).

Silverman (2004) identifies the dilemma of an interviewer in determining if the interview is a true and accurate account of the experience. It may be a shadow of reality.

Validity has been historically attached to quantitative data analysis whereas other means of addressing this issue such as credibility and trustworthiness have been adopted by supporters of qualitative research (Lund, 2005).

5.9 SUMMARY

This exploratory descriptive study used both semi-structured interviews and focus groups to gather information from identified stakeholders who had participated in a mentoring program to improve information provision for acute stroke survivors and their carers.

A thematic analysis of the interviews, with the inpatient stroke survivors/carers, and focus groups, with the mentors and acute stroke team was used to obtain the qualitative data that described the experiences of participants in relation to claims, concerns and issues regarding the mentoring program. The following chapter presents the results of the data analysis.

CHAPTER 6: DATA ANALYSIS

In this chapter results of the analysis of the data obtained through interviews with stroke survivors/carers and focus groups with the mentors and members of the Acute Stroke Team (AST) will be presented. Even though interviews were undertaken using two forms of recording devices, one of the interviews was too inaudible to be transcribed. Consequently, the number of transcribed interviews with the stroke survivors and carers for analysis was forty-five. Commonalities within the data were identified and defined under the categories of claims, concerns or issues in line with fourth generation evaluation. Individual quotes from the interviews will be used to illustrate the discussion. At the end of the quotations, it will be identified if the participant was an inpatient stroke survivor or carer. The direct quotes used throughout the discussion will be followed by a code that indicates the participant and interview. For example 12B indicates the first interview and 12C indicates the second interview, with the 12th participant.

6.1 PRESENTATION OF THE ANALYSIS OF INTERVIEWS

For ease of interpretation by the reader each section of the data analysis will be presented separately with the inpatient stroke survivors/carers claims, concerns and issues being presented first. In this discussion, there will be reference to the identified theme followed by a definition of that theme and quotations used throughout the course of the discussion to support the findings. Then at the end of the identified claim, a table will be used to illustrate some of the common threads. Subsequently, this will be presented in relation to both concerns and issues.

6.2 INPATIENT STROKE SURVIVOR/CARER CLAIMS

This section presents the claims that emerged from the interviews undertaken with the stroke inpatients and their carers. There were three predominant claims that arose from the analysis. Claims are the positive assertions made by the participants (Guba & Lincoln, 1989).

6.2.1 PROVIDING HOPE AND UNDERSTANDING

The stroke survivors and carers claimed that the mentoring experience gave them direction, hope and inspiration in regards to their own future. Many of the participants indicated that having the opportunity the talk to people who had firsthand experience with stroke had allowed them to understand what was happening to them:

> "Certainly sure, yeah I could've asked him anything and you know he had an answer for me, you know it was just nice to be able, you wouldn't talk to a Doctor the way you'd talk to him, probably not a nurse and he knew a lot more answers to the questions I wanted than doctors and nurses cause he'd been there done that you know." 18C (Stroke Survivor)

The ease of communication that the stroke survivors/carers developed with the mentors and the individualistic approach that mentoring provided was prominent throughout the data. The one-on-one personal approach offered by the mentors revealed a need for understanding and communication that was obviously not being met by health professionals within an acute hospital setting:

> "…..and it was spoken …not in a doctor's language or a nurse's language, in just like one mother to another mother, and that to me was the best thing, and just an everyday person, not someone wearing a suit and a coat or a nurse's apron or what ever you want to call it, but someone who is an everyday person that's got a child, and you know, has been through a horrible experience, and how she has come out of that and I don't think there's anything you could have done to change it (the mentoring experience) to make it any better." 8B (Stroke Survivor)

With the mentor they did not feel that their questions were burdening anyone or that the questions they asked may seem irrelevant or insignificant. With the mentors, they felt recognised and valued through their affiliate experience. The shared experience and unique personal interest afforded by mentoring provided an avenue for open discussion. This was also highlighted by one health professional, a stroke survivor participating in the study, who identified that at times identities and professional lives can in fact be an impediment to gaining information and support. In this particular instance, the participant felt that there was an assumption by others that their professional life empowered them with knowledge and understanding of what was occurring, which was in fact a misassumption. The mentor placed no such assumptions on their meeting and it was recognised as one stroke survivor talking to another:

> "because I feel as a professional sometimes you get, not forgotten but they think you understand, you can cope, they forget you can't, that you're vulnerable, you're actually in a whole different position, different situation, and you know I have found that at times. So I think yes, professionals definitely need it (mentoring)" 12C (Stroke Survivor)

The participants of the study also identified that the meeting with the mentor provided understanding and validation of their own responses to the stroke or to the responses identified by their carers. They reflected on the fact that emotional responses, which often seemed so out of character, were acknowledged by the mentors as being "normal" and hence facilitated acceptance. Through mentoring they were able to acknowledge the strong psychological and emotional component that can be attached to stroke and this knowledge then gave them understanding and acceptance of their response. This understanding of the emotional responses to stroke was not just evident from the stroke survivors but also from the carers:

> “We got both sides of their story and then we could understand how he was feeling and how she was feeling, so I understood that what I was feeling was ok.” 3C (Carer)

The analysis revealed that stroke survivors and their carers valued the mentoring experience for providing hope, inspiration and direction through the recognised accomplishments and positive attitudes of the mentors. Mentoring was identified as a personal approach to providing meaningful answers in lay terms. It allowed the participants to gain understanding and acceptance of their responses to stroke from psychological and emotional perspectives which participants valued:

> “If someone gave me a thousand dollars or the opportunity to talk to (mentor), I’d say I want to talk to (mentor) anytime” 6B (Stroke Survivor)

The following table illustrates a small proportion of responses that supported the extraction of this theme. Bracketed sections indicate either the mentor’s name, a question from the interviewer or the name of the person being interviewed.

TABLE 6.2.1 PROVIDING HOPE AND UNDERSTANDING

Providing Hope and Understanding
Yes that's what (Stroke mentor) told me. I mean if someone told this is what's you know da da da I would've probably said "oh yeah" and come home and been flogging myself for being so slow and I'm not slow like a tortoise but you know, instead of taking, you know, probably 30 minutes to do some ironing it took me nearly an hour.
That there are other people out there that are going through the same , probably emotionally more than physically [Ok alright, and that was significant for you (Stroke patient) the emotional aspect of it] Yeah, very much so I think physically you recover from things a lot quicker than you do emotionally.
Oh well the support and they made sure that I knew about all the help that was available and how he felt about when he had his stroke and that, and I, you know sort of cried and let out how I felt, he was very understanding I remember that.
You know just someone there who knew exactly what had happened, knew what was going on, and was able to say look you know its ok, you know, it was great we had a great time.
Yeah it made a difference because I was talking to somebody who'd been through the same thing I had been through.
Its all very well for a Doctor to say, you know, oh this and that, or a nurse this and that and the booklets you read, but someone, you know, there's a human side to that too and she was the human side to it.
I think you know, in any of us, or any major trauma in your life, the feeling that you're the only one. That other people that don't experience something don't really know exactly what it's like................You know you've been there, you've done it you know...I mean we can always sympathise with people and be supportive but if you haven't been there it's pretty hard to know what it's like.

6.2.2 THERE IS LIFE AFTER STROKE

The mentoring experience was also recognised as providing living proof to the stroke survivor / carer that others who had travelled a similar path to their own had come out of the experience and were getting on with their lives:

> "In any of us or any major trauma in your life, the feeling that you're not the only one, that other people that don't experience something, don't really know exactly what it is like........You know you've been there, you've done it, you know... I mean we can always sympathise with people and be supportive but if you haven't been there it is pretty hard to know what it is like." 16B (Stroke Survivor)

The participants expressed a sense of a common link because of this shared experience and a sense that what the mentors had achieved was now within their grasp. There was acknowledgement that even though the experience of stroke may be different for everyone, that others had managed to get on with the living and had not let the stroke be the end of their story.

> "there is life after, you know a lot of people would say I've heard of people having a stroke and just coming out and saying well that's it, like that's it, like I'm finito, I'll sit around like a piece of rotten garbage or something like that, but he let you know that it could be done." 18C (Stroke Survivor)

Participants expressed that they no longer felt alone in the experience. Even though they knew that other people had strokes, the mentoring experience placed more credence on the fact that this was a shared experience through one-on-one conversation with a fellow survivor or carer.

Not only did the participants identify that there was life after stroke but they also placed substance on what the mentors told them to expect afterwards. Some participants identified that this helped prepare them for what might happen once they were discharged from hospital and how they could best adapt to their own life after stroke.

The interviews clearly demonstrated that people were wanting validation that there could be life after a stroke. That others had come through the experience and still remained positive and went on to lead productive lives.

TABLE 6.2.2 THERE IS LIFE AFTER STROKE

There is Life after Stroke
I'm going through what somebody else has gone through so I knew I could get through it, you know, and be able to cope with it. 'Cause you see somebody come out on the other side of it, um, so you know that everything's going to be OK.
Wonderful. It was marvellous. It made you feel… you look at her and you think well, she's absolutely wonderful. If she's like that, you can be like it. I mean I've had nothing compared to what she's had, 'cause she's a lot younger too, but I mean, you know. Yeah, no, she was wonderful.
I'd say to hear what he's involved with now, all the different groups he talks to, and what he does week to week, you know, it's reassuring to say well he's not sitting in a dark room waiting for anything to happen, he's out there, which is good.
Yes I would (recommend mentoring program) I do think that you need to see that there is life after stroke. Like I think I said earlier it just puts things into perspective its like if they can do it and their stroke was so much worse then we should be able to come through this too.
Well I found it interesting so it was, you know, somebody that had a stroke and they had difficulties and he told me how he overcame them and how he's getting on with life and that was good.
In addition, that she was also good and healthy and she is getting on with life and all that, it is not the end of the story.
Because of the person that came to see me, you know that there's people out there that have been affected a lot worse than I was and they've still got the courage and the ambition to carry on and do things for other people.
I think it's very good and I think that you know it should be encouraged to be able to keep going because it does give you a bit more confidence to go out and you know tackle your everyday life again, and see other people that have been through things.
Again I don't see myself as having suffered as badly as what he did that's good, fortunately for my part, but yeah, it was reassuring to hear that, yeah, you're not Robinson Crusoe obviously, there are people around to help you, and people have bounced back further than what I need to.

