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A QUALITATIVE STUDY INTO PATIENT PARTICIPATION IN DECISION-MAKING IN SPINAL CORD INJURY REHABILITATION

By

GLYNIS COLLIS PELLATT

A thesis submitted for the degree of Doctor of Philosophy of the University of Luton

January 2005

DEDICATION

In memory of Mam (Minnie Fugill) 27/3/1911- 31/3/03

and

Dad (John Fugill) 2/3/1919 – 14/5/03

ACKNOWLEDGEMENTS

There are a number of people who without their help and support this thesis would never have been completed. People who have been there for me during my high points and low points and who encouraged me to stay the course.

I would like to thank Fiona Brooks and Sandra Jowett for their encouragement, for their constructive feedback on just about everything related to this thesis: conducting the research, writing it up, the psycho-social aspects of undertaking the work.

I would like to give a big thank you to Brian Pellatt for his support and encouragement, and for accepting that 'for better or for worse' includes the ups and downs of a PhD. Thank you also to Sunny who patiently kept me company during long hours of computer bashing.

Most of all I would like to thank the patients and staff who participated in this research, without their time and interest I would have had nothing to write about.

PREFACE

Spinal cord injury care has been a component of most of my working life. I came to the spinal unit in this study as a young staff nurse in 1972, intending to complete a six- month course and then move on. However I discovered that one either loves or loathes spinal injury nursing and I became hooked. Now in 2003, middle aged and a Senior Lecturer in health care I am still connected with spinal cord injury nursing, as a link lecturer and running post registration education in the speciality.

The impetus to undertake this research stems from my own experiences as a nurse working as a member of a multiprofessional health care team. My longevity in the speciality has enabled me to observe changes in rehabilitation in particular the shifts in government policy and the patients' demands to have more say in the many decisions that have to be made to enable them return to the community. Perhaps the real trigger was meeting up with a patient I had first nursed when he was newly injured in 1972, who had been readmitted thirty years later having not been in hospital in that interim period. He was finding it very difficult to get to grips with the fact that instead of being told what to do he was being asked what he would like to do. It appeared that things had changed in thirty years.

However, I wanted to ascertain if this was really the case, whether patients are involved in the decision-making process, and if they are now part of the team. When I attempted to look at what research has been carried on patient participation I was surprised to find very little research available. What was available came mostly from other countries, in particular North America and most of it did not seem to fit with my experience of the speciality. Most of the research that had been carried out with patients seemed to give an impression of gloom and despair. My own experience however, was that patients tended to be more positive and make every effort to make the best of a bad situation. There was a gap between my own experience and the literature that stimulated a number of questions.

I hope that the findings from this study will contribute to knowledge thereby helping to inform and improve professional practice. Hopefully patients will then get the best possible rehabilitation that will set them up for leading the lives that they wish to lead once they leave the spinal unit.

This thesis has led to three publications in refereed nursing journals.

DECLARATION

I declare that this thesis is my own unaided work. It is being submitted for the degree of Doctor of Philosophy at the University of Luton. It has not been submitted before for any degree or examination in any other University

(Glynis Pellatt)

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ABSTRACT

In recent years there has been considerable pressure from both patients and professionals for greater patient involvement in the delivery of health services, particularly in rehabilitation. However, it has been suggested that involvement by patients is limited. The physical, psychological and social dimensions of a spinal cord injury require major lifestyle changes and therefore many decisions need to be made by patients and professionals. The purpose of this study therefore was to explore and describe patients and professionals experiences of patient participation in decision-making processes in spinal cord injury rehabilitation. A qualitative approach using ethnographic techniques was adopted for the study. Data were collected using semi-structured interviews and participant observation. Twenty patients and thirty health care professionals from a spinal cord injury unit in England participated in the study. The findings contribute to the work already available on patient participation in decision-making by placing it in a spinal cord injury rehabilitation context. This study identified that the experience of team membership for participants was shaped by professional paternalism. Patients and professionals perceive that they are involved in a partnership where patients make decisions. However, there appear to be different levels of paternalism in the professional-patient relationship. Patient participation in team processes is seen to be desirable but does not occur in a in the context of an equal partnership. Rehabilitation was defined as both a process and an outcome that involves developing skills, returning to ones previous life and becoming empowered. The definitions are not mutually exclusive, as patients need skills to be able to pick up their lives again and take control of their own decision-making within an empowering environment. The definitions might also occur as a model for some patients as they progress through the disability career and cope with life changes. Previous work on rehabilitation has tended to define it as a structure a process or an outcome and the concept of a process-outcome model has not necessarily been articulated. The implications of this model for practice are that while in the hospital phase patients need to be equipped with as many physical, psychological and social skills as possible because once discharged they may not be able to return to learn new skills or develop old ones. This highlights the importance of supporting problem solving and decision-

making. This study also found that among professionals there were considerable misperceptions about the roles of others within the team. Findings suggest a 'knowing paradox' in that professionals perceive that they know what their colleagues' role is but that their colleagues have little understanding of their role. This may impact upon the patient experience if they become caught up in power relationships between different professional groups. The thesis concludes by suggesting that there is a need for professionals to examine their own practice to ascertain if they are working in an empowering way. The development of a definition of participation could provide a philosophical focus for patients and professionals. Patients and professionals could jointly identify ways of improving patient participation in the decision-making process, implement a change in practice and evaluate the outcome.

CHAPTER 1 - INTRODUCTION

INTRODUCTION

It is estimated that between 500 and 700 people sustain a traumatic spinal cord injury each year in the UK. The effects of a traumatic spinal cord lesion are usually permanent and currently there is no cure for the condition (Harrison 2000). Those at highest risk from spinal cord injury appear to be young adult males (Meyers 2000). Spinal injuries vary considerably from those who have no paralysis, through to those who are incompletely paralysed to those whose paralysis is complete below the level of the injury. Those with paraplegia have no movement in their legs, those with tetraplegia may also have variable movement in their arms and some with very high cervical spine injuries may also be ventilator dependent to support their breathing (pentaplegia) (Inman1999). Transection of the spinal cord results in loss of:

- Motor function
- Deep and superficial sensation
- Vasomotor control
- Bladder and bowel control
- Sexual function

(Krause 1992, Bromley 1998).

These pathophysiological processes following spinal cord injury mean that patients are at risk from pressure ulcers, intractable pain, muscle spasms, spasticity, contractures, and bladder and bowel disturbances (Glickman et al 1996). In addition to the physical changes that occur after spinal cord injury there is also a psychological and social dimension to the impact the injury has on patients for example the psychological effects of having to adapt to living with a disability and the effects on an individuals lifestyle (Dijkers and Cushman 1990, Laskiwski and Morse 1993,Carpenter 1994, Williams and England 1997). The physical, psychological and social dimensions of a spinal cord injury require considerable lifestyle changes and therefore many decisions have to be made both by the patient and the rehabilitation team.

The earliest description of spinal cord injury was noted in the Edwin Smith Surgical Papyrus written about 2500 BC. The writer described the condition but concluded that it was an untreatable ailment (Swain and Grundy 1996). This attitude persisted well into the 20th century. Prior to the early 1940s people with spinal cord injury died within weeks (Inman 1999). Improvements in outcome began due to the vision of pioneers that an alternative might be possible - such as Sir Ludwig Guttmann who founded the first spinal cord injury unit at Stoke Mandeville Hospital in 1944. The purpose was to rehabilitate people with spinal cord injuries by comprehensively managing all aspects of physical and psychosocial care (Swain and Grundy 1996, Bromley 1998). Comprehensive management was defined by Guttmann (1976 p. 9) as:

> A synthesis between all clinical procedures and all measures to be taken for the social resettlement of these patients, which were not considered as separate entities but, *a priori*, and throughout all stages to be planned and carried out as one common operation.

It is clear that spinal cord injury rehabilitation has come a long way from those early days. Survival rates amongst younger spinal cord injury patients have risen to 88% of what would be expected in the absence of injury (Inman 1999). Patients do more than survive, they return to their communities with the expectation of a fulfilling life, albeit with some level of disability. However, a recent change over the last few decades has been a change in patient perspectives and now patients are less likely to accept health care passively, wanting to be active participants in the rehabilitation process (Smith 1999).

Patient centred care has been advocated by professionals and service users for some time and has created pressure for patient empowerment, with more patient involvement and representation in the delivery of health services (Dinsdale 2002). This had led to policy initiatives, such as the NHS Plan, which states that patients must have more say in their treatment and more influence over the way the NHS works (Department of Health 2000) and a range of structures have been set up to facilitate this (Tennant 2001). The NHS Executive (2000 p 2) aims to "promote patients' involvement in their own heath care as active partners with professionals."

This philosophy has been seen as fundamental to the aim and purpose of rehabilitation in recent years. As Smith (1999a) points out, people who have been subjected to rehabilitation are in a prime position to make a valid and valuable contribution. Within the discipline of nursing it has been argued that rehabilitation 'belongs' to the person with disability; as such their goals are of central importance and as a minimum there should be agreement about the goals of care between the disabled person and the professionals involved (Nolan et al 1997). However in reality disabled people's experiences with health care professionals are fraught with difficulty. The limited involvement that does occur is often tokenistic with poor communication between professionals and disabled people (Oliver 1990, 1996, Nolan et al 1997). Oliver (1990, 1996) sees this as a reflection of the power differentials in health care. This lack of communication may also be a feature of medical specialities that differentiate between 'high-tech' medicine where life saving is seen to take precedence over participation and caring for people with chronic illness and disability (Smith 1992).

Analysis of interprofessional relations has more frequently focussed on the significance for health care of working relationships between professionals (McLeod 1995). Less attention has been paid to the patient's part in interprofessional health care, although the concept of patients as co-workers is not new: work on this in childbirth has encouraged a growing demand by women to be able to make informed decisions about the way their pregnancy and childbirth are managed (Savage 1986, Warriner 2002). However, it has been suggested that the notion of 'woman centred care' has not necessarily led to empowerment and participation by women in maternity care (Buggins et al 1996,Walsh 1996). Equally, it has been argued that the concept of patient centred care in rehabilitation has not led to the empowerment and participation of users of rehabilitation services. Rehabilitation has been criticised by disabled people as focussing on returning disabled people to normal and this discourse of normality colours the health care professionals' perception of the rest of the disabled person's life (Oliver 1990). If normality means returning to pre illness levels of physical ability then this is a major problem for patients with spinal cord injury, as most will never achieve this.

This makes it of vital importance that spinal cord injury patients are involved in the decisions that are made about their rehabilitation treatment, yet spinal cord injury

patients have stated that they feel left out or even excluded from the rehabilitation team despite the philosophy of having the patient at the centre of the team (Glass 1999). The scope of the research reported in this thesis was to investigate whether this was the case in the spinal cord injuries unit being studied. The aim of the research was to inform and therefore improve practice and to add to the body of social science theory.

There are considerable gaps in knowledge about partnerships and empowerment of patients in spinal cord injury care. Research on rehabilitation addresses a whole range of disabling conditions and has concentrated on interprofessional relationships rather than the definitions of rehabilitation held by users and professionals. Consequently the impact of any differences or similarities on the construction of user experience has been under explored. There is little research available about the experience of team membership, or team involvement for patients in spinal cord injury rehabilitation settings, or for that matter the experience of the professionals in the spinal cord injury rehabilitation team.

What work is available comes mostly from other countries such as North America with different cultures and health care systems (Rinehart 1990). Research that has been done focuses on stroke rehabilitation (Enderby 2002, Watkins et al 2001, Gibbon et al 2002) or the care of older people (Rowe 1996, Gair and Hartery 2001, Hudson 2002). While there is much about the discourse of power and doctor/patient (Edwards 1997, Paterson 2001) or doctor/nurse relationships (Dimond 1987, Porter 1991, Adamson et al 1995, May and Flemming 1997) there has been little attention paid to the impact this has on the lived experience of all team members, including patients, in their interactions with regard to patient participation in decision-making processes. For example, although in their research Scholes and Vaughan (2002) address the interprofessional relational issues in acute and primary care teams they do not address the impact on patients. Where the impact on patients has been studied it was found that they were keen to be part of the team but were frustrated by lack of information to allow them to fulfil that role to their satisfaction (Edwards 2002b).

Therefore this study attempts to fill a gap in knowledge about team relationships and partnership in spinal cord injury care in a British health care setting. The need for this research at this time is two fold:

1) Current policy initiatives that emphasise the need for patient participation in decision making about their care (Department of Health 2000, NHS Executive 2000). Research evidence is needed to improve and develop ways of meeting the policy requirements.
2) That a National Service Framework for long term chronic conditions that will include spinal cord injury is being developed and is currently at the consultation stage (El Masry 2003). Research evidence is needed to inform the framework.

This study investigated the experience of patients and professionals in a spinal cord injury setting with regard to patient participation in the decision-making process.

1.1. Aim of the study

The aim was to identify:

- Differences between patient and professional definitions of rehabilitation.
- Patient and professional constructions of patient participation.
- The perceptions of patients and professionals of their roles and relationships within the team.
- What supports or constrains patient membership of the team.
- Levels of patient participation in decision-making.

The study focussed on the following objectives:

1. To identify the definitions of rehabilitation among professionals i.e. doctors, nurses, physiotherapists, clinical psychologists and care managers.
2. To identify patients definitions of rehabilitation.
3. To explore how professionals and patients construct the concept of patient participation.

4. To explore the perceptions of professionals and patients of their roles and relationships as members of a team and how this affects team working.
5. To identify to what extent the patient is a member of the team.

A qualitative study using ethnographic techniques was used to investigate a culture i.e. a spinal cord injuries unit. This thesis discusses how patients and professionals defined rehabilitation as both a process and an outcome and this will be discussed in depth in chapter four. A model of spinal cord injury rehabilitation definition has been constructed. The thesis will discuss how power relationships both among professionals and between professionals and patients influence how professional roles are perceived by them and the extent to which patients are active participants in the decision-making process. Levels of patient participation will be constructed.
In this thesis tensions around team membership for professionals and patients are explored by addressing the following questions:

- How do professionals perceive team membership?
- How do professionals define their own role and how do others define their role?
- Do professionals and patients agree about what the patient's role is in their rehabilitation?

This research attempts to fill a gap in qualitative knowledge about spinal cord injury rehabilitation by both talking to and observing patients and professionals to ascertain the lived experience of team membership and patient participation in a spinal cord injury unit.

1.2. Mapping the thesis

Chapter Two explores previous research that has been carried out in this field. The aim of the chapter is twofold; one is to critically examine the literature on rehabilitation from across the English speaking world, where appropriate going back five decades. The literature review has not only drawn on spinal cord injury rehabilitation work but also other rehabilitation areas such as stroke rehabilitation and neurology, as the work available on spinal cord injury is limited. The chapter also

aims to identify gaps in knowledge about patient participation in decision-making in spinal cord injury rehabilitation particularly in the UK.

Chapter Three discusses the methodology employed in researching 'patient participation in decision-making in spinal cord injury rehabilitation.' Qualitative research using ethnographic techniques will be discussed in relation to ethical issues and being a 'marginal native' in that I am a health care professional with past experience of working as a member of the team in the spinal unit studied. A reflexive approach has been taken to the writing up of this thesis.

Chapter Four presents and discusses the findings related to the definitions of rehabilitation articulated by patients and professionals. It presents a model of rehabilitation and discusses the relationship between three definitions as either process or outcome. The concept of an end point to rehabilitation is also discussed. The chapter attempts to put all this within a context of power and power relationships.

Chapter Five presents and discusses the findings related to patients and professionals perceptions of interprofessional relationships. The discussion focuses on how professional groups i.e. nurses, doctors, physiotherapists, occupational therapists (OTs) and allied health care professionals (AHPs) perceive their role. It also discusses how patients and professionals see those roles and also the perception professionals have about the understanding that other team members have of their role. The lack of congruence between these perceptions within a context of power relationships is discussed.

Chapter Six presents and discusses findings related to the patient's role in rehabilitation and their membership of the team. The structure of patient and professional perceptions of the patient's role and patient membership of the team within a context of paternalism is presented. The dissonance between the ideal of patients being equal partners in rehabilitation and the reality represented by the findings is explored.

Chapter Seven discusses the implications of the findings of this research for professional practice and social science theory. How power relations between

professionals and professionals and patients affect the experience of rehabilitation for both patients and staff is discussed. In this chapter recommendations for developing empowering practice and for further research are offered.

This introduction has identified gaps in knowledge relating to patient participation in spinal cord injury rehabilitation in the UK and the need for research into this area. To identify gaps in knowledge it is important to undertake a comprehensive review of work that has been undertaken in the field. The next chapter will critically examine literature on rehabilitation from across the English-speaking world. It will scrutinize work that has been done on the topic under study, but will also identify areas that need clarification or development.

CHAPTER 2 – LITERATURE REVIEW

LITERATURE REVIEW

The task of reviewing literature involves the identification, selection, critical analysis and reporting of existing information on the research topic (Polit and Hungler 1991, Gould 1994). In this literature review both primary and secondary sources were reviewed to give as broad a picture of the topic as possible. Wilkinson (1995) points out that research studies are central to a literature review but that the topic may also appear in the literature as debate or description and the reviewer must make an informed decision as to what to include. The review employed a cumulative approach across multiple databases until repetition of material occurred and no more new material could be found (Nolan et al 1997). Nolan et al note that a literature review should be systematic, explicit and reproducible therefore the process needs to be documented with supporting material on the management of the literature review.

2.1. Identification and selection of studies

A wide variety of sources were consulted. The databases used were CINAHL and OVID for their nursing and rehabilitation emphasis. MEDLINE for medical coverage and EBSCO Host for medical, therapy and social science coverage. To expand social science coverage the International Bibliography of the Social Sciences (BIDS) was consulted. To prevent a North American bias BNI, AMED and Internurse databases were also used. The Department of Health website (http://gov.uk/doh) was also visited. I did find that there was considerable overlap between databases. I also found further bibliographical information in the reference lists of articles retrieved. Although journals contain more up-to date information, books provide more extensive coverage of a subject (Polit and Hungler 1991). Books were accessed through the library catalogue.

Appropriate search terms were identified by conducting trial searches in the databases and examining naturally occurring terms in the articles retrieved. The following terms were used:

- Rehabilitation – this had to be refined with the addition of physical or medical as I found that drug rehabilitation was being identified. I did not restrict the search to spinal cord injury, as this would have greatly reduced the amount of literature retrieved.
- I then searched using the terms disability, chronic illness and expert patient.
- For the multidisciplinary team I also used interprofessional and multiprofessional team, teamwork, and team leadership as I found these terms were all used interchangeably.
- The terms interprofessional relationships, patient and professional relationships led on to roles, socialisation, patient participation, partnership, involvement, power and empowerment, autonomy, paternalism, compliance, caring and care, emotional labour.

I also had to bear in mind that as I was searching for literature from the whole English-speaking world, terminology might differ in other countries. For example the term physiotherapy is used in the UK whereas in the USA it is called physical therapy. Likewise the use of the words doctor and physician differ between the UK and USA.

