# Nursing Contribution to the Rehabilitation of Older Patients: Patient and Family Perspectives.

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#### **Abstract**

New Zealand, in common with other developed countries, has an ageing population. Although medical advances and health promotion may improve the health of those aged over 65 years of age, an increase in the demands on the health system from this cohort is predicted. It is proposed that improvements which increase the effectiveness of inpatient rehabilitation services will ensure a greater independence in older patients, promoting their wellbeing and enhancing their likelihood of returning home. Nurses form the largest proportion of the multidisciplinary health professionals within assessment, treatment and rehabilitation (ATR) services, but until the last decade, their specific contribution to the rehabilitation of patients has been poorly understood. Previous studies which have sought to clarify their functions in rehabilitation have been mostly undertaken from the nursing perspective. Research seeking the patient perspective has predominately been undertaken with younger patients.

The aim of this qualitative research was to analyse the experiences and observations of older patients and their family members concerning the involvement of nurses in their rehabilitation at a 20-bedded ATR unit. This grounded theory study, using a constructivist approach, resulted in a substantive theory based on interviews with seven patients, aged 72 to 89 years old and six family members. The researcher is a rehabilitation nurse and the study was undertaken at her place of work. Interviews were carried out by the nurse researcher prior to the older patients' discharge and family members were interviewed separately. Interview transcriptions were coded and the constant comparative analysis of this methodology was applied to produce a theoretical framework which was mostly consistent with and added to the findings of previous studies.

The current study suggested that patients had difficulty differentiating between the role of nurses and the role of other members of the multidisciplinary team due to an overlap of clinical activities. However, the most valued nursing role noted by patients and family members was to form "best fit relationships" which fostered motivation whilst nurses coached patients to be independent. Such relationships were possible with therapists as well as nurses. All participants noted that rehabilitation nurses were distinguished by how they performed their role rather than the tasks themselves. The most effective rehabilitation nurses provided a positive environment and included input from family members if they were available. The concept of the "best fit" nurse has implications in patient management as well as in the individual care nurses give. It is suggested that relationship-building and motivational skills

would be important components of future educational programmes for nurses in rehabilitation.

Overall the study implies that rehabilitation nurses need to respond to the individual personhood as well as physical needs of those in their care. A willingness to listen to the older patient ensures patient participation and a better appreciation of potential barriers to progress. Acknowledgment of family members as sources of knowledge and their inclusion in patient care and therapy when possible also appears to facilitate the older person's commitment to his/her rehabilitation programme.

#### **Preface**

I have been fortunate to have the support, encouragement and wisdom of Dr William Levack and Lorraine Ritchie as my supervisors throughout the preparation of this thesis. I am grateful to the Health Research Council for the provision of a Masters scholarship from their Disability Research Placement Programme and would like to acknowledge the added dimension provided by the invaluable input from Dr Sally Keeling as my mentor under that scheme.

I am grateful to NMDHB and the management of Nelson Hospital who allowed me to use my own workplace as the research setting. This research would have not been possible without the agreement and involvement of all of the staff at the Assessment, Treatment and Rehabilitation unit of Nelson hospital, particularly Theresa Terry and Adair Ashton who acted as my Registered Nurse participant selectors.

I thank them and the other nursing staff who were willing to have their practice reviewed. I appreciated too the help of Shirley Terry with the transcription of the interviews.

I have been privileged to share in the lives of the patients and families who were willing to participate in this study and urged me to make a difference to the lives of future rehabilitation patients.

Finally I thank my husband, Charles who was one of the major reasons for undertaking this research. We continue to share our own journey of his rehabilitation together and he has provided not only the inspiration to seek the patient perspective but encouraged me throughout the study. I dedicate this work to him and to my daughters, Elisabeth and Stephanie who gave me insights into the loving care provided by family members.

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#### **List of Abbreviations**

ADLs: Activities of Daily Living

ATR: Assessment, Treatment and Rehabilitation

CVA: Cerebrovascular Accident (stroke)

DHB: District Health Board

EN: Enrolled Nurse

ICF: International Classification of Functioning, Disability and Health

MSQ: Mental Status Questionnaire

NOF: Neck of Femur

RN: Registered Nurse

SCI: Spinal Cord Injury

#### **Chapter 1: Introduction**

Rehabilitation professionals seek to improve the independence of individuals coping with chronic medical conditions or following a sudden traumatic event. Many older people undergoing rehabilitation in hospital wish to return home to their own communities. Nurses form a major component of the rehabilitation team but their role in the team has been poorly understood. This qualitative study considers the input of nurses to the experience of patients aged over 65 years, as perceived from the perspective of the patients and their family members.

#### 1.1 Background

Rehabilitation generally and rehabilitation nursing specifically are a part of the healthcare system in New Zealand that is poorly comprehended. The development of dedicated stroke units in the major New Zealand cities has only occurred in the past decade (Gommans, et al., 2003; Hanger, Fletcher, Fink, Sidwell, & Roche, 2007) and generic beds in Assessment, Treatment and Rehabilitation (ATR) units cater mainly for patients aged over 65 years (Ministry of Health, 2004b). In Nelson Marlborough District Health Board, ATR unit multidisciplinary teams are led by geriatricians and this may be the reason why many staff, patients and visitors regard these inpatient wards as specifically for geriatric care.

Goal-setting is regarded as an essential element in rehabilitation though how it is best performed, and its effectiveness are nevertheless questioned (Levack, et al., 2006; Wade, 1998). In Nelson hospital, it falls to the nursing staff to complete the patient goal sheets each week: a practice which assumes that they are aware of the justification for goal setting and the best strategies to complete them with the patient. Until two years ago, no in-service training in goal planning had been given to the nurses and few had undertaken any relevant post-graduate study in rehabilitation. Nurses joining the unit "learnt on the job" how to approach their practice using a "hands off" approach without any formal rehabilitation education. The need to work closely within a multidisciplinary team so that each patient received a unified, tailored programme was unstated and assumed.

As a registered nurse with a postgraduate diploma in clinical rehabilitation, I believed it was important to clarify the nurses' role within the rehabilitation team and to determine the best means of discovering patient goals. In the past five years I have had the opportunity to challenge my clinical practice as a full-time staff nurse by seeking evidence from current research on goal-planning and rehabilitation of older people. During these studies, I became

aware that an Australian nurse researcher, Julie Pryor (Pryor, 2005, 1999) had completed research into the perspectives of nurses regarding their contribution to inpatient rehabilitation. Using the methodology of grounded theory she analysed the reports of how 53 rehabilitation nurses described their involvement in patient rehabilitation and their experience of accompanying systematic constraints. She suggested that future research would need to encompass the views of patients to compare them to those of nurses and determine the effectiveness of nurses as coaches. I wished to accept this challenge to study the patient perspective and extended it also to include that of family members. I felt it would be useful to focus on patients aged over 65 years since they comprise such a major proportion of our client base. I hoped that these perceptions would contribute to an understanding of the value of nurses in planning rehabilitation with older people and lead to improvements in ward goal-planning systems. A more detailed explanation of the background to this study will be given in Chapter Two.

The methodology of grounded theory was chosen as an appropriate means to explore meanings from participant interviews and the constructivist form described by Charmaz (2006) enabled me to acknowledge the influence of the multiple roles I brought to this qualitative study. I chose to delay the major part of my literature review until after I had developed a substantive theory but in accordance with this methodology, analysis continued throughout the writing up of my thesis. A full explanation of my choice of methodology is given in Chapter Three. In the review of the literature in Chapter Two, I compare patient and family member views of rehabilitation nursing roles to those described in current nursing research including those from the nurse perspective.

#### 1.2 Research question

To determine how patients aged over 65 years and their families perceive the contribution of nurses to their inpatient rehabilitation and subsequent discharge, with an emphasis on nursing involvement in rehabilitation planning.

#### 1.3 Definitions of key terms

'Rehabilitation' can be described as a process whereby an individual is helped to return to a healthy, independent and useful life. This form is most pertinent in addiction therapy where, by removing the source of addiction, physical well-being may be possible. However physical rehabilitation often cannot return a person to their former state of independence and abilities as they may have a permanent disability or chronic health condition. Rehabilitation is no longer seen as what others do "to" an individual but how that

person accepts the support of health professionals, physical aids and social networks to adapt to or cope with a different way of life. There are multiple definitions of rehabilitation in the literature which mirror societal views relating to the person, disability and the role of health professionals (McLellan, 1997; Young, Brown, Forster, & Clare, 1999) and these will be revisited in Chapter Two.

The terms 'goal-setting' or 'goal-planning' are interchangeably used to explain the process in which short-term goals are chosen to help guide the selection of interventions for rehabilitation, with the aim of leading to the accomplishment of personalised long-term goals. It has been frequently recommended that such objectives should be specific, realistic and achievable within a pre-determined timeframe (Wade, 2009). Multidisciplinary team members frequently focus on urging improvements in physical outcomes which are measurable but these objectives may be less important to older patients. If used correctly, it has been suggested that the goal-setting process can enhance a patient's motivation and provide a means for coordinated, focussed activities understood by the patient and the rehabilitation team (Wade, 2009), although the best available research is inconsistent regarding support for these claims (Levack, et al., 2006).

The term 'older people' and 'older patient' are used throughout this study to describe patients aged over 65 years of age, rather than phrases such as "elderly" or "geriatric" or "aged" patients as such terms are susceptible to stereotyping. The age of 65 years was chosen as being the age in New Zealand, UK and USA when citizens are eligible for retirement with social security benefits. With increasing life expectancy and improved health status, older people no longer fit into the socially constructed image of an "elderly" generation, who are a "problem" to society and a "burden" on the health system due to their expected higher dependency. Moreover, researchers have more commonly divided this age group into the "young-old" and the "older-old" (Cornwall & Davey, 2004) and argue that older age does not automatically confer the need for inpatient health care. The implications of ageing in the twenty-first century are addressed further in Chapter Two.

#### 1.4 Nursing roles: tasks or relationships?

Nurses have formed a major part of multidisciplinary teams within rehabilitation settings but their role has been poorly understood. Hutelmyer (1969, p.33) argued that nurses had the potential to provide more than simply "custodial" care but until the past decade, the value of their exact contribution has not been appreciated. Pryor (Pryor, 2005, 2008b, 2010) in her grounded study of rehabilitation nursing in Australia concluded that nurses coach self-

care, create a rehabilitative milieu and help the client and their family to cope during rehabilitation. Other studies, also from a nursing perspective, variously described other tasks nurses fulfil but the nurses being interviewed often expressed uncertainty about their role. O'Connor (2000a) stated that it was the mode of delivery of rehabilitation nursing care which was the essential difference to other forms of nursing. Research from the patients' perspective highlighted that nurses are less visible than therapists but are valued once the ethos of self-care is understood (Secrest, 2002; Sondermeyer & Pryor, 2006). They were not always regarded as being part of the rehabilitation process but supportive nurse-patient relationships were appreciated.

The views of older patients may differ to previous studies (Long, Kneafsey, Ryan, Berry, & Howard, 2001; Lucke, 1999; Macduff, 1998; Pellatt, 2003; Price, 1997; Secrest, 2002) which were mostly based in spinal cord injury (SCI) or stroke units, typically involving younger populations. The findings of the current study suggested that the most valued role of nurses was to motivate and coach independence by the development of "best fit" nurse-patient relationships. A fuller discussion of the results and their implications will be given in Chapter Five.

#### 1.5 Structure of the thesis

Chapter Two provides a background to the reasons for undertaking the study which includes a review of the international research literature relating to nursing's changing contribution to rehabilitation. A justification for the current need to focus on the requirements of older rehabilitation patients in New Zealand is also provided.

Chapter Three describes the rationale for the choice of a constructivist approach using the qualitative methodology of grounded theory. The selection of participants, study setting, form of data collection and means of maintaining rigour and addressing ethical concerns are explained.

Chapter Four provides a description of the substantive theory developed from analysis of the data of patients and family members. This interpretation is offered as an explanation of the categories developed during the iterative process of grounded theory.

Chapter Five is a discussion of the study findings including a comparison with previous literature where nurses' roles are viewed both from the nurses' and patients' perspectives. The current study examined the family member perspective in addition to that of the patient and the value of seeking the family members' viewpoint is explained. The importance of the nurse-patient relationship as a means of coaching independence in older

rehabilitation patients is justified. Finally amendments to present nursing practice and suggestions for future research are proposed. Chapter Six summarises the key findings and implications of this study for clinical practice.

#### **Chapter 2: Background**

#### 2.1 Introduction

This chapter reviews literature on nursing in rehabilitation and its application in the New Zealand health care context, focussing on inpatient care of patients aged over 65 years and thus providing a background to this study. The implications of growing older and having a greater potential need for health services are reviewed within the context of an international trend to promote active and positive ageing. The historical change in rehabilitation is discussed, that is, from a medical focus on repairing broken bodies to one where the individual is encouraged to decide how to use rehabilitation services to determine their own future. A justification for the funding of geriatric rehabilitation services within New Zealand's health system is given and my position in relation to this area of research is described. Finally, research from different perspectives, of the role of nurses within rehabilitation, especially within inpatient settings, is collated, reviewed and critiqued. This literature review leads to the rationale for the choice of methodology and the reason why the patient and family member perspectives were the focus of this study.

Since I have in the past occupied two major positions related to the subject of this study, namely those of rehabilitation nurse and family member of someone with a stroke, I have chosen to integrate my background describing those viewpoints within the review of the literature. The purpose of doing this is to maintain the constructivist, reflexive stance I have taken throughout the research. The reader can follow the process I have used to examine the findings of other researchers to challenge or agree with the substantive theory developed during this thesis (Charmaz, 2006).

#### 2.2 Ageing in New Zealand

A report by the World Health Organisation commented that: "The progressive ageing of populations in the 20<sup>th</sup> century is a triumph for the human species" (World Health Organisation, 1998, p.100). The real "triumph" would be the achievement of healthy and independent lives for more years. Although medical science has increased life expectancy and reduced disability rates, the impact of the overall increase in the world population raises major issues for governments as they determine how to best provide services for their ageing societies. In common with other developing countries, New Zealand has had a shift in its dependency ratio: the proportion of those of working age able to support those aged over 65 years. The World Health Report, Life in the 21<sup>st</sup> Century (1998) states that in the future, older

people will be healthier but they will also need to be more self-sufficient as they will have less family support and governments will need to take stringent measures in the allocation of their health funding.

In New Zealand, the Ministry of Health (2002b) developed the Health of Older People Strategy to provide a framework for the provision of services and funding decisions. This document acknowledged that the proportion of older people in New Zealand was projected to rise by about 22% between 2010 and 2030 and by 25% by 2050. Whilst the majority of people aged over 65 years live in the community independently, the evidence from self-reporting indicates that this group of people are more likely to require hospitalisation than the 50-64 year cohort for stroke, cardiovascular disease, ischaemic heart disease, chronic obstructive pulmonary disease and unintentional self harm due to falls (Ministry of Health, 2006). There are also known geographic areas in New Zealand which have higher numbers of older people than other areas of the country - Nelson being cited as one, where 15% percent of the population is now over 65 years compared to the national average of 12.3% (Statistics New Zealand, 2006). The proportion of the New Zealand population aged 65-79 years was 9.6% in June 2010 whilst those aged over 80 years has increased to 3.5%. With a current total national population of over 4,383,000 in New Zealand (Statistics New Zealand, 2010), this equates to 574,173 people aged over 65 years.

According to a survey of the provision of services by the District Health Boards (DHB's) in 2003 (Ministry of Health, 2004b), delivery of care for older people has tended to be very fragmented. The main aim of the Health of Older People Strategy (2002b) was to provide an integrated approach to health and disability support services which would be easily accessible to older people and amenable to their changing needs: an integrated continuum of care model. Whilst older people usually access hospital for elective surgery or as part of an emergency admission and spend time on acute wards following exacerbations of chronic illnesses or surgery, many require longer periods of recuperation and the opportunity to overcome the negative impact of hospitalisation (Edvardsson & Nay, 2009), such as physiotherapy to address impaired mobility. As a result, it is common for assessment, treatment and rehabilitation (ATR) units to have a high proportion of patients over 65 years old. In a smaller centre like Nelson, without specialist rehabilitation wards for stroke or spinal cord injury (SCI), the ATR unit is predominantly populated by older patients.

#### 2.3 The role of rehabilitation globally

Definitions of rehabilitation abound and have changed in response to views on health. Early descriptions of rehabilitation were based on the medical concept of cure, so that restoration to former function was deemed to be the primary desired outcome. This perspective can be seen as arising during the time of two 20<sup>th</sup> century World Wars when disabled service men were being encouraged to return to any form of viable work. However, several decades later, this viewpoint still dominated the discussion of rehabilitation. For example, in a review of stroke and rehabilitation, Myco (1984) collated various definitions of the concept of rehabilitation which all described what was done to the person with the disability rather than what a person undertook for themselves. This can also be illustrated by the discourse used in a study of nurses by Waters and Luker (1996), where participants used the phrase "rehabbing people" to describe the actions of the staff working at a rehabilitation ward for older people. In contrast to this however, Pryor (1999, p.10) concluded that rehabilitation "is a process experienced and owned by patients, not the place to send them...it is an aspect of the entire continuum of any health care episode."

Authors such as Young et al. (1999) and McLellan (1997) discuss this change in philosophical emphasis with reference to the modification of models of disability developed by the World Health Organisation. The current version (WHO, 2001) entitled The International Classification of Functioning, Disability and Health (ICF) includes the categorisation of social factors in the representation of disability. Thus the impact of the environment on the expression of disability is recognised. This is in contrast with the earlier versions of the WHO classification systems for disability which presented disability as "medical" dysfunction (World Health Organisation, 2010). This change in focus from a model where disability was regarded as a consequence of disease, to a framework placing an emphasis on health and functioning, has had far reaching implications in the form of health care provision. It has reflected the change in viewpoint, whereby disability was acknowledged as being a social created problem rather than just the attributes of an individual (World Health Organisation, 2002). Nolan et al. (1997) in their extensive literature review of the contribution of nurses in rehabilitation commissioned by the English Nursing Board, offered a detailed review of definitions of rehabilitation and noted that patient participation was an essential component of the rehabilitation process together with family participation and a team approach. Young et al.(1999) and Wade (1992) highlighted two other essential ingredients: goal-setting and the iterative, cyclical process of comprehensive assessment and intervention.

Young et al. (1999) welcomed the move from a medical paradigm which looked at the illness, to a social paradigm which looked at the person, as this had implications for older patients. He argued that the social construction of old age was part of the environment for older people so could be included for consideration in the social model of disability. Safilios-Rothschild (1970) suggested that older people, together with those who were severely disabled, were excluded from rehabilitation because it was not considered that they would benefit from it. It is hoped that this ageist attitude is not prevalent today though when funding is stretched, then those who are requiring less intensive therapy or shorter stays may be prioritised during bed allocation. These categories rarely include the frail older patients coping with more severe disabilities. Blackmer (2000) noted that physicians are often forced to be the gatekeepers to rehabilitation centres. Part of the doctor's role is to select the patients most likely to benefit from rehabilitation resources and such hard ethical decisions are particularly difficult with older patients. Their requirements are often greater due to the multiple co-morbidities and complex social needs frequently associated with old age.

Whilst rehabilitation is a key means of ensuring that individuals gain their optimal independence and improve their quality of life, in my own workplace I do not believe it is always appreciated as a unique speciality of healthcare. Rusk (1978), a pioneer in rehabilitation medicine, wrote of the poor understanding of his work by fellow doctors during the development of the speciality in the first half of the 20<sup>th</sup> Century. I have found that rehabilitation is still often not understood or valued by health professionals until they experience it first-hand. Wade (2002) argued that funding for rehabilitation services was hard to gain as purchasers needed convincing that it "works" since it is an approach to care rather than a specific intervention. Perhaps since improvements are progressive and usually slower, rehabilitation does not initially seem as exciting to health professionals as disciplines of medicine using more sophisticated technology. Gerontology nursing has been described as "hard work" (Schumacher, 1999, p.21), so geriatric rehabilitation nursing may seem even less attractive if outcomes are less discernible and individuals have difficulty completing therapies due to the increased likelihood of having age-related complications such as cognitive impairment.

In an observational study in the UK, Birchall and Waters (1996) noted that older patients in hospital spend much of their time doing nothing. This may reflect the setting and time but raises concern that they may develop increased dependency due to staffing shortages or workplace practices. However, Bachman et al. (2010) in their systematic review of randomised controlled trials concluded that inpatient rehabilitation specifically designed for

geriatric patients reduces mortality, admission to residential care and improves functional outcomes. They acknowledged that this form of health care is resource intensive and hence expensive but were unable to assess the cost effectiveness of these programmes.

Even if older patients are allocated an inpatient "bed", some may indicate to their doctor that they wish to be "cared for" rather than embark upon the long journey of rehabilitation "work". This may be a cultural response or simply a belief that this is their right (Faulkner & Aveyard, 2002). Attitudes and beliefs of patients form an essential part of decisions about treatment and therapy particularly for older rehabilitation patients. If they believe that their life has been so radically altered by their disability, then they may choose not to participate in a programme of rehabilitation. Ameratunga and Brown (2000, p.346) found it "disturbing" that 80% of women aged over 75 years, in part of an Australian randomised controlled study (Salkeld, et al., 2000) preferred death rather than the prospect of a "bad" hip fracture that necessitated institutional care. It is part of the challenge of those involved in rehabilitation therapy (Maclean, Pound, Wolfe, & Rudd, 2000) to provide and support the motivation to hope for and achieve what individuals can adapt and cope with in their futures.

Some older patients in the UK, when interviewed post-discharge (Sheppard, 1994), had confused rehabilitation with convalescence. In response to their need for information about rehabilitation prior to transfer from an acute ward, a video was produced explaining the philosophy and principles of rehabilitation. In an Australian study of nine patients with a mean age of 75 years, responses in semi-structured interviews also demonstrated that they were poorly prepared for the change to the rehabilitation setting since they received little explanation to inform them otherwise (McKain, et al., 2005). Similarly, Sondermeyer and Pryor (2006) found in a pilot study into patients' experience of moving from acute wards to a rehabilitation unit, that older patients had little understanding of what to expect, and suggested they may have experienced relocation stress syndrome.

Once older patients have accepted their need for rehabilitation and coped with the change of focus to being actively involved in therapy, then they need to come to terms with future planning. One role of ATR units is to ensure that the outcomes achieved during therapy may be viably maintained upon discharge. The reality of returning home is as dependent upon an individual's determination to maintain and improve their abilities to be independent, as it is on their medical status. Family and social networks may also impact upon their involvement in therapy and their choice of discharge destination.

#### 2.4 Rehabilitation for older people in New Zealand

The Guideline for Specialist Health Services for Older People (Ministry of Health, 2004a) in tandem with the overall strategy for older people (Ministry of Health, 2002b), stated that treatment and rehabilitation plans are most effective when they meet the objectives of the older person and their whanau/family. Rehabilitation providers internationally use goal-setting as a means to ensure that therapy has a focus which is meaningful and achievable (Playford, Siegert, Levack, & Freeman, 2009; Wade, 2009). With the introduction of the Health and Disability Commissioner Act (1994), patients in New Zealand are expected to make their own decisions concerning their health care including setting their own goals.

In a paper prepared for the Ministry of Health, Cornwall and Davey (2004) provided an extensive review of the international and national implications of the demand for health services due to the impact of population ageing. They concluded that although there are likely to be reduced levels of severe disability amongst older people, their projections indicated a possible 77% increase in expenditure for disability support services by 2021. Figures like these taken out of context are often used by the media, even politicians, to reinforce the negative attitude of older people being a "burden" on society. McCallum (2000, p.329) argued that the highest priority when considering the "costs of ageing" debate is to reform our health system so that it responds to the needs of older people which in turn will resolve many cost issues. Promoting and maintaining the independence of New Zealand's older population should be a major health goal and inpatient rehabilitation services will need to be as effective and efficient as possible. Ashton (2000) noted that although specialist geriatric ATR services had been shown to extend and improve the independence of frail older people and reduce their need for residential care, caregiver support and home care, that such services had been greatly reduced in some regions of New Zealand. The New Zealand government has the challenge to provide positive health outcomes whilst wisely using a finite health budget. In the briefing to the incoming minister, the Ministry of Social Development (2009, p.11) noted that "reducing the incidence of disability could offset around a third of the extra health costs of an ageing population" and that the expectation of all ages to receive the most up-to-date technology in health care would continue to have a bigger effect on the health budget than population ageing. So whilst rehabilitation for older people is costly, it has potentially more benefits in New Zealand than might at first be thought.

# 2.5 Rehabilitation from a personal perspective: Family member and rehabilitation nurse

With a previous history of teaching science in secondary schools in the UK, Solomon Islands and New Zealand, I trained as a registered nurse in Nelson, eventually specialising in gerontology and rehabilitation. The 20 bed inpatient assessment, treatment and rehabilitation (ATR) unit where I currently work within a multidisciplinary team is purpose-built and serves the geographical area of Golden Bay, Motueka and Murchison as well as the city of Nelson itself. There is no specific training in rehabilitation in the ATR unit and recent improvements in nurse education have focussed on updating acute patient care. Specific techniques relating to mobility and self-care training are "learnt on the job" from more experienced nurses or by seeking assistance from within the team. Whilst nurses are valued and their assessments sought, they are not generally viewed as "experts" within the hospital and the unit follows a medical model of preparing for an appropriate discharge destination for the patients. In common with other hospitals of their size, Nelson hospital and Wairau hospital, Blenheim have ATR units which accept "outliers" from acute wards, when this facilitates efficient bed management. Nursing staff are allocated patients according to a software programme "Trend Care" which defines the time required for individual patient care. This system has superseded primary nursing where a specific nurse was selected to care for a patient from admission to discharge.