6.2.3 EASING THE BURDEN OF STROKE

Participants also identified that mentors could ease the physical and emotional burden of stroke. The mentors provided insight into what to expect after stroke, how to cope or manage with this sequelae and what resources were available to both the stroke survivor and their carer after discharge from the acute setting:

> “Yes, you know it took a lot of insecurity and a lot of the, what's the word I'm look for, just the confusion away, yeah you know and to recognise that some things will come along and there will be slight differences but not be frightened of it, if you know that these things happen and just to go with the flow, more or less, and not put too much pressure on myself.” 22B (Stroke Survivor)

Some participants identified as significant being made aware of the physical aspects of the stroke and how they could prepare for their impact. For example, the fatigue experienced after stroke can be debilitating. Many of the stroke survivors identified that they would not have been prepared for this had the mentor not identified this feature. For some it was the mentor indicating that it was not unreasonable to indicate to others specific stroke sequelae in order to gain understanding:

> “I don't have the problems, you know the physical problems that a lot of people have and (Stroke mentor) was very similar. I mean she's had problems with her hand sometimes but it was nice to know that my memory meant I knew what I wanted to get out but sometimes it doesn’t happen and things like that and she would say "look I know what I want to say but I can't get it out, you know you'll just have to excuse me". You know and it’s alright to do that and not feel silly and stupid you know all those things that you tend to do.” 22B (Stroke Survivor)

One impetus that was first identified with regards to the mentoring program was to improve information provision and to support stroke survivors and carers. Many of the participants identified this as being part of their experience. They indicated that having their questions answered and being made aware of what was available after discharge, helped to produce a sense of relief that they would have somewhere to turn if they needed support:

> “Just that he sort of let me know what I'm likely to expect and that there are services there if anything happens. That I'm not just sort of left on my own and without anyone to tell me answers to any questions I may have.” 21C (Stroke Survivor)

Carers involved in the study also identified benefits in having the opportunity to talk to another stroke carer. Carers commented that it provided an insight into what may occur following discharge and how to manage this aspect of life from a carer's perspective, hence easing their fears and concerns:

> "Talking to (carer mentor) and knowing how she coped with (stroke survivor) when he came home.... getting on with your life I suppose. It was just relaxing and sort of easing my mind. " 3B (Carer)

Participants also identified that having someone sit down to talk to and provide information about stroke from a personal perspective, was beneficial. It provided relief from the doubts that they were experiencing:

> "I remember I had a lot of, a lot of things running through my head and when (mentor) arrived there, it was like he knew exactly why, what sort of questions I was going to ask and he sort of started, started to bring all this stuff out that I could sort of, you know, ease my mind a lot on what was going to happen to get through my recovery process." 23C (Stroke Survivor)

TABLE 6.2.3 EASING THE BURDEN OF STROKE

Easing the Burden of Stroke
No, you know they were fantastic and they were you know if my dad had got better, if we had needed support or services or things like that then it would've been brilliant cause it would've been ah right now what did you do? It would've been something to tap into.
I feel you know like I feel ready now I can cope, I've gone and I just feel so different mentally too, you know. Yeah my mind and things are clearer and no I think everything was there because I knew there was so much support out there and that I could get it you know. So that was really good, As I said I'm really good now I just feel so much better.
Any questions that we had, not a problem there was an answer, there was a book or a pamphlet or something, and it was very good.

Yeah, I felt so much better afterwards. It's, It's not like she said to me there's an instant cure and you're going to get… you know, there's no magic cure and you'll never have another stroke, she wasn't doing that at all. She was just explaining… she said she has no medical background, like, she's just done research herself and just explained her… what happened to her, what her family went through while it was happening to her and how she's been coping with that, and letting me know that it, you know, it took her a while to get to where she's at now, and because my first one was only six weeks, or whatever ago, it's understandable that I'm having these feelings, so I don't feel like an idiot for having, for being concerned or worried, so she put me at ease.
Excellent, it was good very good. We just learnt not to worry about it so much……so get on with it.
I'm over my anxiety stuff…that's all gone and I am really enjoying life.
..... how long it took, but he said everyone's different, which it is and if you're worried about having another one he said, oh gee you know it makes you worry about not worrying but more what would you call it… set on taking your tablets at the right time and all that sort of thing. He more or less put me at ease in a lot of ways.
And you know he's was a hell of a lot more severe than what mine was but he could you know just sort of ease my mind on a lot of things.
Yeah well I was really grateful for (Stroke mentor) because the mentor, because she really, you know, if I hadn't of known about the fatigue then I would've been stressing like you wouldn't believe.....Whereas I haven't worried about it, which alleviates the stress, which alleviates blood pressure and all the rest of it.
yesterday was the first time in, I can't tell you how long, that I got home relaxed had a nice cup of tea, had a shower, watched some television and I didn't think about or what I had to do for (patient) or what I had to do for college or what I had to do about anything, you know I just sort of chilled out.
To take some of the fears and to know you are not the only one.
…. saying that you don't worry about what people think. Because I was really concerned about that and he said they just have to accept things anyway. Not that I have got any problems now but that was good hearing that.
It was very beneficial at the time and it relieved fear as times gone on I realise that probably I'm not in the category that needs support, ongoing support. But at the time it was very beneficial because of all the doubts you have, is this going to happen again? You know so yes.
I was very reassured, extremely so that I wasn't going to keel over the next minute and die (laughs) I suppose but no it was just very reassuring to know there are people out there that have been through it and have come through.

6.3 INPATIENT STROKE SURVIVOR/CARER CONCERNS

This section presents the concerns that emerged from the interviews undertaken with the stroke inpatients and their carers. Concerns are the negative assertions made by the participants (Guba & Lincoln, 1989).

6.3.1 NOT REALISING THE SAME RECOVERY AFTER STROKE

The reality of stroke is that not all strokes are the same and the outcomes achieved after the stroke may vary greatly. In one instance a carer identified that her father had been unable to realise the same stroke recovery as that of the mentor who had visited them. She felt a sense of sadness as her father had required nursing home placement to facilitate ongoing care. Both the inpatient stroke survivor, who could not participate in the research due to dysphasia, and the mentor who visited had severe strokes. The mentor was able to demonstrate the potential for recovery and return to activities of living that were achievable.

In this instance, the carers had backgrounds in the healthcare profession but differed greatly in their circumstances. The mentor was a spouse carer and the inpatient was a sibling who was still endeavouring to advance their career through ongoing study and professional development. Even though the same outcomes were not achieved, the inpatient stroke carer did identify benefits as demonstrated by the comments below.

> "...you know, they were fantastic and they were you know, if my dad had got better, if we had needed support or services or things like that then it would've been brilliant cause it would've been ah right now what did you do? It would've been something to tap into." (19C – female carer)

The interpretation of the mentoring experience changed when the inpatient stroke survivor had not been able to realise the same outcomes as the mentor. This was in relation to not being discharged home. The following quote indicates that when the inpatient stroke carer was asked whether they felt the mentoring experience had been beneficial:

> "…..initially it was a relief to meet people who had been through a similar situation particularly ones like (carer mentor) and (mentor stroke survivor) that we met who were so intent on providing support and positiveness, things like that. However, we didn't actually, you know, it's a little bit down the track we didn't fit the ramifications you know, their saying that dad's not, although he's in rehab he's not for rehab you know, he's going to a nursing home and that's it sort of thing. So it hasn't worked." (19C – female carer)

The above perception of the mentoring experience had not been the actual intent of the program. The program was developed to provide support and information to stroke survivors and their carers not as a means of comparison of recovery.

6.3.2 UNABLE TO PROVIDE FOR A CARER'S NEEDS

The program was reliant on the availability of mentors to come into the hospital to meet with the inpatient stroke survivors/carers and there were only two carer mentors in the program. In one instance, an inpatient stroke carer wanted to talk to another carer as she was trying to come to terms with the emotional sequelae her partner was experiencing. Unfortunately a carer mentor was unavailable at that time to provide this service. Though the mentor had attempted to broach the subject with the stroke inpatient survivor, the patient had not been willing to engage in this discussion. The inpatient stroke carer felt this engagement would have occurred if the mentor had been able to provide insight from a carer's perspective:

> "It would have been nice to talk to another carer and to share the experience as a couple. That way they could have pointed out how they were both feeling through the stroke. Not just from the person who had the stroke but from their partner. I think having another carer there who said this is what it was like for me, would have made (stroke inpatient survivor) stop and think. Instead of just thinking it's me and I am not the one coping. It helps if you see it from another person's perspective. Don't get me wrong (mentor) was great but a couple may have been able to highlight a few things to (stroke inpatient survivor).

> In all honesty, when (mentor) did try to broach the subject of the emotional side of stroke (stroke inpatient survivor) steered away from the topic, kind of, as if real men don't cry. I just think he is so afraid of the emotional side of this thing that it is consuming him and turning into anger, which he is venting at me." (10C – female carer)

An intervention was considered outside of the scope of the research and no further follow-up from the research perspective was undertaken but it was important to ensure that the participant was supported and so alternative counselling was offered.