The literature review spanned the last two decades from 1980-2003, as rehabilitation became a speciality in its own right in the 1980s, although I have included some earlier material where appropriate. For example it was clear from the work of modern authors that Safilios-Rothschild's (1970) seminal work about the concept of the 'disability career' still informs research about disability. Equally Ducanis and Golin's (1979) work on perceptions of role in interprofessional teams still informs the work of modern researchers. Reviewing the literature is very labour intensive – Nolan et al (1997) estimate that it takes 15-20 minutes to acquire and record each article and this was very true as databases have to be searched, articles read and recorded. Some databases are now full text and this cut down the time I had to wait to receive articles, as I was able to print them off immediately. However, not all are and many articles

and some books had to be requested from other libraries or the British Library with various waiting times. Some were unavailable in the UK.

This chapter will now discuss the previous work that has been undertaken in the topic under investigation to provide a conceptual context for the research. As Bell (1999) points out the literature review enables the researcher to produce a concept or build a theoretical structure that can explain facts and the relationships between them. There is a considerable amount of work, which is relevant to the topic of rehabilitation, empowerment and participation. In this chapter I will concentrate on a selective review of the literature that is relevant to this study. This review will cover:

Rehabilitation for patients with chronic illness/disability

- The problem of definition
- Definitions of rehabilitation
- Lifelong rehabilitation-professional and user perspectives
- Improving ownership of rehabilitation

Empowerment

- Theories and models of power
- Empowerment of patients
- Power, empowerment and health care professionals

The multiprofessional team in rehabilitation

- Professional roles and boundaries
- Doctors and nurses
- The patient and the multiprofessional team

Patients as partners: patient participation in decision-making

- Putting participation into practice
- Patient participation, power and the concept of care
- Conceptual models of caring
- Nurses' and patients' perceptions of caring

This work will be outlined and examined critically.

2.2. Rehabilitation

2.2.1. The problem of definition

The concept of rehabilitation is said to date back to the early 1800s however it was during the two world wars that it was developed. The focus at this time was to restore younger people to fitness so they could either return to battle or productive employment. However, rehabilitation was not recognised as a speciality in England and Wales until 1989 (Hitchcock et al 1998). Since that time as a medical speciality it has grown and flourished by expanding medical expertise and involvement. There is a whole rehabilitation industry that includes a range of health care professionals plus lucrative business for manufacturers of aids and equipment linked to the rehabilitation process. This has meant that the scope for rehabilitation has widened considerably in recent years (Edwards 2002a). The capacity therefore for nursing contribution to rehabilitation has also expanded. The Royal College of Nursing (2000) has acknowledged and promoted the nursing role as being key to the success of the government's agenda for modernisation of rehabilitation services. Nurses have attempted to use nursing models to guide their rehabilitation interventions (Piazza and Foote 1990, Neal 2001). Other nurses are developing new frameworks of rehabilitation, adding to the body of nursing knowledge relating to rehabilitation (Edwards 2002a).

Therefore, rehabilitation is currently a subject of considerable political and nursing interest, for example the National Service Framework for Older People (DOH 2001). Currently, National Service Frameworks are being developed for long-term conditions and will include spinal cord injury rehabilitation (El Masry 2003). Yet there is no real consensus about what rehabilitation is, and the different definitions available, although sharing some common elements differ in their emphasis (Gibbon 1992). Most of the defining has come from a healthcare professional point of view and as there is a wide range of professional theory, knowledge and experience this could account for the lack of cohesiveness in the definitions offered. In fact, developing and validating independent bodies of knowledge by professions to support rehabilitation practice is seen as desirable for professionalisation (Bellner 1999).

2.2.2. Definitions of rehabilitation

When standards are being set for rehabilitation they are seen as requiring structures – what needs to be in place to make it happen i.e. a team of professionals; process – activities to be undertaken and outcome – results (Girvan 1995).

Historically, rehabilitation in spinal cord injury has been perceived as a process i.e. something that is 'done to' people. Over a decade ago Trieschmann (1988 p.6), a psychologist, offered the following definition of rehabilitation:

> Rehabilitation is the process of teaching people to live with their disability in their own environment...there is no tangible end point that can be labelled as rehabilitation because as with all people in all areas of life people with disabilities are continually learning to adapt to their environment.

Trieschmann therefore defines rehabilitation as a process; more recently other authors have defined rehabilitation in terms of outcome, either outcomes that can be measured quantitatively or qualitative outcomes that are much more difficult to measure. Implicit in some of the definitions is the concept of structure in that a team of professionals is identified as being necessary to achieve either the process or the outcome. For example Barnes and Ward (2000) identify that the process of rehabilitation requires professionals give information and help establish goals.

Author	Process	Outcome
Hammell (1995)	Interventions which empower individuals to achieve satisfaction in their social, functional, psychological and emotional interactions with the world	
Chamberlain (1997)	Rehabilitation is interventionist, aiming to maximise a person's abilities in all spheres, intellectual, physical and social	
White and Olsen (1998)	Rehabilitation is an approach, an attitude and a process involving the specialised techniques and interactions of members of an interdisciplinary team	
Graham-Eason (1996)		Clients in rehabilitation tend to focus on their losses, and want

		to be mended and functioning better than they did before
Kennedy et al (1996)	Institutionalisation and dependence are often unintended consequences of hospital based rehabilitation programmes and this can be prevented by using strategies such as goal planning	
Yarkony (1994)		Attainment of physical goals of rehabilitation
Yavuz et al (1998), Beck et al (1999)		Use of quantitative tests to measure functional outcomes
Glass (1999)	Rehabilitation is concerned with qualitative and quantitative aspects of life	
Thomas (1995)	Rehabilitation is about preventing complications, therapy, psychological assessment and counselling	
Edwards (2002)		Optimal recovery and maximal quality of life
Craddock (1996), Begum (1996)		Rehabilitation should focus on independent living
Richardson (1997), French (1993)		Independence is about personal control and control over ones life rather than doing things unaided

Figure 1 – Process – outcome definitions

In figure 1 definitions of rehabilitation are mapped in relation to process and outcome. So the definitions of rehabilitation provided in the literature suggest that rehabilitation is either a process or an outcome. In the definitions reviewed it could be that defining rehabilitation as either a process or an outcome may be problematic for both the providers and recipients of that rehabilitation. For example many of the professional definitions emphasise the attainment of physical goals of rehabilitation (Yarkony 1994). Where they are appropriate, physical goals are important. However, therapists develop measures of attainment and there appears to be a relationship between agreement among the professionals and patient on the expected independence in mobility and positive outcomes (Schonherr et al 2000). This suggests that collaboration between professionals and patients is important, requiring a collaborative approach to the rehabilitation process.

The reason why there is a heavy emphasis on measurable functional goals is due to the way rehabilitation has evolved since the Second World War (Nolan and Nolan

1998). The first phase attempted to build a service that addressed the deficiencies in rehabilitation that became apparent after the war. Next came a phase of idealism as life expectancy increased due to developments in treatment and care with seemingly limitless resources. Current financially restricted times have shifted the emphasis to a phase of practical realism based on readily observable outcomes as indicators of success, particularly in functional gain. Quality care is being redefined in terms of efficiently delivered, effective services that produce desired functional outcomes (Kerkhoff et al 1999).

These functional measurements have been criticised as being viewed as universal rather than context bound, the implication being that they can be used across multiple settings without any consideration being given to the meaning of the functional outcomes for the person with the impairment (Williams 1996). It could also be argued that spinal cord injured patients with a high level of injury are seen to have less potential than those with a lower injury. It may also mean that the value of qualitative aspects of people's lives such as satisfying and meaningful relationships and interactions is ignored. Therefore, rehabilitation may be seen as a process or an outcome but as either it is should encompass an approach and philosophy that stresses abilities rather than disabilities (White and Olsen 1998). However, an acute/rehabilitation split in the organisation of services may make this difficult.

Rehabilitation has struggled to gain recognition against the 'glamour' of acute medicine. Acute care is dominated by a curative orientation (Nolan and Nolan 1999) and there can be considerable difficulties when professionals with an acute care mind set, where curing patients is the focus, care for rehabilitation patients. In spinal cord injury rehabilitation nurses and therapists who are seen as caring are central to the main outcome of rehabilitation which is 'getting back together' – that is the integration of self in preparation for returning to the family and the community (Lucke 1997). A positive approach by professionals may not always concur with the perceptions of patients, most of who will have only experienced (either personally or from the media) acute medicine. Rehabilitation professionals expect patients to regain a perspective of their self worth, whereas clients in rehabilitation may tend to focus on their losses, wanting to be mended and functioning better than they did before (Graham-Eason 1996).

Nurses face a dilemma of working from a position where they hold a philosophy of patient participation in the decision-making process but are caring for people whose decisions may not reflect values of independence and wellness (Graham-Eason 1996). Some patients may be reluctant to take part in the decision-making process. Indeed, it has been found that stroke patients in hospital settings are less likely to take the initiative in their rehabilitation than those being managed at home (Holmqvist and Von Koch 2001). Yet ethical rehabilitation includes the tenets that clients participate fully in the plan of care and clients will value independence, wellness, and self-worth. Rehabilitation should be as short as possible, at the same time being cost effective (Graham-Eason 1996). Kennedy et al (1996) argue that for people with complex needs to reintegrate into the community they should engage in appropriate rehabilitation but institutionalisation and dependence are often unintended consequences of hospital based rehabilitation programmes. Rehabilitation should aspire to prevent this dependency by strategies such as goal planning where patients are involved in setting their own rehabilitation goals.

Dependency could be a product of what has been called the fiduciary model of rehabilitation (Blackmer 2000). In this model the doctor initially takes a very paternalistic approach as the patient adjusts to their disability. After an initial period of adjustment the patient becomes free to make voluntary choices. This model may have some credibility where newly injured patients are acutely ill and professionals are focussing on life saving measures, however there is a danger of the paternalism continuing.

The literature therefore suggests that rehabilitation tends to be defined as either a process or an outcome with structure implicit in these definitions. I have argued that this may affect how rehabilitation is delivered to patients. This separation of the two elements may encourage a less participative and empowering approach by professionals, particularly if there is an emphasis on functional outcomes.

It is also recognised that long term follow-up is needed to prevent and treat medical complications and to maintain functional gains achieved during initial rehabilitation (Thomas 1995). So for some writers rehabilitation has no end point.

2.2.3. Lifelong rehabilitation – professional and user perspectives

The issue of where rehabilitation ends – if it ends- and where long-term health maintenance begins, is viewed differently by professionals and users. Davidhizar and Shearer (1997) prefer the term 'high level wellness' that includes psychosocial functioning. What is clear is that there is considerable concern about long-term health maintenance as people progress through life with a spinal cord injury. As they age people with spinal cord injury are likely to develop complications such as respiratory problems and urinary tract infections (Frankel et al 1998, Vaidyanathan et al 1998, Roaf 2000). Spinal cord injury professionals are considering how to enable people with spinal cord injury to maintain their health and keep abreast of new developments in equipment and techniques for such things a bladder and bowel management. However, it is not clear whether this is seen as a continuation of rehabilitation.

The concept of a 'disability career' has been around for a long time (Safilios-Rothschild 1970). This 'career' spans the first instant that symptoms or an accident is experienced to the final stage when no further effort is made to change the extent of the residual disability. In this model disabled people follow different pathways as they pass through a series of definable stages during this 'disability career'. The Disability Movement has however questioned whether they need heath care professionals at each of these stages. Health care professionals are criticised for adopting a medical model in their approach to rehabilitation (Oliver 1990, Oliver 1996). If medicine is seen to be reliable and effective then it follows that patients should accept the authority of the medical practitioner and their right to prescribe treatment. Disabled people have questioned whether this approach is valid for professionals working with disabled people once their condition has stabilised. They suggest that if an independent living paradigm is adopted rather than a rehabilitation paradigm then the focus is moved from an emphasis on impairment and need for treatment to the importance of removing external barriers and self-direction (Craddock1996, Begum1996). Independence in this context is seen as personal control and control over one's life, rather than doing things unaided. In fact independence in the form of 'doing it yourself' has been described as a form of oppression as it individualises disability (Richardson 1997). This may also have implications for the way disability is perceived by professionals with regard to 'illness' or 'wellness'.

Disabled people have tended to be defined as 'ill'. This has meant that disabled people's lifestyles have tended to be broken down into segments when care needs are being assessed (MacFarlane 1996, Pinder 1996). The reality is that for some disabled people their impairments are associated with illness, but many disabled people are fit and healthy. Problems seem to occur when doctors try to treat the disability rather than the illness (Finklestein and French 1993). The disability movement sees disability as a long-term social state that is neither treatable nor curable. They suggest that medicine has generated a range of psuedo-professionals in its own image, each of which has developed their own skills and knowledge base, which further segments the disabled person's life (Oliver 1996).

The Disability Movement goes further to suggest medicalisation serves the needs of professionals in the way that it defines disability and provides a lucrative way of earning a living (Gregory 1997). Doctors are seen to dominate the lives of disabled people from clinical diagnosis to the end of their lives (Bury 1996). Some of these involvements are appropriate (Harrison 1993) but doctors also have a role in assessing driving ability or prescribing wheelchairs, which do not appear to require medical skills (Oliver 1990, Begum 1996). Disabled people have begun to see professionals as part of their experience of oppression, in that services may often only be accessed through professionals, although it is acknowledged that such oppression can arise from well-intentioned acts (Northway 1997). So there has been increasing pressure from disabled people to improve user ownership of rehabilitation

2.2.4. Improving user ownership of rehabilitation

Over the last 50 years rehabilitation has been shaped by seven 'mega trends' that have extended its scope and provided increased input by burgeoning numbers of professional groups (Symington 1994).

They are:

1. The changing demography of illness and disability, particularly the rise of chronic disease.
2. The emancipation of disabled people.
3. A shift in policy from isolating disabled people from the wider community through to their segregation and hopefully final integration.

4. Shifts in service delivery from institution to community settings and the emergence in most countries of rehabilitation as a distinct speciality.
5. Concerns over the rising costs of healthcare in general and rehabilitation in particular with a resultant focus on efficiency and effectiveness.
6. The development of assistive technology ranging from simple aids to complex information systems.
7. The shift from empiricism to applied science and the growth of rehabilitation as a scientific discipline.

This framework highlights the evolving and dynamic aspect of rehabilitation but also emphasizes how increasing numbers of professions are likely to be involved in that evolution. This increase throws up two issues that I have investigated in this research. One is that the more professions that are involved the more scope there is for conflict and lack of communication between them. The other is that the patient's voice may be more likely to be lost in this plethora of professionals. Even when authors purport to offer an approach to rehabilitation, on closer examination there is much more emphasis on the therapists role than on giving the patient ownership of the process (McGrath and Davis1992).

In spinal cord injury rehabilitation, empowering the individual to direct and plan his or her own care has been advocated as an ultimate goal of successful rehabilitation (Sandstrom et al 1998).

2.3. Empowerment

The vast amount of literature on empowerment is problematic to the reader as the term is ill defined and highly contested. The term empowerment appears to have many meanings depending on whether the author is defining it from a professional perspective or a user perspective. However, much of the defining has tended to come from health care professionals. It has been suggested that research on health care relationships and chronic illness has shifted towards viewing the individual as empowered and capable of participating in health care decisions (Thorne and Patterson 1999). In addition, linked to the problematic nature of the definitions of

empowerment few studies that have claimed to adopt empowering practices have clearly defined power (Gilbert 1995). There is little evidence to support the use of an empowerment model in practice (Skinner and Craddock 2000). The reason why this is the case is elaborated by Pieranunzi (1997) who makes four key observations on the studies of power and powerlessness in the cross disciplinary literature:

1. The relative lack of research studies which examine these concepts.
2. The overwhelming focus on a reductionistic and narrow perspective of power and powerlessness.
3. The predominance of an intrapsychic view of power and powerlessness even though much of the literature itself agrees that the concepts are relational.
4. The complete absence of any phenomenological or hermeneutical studies of power.

Notwithstanding these limitations there is still much to be found in the debate about theories and models of power.

2.3.1. Theories and models of power

Theories of power have been argued from a variety of perspectives: Weber argued that power is evident when one party gets their own way despite opposition; the radical approach is that power is held at the expense of others; functionalist, pluralist, Marxist and Neo-Marxist approaches emphasise the primacy of structure over agency (Wilkinson 1999). Feminist discourse around power tends to be associated with socialist feminism, radical feminism and liberal feminism. The various approaches take different standpoints both in explaining men's power and the means to redress imbalances between men and women (Hugman 1991). Postmodernist approaches however, reject the search for rational explanations arguing that accepting and understanding difference offers an alternative theoretical position (Wilkinson 1999). Foucault (Rabinow 1984, Minson 1986) identified disciplinary power, which focuses on the body. It has two forms; one concentrates on productivity and has seen the development of disciplines such as medicine. The other concentrates on the species and has produced a concern over the health of the population and the introduction of surveillance methods such as registering births and deaths. Disciplinary power with its knowledge and technologies means that people are both objects and subjects. The most intimate areas of a patient's life are open to surveillance. It has been suggested

that from Foucault's standpoint those who are able to lay claim to legitimate areas of knowledge also have the power to shape interactions and who or what is included in the discussion (Du Plat-Jones 1999). Power can however be a variable force in that an individual may have power in some situations but relatively little power in others (Turner 1987, Du Plat-Jones 1999). It is these concepts of power that have informed this thesis.

Just as there are many theories of power, there is a range of models of power: There is a psychological model, where power is seen as a personal attribute. There is a political model, which draws upon the concept of synergy where people or communities work together, all, having equal access to resources. There is also a three dimensional model where power operates to reduce conflict in that people do not consider alternatives to the present order of things. The first two models link power to humanistic perspectives, which see power as being located in the minds and actions of people but fail to identify how these individuals are themselves a product of power (Gilbert 1995).

The development of the concept of empowerment of patients in health care has occurred over the last two decades. Consumerism was encouraged in the 1980s as a challenge to professional domination in the health services, as part of the Conservative government's drive toward individual responsibility in social welfare. Empowerment of consumers would occur across five dimensions: access, choice, information, redress of grievances and representation (Melville 1997). However, in reality consumer choices are restricted by limited option and information that is available is limited to hospital league tables and waiting times. The health service is a monopoly, not a free market and patients are not purchasers (Melville 1997, While 1999).

The concept of consumerism became at that time an integral part of health service rhetoric. Patients were often cast in a passive role as recipients of care, whereas consumers were seen in an active role associated with rights, power and empowerment (Melville 1997). The impression of consumer power was fuelled by initiatives such as the Patients' Charter, quality standards and complaints procedures (Department of Health 1998). The notion of patients as consumers of health care

suggests that they share power with professionals and this sharing relationship is often referred to as a partnership (McDougal 1997). However, in reality there is often an imbalance of power around issues of control and compliance. In some cases empowerment strategies can be used to disempower by delaying decisions, co-opting groups in order to make them ineffective, using a group to validate predetermined plans and by tokenism – minor involvement to demonstrate participation (Musker and Byrne 1997). The emphasis on consumerism has more recently been replaced by the notion of patient involvement and representation in the delivery of health services, patient empowerment is therefore reflected in the current government's policy by documents such as the NHS Plan (Department of Health 2000)

Power has two forms: power to, or power over. Power to, being the actual or potential ability to or capacity to achieve objectives through an interpersonal process in which the goals and means to achieve goals are mutually established and worked toward. Power over requires the acceptance or non-acceptance of authority by subordinates (Hawks 1991). How power is perceived may therefore have an impact on whether there is a will on the part of professionals to empower patients.