It is important to acknowledge the constraints placed upon the functioning of the ATR unit: continuity and training of staff; the need to comply with bed management requirements for the hospital overall and the ongoing implications of allocation of funding in a period of economic recession (Johnston, 2009). In addition there is a lack of clarity about the meaning and implications of rehabilitation for both patients and nursing staff. There are few postgraduate papers in rehabilitation nationally and a lack of recognition of those which exist by the Nursing Council of New Zealand. The implication (rightly or wrongly) for nurses wishing to achieve Nurse Practitioner status is that rehabilitation is not regarded as a speciality of nursing. This hurdle together with lack of funding means that nurses willing to undertake postgraduate courses are more likely to focus on acute nursing care options.

Whilst appreciating being part of a professional team which works together extremely well and has good leadership, I wished to determine if we were being as effective a service for

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<sup>&</sup>lt;sup>1</sup> A colloquial term for a patient who is cared for at the ATR unit for bed management reasons but remains under the medical care of consultants from another speciality e.g. a medical patient who is stable

our patients and their family members as we desire. The role of nurses as rehabilitators within the unit is poorly understood and individual nurses find it hard to explain what is unique about their skills and knowledge. This is particularly evident when student nurses or new staff are orientated to the ward.

In 2005, my husband suffered a subarachnoid haemorrhage and subsequent stroke and was admitted to the unit for a two month period. I was then able to see the overall expertise and individual skills of team members from a different viewpoint whilst still working as a nurse at the unit. I reflected that I would be treated differently to other family members being an "insider" but was able to hear from my daughters, their view of the care provided. I became increasingly interested to see what other family members' experience of nurses was and whether other patients' experiences at the unit would reflect that of my husband. I wished to discover whether the viewpoints of the older patients would match his and whether they felt they were treated any differently. The implications of my various roles are discussed further in Chapter Three.

Research about family members in rehabilitation (Nolan, Booth, et al., 1997; Nolan, Nolan, & Booth, 1997; Pryor, 2008a) has tended to focus on their involvement in caring for their loved one especially after discharge home. Few studies have sought the family member perspective whilst the person is still an inpatient. Jonasson et al. (2010) interviewed next of kin about the caring of older patients by nurses and concluded that "being amenable" or being available for their needs was a key role. Family members' opinion should be sought since:

- 1. this may be what the patient wants (Engel, 2009).
- 2. nurses state that caring for family members is part of their role, so families' needs should be identified (Brereton & Nolan, 2002).
- 3. family members have "person knowledge" (Brereton & Nolan, 2002) and will have expertise about patients' personal attributes, likes and needs prior to their rehabilitation which may be particularly valuable for older people with cognitive deficits (Routasalo, Arve, & Lauri, 2004).
- 4. family members may have a strong influence on a patient's decision-making (Hedberg, Johanson, & Cederborg, 2008) and motivation (Young & Resnick, 2009).

I believe that family members can have an influence upon an individual's progress and wellbeing during inpatient rehabilitation and this thesis seeks to explore whether other family members have shared my experience.

In my other role as rehabilitation nurse, I was interested to learn how patients perceived my input to their rehabilitation. I wished to know whether Henderson (1980, p.246) was correct when she wrote her oft quoted statement that "nurses are rehabilitators par excellence". In Australia, Pryor and Smith (2002) sought to determine the role of nurses within rehabilitation in order to develop a national framework (ARNA, 2004) which would address the competencies required for registration. This achieved recognition of rehabilitation nursing as a speciality in the same manner in which it has existed in the United States for over thirty years (Association of Rehabilitation Nurses, 2010). In the conclusion to her doctoral thesis, in which she had developed a model of nursing roles from the nurses' perspective, Pryor (2005) challenged researchers to seek the view of patients as "only they can determine the value of nursing's contribution" (p. 247). Price (1997), working in New Zealand, used a brief questionnaire to seek patient input though her emphasis was on collating a nursing discourse regarding nursing roles. This current thesis accepts Pryor's challenge and extends and updates the work of Price (1997) by ascertaining the views of family members as well as patients.

There is a need for nurses in this ever-expanding speciality to understand their distinctive input and to ensure that it is provided as effectively and efficiently as possible within the unique setting of New Zealand. A participant in Collins' (2002, p.49) study of rehabilitation nurses' voices in New Zealand noted that "the traditional view of many people, especially older persons" was that nurses are there to "tend them, to look after them, to make them comfortable". A review of the literature internationally will determine whether this is indeed true or whether nurses have a more active role in facilitating the rehabilitation of even older patients. In addition, such a review will provide information which can be applied to our country's particular needs and strengths, fashioned as they are by our geographical location, small population size, culture and resources.

#### 2.6 Searching the literature

In order to explore previous research into nursing in gerontological rehabilitation and the concepts which emerged from the analysis of this study's data, a review of the literature on ageing, rehabilitation, nursing, family systems and patient-professional relationships was undertaken. The electronic databases Medline, CINAHL, AMED and the Cochrane library were searched from their date of inception to 2010 for literature on nursing and rehabilitation of older people. Key terms and synonyms were grouped using the Boolean conjoiner 'OR' to focus on studies examining the patient, the therapy and the aspect of nursing. Patient terms

included key terms or MeSH terms including: rehabilitation patients, elderly, geriatric, older, stroke and fractured neck of femur. Activity terms were: mobility, mobilizing, gait, muscle tone, positioning, passive exercises, walking, movement and physical therapy. Nursing terms included rehabilitation nursing, nursing (interventions, assessment, outcomes, diagnosis), gerontological nursing and nurse-patient relations. The three major themes were then combined with the Boolean conjoiner 'AND'. Limits were applied to restrict searches to studies in the English language including older people.

Further searches in CINAHL grouped patients, family, significant other, aged, aged 80 and over, aged hospitalised, geriatrics or rehabilitation, geriatric, elderly, frail elderly, old\$, aging and caregivers together with 'OR' and combined with a group including: professional-patient relations, patient viewpoint, patient perspective, patient attitudes, nurse attitudes, attitude to health, nurse-patient relations and interpersonal relations.

Papers of interest were read thoroughly and important references were retrieved and compared. Greater attention was paid to studies giving clear descriptions of methodology including analysis which focussed on the role of nurses in physical rehabilitation setting from the perspective of the nurse, patient or family member. Expert opinion papers were included if they were focussed on nursing rather than rehabilitation generally. In addition, resources cited by Pryor (2005) were sourced to determine how they justified her findings and whether they added to the current study. Using the "similar studies" function for these original sources in Medline and CINAHL, additional resources were checked for their value and relevance to the current study.

#### 2.7 Literature describing the role of the nurse in rehabilitation

Most of the literature describing the role of a nurse in rehabilitation was written by nurses and the functions listed reflect the history of rehabilitation as it has developed internationally. The nurse theorist, Lydia Hall (Pearson, 2007) developed the "Care, Core and Cure model" of nursing and subsequently used it in the Loeb Center for Nursing and Rehabilitation when it was established in New York in 1966. Nursing units based on a similar model developed in the UK in the 80's, where again nurses were viewed as the main therapists.

However in a world where rehabilitation starts in hospitals using a medical model, the emphasis has mostly been on physician-led teams where physical therapy has been the main focus after medical stabilization. The nurse author, Hutelmyer (1969) proposed that nurses in rehabilitation would have four main roles:

- To plan and implement basic nursing care.
- To guide and teach the patient and their family.
- To collaborate with the rehabilitation team so that all nurses are used effectively.
- To use resources to plan for effective continuity of care in the community.

She felt that nurses required appropriate education to be rehabilitators and that motivation of the patient would be the key element in that role. She believed that nurses' attitude should model a belief in the patient's potential. Table 1 (pp. 17-18) demonstrates the functions described for nurses within rehabilitation over the subsequent forty years: from being an adjunct to the physiotherapist to providing the very environment conducive to rehabilitation. (The purpose of this table is to highlight aspects of change rather than to provide an exhaustive list of all the available literature). Nurses saw themselves as teachers, advocates and providers of holistic care. However team members were more likely to mention their involvement in basic nursing care such as pressure sore prevention or following up their specialised instructions when they are unavailable (Atwal, Tattersall, Caldwell, & Craik, 2006; Booth & Waters, 1995; Waters & Luker, 1996).

Table 1: Development of the concept of nursing roles in rehabilitation described in the nursing literature (1980-2010)

Task/Function	Author/Date	Comment
"Carry out treatment prescribed by physicians". (p. 256)	Henderson (1980)	Noted international nurse educator.
"are rehabilitators par excellence". (p. 256)		
Physiotherapy assistant.	Myco (1984)	
Understudy to other health professionals in their absence.	Waters (1986)	Cited by Price (1997).
Support for family.	Gillies (1987)	USA. Nurse author opinion.
	Long et al. (2001)	UK 2 year ethnographic study from multiple viewpoints.
Forms relationships with patient and with family.	Hahn (1988)	USA. In-patient ward model.
and with raining.	Price (1997)	NZ grounded theory study including nurse and patient views.
	Lucke (1999)	USA grounded theory study of patients' views.
	Pryor & Smith (2002)	Australian pilot study.
	Pryor (2005)	Australian grounded theory study based on nurses' views.
Provider of spiritual care.	Hahn (1988)	
	Davis (1994)	USA. Nurse author opinion.
Collaborator with other disciplines.	Brillhart & Sills (1994)	USA. Analysis of work diaries.
	Benson & Ducanis (1995)	USA. Nurse author opinion.
	Association of Rehabilitation Nurses (2010)	National organisation of nurses in USA.
Coordinator of patient's physical care (custodial).	Benson & Ducanis (1995)	
"Lynchpin" in coordination.	Booth & Waters (1995)	UK action research study of multidisciplinary team views.
	Hill & Johnson (1999)	UK "exploratory qualitative study" of nurses' views.

Task/Function	Author/Date	Comment
"Carry on" work of therapists.	Booth & Waters (1995)	
	Waters & Luker (1996)	UK study of multidisciplinary team views based on grounded theory methods.
	Routasalo et al. (2004)	Scandinavian study on nurses' views using questionnaires.
Educator to patient and family.	Benson & Ducanis (1995)	
	Price (1997)	
	Association of Rehabilitation Nurses (2010)	
Coaching self care.	Price (1997)	
	Hill & Johnson (1999)	
	Pryor (2005, 2009)	Australian grounded theory study of nurses' views.
Facilitator of personal recovery, care manager and care giver.	Burton (2000)	UK "reflective study of 13 nurses' views.
"Management and promotion of homeostasis" (p. 788) in its broadest sense.	McPherson (2006)	Expert opinion.
Provider of rehabilitation milieu.	Nolan et al. (1997)	UK major project using literature review for English National Board.
	Pryor (2010)	Australian grounded theory study of nurses' views.
	Association of Rehabilitation Nurses (2010)	
Provider of dignity and respect (by all members of rehabilitation team).	Mangset et al. (2008)	Phenomenological study of views of older patients who had experienced a stroke.
"It is the mode of the delivery of nursing care that differentiates rehabilitation from acute nursing practice and hence could be seen as the defining characteristic of the	O'Connor (2000a) O'Connor (2000b)	Review of Kirkevold's perspective of nursing roles based on qualitative study of views of 90 nurses in stroke units in UK.
role of the nurse in stroke rehabilitation." (2000a, p. 187)		Mode of delivery describes tension between non-intervention and "doing for" and when to use each.

Table 2 (pp. 20-22) provides a critical review and summary of some of the studies on rehabilitation from the nursing (and health professional) perspective including the work of Julie Pryor. Since Australia and New Zealand have a reciprocal relationship for nurse employment, Pryor's studies are particularly pertinent for New Zealand. Much of the literature regarding the role of nurses is based on expert opinion or practice experience and the majority of studies are focussed on rehabilitation following stroke or spinal cord injury (SCI). The latter may be less helpful when considering the rehabilitation of over 65 year old patients as SCI patients tend to be much younger and this will impact on attitudes and beliefs. Stroke rehabilitation studies are often undertaken in dedicated stroke units where the nursing staff may have had more specialised training than the nurses in my study setting whilst others including older patients include a range of inpatient settings.

Table 3 (pp. 23-25) reviews empirical studies from the patient perspective though only the studies by Macduff (1998), Long et al. (Kneafsey & Long, 2002; Long, Kneafsey, Ryan, & Berry, 2002; Long, et al., 2001) and Secrest (2002) specify that patients aged over 65 years were included in their research.

Both Tables 2 and 3 include a column to signify the quality of the research which underpinned the study findings. The method of quality assessment implemented, categorises each of the qualitative studies according to criteria used by MacEachen et al. (2006). Whilst there are other systems to evaluate and categorise the quality of studies, this assessment tool focuses on concepts central to qualitative research and thus was most appropriate for the groups of papers under consideration. There are four levels within the classification system, from "low" where data is too variable and/or analysis is poor and possibly imposed by the authors to "very high". The latter shows evidence of a theoretical focus with a consideration of the context, subjects and environment in an integrated manner such that the description could be transferred to other research situations.

Table 2: Overview of studies to determine the role of the nurse in rehabilitation: from the health professional perspective

Reference	Focus of study	Methodology	Participants	Key findings	Limitations	QA <sup>2</sup>			
Empirical studies									
Booth & Waters (1995)	To explore and improve rehabilitation practice in a geriatric day hospital.	Action research	UK study. Observational study. Interviews with13 MDT members including 5 nurses.	Nurse's role is multifaceted and nurse is 'lynchpin' in coordinating role. Conceptual model includes: carry on; custodial; atmosphere and environment. Nurses' work is 'hidden' and so not acknowledged. Role conflict of rehabilitation versus safety	1 hospital - "small case study". Rehabilitation involved but part of post-discharge care.	Medium			
Waters & Luker (1996)	Perceptions of roles of nurses by members of multidisciplinary team.	Unclear, drawing on grounded theory methods for analysis	56 members of multidisciplinary team in 2 rehabilitation wards, UK.	Hard to elucidate nursing role but mainly that of 'maintaining' overall wellbeing and 'carrying on' roles of the therapists. Therapists seen as experts in rehabilitation	Described as study of nurses but method and results infer study about concept of rehabilitation and roles of all multidisciplinary staff.	High			
Hill & Johnson (1999)	To increase knowledge regarding the role of the neurological rehabilitation nurse.	Unclear. Reported as 'exploratory qualitative study'.	9 RN's interviewed.	UK study. 1 <sup>st</sup> theme: nursing interventions related to patient care: promotion of patient independence, routine nursing tasks, management of individual patient care and counselling. 2 <sup>nd</sup> theme: organizational issues that affected practice and 3 <sup>rd</sup> theme: nurses' beliefs and opinions about their role.	Neurological rehabilitation unit.	Medium			
O'Connor (2000a)	Manner of delivery of nursing roles as important as roles themselves.	Review of Kirkevold's model based on O'Connor (2000b)	n/a	Mode of delivery as important as the roles of the nurses themselves and guides the nurse-patient relationship.	Stated as being from patient perspective but the quotes are all from nurses.	n/a			
O'Connor (2000b)	To identify nursing interventions of rehabilitation nurses	Interviews with nurses working in stroke units	90 interviews of nurses analysed by Riley's method	Themes: focus of care, outcomes of care, direct care, continuity of care, mode of care and context of care.	Nurses caring for stroke patients only.	Very high			

 $<sup>^2\,\</sup>mathrm{QA}$  shows the quality assurance rating according to MacEachen at al. (2006)

Reference	Focus of study	Methodology	Participants	Key findings	Limitations	QA
Empirical	studies continued					
Pryor & Smith (2002)	To explore the role of registered nurses working in rehabilitation in Australia.	Individual interviews and focus groups with analysis based on grounded theory methods.	13 RN's in individual interviews and 21 RN's in focus groups from 3 states in Australia.	Suggested framework of what and how nurses function in rehabilitation.	Interviews not taped. Confined to inpatient rehabilitation.	Very high
Pryor (2005)  Pryor (2007)  Pryor et al. (2009)  Pryor (2009)  Pryor (2010)	How do nurses contribute to patient rehabilitation in inpatient units?	Grounded theory	35 RN's & 18 EN's	Primary role of nurses is working directly with patients coaching them to self-care. System-based problems impact on the nurses' ability to care as they wish.  To facilitate the transition from the role of acute care patient to rehabilitation patient, nurses used: easing patients into rehabilitation, maximising patient effort and providing graduated assistance.  Nurses used various strategies to create a physical and psychosocial milieu conducive to rehabilitation.	Based on nurse opinions only. (Authors note: they were unable to distinguish between RN and EN ability to coach effectively.)	Very high
Barreca & Wilkins (2008)	To explore the perceptions, beliefs and feelings of nurses who provided care at stroke rehabilitation unit.	Phenomenology	8 nurses in Canadian stroke unit.	Nurses felt their role was pivotal in team but was devalued by others in the team and they lacked the time to provide appropriate care to stroke patients.	Mixed neurological ward but focussed on care of stroke patients. Focus of study on ability to perform role than explanation of role.	High

Reference	Focus of study	Methodology	Participants	Key findings	Limitations
Literature review					
Kirkevold (1997)	To develop a theory based on existing literature of specific role of nursing in stroke recovery.	Development of model based on literature review and 3 previous studies including 3 month study of an acute stroke unit: fieldwork: observations and documentation and interviews.	Unknown	States nursing has unique role. Develops a model of nursing where the roles or functions include: interpretative, consoling, conserving, integrative.	Review not explained. No details of method of collection or analysis of data. Data from only one unit in Norway.
Nolan et al. (1997)	To synthesise knowledge of nursing roles (generalist and specialist) in rehabilitation and analyse available nursing curricula.	One year UK project including literature review for English National Board (ENB).	n/a	Roles included: maintenance of physical wellbeing; specialist role in care of skin and continence, reinforcers for input from others in MDT; maintenance of rehabilitation environment and a 24 hour presence.	Wide ranging literature search. Some of this based on Waters (1991) unpublished thesis.
Nolan & Nolan (1998)	Review of literature and proposal of a framework for role of nursing in rehabilitation.	Based on 1997 work and refers to two research reports.	n/a	Suggested framework of nursing roles to focus on future needs to improve provision of care.	Discussion of findings of 1997 research project.
Nolan et al. (2001)	Exploration of nursing contribution to patient education in rehabilitation.	Literature review and analysis of curricula from a range of courses.	n/a	Nurses are less effective in their educative role in practice than in theory. Nurses are poorly prepared by education programmes for this role.	Update on Nolan et al. (1997).

Table 3: Overview of studies to determine the role of the nurse in rehabilitation: which include the patient perspective

Reference	Focus of study	Methodology	Participants	Key findings	Limitations	QA
Nelson (1990)	Patients' perspective of a spinal cord unit.	Ethnographic interviews, observational study and document review. Analysis using grounded theory.	US study. All staff and patients of a 30 bed spinal cord unit during a 4 month period in 1988.	Four themes emerge of how patients reintegrate: buffering, transcending, toughening up and launching. Staff-patient relationships form an essential part of helping patients cope with rehabilitation.	Poor explanation of methods used so could not be repeated. Nurse author uses term "staff" more frequently than "nurses" so difficult to determine which roles apply to nurses. Age of patients not stated.	High
Sheppard (1994)	Patients' views of rehabilitation.	Action research	UK study. 17 patients. Interviews post- discharge at home. Then another set of 11 patients.	Move from acute care to rehabilitation is quite a change for patients, and nurses need to educate them what rehabilitation is.	Based on one rehabilitation unit. Does not describe specifics of participants. No explanation of analysis.	Medium
Brillhart & Johnson (1997)	To discover what motivates patients and how they cope positively.	Unclear	USA study. 12 SCI patients interviewed but only one > 65 years.	5 themes: independence, education, socialization, self-esteem and realization. Nurses provided individualised teaching of ADL's and promoted self-esteem in patients.	Could not replicate as methodology unclear. Patients focus on post-discharge issues.	High
Price (1997)	To determine aspects of nursing viewed by participants to help 'customers move towards independence and healing'.	Grounded theory	NZ study. Focus group of 8 nurses. 9 respondents to patient questionnaire.	Coaching role is central. The nurse: coach as a face-to face leader has a pivotal role with the individual and the family and within the team. The nurse: coach is in a unique role to offer guidance and direction to the whole team.	Exploratory study for Masters thesis. Only 2 questions in questionnaire. Patients aged 16-64 years.	High

Reference	Focus of study	Methodology	Participants	Key findings	Limitations	QA
Macduff (1998)	Exploration of stroke patients' views of nursing care to clarify the meaning of the nursing role.	Phenomenological study.	UK study. 8 patients from stroke rehabilitation unit. Mean age of females was 74 and mean age of males was 71.	Two themes: having the necessary done and do it yourself approach.	Interviews conducted post discharge possibly impacting on recall. Small number of participants but appropriate for this methodology.	Very high
Lucke (1999)	Contribution of nursing care during inpatient rehabilitation.	Grounded theory	US study. 22 spinal cord injury patients.	Substantive theory that nurse- patient relationship supports patient reintegration of self. Nurses provided encouragement, motivation, fostered independence and autonomy in decision-making.	All younger spinal cord injury patients.	Very high
Secrest (2002)	How patients and family members experience nurses during rehabilitation.	Phenomenological study.	US study. 6 stroke patients and 7 primary supporters.	Single theme emerged of nurses being helpful or adversarial on a continuum.  Nurses mostly "invisible" as in earlier study by Secrest & Thomas (1999) though study describes experiences with other therapists.	US study and stroke patients specifically.	Very high
Long et al. (2001)	To identify the role of the nurse within the multidisciplinary team.	Ethnographic study with interviews and observations.	2 year UK study of role from multiple perspectives – nurse, patient and multidisciplinary team members. 49 patients interviewed.	6 core nursing roles: assessment, co-ordination and communication, technical and physical care, therapy integration and therapy carry- on, emotional support, and involving the family.	An extensive research report of the state of rehabilitation and nursing in UK.	Very high

Reference	Focus of study	Methodology	<b>Participants</b>	Key findings	Limitations	QA
Long et al. (2002)				Challenges whether nurses' contribution is restricted by expectations of patient and carer.		Very high
Kneafsey & Long (2002)				Asks if the nursing roles identified are different in rehabilitation to other wards. Whilst nurses input into rehabilitation appreciated by team members, effective team work was impeded by lack of time for nurses and shortage of		
Pellatt (2003)	To define the role of SCI (spinal cord injury) rehabilitation nurses.	Involved patient interviews and thematic analysis.	14 SCI nurses and 14 patients.	nurses and therapists.  4 categories: The bedrock of rehabilitation; Making the transition from an acute care philosophy to a rehabilitation philosophy; Nursing as the low profile aspect of rehabilitation; Caring and nursing power.  Nursing seen as important by patients but NOT viewed as providers of rehabilitation.	Methodology unclear. One SCI unit and only SCI patients.	High
Sondermeyer & Pryor (2006)	Patient view of change from acute care to rehabilitation including role of nurses.	Longitudinal interviews and thematic analysis.	Australian pilot study. 11 patients.	Patients' views of nurses changed as they appreciated role of rehabilitation over time. Patients remain dependent so nurses help them cope.	Brief write up of findings. Form of analysis unclear.	High

At the time when Pryor and Smith (2002) developed a framework for rehabilitation nurses working in Australia, most research on the role of nurses in rehabilitation described tasks which nurses or team members suggested that they fulfilled. A model specifically for stroke rehabilitation integrating some of these functions was proposed by Kirkevold (1997) and was subsequently critiqued by O'Connor (2000a) who suggested that it was the mode of delivery of nursing care which was as important as the interventions themselves. In a major UK two year study of the role of the nurse in the multidisciplinary rehabilitation team, Long et al. (2001) sought the views of patients, team members and nurses as well as holding four national expert workshops using interviews and focus groups. This followed an initial phase in which data was gathered from an ethnographic study of the rehabilitation case studies of patients, who had experienced a fractured neck of femur, rheumatoid arthritis or a stroke. Six core nursing roles were defined: assessment, co-ordination and communication, technical and physical care, therapy integration and therapy carry-on, emotional support and involving the family. Drawing on this research, Long et al. (2002) asked whether the roles described were unique to rehabilitation or just the same as those undertaken in other areas of nursing. Moreover focussing on the nurses' role within the multidisciplinary team, Kneafsey and Long (2002) noted that nurses were often constrained in fulfilling some of these roles due to the time available to them or shortage of staff.