6.3.3 SEEKING MORE FROM THE MENTORING EXPERIENCE

This particular concern related to the fact that one person had not gained what they felt they needed from the mentoring experience. The inpatient did not feel that the mentor had experienced the same concerns. Consequently, the inpatient stroke survivor did not gain the anticipated guidance and sharing in relation to the financial burdens of stroke. The inpatient stroke survivor felt that the financial strain he would experience by being unable to return to his previous occupation as a labourer, had placed him in a situation that the mentor could not relate to:

> "… he didn't have that extra pressure apart from getting better sort of thing, so, whereas me I've got to go work as soon as, you know, not necessarily doing what I'm doing, you know, I'm not saying I'm a pauper or nothing but, you know I'm not going to lose my house I think, but ah… you've still got to keep something coming in at some stage, but ah… He couldn't help me much that way 'cause our situations are so totally different, that's all I found."
> (4B – male stroke survivor)

Though the mentor had not experienced the same financial difficulties, he was able to provide some guidance. The mentor highlighted the available services and resources within the stroke folder that may be of assistance:

> "Yeah, I think we've already got details on so, CWSR... some, some mob anyway that can, as I said I can't think... I think (wife) wrote it down... it's in the, you know, the stroke book we got... it's in there, you know, once you're sort of on-the-mend a lot, and then they're... they can sort of guide you. I forget what it's called now to be honest, but ah... It's in the book I know that". (4B – male stroke survivor)

However at the final interview this had been forgotten:

> "No. I don't even know... I can't remember that actually Jenny. No, I don't know... I'm not sure about that one. I've got the book but... you know the thing. I don't know that he mentioned it... he may well have done but I can't remember that bit."(4C –male stroke survivor)

It was not clear within the data whether forgetting related to cognitive impairment, or memory deficits. The inpatient stroke survivor may have been unable to remember suggestions that the mentor had provided due to an inability to relate with the mentor because of the identified disparity in financial situations.

6.4 INPATIENT STROKE SURVIVOR/CARER ISSUES

This section presents the issues that emerged from the interviews undertaken with the stroke inpatients and their carers. Generally, issues are unable to be addressed within the scope of the study or are items that must be agreed to be disagreed upon (Guba & Lincoln, 1989).

6.4.1 PARTICIPANTS FROM OUTSIDE THE LOCAL GEOGRAPHICAL AREA

The mentor program aimed to provide information and support from a local perspective but patients are not always necessarily from the local demographic area. Two participants of the study were from other geographical areas and had been visiting the local area at the time of their stroke. Therefore, the information provided to them needed to be more generic in nature.

Their mentors highlighted those resources available nationally, such as the National Stroke Foundation and the Stroke Recovery Association. Both of these inpatient stroke survivors consequently identified benefit from talking with the mentors.

One inpatient stroke survivor highlighted the generic aspects of the Stroke Folder in providing information to reassure her after discharge from the acute setting. She stated that she had used the Stroke Folder as a resource on discharge and had even shown it to their local neurologist, making recommendations that this should be an available resource for all stroke survivors.

> "Oh for me it does especially because when I, you know, first got on the net, it just blew my mind away, and I went, no I can't, that was, to me that was depressing, reading all that information, like, coming to your hospital and getting the stroke book was better for me because it was a bit more in layman's terms for me to understand.."(8C - female stroke survivor)

The other inpatient stroke survivor who lived outside of the local geographical area highlighted the struggles faced with living in a remote geographical area. She indicated the issues related to transportation and support, when living in isolated areas. In this instance, the inpatient stroke survivor stated that one of the major benefits for them was the recognition that fatigue could be an issue after stroke and that this was a normal, yet often debilitating, part of the stroke sequelae. She identified that the mentor had highlighted the fatigue experienced after stroke and stated that if they had not been made aware of this aspect of stroke recovery she would have been fearful and burdened with the concerns over whether this was a normal response to stroke or a sign that there was something wrong.

She stated that she would have been “racing to the doctors every five minutes” if not alerted to the fact that fatigue was something that you needed to factor into your life after stroke and strategies that can be utilised to manage it.

This was certainly not an isolated report of the impact of fatigue and in fact, a number of participants in the research pointed out that fatigue had impacted heavily on their lives after stroke. It was through this discussion and other feedback from participants of the research that further investigation into fatigue was undertaken.

6.5 MENTORS’ CLAIMS

This section presents the claims that emerged from the focus groups undertaken with the mentors. Each claim is discussed individually and then a table will demonstrate the data that led to the construct.

6.5.1 POSITIVITY OF MENTORING

During the course of the mentoring program all of the mentors had identified a strong desire to “give something back” in relation to their accomplishments in overcoming the adversities attached to stroke. These qualities are supportive of those recognised as requirements for those undertaking mentoring roles (Hibbard et al., 2002). The mentors discussed the positive aspects of being involved in the mentoring program. They claimed they were very relaxed in the role and that they had enjoyed the experience.

The mentors indicated the sense of achievement that comes from being able to help others and share their experience.

In addition they felt they were "giving something back" in providing assistance, ensuring that others were aware of the available support in the community. Many of the mentors felt they had not been made aware of available resources and support after their stroke. They spoke of a sense of community worth especially those in retirement; and a sense of pride from other family members in what they were doing.

The mentors felt that in some instances it was helping even just by listening to the inpatient stroke survivors/carers. Finally, the mentors felt that the experience of mentoring turned a horrible thing (stroke) into something positive as evidenced through Table 6.5.1:

TABLE 6.5.1 POSITIVITY OF MENTORING

Positivity of Mentoring
Felt very relaxed in the role
Enjoyed the experience
Wonderful and happy experience lasting a long time
Overwhelmed by appreciation
Felt that I was helping even just by listening to them
Sense of wellbeing
Terrific experience, able to do for others what we missed out on. It felt great to encourage them
Happy to be able to contribute and help others
Meeting up with participants in the community at a later date gave a sense that it had a long lasting impact as they were still appreciative
Felt fortunate to be in a position to help
Families are proud of us to be so involved despite the fact that we have had a stroke
Liked the feedback from the patients
Giving something back makes me feel good
Makes me feel good to tell them there is help out there because I didn't know about it
Gives me worth to do something for the community despite retirement.
Mentoring turns a horrible thing into a positive thing.

6.5.2 PERSONAL GROWTH AND DEVELOPMENT

The mentors identified their own personal growth and development from the mentoring experience. Many claimed that participation in the program had boosted their confidence. They were now more willing to 'give things a go' even if they felt they may fail. A sense of fulfilment was gained from their involvement. They recognised that the support group they were involved in, WAGS (Working Age Group Strokes), and the mentoring program complemented one another. Some felt they had improved life skills, such as respect and tact.

Finally, it was acknowledged that this had been part of their recovery as it had benefited them to aid in another's recovery as evidenced in Table 6.5.2.

TABLE 6.5.2 PERSONAL GROWTH AND DEVELOPMENT

Personal Growth and Development
Makes me feel still useful and effective. It helps to fulfil me
Boosts my confidence
Fills in my time and I love to help
Give everything a go now, even if I fail.
Makes me feel happy, important and gives me more confidence
It has made me want to publicly speak about stroke
Able to give me what I craved. It has made me come out of myself. The two activities of the support group and the mentoring program complement one another
Developed more tact, learnt respect. Felt good to help
This has been part of my recovery. It benefited me to aid another's recovery.

6.5.3 BEING PART OF THE TEAM

It was an important aspect to the development of the curriculum that the mentors were included by the acute stroke team (AST) as valuable assets to the service. The mentors appreciated the support of staff which made them feel like part of the team. They felt that as a team of mentors they could overcome challenges. They spoke of looking forward to being called in to see someone. As survivors, they were living proof that there was life after stroke. The mentors also identified the emphasis placed on the carer role in the mentoring program, recognising the value of the carer. This is supported through the constructs listed in Table 6.5.3.

TABLE 6.5.3 CONTRIBUTING AS PART OF A TEAM

Contributing as Part of a Team
Appreciate the support of staff who make you feel like part of the team
Felt that as part of a team of mentors we could overcome challenges
Felt good to be able to empower and educate the carer
Look forward to getting called in to see someone
Provides living proof to patients that there is life after stroke
This program appreciates the carer role as being more than just a role

6.6 MENTORS' CONCERNS

This section presents the concerns that emerged from the focus groups undertaken with the mentors. Concerns again refer to negative assertions made by the participants (Guba & Lincoln, 1989).

6.6.1 MORE ALLIED HEALTH INVOLVEMENT

The mentors were introduced to the allied health team as part of their training and a tour of the ward allowed for introduction to many of the nursing staff. However, the mentors stated that they would have liked more allied health input throughout the program to help them understand the best person to support the specific needs of inpatient stroke survivors/carers. The mentor program information booklet had included descriptions of all the roles of each of the disciplines involved in the acute stroke team, although the names of the members of this team had not been included. Over time, familiarity with allied health personnel decreased as there had been significant changes in staff. The mentors also indicated a need to improve their knowledge of specialty communication requirements to improve their ability to communicate with people with communication issues.

6.6.2 TIMING

The concern of timing related to two aspects of the program. The first concern was determining exactly when during the course of the inpatient stroke survivor's stay in hospital would be most appropriate to meet. This included confirmation of stroke diagnosis.

On two occasions, there was an uncertainty around a confirmed diagnosis in mild stroke. In these instances the mentoring occurred based on the provisional diagnosis of the neurology team. Both inpatient stroke survivors were later given a confirmed diagnosis of stroke from MRI. The delay in confirmed diagnosis caused some uncertainty amongst the mentors.

The second concern related to their own availability, as many of the mentors were living active lives. Though a timetable was developed at the onset of the program, there were still difficulties in scheduling the most appropriate mentors to match the needs of the inpatient stroke survivor/ carer.

6.6.3 MEETING THE DEMANDS

The mentors identified the impact of fatigue on their participation in the program. They indicated that mentoring could be tiring. Nevertheless, they felt they could 'handle it' and that this was the reality of a stroke survivor. Being realistic about energy levels, most stated that they would not undertake more than one meeting at a time. Others said that they may require time out to regroup if they were seeing more than one patient on the one occasion.