2.3.2. Empowerment of patients

Just as there is no consensus on the meaning of power, neither is there consensus on what empowerment is. If a concept lacks a clear definition each person defines it according to his or her personal context, or personal agenda, to give it meaning. Therefore exactness in the scientific sense is thwarted (Gibson 1991, Fraher and Limpinnian 1999). There appears to be two approaches to empowerment described in the literature. The first suggests that individuals, professionals and organisations can empower their clients and colleagues by empowering themselves. The second maintains that power relations between client and professional undermine the empowerment process making it impossible for one person to empower another (Ryles 1999). Although the notion of empowerment of users of health care has only been the source of debate in the last two decades, as a political concept it is not new. Historically, the concept of empowerment has come from the self-help and political awareness movements of the late 1960s/early 1970s. These movements emphasised the raising of political consciousness both in the minds of activists and oppressed communities. Critical social theory, associated with improving the conditions of

oppressed groups can be traced back to the 1920s (Kuokkanen and Leino-Kilpi 2000). From these viewpoints empowerment is a social and political phenomenon that has fuelled considerable discussion in the professional literature in recent years.

At the most simplistic level patient empowerment has been defined as a patient's ability to voice any concerns, ask any questions and make decisions about their medical treatment and care (Melin 1996). Linked to this view is the belief that simply giving clients information and education will empower them (Brown 1997, Vander Henst 1997, Du Plat-Jones 1999), although information is only one factor in a very complex process. The current emphasis on the importance of information giving still implicitly suggests that the information belongs to the professionals and is theirs to give away. It has been suggested that in facilitating information giving, rather than empowering patients, nurses are supporting medical power (Miers 1999). Information giving in the form of health education and health promotion may not fit with professionals' goals for patients.

An autonomous person may do what another person tells them to do, but not because they have been told to do it. Attaining autonomy depends on certain conditions: the ability to make independent choices, freedom from coercion, rational and reflective thought and adequate information and knowledge (Dworkin 1988). Empowerment therefore is a way of creating autonomy. This may mean that strategies such as health promotion, which are seen as ways of empowering clients (Sturt 1999), may be a source of tension when people do take responsibility for their own health and yet choose to act in an unhealthy way (Hugman 1991). On the other hand empowerment of patients has been described as both a process and an outcome.

Empowerment is a social process of recognising, promoting and enhancing people's abilities to meet their own needs, solve their own problems and mobilise in order to feel in control of their own lives (Gibson 1991). However, as a process it is difficult to operationalise and as an outcome cannot be measured in and of itself, although attempts have been made to operationalise and measure empowerment - in men with newly diagnosed prostate cancer (Davison and Degner 1997) and in older people in hospital (Faulkner 2001).

It has been argued that empowerment is a fundamental way of thinking and is not an intervention or strategy. Recommending a set of tactics that if put into practice would bring about an empowering culture is naïve and does not represent a real exchange of power between professional and patient (Martin1998). It has also been argued that professionals such as nurses cannot empower patients, only patients can empower themselves (McDougal 1997).

One way of attempting to empower patients with spinal cord injury is the implementation of goal planning which emphasises a needs driven approach. The emphasis is on involving patients in decision-making and minimising institutionalisation and dependency (Kennedy et al 1991, McLeod and McLeod 1996, Foley 1998, Duff et al 1999, Playford et al 2000). There is evidence that goal planning does help patients feel they have more control over their rehabilitation (Kennedy et al 1996, Wade 1998). Effective goal planning may be the basis for good practice but in itself does not guarantee good practice (McGrath et al 1995). Evaluation of the goal planning process tends to include evaluating compliance with rehabilitation, which does not seem to fit comfortably with the notion of empowerment and implies that power lies with the professional rather than the patient. Relinquishing that power may pose considerable difficulties for professionals. Indeed the findings reported in this thesis suggest this may be the case.

2.3.3. Power, empowerment and health care professionals

Patient empowerment involves a transfer of power from the professional to the patient (Elliot and Turrell 1996). However, people in a position of authority and power rarely conceive the empowerment of others in terms of themselves relinquishing their own privileged position of power (Jacob 1996). Where challenges to professional power occur at an individual level those actions are labelled as un-cooperative, manipulative, obstructive and ungrateful (Hugman 1991).

Nursing, social work and the remedial therapies such as physio and occupational therapy are structured around several aspects of power. Power is structured in formal hierarchies, which are in turn cross cut, by occupational and professional boundaries, relationships between professionals and service users and structures of racism and gender (Hugman 1991). There is much in the literature about nurses empowering

others, but nurses themselves are perceived as being an oppressed group. This is due both to power relationships in health care between professional groups (Turner 1987, Edwards 1997, Oughtibridge 1998), and to the impact of gender issues on relationships between work groups (Hochschild 1983, Turner 1995, David 2000, Valentine 2001).

There is an argument that nurses need to empower themselves before they can empower others (Fulton 1997) but there are dangers in assuming that empowering nurses is the route to empowering patients. Reform may either fall into the trap of professional elitism or fail because it reproduces current power relations in health care (Salvage 1992). The notion that nurses are disempowered is not entirely accurate and although the autonomy of nurses is questionable they have much more freedom of choice and action than patients (McDougal 1997). Nurses who have limited power in their relationships with other professionals may find it difficult to relinquish the power they have in relationships with patients. This thesis suggests that this may be the case in the patient/nurse relationship in spinal cord injury rehabilitation.

It has been argued that reflective practice is a way of enabling nurses to empower patients by encouraging them to be more aware of their attitudes and behaviours in practice (Walker 1998). Empowerment is offered as an alternative to the medical model, which encourages the passive acceptance of treatment and advice, although it can be difficult to impose liberating structures on people. Practitioners such as nurses who have been socialised to be powerless find it difficult to respond to liberating opportunities such as reflection (Johns 1999). Health services today still reflect the professional interests and concerns of the medical profession (Levy 1999). It is clearly not just nurses who may be challenged by patient empowerment: as physiotherapists are also questioning whether they have enough education in the behavioural sciences to equip them to give patients the tools for empowerment (Fosnaught 1997). Empowerment of patients in spinal cord injury rehabilitation is therefore an issue for all the members of the multiprofessional team, but how that team works will impact on the patient's rehabilitation experience.

2.4. The multiprofessional team in rehabilitation

Teamwork by members of different professions has for some time been seen as the cornerstone of rehabilitation (Rinehart 1990, Fountain 1993, Wells and Nicosea 1993, Hoff 1995, Whelan and Hochberger 1996, Scott and Cowen 1997). This collaboration and teamwork been described in many ways, interprofessional, multiprofessional and multidisciplinary being just three terms. However Leathard (1994) suggests that whatever term is used, they all denote learning and working together. When Sir Ludwig Guttmann opened the first spinal cord injury unit in 1944 his philosophy was one of multiprofessional teamwork, encouraging a climate of mutual respect within the team (Guttmann 1976).

Despite considerable discussion in the literature about multiprofessional teamwork there is limited evidence to support claims that team care is desirable, relevant and effective (Halstead 1976, Rowe 1996). There is a political impetus for the development of good team care as a way of achieving improved patient care with The Department of Health defining teamwork as follows:

> To work as a team you need a common aim, means to accomplish a significant part of that aim, willingness to address the remaining problems flexibly and the opportunity and stability to develop mutual trust and respect for each other's contributions (including those of patient and carer). Any system for team working must help and not hinder those processes.
> (Department of Health 1996, p14)

The perceived advantage of a team is that it is a stable alternative to the concentration of power in one individual (Belbin 1981, Ovretveit 1996). However, team membership is often the result of historic staffing decisions and arbitrary fate. Choosing a well-balanced team is rarely possible, except when developing a new team. There is no consensus about which professionals constitute the team in spinal cord injury rehabilitation: the only constant appears to be the physician, with authors citing a wide range of professionals such as nurses, physiotherapists, occupational therapists, social workers, psychologists, speech therapists, respiratory therapists

(Rinehart 1990); recreational therapists (Hoff 1995); dieticians and vocational counsellors (Whelan and Hochberger 1996). With so many professionals attempting to work together it is not surprising that there is considerable scepticism from some authors about the reality of teamwork, for example Nolan et al (1997) suggests that the benefits of teamwork are largely an act of faith and Lenkman and Gribbins (1994) go so far as to suggest that health care institutions do not exhibit cohesive team working, rather they are collections of several professional fiefdoms whose only connections are the heating, ventilation and air conditioning system. Professional roles and boundaries may therefore constitute a major barrier to effective teamwork.

2.4.1. Professional roles and boundaries

The large numeric and diverse disciplinary composition of multiprofessional teams can lead to misperceptions and misunderstandings (Ducanis and Golin1979). These are greater between than within professions because the professional is often not aware of the specific competencies and roles of members of different professions. Overlapping roles, status differences and differing viewpoints can lead to conflict and discord within the team (Torrance et al 1996, Bliss 1998). This may be further compounded by the fact that differing professions may have differing values which may be embodied in formal codes and the theory of the profession – for example nursing values seem to be more individualist whereas social work values appear to be more concerned with collective, structural and political issues (Wilmot 1995). A major problem therefore, is that lack of role definition can make it difficult for the team to function collaboratively (Fountain 1993).

Boundaries between professional groups are seen to be rooted in the perception professional groups have of their role (Hornby 1993, Beattie 1995, Hugman 1995), although traditional boundaries between health care professionals may be under review NHS managers are becoming increasingly keen to explore interprofessional skill mix (Hunter 1992). However, it could be argued that professionals may be unclear not only about the roles and functions of other professionals but also their own roles. There is a great deal of research that suggests this is the case. Occupational therapists have identified difficulties in delineating the boundaries of their role (Sachs and Labovitz 1994), and are unable to differentiate their profession from other health care professions (Lycett 1991), which suggests there is confusion about professional

identity. Professionals have difficulty in clarifying their own role (Weiss 1983, Ovretveit 1994, Benson and Ducanis 1995) and lack clarity in defining other professionals' roles (Lister 1980, Benson and Ducanis 1995, Eppard and Anderson 1995, Davies and Connolly 1995, McGee and Ashford 1996, Long 1996, Waters and Luker 1996). The most commonly cited team relationship is the one that exists between doctors and nurses.

2.4.2. Doctors and nurses

Doctors and nurses are perhaps the 'constants' in a rehabilitation team. However, the relationship between the two groups has been controversial for many years. This relationship is under even greater scrutiny since the publication of the 'New Deal' (NHS Management Executive 1991) to relieve junior doctors of some of their tasks, and the 'Scope of Professional Practice' (United Kingdom Central Council 1992) which some have argued was a vehicle to allow nurses to implement the 'New Deal' (Koefman and Woods 1995). Nurses are facing increased pressure to perform medical activities in order to reduce junior doctors' hours but are seen to lack the assertiveness and identity to influence medical staff and act as independent practitioners (Gee1995).

This balance of power has been cited as stemming from historical, gender based roots (Abel-Smith 1960, Darbyshire 1987, Turner 1987, Walby et al 1994, Sweet and Norman 1995). Studies of the general public (Kaler et al 1989) and students of nursing and medicine suggest that the traditional views of the care (nurse)/cure (doctor) - i.e. doctors prescribe drugs, and nurses administer those drugs - and the gendered divide between nursing and medicine has remained constant throughout the decades (Webster 1985, Ryan and McKenna 1994, Carpenter 1995). Although in reality the distinctions between care and cure are confused and constantly changing (Walby et al 1994). The power difference between doctor and nurse is most clearly seen within a multiprofessional setting, with nurses becoming scapegoats for problems within the team (Warelow 1996).

There is then a great deal of discussion about professional membership of the multiprofessional team. However there is far less written about the patient as a member of that team.

2.4.3. The patient and the multiprofessional team

A problem that has been identified with the use of the word 'professional' is that non-professionals such as patients and carers may become marginalized in an interprofessional context. There is growing pressure for recognition from Government and users, that users and lay carers while not professionals are experts and as such should be involved in interprofessional work (Smith 2000, Thorne et al 2000, Department of Health 2001, McGauran 2001). However, although it has been proposed that patients should be regarded as co-workers whose contributions to health care are equally important as that of health care professionals, the barriers to this happening are lack of physical resources and funding (McLeod 1995). There are contradictions in the rhetoric in policy and professional training and the realities in practice related to limited resources (Tanner 1998).

Decision-making is described as something that is carried out by team members either individually or collectively (Gatlin and Brown 1990, Iles and Auluck 1990, Ovretveit 1995). However, in practice the patient may or may not be involved in the decision-making process (Baker 2001,Sainio and Lauri 2003) and participation may take place at different levels (Roberts 2002).

2.5. Patients as partners: Patient participation in decision-making

Involving patients in their care is seen as a key component of the government's modernisation of the NHS (Department of Health 1999). Participation has been described as occurring on two levels:

1. At an individual level-usually at the level of consultation – this involves patients and carers in decisions regarding their treatment and care and encompasses terms such as shared decision-making and informed choice.
2. The second level is concerned with collective and representational forms of involvement. Here lay people as individuals or groups are involved in strategic decision-making, standard setting and monitoring (Buetow 1998, Milewa et al 1999, Brooks 2001).

As this research is concerned with the first level of participation the literature reviewed reflects that focus.

Participation is a complex notion, with many elements. There appears to be three levels of definition of patient participation within the literature. A simplistic approach, which suggests that participation is about involvement in decision-making but does not define exactly what, this means. The hierarchical approach suggests various levels of participation; and the philosophical approach focuses on patients making decisions. Figure 2 summarises the literature defining patient participation.

The presence of so many approaches suggests an incomplete understanding of participation with little agreement on its meaning between professionals and between patients and professionals (Jewell 1996).

Level of definition	Description	Authors
Simplistic approach	Getting involved or being allowed to become involved in the decision-making process	Brownlea (1987), Guadagnoli and Ward (1998), Maslin-Prothero (2000)
Hierarchy approach	A hierarchy of levels or degrees of participation along a continuum	Ozer (1988), Brearley (1990), Biley (1992), Ovretveit (1997), Hickey and Kipping (1998), Charles et al (1999), Barr and Threlkeld (2000)
Philosophical approach	An approach to health care practice that focuses on an individuals role in care delivery	Wade (1995), Henderson (1997), Cahill (1998), Enehaug (2000)

Figure 2: Patient participation

Of the studies that have considered patient participation in decision-making, very few relate to spinal cord injury patients (Mason (1997, Sallam and Wrightson 1997, Henderson 2003) What work has been done has reinforced the contention that

professionals may not be willing to facilitate shared decision-making. There are several reasons why this is the case. The balance of power in health care relationships is such that participation involves patients who generally have less skill and knowledge than the professionals responsible for making the decision. Patients are also less accountable for the outcome of the decision, or have a more self-interested level of involvement than the professionals who carry ultimate responsibility for the decisions. This can create tensions for health care professionals (Brownlea 1987, McLeod 1995, Elwyn et al 1999). However, closely bound up in the notion of participation is the concept of partnership.

Participation has been called a modern day icon and is a term that is conceptually similar and often used interchangeably with patient involvement, patient collaboration and patient partnership (Cahill 1998). Partnership is perceived as a key factor in patient participation (Abbott 1999, Barr and Threlkeld 2000, Mead 2000). A partnership being an alliance where people work together in mutual respect (Enehaug 2000). However, the apparent consensus about partnership as an uncontroversial 'good thing' has been described as masking a complex and varied cause in which several factors are combined. These factors include:

- Consumerism which drives the need to understand consumers' needs and requirements
- Individual autonomy and responsibility
- The curtailment of professional power
- The emergence of a strong self-advocacy movement.

(Braye and Preston-Shoot 1995)

The current emphasis on participation and partnership is to improve patient outcomes in health care (Department of Health 1999). Active participation is thought to be a significant factor in better quality care (Mead 2000). Patients expect to be given relevant information about their condition, which includes information about treatment options, risks and timescales (Department of Health 2000). Recent concerns about failures in health care systems have prompted commentators to encourage doctors to include patients as active participants in their own care (Snowden et al 2001, Coulter 2002). However, the desire and ability on the patient's part to participate in planning and decision-making may be different to the willingness and

capability of the professionals to include patients in that process (Lund et al 2001). If professionals feel threatened and uncomfortable about relinquishing power to patients this will pose a major barrier to developing participative partnerships (Wade 1995).

It appears then that professionals experience difficulties with the development of partnerships with patients. This thesis addresses spinal cord injury rehabilitation but only Ozer (1988, p56) has offered guidance with regard to degrees of participation in the spinal cord injury rehabilitation planning process:

	Therapist	Patient	% Contribution
Independence	–	Asks for himself Answers for himself	100
Free choice	Asks open ended questions without providing answers	Answers for himself, explores and selects	80
Multiple-choice	Asks by providing several (three) answers'– 'suggests'	Selects answer(s) for himself	60
Forced choice	Asks by recommending (one) answer prior to action	Agrees or disagrees 'yes' or 'no'	40
No choice	Does not ask; prescribes; action predetermined	Compliant (or non-compliant)	20

My research has identified levels of participation for spinal cord injured patients that has both similarities and differences in the levels of participation proposed by Ozer (1988).

It has been suggested that in practitioner-centred care the practitioner attempts to 'fix' patients, whereas patient-centred care involves teaching and guiding rather than 'doing for' patients (Barr and Threlkeld 2000). However, when one considers the meaning of the word guide"– direct, lead, show the way (Oxford Dictionary 1997), this perception of partnership could be questioned. Professionals may be tempted to 'steer' patients into making the decision they think they ought to make by the way they present facts to them (Elwyn et al 1999). Participation may then be something that is difficult to translate into every day professional practice.

2.5.1. Putting participation into practice

It may be concluded from the literature reviewed so far, that changing to a more participative way of delivering health care requires considerable change of attitude from health care professionals. The paternalistic way in which health care is currently delivered can be accused of fostering passivity and dependence (Coulter 2002). However, if it is a complex issue for professionals, it is no less complex for patients: Three continuums have been identified that describe situations that affect patient choice and participation:

1. *'If I am well enough"* a continuum from being too ill to be involved to being well, with greater involvement.
2. *'If I know enough"* a continuum from technical knowledge where the nurse was seen to know best to 'I know best' where patients were actively involved in activities of living.
3. *'If I can"* describes the organisational constraints or freedom that constrict or encourage participation in decision-making. (Biley 1992)

In the field of cancer care there has been a great deal of work undertaken regarding improving cancer patients' involvement in decision making both in Europe and North America (NHS Centre for Reviews and Dissemination 2000, Sainio and Lauri 2003). In one study Canadian women with early stage breast cancer preferred a shared decision-making model because they were afraid of making the wrong decision for which they may blame themselves or be blamed by others (Charles et al 1998). The researchers point out that this finding may reflect the nature of a society where blame is apportioned to individuals who are thought to bring health risks upon themselves by their behaviour. It could be argued that in the UK there is a similar blame culture, which affects both patients and professionals. However, the health care provider is not

responsible for protecting the patient from the consequences of an informed decision and rehabilitation professionals must separate their needs from the patients' (Ridley 1989). It has been suggested that sometimes professionals have vested interests in having their severely dependent spinal cord injury patients perform well for them (Dartington et al 1981). It could be argued that this might be even more so in the case of less dependent patients in a culture that emphasises independence (French 1993).