Pryor's grounded theory study (Pryor, 2005, 2007; Pryor, Walker, O'Connell, & Worrall-Carter, 2009) of nurses' beliefs and perceptions of their role in rehabilitation described the need for nurses to "opt in and opt out" of involvement with a patient as well as within the team (Pryor, 2005, p.xiv). She interviewed and observed a total of 53 nurses working at five different sites in New South Wales, Australia. Her theory of "opting in and opting out" was an integration of six concepts: "incongruence between nurses' and patients' understandings and expectation of rehabilitation, coaching patients to self-care, segregation: divided and dividing work practices between nursing and allied health, role ambiguity, distancing to manage systemic constraints and grasping the nettle to realise nursing's potential" (Pryor, 2005, pp.211-212). Her study is a valuable contribution to the nursing literature about rehabilitation as it describes the roles that nurses were willing and capable of fulfilling, as well as exploring whether nurses chose to perform them. Her findings also acknowledged the lack of time for nurses to fulfil all their desired roles. She also included other systematic constraints imposed on nurses: ambiguity about their role within the team and marginalisation due to the requirement to manage secondary health issues as well as contributing to rehabilitation. Nevertheless, she concluded that a major aspect of the nurses' role was to coach self-care. She highlighted these findings in subsequent articles (Pryor,

2009, 2010) explaining that nurses "eased patients into rehabilitation" (Pryor, 2009, p.82) using strategies suited to their individual needs so that they more effectively made the transition from being an acute patient to being a rehabilitation patient. Strategies included: "finding out about the patient", "informing patients", "engaging the patients in therapeutic relationships", "motivating patients to participate in rehabilitation" and "creating a rehabilitative milieu" (Pryor, 2009, p.83). Two further phases were "maximizing the patient's efforts" (Pryor, 2009, p.84) and "providing graduated assistance" (Pryor, 2009, p.85). The phases were not stepwise stages but elements which nurses adopted to suit an individual, the time and the activity.

It may be argued that seeking a patient perspective whilst ideal, is unnecessary with the number of articles focussed on the nurse's role in rehabilitation. Indeed McPherson (2006, p.787) commented that asking about the role of the nurse is "an old and at times rather boring chestnut". Secrest and Thomas (1999, p.245) were disquieted to find in their phenomenological study of fourteen stroke survivors that "nurses were never mentioned – indeed it was as if they did not exist." However it is unclear whether indeed the participants mentioned any of the team members and since the study was up to two years after discharge and individuals may have experienced various types of memory loss, then this finding may be less significant. What is more pertinent is to consider whether patients should consider nurses at all when they have come through such a traumatic event in their personal life. It may be that their focus is more on their own form of coping and those significant others who helped them adapt in the intervening period. In a subsequent study, Secrest (2002) specifically asked patients about the time spent with nurses but again the nurses' presence whilst considered helpful, was seen as mostly invisible. Secrest (2002) suggested that this may partly be due to confusion as to their identity within the rehabilitation team.

Although nurses may have a patient's interest at heart, unless they are in that role, they cannot fully appreciate the patient's perspective (Hudson & Sexton, 1996). With the move to patient-centred care has come a need to know more about what individuals believe, desire and need (Sahlsten, Larsson, Sjöström, & Plos, 2009), though older patients may need to develop effective partnerships with staff in order to understand how to participate in their own care (Tutton, 2005). There is a plethora of literature exploring the implications of patient participation as health professionals seek to provide appropriate information and promote decision-making. Goal-setting is perceived as a crucial element of rehabilitation, but some patients may not wish to participate or make decisions at all (Schulman-Green, Naik, Bradley, McCorkle, & Bogardus, 2006; Waterworth & Luker, 1990).

There are few examples of rehabilitation literature written from the patient perspective (Cant, 1997; Telfer, 2002). Researchers such as Charmaz and Paterniti (1999) in their seminal work on chronic illness give insight into how individuals cope on a daily basis with ill health whilst others have sought patients' views of the rehabilitation experience itself (Sigurgeirsdottir & Halldorsdottir, 2008). Hammell (2007) found few published studies for a metasynthesis of rehabilitation from the patient perspective and there are even less about the role of nursing. Table 3 (pp.23-25) as described earlier includes key findings of such studies.

Whilst Price's study (1997) is included in Table 3 as involving the patient perspective, in fact this was just one small element of her findings from a broader investigation of the therapeutic contribution of nurses in rehabilitation from a nurse perspective. Price's (1997) findings were based on the responses from a questionnaire which asked just two questions regarding nursing practice in rehabilitation (and which was completed by only nine respondents): firstly about a specifically recalled example of nursing care and secondly three things which were helpful about the care. While Price (1997) acknowledged this amounted to a small set of data on nursing rehabilitation, she concluded that the responses suggested that:

...the characteristics of an interpersonal relationship – trust, encouragement, preservation of dignity, support, motivation, humour – were identified as helpful and assistive in the customer making progress in rehabilitation. (p.149)

Price's research was conducted in a unit dedicated to the rehabilitation needs of patients aged 16-65 years thus limiting its scope for comparison to the age group of the present study. In a SCI unit, Lucke (1999) found that the nurse-patient relationship also aided patients by contributing to their reintegration of self. Her interviewees described nurses as being providers of encouragement and motivation for patients whilst fostering their independence. Pellatt (2003) noted that her participants with SCI did not view nurses as providers of rehabilitation at all though they valued their input with specific nursing skills such as pressure area care. In an earlier study, also with SCI patients, Brillhart and Johnson (1997) stated that the nurses' role in individualised teaching and promotion of self-esteem was an important aspect of increasing their motivation in rehabilitation.

Whilst the importance of their relationship with patients was noted by nurses in Price's study, there was a much greater focus on what they did for and with the patients. Her key finding was that the nurses acted as coaches and she compared the attributes required for the task with a sports coach using motivational skills. Pryor (2005) endorsed and explored these findings further, especially when explaining "coaching self-care" as a key role for rehabilitation nurses.

An extensive study by Long et al. (2001) focussed on the need for change in the role of nurses within multidisciplinary teams in the UK. Subsequent papers (Kneafsey & Long, 2002; Long, et al., 2001) explained specific aspects of the earlier review which included interviews with 49 patients. However, it was difficult to extract specific findings from the patients or their care providers as they were interwoven with data collected from nurses or focus groups. Long et al. (2002) concluded that the nurses' contribution could be inappropriately restricted as patients viewed the nurse as "doing for" them whilst Kneafsey and Long (2002) documented that "clients and carers commented that rehabilitation is 'something that the physiotherapist does'".

Overall, studies about the role of nurses in rehabilitation provided a picture of nurses working within a team. Patients perceived nurses' roles in different ways but especially valued the relationship which they developed with them. Nurses struggled to discern which aspects of rehabilitation they could fulfil, being constrained by time but seeing the nurse-patient relationship as a means of promoting independence and providing routine nursing care. Whilst team members appreciated working alongside nurses, they generally appeared to be unable to clarify a specialised position for them within rehabilitation. Patients hospitalised due to illness or disability may be more concerned with coming to terms with a loss of sense of "self" (Long, et al., 2001) than sharing their views about the role of rehabilitation nurses. To explore the patient perspective of the nurse-patient relationship and its impact on regaining hope, accepting change and working towards optimal independence remain worthwhile goals.

The focus of rehabilitation is not on cure as in some other areas of medicine and so it should not be unexpected to note that patients described their need to adapt to a new life and a new image of self (Sigurgeirsdottir & Halldorsdottir, 2008). In common with palliative nurses (Mok & Chiu, 2004), nurses in rehabilitation may need to help their patients find meaning in life again. Patients may expect that nurses will be "doing for" them and assume that they should remain passively in a "sick role". This may be even more likely amongst older patients familiar with earlier forms of health care where nurses demonstrated caring by ensuring bed rest and alleviating pain. The reality is that some rehabilitation nurses may wish to remain "caring" whilst also ensuring that patients participate in their individualised programmes.

The majority of the extensive nursing literature on caring has focused on how the nurse should respond: how to establish caring, the impact of caring too much and what form caring should take. Jean Watson is just one of the nurse theorists whose model of nursing described the nature and role of caring in nursing (Watson, 1999). In their concept analysis of caring, Morse et al. (1990) identified five epistemological perspectives:

- Caring as a human state
- Caring as a moral imperative or ideal
- Caring as an affect
- Caring as a nursing intervention and
- Caring as an interpersonal relationship.

Considering the latter, these authors stated that, in their own clinical experience, nurses used different styles of caring with different patients. Moreover this form of caring could be learnt and taught. Whilst nursing and caring are often viewed by nurses as synonymous (Forrest, 1989), Watson and others have described caring as the "essence" of nursing (Morse, et al., 1990). Finfgeld-Connett (2008) used meta-synthesis and grounded theory strategies to explore the concept of caring. She conceptualised caring into antecedents which link via attributes of the caring process to nurse and patient outcomes of caring. Expert nursing practice, interpersonal sensitivity and intimate relationships form the caring process. Henderson (2008) critiqued the study by saying that Finfgeld-Connett had made no mention of the patient perspective of caring.

The challenge of the nature of caring in the rehabilitation setting was undertaken by Macleod and McPherson (2007) in their review with a New Zealand perspective. They noted the medical emphasis on "cure" and the therapists' inclination to focus on "motivated" patients and those with particular disabilities. They concluded that psychosocial needs are likely to be as important to patients as any improvements in functional progress and encouraged goals integrating these aspects too. They wrote (p.1592):

Rehabilitation isn't just about restorative or preventative goals. Supportive and nurturing goals will, with the right relationship between the patient and carer, be defined for many and allow a different level of engagement in the rehabilitation process. In order to develop the level of trust, such that people using our service will risk their honesty in saying what it is they really need support with, means time spent listening and trying to understand those things that trouble the person.

Caring has usually been studied qualitatively but in a recent study, McCance et al.(2009) used Likert-constructed instruments to compare caring from the perspective of nurses to that of patients. Some of the patients involved were rehabilitation inpatients. There was incongruence between the two viewpoints indicated by the choice of specific statements describing caring at five time intervals. Nurses consistently chose items related to technical or intimacy aspects of nursing such as "listening to a patient" (McCance, Slater, & McCormack, 2009, p.413) whilst patients' responses were much more variable in both scoring and ranking. Overall, there was little similarity between the nurses' and patients' choice of

statements and the authors concluded that nurses needed to be aware of their patients' perceptions of caring to amend their practice to ensure that their focus was indeed upon the patient.

Such studies suggest that there is a need to discover how patients and family members view caring as an element of nurses' contribution within an inpatient rehabilitation setting. It is timely to explore how nurses "care", who exactly they care for, and whether caring is viewed differently within rehabilitation compared to other health services.

## 2.8 Summary

This study seeks to answer some of these unaddressed issues arising from the literature, especially seeking to determine the contribution of nurses from viewpoints other than that of health professionals. Firstly it focuses on the perspective of patients aged over 65 The selection of older patients, whilst chosen to reflect the major population undergoing inpatient rehabilitation in my place of study, may indicate differences in perspective with younger patients described in several earlier studies. Secondly input was sought from family members since personal experience and the few studies available have indicated that family may play an important part in rehabilitation and that nurses are often the first point of contact for family members. Grounded theory was used for this thesis: a decision which is in common with several of the authors cited in this literature review. Oneto-one, open-ended interviews enabled me to gain a deeper understanding of aspects of caring nurse-patient relationships and explanations of nursing roles. The study was undertaken in my usual workplace where my research was accepted and encouraged by all members of the team. The findings of this qualitative research will add to the few rehabilitation nursing studies already undertaken in New Zealand and may indicate whether previous international research in this topic has relevance to this country's health services. Finally, it is hoped that this thesis will add to current knowledge and form the basis for improvements in nurse management and education.

# **Chapter 3: Method**

### 3.1 Introduction

This chapter describes how I undertook a grounded theory investigation in order to examine how patients and their family members viewed the role of rehabilitation nurses within an inpatient rehabilitation unit. The research was conducted in the Assessment, Treatment and Rehabilitation (ATR) unit of Nelson Hospital, where I work as a Registered Nurse. The study involved collecting data from semi-structured interviews with patients aged over 65 years old and their family members, between July 2009 and January 2010. Analysis of data occurred concurrently and continued until the end of 2010. Ethical approval for the study was sought and given by the Upper South A Regional Ethics Committee and support was gained from senior management and the Iwi Health Board of Nelson Marlborough District Health Board.

# 3.2 Methodology: Grounded theory

I chose to use grounded theory as an approach for this study, as this methodology has been used widely in nursing research since it is considered suitable for studying meanings in social contexts. Grounded theory is based on the theoretical perspective of **symbolic interactionism** described by George Herbert Mead (Crotty, 1998, p.20). Charmaz (2006, p.189) defined symbolic interactionism as "a theoretical perspective derived from pragmatism which assumes that people construct selves, society, and reality through interaction" (p. 189). She explained that symbolic interaction assumes "meanings arise out of actions, and in turn influence actions" (p. 189). In social settings, such as a hospital ward, meanings are modified as a person interprets encounters with their fellow beings. Most research in rehabilitation nursing has been derived from the nurses' viewpoint and Pryor (2005, p.245) challenged nurses to seek the perspective of the patients and their families. Grounded theory is appropriate when little study has been undertaken in a particular area of inquiry (McCann & Clark, 2003) or when researchers are seeking "fresh perspectives on familiar situations" (Stern, 1980, p.20).

Morse et al. (2009, p.17) noted how multiple forms of grounded theory have emerged from the original work of Glaser and Strauss described in their publication, *The Discovery of Grounded Theory* (1967). Charmaz (2009) acknowledged that grounded theory is a method to study process which is itself in process. She distinguished between objectivist grounded theory and constructivist grounded theory (Charmaz, 2000, 2006, 2009). The former arises

from positivism, an epistemology which includes experimentation and prediction leading to the establishment of laws. From his post-positivist perspective, Glaser has always maintained that there is an objective, external reality which can be observed by a neutral witness who "discovers" the data (Charmaz, 2000). Constructivist grounded theory is founded in pragmatism and has a relativist epistemology: there are multiple realities and multiple means of viewing those realities (Charmaz, 2009; Guba & Lincoln, 1989).

Since there are fundamental philosophical differences between objectivist and constructivist grounded theory, the choice of approach influences the methods employed and the part which the researcher undertakes in the study. Common to all variants of grounded theory are the roles of inductive logic, rigorous analysis and the aim of developing a theoretical analysis (Charmaz, 2009).

Charmaz (2006) has argued that the process of grounded theory can meet the challenges of methodological and theoretical developments of the 21<sup>st</sup> century. She viewed grounded theory methods as "a set of principles and practices not prescriptions" (Charmaz, 2000, p.9). The main objective in grounded theory is to develop an analytical theory or framework from the data so that the data has primacy (McCann & Clark, 2003). Data may be collected from interviews, observations or written accounts and is coded and categorised. One core component of grounded theory is that of a constant comparative method (Hallberg, 2006) so that new data is compared to previous data to explore variations and similarities; to constantly review properties and means of interpretation. Analysis and data collection occur simultaneously in an iterative process starting with purposeful sampling to obtain a desired range of material or participants. As results emerge, questions are asked and new data is sourced by theoretical sampling to test ideas and achieve "saturation" of a category or code (i.e. when new data does not add new information to the study). Memowriting is considered an important part of analysis as the researcher describes ideas, reflections and assumptions made about the links between and within data. The process of developing theory from data by forming patterns in this way is an inductive form of reasoning (Thomas, 2006). This interaction with the data and throughout the analytic process is crucial in grounded theory in its constructivist version. Constructivist grounded theory borrows the inductive, comparative technique described in Glaser and Strauss' classic version but utilises the "iterative logic of abduction to check and refine the development of categories" (Charmaz, 2009, p.137). Abduction requires the researcher to be playful with the data so that a surprising finding is not dismissed but considered with multiple hypotheses, tested by gathering more data and integrated into the most plausible theoretical interpretation. Data is constantly being viewed in different ways. Language and terminology are teased apart to seek underlying assumptions, and the social circumstances, location and background of the participants are considered. Researchers adopting a constructivist grounded theory approach also need to acknowledge what they themselves bring to the interviews, as each person becomes a co-constructor of the data and its meaning. Moreover, the constructivist researcher acknowledges that much will remain tacit and unstated during interviews. Meanings will reflect social conventions and power relationships. Finally, even when the analysis is developed, there is no final discovered "truth". As Charmaz acknowledges, the analyses are seen as "interpretative renderings not as objective reports or the only viewpoint on the topic" (Charmaz, 2009, p.131).

Glaser (1978, cited in McCann & Clark, 2003) asserted that grounded theory researchers needed to develop **theoretical sensitivity.** To achieve this ability the researcher is required to enter the field of study with an ability to understand the subtleties of the data. Then theories about the area of interest are made from multiple positions, comparisons are made, new ideas explored and tested. The ultimate aim is to describe the data in such a way that it best reflects reality. This ability to extract, give meaning to and understand the data is advocated by and encouraged as "theoretical playfulness" by Charmaz (2006, p.135).

Since I have been working with older patients in a rehabilitation ward setting for the past six years and have studied the impact of rehabilitation and hospitalisation during this period, it is unrealistic for me to be a passive witness in this study, so I have chosen to use a **constructivist approach** based on a **relativist ontology** (Charmaz, 2009; Guba & Lincoln, 1989). I have assumed that there are multiple social constructions of reality and that as I interviewed the patients and their families, we were co-constructors of these realities as together we attempted to make sense of their experiences of rehabilitation. The theory which evolved from the data did not "emerge" from observed data as stated by Glaser (1992, cited in Levack, 2008) but was constructed by my interaction with the research participants, the questions I opted to ask, and the form my analysis of the created concepts and categories took. This **constructivist epistemology** is a hallmark of the approach of Kathy Charmaz (Bryant & Charmaz, 2007; Charmaz, 2006), so I have based my method on the guidelines and arguments proposed by her, rather than those of the other schools of grounded theory which have evolved from the work of Glaser and Strauss (Morse, et al., 2009).

## 3.2.1 Justification for choice of constructivist approach

My original purpose in pursuing this study was to improve the quality of nursing care provided in rehabilitation and I decided that this was best achieved by asking the patients themselves. Glaser's insistence that the researcher cannot embark on his or her research with

a preconceived research problem precludes my use of his purist approach (Glaser, 1998). Whilst Strauss and Corbin's (1998) methods have been used by many nurses, their approach felt too prescriptive and their description of how much the researcher and participants interact to create data, less clear than is described in Charmaz's (2000, 2006) texts. Charmaz (2000) acknowledged that a researcher will have an influence at several levels and that the finished grounded theory will be a construction of *a* reality not *the* reality. This constructivist paradigm fits with my background of nurse and as wife of a patient who has undergone rehabilitation at the ward and researcher studying in my own workplace. It allowed me to acknowledge the influence that my previous and present attitudes and values may have had and the manner in which I undertook the interviews.

I am conscious that during this study I was fulfilling multiple roles none of which was that of patient. Ritchie (2009, p.17) described the role of the researcher, who is also a nurse, as "wearing two hats" and the impact of this dual role during the interviewing of older people. Hewitt-Taylor (2002) acknowledges that being in these dual roles may influence the responses of those being interviewed as well as the analysis of the nurse researcher. I openly declared my several roles to my participants and have constantly reviewed and reflected how these standpoints may impact on this study. I believe that I am also in a position to access the perspective of family member, coming as I do to the study with an "insider's" view of being the spouse of a man who received rehabilitation after a stroke. I address these issues in more detail in section 3.3.5.

Since the intended product of my research was to gain a better understanding of individuals' perceptions which are useful to amend clinical practices, a constructed interpretation of their experiences was considered realistic (Annells, 1997). Charmaz described the outcome of her studies as a "narrative" (Hallberg, 2006) which was told by the researcher to focus on the understanding of the social processes. I believed this approach would be more helpful to nurses in clarifying how their role is perceived from the patient/family member viewpoint.

#### 3:2:2 Use of literature

The use of background reading of the literature for informing the selection of research questions or for enhancing theoretical sensitivity on a given topic of inquiry has been hotly debated (Charmaz, 2006; McCann & Clark, 2003). Glaser (1998) argued that a literature review in the substantive area of the topic should not be performed until after the data analysis was completed, as the evolving theory would be tainted by knowledge of earlier ideas. Charmaz (Bryant & Charmaz, 2007) countered that those who advise postponing literature are experts who have an extensive knowledge of a vast amount of literature and a general familiarity with key ideas. It was impossible for me to be "untainted" as I brought to my study a knowledge of some research surrounding rehabilitation and nursing research and, in order to clarify which methodology to use, had familiarised myself with the work of Pryor (Pryor, 2005, 2007, 1999; Pryor & Smith, 2002). A literature review formed part of my research proposal. I used the literature to clarify established meanings so as to clarify codes and definitions I was attributing to them. However the bulk of my literature review was postponed until after I had formulated some optional theoretical frameworks from my study data. In constructive grounded theory it is acceptable to acknowledge preconceived ideas about relevant research, as this forms part of what the researcher brings to the study together with their values, priorities and background. Grounded theory requires reflexivity which involves the researcher scrutinising their experiences, background and knowledge prior to assessing how much these may impact on their inquiry (Charmaz, 2006). Constructivists do not attempt to avoid bias by being neutral observers but ensure that all they bring of themselves is revealed and acknowledged during data collection and analysis. Charmaz wrote (2009) "The objectivist looks at the empirical world from the outside as a visitor who does not enter the world of the participants. Constructivists enter the empirical world to the extent that they can" (p. 139).

## 3.3 Method

A flowchart summarising how this methodology was used is presented in Figure 1 overleaf (p. 37). Each box represents a different stage in the process but several steps may be repeated consistent with the cyclical nature of this methodology.

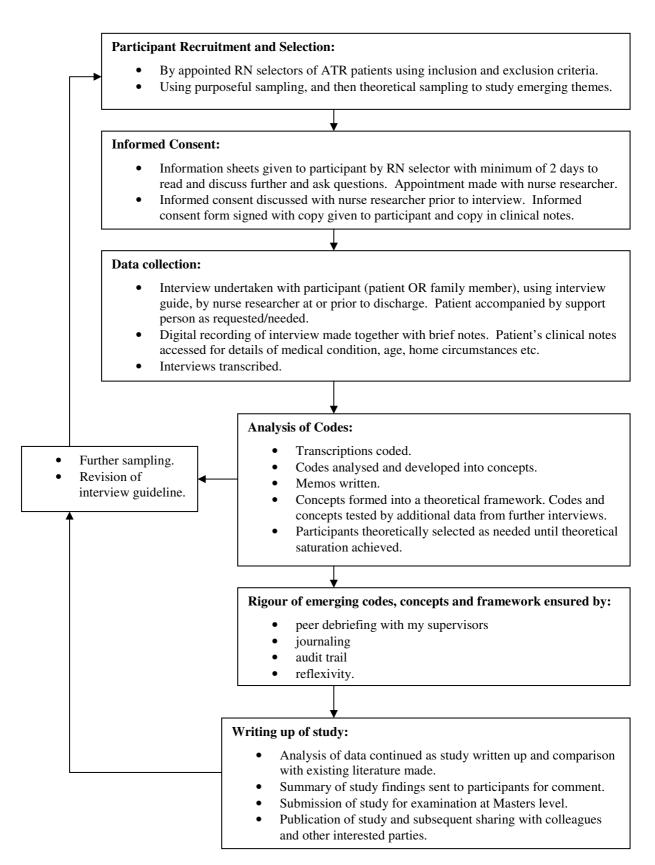


Figure 1: Summary of the use of grounded theory in this study

## 3.3.1 Selection of participants and their recruitment

I invited two registered nurses (RN's) who work full-time at the ATR unit to be responsible for the selection of suitable participants. I explained my proposed study to all members of the multidisciplinary team by sharing a PowerPoint presentation with them in small groups. In addition, I provided my RN selectors with a folder of resources of background material, information sheets and consent forms. We had several meetings where I shared progress and responded to specific questions. The RN selectors earmarked potential subjects using a checklist of eligibility criteria including: age, gender, ethnicity, reason for admission, access to a family network and cognitive ability. Patients were eligible for the study if they were 65 years or older and had been an ATR unit inpatient for a minimum of 14 days. Patients were excluded if they were medically unwell, an "outlier" from another ward, could not communicate in English, declined to participate actively in rehabilitation or had been previously nursed by me. Potential subjects were identified on the ward patient board so that I was not allocated to nurse those people during their hospitalisation.

When an older person agreed to participate then they were invited to nominate a family member to be included in the study themselves. These family member participants were interviewed separately. Patients were not excluded if they did not have a family member available for interviewing. Indeed one patient was purposefully selected as she had no family member living in the local area to support her. This was to represent the increasing number of older patients admitted to the ATR unit who have no local family network. In accordance with the consent policy, no family members were coerced into participating against their wishes even if the older patient was keen to be interviewed. Although I anticipated that only one family member per patient would wish to be interviewed I had made no restriction regarding number of family members in the information sheet so this was open to interpretation.

The RN selectors provided the selected participants and their family members with an information sheet (see appendices A and B) and after a minimum of two days I met with the potential participants to discuss any queries before inviting them to sign an informed consent form (see appendices C and D) and to arrange an interview time.

It was important to develop a trusting relationship with the older patients and to ensure that they had the support of a family member or significant other during the interview if they chose. Older patients who are chronically ill, newly disabled, frail or recently hospitalised may feel more vulnerable (Gilhooly, 2002; Green & Thorogood, 2004) and thus agree to participate in the study contrary to their true wishes. To ensure that these older patients did

not feel pressured into consenting, the RN selectors and I stressed the need for the older person to discuss the study with a significant other and gave all participants at least two days to decide whether or not to participate.

Severity of injury (including severity of any cognitive or communicative impairment) or duration of time since the onset of acquired brain injury was <u>not</u> considered a reason for exclusion from this study. However all participants who were unable to give consent to the study for themselves or were unable to participate in a semi-structured interview, were required to have an English-speaking family member who was able to agree to the study on their behalf and participate in interviews with them. Patients with a score of less than 7 (highest score being 10) on the Mental Status Questionnaire (MSQ) (Qureshi & Hodkinson, 1974; Wilson & Brass, 1973) were required to have a Statement by Relative form (see appendix E) completed and signed by a family member and the appropriate consultant, following Guidelines of New Zealand Health and Disability Ethics Committees (2005). Whilst inclusion of those with cognitive or communication issues can be problematic, their exclusion from research prevents them from 'having a voice' in how they perceive their nursing care. A study of those with moderate to severe dementia (Clare, Rowlands, Bruce, Surr, & Downs, 2008) suggested that even people with significant psychological impairment retained an awareness of their situation and functioning, indicating that semi-structured interviews are still worthwhile.