6.6.4 CHALLENGES OF THE ROLE

In some instances, there was a delay between the training of the mentors and the meeting with the inpatient stroke survivor/carer. The mentors suggested a short refresher course to revise the requirements of the role would have been beneficial. Another challenge identified was that there is a fine line between hope and realism. The mentors wanted to ensure the inpatient stroke survivors/carers were aware that there would be good days and bad days but they did not want to frighten them.

The mentors indicated that in some instances they felt a degree of 'emotional baggage'. This included feeling worried and a sense of concern; particularly for the inpatient stroke survivors/carers who seemed to be struggling with coming to terms with their stroke.

6.6.5 MAINTAINING BOUNDARIES

The mentors expressed concerns regarding the boundaries associated with the mentoring program, including the Occupational Health and Safety requirements of being volunteers in the hospital setting. In the role they were undertaking, mentors were not to assist the patient physically, such as mobility or feeding, as they could inadvertently cause harm. The mentors highlighted the instinctive need to assist people, like holding a bowl while someone eats. This was something that the mentors had to learn to manage. The mentors were keen to hear about the outcomes of the inpatient stroke survivors they had mentored. It had been highlighted during the course of the program that there were strict boundaries surrounding privacy and confidentiality and as such no follow-up information could be provided to the mentors.

6.6.6 PROCESS CHECKS

Process checks is the term adopted by the mentors to identify items that impacted upon the mentoring program. The concern identified by the mentor was the need to ensure all the necessary resources were readily available, such as the inpatient stroke survivor having a copy of their stroke folder. A sign-on book was established to allow the mentors to 'sign in and out' of the ward. The book also contained next of kin or emergency contact numbers for each of the mentors.

This book was set up as part of the program so that staff would be aware of who was on the ward and who could be contacted in the event of an emergency. In one instance, the book had not been stored in the correct location and this caused some concern for the mentor.

Ensuring that there were no prior bookings for tests or procedures for the inpatient stroke survivor was also identified as a process check. The mentors felt that it was important to draw attention to the mentoring program to other staff in the unit, to enlighten people as to the aim of the mentoring program in order for them to recognise the significance. Table 6.6 illustrates the emergent concerns that arose from the data collected from the focus groups undertaken with the mentors.

TABLE 6.6 CONCERNS OF THE MENTORS

Concerns of the Mentors	
More Allied Health Involvement	Introductions to new people involved in the program
	More allied health input into the training
	Communication sessions need to be more specialised to cope with specific requirements of communication in stroke patients

Concerns of the Mentors (cont'd)	
Timing	Choosing the most appropriate time during the person's stay in hospital
	Fitting in with other obligations can be difficult
	Confirmation of stroke diagnosis
Meeting the Demands	Might need time out to regroup if seeing more than one patient
	Can be tiring but can handle it and this is the reality of a stroke survivor and fatigue. Most wouldn't undertake more than one meeting at a time / Being realistic about energy levels
Challenges of the Role Challenges of the Role continued	Initial apprehension about the role – suggest a refresher training course
	Difficult to offer hope but be realistic - it is a fine line
	Taking on some of the emotional baggage from the experience and feeling a sense of worry / obligation
	Recognising that things are harder after a stroke that there will be good days and bad days - don't want to frighten them
	Survivor not opening up - denial
Maintaining Boundaries	Mentors wanting to follow up with patients after they had met with them.
	Ensuring that you don't cross the boundaries sometimes it is instinctive to assist someone - like holding a bowl while someone eats
Process Checks	Ensuring that all necessary details and equipment are available and up to date - sign on book and no previous bookings on the patient's time and stroke folder

6.7 MENTORS' ISSUES

This section presents the issues that emerged from the focus groups with the mentors. Remembering that issues are unable to be addressed within the scope of the study or are items that must be agreed to be disagreed upon (Guba & Lincoln, 1989).

6.7.1 PARKING

The issues identified by the mentors were not related to the mentor program; rather they focused on the practicalities of meeting with the inpatient stroke survivors/carers. Parking was identified as an issue. Even though many of the mentors had disability parking tickets and all mentors participating in the program had been issued with identification that allowed access to free parking, it was sometimes difficult to find parking within a reasonable walking distance to the ward. Clear instruction on how to use the volunteer parking card had not been reinforced. Subsequently, those who did not use them frequently were unfamiliar with how to use them correctly. One mentor thought that the card was to be left on the dash of the car rather than realising that the card opened a boom gate allowing for access to the top levels of a multi-storey car park.

6.7.2 PRIVACY IN A BUSY WARD

Maintaining privacy and confidentiality during the actual mentoring experience was often difficult. The eight acute stroke beds in the unit are divided into two rooms, so there were four patients to a room. When the mentors visited there were often visitors seeing other patients and different healthcare staff would interrupt.

The mentors discussed pulling around the curtains to maintain privacy but stated they felt a little unsure whether this would be appropriate or acceptable.

6.7.3 PREVIOUS ACQUAINTANCE

Two mentors knew the in-patient stroke survivor. This was not realised by either the mentors or the in-patient stroke survivor until they met. When asked about this, neither the mentors nor the patients identified this as an issue at this time but they did acknowledge the potential. The mentors did comment on the fact that in a relatively small community it could be quite common to come across people that you had known in the past and even though this was not a problem it should be noted for future reference.

6.7.4 WANTING FEEDBACK ON THE PATIENTS

This related to the mentors wanting to have feedback on how the patients and carers they had mentored got on after discharge and how their recovery was progressing. Due to issues of confidentiality, this information could not be provided. Though the mentors were accepting of the need to maintain privacy and confidentiality it did not stem their natural curiosity as to the outcomes for these people.

Table 6.7 illustrates the emergent issues that arose from the data collected from the focus groups undertaken with the mentors.

TABLE 6.7 ISSUES IDENTIFIED BY THE MENTORS

Issues Identified by the Mentors	
Parking	Parking problems including using the access card
Previous Acquaintance	Knowing the patient from the community before they had their stroke
Privacy	Noisy ward at times knowing whether it was appropriate to draw the curtains for privacy or having a room that they could go to
Wanting Feedback	Wanting feedback - issues of confidentiality

6.8 ACUTE STROKE TEAM (AST) CCI

Claims, concerns and issues were identified from the perspective of the AST and on follow-up consultation the team felt that this one session had addressed all the constructs entertained by the group and confirmed that the constructs were an accurate representation of the data. The claims will be elaborated upon in section 6.9, then 6.10 will detail the concerns that the group identified and 6.11 will reveal the issue.

6.9 SUSTAINABLE WITH FINE TUNING

The members of the AST identified that the program was sustainable and had the potential to continue within the unit with some revisions of the scheduling. They felt that the program merely needed to be identified as to when the mentors would be visiting so that care of the patient could be organised around the mentor's visit.

6.9.1 POSITIVE MOOD

Members of the allied health staff reported that the mood of patients seemed more positive and that they demonstrated increased participation in rehabilitation.

6.9.2 FEARS OF INCREASED WORKLOAD NOT REALISED

When the program was first presented to allied health, nursing and medical staff, there were some concerns over the impact it may have on their workload. During the focus group allied health and nursing staff noted that their original fears were unmet as any recommendations were generally through verbal discourse. As the researcher it was my responsibility to ensure that those who may be suitable for the program were included. Medical staff generally identified potential inpatients.

Though the AST did claim that the mentor program did not impact on their workload, it did however, impact on the workload of myself as CNC for stroke. This included time required in: training of the mentors; identifying inpatients stroke survivors/carers suitable for the program; matching mentors to inpatient stroke survivors/carers; and scheduling visits by the mentors to meet with inpatient stroke survivors/carers.

6.9.3 POSITIVE RESPONSES VERBALISED TO AST

The allied health staff had patients tell them that they found the program beneficial. Medical staff had patients who had offered to become mentors themselves after they had been discharged from hospital.

This positive response to the program was reflective of the interviews from inpatient stroke survivors/carers and the feedback from the mentors. Table 6.8 illustrates the claims identified by the members of the AST.

TABLE 6.8 CLAIMS FROM THE AST

Claims From the AST	
Sustainable with fine tuning	Sustainable with fine tuning of scheduling
Effects on mood and motivation	Improved mood in patients and participation in rehabilitation
Little impact on workloads	Initial concerns over impact on workload not realised - very little impact on work
Positive response from participants	Positive feedback verbalised to allied health staff by a few of the participants
	Have had patient offer to be a mentor

6.10 AST CONCERNS

This section presents the concerns that emerged from the focus group with the AST. Section 6.10 will detail each aspect individually and Table 6.10 will provide an overview of these concerns.

6.10.1 GREATER INPUT

Members of the AST stated that they wanted to have greater input into the program. They felt that greater involvement with the mentors or profiles of the deficits the mentors had faced as a result of their stroke, would aid them in identifying suitable mentors to match inpatient needs. They also felt that the rotation of staff and their lack of personal involvement with the program meant that familiarity with the mentors was compromised.

They suggested that informal get togethers with the mentors could have aided in building rapport and in matching them with specific patient needs.

6.10.2 MISSED CARER PARTICIPATION

Members of the AST identified that although dysphasic patients had been excluded from the mentor program because of the criteria for exclusion, they felt that many of their carers had been overlooked. They felt that matching mentors and carers who have had to deal with dysphasia and dysphagia would be beneficial.

6.10.3 TIMING

On a couple of occasions, the therapists had wanted to work with a patient but noted that a mentor was present and did not want to interrupt. Mentors had been obliging enough to offer to wait but the therapists rescheduled to allow the mentor visit to go ahead. The team identified that the timing of the visit was an important factor ensuring that mentoring does not clash with tests or scheduled therapy.

This would be a part of the agenda for future program development. Table 6.9 is a summary of the concerns identified by members of the AST.