Even where professionals suggest that they are fostering partnerships this may not be the reality. For example Enehaug (2000) suggests that to create healthy partnerships health care professionals have to leave the traditional way of thinking that they know what is right and that patients are to be informed of the right decisions. In her hospital in Norway a patient/relative panel has been set up, however the panel cannot make decisions, only give advice, so that professionals are still in control of decision-making. This approach to partnership appears to be worldwide: Lord and Church (1998) reflecting on their experiences of partnership in Canada describe a 'meetings as partnership' metaphor. They suggest that while the language of partnership implies equal contribution and equal benefits, the reality is that service users are entering a partnership where more powerful partners outnumber them. However, Spinal cord injury patients have identified that caring relationships with nurses and other professionals have an important influence on their autonomy in decision-making, independence and hope (Lucke 1999).

2.5.2. Patient participation, power and the concept of care

It has been argued that the traditional caring role of the nurse may disempower patients by creating a parent-child relationship. This has been described as 'nutrient power' where power is exercised on behalf of that patient without that patient being involved in the process (Martin 1998). On the other hand the notion of caring can be empowering (Falk-Rafael 1996). 'Empowered caring' facilitates the patient's empowerment in appropriate ways, as it also reflects and encourages empowerment of nurses. It is seen as enhancing the nurse-patient relationship (Rankin 2000).

Caring and curing are often seen as two distinct processes by health care professionals (Joudrey and Gough 1999). Historically, nurses have cared and doctors cured, curing

was thought to require years of education while caring was seen to be instinctive (Salvage 1985). At some points caring effectively crosses over into curing (Walby et al 1994) but with changing patterns of disease the notion of a cure may be inappropriate for many patients (such as those with spinal cord injury) with the concept of care taking on greater significance for those with chronic illness and disability. Caring has been seen as integral to the healing process in that there can be caring without curing, but there cannot be curing without caring (Valentine 1997). It has been suggested that caring has a relationship with helping as it has elements of warmth and genuineness (Barker and Reynolds 1994). However, if this is all it is then it might not be therapeutic. Caring has been seen as so fundamental to nursing philosophy that attempts have been made to identify the concept.

2.5.3. Conceptual models of caring

There are numerous theories of caring which come from three perspectives: philosophical, psychological and anthropological (Forrest 1989).
Leininger's (1984) anthropological approach proposed that care is a universal human trait composed of constructs that include comfort, concern, compassion, stress alleviation, support and trust. These constructs vary in emphasis between different cultures.

From a psychosocial perspective Watson (1988, p 75) describes caring as a science with ten 'carative' factors:

1. Humanistic-altruistic system of values
2. Faith-hope
3. Sensitivity to self and others
4. Help-trusting human care relationship
5. Expressing positive and negative feelings
6. Creative problem-solving caring process
7. Transpersonal teaching-learning
8. Supportive, protective, and/or corrective mental, societal and spiritual environment
9. Human needs assistance
10. Existential-phenomenological-spiritual forces.

Watson suggests that caring is central to nursing and without it nursing has no substance or soul.

On the other hand, Roach (1991) views caring from a philosophical perspective suggesting that caring is not unique to nursing in the sense that it distinguishes nursing from other professions. Rather, it is unique in nursing as the concept that subsumes all the attributes descriptive of nursing as a human, helping discipline. Roach categorises caring under 5 'C's": Compassion, Competence, Confidence, Conscience and Commitment. Care is our human mode of being and when we cease to care we cease to be human. Because caring is so fundamental to nursing identity there have been an increasing number of studies into nurses' perceptions of what caring entails.

Caring is seen as central to nursing and caring is a human need. Caring is the root of nursing history however, despite the attempts to define it as an essence of nursing there is still not an explicit and implicit understanding of what professional caring entails (Radsma 1994).

2.5.4. Nurses' and patients' perceptions of caring

Nurses perceive caring as developing close and trusting relationships with patients (Cody and Squire 1998,Bertero 1999, Beeby 2000, Pejlert et al 2000). However, the emotional closeness required for a caring relationship can be a potential source of stress and burnout (Bignold et al 1995, Chiverton 1997, Roberts and Snowball 1999, Watson et al 1999) and may lead to nurses learning to distance themselves from patients in order to protect them from burnout (Cheung 1998).

Studies into patients' perceptions of caring offer no clear consensus on what patients perceive as caring. Some studies suggest that patients have different perceptions to nurses of what caring comprises (Keane 1987, Valentine 1991, MacDuff 1998), with patients valuing technical competence more than relationships (Hegedus 1999) or in conjunction with a close relationship (Radwin 2000). Schroeder and Neil (1992) Patients with HIV/AIDS were found to value emotional support highly in the form of hugs and smiles but older patients may not see touching as caring and may feel uncomfortable with it (McCann and McKenna 1993).

Caring has been identified as a verbal icon of the movement towards professional identity for nurses (Phillips 1993) yet caring may have a more negative side. Nurses may 'care for' causing disempowerment and dependency rather than 'caring with' to allow a participatory model of care (Nay 1998). Conversely, it could be argued that the bureaucratic health system that nurses work within has resulted in the quantification of health care which has undervalued the art of caring (Thomas and Bond 1990, MacGuire 1991, Butterworth 1996, Fitzgerald 1998). Nurses are not emotionally, socially or economically rewarded for time and energy spent on caring (James 1989, James 1992, Patistea 1999). Where nurses do utilise a model of empowered caring patients are able to become active participants not only in their nursing care but also in their interactions with other health care professionals (Falk-Rafael 2001).

Therefore, empowerment may impact upon both the patient/nurse relationship and the relationships between team members.

2.6. Conclusion

The literature review has revealed that compared to other areas of rehabilitation (such as stroke care and the care of older people) work relating to spinal cord injury is limited. Very little research has taken place in the UK. Most of the research that has been carried out was conducted in other countries – in particular North America where there are likely to be cultural differences and differences in the health care systems. What literature is available has polarised and simplified the complexity of the issue of rehabilitation in spinal cord injury by suggesting that rehabilitation is either a process or an outcome. Research into the effectiveness of the rehabilitation process is problematic because of relatively small numbers and diversity both of condition and patient goals (Inman 1999). Patients with spinal cord injury in the UK tend to be concentrated in a small number of regional services each with their own philosophy and each with different attitudes to outcome measurement. These outcome measurements tend to be concerned with physical function. There have been considerable improvements in outcome after spinal cord injury, which does argue

strongly for the effectiveness of rehabilitation programmes. However, Nolan and Nolan (1998) have suggested that all is not well in rehabilitation, pointing out that there are considerable differences between how professionals and those suffering from spinal cord injury perceive their needs.

Rehabilitation tends to be defined in terms of either process or outcome with structure implicitly implied whereas this thesis proposes that rehabilitation is in fact both process and outcome.

Although the patient's role within the process of rehabilitation has been discussed in the literature there appears to be considerable differences between policy, rhetoric, professional literature and the experiences of service users (Nolan et al 1997). Much has been written about empowerment and how it is a 'good thing,' but the literature suggests that that there are many obstacles that prevent empowerment of patients in health care. These obstacles are created by the current structure and culture of the NHS but also reflect societal and personal structures and attitudes.

Teamworking in rehabilitation is widely regarded as the most appropriate way to deliver rehabilitation but with little evidence to support that view. There is very little work about the multiprofessional team in spinal cord injury in the UK. Work that has been carried out with rehabilitation teams in other specialities suggest that team members have difficulty defining both their own roles and the roles and functions of their colleagues from other professions. This can lead to conflict amongst members of the team. Patients are generally not viewed as members of the team and although they may be consulted about decisions and considered therefore to be participating in those decisions, in reality they may be marginalized because of their non-professional status.

The research reported in this thesis aimed to generate theory and add to the body of nursing knowledge. In this report therefore newly discovered concepts, dimensions of the concepts and relevant propositions will be presented (Fawcett and Downs 1992). The research therefore used the process of induction; that is observing a relationship in several cases and constructing a theory to cover all the cases (Gilbert 2001). It has been suggested that to move nursing practice nurses need to move beyond theoretical

models, which both segment patients and imply a static relationship between nurse and patient (Purkiss 2003). The literature in this review has therefore informed the study. It has fuelled the questions that were addressed – for example, the literature appears to define rehabilitation as either a process or an outcome. This caused me to question whether this is the case or if it is more complex. The literature review has suggested the type of research required – the gaps in knowledge in spinal cord injury rehabilitation suggested that a qualitative approach would enable greater understanding of an area about which little is known. Knowledge would also be gained from the participants' perspective. However, no single theory has been adopted to act as a framework for this research.

There is pressure for further research on rehabilitation, but there is a tendency to argue for research within a quantitative paradigm, measuring quality or outcomes, rather than qualitative research (Pollock et al 1993, Inman 1999 Eldar 2000).
This study is an attempt to fill the gap in knowledge about patient participation in decision making in spinal cord injury rehabilitation in the UK. The research reported in this thesis has taken a qualitative approach to enable this phenomenon to be described from the perspective of patients and professionals. The next chapter will therefore provide a discussion of the research methodology used to conduct this research. Ethnographic techniques will be discussed in the context of data collection and the ethical issues involved through a reflexive account of the conduct of the research.

CHAPTER 3 - METHODOLOGY

METHODOLOGY

The aim of this chapter is to describe the methodology used to accomplish the aims of the research i.e. to identify:

- Differences between patient and professional definitions of rehabilitation
- Patient and professional construction of patient participation
- Patient and professional perceptions of their roles and relationships within the rehabilitation team.
- What supports or constrains patient membership of the team.
- Levels of patient participation in decision-making.

The research design was qualitative and used ethnographic techniques to collect data – interviews were the principal data collection method supported by participant observation.

This chapter will discuss the methodology used to collect the data and the data analysis techniques used to analyse that data.

3.1. Rationale for the method selected

A qualitative approach was adopted for this study as qualitative enquiry is concerned with real-world observations, dilemmas and questions that have emerged from the interplay of the researcher's direct experience, tacit theories and growing scholarly interests (Marshall and Rossman 1995). A strong autobiographical element drove the scholarly interest. As indicated in the preface my interest in studying spinal cord injury rehabilitation comes from many years of working with patients and health care professionals in this speciality. This experience meant that I had considerable insight into spinal cord injury rehabilitation, which enabled understanding of what was being heard and observed. However, I was not prepared for the emotional impact that field research would have on me. A reflexive approach has therefore been taken in this thesis to make my research transparent to reveal the workings of my world. By doing so I hope to bridge the academic/practice gap by questioning my practice, values and

preconceptions (Pellatt 2003a). My challenge was to demonstrate that this interest did not bias the study (Gerrish 2003). As my direct experience stimulated the initial curiosity I had to link that curiosity to general questions.
Qualitative techniques emerge from phenomenological and interpretive paradigms, the emphasis being that there is no clear-cut objectivity or reality, in this approach theory is generated from the data collected (Cassell and Symon 1994). Qualitative research has the following elements (Holloway and Wheeler 1996), and these were the elements of my research:

1) Qualitative research takes the 'emic' perspective – the insiders point of view
2) Researchers immerse and involve themselves in the setting and the culture under study
3) The theoretical framework is not predetermined by the data but derives from it
4) The method includes thick description
5) The relationship between the researcher and research is close and is based on a position of equality as human beings
6) Data collection and analysis interact

There were three main reasons why this research utilised a qualitative approach. Firstly I acknowledge that I am unable to put my own knowledge of the social world aside to achieve objectivity. In an inter-subjective world both researchers and subjects use the same resource to understand meaning (Barnes 1992). Secondly statistical knowledge and an experimental approach are no longer considered appropriate for studying the meanings of the everyday world in which we live. A qualitative approach develops understanding of human experience, which is important for health professionals who focus on caring, communication and interaction (Holloway and Wheeler 1996). Thirdly because as a researcher I am dealing with an intersubjective world of different meanings: policy interventions based on the perceptions of 'objective experts' are neither analytically or politically acceptable (Barnes 1992).

Qualitative methods are often used when there is little known about a domain, or when the research question pertains to understanding or describing a particular phenomenon about which little is known (Fielding 2001). As discussed in the literature review there is very little literature about the phenomenon under investigation in this study i.e. patient participation in decision making about spinal

cord injury rehabilitation in the UK. Although work has been undertaken on roles and relationships within teams, and patient participation in other rehabilitation specialities there are considerable gaps in knowledge about spinal cord injury rehabilitation.

My research therefore has the following characteristics:

- It attempts to understand the entirety of some phenomenon rather than focus on specific concepts.
- It has few preconceived ideas and stresses the importance of people's interpretation of events and circumstances rather than the researcher's interpretation.
- Information was collected without formal structured instruments
- It did not attempt to control the context of the research but rather attempted to capture the whole phenomenon.
- It attempts to capitalise on the subjective as a means for understanding and interpreting human experiences.
- Narrative information was analysed in an organised but intuitive fashion. (Polit and Hungler 1991 p 25)

This study describes phenomena from the 'emic' perspective or the 'native's point of view'- that of the members of the interprofessional team and patients. This approach encourages the researcher to refute his or her own value system and focus entirely on the world of the informant (Hodgson 2001).

The nature of the question being asked in this study necessitated the use of ethnographic techniques: as they allowed me to view all aspects of the phenomenon in the context in which it occurred (May 1997). Differences in perception between the participants and myself could be clarified as they occurred and I was able to understand the issues under study from the participants' perspective. By using ethnographic techniques I was participating with informants within their natural environment (Laugharne 1995). This study was inductive in that it made few implicit assumptions about sets of relationships (Fetterman 1989). My aim was to attempt to understand the meaning behind the actions and beliefs of the people being studied.

3.2. Ethnography

The use of ethnographic techniques enabled the collection, description and analysis of the ways in which the research participants categorised the meaning of their world (Aamodt 1991). The study was designed to explore how participants interpreted their experiences of the world (Williams 1995). The philosophical basis of ethnography has three facets – culture, naturalism and holism (Laugharne 1995).

The philosophical basis of ethnography has its roots in social anthropology, which traditionally studied small alien communities that were seen to share culturally specific beliefs and practices (Baillie 1995, Bailey 1997, Savage 2000). Approaches to ethnography have changed considerably over the last 30 years partly due to the Chicago School of anthropologists who pioneered the study of cultures closer to home than remote equatorial regions studied during the 1920s and 1930s (Hodgson 2001). However, these researchers were studying "deviant" groups and subcultures. Since the 1960s and 1970s ethnography has been used to study and understand every day life (Foley 2002). The goal of this study was to examine a culture by studying people in their natural setting (Leinenger 1987). A culture can be described as a society, a community, an organisation, a spatial location or a social world (Ploeg 1999). The culture studied in this research was a spinal cord injury unit in England. Culture usually consists of origins, values, roles and material items associated with a particular group of people (Byrne 2001b). The research was interpretive in that it interprets and creates meaning, as a social scientist I believe in the importance of understanding human experiences ((Holloway and Wheeler 1996). My research fits with the goals of ethnography in that it attempts to describe a variety of aspects and norms of the patients and staff who inhabit the spinal unit. The focus is therefore on cultural description - what the world is like to people who have learned to see, hear, think and act in ways that are different (Lipson 1991).

Participants were studied in their natural setting because actions and beliefs are seen to be impossible to separate from the social context within which they occur (Laugharne 1995). The philosophy of holism views the cultural identity of a group as

being more than the sum of its parts. Therefore the whole culture was studied (Laugharne 1995, Byrne 2001b).

Ethnographic research techniques therefore, can be seen as away of accessing beliefs and practices, allowing them to be viewed in the context in which they occur (Savage 2000). This study attempted to enhance understanding of behaviour surrounding the organisation of health care and the experience of illness or delivery of health care. This is particularly important in the light of current initiatives to involve patients more in decision-making processes (Department of Health 2000).

3.3. Fieldwork

It has been suggested that fieldwork has an important role in developing and linking theory with practice as theory that is directly linked with clinical experience has far greater relevance to nursing practice (Schwartz-Barcott et al 2002). Fieldwork involves not just the initial access but also the ongoing maintenance of relationships (Mackenzie 1994). Some time ago Field and Morse (1985) described four stages of fieldwork: negotiating entry, selecting informants, acceptance and cooperation and withdrawal from the setting. More recently other research authors have described similar stages in the process (Hammersley and Atkinson 1995, Schwartz-Barcott et al 2002). Field and Morse's (1985) four stages will form the basis for the following discussion of my research methodology.

3.3.1. Phase 1- Negotiating access

3.3.1.1.Ethical approval and access to the research site

The setting for the research was an English spinal cord injury unit. The unit admits both newly injured patients and patients who have been injured for some time who need treatment for spinal cord injury related and non-spinal cord injury related problems. The unit has an outpatient service so that patients can be followed up with check-ups, advice and support after their discharge from hospital. There were several reasons for choosing this spinal unit.1) It is the largest spinal unit in the country and therefore enabled access to a large number of potential participants. 2) It is one of the original spinal units and therefore offered access to patients who have been living

with a spinal cord injury for many years. 3) It was physically accessible to me both in terms of travel and permission from senior staff.

The ethical review process is designed to protect research participants and balance interests, rights, risks and harm (Pickering 1996). The mechanism for ensuring that this happens is the Research Ethics Committee. Ethical approval for the study was gained from the Local NHS Trust Ethics Committee and permission was obtained from the Trust Research Committee. Permission to access patients was obtained from the consultants of the spinal unit. Permission to access staff was obtained from the appropriate heads of department. Participants were provided with a consent form and an information leaflet about the research (Appendix 1). Participants were given a week in which to read the information and decide if they wished to participate. Holloway and Wheeler (1996) have pointed out that qualitative researchers have inherent problems with informed consent in that qualitative research is flexible, the use of unexpected thoughts that arise during data collection and prompts that are allowed during interviews. As I was developing ideas, which were grounded in the data, I was unable to inform research participants of the exact path of the research. Informed consent was therefore not regarded as a once-and for-all permission but was an ongoing process of informed participation by discussing with participants each time we met whether they were still willing to participate. Patients in the high dependency unit were not approached, as they might not be well enough to make a rational decision about taking part in or continuing the research.

I informed participants throughout of the voluntary nature of the participation and assured them that they could withdraw from the study at any time. I tried to be as clear as possible in stating the demands on the time of the participants by telling them how long I expected an interview to last. However, I was also aware that participants might have some feelings of obligation, and that some might feel powerless to refuse or withdraw from the research (Holloway and Wheeler 1996).

In accordance with the Nursing and Midwifery Council Code of Professional Conduct (Nursing and Midwifery Council 2002) all participants were guaranteed anonymity and confidentiality. Qualitative research involves work with small samples and it is not always easy to protect identities (Holloway and Wheeler 1996). Some groups of

professionals have only one or two participants so I have not identified the profession to ensure confidentiality, or likewise where identifying gender may identify the participant. All the names of the participants are pseudonyms. Audiotapes and field notes were kept secure. The only place that participants' names were recorded was on their consent forms, which were kept apart from the data collected. Some people have considered the supervision that a researcher receives as a threat to confidentiality (De Raeve 1996). There was therefore no way that my supervisors could identify participants' identity and there was no typist involved as I transcribed tapes and field notes myself. The audiotapes will be erased once this thesis has been examined. In research where words and ideas from participants are used, full confidentiality cannot be promised. In this study confidentiality meant keeping confidential that which the participant did not wish to be disclosed to others (Holloway and Wheeler 1996). In reality no participants asked for any of their contribution not to be divulged.