As I was working in both the role of nurse and researcher there was also the possibility of role confusion. To overcome this, I was employed part-time during the study and was not involved in actively nursing any of the participants except on night duty when my colleagues were asked to respond to their needs. I worked one week as a nurse and the alternating week as a researcher. Other members of the multidisciplinary team were made aware of this conflict of interest and were asked not to include me in the direct care of the patients in the study. No emergencies arose during the study period requiring me to exit the role of researcher for that of clinical nurse. Patients whom I had nursed previously or were known to me were excluded from the study to prevent this relationship impacting on their responses during interviews and thereby reduce bias.

#### 3.3.2 Data collection

I performed a practice interview prior to collecting any data in order to become familiar with interviewing techniques (Green & Thorogood, 2004) and to trial an interview guide based on a format by Macduff (1998). I interviewed patients at the ATR ward but family members chose a venue which suited them. In all cases privacy and quiet were

maintained. The older patients chose whether to have a support person present with them and interviews were scheduled when they were not fatigued. At the beginning of the interview, I gave each interviewee an opportunity to discuss the meaning of informed consent, the purpose of the study and to ask any questions they had. I showed them a photograph of a nurse dressed in the uniform of Nelson Marlborough District Health Board (NMDHB) as personal experience and background literature (Duffield, 2009; Loveday, Wilson, Hoffman, & Pratt, 2007) had suggested that the general public are often unable to distinguish between the identities of different health professionals. I discussed the participants' ability to distinguish nurses from the other members of the multidisciplinary team and reminded them that the study was focussed on nurses at the ATR unit.

The interviews were semi-structured (Opie, 1999; Patton, 2002) based on an interview guide (see appendix F) which I amended as the study progressed in accordance with the constant comparative method of grounded theory (Charmaz, 2006). Interviews were undertaken prior to discharge to facilitate the participants' recall of events. One patient was discharged before an interview could be arranged and this was performed the following week in a private office at the ward when he returned for out-patient physiotherapy. I made digital recordings of the interviews together with brief notes which recorded emotions or other interactions during the interviews. Interviews ranged in duration from twenty minutes to over an hour. Two interviews were shortened when the patients became distracted as they became physically uncomfortable. One patient was interviewed on two separate occasions as he was very articulate but verbose. He was keen to complete all the questions I had developed but the first interview was curtailed for his midday meal.

The interviews were transcribed verbatim and a copy of the conventions used for transcription is included in appendix G. I completed all but one of the transcriptions myself. A statement of confidentiality was signed by the typist who transcribed the longest recording (see appendix H). The participants were offered the opportunity to review the transcriptions for correction purposes and no amendments were required. In two interviews the support person interjected into the conversation although we had discussed their role as spectators rather than participants. Their comments were transcribed but not analysed as being part of the patient's viewpoint.

Details of family members' relationships to the patient were gained prior to or during the interview. I accessed patient hospital records to glean further information concerning patient goals, their medical condition, reason for hospitalisation, family background and other demographics. This additional information added to my theoretical sensitivity of the data during analysis and writing up my findings.

I used a numbering system to identify study participants and their family members in order to maintain confidentiality. All transcripts, memos, recorded or written material were stored in a locked filing cabinet and electronic versions were accessible only by password. In order to preserve confidentiality, pseudonyms were used in writing up my findings and other potentially identifying features were removed from interview transcripts, including place names and specific details about the history of illness. This was particularly important in conducting research in a community as small as Nelson with its relatively stable population of older citizens, where individuals are more easily identifiable. I also gained permission from all the participants prior to disseminating the study findings (Chenitz & Swanson, 1986).

## 3.3.3 Sampling techniques

Initially I used **purposeful sampling** to ensure a broad representation of individuals from different backgrounds as described earlier (Patton, 2002; Strauss & Corbin, 1998). The last two patients were selected to further examine the emerging theory of the role of nurse-patient relationship that developed from the iterative process of interviewing, coding and analysis. Such **theoretical sampling** is consistent with this methodology.

Nine patients accepted the invitation to participate in the study but two subsequently dropped out at the time of discharge from the ATR unit prior to being interviewed. The first was a woman with dysphasia who was excluded as she appeared too distressed after being transferred to residential care. The husband of the second potential patient participant withdrew his initial consent when his wife also required admission to long-term hospital care.

I had hoped to include a Maori patient amongst my sample both initially when sampling purposively and later as part of theoretical sampling when wishing to compare relationships. Whilst we have few Maori patients receiving rehabilitation at the ATR unit, I was keen to determine if there are any disparities in their hospital care which may impact on their health outcome (Rumball-Smith, 2009). I had invited Te Pukenga Hauora (the hospital Maori Health Practitioner) to be part of the interviewing process and we had worked collaboratively on the wording of the information sheet and consent form to ensure its suitability for tangata whenua. However no Maori patient fitting the study eligibility criteria was admitted during the study period.

## 3.3.4 Analysis of data

I **initially coded** each interview transcript line by line to capture and name instances when a segment of data highlighted examples or descriptions of nurses' roles from the interviewee's viewpoint. This is also described as 'open coding'. As further interviews were

performed, codes were amended and defined as similar ideas, phrases or actions emerged which better described earlier codes. Some codes used the words of the person expressing them (in vivo codes). I repeated the process of coding as themes and patterns developed and tested them from interview to interview to ensure consistency whilst compiling a list of definitions which I refined and tested. Then I recoded all interviews using focussed coding so that earlier codes were amended to ensure that they '[made] the most analytical sense to categorise [my] data incisively and completely' (Charmaz, 2006, p.57). I developed tables of data, codes and categories in response to **memos** which I had written to test and evaluate ideas regarding connections within the data (Lempert, 2007). Using the constant comparative approach of grounded theory, I eventually grouped codes into more abstract categories and developed theoretical frameworks which I reviewed and changed as I delved back into the data. As each new set of raw data was coded and compared, I remodelled the categories themselves whilst constantly referring to the raw data to ensure that the original sense of the interviews was truly represented. Codes emerging from interviews with patients were analysed separately to those with family members and then comparisons made. When no new patterns were appearing to prompt further data gathering to amend the existing categories, I judged that I had reached theoretical saturation for this study. I felt that I had sufficient data, and that further interviews with more participants would not change the detailed explanatory scheme I had developed of what was happening for patients and their family members at the ATR unit, Nelson hospital in this time frame.

### 3.3.5 Roles and Reflexivity

The manner in which an individual carries out their research: their past experiences, the decisions they make during the study, and their analyses need to be scrutinised in qualitative research. This reflexive stance is important when constructing meaning with others in interviews since there is a temptation to anticipate participants' responses. As a rehabilitation clinical nurse I have learnt not to make presumptions about how individual patients will respond in a ward setting. My profession requires me to reflect on my practice, and my role as a preceptor to student nurses or new staff ensures that I share these reflections with my peers. Post-graduate study had challenged me to question the source of my beliefs and knowledge whilst learning of the viewpoints of patients and other health professionals. In addition, since my husband continues to recover from the impact of a subarachnoid haemorrhage and stroke, I have to acknowledge that becoming a "family member" of a rehabilitation patient has given me quite a different perspective to that of nurse. Moreover working alongside my husband as he rehabilitated has added another dimension to my

understanding of rehabilitation: that of "family member". In common with Pryor, I have to acknowledge my role as a "passionate participant" (2005, p.59) since approaching the research from these different perspectives has contributed to my understanding of patient and particularly family members' attitudes to rehabilitation nurses. I used memoing and regular discussion with my supervisors to share my reflections about my involvement with the participants and my analysis of my findings. I believe these methods enhanced my theoretical sensitivity to my research topic.

In an attempt to view the world through the eyes of a patient and not that of nurse, I tested my assumption about the time nurses spend with their patients. To do this I spent some time on the ward in my role as researcher, collecting no data but rather just observing daily routines with patients. Noting the times that different staff members entered and exited a patient's room during a sixteen hour period, I discovered that nurses spent far less time with their patients than I had anticipated. The nurses' visits were more frequent than those of other health professionals but brief and apparently task-orientated.

I also pondered whether nurses attribute roles to themselves which are not evident to others. It is part of the ward routine to hold a weekly review of patients' progress when all members of the multidisciplinary team are present. By participating as a silent observer on one occasion rather than an active participant, I noted the institutional constraints placed upon the nurses. Although the nurses were invited to speak, some lacked the confidence and experience to share their knowledge of the patients and others based their reports on the knowledge only gleaned that morning. Whilst believing themselves to be advocates for their patients, their input to decision-making was dependent upon their communication skills and the authority they held within the team rather than their detailed understanding of the patient.

Having acknowledged my multiple roles as nurse, educator, family member, colleague and team member, my focus during this study has been that of researcher. I attempted to form my relationship with the participants as a professional enquirer seeking views and information to describe the nursing care of patients and families. During analysis of the written data I constantly reviewed whether I was coding, sorting and interpreting emerging ideas based on the transcripts alone, rather than prior, personal beliefs, knowledge and interpretations. I amended my techniques of interviewing as well as the format of the interview guide as I learnt how to probe and prompt my interviewees so that they explored issues of personal importance without straying away from my topics of interest. I discovered the fine balance of being a nurse researcher whose natural tendency is to identify with the nurses the participants were describing whilst accepting the older patients and family members' views as valuable and valid.

# **3.3.6 Rigour**

Glaser's (1978, cited in Charmaz, 2009) original criteria to evaluate grounded theory were: fit, work, relevance and modifiability but Charmaz (2009, p.139) states that "constructivists aim for an interpretive understanding of the empirical phenomena in a theory that has credibility, originality, resonance and usefulness, relative to its historical moment." In common with Pryor (2005) and Koch (1994) I have used several of the strategies recommended by Guba and Lincoln (1989) to ensure trustworthiness in my research: memoing, audit trails, member checks, journaling, peer debriefing and engaging in reflexive self-awareness. These are described below.

#### 3.3.6.1 Credibility

During analysis of the transcripts from early interviews, I included memos within the text in order to challenge me to consider not only the codes I was introducing but how to elicit a clearer understanding of the interviewee's meanings in future interviews. I then discussed my ideas with my supervisors which gave me fresh insight into how to interpret past interviews and how to reword future questions. One of my supervisors coded four of the twelve interviews independently and we reviewed and discussed our results. The purpose of this peer-coding was to ensure that the concepts coded in the transcript did indeed emerge from the data rather than being imposed on it, and to enrich the process of data analysis. In another exercise, I made notes on interviews by listening to the digital recordings alone and then compared my findings with the coding done on the transcribed interviews. I wished to discover whether nuances of meaning had been lost in committing words to paper and this gave me a different understanding of the "strength" of the statements being made. I checked whether I introduced concepts unrelated to the participants' experiences or beliefs by producing tables of data, their codes and potential concepts and then comparing these to the original transcripts.

My **audit trail** of memos, journal entries and audio conference notes with my supervisors demonstrate my **reflexivity** (Koch & Harrington, 1998), as I scrutinised my decisions, interpretations and manner of dealing with my participants. Throughout interviews I ensured that expressions and ideas were clarified to ensure that I was not putting personal interpretations on them. I discussed my first theoretical model with a visiting nurse researcher from the University of Alberta, Professor Karin Olsen as well as my supervisors thereby ensuring a wider peer review.

### 3.3.6.2 Originality

Throughout the study I was collecting relevant literature but in keeping with grounded theory I was careful not to read any in depth until my codes and concepts had been developed in order to keep my analysis fresh (Charmaz, 2006). I opted to use 'in vivo' codes where possible and was challenged by my supervisors to avoid nursing terminology in developing a model since the study was to reflect a patient and family member perspective. This study was inspired by the work of Pryor (2005) whose research on rehabilitation nursing has been from a nursing viewpoint. By including interviews with family members, this study added a further dimension to the present trend to study the patient perspective and augmented the limited Australasian literature on the topic of patients' views on the role of nurses in rehabilitation (Price, 1997; Sondermeyer & Pryor, 2006).

#### 3.3.6.3 Resonance

I have proposed to share my research findings with all participants at the completion of the study to determine whether they identify with the "narrative" I have developed. To date I have shared my findings with two former patients and they have asserted that they are consistent with their own experiences.

### 3.3.6.4 Usefulness

Since I work within my research setting, any findings can be used to prompt discussion within the multidisciplinary team regarding adjustments to internal processes as well as forming a basis for improvements to in-service nurse education.

## 3.4 Conclusion

I used grounded theory following a constructivist approach as described by Charmaz (2006) to develop a "narrative" or theoretical model to guide improvements in nursing in a rehabilitation inpatient unit. I performed twelve interviews with patients aged over 65 years and their family members. Rigour was provided by a range of methods and ethical issues regarding consent, confidentiality and potential for duress were addressed.

# **Chapter 4: Results**

## 4.1 Introduction

The substantive theory which emerged from these study findings in this ATR ward setting described the need for nurses to adjust *how* they performed their nursing roles to the individual needs of the rehabilitating patient. The older patients and their family members responded most effectively to nurses who "best fit" their concept of a nurse, with this concept differing from patient to patient; family to family. The patient's focus was on their own dependency and their desire to return to or improve upon their pre-admission status. They noted that rehabilitation nurses work within a multidisciplinary team but found it difficult to distinguish the nurses' specific skills from those of other staff.

Table 4 overleaf (pp.47-48) defines the codes and the categories which emerged during analysis. Four main themes or categories evolved from the analysis: *looking after, stepping in, coaching independence and creating best fit relationship.* The connection between these categories and how they link the nurse, older person and their family are expressed as a visual framework in Figure 2 (p.49). The aspect of nursing which was most valued by older patients was the nurse-patient relationship which was created as nurses were involved in "*looking after*" and "*stepping in*" during patient care. The stronger the connection between the two, the more readily the older person responded to the nurse who was "*coaching independence*". The nurse who was "*attuned*" and "*available*" to the older person was more likely to become "*connected*" to their patient who in turn acknowledged their caring by an increased effort to achieve independence.

Family member and patient responses were coded and analysed separately but there was a discernible agreement between the viewpoints of an older person and their family member/s. In the description of the study findings in this chapter, patient and family member perspectives are attributed separately where necessary to illustrate commonalities and distinguish between any disparities.

**Table 4: Codes and categories** 

Category	<b>Description of Category</b>	Codes	Description of Code
Looking after	Performing nursing tasks traditionally associated with nursing which focus on providing	Doing expected nursing tasks	Aspects of nursing care such as monitoring, documentation, assessment etc. as well as technical skills such as medication administration and wound care which are common to ALL nurses.
	for patient needs. Nurse seen as working within a group of health	Giving comfort	Providing physical or emotional comfort e.g. by use of positioning, medications or active listening and touch.
	professionals and being the primary contact for the family.	Working within the team	Variously seen as following the directions of another team member acting as a 'technician' OR following up work of another in team but having own rehabilitation skills though not so specialised. Sometimes seen as multi-skilled
	These roles are common to all nurses but rehabilitation nurses		with knowledge of all of the other team members. Also viewed as having pivotal role to link together the members of the team.
	work more closely with other members of the multidisciplinary team and include the family and patient as part of the team.	Working with the family	Includes nurses providing patient-family communication, caring for whole family, being sensitive to and responding to family needs e.g. information, acknowledging family time, listening to their input.
Stepping in	The nurse who acts as a source of	Assisting with ADL's	Supervising or assisting with showering, toileting, feeding etc.
	support or assistance with basic	Assisting mobility	Mobilising patient directly or supervising including use of aids.
	needs but can determine exactly	Providing safety	Presence or supervision during activities where potential for fall etc.
	when and how best to respond to the changing dependency of the patient throughout their rehabilitation "journey". These roles are used by nurses in other settings but form the FOCUS of rehabilitation nurses.	Providing for patient needs	Giving assistance which can be performed by less trained such as hospital assistants including fetching bedpans to filling in menus or pulling curtains.
Coaching independence	The nurse in common with other team members acts as a teacher	Teaching and coaching	Teaching patient or family member an aspect of care or rehabilitation e.g. use of mobility aid.
	and source of encouragement for the patient to achieve realistic	Providing encouragement	Use of voice or manner to promote patient performing task or supporting their focus on rehabilitation.
	goals and greater independence.	Being a motivator	Includes cajoling and persuading the patient by use of "self", the nurse-patient relationship and words to achieve their greatest potential in rehabilitation.
	These roles are used by nurses in other settings but these skills form the ESSENCE of rehabilitation and are key tools for rehabilitation nurses.	Allowing patient control	When nurse accepts patient's need to make decisions about how and when interventions and therapy are done. Letting patient be "their own master". May involve permitting patient to determine their activities rather than comply with nurse's own ideas or ward routine.

Category	<b>Description of Category</b>	Code	Description of code
Coping with Time Constraints	In spite of busy workload, nurse is willing to spend time with an	Being busy	Nurses noted as being constantly active as observed to be rushing to complete unknown tasks.
	individual and focus attention on that person so that they feel	Being absent	Whereabouts of nurse may or may not be known. Sometimes believed that they are deliberately delaying or absenting themselves.
	valued. This use of time is described as being "available".	Being with other patients	Known or assumed that caring for other patients.
Having Nursing Knowledge	Expectation and observation that nurse has professional skills and understanding based on training and experience. When this knowledge is used to respond effectively to an individual's needs, then the nurse is felt to be "attuned" to that patient.	Having expertise	When nurses described as being professionally qualified and trained with practical skills or experience so that they are experts in their particular field. Skills may not necessarily be in rehabilitation.
		Being intuitive	Demonstrates a willingness to try new ways, be adaptable and not constrained by routines.
Creating Best Fit Relationship	Nurse using innate and learnt attributes to communicate with a patient so that their way of being as well as what they are doing are evident. Nurse also uses her/his nursing knowledge and time to develop a relationship where the patient feels they are cared for in a unique and real manner so they respond more readily to the nurse's directions and prompting.	Nurses' "nature"	Descriptions of attributes of personality or traits which are valued in nurses e.g. kind, friendly. A 'people person.' Such nurses regarded as dedicated to their work seeing nursing as a vocation.
		Being caring	This is not the same as providing nursing care. It is about the quality of the relationship with the patient and the attitude of the nurse doing the caring. May be quite different things to different people but the reason for caring seen as being the most important aspect.
		Being "best fit" nurse	Complying with image of nurse which results from past experiences of hospitalisation, current experience of rehabilitation, past/present nurses and may be based on contextual detail within the interview.
		Being "connected"	Some patients identify with particular nurses and vice versa so a positive relationship is established which is mutually beneficial and motivating for the patient in rehabilitation. Also acknowledges that nurses are in a special position to gain insight into patients as often with them when most vulnerable.

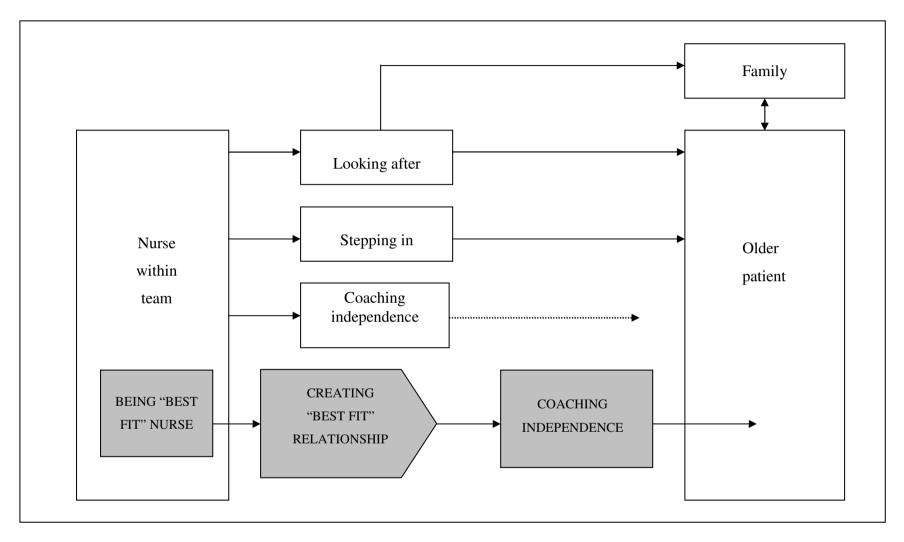


Figure 2
Framework to describe the role of nurses in the rehabilitation of patients aged over 65 years

# 4.2 Description of participants

Two older patients and their spouses initially accepted the invitation to participate in the study but subsequently withdrew after they learnt that the patients were being discharged to residential care. Seven older patients, four male and three female, were consequently included in the study. Family members of three of these patients were unwilling or unable to participate. One family chose to have three members interviewed together, meaning a total of six family members were interviewed for this study. Table 5 (p.51) summarises the details of the participants included in the twelve interviews which were conducted between July 2009 and January 2010. One patient was interviewed on two occasions due to time constraints and a mechanical failure of the recorder during the initial interview. The patients were aged between 72 and 89 and all except one scored the highest score of ten out of ten on the Mental Status Questionnaire (MSQ), which was used to assess cognition. To ensure participant confidentiality, description of individuals' personal characteristics has been kept to a minimum and pseudonyms are used to refer to the participants throughout this thesis.

**Table 5: Description of participants** 

Pseudonym	P = Patient F = Family member	Reason for admission (P) Relationship (F)	Family situation pre-admission	Living alone Y/N	Age Group	MSQ	Basis for sampling
John	P	Fractured pubic ramus. History of Parkinson's disease.	Living at home with wife. Family members live locally.	N	75-79	10	Male <80 Typical ATR patient
Mary	F	Wife of John.					
Madge	P	Fractured right neck of femur. Newly bereaved.	Living in rest home apartment with minimal supports. Recently bereaved and was main caregiver. Family members live locally.	Y	85-89	10	Female >80 Fractured NOF
Kate	F	Daughter of Madge.					
Lucy	P	Fractured neck of femur. History of cardiac failure.	Living at home independently as main caregiver to husband. Family members live locally.	N	80-84	10	Family concerns
Adele	F	Daughter-in-law of Lucy.					
Harry	P	CVA. History of previous stroke.	Living at home pre-admission with wife. Other family members living locally.	N	80-84	10	CVA Male > 80
Margaret Sue Amy	F	Daughter of Harry. Daughter of Harry. Wife of Harry – attended ward daily at family request.					
Bruce	P	Fractured neck of femur. History of cardiac failure.	Living independently in own home with wife.	N	75-79	10	Male <80 Multiple hospitalisations
Ida	P	CVA.	Living independently in own home. Newly retired from paid employment. No family in local area.	Y	70-74	7	Female <80 CVA**, reduced cognition. Lack of family
Sam	P	CVA with multiple pre-existing co-morbidities.	Living with wife independently in own home.	N	70-74	10	CVA** Male <80 Chronic illnesses

<sup>\*\*</sup> selected by theoretical sampling

# 4.3 Looking after

After initial introductions, all interviewees were asked an initial very broad, openended question about what they thought was the nurses' role at the ATR ward. In most cases, the participants struggled with a response with some intimating that the answer was selfevident. John, for example replied that a nurse "just looked after the patients." There was also a belief expressed that the nursing role would be the same as that in the acute wards. Other replies suggested that the nurses were involved in "rehabilitating" though it was unclear initially what they thought this involved. When probed, one respondent Harry said it related to helping with mobility and routine activities of daily living.

## 4.3.1 Doing expected nursing tasks

In spite of my expectations that participants would readily name a number of nursing tasks when asked about the role of nursing, throughout all interviews they only briefly referred to what nurses *did* before they went on to explain another aspect of nursing or nurses. Recording blood pressure and giving medications were noted as nursing roles by some family members as well as patients. One patient did not mention that she was having regular dressings done for her leg ulcers by the nurses, although her daughter did. Patients focussed on the fact that nurses asked about their bowel habits and ensured that they had an adequate and appropriate diet. A few noted that nurses would "check" on patients to ensure that their needs were met but overall their responses indicated that specific nursing work was almost "invisible".

## 4.3.2 Working within the team

Patients and family members observed that the nurses worked within a team framework and that the team had a good rapport. Lucy said "You didn't have one person, you had a whole group who were working together to try and get you back on your feet and home..." Most participants found it difficult to distinguish between the separate roles of the different team members but noted that their skills overlapped and believed that nurses implemented therapy instigated by health professionals with more specialised training. Harry's family proposed that the nurses had a unique position in the team as they saw them as the "glue" holding the team together and the "hub" of the team. They explained that the nurse was the link for the family and within the team as well as being responsible for bringing in other expertise as needed.

## 4.3.3 Giving comfort

Giving comfort was an expected integral role of nurses. It was viewed as part of caring and included physical and emotional comfort. Comfort was given to respond to something acknowledged within the patient as well as to address a request for help. Sam experienced regular pain and needed good positioning during his initial dependent period. He explained how the nurses responded:

It doesn't matter who it is you ask them for something—late at night—you're desperate perhaps for something to kill pain and there's no question about it. 'OK, where's the shoulder hurting?' and that's it and [anti-inflammatory cream is applied] smartly. Even one night, I was having spasms with my right leg. I'd kicked the bedding off me completely and [had] not a hope of getting it up but the nurse just calmly pulled the blanket back—tucked it in again. In short order I was made comfortable. That was when I wasn't able to turn myself very well.