TABLE 6.9 CONCERNS OF THE AST

Concerns of AST	
AST involvement and updates	AST wanting greater input into program
	AST input needs to be enhanced to identify suitable patients and match with mentors - Profile of mentors for all members of AST to allow for enhanced matching of mentor to patient
	Rotation of staff and staff involvement may mean that familiarity with program is compromised
	More informal get togethers between allied health staff and mentors would have aided in building rapport and in matching patients
Greater potential for carers	Dysphasic stroke patients couldn't participate because of the research criteria but often their carers were overlooked. Matching mentors and carers who have had to deal with dysphasia and dysphagia would have been beneficial.
Timing	On a few occasions, Allied Health needed to attend to therapy during time when the mentors were visiting but mentors were always accommodating - Allied Health did not want to impose on the mentors.

6.11 AST ISSUES

This section presents the issues that emerged from the focus group undertaken with the AST which are unable to be addressed within the scope of the study (Guba & Lincoln, 1989).

6.11.1 RELIANT ON A LEADER

The AST identified only one issue in relation to the mentor program. Though the team had initially been concerned over increases to their workload, with the introduction of the program the team felt that they would like more involvement as indicated in the previous concerns. The team identified that the mentor program appeared to be reliant on a leader to coordinate the program. Without that degree of coordination the future of the mentoring program would be compromised. Table 6.10 demonstrates the issue identified by the members of the AST.

TABLE 6.10 ISSUE OF THE AST

Issue Identified by the AST	
Reliant on a leader	Reliant on a leader (as is currently occurring) to drive the program

6.12 SUMMARY

The claims identified by the stroke inpatients and their carers showed that the mentoring experience had, on the whole, fulfilled a definite need. They recognised that there was life after stroke, that it was possible through shared experience to find hope and understanding after stroke, and that the burden of stroke could be eased through the mentoring experience. No concerns and issues were consistently identified by the inpatients and carers. Isolated incidents where stroke inpatients and carers felt that something had been lacking in the experience generally related to unrealised expectations or from difficulties in providing a suitable mentor.

Some of the isolated incidents may be able to be addressed by increasing the number of mentors, which would be necessary if the program were to extend to a wider range of patients.

The focus groups held with the mentors identified claims relating to the positivity of mentoring, personal growth and development and feelings of self worth from contributing as part of a team addressing the needs of other stroke survivors and their carers. The concerns that the group identified included recognising challenges of the role, ensuring that all of the requirements of the role were being met and having all the necessary resources available, which were collectively identified as process checks. The group also acknowledged the demands of meeting the role such as fatigue and the internal conflict that can arise from complying with boundaries when the response is a natural instinct. Timing of the visits was considered challenging in knowing when an appropriate time in the patient's length of stay was and trying to fit in with busy schedules of both the patients and the mentors.

The mentors also suggested they would like more familiarity with members of the allied health team and more specialised training in communication difficulties that can be experienced by stroke patients. The issues identified by the mentors included parking, prior knowledge of the stroke patient as a previous acquaintance, issues of privacy in a busy acute stroke unit and wanting feedback on patients but recognising that confidentiality meant this was not appropriate.

The AST focus group revealed that the program was considered sustainable with fine tuning of scheduling and that it had a positive effect on mood and motivation and had increased participation in rehabilitation.

The group stated that initial concerns surrounding an increase in workloads were not realised. The group also claimed that they had received positive verbal feedback from patients, with some recipients even offering to be mentors.

The one major issue that the team had identified was the fact that the program was reliant on a leader to drive it, a role I was currently undertaking.

CHAPTER 7: AGENDA

The purpose of this chapter is to discuss the agenda developed from the analysis of the data. The agenda comprises the claims, concerns and issues of all stakeholders. As discussed in Chapter 4 the purpose of an agenda in FGE is to provide a platform or focal point from which negotiation and modification of the mentor program can take place. The negotiation seeks to find solutions to identified concerns and issues so that the focus of evaluation can progress in response to the evaluation process.

The elements of the analysis, which have common links have been colour coded and combined into the one table to allow for ease of interpretation by the reader (see Table 7.1). Within this table, the sections shaded pink are claims or positive assertions that support the application of mentoring in acute stroke. The sections shaded yellow pertain to the timing, scheduling and need for coordination of the program, which will be discussed jointly as part of the agenda, as they are interrelated. The sections shaded blue located in the concerns column are negative assertions that are linked as they all relate to the role of the mentor within the program. The sections shaded green are concerns that can be addressed through greater involvement and interaction between members of the AST and the mentors. Those sections shaded orange are largely outside of the scope of the research to rectify but certainly need to be factored into future considerations of the program. Primarily the concerns and issues become the focus of negotiation and program development.

TABLE 7.1 TABLE OF COMBINED CLAIMS CONCERNS AND ISSUES FROM ALL STAKEHOLDERS

Claims	Concerns	Issues
There is life after stroke 1	Meeting the demands of the mentoring role – mentors pacing themselves to avoid fatigue 2	Parking at a busy hospital for mentors can be difficult, especially for disabled drivers 2
Providing hope and understanding 1	Challenges of the role for the mentors - the fine line of hope and reality for stroke survivors and their carers 2	It is difficult to maintain privacy for discussions between mentor and stroke survivor/carer in a busy ward 2
Easing the burden of stroke 1	Maintaining boundaries – mentors ensuring that they adhere to their role and responsibilities 2	Previous acquaintance – when the mentor has known the stroke survivor previously 2
Positivity of mentoring 2	Process checks –ensuring that all of the necessary resources are available 2	Mentors wanting feedback on the stroke survivor's progress. Privacy needs to be maintained 2
Gains for the mentors – personal growth and development 2	AST wanting greater input into the program to enhance their knowledge of mentors and their profiles 3	Need for a coordinator/ leader to run the program 3
Being part of the team – being valued at a contributor 2	Mentors wanting more allied health involvement to aid them with stroke inpatient/carer referral 2	
Positive feedback – Patients offering to be mentors 3	Staff retention rates can compromise familiarity with the program 3	
Improved mood and participation in rehabilitation by inpatient stroke survivors 3	Timing – when should the mentor visit during the inpatient stroke survivor's stay 2	
Sustainable with fine tuning of the scheduling 3	Timing / scheduling – making sure that the meeting between mentor and stroke survivor/carer doesn't conflict with other things scheduled for the inpatient and trying not to impact too much on the personal lives of the mentors 2 and 3	
Very little impact on workload of AST 3	Delays in confirmed diagnosis 2	

LEGEND
1 INPATIENT STROKE SURVIVOR/CARER
2 MENTOR
3 AST
🟥 CLAIMS
🟨 TIMING / SCHEDULING
🟦 ROLE OF THE MENTOR
🟩 GREATER INVOLVEMENT
🟧 ISSUES/ OUTSIDE SCOPE OF RESEARCH

7.1 TIMING AND SCHEDULING OF THE MENTORS (YELLOW)

Timing and scheduling refers to a number of timing aspects for consideration on the agenda. The first is identifying the best time to provide the mentoring experience to the inpatient stroke survivor. This was not clear from the original discussions with the stroke inpatients (when trying to match them to their mentor) with times ranging from straight away to just before discharge. This variation indicates that timing is an individual need for each patient and carer. Future programs will need to identify scheduling on individual needs basis, considering both the needs of the stroke survivor / carer and the mentor.

The members of the acute stroke team (AST) also identified the need for a designated coordinator for the program, to schedule in mentor visits at an appropriate time for stroke survivors/carers and to make the necessary preparations for the visit by the mentor. The AST did suggest a means of assisting staff in identifying the scheduled mentoring visit by including it on the bed board. The bed board is a wall chart listing all bed numbers and patients, with a column designated to tests and procedures scheduled for individual patients. Indications on the board would allow for therapy sessions and nursing management to be scheduled around the mentor visit. As such there should be fewer interruptions to the mentoring visit.

The need for a program coordinator or leader is a key requirement of sustainability. Though members of the AST had identified little impact upon their workload, there was considerable work required to run the program. In order to sustain the program additional recruitment and training of mentors would be necessary for future planning and a designated coordinator would be required.

It would be necessary to seek funding to support such a position. Sourcing funding is why the AST considered this an issue because seeking funding for such projects in the current financial climate of the healthcare system could pose an issue.

Timing was also affected by brain scanning requirements to confirm diagnosis of stroke. Without a confirmed diagnosis of stroke, it would be inappropriate to initiate a mentor. The dilemma is that more subtle strokes are now confirmed by magnetic resonance imaging (MRI), which is generally not undertaken as quickly as computer topography (CT) and may be undertaken as an outpatient. Previously these strokes would have probably been discharged as transient ischaemic attacks with all of the necessary follow-up. These are often the very mild strokes and it would be necessary to factor this into inclusion criteria for participation in the mentoring program.

7.2 ROLES, RESPONSIBILITIES, FATIGUE AND RESOURCES (BLUE)

During the focus groups the mentors identified the struggle they experienced in dealing with the 'fine line' between hope and reality. Wanting to adequately prepare the inpatient stroke survivors/carers but not wanting to scare them. They suggested additional training in respect to this, during mentor preparation would be useful. During the course of the mentor preparation it was made clear to the mentors that they were to share their experience but not necessarily compare their experience with that of the stroke inpatient/carer. Every stroke has the potential for unique outcomes and what may occur for one stroke survivor may be totally different for another. Analysis of the stroke survivors'/carers' interviews supported the fact that this had been appropriately addressed by the mentors.

However, in one instance an inpatient stroke survivor did not achieve the same outcomes as their mentor and this was a source of regret for the carer.

Further discussion around dealing with hope and realism during the mentor preparation may help clarify this for the mentors, improving their self confidence. Comparisons with other patients in regards to recovery can be both positive and negative and is sometimes inevitable. Some patients have identified the achievements of other stroke survivors as a source of motivation (Mold, McKevitt, & Wolfe, 2003). Alternatively other patients can view their lack of progress compared to the accomplishments of others as a source of depression (Maclean, Pound, Wolfe, & Rudd, 2000).