Ersser (1996, p 42) suggests that there are four major areas of ethical consideration that arise from ethnographic work:

1. Avoiding or limiting deception
2. Protecting the autonomy of patients
3. Avoiding or limiting intrusion/respecting the welfare of participants
4. Encouraging ethical use of research findings.

The second and third of these covers informed consent, access and confidentiality and have been discussed in this section. The other two ethical considerations will be discussed in the appropriate sections.

3.3.2. Phase two – selecting informants

3.3.2.1.Sampling

The selection of informants was the key to conducting a sound ethnographic research study. The purpose of sampling in this study was to develop and discover categories on the way to developing theory. It was concerned not only with the selection of key informants to give insight into the phenomena under study but also sampling across time and place (Mackenzie 1994). This purposive sampling (May 1997) selected informants who would most facilitate the development of emerging theory. These informants had specific characteristics or knowledge, which would add to theory, therefore enhancing the researcher's understanding of the setting. Many informants

were needed to represent different sectors of the team and to verify data. At the same time the amount of data needed to be of a manageable size for a single researcher. Therefore thirty professionals and twenty patients were selected. This sample was large enough to allow the collection of data until no new information was being obtained. To understand team members' behaviour it was necessary to understand the norms and values of the total system. Therefore the selection process attempted to include patients who were newly injured and therefore at the beginning of their disability career as well as patients who had been living in the community for a period of time. Both male and female patients were recruited. To enable a breadth of experience and perspectives patients were recruited across a range of ages – the youngest was 18 and the oldest was in their 60's. As the age group for spinal cord injury tends to be younger than for other disabling conditions (Meyers 2000) this age range provided a good representation of ages. An important criterion for the health care professional participants was that they were involved in decision-making processes but had a spread of years of experience in the speciality. Male and female professionals were recruited. Valuable informants will not only have experienced the phenomena being studied but will also be able and willing to share those experiences. To ensure that informants were selected that could provide the information required or complement data obtained from interviews and observation potential informants were identified during periods of observation or selected because of their role in the spinal unit. Care was taken however, as informants chosen for their willingness to participate may have their own motivation for doing so (Baillie 1995).

Validity in qualitative research is the extent to which an account accurately represents the phenomena being studied (Clarke and Jack 1998). However, not only is the choice of informants important but also the place and timing of data collection (Mackenzie 1994). This is because although appropriate sampling at the start of the study will increase ecological and construct validity, threats to validity may arise from contextual problems i.e. people act differently in different contexts or timing in that changes occur in practice settings so it is important to see activities over time. Therefore both participant observation and staff and patient interviews were carried out simultaneously throughout the period of data collection.

In qualitative research using ethnographic techniques the categorisation of those being studied as subjects has been rejected in favour of the category 'informant' which originates from the anthropological and sociological roots of ethnography. This suggests that in ethnography the researched take on a more active role as informants whose perspective on the world is the focus of the research rather than the passive role of subject (Baron et al 1995). In my study informants were recruited from health care professionals and patients:

- Fourteen nurses- all female whose clinical grades ranged from E grade to clinical nurse specialist. Nurses at these grades take on the role of named nurse and key workers and who are therefore involved in decision-making processes. To maintain confidentiality the grades of individual nurses are not identified in the report.
- Five doctors- one female and four male whose grade ranged from senior registrar to consultant. At these grades doctors are responsible for autonomous medical decision-making. For reasons of confidentiality neither the grade or gender is identified in this report
- Three occupational therapists (OTs)'– all female whose grade ranged from senior grade to superintendent and who are therefore involved in decision-making processes as occupational therapists and as key workers. To maintain confidentiality the grade of individual occupational therapists is not identified in the report.
- Five physiotherapists – 3 female and 2 male, their grades ranged from senior grade to superintendent and they were therefore involved in decision-making processes either as physiotherapists or as key workers. For reasons of confidentiality the grade of individual physiotherapists is not identified in the report.
- Two clinical psychologists – one male and one female
- One discharge planning co-ordinator – male

To maintain confidentiality the clinical psychologists and discharge planning co-ordinator are referred to as Allied Health Professionals (AHPs) and gender is not identified.

- Eight patients who had been injured for some years and therefore had been living at home since their initial acute injury and had either been readmitted as in-patients or attended outpatients regularly:
    1. George – had been injured for 16 years, had a complete tetraplegia and had been re-admitted with pressure sores. He was also in isolation due to multi-resistant staphylococcus aureus (MRSA) infection
    2. Gordon – had been injured for twenty-eight years, had a complete paraplegia and attended out patients for regular check-ups
    3. Mark – had been injured for forty years, had a complete tetraplegia and had been readmitted for surgery. He was also in isolation due to MRSA infection
    4. Denise- had been injured for twenty-five years, had a complete tetraplegia and had been readmitted for surgery
    5. Mack- had been injured for twenty-eight years, had an incomplete tetraplegia and been readmitted with septicaemia which had led to amputation of one leg. He was in isolation due to MRSA infection
    6. Harry – had been injured for forty years, had a complete tetraplegia and visited out patients regularly for check-ups.
    7. Peggy'– had been injured for forty-four years, had incomplete tetraplegia and had been readmitted with bladder problems.
    8. Martha – had been injured for thirty years, had a complete paraplegia and had been readmitted with a fractured tibia and for surgery on her shoulder.

- Twelve patients who were recently injured and were still in their initial hospital in-patient phase.

1. Mick –patient with complete paraplegia
2. Sam – patient with an incomplete paraplegia
3. Marina –patient with complete tetraplegia
4. Jemma- patient with complete tetraplegia
5. Phil – patient with complete tetraplegia
6. Margaret – patient with incomplete paraplegia

7. Clive – patient with complete paraplegia
8. Basil – patient with complete tetraplegia
9. Shaun" – patient with complete tetraplegia and was in isolation due to MRSA infection
10. Laura – patient with complete paraplegia
11. Dave – patient with complete tetraplegia
12. Lillian" – patient with complete paraplegia who had also had a mastectomy.

I have therefore selected participants on the basis of their experience with spinal cord injury rehabilitation. Informants have been described as any person willing to talk to the researcher (Field and Morse 1985). I therefore undertook some preparatory work to build up a rapport with potential participants by working in clinical practice with them and participants were selected on their willingness to participate in the research. I did have to be aware at this stage and throughout the research of my dual role of nurse and researcher. I had to be clear about both my identity and also that of the patients as this can pose a dilemma (Holloway and Wheeler 1996). When interviewing patients I did not wear uniform. I did have to wear uniform when I was undertaking participant observation, but my uniform was very different to the one worn by the nurses on the ward – my uniform is a tunic and trousers whereas the ward nurses wear a dress. This was an advantage because it signified that I had a different role to the ward nurses and usually patients would ask me why I was dressed differently. I then had an opening to explain what I was doing on the ward. In my professional role people are seen as patients whereas in the researcher role they are participants or informants. It may be difficult to settle the different components of this professional identity. Likewise patients may not have understood this dichotomy in my role. A reflexive approach was therefore taken to the research and the writing of this thesis to make explicit any issues that arose from this dichotomy.

By inviting a selection of patients with differing levels of injury and differing lengths of time since injury, and likewise a range of professionals with differing levels of experience I was able to cover a broad spectrum of spinal cord injury experience.

It has to be acknowledged that there will be 'reluctant informants' (Field and Morse 1985) which can be compared to a non-response rate in quantitative research. Such

bias has to be identified but some lack of response is to be expected. Clear description of those refusing to participate or the circumstances that created any failure to obtain information increases the credibility of the study. I only had one patient who did not wish to participate, although he had at first expressed an interest in the research. I subsequently discovered that he sustained his injury while undertaking a criminal activity. Two other patients were interested in participating but were discharged before this could happen. These patients lived some distance away and I did not have the resources to travel to undertake interviews. I originally found it difficult to recruit occupational therapists and at first only one participated. However, when I approached the occupational therapists a year later, when more staff had joined their team, two more were willing to participate. All the staff groups that comprise the multiprofessional team in spinal cord injury management in this unit were represented in this study.

3.3.3. Phase 3 – Acceptance and Cooperation

Data were collected from various sources – my research journal, interviews and participant observation.

3.3.3.1.Research Journal

Throughout the research study I kept a research journal where I wrote notes to myself as an integral part of the research process. This journal, as suggested by Maykut and Morehouse (1994), recorded insights, beginning understandings, working hunches, recurring words or phrases, ideas, questions, thoughts, concerns and decisions made during the research process. This journal was kept from the beginning to the end of the research project, during each phase of the research. However, although journal keeping is an essential activity in interpretive research it requires analytical skills to move it beyond mere documentation. Reflexivity occupied a central place in this study (Pellatt 2003a) and involved intimate interaction with text to make some sense of the meaning (Williams 1995, Manias and Street 2001). In the process of undertaking the research I attempted to undertake ongoing self- critique and self-appraisal (Koch and Harrington 1998). Throughout the course of this research I conducted an ongoing 'reflective conversation' (Mulhall et al 1999) that addressed three questions:

1. How have I affected the process and outcome of the research?

2. How has the research affected me?
3. Where am I now?

The answers to these questions will be addressed throughout this thesis in an attempt to be open about the conditions in which the report was created (Mulhall 1997).

3.3.3.2. Interviews

The interview may appear to be a straightforward way of finding things out and has been described as "a kind of conversation with a purpose" (Robson 1993, p 190). However, such simplicity is deceptive. It soon became apparent that research interviewing is a skill that can be complex and daunting (Rose 1994, Jones 1997).

The aim of the interviews was to elicit the structures that guided participants' world-views (Marshall and Rossman 1995) and describe the cultural knowledge of the informant (Sorrell and Redmond 1995). Three types of questions: descriptive, cultural and contrast, were introduced in sequence. Descriptive questions are usually open-ended and referred to as 'grand tour questions' as they give the researcher a general view of the informant's perspective on the culture. For example, my first question to professionals was "Describe your experience of being a member of the interprofessional team in spinal cord injury rehabilitation." Structural questions ask for more specific cultural information – for example "Who would you say leads the team?" Contrast questions provide the ethnographer with the meaning of various terms in the participant's language for example "How would you define rehabilitation?" The interview began with descriptive questions then structural questions were added. Descriptive and structural questions were then used concurrently. The interview ended with contrast questions to uncover specifics about the cultural meanings in the data (Marshall and Rossman 1995, Sorrell and Redmond 1995).

The interviews were semi-structured to enable me to focus on issues of importance to the research question, probe and clarify comments made by the participant (see Appendix 2 for interview schedules). At the same time the participant was able to address issues that they felt to be important and to talk about them in the way they chose (Rose 1994, Fielding 1994). The interviews ranged in length from thirty minutes to an hour and were all tape-recorded.

It was important to consider the ethical issues involved in interviewing. I was aware that I needed to distinguish between right and wrong and understand my duty and obligation. Balance is a component of ethical interviewing; balance being the potential good that may come from a research study, matched by the potential harm the study may cause a participant (Smith 1992). The topics addressed in the interview did not appear to be ones that would cause distress to participants but an interviewer can never be sure that what appears innocuous to them might not trigger off painful feelings to the participant. Sullivan (1998/99) points out that the probing nature of an interview is an invasion of a person's psyche. For some participants this may be therapeutic, providing a valuable opportunity to express themselves (Ersser 1996) and indeed some participants did talk in depth about their feelings and frustrations. However, for some it may produce possible risks to their health. I did reflect on whether I was stirring up what might be strong emotions and feelings in participants but most of them thanked me for listening or said they had enjoyed the experience. For example, one patient said at the end of the interview:

"You've made me think; made me talk a lot...I've enjoyed this, I hope you're successful with it."

For all of the patients the interview was not my only contact with them, I had worked with them giving nursing care before the interview, after the interview or both. This helped me to build up a rapport with them and enabled some of the participants to elaborate on what they had said in the interview when we met again.

Literature about conducting interviews discusses how the physical environment must be conducive to the purpose: that the room must be warm and comfortable with no distractions (Jones 1997); that the venue must be private, quiet and free from interruption (Clarke 1999). However, I found that this was difficult to achieve in practice. Clarke (1999) suggests that the time and venue should be at the convenience of the participant. Some members of staff preferred to be interviewed in the University building that is on the hospital site. This meant that I could book a room in the building that would be private, we would not be interrupted plus I could provide a drink for them. However, other members of staff preferred to be interviewed in their

offices at work and this was much less satisfactory. I discovered that even in a closed office there could be interruptions from telephones, bleeps or people entering the office. I also did not realise how noisy offices in a hospital can be with ambulance sirens wailing, noisy air conditioning and footsteps in the corridor outside.

However, the most problematic was interviewing patients on the wards. Some patients were in side wards or were in wheelchairs and therefore could be interviewed in a ward office although there were some problems of noise and interruptions as mentioned above. Some patients were confined to bed and could not be moved elsewhere, so I had to pull the curtains around and compete with noisy televisions, visitors talking to other patients and staff entering or shouting to the patient from outside the curtains.

As stated I used a tape-recorder to give a permanent record of the entire interview although there is a danger that some participants may feel intimidated by the presence of the recorder and may take longer to 'open up' (Rose 1994). However, this did not appear to be an issue, as participants appeared to be quite relaxed. No participants refused to be recorded and some were concerned that the tape-recorder was in the best position to pick up what was being said. Clarke (1999) points out that the researcher should be familiar with the recording equipment and spare batteries and tape should be carried. Rose (1994) suggests having a few 'test runs' and I piloted my interview with a nurse and a patient who I knew well. This was useful both to finalise my interview schedule and also one participant showed me how to use the long play facility on the recorder to prevent the tape running out halfway through the interview. However, I did find myself sometimes during the interviews trying to listen to the tape to make sure it was still running. I did not attempt to take notes, as I could not have concentrated on listening and writing at the same time.

It became clear that effective facilitative communication skills and interpersonal sensitivity are essential elements of interviewing (Gordon 1997/98). Nurses are often attracted to this methodology because they perceive it to be an extension of the skills they use in every day practice and that there may be some truth in this. I have had considerable experience of interviewing patients, students and applicants for jobs, although those interviews had a very different focus. My previous experience did help

me to build up a rapport with participants thus enabling them to tell their own stories. However, there were issues that arose that made me realise that research interviews are not like social discourse. The researcher has power over the participants, shaping the agenda for the interview and possibly drawing the participant back to the focus of the interview if they stray (Price 2002). For example if I felt patients were starting to stray from the point I would try and incorporate what they were saying into my next question to attempt to gently bring them back to the focus of the interview. When interviewing patients if the wrong questions are addressed the patient's health and well-being may be compromised. Price (2002) says that, the way in which information is shared in a research interview differs from social conversation. Instead of individuals sharing thoughts equally the researcher becomes a detective searching for key information. In a research interview participants are helping the researcher and may have their own agenda for participating. I did find I was taken aback when occasionally participants would ask me what I thought about an issue, or what other people had said about the issue. As I was concerned not to 'lead' them during the interview, I asked them if they minded if we spoke about it at the end of the interview, as I wanted to record their views. I then had a chat with them after the interview – when we would have a social conversation about the issue.

The qualities of a good interviewer have been described as:

- Has the capacity to listen intelligently
- Is enthusiastic regarding the topic
- Is interested in what the (expert) interviewee has to contribute
- Can share joy and sadness
- Is compassionate
- Is totally focussed at all times and can handle contradictory information and complex situations with sensitivity.

(Grbich 1999 p 89)

I hope that I was able to fulfil all these criteria. Certainly I was interested in what the participants had to say and the topic is one that I am very enthusiastic about. As I became more experienced I found that I developed my listening skills. I hope I was sensitive to joy and sadness and was compassionate. Certainly the feelings that were

aroused from the interviews made me examine my own practice as a nurse (Pellatt 2003a). I have certainly learnt a great deal about listening and about concentrating on what is being said by participants.

When preparing for the interview planning is necessary in the form of guidelines to oneself about the areas of importance (Rose 1994). I had an interview schedule but it was a very loose framework with the participants able to introduce other points that they felt were important. Hutchinson and Wilkinson (1994) suggest that an interview involves an internal self dialogue in that the researcher is not only listening but also thinking about what question to ask next and how to frame it. As a relatively inexperienced research interviewer I had to try and listen to the participant without worrying about what the next question was and how to phrase it. Care has to be taken in the way questions are phrased to avoid leading the informant. The aim is to ask questions in such a way that the participant gives their own answers in their own words and also enables them to diverge into other areas of experience. On reflection I may have made the odd comment that could have been construed as leading, such as "It can be very frustrating." I may also by smiling, or nodding in agreement with a comment have unwittingly 'led' the participant. I also found that people differ in the way that they respond to being interviewed (Rose 1994). Although most of my participants, both patients and staff, needed very little prompting or active guidance, some tended to answer with yes or no, or a single word and required more probing to elicit fuller answers. For example this happened during an interview with a doctor:

Me: "Who would you say leads the multidisciplinary team?"
Participant: *" The doctor."*
Me: "Why would you say that?"

I then received more information about why the participant felt the doctor led the team. On the other hand, now that I have gained greater experience in interviewing I am aware that the original question despite having the appearance of an open question was in fact was a closed question (Simmons 2003). The answer was clear-cut to the participant who responded to a closed question with a closed answer.

These issues highlight that the essential interview skill is listening (Ely 1991). However, I found that this active listening was very demanding and it became clear to me through the course of the project that I could only undertake a maximum of two interviews a day; otherwise I could not make best use of the interview. This could be seen as an ethical issue in that the participant has given up their time, is sharing confidential and sensitive information and it would be wrong not to make best use of the time and information by being too tired to concentrate.

Silence is a valuable interview strategy (Fetterman 1989) and learning how to tolerate the empty space between question and reply is difficult. As a nurse who has experience of interacting with patients and interviewing prospective nurses I have learnt to wait and not to 'jump in" and clarify a question when a silence falls. This was something that I did have to concentrate on at first, until I became more confident so that I gave participants the opportunity to fully consider questions before answering.

Ending the interview was something I found quite difficult. The researchers responsibility is seen as ending the interview constructively (Jones 1997). There should be clear understanding of what has taken place during the interview and a process for checking whether the participant has any concerns about the interview. At first I simply closed the interview by saying that they had answered all my questions and thanking them. However I realised that this was a weak ending and could sound quite dismissive. So I changed my conclusion by asking them if there was anything they thought I might have asked but didn't. This provided some very useful additional data. For example I asked one of the nurse participants if there was anything else she thought I might have asked but didn't. She replied:

"One of my: one of my (sic) *bugbeary things is..."*

Which continued with further discussion about power relationships in the multiprofessional team and the nurse's role in supporting the involvement of patients in decision-making. So as my interview technique developed throughout the course of the study so also did my self-awareness as a researcher.

It became apparent that there is significant investment of 'self' in qualitative interviewing (Smith 1992, Holloway and Fulbrook 2001) which can make the research subjective. To be objective researchers must not influence the research by their own value judgements. However, this can be difficult to achieve because of the closeness of the participants and the researcher and because the researcher is the main research tool. Therefore I had to be aware of my own mindset regarding the research topic, particularly when I was formulating the questions, because my own knowledge and experience helped to shape them. I had to be aware that my values, the fact that I had been a member of the group being studied and my experiences, even my personality could affect both the collection and analysis of data. However, as Schutz (1994) points out an openly subjective approach allows researchers to be partners with participants and to use their own experiences and reflections to uncover valuable meaning and to find a different type of objectivity. Although I recognised that I began with biases and preconceived notions about how people behave and what they think (Fetterman 1989), I was able to control those biases to focus the research effort. In fact some of my findings have surprised me and caused me to look into areas I had not thought of prior to data collection (Pellatt 2003a).