Lucy was separated from her husband and worried about his health as much as her own progress. She valued especially the nurses who appreciated her need for emotional support and described a significant incident during her stay:

I was just that sad and this nurse came and said 'What's the matter?' and I said 'I'm on a bit of a low at the moment. Thinking about home and thinking about my husband and I feel I'm not pulling my weight.' And she put her arm round my shoulder and 'It'll be alright. There's another day tomorrow'.

# 4.3.4 Working with the family

Finally, a strong element within the interviews was the need for nurses to listen to, support and accept the involvement of family members in the rehabilitation and overall care of the older person. Sam felt that when the nurses initiated conversations with his wife it enabled her to feel less of an "outsider" which was important to him as she was "part of" him. Facilitating communication with those unable to visit was deemed crucial for both the patient and the family member. This role was appreciated both for the provision of information and the wellbeing of those who were separated. The nurses who were most effective in this role were those who did not make the enquiring family member feel as if they were "intruding or interrupting their day". Family members believed that they too had a part to play in the best care of their loved one and that the nurse who allowed them to share their deeper knowledge of the individual's traits and background, was respected and appreciated. Margaret said:

I don't think I have been made to feel, you know, that I'm sticking my nose in or anything. It's ...just all information and communication I think and...having the nurses being open to communication from the family as well as the patient is really important too.

Adele likened a family member's knowledge to that of a mother taking her child to the doctor and thought that "even if it's not helpful—or what you want to hear, it's still knowledge about that person...it will be helpful..." She believed that the nurses who were receptive to listening to family member input were those who ultimately became more "attuned" to their needs.

This category of "looking after" includes roles which are at the core of nursing. It highlights aspects of nurses' work which constitute the traditional image of a nurse who "looks after" patients by responding to physical needs, providing comfort, linking with others within the health professional team and addressing the needs of the patient's family. The nurse was viewed as the person who was at the end of a call bell to respond to all requests for help. The only specialised skills ascribed to nurses were the administration of medication, blood pressure monitoring and wound care.

# 4.4 Stepping in

When attempting to get patients to describe nurses' roles, patients more often spoke of their personal progress. "Stepping in" summarises how they perceived their personal journey from dependency and their changing need for the nurses' support. They acknowledged that the nurses "stepped in" to provide assistance or supervision with mobility and self-care. From the patient viewpoint this category concerns how individuals came to terms with their inability to cope for themselves. Patients expressed their dependency in different forms. Family members described roles which nurses could undertake but relied on patient accounts or past personal experiences rather than current observations. Dependency was variable depending upon the time of day, the individual's current wellbeing and their overall motivation. Nurses were expected to understand when support was required and when to allow an individual to persevere.

## 4.4.1 Assisting with activities of daily living (ADLs)

John and his wife appeared to expect that the nurses would need to do everything for him and that this was their major role even in a rehabilitation setting. He said "The nurses shower me, dress me, make sure I'm comfortable…" whilst his wife, describing his time throughout his stay, stated "…he had to be helped all the time." When probed, she admitted that at the time of the interview, he was independent with his ADLs in readiness for discharge

without acknowledging that change had been expected, encouraged or achieved. They had both accepted his dependency whilst in hospital and his wife was critical of nurses who did not cooperate with his requests and saw them as unhelpful and unconcerned with his needs. Her expectation was that they should always support him without questioning, whether that help was beneficial to his recovery or not. There did not appear to be an appreciation that nurses who offered such support would in fact be increasing his dependency thereby reducing the effectiveness of his rehabilitation therapy.

Two of the most dependent patients were recovering from severe strokes. Harry, according to his family, had expected to die and was close to giving up the challenge of being rehabilitated. He accepted that he was dependent but it was a source of embarrassment to him. He needed help with showering, toileting and feeding but realised that the nurses offered suggestions to enable him to become more independent. He explained "I couldn't lift a fork properly with food on it and I spilt some down the front and one nurse said 'pick it up with your hands, with your fingers'." He disliked going to the dining room as he felt that others were watching him, initially whilst being fed by the nurses and later on when he struggled by himself. His daughters encouraged him to persevere explaining that this was part of the rehabilitation programme but Sue, the youngest daughter, acknowledged that he was given the option by the nurses to make his own decisions when he was fatigued:

So he is still in control...but he knows that <u>they</u> know whether or not it's best that he goes down to the dining room to have his dinner or if it's OK for him to stay in his room and have his dinner.

Harry hated being so dependent initially, so the nurses and his family redirected this energy into a determination to succeed by encouraging his independence in ways he could manage. Ida, a much younger patient, acknowledged her dependency: "I thought I was going to be able to look after myself. Now obviously I'm not going to be able to." She explained how the nurses taught her to dress herself after her stroke and how to position her food in her mouth so she could eat safely. At other times, perhaps as a coping mechanism, she denied her dependence and implicated the nurses in her belief: "they seem to think—with all the care—here that I'll be able to look after myself again like I've been doing up 'til now."

Others were more fortunate as they made good progress and were close to being discharged home when they were interviewed. Lucy explained her changing dependency with her showering and dressing, acknowledging that at times she allowed the nurses to help when she could do something herself. She recalled that the nurses: "...put on my shoes and socks. Actually one put them on this morning. I still can't get the socks on. Get the shoes on but I

couldn't get the socks on." Most of the time she felt she "did what I could" and the nurses would help with tasks which were too difficult or required supervision for her safety. Her daughter-in-law, Adele, noted that nurses would assist with Lucy's toileting but "that was before she could do that herself or before she was allowed to do it herself."

Other patients seemed unable to refer to their own dependency so described that of fellow patients. Bruce described the care which the nurses needed to provide for stroke patients but enforced the notion that when these patients progressed, the nurses adjusted the amount of support they gave. He admired nurses for performing tasks which he felt he would be unwilling to undertake himself. He noted that nurses had to attend to all aspects of care when patients were totally dependent including dealing with incontinent patients. His personal experience of seeing his mother in a rest home with dementia made this an important though emotional point for him. He felt nurses in caring for such dependent patients needed "to be prepared to get in boots and all and get dirty and mucky if you know what I mean."

### 4.4.2 Assisting mobility

Supporting a patient's ADL's was regarded as a nursing role by all participants, both patients and family members, but there was more uncertainty when discussing the teaching and practice of mobility skills. Some participants acknowledged that mobility was the area of expertise of the physiotherapists and saw the nurses as following up their instructions. Kate, Madge's daughter, attempted to clarify her own ideas during the interview. Initially she stated that the nurses would be responsible for getting her mother in and out of bed and then reflected that more team members were involved:

And just showing her which—virtually which toe to move next or hand to move next... They were making things as easy as possible. They – the royal they. Physios, occupational therapist, nurses.

Madge herself was unable to distinguish between different team members and got angry with a nurse who wanted her to transfer out of bed overnight. Madge responded "I was rather aghast...and I said 'But I'm not supposed to...I can't do that yet'."

In spite of this confusion, there was a prevalent impression from all other participants that nurses were responsible for "helping" with the mobility of patients and ensuring their safety. Only one patient described his own efforts at walking or transferring but the remainder inferred that this was a major area of dependency. Mobility and rehabilitation appeared to be synonymous for some patients as they described this as an essential aspect of becoming independent. Harry put it most succinctly: "one of the nurses said to me 'What is

your <u>aim</u> this week?' and I said 'I want to walk' and ...that's rehabilitating me." Though walking with the nurses was seen as extra exercise, it was valued and viewed as a means of making more rapid progress. There was no evidence that nurses were viewed as having made conscious decisions to promote or teach independent mobility. This was considered to be the jurisdiction of the physiotherapist. Some participants acknowledged that nurses may not always have the time to practise mobility exercises whilst one family member, Mary, felt that this should be their main role. Sam was very affirming of the nurses' efforts to promote his independence:

This was [during the] first few weeks when I started on a walker and they would walk me round the ward. Didn't matter how long it took. That ...time was <u>valuable</u> for me and I appreciated that.

## **4.4.3** Providing safety and providing for patient needs

Whether the nurse was there to assist with ADL's or mobility, there was awareness that part of the nursing role was to ensure that the older patient's safety was maintained. Lucy explained that the consultant had told her that she must have a nurse present during showering as she was at increased risk of a fracture if she fell due to her osteoporosis.

Then she described how nurses ensured safety when she and others were remobilising:

They show you how to use [the walking frame]...your knees [should] touch the toilet before you take the grips on the sides...to sit down. They make sure of that. Now a person left to their own devices...when you first start to try and get around you wouldn't think about any of those things without the nurse telling you what to do. So they must save an awful lot of falls.

Some participants included simple tasks as being those fulfilled by nurses though they realised that these were actions which could be performed by less skilled nursing assistants, members of the household or even family members. Such everyday jobs included filling in menus or fetching items but for Harry it was pulling the curtains:

I'm trapped in the bed and I would dearly love to pull the curtains but I can't. There's something on the other side of the room that I want to reach out and get, and I just can't reach it.

# 4.5 Coaching independence

Goal-setting is an important element in rehabilitation from the health professionals' perspective and part of the routine procedure at the ATR unit, though this did not appear as an important feature in participants' interviews. Phrases which did occur quite regularly were "being encouraged", "having confidence" and "motivation".

## 4.5.1 Teaching and coaching

All those interviewed noted that an important role of nurses was to teach them how to transfer, walk, dress, eat and attempt to do routine activities for themselves. Madge, describing her fellow patients, said "eventually they do learn to do everything for themselves but initially they've got to be shown." She felt that nurses knew when to teach individuals as "they somehow achieve the knowledge of knowing that the patient is ready to get on and do things for themselves." Some patients felt that they gained confidence especially when tackling new challenges if they had instructions from the nurse who taught them clearly and in the safest manner. Sam's experience of being asked, not told, made him feel obliged to say "Well yes, I'll give it a go." Sometimes confidence in the nurse was required before the patient was open to teaching.

Lucy described her efforts with a low walking frame:

Making sure that I had enough confidence to be doing what I was doing or supposed to be doing. They always bring the walker and they show you how to use it. Back up to your chair...the chair touches behind your knees and then you take both arms of the chair and sit down.

Teaching and coaching took different forms. In the example above, Lucy was "shown" but often nurses would describe what to try and some patients would then experiment. Sam worked out another way of repositioning himself in his wheelchair after the nurses had prompted him to improve his position. Then a nurse worked together with him to experiment with better ways of transferring. He tried a new technique.

She's got me onto the chair and the wheelchair and it hasn't, when I've been tired, always been a soft landing and she'll say 'Get that hand back' rather sternly you know. 'Get it back to feel for the arm of the chair'. I found that I lifted my right arm first off the high walker and slung [it] down at my side and she said to me 'Well, try putting it round and feeling for the rail of the chair' which I thought was very good. Sometimes it goes back but I can't get generally get the right arm back that far...

One stroke patient, Harry, realised that a nurse would keep repeating instructions to reinforce a technique so "she was sort of drumming it into me." Both patients and family members trusted the nurses to have the knowledge to do this kind of teaching though the extent of the nurses' knowledge was presumed to be less than the physiotherapist. Harry's family explained that they learnt from the nurses about how much assistance to offer. His daughter Margaret, by watching the nurses, realised the balancing act of when to assist and when to allow the patient to keep practising. She explained what she had learnt:

...actually being disciplined too—not to jump in and do it—to be able to let the patient learn even if they are getting frustrated [and] to know when—he's had a good try and he's got one slipper on and he can only get the other one half way on so go in and help him with the last one—knowing [that you gave him] time to let him do [it].

Bruce noted that nurses would have a different teaching role to the physiotherapists in their therapy sessions but that encouragement was another key role.

The nurses [are] not responsible for <u>that</u> side of the physio work but up to a certain point they <u>are</u> still doing a bit of physio work with the patients and giving the encouragement—to go on and do what the physio did with you. It might have hurt but just go a little bit further. 'Don't drag your foot, lift your foot'.

## **4.5.2 Providing encouragement**

Encouragement took different forms. Instead of talking of "the carrot or the stick", Adele described patients being "shoved or led" by nurses. Her mother-in-law, Lucy, was learning to walk with a walking frame after fracturing her hip. Shoving was not perceived as an act of bullying but rather a means of gentle but firm cajoling. Adele suggested that both shoving and leading were involved:

To achieve a goal you need to have somebody to be giving you a gentle shove and encouraging you 'Yes you can do it' and I—imagine it would be easy to give up for a lot of people because it would seem—hopeless. It would be easy just to lay there and feel sorry for yourself. So you need somebody to be able to come along and—really encourage and push at the same time with just a gentle shove. Possibly so you don't even feel that you're being shoved or pushed but just leading—leading.

Lucy explained her personal experience of the nurses "...demanding that you do so-and-so but the way they do it, you wouldn't fight back forever because they do it in such a way that you don't even know that it's happening!" She described this ability as a "gift" and a skill

which some nurses possessed more than others. She was thrilled when she was able to be independently mobile with her frame and surprised at how nurses and others congratulated her on her achievement.

Some patients appreciated the use of humour to encourage them with their progress. Sam enjoyed working with a particular nurse who "jollied" him along and shared his sense of wit. Others like Bruce noted how nurses would comment upon progress as a means of encouragement using phrases like "'Oh, you're getting on well' or 'You're moving and going well' or 'I see an improvement in you. You're better than you were yesterday'."

One family member, Adele, noted that nurses encouraged the older patients to attempt what they might not have believed they were capable of whilst still ensuring their safety needs:

...it doesn't matter even if you are a strong person yourself, you're still needy because you're dependent on them to be there and to sort of do the things that you can't do for yourself or to help you do those things. Encourage you to do those things for yourself which...in years gone by, you just laid in bed, didn't you but now you're encouraged to get up and do things that you possibly might not even think you're ready to do yet but you're encouraged to do it and the nurses—that's one of their big roles isn't it, is to encourage...as well as help you perform those things that you need to do...because it's getting you ready to look after yourself.

## 4.5.3 Being a motivator

Encouragement was linked with reminding patients of their purpose in rehabilitation. Nurses were seen as motivators to extend current capabilities. Bruce observed that nurses fulfilled two dimensions: to motivate those who wanted to give up and to challenge those who were self-motivated. He described this form of encouragement as "insistence" and felt it was an essential part of rehabilitation. Watching nurses working with fellow patients he said that "you could see how they didn't want to do some of the things…but the nurses insisting…that they try and do a bit more than before." He watched the techniques of nurses when getting another patient out of bed recalling the attitude of "you know 'I can't do it. I can't do it' sort of style and then [the nurse] gradually encouraging 'Yes you can' and getting to the stage where 'Yes I can do it'."

Bruce added that the most important means that nurses had to motivate was the ability to make their patients believe in their future. In order to do this he believed that each nurse needed to:

...have a desire to see people improve—which would be quite essential actually. They need to...want to help the people improve. They certainly wouldn't want to be the one who accepted the person as they are and say

'You are. You're that.' They'd have to say 'No, you're better than that.' Yeh, that certainly would be an essential thing.

Family members noted that nurses were motivators in the rehabilitation process and acknowledged that this would not always be easy. Madge's daughter, Kate, knew that her mother had declined to cooperate at times and Harry's family noted that encouragement was more effective when linked with explanations. For example, when he was not keen to walk to the dining room, he was urged to do so by being told "you really should because it's the exercise that's going to help you to get better quicker."

More importantly this family and Adele, Lucy's daughter-in-law, commented that it was the relationship which the individual nurse had with the patient which contributed most effectively to the desire to work harder at becoming independent. Harry's daughter Sue described how he responded differently to a particular nurse who worked to develop a relationship with him:

...she's chatty, she's bright, she's energetic and would take the time to talk to Dad and found out about him and you know, his life and bits and pieces and so he would open up and share stuff with her - about how he felt. But he would want to—he would want to appear—he would try harder to appear better and just by trying harder he would. Things would be better.

Adele expressed the relationship as a "connection" and observed of Lucy that "the ones that she connected with—she took more notice of them and I think she probably tried <u>harder</u> because she had that connection with them."

### 4.5.4 Allowing patient control

Patients preferred nurses who were flexible, were willing to change routines and allowed them to take control of their own rehabilitation. Sam liked the independence of being in a wheelchair, deciding where he went and being his own master. He said:

It's a necessary thing because unless you're going to <u>be</u> your own master when you're rehabilitating, you're depriving yourself of that help you're getting from the nurses and the physios. Whereas you should be accepting it and <u>stretching</u> yourself to—to get so much further ahead.

Others felt that nurses who gave the patient the opportunity to have control but knew when to intervene were better at rehabilitation. Allowing control included permitting the patient to choose their way of doing something even though this might not be the usual technique. Bruce felt that nurses better practised in rehabilitation skills were "more prepared

to try and think in terms of what the [patient] <u>wants</u> or <u>needs</u> rather than what <u>they</u> think the person needs."

Throughout the interviews, patients and family members stressed that nurses were able to motivate and teach effectively if they had entered into an acceptable relationship with the older person. This relationship reflected the expectations, personality and needs of the patient and the "nature", knowledge and time given by the nurse.

# 4.6 Creating best fit relationship

All participants focussed on the "nature" of the nurses whom they met. In fact, even when interviewees were expressly redirected during the interviews to discuss the roles of the nurse on the rehabilitation ward, they consistently focused on how the nurse related to and treated the older person rather than describe what they did. Both patients and family members explained that the personality and attitude or "nature" of the nurses they met was a key component to how well they felt that nursing care had been given. Some spoke of "good" nurses being "dedicated" to their work so that their main desire was to help their patients. Others required nurses to be "caring" but struggled to explicate exactly what this meant. Several noted that they wished the nurse to be compassionate and to treat the patient with respect. It was acknowledged that not everyone would be suited to work as a nurse. Adele, a family member who had witnessed nurses caring for her step-father as well as her mother-in-law summarised the ideal rehabilitation nurse she would employ thus:

I'd be looking for kindness and a gentle but firm personality and somebody that could put their foot down if they needed to because I imagine in the rehabilitation ward that it has to happen but it would have to happen in a special way. ...I would be looking for somebody with the nursing experience and background but somebody that could empathise with people from all sorts of different backgrounds. Not judgemental and just a kind person.

Although there was a need for patients to be treated as individuals, certain aspects of the ideal nursing personality were more frequently described such as: kindness, friendliness, cheerfulness and the ability to share a sense of humour. Interviewees rarely criticised the nurses but the few instances of criticism included observations of nurses who did not appear to enjoy their work and who lacked compassion.

Bruce felt that if a nurse had a "vibrant" personality then that contributed to making patients progress in their rehabilitation. When asked to explain the meaning of "vibrant" he replied:

Quick to see the humorous side of something. Alive. I can think of someone that did a dance in the dining room one night. Somebody who is obviously enjoying life ...which [is] quite a main thing about your rehab nurse. She must show enjoyment in what she's doing.

It was difficult to determine when participants were describing nurses generally and when they were only referring to those working in rehabilitation. Sam however was quite specific that he was describing the nurses working at the ATR unit as he concluded "It's got to be a special person who's in this ward. Just not anybody is cut out for it."

## 4.6.1 Coping with time constraints: Being "available"

Although nurses may have many of the attributes believed important in the participants' perspective of a "good" nurse, this did not ensure that they were viewed as an individual patient's "best fit" nurse (see Figure 3, p.71). The nurse-patient relationships which were most valued involved those where the nurse was able and willing to spend time in a busy schedule to "be available" to the patient and sometimes to their family members too. "Being available" was not simply about the nurse spending longer being with the person but involved providing opportunities to "connect" and interact.

All those interviewed stated that nurses were constantly "busy" though participants were not always aware of what they might be doing. When probed to suggest what roles nurses would be performing when they were "busy", most frequently it was suggested that they were "with other patients". Family members proffered more explanations of what the nurses might be doing when they were "absent" from working with a specific patient. They described nurses completing documentation, answering patient call bells, running errands, answering the telephone or responding to family enquiries.

Time was viewed as a precious commodity. Mary, John's wife, had imagined that nurses at the ATR unit would spend far more time with him than they did as that was part of her expectation of rehabilitation nursing. However she also believed (incorrectly) that nurses had a maximum of three patients per shift and conceded that it may be physically impossible to be "more available...to the patients...if the nurses are loaded with work or have too many patients to look after..." At the other extreme, Sam, a patient who had been at the unit for over seven weeks, worried that the nurses were working too hard within the time constraints of their fixed shift hours. He observed that "it doesn't matter whether time's running out of their shift, they are there. They give, give, give, give."

Family members appreciated the willingness of nurses to be "available" to provide reports of progress or to act as messengers for relatives confined at home. Adele remarked how they coped in spite of being so busy:

They're running. They run! I remember hearing them running, you know. So they can't get a lot of time to spend with each individual patient. I don't know how your rosters work but they do, they run. ...all the nurses seem to walk incredibly quickly or they would almost be running but they—would always stop and talk and answer your questions.

### 4.6.2 Being "connected"

Some participants named or intimated that they had specific nurses in mind when they were describing the relationships they formed with nursing staff during their hospitalisation. Family members were more explicit when they described these favoured individuals who were caring for their loved ones. Adele explained that her mother-in-law had favourites whom she looked forward to seeing each day:

There [were] a couple that she would say "Oh, so and so came in today", was lovely and did this with me and other nurses would come in and probably do exactly the same thing but she hadn't connected so well with them. I think there's a connection...

The family of Harry felt that they benefitted too if their father had formed a 'connection' with some of the nurses, as they trusted these individuals more to care for him especially when they were absent themselves. His wife, Amy, had been allowed to spend long periods of time during the day with him to provide a reassuring presence as he was very homesick and also to learn about his therapies from the ATR team. The family trusted the nurses who had developed a rapport with Harry regarding them as surrogate family members and believed Amy slept better at night as she had seen the quality of care these 'connected' nurses had given.

### 4.6.3 Having nursing knowledge: Being "attuned"

Although a nurse's "nature" helped forge a rapport with a patient, those nurses who demonstrated knowledge and intuition had the potential to be more "attuned" to the patients needs. Whilst nursing experience and training were acknowledged as necessary to fulfil nursing roles, the knowledge valued by patients was the ability to understand from the patient perspective. This necessitated the nurses listening to the patients and appreciating their unique experience in order to understand how best to work with them. Lucy felt that nurses who were good at observation were able to pre-empt her needs whilst Bruce appreciated those who were willing to use their initiative to come up with solutions to an individual's problems.

### 4.6.4 Being "caring"

Underpinning the interviewees' evaluation of nurses to find a "best fit" nurse, there was a requirement that nurses demonstrate their roles in a caring manner. Caring had varied meanings for different participants depending upon the circumstances of the older person's need for rehabilitation and images of nursing based on past experience. Mary believed that the role of the rehabilitation nurse was to provide time and comfort for her husband John, so that he could walk again after fracturing his pelvis. Her concept of *caring* was that the nurses should demonstrate empathy and sympathy by helping him with these needs. John himself described all the nurses as 'angels of mercy' as they had provided him with physical comfort. He appreciated their "help" when they were able to give it but had not expected them to participate in activities which he saw as physiotherapy.

Madge had looked after her husband at home after a severe stroke and her daughter, Kate believed that her loving attention had made her father more dependent. Madge admired nurses who fulfilled their roles in a similar way to how she had "nursed" her husband. Her daughter's definition of *caring* reflected both these views:

Caring would be making sure that she's comfortable and all her needs are looked after, however, also encouraging independence. I don't mean being at my mother's beck and call. Well probably I do mean that—also if its something that the nurse thinks Mum can actually do for herself, in a courteous and caring way encouraging her to do it for herself. ... sometimes you have to be cruel to be kind—cruel in a <u>caring</u> way.

Another family member, Adele, first mentioned *caring* when describing the characteristics of a rehabilitation nurse and in order to explicate this concept she described the scenario of a nurse she had witnessed sitting and talking with a distressed patient. She linked *caring* to a mothering role and when challenged to explore the term further, she explained that she expected *caring* to be part of the *nature* of the nurse as well as describing their *actions*. She concluded that "to be and to do is caring" and that it was a role which she observed caring nurses extended to family members.

Harry stated that *caring* was only evidenced when a relationship had been formed. He did not find it easy to "get to know" the ward staff and the only nurse he perceived as being *caring* to him had spent time discovering more about his life and current situation. His daughter, Margaret felt that part of *caring* was to communicate effectively and that the nurse should:

...have the conversation and ask the questions and not just assume this is what this person wants to do. ...one of my expectations of the staff is that

they would, you know, <u>communicate</u> with the people and you know find out exactly what it is rather than think, you know—be lumped all into the one lot and oh well, this is what, you know, people of this age do sort of thing or—you know that like Dad's got a very good sense of humour and he hasn't lost any of that or his memory…he hasn't lost any marbles but…it takes a wee while sometimes for him…and I think having that patience to have a two way communication is really important too.

Caring, as described by the participants in this study, had two elements. Nurses demonstrated the first element of caring by their actions and this facet of caring was viewed as *doing*. This was illustrated by giving time to a person, learning about them and forming relationships involving trust and reciprocity. Sometimes it was simply providing a presence which was felt as comfort or support. The second powerful element of caring was shown by those nurses with an innate, kind, friendly personality. These nurses recognised the older patients as individuals and sought to see the world through their eyes. This aspect of caring was not simply an acquired empathy but was viewed as the very core of their *being*.