The fatigue associated with stroke was identified by both mentors and inpatient stroke survivors during the evaluation. The inpatient stroke survivors were grateful that the mentors had indicated the impact of fatigue after stroke as it meant they were prepared. The mentors also identified that, for many of them, fatigue still impacted on their lives. The impact of fatigue would need to be taken into consideration by the person responsible for coordinating the program. Firstly, to ensure that the mentors were not unduly fatigued during the course of their mentoring experience; and secondly that designated rest periods for stroke inpatients would be factored into scheduling appointments.

Process checks included ensuring that the sign on book for the mentors was readily available and the inpatient had received their stroke folder prior to meeting the mentor. If these resources were not readily available, it impacted on the mentor's time with the inpatient stroke survivor/carer.

By the inpatient stroke survivor having their own stroke folder during the visit, the mentors were able to provide clear instruction as to what this resource offers.

7.3 GREATER INTERACTIONS BETWEEN AST AND THE MENTORS (GREEN)

Within this section both the mentors and the members of the AST identified the need for greater involvement and understanding of one another's roles and what they can offer. Even though the mentors received information about the roles of the specific disciplines of the AST in the curriculum and within their mentor folders, they identified that their familiarity with the people in these roles was lacking. Introductions between members of the AST and the mentors were undertaken as part of the curriculum, but over time, changes in staffing had affected their familiarity with one another.

Members of the AST wanted to have a greater knowledge of the mentors and their profiles so that they could refer patients, based on the specific needs, to the coordinator of the mentor program. For example, a patient who had a residual arm weakness could be linked with a mentor who had a similar deficit in order to facilitate greater understanding of how to adjust after the stroke. Mentors also wanted more familiarity with members of the AST so they knew who to refer the inpatient stroke survivor/carer onto for additional information or support.

The fact that both of these stakeholders identified this as an important factor meant that this needed to be addressed within the agenda.

Both groups agreed that scheduled informal meetings between the two groups would enhance knowledge of the program and familiarity with these stakeholders. Having both groups participate in ongoing curriculum refresher courses as suggested earlier in this chapter would assist in developing a stronger relationship.

7.4 SUMMARY

The agenda allows for greater potential for development of the program as the review of concerns or negative assertions are addressed in line with the suggestions from all of the stakeholders. Suggested enhancements to the education of the mentors included information and support regarding fatigue, increased interaction with members of the AST and improved coordination and communication of appointments between mentors and inpatients / carers. Suggested supplements to the curriculum would afford the potential for additional recruitment of mentors with each new education session held. Patients offering to be mentors through experience with the program may also be a source of recruitment. In the final chapter, the identified agenda will be reviewed in relation to the literature. The strengths and weakness of the study are also to be discussed,

CHAPTER 8: DISCUSSION

In this chapter the findings of the evaluation will be compared to information provision for stroke survivors and their carers studied in previous research as presented in the literature review. Specific aspects of stroke survivor and carer requirements will be addressed individually and varying perspectives will be included. The benefits and limitations of mentoring will be explored along with any limitations identified with this particular evaluation.

8.1 COMPARISON OF NEEDS OF STROKE SURVIVORS AND THEIR CARERS

As highlighted in previous research there are a multitude of challenges faced by stroke survivors and their carers and very little consideration is given to the social aspects of recovery in the clinical setting (Dion, 2004; Rittman et al., 2004) with many survivors who achieve high functional scores still reporting poor social adjustment (Anderson & Marlett, 2004). In other research it has been suggested that interventions targeting mood have the potential to improve quality of life for stroke survivors regardless of physical impairment and disability (Pan, Song, Lee, & Kwok, 2008; Sturm et al., 2004). The need for further psychosocial support for carers is recognised as they are also at risk of emotional strain and psychological burden (Jonsson, Lindgren, Hallstrom, Norrving, & Lindgren, 2005). The mentor program incorporated the social aspects of stroke within the clinical setting, allowing for stroke survivors and their carers to be able to express specific concerns to people who had experienced similar concerns and adjustment. It allowed the participants to see that there was life after stroke and that meaningful engagement within the community could still take place after stroke.

8.2 ACCOMMODATING THE NEEDS OF PATIENTS / CARERS IN A TIMELY FASHION

The introduction of acute stroke units means that many patients are discharged home directly from the acute setting. The reduction in the length of stay impacts on staff ability to accommodate information provision for stroke survivors and their carers (Adams et al., 2003; Dion, 2004; Foley et al., 2007; Forster et al., 2005; Martin et al., 2002; McKevitt et al., 2004; O'Connell & Baker, 2004; O'Connell et al., 2001; Stroke Unit Trialists Collaboration, 1997). By introducing the mentoring program into the acute setting the mentors were able to ensure that the patients and their carers were provided with valuable information in a timely fashion and by presenting this in lay terms there was greater understanding in relation to communication.

8.3 TAKING INTO ACCOUNT THE VIEWS OF CONSUMERS

Much of the research identified in the Cochrane Review (Forster et al., 2005) was criticised because consumers had not been approached to determine specific needs of this particular population (Forster et al., 2005). Prior to commencing the mentoring program a local support group was approached to clarify this very issue. The discussions undertaken with the local support group named WAGS had provided valuable insight into what people who had experienced stroke or carers of stroke survivors felt may be of benefit. The group was very supportive of the proposal and went so far as to offer their services as mentors based on their view that this was a necessary and worthwhile endeavour.

8.4 IDENTIFYING SPECIFIC NEEDS OF PATIENTS

Past research has identified that there are often differing perceptions between healthcare workers and the stroke survivors and carers; and it is suggested that there should be far more collaboration between healthcare workers, consumers and researchers in order to address specific needs (Choi-Kwon et al., 2005; McKevitt et al., 2004). By incorporating past consumers into the process of information provision there is allowance for accommodation of specific needs of patients and the information is much more tailored to the stroke survivors and their carers as they themselves become part of the process of delivery. This addresses the issues identified in previous research relating to perceptions of need rather than actual need (Choi-Kwon et al., 2005; J. Smith et al., 2004; Suhonen et al., 2005) in that the participants can directly relay their questions to the mentors.

8.5 TAKING THE TIME TO LISTEN

The literature discusses health professionals taking the time to listen to the stories of those who have travelled the path of stroke in order to gain greater understanding of what stroke survivors and their carers require. It also makes reference to the need for varied and novel approaches to address these needs regarding information provision and support as traditional methods do not seem to be achieving the desired results (Forster et al., 2005; McKevitt et al., 2004; O'Connell & Baker, 2004; O'Connell et al., 2001; Pilkington, 1999; Wachters-Kaufmann et al., 2005).

Yet the development of designated stroke units has not just impacted upon improved outcomes and shorter length of stay but it has also contributed to the work load of the healthcare professionals providing the care, as new treatments and advancements in evidenced based practise require greater input to deliver care. These increased care needs include more rehabilitation-focused care and specialised care for patients having thrombolysis for ischaemic stroke. This does not afford a lot of time for healthcare professionals to sit and listen to specific needs of patients and their families.

Mentoring is a voluntary service that provides for this need and as such was identified by both the mentors and the inpatient stroke survivors and their carers as being valuable. Sometimes it was just having someone take the time to listen to their particular fears or concerns that made a difference. As one participant stated, it was like debriefing and it provided them with peace of mind. Yet it must be stressed that any form of information provision should not take the place of verbal communication between patients and healthcare workers but rather act as a supplement (Toofany, 2006). The mentors do not take the place of healthcare workers but they are able to provide for identified needs in patients and carers, perhaps not needs easily recognised or accommodated by health professionals but needs nonetheless. Participants of this study identified an easing of the burden associated with stroke. They identified hope and understanding and they were able to see that there is life after stroke. The ease with which the mentors were able to provide this comes predominantly with their own personal experience and the sense of wanting to provide a service to those who are experiencing the same journey. These traits cannot always be accommodated by health professionals.

8.6 TIMING

Previous research identified that the time spent in hospital and the months following discharge are the most significant for patients and carers and that people are seeking verbal communication supplemented by written information (King & Semik, 2006; Wachters-Kaufmann et al., 2005). By having the written information discussed by the mentors in lay terms it allowed the participants to seek clarification from someone with firsthand experience. The ease of communication and the understanding identified by the inpatient stroke survivors and their carers reinforced the value of hearing about the mentor's experience.

As identified by the mentors and members of the Acute Stroke Team, it was difficult to determine exactly when to initiate the visit but with decreasing lengths of stay (Stroke Unit Trialists Collaboration, 1997) the time afforded to coordinate the visit was often predetermined by an impending discharge date. The mentors also recognised that it was sometimes difficult to accommodate the visits in regards to other commitments and certainly, as was mentioned in the analysis, there would be a need to both increase the number of mentors and succession planning to accommodate mentors leaving the role.

8.7 CARERS' NEEDS

In 2003 there were 146, 400 Australians left with disability as a direct result of their stroke (AIHW: Senes, 2006). The high incidents of stroke survivors left with permanent disability means that there is also a large number of informal carers within Australia.

Adopting the carer role often requires as much adjustment as the stroke survivor to their changed circumstance. In light of this there is a recognised need for support, both emotionally and in regards to available services to support this role, yet this is identified in the literature as lacking (Brereton et al., 2007; Kalra et al., 2004; O'Connell & Baker, 2004). It is often a relative who assumes the role of carer and yet the sudden impact of stroke upon the lives of those whose family member has experienced a stroke can lead to a situation of "being in chaos" and ultimately "seeking order in the chaos" (Wallengren, Friberg, & Segesten, 2008).

Research has shown that carer psychological distress often occurs early after assuming the carer role and this distress can continue if interventions to address it are not implemented (Simon, Kumar, & Kendrick, 2008). Further study is required to identify interventions. Carers have been identified as requiring individualized information about stroke and care needs of stroke survivors (Morris, Payne, & Lambert, 2007). A lack of discharge planning in combination with early discharge can often place unrealistic demands upon carers. This includes understanding the expectation of the carer role in greater detail and feeling capable of initiating rehabilitation in the home until formal home therapy or outpatient therapy is commenced (Ski & O.Connell, 2007).