What also surprised me was the emotional impact that listening to patients had on me. If as Kleinman (1991) suggests field researchers feelings not only affect the research, but also become part of the process itself then it is important to record those feelings in the report. I found that when listening to patients I experienced a range of emotions (Coffey 1999).

I have felt sad when a newly injured patient with tetraplegia said:

"I really can't picture the future being in a wheelchair at all."

I felt angry about the health care system that prompts a patient who has been living with a complete tetraplegia for over 30 years to say:

"I'd like to say that life as a spinal injury is like a game of roulette and it's becoming more and more like this that some bets you'll win and some you'll lose and zero's

going to come up for all of us eventually...if you're in the right place at the right time you'll get away with it, if not you've had it."

I felt respect when a newly injured teenager said:

"So I can sit back and say oh well this has happened to me, moan, moan, moan, or I can say it's happened to me, get on with it, work hard in here and get out and try whatever I've got left of my life get it back together again."

Fieldwork has been a personal journey of self-discovery (Coffey 1999). I had assumed that having been a practitioner for so long I would not be so emotionally affected by patients' feelings. This may say something about how I worked as a practitioner – always busy, talking to patients on a fairly superficial level – and for the first time I was able to sit down and talk to patients for up to an hour. When I trained more that 35 years ago we were told 'not to get involved' and to suppress our feelings (Hector 1965). Although today it is recognised that nursing involves emotional labour as an important aspect of the caring role (Bolton 2000), emotions are still seen as something to be managed and suppressed (Reynolds et al 2000). However, this research gave me the opportunity to really confront what patients feel and to experience those feelings myself (Pellatt 2003a). As ethnography should have a 'funnel' structure, being progressively focussed over its course (Hammersley and Atkinson 1995), understanding my own feelings has enabled understanding of the informants' feelings and in turn has enabled the repositioning of focus with regard to the data (Mulhall 1997).

3.3.3.3. Participant Observation

This study employed participant observation to explore from the inside the social reality of the people being observed (Holloway and Wheeler 1996). The aim of the participant observation in this study was to examine interactions between individuals i.e. between staff and patients and between members of staff. It also allowed the opportunity for expanding and clarifying issues arising from semi-structured interviews both on my part and for informants. On more than one occasion informants would think about what they had discussed in the interview and continue the discussion or add to it when we met again during a period of observation. For

example one patient who I interviewed was discharged home. When she was readmitted some months later she was keen to update me on how her life had improved since I last saw her.

I would spend one day a week in the spinal unit carrying out participant observation throughout the period of data collection. Having its origins in anthropology and sociology, participant observation generates in-depth knowledge of a culture or subculture. Traditionally a standard typology of four types of participant observation, classified according to the amount of involvement the researcher has in the research setting has been described (Mulhall 2003): complete participation, participant-as-observer, observer-as-participant and complete observer. Most of the observation in this study was carried out as a participant–as-observer so that the participants were aware of my role as a researcher and nurse. In this situation the expectations of my behaviour that are associated with these roles may have conflicted with each other rather than coincided (Boswell 1992). In the nursing role one is perceived as a carer, counsellor and educator whereas the researcher role is one of investigation (Holloway and Wheeler 1996). There can be some disadvantages to this type of observation in trying to do two jobs at once. Where meetings were being observed I took the role of observer-as-participant with the majority of my time spent observing with minimal participation in the work role. This role caused less role conflict. Lathlean (1996) suggests that the former implies comparative involvement and subjectivity whereas the latter implies comparative detachment and objectivity.

However, it has been suggested that it is becoming increasingly common for researchers to be part of the social group they intend to study (Bonner and Tolhurst 2002). There are a number of advantages to being an insider which include: having a greater understanding of the culture being studied, not altering the flow of social interaction unnaturally, and having an established relationship with participants which promotes both the telling and the judging of truth. Certainly, I am an insider in that I am a spinal cord injury nurse – I understand the terminology and the physiology of spinal cord injury. I was accepted as a member of staff and had a rapport with many of the participants. However it could also be argued that I was a 'marginal native' (Gerrish 1997) in that I am no longer a full team member as I have moved into teaching and am not therefore involved with the day-to-day work in the Unit. The fact

that I am no longer fully immersed in the every day work of the unit enabled me to prevent over-familiarisation and therefore control assumptions about what I was observing.

Data were collected by writing field notes where the participant observer's task is to record what happened without inferring feelings to the participants, and without inferring why or how something happened (Maykut and Morehouse 1994). As I was working in the clinical setting I could not make copious notes but I tried to excuse myself from the setting and jot down key words relating to the observation that I could then write up in full later.

To organise the observational research I adopted Silverman's (1993) five stages – beginning research, writing field notes, looking as well as listening, testing hypotheses and making broader links. One way to assemble data is to start out with a set of very general questions so during my observations my initial questions were: "What is going on here?" "What are they saying to each other?" "How are they interacting with each other?"

Observation was carried out in ward areas and in offices and sometimes with several people around a bed. In most of the situations observed I knew the actors, some very well and by the same token I was well known to them. I have to acknowledge that my presence may have affected the situation being observed. I also have to acknowledge my own previous experiences (Koch and Harrington 1998). I had to be aware that professional experience is a source of theoretical sensitivity and the more professional experience one has the richer the knowledge base and insight to draw upon in the research. However, this experience can block the researcher from seeing things that have become routine or obvious (Strauss and Corbin 1991), such as the conduct of a ward round. What I found in this case was that when observing a multidisciplinary team meeting I felt empathy for a nurse in a nurse-consultant interaction as the interaction seemed to bear out Warelow's (1996) observation that it is in the multidisciplinary team meeting that the power difference between doctor and nurse is most clearly shown. I could remember being in very similar situations in the past. However, my experience is from some while ago so for me they are not routine, enabling me to view these occurrences from a researchers perspective. Also, as Steier

(1991) highlights, ones own experience of similar situations can inform or provide further questions. Another important issue to be considered with regard to participant observation was the ethical consideration.

3.3.3.4. Ethical issues related to participant observation

A major ethical concern with participant observation is whether those in the research field are, or remain aware of, being research participants and are in a position to give informed consent. Moore and Savage (2002) argue that in the complexity of health care situations it is naïve to assume that everyone from whom data may be collected can be informed to the same extent, or know exactly to what they are consenting. Gaining consent may therefore be an ongoing process. As I have already discussed I used consent forms for participants in the study. However, there were sometimes other people who were not the main actors (other members of staff) and although where possible I introduced myself as a researcher and explained the purpose behind the study it was not practical to gain consent from everyone who was involved tangentially in the study. Gerrish (1997) notes that because the research takes place in natural settings the researcher' control over the setting is limited. For example in my research I had no control over what might happen in the field"– patients' timetable for the day, the workload of the staff, timing of visits from staff such as physiotherapists and occupational therapists or the arrival of patients visitors. It is little wonder then that carrying out observation fieldwork has been described as challenging (Kennedy 1999) and problematic (Sherif 2001), if not impossible (Kite 1999).

The difficulty lies in establishing and negotiating the boundaries for a partial insider: boundaries are often ambiguous and are constantly shifting. Sometimes in an attempt to provide an account of the participants' world from their perspective I found that the personal demands on the researcher could be overwhelming (Bonner and Tolhurst 2002). The researcher's notions of self intersect with those of the people being studied in many ways, which can affect the formulation of knowledge and its interpretation (Sherif 2001). However, observation provided the whole dimension to data analysis that cannot be captured from interview alone. Observation allowed the examination of behaviour and the interactions between individuals in a setting that informants may not be able to describe in an interview: thus allowing aspects of practice that would otherwise be difficult to access to be explored (Kennedy 1999).

By utilising both interviews and participant observation as methods of data collection I was able to develop concepts to understand the beliefs and practices of a culture, in fact as the spinal unit is a small and to some extent separate unit within a larger hospital it could be viewed as a subculture. The interviews allowed areas to be explored with participants, allowed them to tell their stories and provided in depth information about beliefs and practices. The participant observation enabled me to make sense of the context in which those beliefs and practices were occurring. Using both methods of data collection enabled the various phenomena as perceived by participants to be examined and represented as accounts (Berg 2001).

3.3.4. Phase four – withdrawal from the setting

When I reached the stage that theory was developed sufficiently to focus on missing information to fill in gaps in the developing theory and confirm the theory, I prepared to leave the setting. It was after leaving the field that the final phase of data analysis took place. Coffey (1999) suggests that leaving the field also means leaving people and perhaps part of yourself. It also marks the closing of a chapter in one's life and I recognised that I was unlikely to ever have the opportunity to have such in-depth interactions with staff and patients again. However leaving the field also meant that I was at the beginning of a new phase, the analysis and writing up. It brought both relief that I was another step nearer the completion of my thesis and sadness at the changing of the relationships I had made. I would be returning to my nurse/lecturer relationship and therefore less able to access patients' and staff's deeper feelings and emotions.

3.4. Data analysis

Data analysis in this study was not a distinct phase of the research: rather, the initial analytic process was embedded in the process of recording and analysing field notes and interviews and also fed into the research design and data collection (Hammersley and Atkinson 1995). Making sense out of the data seemed at times to be a monumental task. The data were in the form of narrative texts derived from interviews, written descriptions of observations in field notes and reflections on the

dynamics of the setting in my research diary. I found that these records were voluminous – fifty audiotapes and a full notebook. Patton (1990, p 371) says that:

> Analysis brings moments of terror that there's nothing there and times of exhilaration from the clarity of discovering ultimate truth. In between are long periods of hard work, deep thinking and weight lifting volumes of material.

Patton (1990) goes on to say that each qualitative study is unique therefore the analytic technique will be unique. The initial task in analysing the data was to find concepts that helped make sense of what was going on in the scenes documented by the data (Hammersley and Atkinson 1995). However to enable this to happen the tapes and field notes had to be transcribed.

3.4.1. Transcribing the interviews

It is assumed by some research authors that the researcher will have a typist to transcribe the tape directly into the computer (Field and Morse 1985, Morse and Field 1996). However, others (Maykut and Morehouse 1994, Appleton 1995, Rose and Webb 1998) see transcribing one's own tapes as an opportunity to relive the interview and become familiar with the data. I listened to each tape, transcribed each myself and then read each transcript several times to familiarise myself with the data. Estimates for transcribing an hour-long interview are four to six hours (Johnson 1995a) to ten hours (Maykut and Morehouse 1994). I found these timescales rather optimistic, as I am a two-finger typist. I transcribed the tapes into handwriting first and then typed them into the computer. Although this was a tedious procedure it meant I became very familiar with my data and was a very worthwhile exercise.

As an inexperienced typist I had to be aware of the errors that can occur during transcription. These can be as simple as inaccurate punctuation, or as serious as mistyped words that change the entire meaning of a sentence. To avoid some of these pitfalls ideally the researcher should be the interviewer and transcriber (Easton et al 2000). So this was another reason for my spending considerable time transcribing the tapes. Once the tape was transcribed I was able to listen to it again, check it with the transcript and thus correct any errors.

I ensured that I kept a hard copy, which was the working copy, a copy on the computer hard drive, and a copy on disc of each transcript plus the original tapes in case of unforeseen disasters (Johnson 1995a).

Field notes from the participant observation were also transcribed using the above format.

In recent times a number of computer software packages have been developed to speed up the process of coding qualitative data and to search and retrieve data. However, in most PhD studies the data set is not large and therefore the additional work of data management may not be justified (Webb 1999). Although it felt as though the quantity of data in this study was vast, in relation to other research it was not. I found that 'Webb's osmosis method' whereby conducting the analysis by hand gives a 'feel' for and intimacy with what participants have said and done led to an almost automatic process of analysis. The manual analysis carried out in this study was an important learning experience. To make the process manageable files were created using Microsoft Word. Morse and Field (1996) suggest that for medium size data sets coding can be quite comfortably performed with a word processing programme. In reality it was a combination of manually coding but storing the categories on computer files instead of paper files.

3.4.2. Ethnographic Analysis

Ethnographic analysis is the search for patterns in the data by reducing them to their component parts (descriptive analysis) and the explanation of how the component parts fit together according to some rule (theory). This study utilised the traditional approach to ethnographic data analysis where the researcher holds pre-existing theoretical interests and these interests guide the questions and observations (Boyle 1994). These sensitising concepts are those that the analyst brings to the data and have their origin in theory or research literature, providing a direction for the investigation (Patton 1990). So for example, a sensitising concept used in this study was 'patient participation'. Analysis involved switching backward and forward between the 'etic' perspective (my assumptions, ideas questions and explanations) and the 'emic' point of view (observations, interviews – the data generated from the participants) and testing the former against the latter (Boyle 1994). So at first the data appeared to

indicate that patient participation was something that did or did not happen. However, as the former was tested against the latter it emerged that there were different levels of patient participation. Participants seemed in some instances to think participation was happening but in reality the data suggested this was not necessarily the case. Analysis was inductive in that the patterns, themes and categories emerged from the data rather than being imposed on them prior to data collection and analysis (Patton 1990).

Therefore my comprehension of ethnographic techniques increased as data collection increased, as Morse (1994) suggests:

- Comprehension is complete when the researcher has conducted enough participant observation to describe fully the behaviours and actions of the participants and to describe the events, incidents and exceptions from an emic point of view. The focus is on the experience of participants.
- The process of coding facilitates synthesis - theorising by identifying beliefs and values in the data and by linking these with established theory. New explanatory models and theories may be obtained in the course of analysis.
- Retextualisation is achieved by forcing the theory to a level of abstraction. The degree of abstractness determines the generalisability of the theory.

I have attempted to achieve abstraction of theory in this study by developing models that identify orientations and strategies of various related kinds (Hammersley and Atkinson 1995). The underlying principle was one of making sense of what is going on in the scenes documented in the data.

Analysis was an iterative process in which cultural ideas that arise during fieldwork are transformed, translated or represented in a written document (Thorne 2000). Iteration is an interpretive/interactive field-based approach, which can comprise several levels of analysis (Grbich 1999). It involves sifting and sorting through pieces of data to detect and interpret thematic categorisations, searching for inconsistencies and contradictions about what is happening and why (Thorne 2000). As outlined by Grbich (1999 p 231) the data were analysed using the following levels of analysis:

- Ongoing preliminary analysis;

- Thematic analysis; and
- Coding.

3.4.2.1.Ongoing preliminary analysis

Data from interviews and observations were transcribed as soon as possible after they were collected. Self-assessment comments were added, highlighting any misunderstandings, lack of clarification or issues to be addressed in subsequent interviews. For example, I added comments as I began to realise that I needed to end the interviews in a different way. Hammersley and Atkinson (1995) suggest several readings of the data to become thoroughly familiar with them. Doing this enabled me to look for patterns, anything that was surprising or puzzling, inconsistent or contradictory. For example, on the one hand participation was articulated as being a feature of the rehabilitation process, but the way participants were saying it happened in practice contradicted the notion of participation. The aim of the preliminary analysis was to critique the data as they came in to identify gaps in the information and to start utilising various concepts and frames to see whether they shed light on the issues being identified in relation to the research question (Grbich 1999). Hammersley and Atkinson (1995) have pointed out that sometimes, analytical concepts arise spontaneously in that the participants themselves use them. This was the case with one definition of rehabilitation when two participants used the term 'toolbox' to define rehabilitation.

I attempted a summary of themes every three interviews or observations and continued this preliminary analysis until the fieldwork was completed. My supervisors and I were then sure that as broad a picture of the topic as was realistically possible had been achieved.

3.4.2.2. Thematic analysis

Once I was convinced that the picture of the topic was complete I discussed my interpretation of emerging themes and issues with my supervisors.

Thematic analysis of the data is summarised in Figure 3:

Activity	Example
Contextualisation of tentative themes from preliminary analysis and creation of file.	Patient participation
Each file examined for theme classification systems made up of categories that divide an aspect of the world (Patton 1990)	Patient participation in decision making
Each system examined and propositions generated. These propositions were laid across all other identified themes and system to see whether there were more complex aspects and associations that needed to be incorporated	Patient participation in decision-making related to power relationships between professionals and patients within the spinal unit

Figure 3 - Thematic analysis

Data were de ntextualised and recontextualised by sorting and sifting the data. The transcripts were cut and pasted into a series of fragments that were then regrouped under thematic headings (Boyle 1994).

The data, rather than concrete units directly descri ticip nts often indicated the themes (Morse and Field 1996). When identifying themes relating to rehabilitation the 'toolb erment' definition were very near the surface of the data. The 'gettin c together' definition took much longer and required considerable reflection on what exactly participants were saying. However, once identified it was an important concept that linked considerable portions of the interviews together.

3.4.2.3. Coding

Coding both began the analysis and went on throughout the analysis. Codes are labels that are put against pieces of the data (Punch 1998). Byrne (2001) suggests there are five elements to good coding:

1. Labels;
2. Definitions of what each theme concerns (the characteristics or issues constituting each theme);
3. Descriptions of how to know when each theme occurs (how to 'flag' themes);
4. Descriptions of any qualifications or exclusions to identifying themes; and
5. Examples both positive and negative to avoid confusion when looking for themes.

Coding took place to develop a broad range of themes, classification systems, propositions and concepts. The data were checked against these codes to see if they 'fitted'. The developed codes were then used to frame the remaining data. It has been suggested that a disadvantage of coding schemes is that they become a straightjacket from which it is difficult to escape (Silverman 1995). Care was taken not to force the data into predetermined frames and to ensure that the frames emerged from the data. The first step was to look for recurring regularities. These regularities formed the basis for initial sorting of information into a category. Coding allowed the identification of patterns in the data (Guba 1978). There are two main types of code: descriptive codes and inferential (pattern) codes. The early labels were descriptive codes, which allowed me to get a feel for the data. Later codes were more interpretive and pulled material together into smaller and more meaningful units (Punch 1998). Categories were judged by two criteria: 'internal homogeneity' and 'external homogeneity' (Guba 1978). The former concerns the extent to which the data in a category 'dovetail' in a meaningful way. The latter concerns the extent to which differences among categories are bold and clear. A large number of unassignable or overlapping data is seen as a fault in the coding system. However, in this study there was little data that were unassignable or that overlapped.

The data were returned to again and again and as this was occurring at an early stage, simultaneously with data collection although not a grounded theory study could be seen as a variant of the constant comparison method (Rose and Webb 1998, Walsh 1999). In constant comparison the coded concepts are refined, extended and cross-referenced with the data as a whole and related to each other (Smith and Biley 1997). Punch (1998) suggests that comparing is essential in identifying abstract concepts and in coding. At the first level and higher level of coding the researcher arrives at the

more abstract concepts behind the empirical data by comparing different indicators in the data. It is therefore essential for conceptual development.