Whilst not always overtly stated, participants described an important role of nurses as being "a best fit nurse". Such a nurse fulfils her/his interactions with the patients and their family by presenting with a personality, attitudes and values which are perceived as "being caring" for those individuals. Secondly, nurses who can develop a "best fit relationship" with the patient were valued for demonstrating their skills by "being and doing" through nursing interventions and commitment of time. It was a role which is not specifically cited by patients and their families but could be recognised from their illustrations of "good" nurses and how they had facilitated more effective progress in rehabilitation. For example, Bruce's background meant that he was used to managing problems for others as well as himself. He appreciated intelligent conversation and wished to make decisions about his own rehabilitation. The nurses who fulfilled his "best fit" requirements were those who were willing to adjust techniques to allow him to have more say in how he completed therapy. Describing a fellow patient with a chronic condition he explained:

They know their body and they know what they can do. Now this is something which I do think <u>all</u> the nurses need to be aware of—most of them are but there were some that were not and they were convinced it must be done this way but the person...had been in trouble for many, many years and he knew just what he could do and how to do it and it was not quite what...one of the nurses thought anyway. I thought: 'You need to realise a bit more about that person, to help him better than you are doing and that's one thing I would say the majority were pretty good on it but there is the odd one that probably needs to learn that lesson...to work <u>with</u> them and not unintentionally against them.

Bruce felt he made better progress when nurses fitted in with his schedule and allowed him greater independence to perform tasks in his way and at his pace.

Thirdly it was understood that nurses would have varying expertise both in nursing skills and life experiences, so nursing knowledge including intuitive thinking was noted as being part of the requirement for an "ideal" rehabilitation nurse. Using and tailoring this knowledge for the benefit of the individual was another key nursing role described during the interviews. Some older patients noted when nurses modified equipment or procedures to allow them to be more independent. Other interviewees explained how some nurses sensed an older patient's discomfort or specific needs without being told. They became "attuned" to the patient and this was helped if the nurse was allocated to work consistently with the older patient. These favoured nurses were then able to teach development of skills towards their independence. Harry's daughter, Sue explained her observations of such nurses:

...they were working on short term goals all the time and they were extending Dad just a little bit further and that's where the continuity of nurses came in. So if he got to know a nurse and that was her shift coming on again, she would be able to extend out and that was happening with the good nurses that he had set up a rapport with...whether it was a discussed thing or it's just that nurses were helping patients to attain the next goal, I don't know but, you know, the continuity of nurses helped that because they would actually know.

She concluded that his motivation to cooperate in therapy was reliant on nurses fulfilling these roles: "just from their caring and their personality and their nursing and the way that they dealt with Dad, when he built up that rapport..."

In later interviews, the question was posed whether nurses needed to fulfil any special role when rehabilitating *older* patients. Bruce summed up:

Yes and I think it would be, not having the attitude 'well you've had your life' or 'you're near the end of your days'. The attitude of 'OK there is a tomorrow and it's worth going for'. And I think that that is essential. ... Again going back to the stroke individual. I know they can have some marvellous changes from strokes and that and you might think that this person's not going to but you've got to make them believe they can get further. Make them believe that it's worthwhile trying for tomorrow.

# 4.7 Linking nursing roles within the infrastructure of the ATR ward

The framework (Figure 2, p.49) illustrates how the patients and family members view where the nurses' roles are delivered within the system of the ATR ward. The nurse is seen as an integral part of the multidisciplinary team but fulfils roles which may be delegated from

others in the team, most notably the doctor or the physiotherapist. Most participants were unclear whether nurses were able to initiate therapy but they were seen as capable of 'following on' the instructions of the specialised team member.

"Looking after", "stepping in" and "coaching independence" were activities which nurses undertook throughout the older person's stay at the ward. Nurses were seen as being the team members responsible for developing a relationship with the family ensuring that they were provided with information and support when necessary. Family members believed that nurses should be their link to the team, passing on information which may be useful in understanding the needs of the older person. In these categories, the nurse was seen as fulfilling the needs and expectations of the "other" in the relationship and care was directed primarily to the patient. However, the connection between the patient and the family was two-way as the older person may also have been concerned about the family at home as illustrated by Lucy who shared with a nurse that she was worried about her seriously ill husband. She was keen to rehabilitate quickly to return home to her caregiving role and described that she was found crying one day, and "this nurse came and said 'What's the matter?' and I said 'I'm on a bit of a low at the moment...thinking about home and thinking about my husband and I feel I'm not pulling my weight'..."

Family members contributed directly, as well as via the nurse, to the care of the older person. Both John's wife and Harry's wife spent time on the ward, practising with their spouses skills which they had gained in physiotherapy sessions. Others visited frequently and even Ida who had no family contacts in the area had the benefit of phone calls from a sister in Christchurch or friends who attended during visiting hours. It was the nurses who facilitated her sister's contact as she explained that they "come and get me to take me to the phone."

The most effective form of nursing took place when the older person was cared for by a nurse who fitted their specific needs and idealised nursing image. Bruce wanted to be in control of his own rehabilitation and appreciated nurses who listened to his suggestions and worked in with his personal daily schedule. The only nurse he named was one who displayed a *joie de vivre* and he believed enjoyed her work as a nurse. John's ideal or "best fit" nurse was there to look after him and keep him comfortable. Harry and Ida who had suffered strokes wanted to be treated as individuals with a history of independence. They appreciated nurses who tried to learn about their background and focussed on aspects of care most valuable to them. For Ida, her personal appearance was crucial and nurses who understood her need to have make-up applied as well as helping her with her shower were valued.

Having found a "best fit" nurse, the older person was more willing to develop a stronger relationship with them if they subsequently demonstrated "being available", "being

caring" and "being attuned". In addition their personal qualities or "nature" confirmed whether they were capable of "being connected". The resultant "best fit relationship" not only provided a means of coping with the challenges of rehabilitation and hospitalisation but also acted as a catalyst for them to achieve greater independence. This part of the framework is illustrated in greater detail in Figure 3 (p.71).

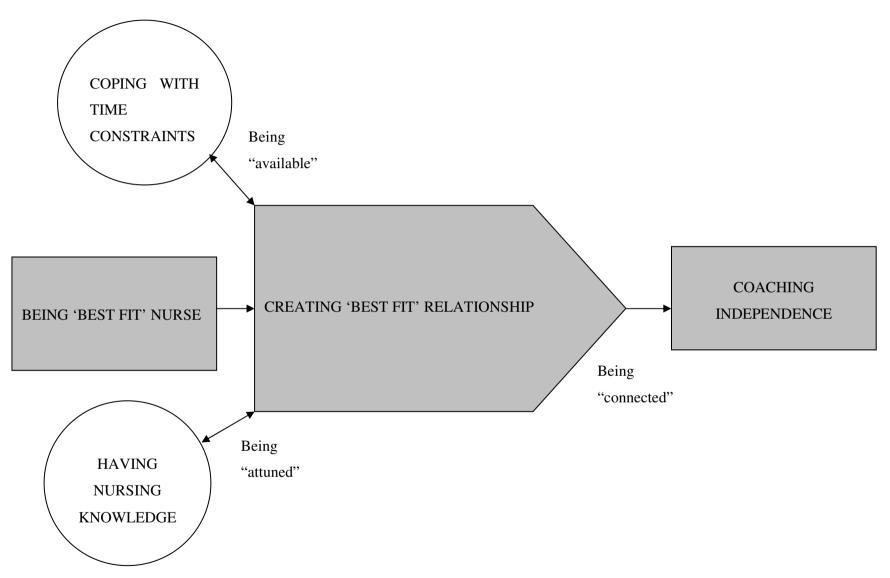


Figure 3: Creating a "Best Fit" Relationship

# 4.8 Summary

Nurses were seen as working within a team of health professionals who all had their part to play in the care of the patients at the ATR ward. All participants had difficulty describing the role of rehabilitation nurses and accounts were based as much on previous experiences and traditional nursing images as they were on specific interactions or observations. They spoke more about *how* the nursing roles should be completed rather than what nurses did. Whilst participants required nurses involved in their care to be knowledgeable and skilled in rehabilitation, this was not as preeminent a quality as caring and a willingness to share of their time. Most of those interviewed stated that rehabilitation nurses did the same work as all nurses but conceded that much of their time was spent in assisting with mobility which patients initially felt was the jurisdiction of the physiotherapists. Nurses who had a positive outlook on life and their work were valued. A sense of humour, a willingness to seek "the person within" and empathy for the challenges facing the older person were also highlighted. It was suggested that a "connection" was made with specific nurses whose attributes matched those desired by the patient, if time was given to the relationship by the nurse. In addition to being "available", these nurses were noted to be "attuned" either by past knowledge, experience or intuition to the needs of the patient and some patients felt more confident in their care. The outcome of such a nurse-patient relationship was that the older person was more motivated to participate in their therapy and daily activities and hoped to be consistently "looked after" by their "best fit" nurse. Family members were aware that the older person had such favoured nurses and also appreciated nurses who were more accepting of their input. So whilst "looking after", "stepping in" and "coaching independence" were required nursing roles described by participants, the most valued was that of "creating best fit relationships" with the older patient.

# **Chapter 5: Discussion**

#### 5.1 Introduction

This chapter discusses how the findings of the study reflect and extend existing ideas on the role of nurses within rehabilitation. A model is presented and explored which summarises how patients aged over 65 and family members view the contribution of nurses within an inpatient rehabilitation unit.

Insights into the patient and family member perspective of rehabilitation and nursing care will be offered. The nature and importance of the nurse-patient relationship from the patient viewpoint will be examined and the implications of facilitating family members' involvement during the hospitalisation of the older person will be considered. Suggestions will be made for changes in how nursing care is provided and nurse-patient relationships are developed in the light of the experiences shared by patients and family members. Finally the implications for changes in nursing practice and ward management are made and recommendations for the direction of future research are given.

## **5.2** A patient perspective

Since patients and family members are at the receiving end of nursing care, it has become increasingly important to determine their perspective on how nurses fulfil various roles. Whilst other studies from the patient viewpoint have been undertaken in the rehabilitation of spinal cord injury and stroke patients (Long, et al., 2001; Lucke, 1999; Pellatt, 2003; Secrest, 2002), few have focussed specifically on older patients undergoing rehabilitation. Studies of the family member perspective are scarcer and focus more on general geriatric nursing care. The intention of this study was to discover which roles patients and family members saw nurses fulfilling in rehabilitation. My findings demonstrated that the participants were keener to explain the relationships they forged with nurses and other members of the multidisciplinary staff rather than roles per se. Greater emphasis was put on the manner in which care or therapy was delivered and the "being" of the nurse. They described the "doing" of their nursing tasks or roles only as it gave a context to relationships they experienced each day.

Patients were (perhaps understandably) more concerned with their personal journey of ill health or disability than reviewing the function of the health professionals who were working with them. When asked to describe the roles that nurses fulfilled, patients struggled first to identify exactly who nurses were, though some named particular individuals who had

shared special moments of care. Secrest and Thomas (1999) found that patients did not even mention nurses in their study of life-after-stroke experiences. It was suggested that this implied that nurses and their roles are "invisible" in rehabilitation but their conclusion assumed that patients' reality was the same as that of health professionals. The reality described by patients in this study was their loss of self and the effort it took to cope with their newly acquired disability. This is an understandable consequence of such a major disruption in their lives. Ellis-Hill et al. (2008) in their model of life after a stroke compare this experience to broken strands of a woven thread, which served as a metaphor of a disrupted life narrative. A whole strand of threads represents memories and future plans but after a stroke, the predictability of life is suddenly lost and the threads become frayed and broken. They argued that patients and professionals have different agendas whilst working in the rehabilitation setting and urge health professionals to recognise the identity change for patients after they experience disability, suggesting that they include "being" with the patient as just as an important part of the rehabilitation process as "doing for" them.

This emphasis on an understanding of the psychosocial impact of disability and chronic illness is a key finding in the current study. Whilst therapists focussed on improving functional abilities to achieve goals of walking, using a wheelchair or showering independently, patients spoke of being exhausted or in pain. These older patients wanted immediate rewards for their efforts and expected, often unrealistically, to return home to pick up their former lives again. Even though they regularly struggled to agree to or comply with staff expectations of physical therapy, they frequently saw themselves as being independent. To enter into a patient's world of adaptation to, and acceptance of, changes in health status, the health professional needs to hear their story and discover the person behind the illness or disability.

Since this research set out to focus on nursing roles, interviewees were redirected to consider the nurses' involvement in their dependency, goals or pain. Interspersed throughout the transcripts were threads of narrative depicting individual nurses sharing in something meaningful for that moment, which included the tasks commonly described in studies from the nursing perspective (Hill & Johnson, 1999; Nolan, Booth, et al., 1997; Pryor, 2005): assisting with mobility or ADL's, providing comfort both physical and emotional and completing the "doing for" helpful tasks commonly understood to be nursing functions.

At times, patients would explain key occasions when a health professional would assist or support their dependency but it was not always clear whether they were speaking of nurses alone. This may have been a confusion of roles as suggested in Pryor's study (2005, 2007) when she explained that nurses experienced role ambiguity as the boundaries between

team members' roles were not only blurred but often not formally recognised by the allied health staff. An alternative reason was that older patients simply valued another person's help or professional expertise to overcome their current state of dependency, but that the formal role of that person within the team was not important to them. All participants however explained how they valued relationships forged with often specific individuals amongst the ward team. This appreciation extended to even the household staff, though interestingly few recalled the names of these valued staff members.

# **5.3 Forming relationships**

A common thread running through this study's findings was the patients' need to find someone with whom to share the experience of being hospitalised. Whilst not described as the most important finding in research from the nurses' perspective, there was still evidence of its value. Pryor (2009) described how nurses deliberately found out about patients as individuals and compared this to Nelson's (1990) notion of "buffering" where nurses established rapport with patients, supported them psychologically and aimed to "hook" them into the programme. Price (1997) saw the role of coach as existing within a trusting nurse-patient relationship. She saw this relationship within the framework of the team where the nurse fulfilled a coordination role.

#### **Types of nurse-patient relationships**

Morse (1991) described four types of nurse-patient relationship in her grounded study from the nurses' perspective, namely: clinical, therapeutic, connected and over-involved. However, Morse's (1991) study involved the use of nurses as key informants to provide information about the patient perspective, so do not actually reflect the beliefs and experiences of patients themselves. Nevertheless the description of a "connected relationship" as being important in rehabilitation nursing is evident in other research (Fosbinder, 1994; Shattell, 2004). Common features of these studies were the patient wishing to be treated as an individual; believing that the nurse has gone "the extra mile" and patients evaluating the nurses' dependability. Morse's (1991) nurses used humour, offered time and looked for a "personality click" (p. 461). Patients in a phenomenological study by Shattell (2002, cited in Shattell, 2004) also actively sought deeper relationships with nurses even when they felt the nurses were working too hard. In her review, Shattell (2004) noted that patients "want nurses who are genuine, do not seem in a hurry, and are available and willing to talk to them" (pp.717-718). Patients focussed on this relationship rather than any other

aspect of their nursing care (Fosbinder, 1994) and this concurred with this study's findings. O'Connor (2000a) concluded that it was <u>how</u> nursing was performed rather than the tasks they <u>did</u> which marked out rehabilitation nursing. This study suggests that the best quality rehabilitation nursing occurs when that performance is based on a positive relationship.

The interviewees in this study, both patients and family members, spoke of friendships, shared moments and both positive and negative associations with nurses. They also described the relationships they had developed with other team members such as the occupational therapist or the physiotherapy student. Close and Proctor (1999), nursing researchers, also noted that patients may opt to form bonds with team members other than nurses. Occupational therapists, Guidetti and Tham (2002) highlighted the value of therapist-patient relationships when teaching self-care and the chameleon ability they needed to adapt their techniques and behaviour to the individual patients. The oft-repeated unique contribution of nurses working 24 hours a day, seven days a work (Henderson, 1980) does not imply that they have any distinction in relationship-building. It is how the time is spent with a patient or family member, which is the key and whether each is open to a "connected" rapport.

One model of relationship with potential for developing the concept of rehabilitation nursing is that of Christensen (1998), a New Zealand researcher who used grounded theory to study the views of hospitalised patients. She advocated that nurses should work in *partnership* with patients. Subsequent authors, notably Gallant et al. (2002) and Hook (2006) argued that partnership is not possible when equitable power sharing and patient autonomy in decision-making are not included. Gallant (2002) stated that in some cultures and for older people, there may be no desire for power-sharing nor for decision-making as noted earlier (Schulman-Green, et al., 2006; Waterworth & Luker, 1990). More recently however, Christensen (2009) explained that she was aware that these nurse-patient partnerships were unequal in nature and she saw them as dynamic in nature, changing according to the specific needs of the patient and time of day. The most important element was that the two were journeying together, with the patient acting as a "participant in care" rather than a "recipient of care" (Christensen, 1998, p.31). She continued:

For the patient, the nurse is a buffer, a present source of help, a companion through an ordeal. The service is usually valued and the nurse who provides it is also regarded with kindness and gratitude. For the nurse, benevolence is a major characteristic of an altruistically motivated profession in which specialised knowledge and skill are intertwined with compassion (p.34).

These descriptions counter the popular notion of the nurse as "handmaiden" not only to the doctor but to the patient too. Rehabilitation is not possible without the involvement and

participation of the patient, so the concept of a patient as a working partner being guided and prompted by a nurse (or member of the team) has some resonance. The concept of the connected relationship (Morse, 1991) indicates that the relationship is of longer duration or involves a patient with higher dependency. In a grounded study of patients living with chronic illnesses after discharge from hospital (Lamb & Stempel, 1994), some nurses were defined as "insider-experts". Described as expert because of their nursing knowledge, they were also viewed as insiders, as they were seen as being part of the patient's family suggesting the development of a more intimate relationship.

### Being "connected"

In their systematic review of older people recovering from a stroke, Lamb et al. (2008) stated that patients were looking for "connectedness" with health professionals. It is interesting to note that this was the same term used by a family member in the present study when describing how her mother-in-law responded more positively to nurses with whom she had greater rapport. In the present study, "being connected" infers that the patient works at the relationship and has an interest in the nurse as an individual too. By working harder to achieve outcomes, the patient is doing it for the other person in the relationship as well as for themselves. In the "connected" relationships described, the patient discovered more about the nurse: their name and background. They would anticipate being cared for by them each day and be disappointed when they were absent or not allocated to work with them. They regarded the input of these nurses as more worthwhile and attempted to achieve more to please them. Sometimes different nurses were noted to use similar strategies to teach and encourage but the nurses who had achieved a "connection" often knew how to foster the best from the older person by the manner in which the actions and words were delivered. If such "connections" do indeed result in better patient outcomes, then it would be important to determine if this ability is innate or a skill which can be taught.

Nursing leader, Benner promoted the use of narratives to reflect upon nursing practice and with fellow authors, (Benner, Tanner, & Chesla, 1997) suggested that expert nurses connected and became attuned to individuals in their care when they focussed on their needs and concerns rather than their own abilities. Nurses tend to emphasise the development of effective strategies to communicate with patients in order to establish positive nurse-patient relationships. In a systematic review of studies of nurses working with older patients, Caris-Verhallen et al. (1997) concluded that although nurses regard their relationships with patients as important, their actual social interaction did not reflect this. They noted that this may have been due to individual nurse's skills and attitudes, patient willingness to participate or the

time constraints within the hospital setting. In their observational study comparing a stroke unit, general ward and elderly care unit, Pound et al. (1999) attempted to determine whether outcomes for stroke patients at a specialised unit were improved due to better quality interactions and activities. Nurses were noted to spend more time with patients in the stroke unit and especially on the elderly care unit. The authors suggested that the unit care philosophy of holistic care may have been the reason for the greater nurse-patient interaction though they hinted that the nurses found this form of care more rewarding.

The other salutary finding from the Pound et al. (1999) study was that patients from three different rehabilitation settings spent half of their time doing nothing. This finding concurred with Birchall and Waters' (1996) earlier study which reported that 64.4% of patient time in two elderly care wards was spent "lying/sitting doing nothing" (Birchall & Waters, 1996, p.174). While nurses may imagine that they are using every opportunity to develop connections with their patients, this was not borne out by the research. Such observational studies (Birchall & Waters, 1996; Pound, et al., 1999) and individuals' narratives described patients spending a lot of time alone and unoccupied, especially in single-bedded rooms. This may be less apparent to a nurse with a busy workload who has to focus on specific tasks rather than giving time to establishing "connections". The challenge for health professionals is to be able to make "connections" as quickly as possible and use all opportunities to form working relationships with the patients assigned to their care. Nurses in the study by Sahlsten et al. (2009), some of whom worked in rehabilitation, stressed the need to "know the person" through intentional strategies such as a focus on listening and using stimulating questions. Rehabilitation nurses (indeed all nurses) need to develop their ability to "connect" with their patients in order to promote their fullest participation in their own recovery. Patient participation is the foundation of the Health of Older People Strategy (Ministry of Health, 2002b) and by "being connected" nurses may be able to motivate even the more reluctant patients to participate in their own rehabilitation.

### Being "attuned"

Although the patients in this study described their relationships with team members as essential, they also acknowledged that they wanted skilled, intuitive nurses who were experienced in rehabilitation. Nursing theorist Carper, in her seminal work (1978) on nursing knowledge, described four fundamental patterns of knowing: 1) empirics (the science of nursing); 2) aesthetics (the art of nursing); 3) personal knowledge; and 4) ethics (the moral component of nursing). Current nursing proficiencies in New Zealand are based upon the work of Benner and her colleagues who described five levels of nursing knowledge from

"novice to expert". Benner and Tanner (1987) discussed how an expert nurse could grasp a situation and act promptly as their "intuition" was based on experience using pattern recognition. This research was based largely on intensive care nursing and sample exemplars include nurse descriptions of emergency actions based on rapid physiological changes. Participants in this study commented upon the flexibility of nurses in rehabilitation to respond to the unique needs of patients. Although rehabilitation nurses rarely need to respond as quickly as those in intensive care, they also adapt knowledge from past experiences to fit the individual needs of current patients. Whilst mobility and self care techniques follow certain recognised processes, there is no "one size fits all" means of providing care. An "expert" rehabilitation nurse tailors methods and aids to suit a patient in a similar automatic manner to the intensive care unit (ICU) nurse responding to the signs and symptoms of cardiac distress.

Bonis (2009) argued that knowing in nursing is a uniquely personal form of knowledge and based on an individual nurse's experience. This nursing experience together with reflection and awareness are the antecedents of knowing. Knowledge of a patient requires understanding a patient's unique perspective of their own health. She suggested that nurses weave empirical knowledge, with personal experience of applying that knowledge, together with their knowledge of the patient. Brereton and Nolan (2002) advised that nurses heed the input of families who have "person knowledge" just as family members intimated in this study. The "connected" nurses in the current study had gathered information from the family and utilised it. This has the added advantage that the family felt they were part of the team, their input was appreciated and they achieved a greater appreciation of the rehabilitation process. They shared observations of progress which may otherwise have been missed. They "connected" with the favoured nurses as well.

So a nurse can become a partner in knowledge with the family and with the older patient and by pooling their resources they can determine ways of improving an individual's progress and respond to their needs. Furthermore, the older person believes that nurses who are interested in their knowledge are more caring and may be more likely to enter into a connected relationship with them. The ability for a nurse to be "attuned" to the older person is reliant on their knowledge about the individual but is only one element vital to the creation of a productive nurse-patient relationship. A second element is "being available" which concerns the time which the older patient sees a nurse being willing to commit to the relationship.

# Being "available"

A consistent finding in all the interviews was that nurses were described as being constantly busy. The interviewees were mostly unaware about what roles or tasks the nurses were doing when they are not available, but assumed that they were working with other patients. This should not be surprising since it may not be possible for members of the general public to describe the specifics of many professionals' roles unless they have had an opportunity to enter into the professionals' sphere of work. Throughout the nursing rehabilitation literature, studies have noted that nurses and patients alike complain of the lack of time which nurses have to spend performing rehabilitation and nursing tasks as well as establishing and maintaining good nurse-patient relationships. Pryor (2005) included lack of time and staffing shortages as issues which impacted on nurses' ability to contribute to patient rehabilitation. From the nursing perspective, she stated that "allowing time was the single most important strategy to create a rehabilitative milieu" (Pryor, 2010, p.125).

Patients in this study, in common with other research findings (Jones, O'Neill, Waterman, & Webb, 1997; Macduff, 1998; Penney & Wellard, 2007), explained how they "fitted in" with nurse availability, trying to be undemanding and timing their needs such as toileting so that nurses could complete their busy schedules. Jones et al. (1997) described how nurses had to prioritise whilst therapists had dedicated time with patients. Nurses in Collins (2002) study in New Zealand complained that certain patients were "heavy" meaning that they were very dependent and took more time to care for, whilst Pryor (2005, 2010) noted that when acute patients were located on rehabilitation wards, they also took up greater amounts of the nurses' time which could not then be used to allocate to rehabilitation patients.

From the patient perspective in this study, if nurses were willing to spend time listening to their concerns, even when it was believed that they were busy, then this was pivotal in making them feel they were seen as individuals rather than a number. A hospital ward to an external observer may seem frenetically busy as staff members juggle their commitments within institutional time constraints. Nevertheless time may pass slowly for a patient waiting for the care of basic needs or therapy or the visit of a loved one. Observational studies (Christensen, 1998; Pound, et al., 1999) as well as my own experience indicate that care delivery is episodic. Christensen (1998) used the term "episodic continuity" to describe the situation for most patients where nursing care is available when required by a call system, but nurses are not in attendance constantly. The episodes of nursing care are occasional and often brief. For patients dependent upon others for mobility, especially if they have sensory deficits, then they can be very restricted in activities which they can participate in whilst waiting for input from others. Whilst rehabilitation patients need periods of rest,

they may feel isolated from others and the nurse is the one at the end of the bell alert system. The frequent visits from the nursing staff to ensure safety and comfort are another opportunity to develop relationships. This is invaluable when a "connection" has been established and continuity of care by the same nurses ensures that the relationship can be forged more deeply.