Carers have identified that prior knowledge of what to expect during the early discharge recovery period would have eased their distress (Ski & O.Connell, 2007). The use of the mentors or experienced stroke carers to support people newly entering the role of carer has been suggested in previous studies.

Even with the limited number of carers involved in this study there were strong suggestions that this form of approach provided beneficial input; and the one instance where a carer was unavailable it was identified by the participant as being significant for them, as they felt that this would have provided them with support (O'Connell & Baker, 2004). One issue clearly identified was there is an ongoing need for research into the transition from hospital to home for carers of stroke survivors (Mak, Mackenzie, & Lui, 2006; Morris et al., 2007; Simon et al., 2008; Ski & O.Connell, 2007).

8.8 MENTORING THE BENEFITS AND LIMITATIONS

Mentoring in this instance has proven to be beneficial for the participants of this study similar to other disease states (Coull et al., 2004; Greiger et al., 2000; Hibbard et al., 2002). Through investigating the intervention of a mentoring program to provide information and support to stroke survivors and their carers, it has been identified that there are beneficial outcomes in regards to "providing hope and understanding"; "easing the burden of stroke" and revealing that "there is life after stroke".

The program not only identified positive outcomes for the stroke survivors and carers who participated but it was also beneficial to the mentors who participated in the program. This is consistent with identified literature that acknowledges that the benefits of mentoring should work both ways; that a mentor can gain just as much insight and reward from undertaking the role as those who they are endeavouring to mentor (Hibbard et al., 2002; Lister, 2004).

The program was also well evaluated by the members of the acute stroke team who participated. It was identified that the program was heavily reliant on a leader to drive it. The impact of the mentoring program on the workload of the acute stroke team members who participated in the research was not realized, however, the impact upon the researcher was significant. Without financial backing or additional financial support, the program would be unable to be sustained. Other research identified the need for financial support to run a mentoring program (Greiger et al., 2000). An estimated $100 000 was attributed to the cost of running the breast cancer mentoring program out of two proposed sites. Much of the expense was attributed to a project coordinator's salary but incidental cost associated with written information, phone calls, allocated space and supplies for the coordinator and expenses associated with future training of mentors were also considered (Greiger et al., 2000). This formulation of required fiscal support for the continuation of the mentoring program in the acute setting would need to be addressed in order to sustain the program.

8.9 LIMITATIONS OF THE STUDY

In regards to transferability, qualitative studies of this nature are often small and it does affect the ability to generalise from the evaluation, however there would be aspects of the study with the potential to be replicated to another setting. Other aspects need to be considered in regards to transferability including the fact that the mentors belonged to an established local support group and this could be relevant to how they functioned in this role.

There were also only a small number of carers involved in the study, which needs to be considered, and stakeholders were supportive of the initiative.

The fact that the follow up was four weeks post meeting with the mentor meant that many of the inpatient stroke survivors had been discharged from the acute or rehabilitation setting. In fact, only one of the participants (a carer) still had the stroke survivor as an inpatient. It may be that certain issues had not yet arisen for the participants of the study. Indeed, as has been suggested in other research, longitudinal follow-up of stroke survivors and carers after stroke may provide a better indication on the effectiveness of coping and quality of life issues (Hopman & Verner, 2003; Ostwald, Swank, & Khan, 2008; Young, Murray, & Forster, 2003).

A quantitative approach would allow for far greater numbers of participants, without vast amounts of data requiring transcription and analysis. Findings of this evaluation could guide future research towards appropriate measurement tools for a quantitative study. Longer follow-up periods could establish a more substantial longitudinal perspective, which would provide insight into how effective the information provision was further down the journey of the stroke survivor/carer.

The age criterion was based on an identified increased incidence of catastrophic complications and co-morbidities amongst stroke survivors aged more than 75 years (IPART, 2010). This may need to be reconsidered in any future research as the average age for strokes admitted to the unit during this period was 79 years and this meant that many people were excluded.

8.10 CONCLUSION

The initiation of a mentoring program in the acute setting of Gosford Hospital proved to be a viable means of addressing a complex problem. Members of a local support group who felt that this program would address a valuable need in the stroke care continuum endorsed this novel approach to provision of information for stroke survivors and their carers. The challenges faced by stroke survivors and carers are individual and diverse and this type of intervention allows for the accommodation of individual needs and concerns.

It can be difficult for clinicians to relate to the experience of stroke and it is not simply enough to assume that functional scores and adaptation are indicators of either social adjustment or quality of life. Previous research has shown this is not the case. The participants of the study identified the following themes: "there is life after stroke", "providing hope and understanding" and "easing the burden of stroke".

The mentor program allowed for stroke survivors and their carers to be able to express specific concerns to people who had first hand experience with stroke and to see how the mentors had come through that experience. The mentors were able to highlight available resources and services in lay terms and to provide the stroke survivors and their carers with the opportunity to communicate with ease and understanding. Undertaking this program in the acute setting afforded the best opportunity of capturing patients and carers at risk of not receiving relevant information regarding stroke and recovery because of accelerated discharge.

Mentoring is a voluntary service identified by both the mentors and the participants in this research as being valuable, even if it was the mere fact of having someone takes the time to listen to their particular fears or concerns. This supplementary adjunct to written information distributed by the health service has proven to be valuable not only for the stroke inpatients and their carers but also for the mentors who took part in the program.

By alerting the patients to specific sequelae after stroke the mentors have highlighted key issues of fatigue, anger and emotional response to stroke not only to the stroke inpatients and their carers but also to health professionals involved in the program. Though this research does not allow for generalisability of the results, there is certainly the opportunity for replication of aspects of the program to other settings – a fact which both the Stroke Recovery Association and the National Stroke Foundation have been pursuing. A lack of discharge planning in combination with early discharge can often place burden upon both the stroke survivor and carers adopting new roles.

The uses of mentors have been identified as a viable and worthwhile intervention into information provision for stroke survivors and their carers within this setting. It is however important to remember that this is a small study and further research into this form of information provision is recommended. For others seeking to undertake a similar strategy it is suggested that a local stroke support group be approached in regards to their opinion and support of such an initiative. Consideration should be given to who might coordinate the program and provide or support educational requirements for the mentors.

This may include fiscal support such as funding. Strong communication links between all stakeholders need to be established. The educational curriculum for the mentors should be developed prior to the setting up of the program and should be supported by written material. Evaluation of the educational curriculum should be undertaken to identify any unmet learning needs of the mentors.

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Appendices

APPENDIX 1

Educational Program and Research Requirements for Mentors

Objectives	Mode of delivery	Evaluation
1st Session Introduction to proposed research	Power point presentation by research Coordinator. Stroke folders will be provided for participants to review	Attendance only
1st Session Identification of participants who may be interested in taking part in the research	Participants will be offered the opportunity to participate in the research provided with details to contact the research coordinator if they would like to be involved	Participants will have contact details of the research coordinator and be provided with the opportunity to participate
2nd Session Undertake the required record checks for volunteer services	Group meeting with coordinator of volunteer services	Required forms to be completed and submitted

2nd Session Introduction to volunteer requirements	Discussions with coordinator of volunteer services regarding "Privacy and Confidentiality Obligations" and Occupational Health and Safety Obligations"	Group will confirm their individual understanding of both of these directives and complete the required paperwork confirming their commitment
2nd Session Establish a means of contact with the mentors	Mentors will provide the research coordinator with a means of contacting them	A line of communication will be established between the research coordinators and the mentors
3rd Session Mentors will be given information regarding requirements and obligations of being a mentor and effective communication techniques	Power point presentation by research coordinator Written material that will reinforce the purpose of the research, obligations of a mentor, roles and responsibilities and available resources	Attendance and feedback from group Mentors will receive the necessary paperwork and complete an evaluation form regarding the power point presentation