Codes were derived from d[illegible]mining each unit of data for words or phrases (Morse and Field 1996). Fo[illegible], when asking patients what they thought their role was [illegible] abilitation process some patients talked about having to put in a great deal of effort and that might mean accepting pain. At first I labelled this category 'Work hard, push myself to my limit.' However as I read the transcripts again I became aware of phrases such as, *"The harder I work, the quicker I get out is the way I look at it." "If it's painful, you've got to have a certain amount of pain." "It entails pushing yourself I think. It means accepting a bit of pain here and there."* Thus the theme was labelled 'no gain without pain.' Metaphors can be a powerful way of communicating findings (Patton 1990), however I was aware that I had to take care not to overuse metaphors or manipulate data to fit the metaphor. Another metaphor that was used was 'Why grandma what big teeth you've got,' to communicate the data about hidden paternalism in patient/professional interactions.

As previously mentioned the search for themes involves both the discovery of commonalities and how the themes are patterned. Polit and Hungler (1991) suggests that questions should be asked about whether the theme applies only to certain subgroups, in certain contexts or at certain periods. For example, with regard to healthcare professionals and their role there were themes such as 'difficulties crossing from an acute care philosophy to a rehabilitation philosophy' that arose only in the nursing subgroup.

3.5. Rigour

All research methodologies have their limitations (Clark and Jack 1998). The limitations in qualitative research tend to arise from the in-depth nature and the interactive researcher/subject relationship (Marshall and Rossman 1995). It is important to consider the trustworthiness of this research. In health care research, which has traditionally used conventional quantitative methods, qualitative research has been criticised for lacking scientific rigour. The three criteria being:

- Reliability – the consistency of research findings and the extent to which a similar process would produce the same results;
- Validity – the extent to which a study measures what it purports to measure; and
- Generalisability – the degree to which the findings can be applied to other settings

(Clarke and Jack 1998)

It has been argued however, that the evaluation of rigour in qualitative research has been borrowed from the quantitative paradigm, and that rigour in qualitative research should be recontextualised (Koch and Harrington 1998). I have therefore, included a reflexive account which signposts issues that arose during this research to readers of the research who can decide for themselves whether the text is believable and plausible. This will allow both consumers of the research and fellow researchers to determine the authenticity of the research (Bailey 1997). If rigour is recontextualised the following terms are used for addressing issues of reliability and validity in qualitative work (Appleton 1995):

3.5.1. Truth Value – is measured by its credibility. To do this data and the conclusions are taken back to their source and people asked whether they find the results plausible. This is seen to improve face validity (Grbich 1999). Some authors are adamant that data should be returned to participants in an attempt at rigour (Morse and Field 1996, Cutcliffe and McKenna 1999). However, member checking can be problematic (Koch and Harrington 1998). There were practical problems in that most patients had been discharged and it was not feasible due to lack of resources to trace them up to a year after their interview. Also most of the more junior staff had left and two of the senior grades had retired. Appleton (1995) describes how she discussed her interpretations with two of her informants. I similarly discussed my findings with two patients and two professionals who concurred with my interpretations.

3.5.2. Trustworthiness – relates to the extent to which data provide insights, knowledge and understanding of the meanings, attributes of the people being studied (Bailey 1995). The qualitative approach enabled in-depth study, which has yielded

both insight and understanding. Once the patterns, linkages and explanations through inductive analysis had been explained it was important to look for rival or competing themes and explanations or negative cases (Patton 1990). When developing themes for patient participation in decision-making I initially identified that patients felt they were involved. However, when I revisited the data it became clear that what participants were describing were variations of paternalism. As Patton (1990) points out when well written this part of the report reads like a detective story in which the researcher looks for clues that lead in different directions and tries to sort out which direction makes the most sense, given the clues that are available.

3.5.3. Applicability – is related to external validity or the generalisability of the findings and the representativeness of participants, tests and situations. The term fittingness may be more appropriate and is supported when readers view the study findings as meaningful and applicable to their own experiences (Appleton 1995). In this study the observation and interview data were constantly referred to during theme development. I also had supervision from two very experienced researchers during each stage of the process. As Barbour (2001) points out multiple coding of entire data sets is usually prohibitive in terms of cost and effort, but is useful to have someone else look at segments of data or emerging coding frameworks. This has been a core activity of some supervision sessions.

3.5.3. Consistency – the repeatability, replicability or stability of a study in terms of the clarity and accuracy of the final research report. Morse and Field (1996) suggest the development of an audit trail to clearly document the researcher's decisions, choices and insights. This thesis has therefore been written reflexively to give the reader sufficient detail and information to check the decision trail. Two pilot interviews were conducted to develop my interviewing skills, thus increasing interviewer reliability. All interviews were tape recorded to increase reliability.

3.5.5. Neutrality – the freedom from bias in the research study. By leaving a clear decision trail auditability is achieved. By writing reflexively (Pellatt 2003a), describing each stage of the research process, explaining and justifying decisions I have attempted to recognise my biases and preconceptions and how this may have

affected the collection and analysis of data. A clear report will allow readers to make their own judgements.

Data analysis has identified a number of themes that address the stated aim of this research. In the next chapter the results of this data analysis related to the definitions of rehabilitation articulated by patients and professionals is discussed by interweaving the findings with the interpretation. A model of rehabilitation is presented and the relationship of the three identified definitions as either process or outcome discussed. The concept of an end point to rehabilitation is also discussed. The model is also examined in the context of associations with power and power relations.

CHAPTER 4 – DEFINING SPINAL CORD INJURY REHABILITATION

DEFINING SPINAL CORD INJURY REHABILITATION

One of the aims of this research was to identify differences between patient and professional definitions of rehabilitation. The objectives being to identify the definitions of rehabilitation among professionals i.e. doctors, nurses, physiotherapists, occupational therapists, clinical psychologists and care managers and patients. In this chapter findings from the data analysis will be presented and interpreted. The three definitions of rehabilitation articulated by patients and professionals will be discussed. Also, three definitions of the possible end point to rehabilitation emerged from the data.

4.1.Definitions of rehabilitation

This chapter will identify both professional and patient definitions of rehabilitation and put them within a context of power and power relationships. These definitions form a model that will underpin the findings discussed in the following chapters. The findings from my study suggest that patients and health care professionals perceive spinal cord injury rehabilitation in three ways with three rehabilitation definitions emerging: "toolbox", "picking ones life up" and "empowerment" definitions.

4.1.1. The 'Toolbox' definition

A toolbox approach in the context of research enables the researcher to manipulate tools from each research approach in ways to take advantage of the benefits and minimise the constraints (Manias and Street 2000). Participants in my study described the tools as physical and psychosocial skills that patients can utilise to live as independently as possible:

'I would say it's giving them the skills to be able to live as independently as possible. I like to think that rehabilitation is a toolbox. That everybody comes in according to their level of injury, the toolbox will be a certain size and it's our job to put as many tools as possible into this toolbox that they're not going to use just now but really for the rest of their lives."(Physiotherapist)

Although in my study other professional groups, particularly nurses, used the concept of providing a range of skills to patients, two physiotherapists used the term "toolbox".

For patients, physiotherapy played a key role in providing the tools for this toolbox:

'Mainly the physio – they try to get me independent." (Jemma, newly injured patient with tetraplegia)

The physiotherapist is identified as one of the most important members of the team, second only to the physician because they teach independence by helping the spinal cord injured person to regain and maximise strength in muscles and joints (Senelick and Dougherty 1998). Physiotherapists in many specialities see themselves as being involved primarily with physical movement (Miller et al 1999). From the early days of rehabilitation at the spinal unit under study there has been considerable emphasis on providing patients with physical skills to enable them to function in the community. Over two decades ago Bromley (1981) provided a chart depicting the skills needed to move from dependence to independence. These skills taught by physiotherapists include strength, balance, mobility, and transfers (for example from bed to wheelchair and vice versa). Although Bromley also included social activity the emphasis was very much on physical skills underpinning the psychosocial aspects of rehabilitation.

There has over the past two decades been considerable emphasis on functional outcomes in rehabilitation practice. These functional outcomes may be physical, concentrating on self-care and activities of daily living (Yavuz et al 1998) or they may be psychological (Piazza and Foote 1990). Professionals are seen as key determinants in successful rehabilitation and they convey powerfully their expectations and values

to disabled patients by the way they interact with them (Scullion 1999). Glass (1999) sees rehabilitation programmes as endeavouring to provide spinal cord injured people with the skills necessary to return to the community safely and with the ability to move forward and progress.

It could be argued that the emphasis on the toolbox approach by both patients and the health care professionals has its roots in the historical development of spinal cord injury management by Sir Ludwig Guttmann. This is illustrated by the foreword written by Sir Ludwig Guttmann in Bromley (1981):

> Actually, it is the detailed programme of physiotherapy, so instrumental in developing the remaining capabilities of paraplegics and tetraplegics, which helps them in their social reintegration into the community as useful citizens. (Guttmann 1975, Foreword in Bromley 1981)

This could therefore be the root of the 'toolbox' definition and could explain why the whole range of professionals and patients so commonly articulated it. Certainly this approach to rehabilitation was seen as being of considerable practical benefit by patients in an earlier study of spinal cord injured patients (Oliver et al 1988). In that study the rehabilitation process was seen as providing a 'golden rule'; a set method of doing things (that identified patients as having been rehabilitated at a particular spinal unit) that patients followed for the rest of their lives.

Patients in a study carried out to identify what people with spinal cord injury believed to be the fundamentals of rehabilitation (Smith 1999a) identified that rehabilitation involves the emotional, physical and practical skills needed for living and this was echoed by patients in my study:

I think it's enabling you to make the most of what you've got through various ways, practically rather than physically. I mean it's what you can end up doing in the real world. (Shaun, newly injured patient with tetraplegia)

In the spinal unit studied, and other spinal cord injury units and rehabilitation units across the country, systematic goal planning has been introduced to enable patients to

monitor and plan their rehabilitation needs (Duff et al 1999). This may also have a bearing on the emphasis placed by patients and professionals on the functional outcomes of rehabilitation. In the spinal unit studied goal planning is well established and has been operating since 1992. Goal planning is a behavioural intervention strategy, which involves the multidisciplinary team and the patient in negotiating, and establishing goals based on the individuals needs (Kennedy et al 1996). The goal planning process involves 11 areas of need assessment, which cover physical, psychological, social and functional aspects of living (Foley 1998). The aim of goal planning is to provide a wide range of skills necessary for reintegration into the community (MacLeod and MacLeod 1996). Goal planning is also seen as a way of maximising the therapeutic potential of the rehabilitation environment (Kennedy et al 1991), and of increasing patient compliance (McGrath et al 1995).

So, given the history and philosophy of the Unit it is perhaps not surprising that there is such a heavy emphasis on the toolbox definition by both patients and professionals.

4.1.2. 'Picking Up One's Life Again'

For some of the participants in this study rehabilitation was picking up their lives where they left off, getting back to the real world or to normal living. As an occupational therapist said:

'It's just getting back to where you used to be. It's a state of mind: it all happens in your head.'

In stroke rehabilitation regaining involvement with normal life in such things as family roles and responsibilities, social activities, lifestyle and employment are of crucial importance (Burton 2000). For some of my participants this was important to them:

'So try and as much get back to a normal life, be it that you might have to accept that certain things won"t be the same.' (Sam, newly injured patient with paraplegia)

Chronic illness has been described as a lived experience that requires a permanent alteration in an individual's way of life and involves permanent deviation from the

normal (Price 1996). Paterson (2001) has identified a Shifting Perspectives Model in which some people with chronic illness hold the burden of illness in the background, this behaviour may be seen as "denial" but it enables the patient to sustain a feeling of well being that permits them to live as they desire. It is possible that the notion of picking one's life up again is part of the process of working through the experience of illness and injury and could correspond to the concept of hope identified by Morse and Penrod (1999) where people see 'the light at the end of the tunnel.'

A patient who had been injured for only two months articulated this perspective.

"I actually don't intend it to make a lot of difference. I'll take up flying and get back to work. I'm sure it will have its ups and downs but yeah I've got a good family around me, so..."

Work has been described as the backbone of many people's lives as it provides some definition of who we are (Palmer et al 2000). And some participants saw returning to work as part of the process of picking up ones life:

'Well Guttmann defined rehabilitation as making a person a taxpayer again.'(AHP)

'Getting me as independent as possible and when I go back into the real world of work" (Basil, newly injured patient with tetraplegia)

However, it has also been argued that this emphasis on normality reflects societal views about health and illness. As Radley and Billig (1996) point out to be a 'good' patient those suffering from disability must claim to recover normality. The person may construct a normal everyday identity in which the extraordinary is made ordinary. The notion of normality, where people conform to a standard way of living and behaving, is seen as a consequence of the power exerted by healthcare professionals to fix an identity and define and construct the behaviour and experiences of patients (Hughes 1999, Gastaldo and Holmes 1999). There appears to be tension between what the participants are saying about picking up their lives and getting back to normal life and the critical stance taken in the literature about normalisation. For

the participants in my study it is almost as if life in hospital is life on hold and real life starts again when patients leave hospital. Patients pointed this out:

"It's what you can end up doing in the real world rather than what you can do in hospital which is a world that is theoretical." (Shaun, newly injured patient with tetraplegia)

"You still get the feeling of being institutionalised no matter what. Because you are in hospital and the meals are set out at the same time every day. All that will change when I get home..." (Marina, newly injured patient with tetraplegia)

In the area of employment after spinal cord injury the reality is that gainful employment, as a rehabilitation goal is often not achieved. In a small study carried out in the UK (Tasiemski et al 2000) barriers such as inaccessible workplaces, transport and lack of suitable housing close to work were the main factors cited by spinal cord injured individuals as adversely affecting their employment. Oliver (1996) has also cited transport and lack of suitable housing as a barrier to employment while pointing out the importance of employment in active social participation.

Active social participation in the form of voluntary work was quite noticeable in enriching the life of one patient. I had interviewed Denise – a woman who had been injured for twenty five years- earlier in my study and she had talked about being angry at how difficult it was to get any help out in the community, and how she felt she had little say in decisions that were made about her. A few months later she was readmitted, I was carrying out participant observation on her ward and was helping her bathe. She asked me how my research was progressing and then went on to explain that since I had last spoken to her she was doing voluntary work with the Citizens Advice Bureau organising their files. She said that she thoroughly enjoyed it and that they were so pleased with what she was doing that although they could not pay her they were giving her little gifts. Denise said she felt good being able to do something useful.

For Denise, normality in the form of playing an active role in her community had made a difference to her self-concept.

Humpage (2001) calls this "getting back to life" and Boothe (1999), a person with spinal cord injury, calls this achieving normalcy. This concept is possibly the most complex to define as getting one's life back means different things to different people. The notion of normalisation has been around for many years in the care of people with learning disabilities. It has been suggested that it has a far wider remit, which is relevant to other client groups. Normalisation means offering disabled people patterns of living, which are as close as possible to the rest of society (Spalding 1995). In Norway rehabilitation is seen as being concerned with both normalisation and optimisation and this requires professional and non-professional collaboration in environmental and individual changes (Wyller 1997). However, much of the discussion on normalisation seems to focus on providing an 'ordinary life' i.e. a life in the community, not in an institution, for people who for many reasons have not had access to an ordinary life (Mittler 1988, Chappel 1992). Spinal cord injury patients have been leading ordinary lives until the their injury and most have home, family and job networks already established. So normalisation may not be the most appropriate description of this definition.

Normalisation is also seen as a form of coping in that the individual learns how to tolerate the effects of chronic illness. In this sense the term refers to a feeling of self worth. Normalisation as a form of coping involves a process of 'bracketing off' the impact of illness so that its effect on the person's self identity remains slight, or of treating the illness as 'normal' in order to incorporate it more fully into the persons identity or public self (Williams 2000). This seems to have some links with the notion of self-concept. Self-concept may change due to disability. Yoshida (1994) describes how the disabled self is the person with a spinal cord injury. The non-disabled self is the person prior to spinal cord injury.

Rehabilitation is seen as a way of maintaining continuity with the non-disabled self of the individual. Self-esteem has an important part to play in this context. In a small qualitative study of spinal cord injured individuals participants identified resuming old hobbies with revised methods or techniques as an example of their own personal contribution to a sense of positive self-esteem (Brillhart and Johnson 1997).

4.1.3. Empowerment

Empowering care is advocated in a number of professional and governmental guidelines where it is seen as a vital ingredient in the provision of quality health services (Faulkner 2001); yet empowerment was espoused much less by all participants

Leino-Kilpi (1999) defines empowerment as being close to the concepts of mastery, management, coping, adjustment and locus of control but notes that it has a special emphasis on the inner feeling of having control over one's own health life. Of the participants who articulated this definition, some saw it as a process and others as an outcome. Empowerment can be either a process or an outcome. As a process it can help people to assert control over their own lives, as an outcome it reflects a quality or a property (Gibson 1991). For the participants who articulated this discourse this control over one's life enabled decision-making and self-determination:

'You would hope that you had got somebody well enough both physically and psychologically to make decisions for themselves.'(Doctor)

Sandstrom et al (1998) defined empowerment as an outcome and used quantitative tools to measure empowerment of 17 individuals with spinal cord injury. They found that the subjects of the research had a strong perception of control or influence in their lives. This study was small and limited by the fact that participants were recruited from a Spinal Cord Injury Association or a Paralysed Veterans of America Education and Training Centre. However, participants in my study echoed the authors' point that in order to be a full participant in a rapidly changing society individuals with disabilities need the skills and abilities to adapt and lead in their homes and communities:

'Rehabilitation is to be able to go back into the community, is to have confidence. And it is the communication with people to be able to instruct carers as well. I'm able to instruct them now confidently."(Marina, newly injured patient with tetraplegia)

Rehabilitation professionals have been criticised for exhorting disabled people to function with the help of equipment; to push their own wheelchairs, to dress

themselves, toilet themselves, shop and cook for themselves and so on. Disabled people on the other hand are much more concerned with being in control of the processes by which their personal mobility is ensured, to decide who will dress them, when and what clothes they will wear and so on (Oliver 1999). This was articulated by one of the participants who had been injured for many years:

'I think to confidently lead your life – not getting in and out of cars but knowing what car to buy, adapting your own lifestyle to your needs." (Gordon, patient injured 20+ years with paraplegia)

Disability writers have argued that rehabilitation should not be the only goal of care for disabled people. Independence is about personal control and control over one's life rather than doing things for yourself unaided (Richardson 1997). Four criteria for independence have been defined by people with disabilities: First, not living in an institution; second, not being dependent on the good will of family members to meet basic needs; third, being able to make important decisions about daily life knowing they will be carried out and fourth, being able to do meaningful work, preferably for an income sufficient to be self-supporting and to buy necessary services (Wendell 1996).

Two personal variables are significant in empowerment within both the family and the community. These are mastery and self esteem (Itzhaky and Schwartz 1998). Mastery is related to feelings of control of the environment and of the future. Self-esteem relates to how valuable a person feels in relation to others. Mastery has also been cited as being linked to empowerment by community psychiatric nurses (Tilley et al 1999) Self-esteem has also been identified as a feature of empowerment in clinical practice by nurses (Vander Henst 1997). However, empowerment has been described as an abstract concept that takes on different forms in different people and within various contexts and as such may'be difficult to measure (Gibson 1991).

Nurses make up the largest group of health care professionals. However, there is a considerable body of literature that identifies nurses as a disempowered group in relation to other members of the multiprofessional team (Fulton 1997, Fatchett 1998,

Du Plat-Jones 1999, Johns 1999, Rankin 2000). It is difficult for professionals to empower others if they themselves do not feel empowered.