Some family member interviewees saw the nurses as the "glue" holding the team together as well as the first point of contact for family members. This commitment of time for and with next-of-kin is noted in other studies (Clark & Wall, 2003; Long, et al., 2002; Nolan, Booth, et al., 1997). Strongest relationships were made with nurses whose qualities were valued though the combination of these desirable attributes varied from one patient to another. Family members were more likely to bond with the older patient's favoured nurse.

#### "Best fit" nurse

Whilst some nurses may enter the profession with an altruistic attitude or religious beliefs, the reality is that nurses vary in personality, strengths and knowledge. Suzanne Gordon is a crusader for challenging commonly held international images of nurses based on outdated ideas of what is nursing (Buresh & Gordon, 2006; O'Connor, 2009). Some participants described nurses as angels, an image fostered by the media according to Bridges (1990) whilst others favoured those who were dedicated and loving, which reflects the image of the religious nursing sister of the 19<sup>th</sup> century. However other interviewees in the current study valued nurses who were outgoing and fun whilst some appreciated those willing to show their individuality.

It was interesting to note how descriptions of "ideal" nurses by patients were echoed by their family members. From a consideration of their background shared within their narrative, it appeared that these idealised nurses correlated with the past experiences and media nurse images recalled by the interviewees. Some patients may have preferred a nurse with a similar personality to themselves so that they could readily share a sense of humour. Some found it easier to converse with someone of similar interests. An acknowledgment of their former strengths, abilities or profession was important to other patients. Images of caring, which were based on their personal experience of caring for others, influenced how some participants perceived the qualities of individual nurses. In each case, the "ideal" nurse was someone who best fitted their image of how they wished to be cared for. This "best fit" nurse was in a good position to create a "best fit nurse-patient relationship".

A vital aspect of how individual nurses were viewed by the participants was the kind of "nature" they displayed in their interactions with both patients and family members. This

appeared to be a combination of nurses' personality and the nursing persona they presented. In this study, this "nature" in the context of a nurse's caring was explained as the nurse "being". It described the impact of their presence and their caring manner rather than any specific actions. Activities performed in a caring way were noted as caring by "doing". Using the perspectives of caring described by Morse et al. (1990), this attribute of a nurse "being" cannot be readily classified in this study without knowledge of the individual nurse and indeed is more likely to be a combination of a human trait, an affect and possibly a moral imperative. What is clearer is that patients appreciate the result of caring through an interpersonal relationship when they respond to the nurse's "being".

In their qualitative study of how stroke patients cope with hospitalisation, Close and Proctor (1999) found that patients proactively sought out specific nurses or health professionals in order to cultivate a relationship with them. Team members in Jones et al.'s study (1997) on patient-staff relationships in an inpatient rehabilitation ward, stated that patients chose to form deeper relations with some of the staff based on perceptions of their physical or cultural attributes. Similarly, Fagerstrom et al. (1998) concluded in their qualitative study of patient opinions of nursing care, that the quality of nurse-patient relationships was based upon how well a particular nurse met their particular needs, expectations and wishes. These studies tend to support the proposal of a "best fit" nurse. Whilst individual nurses, therapists and medical staff cannot change their essential nature, it should also be noted that many may adapt their approach to different patients in order to facilitate communication or foster a working relationship. This skill has been referred to as a chameleon quality that some health professionals develop in their clinical work (Guidetti & Tham, 2002).

# **5.4** Coaching independence

In common with Pryor (2005, 2007, 2009) and Price (1997), one of the major findings of this study was the role of nurses in coaching patients. Price focused on how the nurse has coaching roles within the team and family as well as with the individual. In comparison to this, the present study found that from the patient/family member perspective, the patient's relationship to the nurse (or therapist) is the key to effective coaching. This difference in approach to coaching may be attributed to how this training is viewed. The nurses may view the teaching and coaching as part of their expected role whilst the patient considers and then accepts the invitation to be coached after first evaluating the person who is acting as coach. Price contended that the nurse needed to return the locus of control to the patient within a trusting relationship. Trust and control were valued by the older patients but not described as

essential ingredients in fostering independence within this study's client group. Pryor (2009) viewed the development of independence in self-care as primarily a nursing role and a key aspect of their work. Whilst regarding the "hands off" approach adopted by rehabilitation nurses as the essential means to coach individuals she viewed this rehabilitative approach as happening within the framework of an interpersonal relationship. She acknowledged that the provision of technical and physical care as noted by Long et al. (2001) was overshadowed by the need to support the psychosocial needs of patients as they undertook their own rehabilitation. Her argument was that nurses' ability effectively to coach patients is dependent upon their nature, insight, skills and experience in applying those skills.

Whilst this study supports Pryor's conclusions regarding the need to attend to the psychosocial needs of individuals through nurse-patient relationships, the emphasis in her work is necessarily about how nurses achieve self-care with patients. They "eased them into rehabilitation", "maximized the patients' efforts" and "provided graduated assistance." Whilst clarifying strategies which rehabilitation nurses use, Pryor argued that nurses in her study believed that rehabilitation was not done "to" patients but done "by" patients.

The present study adds the missing dimension of how patients view "doing rehabilitation". While coping with their personal struggle to gain independence, the patients failed to perceive or acknowledge the multiple roles nurses fulfilled but valued those who sought to participate in their experience, to elicit and promote inner hopes and strengths, and to accept the challenges of rehabilitation. These findings imply that the motivation essential in all rehabilitation therapy is enhanced by the quality of the nurse-patient relationship. Interviewees described how nurses encouraged them and attempted to motivate them, just as described by Pryor (2009) using bargaining and persuasion but this manner of "actively driving patient progress towards self-care and independence" (p. 85) may not be as effective as promoting the individual's own motivation. In Figure 2, (p. 49) there are two pathways illustrating the nurse coaching the older person to independence. Where nurses use strategies such as focussing on discharge or current abilities, praising efforts or prompting practice, individuals will respond at different rates depending upon their commitment, physical and mental health and time of day. Older patients who are working with their "best fit nurse" will make extra efforts without necessarily being prompted in order to reward her/him for their care and input. They achieve and surpass their personal goals more readily. This progress was noted by family members who were also sources of inherent motivation.

Another aspect of the "best fit nurse" is that they are viewed as more sensitive to the individual's needs, having gleaned knowledge from various sources including the patient and family about issues which facilitate or impede progress and patient motivation. For example,

nurses whilst promoting self-care need to be aware when it is timely to offer assistance. This was described in this study as "stepping in" but Pryor described it as "graduated assistance" and it is also noted by Gibbon (2004) in his study of older stroke patients. One of Gibbon's (2004) participants explained "It was nice to have some things done for you...whilst you recharge your batteries" (p.10). He felt it was a dilemma facing nurses who had to decide when to provide basic nursing care but this is an ability which "expert" rehabilitation nurses develop as explained in section 5.3. Nelson (1990) saw the need for inexperienced staff to learn to "push" and "toughen up" patients by ensuring that they did not always respond to patients' requests for help. This "tough love" approach may be appropriate for some patients, such as those in the study with spinal injuries, but may be counterproductive if used for older frailer patients. The "best fit" nurse being "attuned" to his/her patient, knows how and when different strategies are best employed to coach independence.

# 5.5 Motivation and older people

Participants in this study spoke of nurses being involved in "pushing" or even "shoving" them to achieve their goals. Pryor (2005, 2009) described nurses being involved in pushing too. Nurses in Price's study (1997) described occasions when they "confronted" and "challenged" patients. These appear at first glance to be pejorative terms to describe how a "caring" profession works with a vulnerable group of people. However when understood within the context of the interviews, they may be viewed as a gentler form of motivation than originally understood.

Motivation is an essential tool in the kit of any health professional working in rehabilitation and there is a vast literature on the topic from multiple viewpoints. Goal-setting did not appear as an important element in this study even though it was raised in earlier interviews. Goal planning forms an essential part of rehabilitation therapy (Wade, 1998) and realistic goals which are owned by the individual may promote motivation. Siegert and Taylor (2004) argued that the patient/person needs to be known as an individual before meaningful goals can be set with them. Health professionals are warned by Maclean and Pound (2000) of falling into the trap of labelling patients as "unmotivated" suggesting that they are therefore "bad". In a study of patient motivation, Maclean et al. (2000) concluded that patients labelled as "highly motivated" identified with the aims of the health professionals in the rehabilitation setting but warned that professionals' negative attitudes could influence patients' motivation.

Patients labelled as "highly motivated" in Maclean et al.'s (2000) study acknowledged that nurses were "cruel to be kind" though nurses were criticised by other patients for

maintaining their dependence. Those deemed to have "low motivation" expected that nurses would have done more for them. These perceptions were reproduced in this study. However there was no overt reference to the nature of the relationship with the health professionals impacting on their level of motivation. Resnick (1996), a nurse researcher in rehabilitation, documented in her ethnographic study of geriatric patient motivation that her informants stated their motivation was based upon a desire to reward the staff for caring about them during their rehabilitation. She also recorded that if participants did not believe that therapy was necessary, or if nurses' actions did not comply with their beliefs about what nurses should be doing, then they had no motivation to engage in activities required of them. These findings were replicated in a subsequent study (Resnick, 2002) where she concluded that her results supported Bandura's theory of self-efficacy (Bandura, 1997). Her older patients were willing to participate in activities if they believed that they were physically capable of completing them and if they thought their completion led to desired outcomes. Bandura (1997) suggested that older individuals were more likely to be brought up to believe that others should have control, so they relinquished personal control, allowing others to take charge of their lives. However he wrote that (p.207) "regardless of age, those with a high sense of efficacy seek an active role in their health care" and that efficacy belief outweighs physical ability even after surgery. Kemp (1988) and Philips et al. (2004) included equations to explain how motivation in older people should be considered. Kemp's model included four variables which impact on motivation, namely: wants, beliefs, rewards and costs. contended that everyone is motivated but that others may misunderstand why someone is acting as they are.

Patient and family member participants in the current study commented on how verbal encouragement was routinely used by nursing staff but family members noted that the older patients were motivated as a result of their positive relationship with particular staff members. Positive verbal feedback by nurses has been noted in other studies as a means of motivation (Price, 1997; Pryor, 2005; Resnick, 2002; Young & Resnick, 2009) yet this study confirmed that it is also a valuable job of the family members themselves (Young & Resnick, 2009). Family members related how they suggested future events older patients could participate in on discharge or encouraged them to participate in therapy or ward routines. For one patient, her source of motivation was the need to return home to be with her dependent husband, whilst for another the desire to be with his wife of many years spurred him on. It is important for nurses to discover such powerful sources of motivation by tapping into the collective knowledge of their patients, family members and fellow health professionals.

## **5.6 Family involvement**

Few studies consider the role of family members in rehabilitation. Long et al. (2002) described the task of involving the family in rehabilitation as a nursing role. In a grounded study of older people, Jonasson et al. (2010) noted that nurses should utilise the family as a source of knowledge. Pryor (2008a) summarises issues which patients and families need to address during rehabilitation and their coping strategies. However most research which focuses on the family members of older people relates to caregiving in the community post-discharge.

This study demonstrates that whilst families needed nurses to provide "support", their main need was for information. Moreover, they were keen to share their knowledge of the individual to ensure that they received the most appropriate care. Whilst family members can be over protective at times, this may be an understandable response to acknowledging the need for the older person to be hospitalised. Families' views of how health care, especially nursing care, should be given may be based on out-dated images or previous bad experiences. By forming good relationships with family members in the presence of the older person, nurses have access to a valuable resource. By involving them in education about rehabilitation philosophy, practical techniques and answering their questions, family members can appreciate and accept why rehabilitation nursing roles are different. They can also be trained in readiness for tasks they may need to undertake on discharge. For older patients where a major life change is required by accepting extra support at home or entering residential care, informed family members can act as allies and advocates with nursing staff.

Taking an interest in the details of the family of an older patient also helps the nurse appreciate an important aspect of who that older person is and what concerns them. Whilst their focus may be on their own needs, many older people have fewer but often stronger bonds with friends. They are more likely to be widowed or have a sick spouse/partner at home and need the support and comfort of the nurse to cope with these worries. They are more likely to have family members scattered globally.

Figure 2 (p.49) summarises the links of the nurse's roles with the family. "Looking after" is the term used by one patient to refer to what he wanted of his nurse but families have a similar need as well. The nurse has to action this by involving the family as well as supporting them if this is what they seek. The family members who wish to be involved, will care for the patient anyway as indicated by the direct link. Coordination of care with the family is likely to prove the most effective albeit more time-consuming role for the nurse.

## 5.7 Implications of study

Pryor (2005, 2007, 2009) and Price (1997) both concluded that the rehabilitation nurse has a major role in coaching patients to care for themselves. The findings of this thesis suggest that patients acknowledge that nurses perform this role but that the mode of delivery of the teaching is as important (if not more important) than the specifics of the task itself. Nolan (2001) concluded that nurses were inadequately trained to undertake a role in rehabilitation education though they were in a good position to provide this service in clinical practice. Pryor and Smith (2002) responded to the need to explicate the roles of nurses in rehabilitation and Pryor subsequently advocated their vital role in creating a rehabilitative milieu (Pryor, 2010) but there is still a need to clarify and promote the educational needs of rehabilitation nurses in relationship-building and motivational skills. The difference between nursing in the rehabilitation area compared to other specialities is very subtle and to the novice, the approach of an expert rehabilitation nurse may seem uncaring and tough (Nelson, 1990). There is a need for nurses to receive appropriate educational programmes during clinical orientation to a rehabilitation unit including their expected roles within the team and when to utilise a "hands off" approach. Additions to current rehabilitation and nursing postgraduate courses should include evidence-based research about motivation, nurse-patient relationships and family therapy.

Patients and family members too, need more education about rehabilitation, the implications of moving to a rehabilitation unit and the expectations of the staff in order to receive the most benefit. As a result of this study, information pamphlets have been introduced and admission processes have changed in my own workplace. A first informal audit indicated that patients had a better understanding of the philosophy of rehabilitation as a result of these additions to ward procedures, but that nursing staff were variable in their acceptance of the need for the changes. This may reflect a poor appreciation of the patients' perspective of the nature of rehabilitation.

New Zealand's Minister of Health, Tony Ryall (NZNO, 2009), who began his role in 2009, advised nurses to spend more time with their patients and less with administration. Whether time constraints are due to the changing needs of more acutely ill patients (Long, et al., 2002), the increased amount of documentation to fulfil legal requirements or the introduction of new systems to conserve the health dollar, nurses will always have to prioritise their time. This study has highlighted that patients and family members acknowledge the restraints placed on individual nurses but indicated that time spent with patients can be more wisely used. There is also a need to advocate to hospital management for the time required in rehabilitation nursing (O'Connor, 2000a) to allow the patient to achieve independence in a

safe environment whilst nurses coach self care and continue the therapy of others in the team. The impact and importance of effective nurse-patient relationships with this age group justifies the reintroduction of primary nursing where nurses are allocated to work with specific patients for the duration of their stay at the rehabilitation unit.

Acknowledging that patients spend so much time in hospital being inactive and that hospital care is expensive, consideration should be given to medically stable patients undertaking more of their rehabilitation at home, using either a community multidisciplinary team (Dow, Black, Bremner, & Fearn, 2007) or with more training, the use of expert rehabilitation nurses. Whilst families are currently involved in certain aspects of the rehabilitation process notably discharge planning, this study strongly suggests that family involvement should be improved and promoted. This may be easier in the community setting. As Kendig (2004) argued, as a society we should be working towards what the older person wants, not what suits the interests of aged care providers. For the participants in this study at least, the goal was to return home.

Rehabilitation is a costly exercise and older people often take longer to recover so any interventions which enhance patient progress should be seriously considered as a means of saving costs as well as achieving patients' personal goals. If nurses can participate more effectively in the motivation of older people during rehabilitation, then these patients may not only be discharged earlier but may have achieved a greater level of independence and be able to return home.

## **5.8** Limits of study

In qualitative studies particularly, the means of obtaining data and its analysis are dependent upon the skills of the researcher. This was my first venture into grounded theory and I acknowledge that my findings are dependent upon my ability to elicit useful information from my participants and construct it, following this methodology, into useful findings to enhance current knowledge in this field.

Data collected from this study is based on experiences specific to the participants I interviewed at this point in time and, as for any qualitative study, it would not be appropriate to generalise from these findings to other patient populations in other localities. Although participants were invited to join the study by a third party (nurse selectors) following a set of criteria, their willingness to contribute may reflect a more positive attitude to both the rehabilitation setting and the health professionals working there. Therefore, it is possible that less positive perspectives of the role of rehabilitation nurses may exist, but may not have been reflected in the data gathered for this study. This said, the findings from this study, reporting

on the experience of patients from a provincial New Zealand hospital are consistent with findings reported in other studies of rehabilitation nursing in other settings and counties including, for example, those of Lucke (1999) in USA and Price (1997) in New Zealand.

It was unfortunate that it was not possible to interview any Maori patients and their whanau for this study and that all the participants recruited to this study were people who identified as Pakeha (New Zealand European). Including interviewees from other ethnicities may have highlighted cultural differences in patient and family member perspectives.

The substantive theory in the current study was developed solely from interviews with patients or their family members. The inclusion of observation of nurse-patient interactions, as another source of data collection, like in the grounded study of Pryor (2005) would have provided a different perspective to the findings. Whilst not a key theme of her final model of "opting in and opting out", Pryor's findings do however agree that conscious development of the nurse-patient relationship is a strategy which nurses stated they used to encourage participation in self-care, lending support to this study's findings.

The inclusion of interviews with the nurses caring for specific patients would have indicated whether the patient perception of a reciprocated relationship was also experienced by the nurse in the nurse-patient dyad. Future studies should include observational studies of patients and family members with nurses as well as other team members to determine whether patient or family relationships with health professionals exist as suggested in the present study and how they are developed and maintained.

#### 5.9 Recommendations for future research

For health research to be worthwhile there is a need to predetermine whether the outcome of the studies will provide feasible, practical and cost effective interventions. Craig et al. (2008) in their summary of the updated guidance of the Medical Research Council in the UK, acknowledged that the evaluation of complex interventions is complicated and advised researchers to consider carefully the existence of any underlying theory, the quality of their study design and their choice of outcomes. Rehabilitation is a complex form of therapy since there are many health professionals involved in working with the patients, the client group is extremely variable and there are multiple processes involved in promoting improvements in wellbeing and independence. In addition, it is a relatively young branch of medicine and the areas for research are endless, so the researcher needs to focus on aspects of patient care which will have the greatest benefit. Qualitative study is often the most appropriate means to evaluate the social processes involved in everyday rehabilitation, though as Craig et al. (2008) discussed, it is less likely to produce reliable estimates of effect. The following

recommendations for future research are made, acknowledging that preceding their implementation there would be an examination of best practice evidence, a review of appropriate theories and an evaluation of the relevance of the study findings.

Motivation is an important element of rehabilitation and therefore a justifiable area for enquiry. This thesis suggests that the nurse-patient relationship influences patient motivation and that training in motivational skills could be a useful adjunct to nurses' basic educational programmes. A pilot quantitative study comparing patient groups prior to and after the implementation of such training at one rehabilitation unit could be designed to justify the wider implementation of motivational training for nurses in rehabilitation nationally. An optimised balance block design controlled study would be an appropriate method as there would be high risk of cross-group contamination in a randomised controlled trial and it would be very difficult to blind the patients, nurses and researcher to the use of the newly introduced motivational programme. Holliday et al. (2007) used this design of study to test the impact of patient participation in goal-setting in rehabilitation.

Although the current study identified that older patients worked harder when "best-fit" nurse-patient relationships were created and maintained, it would be valuable to test this with other age groups. It may be that younger patients, who wish to return to paid employment or have dependents to care for, are motivated by other factors unrelated to or in addition to the quality of nurse-patient relationships. It was not clear from this pilot study whether the rapport with health professionals supported the older patients' intrinsic motivation (Siegert & Taylor, 2004) or whether this relationship changed any unstated goals they were pursuing. Ethnographic research into how rehabilitation professionals seek to develop a rapport with older patients and the impact of poor or positive relationships on motivation would be valuable.

Optimal independence is the goal of rehabilitation and interventions which encourage older patients to self-care are essential. The conclusions of this investigation agreed with studies from a nursing perspective (Price, 1997; Pryor, 2009) that coaching towards independence is an important role of the rehabilitation nurse, but further research is needed to determine the most effective means to implement this role with this patient group. Although nurses in Pryor's study (2005, 2007) clearly described possible strategies which they used (based upon the needs of specific patients), clarification is required to discover when strategies are utilised, why they are used and the effect of their implementation. The use of conversation analysis or discourse analysis of nurse-patient interactions whilst negotiating self-care with and without family members would help explicate the benefit of specific

strategies and discourses, and the means by which nurses modified their coaching to the needs and wishes of older patients.

Family members are a key component in effective ongoing rehabilitation and therefore were included in this study. It would be worthwhile to elucidate further from the perspective of family members, the nature and degree of their involvement with older patients on a rehabilitation ward. This would involve discovering what they consider is their current contribution and what they believe they are capable of doing with appropriate support. The findings of a study such as this could form the basis of an educational programme provided for family members by appropriately skilled rehabilitation nurses. An initial qualitative study, with a questionnaires-based survey to capture information from a larger sample, could determine whether sufficient family members had the ability, need and desire to participate in such a programme before it was implemented. A further grounded study focussing on family needs specifically, would highlight whether findings from this present study were common to other family members.

One objective of the Maori Health Strategy (Ministry of Health, 2002a) is to improve access for Maori to mainstream health services, of which inpatient rehabilitation units form a part. Older Maori patients may be more willing to participate in rehabilitation if their whanau are able to participate more fully in their therapy. A Kaupapa Maori study, conducted by Maori researchers would probably be the most appropriate means to explore the current and potential contribution of whanau, especially in coaching self-care, during the older person's hospital stay. Such a method may also have more success in the recruitment of Maori participants and would be a valuable addition to the knowledge of rehabilitation professionals in New Zealand, potentially highlighting the varying needs of families of different ethnicities.

Lastly, patients participating in rehabilitation are required to participate in therapy with members of a multidisciplinary team at a time when they are feeling physically unwell and emotionally stretched. Any stratagems which health professionals can use to ensure patient co-operation are valuable. It would be helpful to determine whether nurses (indeed all health professionals) working in rehabilitation do consciously adopt "chameleon-type" techniques to adapt to suit the personality and changing needs of their patients or whether this ability is part of their innate "nature". If this "chameleon" behaviour is a teachable skill, then a randomised controlled trial could test whether the adoption of such techniques by nurses trained in their use improved outcomes such as reduced length of hospital stay, for a test group of older patients. Observational studies as well as interviews could confirm whether these staff members are actually making such changes and the type of verbal and/or non-verbal communication which occurs. The form of delivery of responses within interviews in

the current study suggests that discourse analysis of video-recorded interactions between nurses and older patients would be a suitable means of discovering the exact manner in which nurses and their team members adapt to "best fit" the patient's needs of the moment.

Each of the possibilities for future research recommended above would provide valuable insights into the means by which nurses can contribute to the rehabilitation of older patients.

# **Chapter 6: Conclusion**

This thesis has explored the contribution of nurses towards the rehabilitation of older patients at an ATR unit from the perspective of the older person and their family members. It has demonstrated that the viewpoint of older patients and their family members differs from that of nurses described in the rehabilitation nursing literature. Nurses tended to focus on the performance of activities to maintain the wellbeing and safety of their patients. All participants noted that nurses provided assistance in a graduated manner to coach their older patients to achieve independence or follow up the therapies of other members of the multidisciplinary team and that they were expected to complete these tasks in a timely manner. Patients focussed more on their own lives, taking little notice of specific nursing roles, as they were still coming to terms with the often sudden change in their independence and health. They were vulnerable and needing members of the team to be sensitive to their point of view and changing support needs.

This study has introduced a substantive theory that explains the relationship a patient has with a specific health professional to strengthen the older patient's resolve to participate in rehabilitation. Patients sought out individuals, though not exclusively nurses, whom they identified as "best fitting" their image of someone able to care for them in the way they chose. Patients then determined whether that individual staff member fulfilled their specific interpersonal needs and a productive connection was established. The relationship which older patients had with his/her "best fit" nurse was marked by an increased motivation to achieve maximum independence, partly as a means of rewarding that nurse for his/her input. Family members valued these "best-fit" relationships and believed that they enhanced the older person's progress and ensured their optimal care.

If the findings of this thesis are supported by future research, then changes in nurse education and ward management would be justified in order to facilitate the promotion of such beneficial associations. The implications of this study are that nurses (and other health professionals) would benefit from the inclusion of motivational skills and relationship development in their training. Moreover the introduction of strategies which encourage the regular allocation of nurses to the same patients where positive relationships were being forged could also prove effective in promoting independence and reducing a patient's length of stay.

Glossary

Abduction "A cerebral process, an intellectual act, a mental leap, that

brings together things which one had never associated with one another: A cognitive logic of discovery." (Reichertz,

2009)

Activities of daily living Activities thought to be important for daily life including

personal care such as toileting and showering and domestic

duties such as cooking and house cleaning.

ATR unit An inpatient unit which provides assessment, treatment and

rehabilitation services using a multidisciplinary team and

funded by a District Health Board.

Code A description given to a key point extracted from the text of

the data.