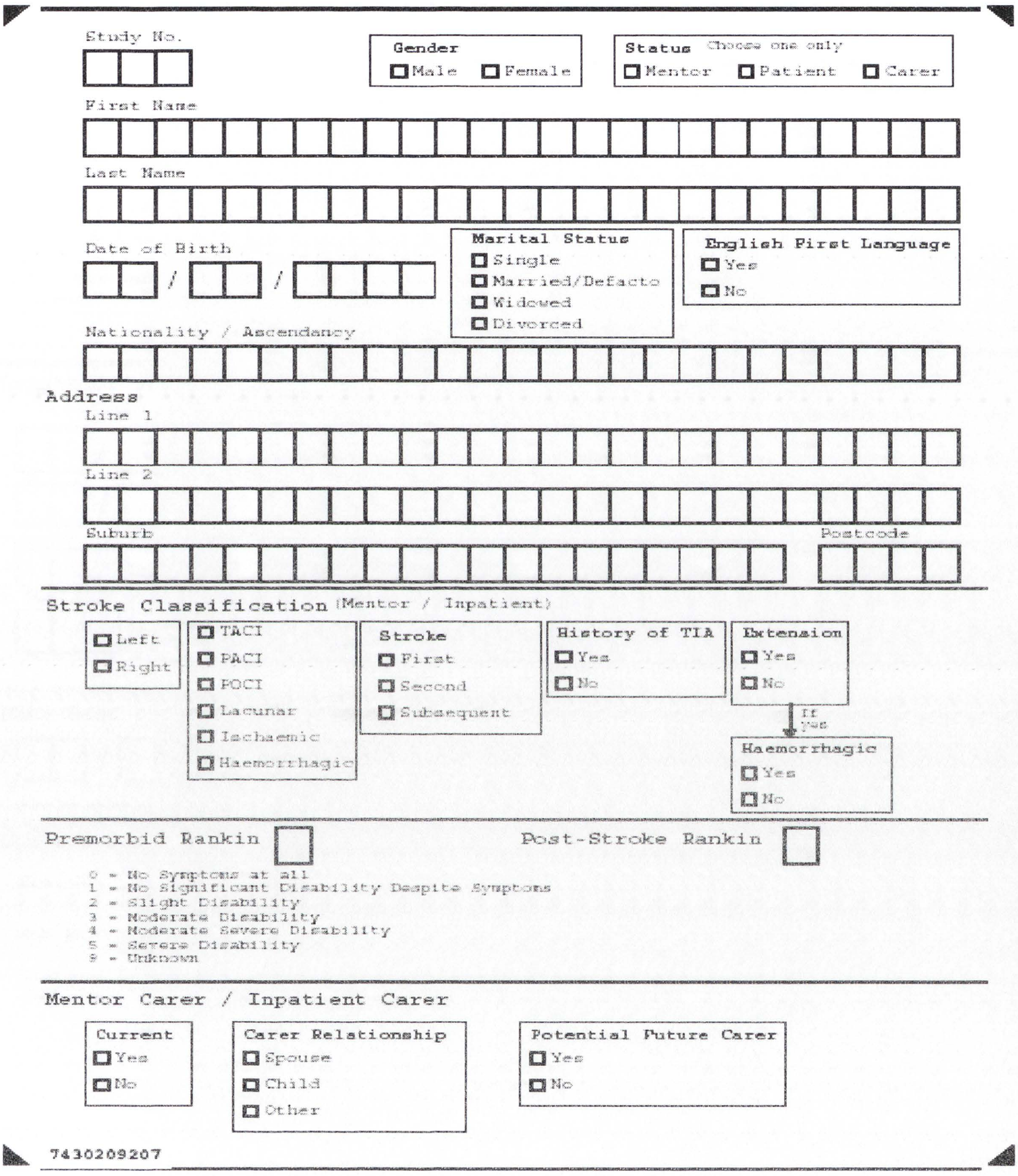
3rd Session The facilitator will be organized to come and be introduced to the mentors	Mentors will be introduced to the facilitator who will be running the focus groups	Mentors will meet with the facilitator
3rd Session Timetable for remaining education sessions and proposed focus groups	A timetable will be developed with the participation of the mentors and the facilitator	A timetable that is agreeable to participants and the mentor will be devised
3rd Session Accommodating needs of the mentors	Volunteer parking forms will be completed to facilitate ease of access and no monetary incurrence by the mentors for parking. Diaries will be provided to document their progress in the mentoring role. Identification badges for each of the mentors will be provided	The required paperwork will be completed and submitted. Diaries will be provided and explained. Identification badges will be supplied

3rd Session Meeting the members of the acute stroke team	The members of the acute stroke team will be organized to come and meet the mentors and formally introduce themselves and their role	Members of the multidisciplinary acute stroke team will meet with the mentors
4th Session The mentors will be instructed in the role of the carer support services. Looking after the mentor and signs and symptoms of stress	Carer support services will provide a power point presentation on their role and will provide written material. They will also highlight what is necessary to look after ones self in the role of a mentor	A standard evaluation form will be completed regarding the power point presentation and its usefulness to the mentor
4th Session The mentors will be instructed in the role of the community stroke support service (CSSS)	The community stroke support service will provide a power point presentation on their role and will provide written material	A standard evaluation form will be completed regarding the power point presentation and its usefulness to the mentor

4th Session Effective communication techniques	Power point presentation by research coordinator or social worker. Role-play of sessions will be undertaken	A standard evaluation form will be completed regarding the power point presentation and the effectiveness of the role-play
5th Session This session will reaffirm the previous sessions and provide examples of the expectations of the mentor role	Mentors will first witness and then be involved in a role-play to highlight how to be an effective mentor	Verbal feedback will be undertaken regarding any issues the mentors have
5th Session Introduction to the ward and staff of the acute stroke unit	Mentors will visit the acute stroke unit, be provided with a tour of the ward and meet with other members of staff. Mentors will also be shown the book that will be required for sign on and sign off	A standard evaluation form will be completed regarding the benefits of the tour and its usefulness to the mentor

5th Session Mentors will sign the formal consent form to be a part of the research	A consent form will be explained to the mentors and then signed as part of the required ethical obligation	If any participants feel they no longer wish to participate see if they would be willing to complete a reason for exclusion form
5th Session Evaluation of the overall education program	Mentors will have the opportunity to provide feedback on how they felt that the education sessions went	Focus group using butchers paper to provide feedback on sessions, any additional learning requirements will be identified and additional education sessions will be organised if so required

APPENDIX 2



Study No.

Gender
☐ Male ☐ Female

Status Choose one only
☐ Mentor ☐ Patient ☐ Carer

First Name

Last Name

Date of Birth
/ /

Marital Status
☐ Single
☐ Married/Defacto
☐ Widowed
☐ Divorced

English First Language
☐ Yes
☐ No

Nationality / Ascendancy

Address

Line 1

Line 2

Suburb

Postcode

Stroke Classification (Mentor / Inpatient)

☐ Left
☐ Right

☐ TACI
☐ PACI
☐ POCI
☐ Lacunar
☐ Ischaemic
☐ Haemorrhagic

Stroke
☐ First
☐ Second
☐ Subsequent

History of TIA
☐ Yes
☐ No

Extension
☐ Yes
☐ No

If yes

Haemorrhagic
☐ Yes
☐ No

Premorbid Rankin ☐

Post-Stroke Rankin ☐

0 = No Symptoms at all
1 = No Significant Disability Despite Symptoms
2 = Slight Disability
3 = Moderate Disability
4 = Moderate Severe Disability
5 = Severe Disability
9 = Unknown

Mentor Carer / Inpatient Carer

Current
☐ Yes
☐ No

Carer Relationship
☐ Spouse
☐ Child
☐ Other

Potential Future Carer
☐ Yes
☐ No

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Occupation / Education

Currently Employed
☐ Yes
☐ No
☐ Retired

Highest Level Of Education
☐ School Certificate (or less)
☐ Higher School Certificate
☐ On-The-Job Training
☐ Business Course
☐ Trade Course
☐ Tertiary

Does the participant have a visual impairment
☐ Yes
☐ No

Does the participant have a hearing impairment
☐ Yes
☐ No

What was your last position
☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐

Stroke knowledge / Medical Education (Inpatient / Carer only)

Did the participant have knowledge of stroke prior to this event ☐ Yes ☐ No

Length of stay (Inpatient only)

☐☐ / ☐☐ / ☐☐☐☐ Acute Admit date

☐☐ / ☐☐ / ☐☐☐☐ Acute Discharge date

☐☐☐ Length of stay in Acute Setting (days)

☐☐☐ Length of stay in Rehab Setting (if applicable after acute) - (days)

Date Seen by Mentor

☐☐ / ☐☐ / ☐☐☐☐

Contact Details

Home Ph: ______________________

Mob Ph: ______________________

APPENDIX 3

PATIENT INFORMATION SHEET

Title of research project:

Stroke Survivor and Carer In-patient Support Program

Name of researcher:

Jenny Burrows. Clinical Nurse Consultant Stroke

General Purposes Methods and Demands

The purpose of this research study is:

To look at the outcomes of a support program for stroke patients and their carers. People who have had strokes, or have cared for people, who have had strokes, in the past, would provide the support.

This program will allow you and your carer the opportunity to talk to a past patient and their carer (called mentors) that have been trained in providing education and support to stroke patients who are currently in hospital.

If you agree to participate in the study, you will be asked to:

- Undertake an initial interview with one of the researchers to determine what your expectations of the support program are and to see how the program may best suit your needs.
- Meet once with a mentor who will provide you with resource material and who will allow you the opportunity to discuss any issues or concerns you may have.

- At your convenience, you will undertake two further interviews with the researcher. One interview will occur within forty-eight hours of your meeting with your mentor. The next interview will occur four weeks after the meeting with your mentor and may be either face to face or by phone.

- The interviews aid us in determining the possible benefits of the scheme or areas that might require changes to provide a better service.

You should not agree to participate in the study if:

- You do not feel that you or your family will benefit from such a service or if you feel that, the interviews will be inconvenient.

Stroke Survivor and Carer In-patient Support Program

You will be withdrawn from the study if:

- You or your family feels that you no longer wish to participate. Your participation in this project is voluntary and you may withdraw from it at any time without disadvantaging your future treatment in any way.
- The researcher or research assistants feel that participation in the study is having a negative effect on you, your family or the mentor.

Risks, inconvenience, discomforts:

- If you do not feel comfortable with the mentor allocated, then contact the research coordinator listed below and other arrangements will be made, depending on whether you wish to choose an alternative mentor or end your participation in the study.
- If at any stage you have any concerns that you wish to express about the study, do not hesitate to contact either of the research coordinators listed below or one of the research assistants.
- Mentors will consent to maintaining the privacy and confidentiality of the person they are mentoring.
- All names will be removed from responses to the interviews to ensure privacy.
- A mutually suitable time will be arranged for you to meet your mentor.

- The planned Interviews should take around 45 minutes and will be undertaken at a time that is suitable to you. To make the evaluation of these interviews easier they will be taped.
- Jenny Burrows, as part of the study evaluation, may inspect your medical records. All other records of the study will be identified by a code instead of your name to ensure confidentiality.

Stroke Survivor and Carer In-patient Support Program

The researcher will answer any questions you have about the research project and will give you a copy of this information to take away with you. You are free to consult your own doctor before agreeing to participate in the study.

If you have any questions or difficulties that arise during the research study please contact:

Student UTS: Masters of Nursing (Honours)
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NSW 2250
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Supervisor:
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(02) 9514 5072
Faculty of Nursing, Midwifery and Health
Ku-ring-gai Campus
Eton Road

Lindfield

NSW 2070 Australia

Jacqueline.Baker@uts.edu.au

General information about the research study may be obtained from Ms Pauline Chapman (Executive Secretary of Central Coast Health Ethics Committee), Telephone: 43203070 Fax: 43250566.

Ethics approval NSCCAHS: CHREC 05/43

Ethics approval for UTS: UTS HREC 2006/206