Constructivism A psychological theory of knowledge which argues that

humans construct knowledge and meaning from their

experiences.

Enrolled Nurse Second-level nurses who practise under the direction and

delegation of registered nurses and are registered as such

with the Nursing Council of New Zealand.

Epistemology The study of knowledge relating to the beliefs we hold

regarding how we know what we know.

Grounded theory A qualitative methodology developed by Barney Glaser and

Anselm Strauss which generates theory from data by using a

constant comparative method.

Induction Process of developing theories or conceptual frameworks by

systematically raising data to more conceptual levels.

Likert scale instrument A self-reporting instrument in which an individual responds

to a series of statements by indicating the extent of agreement. Each choice is given a numerical value, and the total score is presumed to indicate the attitude or belief in

question.

Memos "Memos are the theorizing write-up of ideas about

substantive codes and their theoretically coded relationships as they emerge during coding, collecting and analyzing data,

and during memoing" (Glaser, 1998).

Methodology "The research strategy that is employed in a study; not to be

confused with research methods, which are the specific

techniques used for conducting a study, including methods

of data collection and analysis". (Crotty, 1998)

Nurse Practitioner An expert nurse who works within a specific area of practice

incorporating advanced knowledge and skills.

Objectivism The philosophy that all reality is objective and external to the

mind and that knowledge is reliably based on observed

objects and events.

Ontology The study of being and existence e.g. how one perceives the

nature and structure of reality.

Positivism A philosophy which holds that the only authentic knowledge

is that based on actual sense and experience. Such knowledge can come only from affirmation of theories

through strict scientific method.

Post-positivist Those who believe that human knowledge is not based on

unchallengeable, rock-solid foundations; rather it is

conjectural.

Primary nursing A system of nursing ensuring continuity of care by allocating

a particular nurse for the management of specific patients who is responsible for the coordination of all aspects of their

care.

Purposeful sampling Subjects are selected because of certain characteristics so a

sample may, for example, be homogeneous or of maximum

variation.

Reflexivity A research tool in which the researcher considers themselves

and their personal impact upon their findings.

Registered Nurse A nurse who has demonstrated current competency in all

aspects of the scope of practice as required by the Nursing

Council of New Zealand.

Relativist ontology The acceptance of multiple social realities.

Self-efficacy The belief that one has the capabilities to complete certain

actions to achieve given attainments.

Substantive theory A theory which focuses on specific social issues or processes

within a clearly delimited context.

Symbolic interactionism A theoretical perspective which focuses on the relationships

between individuals and the world they inhabit.

Theoretical sampling Sampling which seeks pertinent data to develop the

properties of emerging categories.

Theoretical saturation Point at which no further sampling is required since the new

data adds no new questions or directions to pursue.

Therapist Member of multidisciplinary team providing specialised

therapy e.g. physiotherapist, occupational therapist, speech

language therapist.

Transcription The process of converting speech into written data.

Trend Care A computer software programme which is used for bed

management and the workload allocation of nurses.

Whanau Maori word for family.

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## **List of Appendices**

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## **Appendix A: Information sheet for patients**



#### Information Sheet For Patients

# Patient and family members' perspectives on the role of nursing in rehabilitation for older adults.

A qualitative investigation of clinical practice.

You are invited to participate in this research study

which is being undertaken as part of a Master in Health Science (MHealSc)

by ELAINE TYRRELL (Phone: 03 5488574)

This study has been approved by the Upper South A Regional Ethics Committee

#### **Introduction:**

You are invited to take part in a study about the way in which patients and their family members view the involvement of nurses in rehabilitation at the ATR unit of Nelson Hospital. After reading this information sheet, you will meet with the lead investigator who will answer any questions about the study you may have. You will have at least two days to think about whether you are willing to participate in the study. If you are interested in participating you will be asked to sign a consent form to the study.

Your participation is entirely voluntary. You do not have to take part in this study, and if you choose not to take part you will continue to receive the usual treatment and care.

If you do agree to take part you are free to withdraw from the study at any time, without having to give a reason and this will in no way affect your continuing health care.

#### What are the aims of this study?

To discover how older people and their families perceive the contribution of nurses to their inpatient rehabilitation, with an emphasis on nursing involvement in rehabilitation planning. This study looks at:

- How older patients and their family members experience their rehabilitation planning and what they believe is the nursing role in that process
- How similar these experiences are for different people and whether there are common views about the role of nurses in rehabilitation planning
- How similar the views of patients and family members concerning the role of nursing in rehabilitation are to that described in current research about nurses.

#### Who is the researcher?

I am a registered nurse specialising in rehabilitation at Nelson Hospital. This study will form the thesis component of my Masters degree with the University of Otago. It is funded by a grant from the Health Research Council, New Zealand.

#### What is the reason for doing this study?

Rehabilitation is provided in hospitals to help patients regain as much independence as possible after they have suffered a traumatic event such as fracture or stroke or are coping with a long term illness. Nurses form part of the team of health professionals involved in providing therapy and supporting goal planning for older patients. Family members form an important part of the rehabilitation process. The New Zealand Ministry of Health in its Strategies of the Health of Older People (2002) and of Disability (2001) requires that older people and disabled people are given a voice in how their healthcare is managed. This research will give older adults and their family members the opportunity to share their views about how nurses are involved in their rehabilitation and the process of goal-planning.

#### What will be involved?

I would like to interview 8-12 patients (and one of their family members each) about their experiences during their stay in an inpatient rehabilitation unit. Data will only be collected if all people involved agree to take part in the study.

#### Who can participate in this study?

You were chosen as a possible participant in this study because your stay in the ATR unit of Nelson Hospital will exceed two weeks. If you have communication problems and are unable to speak for yourself, you can help choose one of your family members to speak on your behalf. A cross section of current patients and their family members will be interviewed. Selection will be made independent of the researcher, by the nursing staff, based on specific criteria including gender, age, reason for admission, medical history and family network.

#### What will be involved?

Individuals will be interviewed in a private area at the hospital by the lead investigator in the presence of a support person if you so wish. The interview will take about an hour but can be stopped if you so choose. The interview will be audio taped and then the recordings will be typed up ready for analysis by the researcher. You may see the written transcript to check for its accuracy if you wish. Occasionally, the interviewer may ask for a second or third interview, possibly after discharge to follow up issues arising in the earlier interview. Post-discharge interviews will occur in a place of your choosing, such as your home.

I will also gather some of the medical information from your patient notes such as your type of injury or illness, the length of time since your injury or illness and any goals for rehabilitation that have been written down.

#### How will my research data be managed?

Your research data, such as interview transcripts, will be *confidential* and *anonymous*. You (and any family/whānau member involved) will be allocated a false name that will appear on all information related to your participation in this research. No information that may identify you will be included in the transcripts, published or presented publicly.

Audio-recording will be conducted with a digital sound recorder and stored electronically in a password protected computer. All transcripts will be stored in a locked case or filing cabinet. In addition to myself, coded transcripts may be read by my supervisors as part of the research process.

This research project will take approximately two years to finish. After the research is finished you will receive a summary of the findings if you wish. You can choose to have the audio-files of your interview destroyed or returned to you on completion of the study. A copy of your interview transcript will be stored in a locked filing cabinet by the lead investigator for ten years. Results from this research will contribute to the development of her Masters thesis, which she intends to complete by 2010.

#### What are your rights as a participant in this study?

If you take part in this study, you have the right to:

- Pull-out of the study at any stage
- Have a family/whānau member or friend present during the interview(s)
- Refuse to answer any question
- Have the audio-recorder turned off at any point
- Have your identity protected
- Receive a summary of the results from the study

Have your interview transcript returned to you

Contact myself or my supervisors for more information about this project

What are the benefits of taking part?

Whilst you may not benefit directly from this study during this hospital stay, it is hoped that you will

find it helpful to share your experiences of rehabilitation. As part of the research process you will be

given information about community advocacy and support organizations that may be of help to you.

You will be able to compare these experiences to those of others when the research is completed and

the results known. Other people experiencing similar injuries or illnesses may benefit in the future

from your participation in this research, as nurses and others may gain greater knowledge about how

best to interact with patients and their family/whānau in clinical settings.

What are the risks of taking part in this study?

No actual risk is anticipated for you if you participate in this study. However, should you find it

difficult or stressful talking about your experience the recording of the interview will be stopped, until

you choose to continue. Should you wish, you may withdraw from the research at any time.

any stage you are at significant medical risk, the lead investigator will help you and bring these

concerns to the attention of your health professionals and/or GP as appropriate.

**Results of this study** 

The results of this research will be written up as part of a Master's thesis. It is hoped that they will

be published in a nursing or rehabilitation journal. The findings will also be shared with health

professionals in a teaching or conference setting.

You can receive a copy of the summary report of the study on its completion if you choose. The

findings of this research will not be available until 2011 but will be published to improve the process

of rehabilitation and the education of rehabilitation nurses. The multidisciplinary team at the ATR

unit and your GP can be informed of your involvement in this study if you so wish.

If you have any questions or concerns about your rights as a participant in this research study

you can contact an independent health and disability advocate. This is a free service provided

under the Health and Disability Commissioner Act.

Telephone: (NZ wide) 0800 555 050

Free Fax (NZ wide): 0800 2787 7678 (0800 2 SUPPORT)

Email (NZ wide): advocacy@hdc.org.nz

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Please feel free to contact the researcher or her supervisor if you have any questions about this study. See the contact details below:

### **Principal investigator:**

Elaine Tyrrell, ATR unit, Nelson Hospital.

Tel no. (03) 546 1640

Email: <a href="mailto:etyrrell@xtra.co.nz">etyrrell@xtra.co.nz</a>

### **Supervisors:**

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Lorraine Ritchie, Centre for Postgraduate Nursing Studies, University of Otago, PO Box 4345,

Christchurch.

Tel no. 03 364 3850

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## **Appendix B: Information sheet for family members**



### INFORMATION SHEET FOR FAMILY MEMBERS

Patient and family members' perspectives on the role of nursing in rehabilitation for older adults.

A qualitative investigation of clinical practice.

You are invited to participate in this research study

which is being undertaken as part of a Master in Health Science (MHealSc)

by ELAINE TYRRELL (Phone: 03 5488574)

This study has been approved by the Upper South A Regional Ethics Committee

#### **Introduction:**

You are invited to take part in a study about the way in which patients and their family members view the involvement of nurses in rehabilitation at the ATR unit of Nelson Hospital. After reading this information sheet, you will meet with the lead investigator who will answer any questions about the study you may have. You will have at least two days to think about whether you are willing to participate in the study. If you are interested in participating you will be asked to sign a consent form to the study.

Your participation is entirely voluntary. You do not have to take part in this study, and if you choose not to take part your family member will continue to receive the usual treatment and care.

If you do agree to take part you are free to withdraw from the study at any time, without having to give a reason and this will in no way affect your family member's continuing health care.

#### What are the aims of this study?

To discover how older people and their families perceive the contribution of nurses to their inpatient rehabilitation, with an emphasis on nursing involvement in rehabilitation planning. This study looks at:

- How older patients and their family members experience their rehabilitation planning and what they believe is the nursing role in that process
- How similar these experiences are for different people and whether there are common views about the role of nurses in rehabilitation planning
- How similar the views of patients and family members concerning the role of nursing in rehabilitation are to that described in current research about nurses.

#### Who is the researcher?

I am a registered nurse specialising in rehabilitation at Nelson Hospital. This study will form the thesis component of my Masters degree with the University of Otago. It is funded by a grant from the Health Research Council, New Zealand.

#### What is the reason for doing this study?

Rehabilitation is provided in hospitals to help patients regain as much independence as possible after they have suffered a traumatic event such as fracture or stroke or are coping with a long term illness. Nurses form part of the team of health professionals involved in providing therapy and supporting goal planning for older patients. Family members form an important part of the rehabilitation process. The New Zealand Ministry of Health in its Strategies of the Health of Older People (2002) and of Disability (2001) requires that older people and disabled people are given a voice in how their healthcare is managed. This research will give older adults and their family members the opportunity to share their views about how nurses are involved in their rehabilitation and the process of goal-planning.

#### What will be involved?

I would like to interview 8-12 patients (and one or more of their family members each) about their experiences during their stay in an inpatient rehabilitation unit. Data will only be collected if all people involved agree to take part in the study.

#### Who can participate in this study?

You were chosen as a possible participant in this study because you are the family member of a patient who is participating in this study. For patients with communication problems who are unable to speak for themselves, a different family member to yourself will be chosen to speak on their behalf.

A cross section of current patients and their family members will be interviewed. Selection will be made independent of the researcher, by the nursing staff, based on specific criteria including gender, age, patient's reason for admission, medical history and family network.

#### What will be involved?

Individuals will be interviewed in a private area at the hospital by the lead investigator in the presence of a support person if you so wish. The interview will take about an hour but can be stopped if you so choose. The interview will be audio taped and then the recordings will be typed up ready for analysis by the researcher. The interviewee may see the written transcript to check for its accuracy if they wish. Occasionally, the interviewer may ask for a second or third interview, possibly after your family member's discharge from hospital to follow up issues arising in your earlier interview. Post-discharge interviews will occur in a place of your choosing, such as your home.

#### How will my research data be managed?

Your research data, such as interview transcripts, will be *confidential* and *anonymous*. You will be allocated a false name that will appear on all information related to your participation in this research. No information that may identify you will be included in the transcripts, published or presented publicly.

Audio-recording will be conducted with a digital sound recorder and stored electronically in a password protected computer. All transcripts will be stored in a locked case or filing cabinet. In addition to myself, coded transcripts may be read by my supervisors as part of the research process.

This research project will take me approximately two years to finish. After the research is finished, you will receive a summary of the findings. You can choose to have the audio-files of your interview destroyed or returned to you on completion of the study. A copy of your interview transcript will be stored in a locked filing cabinet by the lead investigator for ten years. Results from this research will contribute to the development of her Masters thesis, which is intended to be completed by 2010.

#### What are your rights as a participant in this study?

If you take part in this study, you have the right to:

- Pull-out of the study at any stage
- Have a family/whānau member or friend present during the interview(s)
- Refuse to answer any question
- Have the audio-recorder turned off at any point
- Have your identity protected
- Receive a summary of the results from the study
- Have your interview transcript returned to you
- Contact myself or my supervisors for more information about this project

What are the benefits of taking part?

Whilst you or your family member may not benefit directly from this study during this hospital stay,

it is hoped that you will find it helpful to share your experiences of their rehabilitation.

You will be able to compare these experiences to those of others when the research is completed and

the results known. Other people experiencing similar injuries or illnesses and their families may

benefit in the future from your participation in this research, as nurses and others may gain greater

knowledge about how best to interact with patients and their family/whānau in clinical settings. As

part of the research process you will be given information about community advocacy and support

organizations that may be of help to you.

What are the risks of taking part in this study?

No actual risk is anticipated for you if you participate in this study. However, should you find it

difficult or stressful talking about your experience, the recording of the interview will be stopped until

you choose to continue. Should you wish, you may withdraw from the research at any time.

Results of this study

The results of this research will be written up as part of a Master's thesis. It is hoped to publish them

in a nursing or rehabilitation journal. The findings will also be shared with health professionals in a

teaching or conference setting.

You can receive a copy of the summary report of the study on its completion if you choose. The

findings of this research will not be available until 2011 but will be published to improve the process

of rehabilitation and the education of rehabilitation nurses.

If you have any questions or concerns about your rights as a participant in this research study

you can contact an independent health and disability advocate. This is a free service provided

under the Health and Disability Commissioner Act.

**Telephone: (NZ wide) 0800 555 050** 

Free Fax (NZ wide): 0800 2787 7678 (0800 2 SUPPORT)

Email (NZ wide): <a href="mailto:advocacy@hdc.org.nz">advocacy@hdc.org.nz</a>

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Please feel free to contact the researcher or her supervisor if you have any questions about this study. See the contact details below:

## **Principal investigator:**

Elaine Tyrrell, ATR unit, Nelson Hospital.

Tel no. (03) 546 1640

Email: etyrrell@xtra.co.nz

### **Supervisors:**

Dr William Levack, RTRU, University of Otago, Wellington, PO Box 7343.

Tel no. 04 385 5541 ext 6279

Email: william.levack@otago.ac.nz

Lorraine Ritchie, Centre for Postgraduate Nursing Studies, University of Otago, PO Box 4345,

Christchurch.

Tel no. 03 364 3850

Email: lorraine.ritchie@otago.ac.nz

## **Appendix C: Patient consent form**



### PATIENT CONSENT FORM

NAME OF STUDY: Patient and family memb	pers' perspectives on the role of nursing in
rehabilitation for older adults.	

- 1. I have read and I understand the information sheet dated \_\_\_\_\_\_ for volunteers taking part in the study designed to determine how patients and their family members view the contribution of nurses to their experience of rehabilitation at the ATR unit, Nelson hospital. I have had the opportunity to discuss this study. I am satisfied with the answers I have been given.
- 2. I have had the opportunity to use family/whanau support or a friend to help me ask questions and understand the study.
- 3. I understand that taking part in this study is voluntary (my choice) and that I may withdraw from the study at any time and this will in no way affect my future health care.
- 4. I have also had this project explained to me by the lead investigator, Elaine Tyrrell.
- 5. I understand that my participation in this study is confidential and that no material which could identify me will be used in any reports on this study.
- 6. I have had time to consider whether to take part.
- 7. I understand that I can change my mind about involvement in the study if the interviewing becomes distressing to me and know who to contact to inform them of this decision.
- 8. I know who to contact if I have any questions about the study.
- 9. I consent to my interview being audio-taped.

YES/NO

- 10. I wish to receive a transcript of my recorded interview so that I can check that it is an accurate record of what I said.

  YES/NO
- 11. I wish to receive a summary of the research findings

YES/NO

12. I want my GP or other cur study.	rent provider to be informed of my participation in this YES/NO
(This is a two year study and the findings are ready for pub	there may be a long interval after your interview before blication.)
I,(F	PRINT full name) hereby consent to take part in this
Signature:	Date:
(Where the patient is unable to sign o	r fully comprehend this consent form, then a family member a "Statement by Relative/Friend/Whanau form" instead.)
CONTACT DETAILS:	
Lead investigator: Elaine F Tyrrell	Phone: (03) 546 1640 or 021 0396949 Email: <u>etyrrell@xtra.co.nz</u>
	by the lead investigator whose contact details are noted and analysing the results of the study. Please contact her
Note: A copy of the consent form medical file.	will be given to you and a copy will be placed in your

## **Appendix D: Family member consent form**



### FAMILY MEMBER CONSENT FORM

NAME OF STUDY: Patient and family memb	pers' perspectives on the role of nursing in
rehabilitation for older adults.	

- 1. I have read and I understand the information sheet dated \_\_\_\_\_\_ for volunteers taking part in the study designed to determine how patients and their family members view the contribution of nurses to their experience of rehabilitation at the ATR unit, Nelson hospital. I have had the opportunity to discuss this study. I am satisfied with the answers I have been given.
- 2. I have had the opportunity to use family/whanau support or a friend to help me ask questions and understand the study.
- 3. I understand that taking part in this study is voluntary (my choice) and that I may withdraw from the study at any time and this will in no way affect my future health care.
- 4. I have also had this project explained to me by the lead investigator, Elaine Tyrrell.
- 5. I understand that my participation in this study is confidential and that no material which could identify me will be used in any reports on this study.
- 6. I have had time to consider whether to take part.
- 7. I understand that I can change my mind about involvement in the study if the interviewing becomes distressing to me and know who to contact to inform them of this decision.
- 8. I know who to contact if I have any questions about the study.
- 9. I consent to my interview being audio-taped.

YES/NO

- 10. I wish to receive a transcript of my recorded interview so that I can check that it is an accurate record of what I said.

  YES/NO
- 11. I wish to receive a summary of the research findings

YES/NO

(This is a two year study and there may be a long interval after your interview before the findings are ready for publication.)		
I,study.	(PRINT full name) hereby consent to take part in this	
Signature:	Date:	
Address for results:		
CONTACT DETAILS:		
Lead investigator: Elaine F Tyrrell	Phone: (03) 546 1640 or 021 0396949 Email: <u>etyrrell@xtra.co.nz</u>	
- · · · · · · · · · · · · · · · · · · ·	by the lead investigator whose contact details are noted u and analysing the results of the study. Please contact her	

with any questions or concerns.

## **Appendix E: Statement by relative form**



## STATEMENT BY RELATIVE/FRIEND/WHANAU

Research Title: Patient and family members' perspectives on the role of nursing in rehabilitation for older adults.

<b>Primary Investigator:</b> Elaine Tyrrell (Phone: 03 546 1640; Email:etyrrell@xtra.co.nz)
Patient's Name:
I have read and I understand the information sheet for people taking part in the study referred to above. I have had the opportunity to discuss this study. I am satisfied with the answers I have been given.
I believe that (participant's name) would have chosen and consented to participate in this study if he/she had been able to understand the information that I have received and understood.
I understand that taking part in this study is voluntary and that my relative/friend may withdraw from the study at any time if he/she wishes. This will not affect his/her continuing health care.
I understand that his/her participation in this study is confidential and that no material which could identify him/her will be used in any reports on this study.  I know whom to contact if my relative/friend has any negative experiences related to the study or if anything occurs which I think he/she would consider a reason to withdraw from the study.
•

I know whom to contact if I have any questions about the study.

This study has been given ethical approval by the Upper South A Regional Ethics Committee. This means that the Committee may check at any time that the study is following appropriate ethical procedures.

I/my relative/friend would like a cop	y of the results of the study.	YES/NO
Signed:	Date:	
Printed Name:		
Relationship to Participant:		
Address for results:		
STATEMENT BY PRINCIPAL INV	/ESTIGATOR	
I, Elaine Tyrrell, declare that this spatients of which		
participation in this study is not adventure.		
I confirm that if the participant becominformed consent, full information was participation will be explained. If the study, written consent will be requested, he/she will be withdrawn.	will be given to him/her as soon as the participant makes an informed cho	s possible, and his/her oice to continue in the
Signed: Principal Investigator	Date	

## (If applicable at a later stage)

I (particip	pant) having been fully informed about this study
agree to continue taking part in it.	
Signed:	Date
Participant	
STATEMENT BY INDEPENDENT CLIN	NICIAN
I confirm that participation in the stu	dy is not adverse to
(participant)'s interests.	
Signed:	Date
Clinician	
Printed Name:	

## Appendix F: Patient interview guideline

## **Patient Interview Guideline:**

Patient and family members' perspectives on the role of nursing in rehabilitation for older adults.

REMIND THEM OF THEIR RIGHTS AND VERIFY THEY HAVE READ THE INFORMATION SHEET AND SIGNED THE CONSENT FORM. Have YOU any questions before the interview starts?

**Preamble:** I am interested in finding out your views about the role of the NURSES at the ATR ward. However, there are many staff working here. Can you tell me how you know which are the nursing staff? (Show photo of person in nursing uniform)

Prompts	<b>Core Structure</b>	Probes
A Try to imagine a typical		
morning/afternoon/night.	What did you imagine was	A What was that like?
What part did the nurses play	the nurses' role at the ATR	
in your rehabilitation? (- your	ward?	B What happened then?
progress towards		
independence?)		C Go on
B What makes a good	Can you give me an example	D Is there anything else?
rehabilitation nurse?	of how the nurses helped you	
	set some goals?	E How did that make you
C What are the most		feel?
important roles which the	Can you give me an example	
nurses do with you?	of how the nurses helped you	F How was that helpful?
	achieve your goals?	
D What kind of activities did		G What do you mean?
you do with the nurses that	Now you have been here a	
helped you progress in your	while, what are your	H Tell me more.
abilities to be independent?	impressions of how the	
EG vi . I . I .	nursing staff fulfil their role	I Are there any other reasons?
E Getting back to your	with the patients on the ward?	
experiences with the nurses		J Why do you think that
F What about other ways in	Describe any other particular	happened?
which the nurses helped you	moments or incidents that you	
to become more independent?	have shared with the nursing	K What did that mean to you
to become more independent:	staff during your time on the	at the time?
G There's no right or wrong	ward which you particularly	
answers. I'd just like to get	recall.	L What were you thinking
your views.		then?
JOHI 110115.		

## **Appendix G: Key to transcription conventions**

The transcripts for this study reflected as closely as possible the actual words and speech patterns of the interview participants. Interview extracts have been edited to illustrate points for the purposes of this paper, but all editing has occurred with the intent of retaining the original meaning of the speech.

Ellipses (...) have been used to indicate where speech was omitted.

**Square brackets** [] were used to insert editorial notes or words not present on the audiotape.

**Rounded brackets** ( ) were used to indicate where non-verbal sounds such as laughter occurred on tape.

**Em dashes** (—) were used in the place of hanging phrases resulting in an incomplete sentence, interruption by another speaker or where the speaker made a meaningful pause.

**Underlining** (<u>yes</u>) indicates stress or emphasis given by the person being interviewed through the use of intonation.

## **Appendix H: Transcription agreement**



## University of Otago, Wellington Transcription Agreement

Name of Project:	Patient and family members' perspectives on the role of nursing in rehabilitation for older adults.
Name of Primary Investigator:	Elaine Tyrrell
Name of Transcriber:	
Agency:	
Confidentiality of audio-files and	d information thereon
I agree that I will maintain full confidence the Privacy Act 1993.	dentiality of material on tapes to be transcribed – under
I will ensure secure location for the	audio-files at all times.
I will return hard copies of the audio	o-files to the researcher in original condition.
Signature of Transcriber:	
Signature of Primary Investigator:	
Date:	