Some of the nurses in this study had strong feelings about this:

"Everybody looks upon the OT and physio as professionals but nurses aren't...nobody seems to understand what the role of the nurse is. Everybody thinks it goes back to dear old Flo mopping the fevered brow. I do get angry, very angry."

"They (nurses) *are not the free agents that maybe the OT or physio is, they can sort of organise their time as a therapist. I will see this patient then, I will do this then and the nurses very much have to fit in with the routine requirements that is imposed by others.""*

It has also been suggested that the paternalistic nature of medicine and health care means that professionals are unlikely to readily give up the power that they have (Melville 1997). Nurses may see themselves as having little power but they have much more than patients do and therefore may be unwilling to relinquish what power they have (McDougal 1997).

Some patients in my study were very aware of an unequal power relationship between nurses and patients:

"I do see it with nurses with me and I do see it with other patients that they don't treat you with the respect that you want to be treated with...you feel guilty almost if you ask them why the decisions are made and I think that's really wrong...I feel as though I'm a little girl again."

(Jemma, newly injured patient with tetraplegia)

On the other hand it has been argued that nurses cannot empower patients: only patients can empower themselves (McDougal 1997). So it was interesting to observe this same patient at 9am one morning having dressing practice with an OT. While this was happening the ward clerk received a phone call from the patient's physiotherapist asking if she could be at physiotherapy at 10am. Jemma said no and the ward clerk

relayed this to the physio. The ward clerk then came back and again asked Jemma if she could be at physiotherapy at 10am. Jemma again said no, because she wanted to have her breakfast after dressing practice. This message was relayed to the physio. The ward clerk came back once more and again asked Jemma who again said no she would not be in physio at 10am. This time the message was relayed and the phone put down. Jemma was demonstrating the concept of the empowerment discourse by making the decision about the time of her therapy and not letting someone else dictate her programme.

To participants who espoused an empowerment definition of rehabilitation there was an end point when this is achieved:

'Rehabilitation is about bringing their lives back together and in terms of power and control aspect there is an end point to which people would say 'I have learned all you can teach me and now I'm going to do it my way.'' (AHP)

However, mastery requires having skills both physical and psychosocial to achieve mastery (Jarrett 2000). So it could be argued that the 'toolbox', the 'picking ones life up again' and the 'empowerment' definitions are not mutually exclusive in that the process of learning and developing skills leads to empowerment and mastery. However, Oliver (1999) has sounded a warning that professions need to adapt their practice to help disabled people to achieve autonomy and control in their lives.

Some participants articulated more than one definition which also suggests that the three definitions are not mutually exclusive: for example Harry, a patient with a high tetraplegia had been newly injured in the days when Sir Ludwig Guttmann was being very positive about the importance of learning survival skills:

"He (Guttmann) *said survival always revolved around the patient learning as much about themselves as they could."*

For Harry, skills such as being able to sign his own name and use a telephone were vital to being able to take control over his life:

"Anything that you can learn to do for yourself that you don't have to ask somebody else to do. In other words take control of your life as much as possible."

Harry saw this independence and control as crucial to picking up one's life again:

"I suppose fundamentally the object of rehabilitation would be to rehabilitate the person to become as independent as possible and to return them to as similar lifestyle as they possibly could prior to their injury."

So for Harry all three definitions of rehabilitation apply to his experience of spinal cord injury rehabilitation.

Some health care professionals also saw rehabilitation as encompassing all three definitions; one nurse had difficulty in defining rehabilitation:

"You know as I walked up the road I thought she's going to ask me what rehabilitation is (Laughs). *I find it really hard to sort of...I mean you can talk about the practicalities I mean physically teaching someone to overcome their disabilities to care for themselves...One of the things we might think is important is achieving a good quality of life or satisfaction with life. Being in control, being in control of your carers."*

Rehabilitation medicine has been described as being as much a concept or philosophy as an exact science (Marks 1997). This lack of clarity has made defining rehabilitation difficult and this has resulted in the emergence of various definitions over time.
In a recent study that explored team working in the rehabilitation of patients with fractured neck of femur, rheumatoid arthritis and stroke, rehabilitation was identified as emphasising the:

> Maximisation of role fulfilment and independence in one's environment including adaptation (personal, social and environmental) to any difference between desired and achievable roles (Long et al 2001, p14).

So although I have identified that three discreet definitions of rehabilitation emerge from the data, for some of the participants in my study rehabilitation encompasses one, two or three definitions. It could be argued that where a person is either in their patient career or their professional career may affect their perception of what rehabilitation is:

Peggy had lived her life with incomplete tetraplegia for 44 years and had helped her husband set up a successful business. She had over the years gained a great deal of experience and control over her life:

"After a few years in a wheelchair if you're not confident, I think you are, I think you leave (the spinal unit) *with a high level of confidence that you're an OK person. You're not just somebody who"s in a wheelchair that doesn"t matter, who can be passed over."*

However, the situation that she now found herself in: widowed, living alone and developing physical problems related to aging with a spinal cord injury caused her to concentrate on a toolbox approach to rehabilitation as a way of helping her to maintain her independent lifestyle for as long as possible. The skills she now needed in her toolbox were transferring on to a toilet in a more energy efficient way and managing a suprapubic catheter (a urinary catheter that enters the bladder through the abdominal wall). She had also had to attend a course to learn dog handling skills as she had joined a 'dog for the disabled' scheme, where dogs are provided as companions for disabled people. For Peggy both physical skills and emotional skills were needed in her toolbox:

"That idea of rehabilitation is (sic) *as very important as the physical side I think. You need that emotional thing wherever it comes from."*

So definitions are not static and patients may move from one to another as they progress through their lives, particularly as their circumstances change. It may be that professionals also change their perceptions of rehabilitation as they gain experience of working in the field. However, it needs to be recognised by professionals that rehabilitation may have a very different meaning for some patients. Some patients

might see rehabilitation as a means to a cure for their condition. Palmer et al (2000) advise that spinal cord injured individuals' rehabilitation should be innovative but that as yet there is no cure for spinal cord injury. Professionals need to be clear about the possibilities and the limits of rehabilitation when dealing with patients:

'I thought rehabilitation was basically recovery in effect.' (Phil, newly injured patient with tetraplegia).

It could be argued that for patients like Phil none of these definitions fit because they have not yet started moving forward in their career as a person with a spinal cord injury.

4.2.An end point to rehabilitation

Just as there were three definitions of rehabilitation, there were three definitions of the possible end point to rehabilitation and these can be seen as fitting in to the overall typology previously outlined. The most commonly articulated definition was that there is no end to rehabilitation. For some participants however there was an end point that was more a state of mind than physical. Others articulated that patients required input from professionals throughout their lives but that this may not be rehabilitation per se. It could be lifelong learning or adapting to changing needs, as people got older. The perspective articulated depended on the individual's definition of rehabilitation.

4.2.1.There is no end point to rehabilitation

The notion that rehabilitation does not end for individuals with spinal cord injury has existed for some time (Trieschmann 1988).
Some participants in my study echoed this feeling:

'I think that this is only the start really. It's almost like doing your driving test you know: once you've passed it although you can say you can drive you don't actually learn to drive until you're out on your own in the car.' (Nurse)

'No I don't think so no, there's always going to be something to learn or something you need to get over. It's all a learning process as even in normal life you've always got something to get over.' (Clive, newly injured patient with paraplegia)

In the rehabilitation literature the focus of rehabilitation when the patient is living out in the community is maintenance and emphasis on independent living and social integration (Eldar 2000). In stroke rehabilitation the Corbin and Strauss' chronic illness trajectory framework has been suggested as offering a long-term perspective on patient recovery. By moving away from a short term, curative model of rehabilitation a long-term focus is more likely to equip patients with the skills and knowledge to be able to cope with life after stroke (Burton 2000). Some participants did feel that rehabilitation was a long-term process:

' We may think they have finished their rehab programme and they think that they are rehabilitated but in fact when they go out in the community they have to learn more and new things and rehabilitation continues." (Nurse)

To some extent the notion that rehabilitation never ends could be seen as there being a need for patients to add to and develop the tools in their toolbox. Some participants also suggested that learning and adapting were all part of normal life:

"No if you talk to patients they actually say that themselves. It happens to all of us irrespective of whether or not we have a spinal cord injury." (Nurse)

4.2.2. There is an end point to rehabilitation

Rehabilitation is a period of personal change and growth and should enable effective coping in spinal cord injured individuals. Spinal cord injury patients in the USA have identified that it took between 1 to 3 years to regroup by confidently returning to their previous lifestyle after the injury. When this happened they were then able to take responsibility for self-direction by exploring long-term goals and the methods for achieving them. They 'made the best of things' and realised that 'I am still me' (Brillhart and Johnson 1997). Psychologically then rehabilitation may end with reconstruction and realisation:

' As regards mental rehabilitation, I think that stops when you accept it and decide you are going to progress or stay in the doldrums." (Lillian, newly injured patient with paraplegia)

'Probably isn't as soon as you leave hospital, probably many years after when you've settled down and got used to it. I'll still be doing stuff and getting on with life.' (Dave, newly injured patient with tetraplegia)

The notion that rehabilitation does end at some stage may well link with the empowerment and the 'picking one's life up again' definitions and when used by some participants was seen as finite:

"Oh yes...go back to life as much as I can.""Laura newly injured patient with paraplegia.

"Yes there does come a time when you've got to say you are rehabilitated...and confidence I think is a big thing, getting your confidence back in people and situations."" (Gordon, patient injured twenty+ years with paraplegia)

4.2.3.Continuing professional involvement: Rehabilitation or Something Else?

Neal (2001) outlines how chronic illness is often composed of a combination of co-morbidities with patients being maintained at home, returning to hospital only for exacerbations of the chronic condition. It could be argued that this is the case in the ageing process for people with spinal cord injury. In the impairment trajectory people with spinal cord injuries often experience a process of gradual deterioration after many years of relative stability (Zarb 1993). Many older disabled people feel that their independence is threatened by physical and/or personal changes associated with ageing. For orthopaedic patients it has been recognised that the success of short-term rehabilitation will change with advancing age and that new functional needs will require team expertise to provide an ongoing programme. Periods of reassessment and retraining may be necessary (Heim et al 1998). Palmer et al (2000) in a guide for spinal cord injured people point out that the changes in health, strength and flexibility

that come with the aging process can compound the challenges of coping with spinal cord injury and this was an issue recognised by participants in this study:

'I'm not sure whether rehab is really the right term for that but they need support, they need information and reassessment but I don't think it ends.' (Nurse)

Jarrett (2000) points out that health care professionals have tended to emphasise acute care and cure. However, in chronic illness they need to work collaboratively with the individual and their family and carers to decide whether acute care or interventions more suited to ongoing management are required. This was recognised by a participant in this study:

'No, no because you've got to cope with getting old and you've got to cope with a partner dying perhaps, adapting to life changes. Maybe rehab's the wrong word, rehabilitation is still the thought of getting better, maybe as opposed to coping with what the situation is.' (Nurse)

On the other hand as spinal cord injury affects a much younger age group than most disabling conditions (Hammell (1995) suggests the most frequent age at injury is 19 years) many patients are not only adapting to life with a disability but are also still developing life skills as young people:

'Is that rehab or normal living and maturing?' (Nurse)

From the point of view of what should be offered by spinal units Hammell (1995) sees an important role for spinal units in offering follow-up care and support. However, rehabilitation is seen to end when the patient leaves hospital.

'We may not think of it as rehab in you know, the term rehab but re-evaluating their needs every time they come in.' (Nurse)

For patients who had been injured for a long time and were starting to feel the effects of ageing, continuing support and follow-up was seen as a lifeline and made the difference between continuing their present lifestyle or going into residential care:

'I do think it (physiotherapy) *needs to be carried on you know after you leave the hospital, especially for people who've been in a wheelchair for a long time. I didn't think about it for years because my physiotherapy was doing the housework...I did it all myself with no help."* (Peggy patient injured 44 years with incomplete tetraplegia)

Trieschmann (1987, p 106) describes ageing with a disability as "going back to the balancing act." In that those who managed the balancing act between disability and living their lives for thirty years or more may now find themselves facing the second onset of disability. One participant who had been admitted with a pathological fracture of her ankle, and who had also received surgery to her damaged shoulder (caused by thirty years of wear and tear) identified this:

"It's almost like being disabled again."

Another participant who had been very unwell and had had a leg amputated due to long term problems of spinal cord injury was facing extensive rehabilitation. He was finding it much more difficult second time round:

"This is going to be another rehabilitation process which I'm not particularly looking forward to...it's got to be done but I don't know it just seems a bit unfair. I think I've done this once, why have I got to do it again?" (Mack, patient with incomplete tetraplegia injured twenty-eight years)

The disability movement is somewhat critical of the way people with disabilities are subjected to the medical gaze i.e. the way professionals, particularly doctors, regard patients as passive objects of their attentions (Porter 1997). Many question whether health care professionals should be involved once the medical condition has stabilised (Craddock 1996). McFarlane (1996) suggests that problems have arisen over disabled people being defined as 'ill'. In reality, although for some disabled people their impairments are associated with illness, many (and this is particularly the case with spinal cord injured individuals) are fit and healthy (Finkelstein and French 1993). Goodall (1995) however, argues that disability retains some medical element

whenever there needs to be some medical intervention. Medical intervention does not necessarily lead to professional domination and the creation of dependency.

It has been suggested that the notion of adaptation to chronic illness and disability is often linked to a view of disability as a relatively stable entity, when in fact the conditions that underpin most forms of disablement involve fluctuating symptoms and uncertain outcomes (Bury 1982). There is currently considerable concern about long-term health maintenance for patients as they progress through life with a spinal cord injury. Over the past several decades clinicians working with the spinal cord injured population have noticed evidence of premature aging. The injury not only affects the rate of ageing but also the quality of aging, in that people with spinal cord injury are likely to have many more problems than the non injured population (Lammertse 2001). As people with spinal cord injury age they are likely to develop complications such as respiratory problems and urinary tract infections (Frankel et al 1998, Vaidyanathan et al 1998). A particularly disabling problem for spinal cord injury individuals is shoulder pain. The shoulders are used for transfers, pressure relief and for pushing a wheelchair, therefore being subjected to repetitive motions they were not designed to perform (Waters and Sie 2001). Sinnott and Mercer (2000) point out that spinal cord injured people have sufficient functional compromise without the consequences of secondary impairment which may result in ongoing pain and functional decline which in turn may affect their work, leisure and social contacts. Successful control of lifetime secondary impairments is therefore the hallmark of successful rehabilitation.

4.3.Conclusion

Rehabilitation is most commonly described in the professional literature as a process (Waters 1986, McGrath and Davis 1992, Nolan et al 1997,Long et al 2001). The toolbox definition that has emerged from my data fits within a process concept of rehabilitation. Eldar (2000) points out that process consists of activities of rehabilitation professionals. Rehabilitation is less commonly seen as an outcome in its own right. The "picking one's life up again" definition is perhaps an example of

rehabilitation as an outcome. This is separate from both the functional outcomes and aims of rehabilitation and rehabilitation as defined by goal planning.
The empowerment definition, despite the fact that empowerment is heavily emphasised in the rhetoric of health care delivery, was articulated by fewer participants and seemed to encompass both process and outcome.

However, it appears that the three definitions are not mutually exclusive, and perhaps for many participants the ultimate goal is that patients pick up their lives again. To enable them to do this both patients and professionals recognise they need to be provided with physical, social and psychological skills. Empowerment, and by the same token disempowerment, may emanate from the professional/patient relationship during rehabilitation. Therefore, rehabilitation in spinal cord injury is not either a process or an outcome but is both. An empowering approach to the rehabilitation process may lead to an outcome of an empowered person.

Nearly two decades ago a study was undertaken in which ex-patients of the spinal unit currently under study were interviewed about their lives (Oliver et al 1988). The findings of the study suggested that the service both in hospital and the community had failed those patients by providing an inflexible service that did not address patients evolving requirements. Lack of resources and poor liaison between health and social care agencies added to these problems.

In this study I have attempted to identify the culture of support and involvement of patients in shaping their own destiny because it appears that what happens during the hospital experience does have a bearing on how patients deal with managing their lives when they go out into the community. That life in the 'outside world' is tough for people with disability has been identified in the professional and non-professional literature (Goodall 1995 Northway 1997,Oliver 1999). This is a fact that has also been identified by participants in my study. One patient who had been living with tetraplegia for twenty-five years highlighted the difficulties she had encountered when she had attempted to obtain equipment that would help her husband who is her sole carer:

"Well I did ask and was told that we weren't important. They would assess our case from time to time, but it hasn't happened. We did ask for a hoist. My doctor asked for some respite care for me and we were told that we couldn't be put into a category and we'll just have to wait until they decide to assess us."

This recognition that life will not be easy for patients once they leave the Spinal Unit may well have a bearing on the definitions that are articulated by participants in my study. Indeed there was little difference between professionals and patients in their perception of rehabilitation. While patients are in hospital there is a need to equip them with as many skills as possible because they may not get the opportunity for many years, if ever, to come back and relearn old skills or develop new ones. The aim is for spinal cord injured patients to be able to pick up their lives again and it may be that empowerment is seen as an outcome of having those skills. However, at the end of the day both professionals and patients are working within a system that for all the rhetoric does not lend itself easily to full participation and empowerment.

In the earlier study a participant responded to the question what was it like being discharged from the spinal unit by saying: 'It was like walking into darkness'. (Oliver et al 1988, p 135)
This perception was echoed by a participant (Martha) in my study who commented:

"When you've been in a unit which you may have been desperate to get out of but when you leave it's like jumping off a cliff."

I would suggest that if patients undergo their rehabilitation in an environment that empowers and supports them to be self-determining when they take that 'leap off the cliff' they might be better placed to deal with the challenges that face them.

The relationships between the members of the rehabilitation team may have an impact on the extent to which empowering practice is carried out. In the next chapter patients and professionals perceptions of the roles and relationships between the professionals in the team will be discussed.

CHAPTER 5 – PATIENTS' AND PROFESSIONALS' PERCEPTIONS OF PROFESSIONAL ROLES AND RELATIONSHIPS WITHIN THE REHABILITATION TEAM

PATIENTS' AND PROFESSIONALS' PERCEPTIONS OF PROFESSIONAL ROLES AND RELATIONSHIPS WITHIN THE REHABILITATION TEAM

An aim of this study was to identify the perceptions of patients and professionals of the professional roles and relationships within the rehabilitation team. The objective being to explore how these perceptions affect team working. This chapter will discuss findings related to the perceptions of professional roles that exist within the spinal cord injury rehabilitation team. The lack of congruence between a professional's definition of their role and how others define them and the impact on team relationships will be discussed. Patient and professional perceptions of the patient's role in rehabilitation in relation to participation and team membership will be discussed in the next chapter.

There is a wide range of disciplines involved in the rehabilitation of people with disabilities. They are all essential but no one of them is sufficient in itself (Hanks 1994).
As a doctor in my study pointed out:

"No one person could do everything in spinal cord injury. It's accepting the fact different people bring in different training and their experience into a big melting pot and patients can benefit from it."

The themes that have emerged from the data in relation to interprofessional team relationships suggest ambivalence among participants in this study.

5.1. Working as a team member

5.1.1 Working as a team member is a positive experience

Most of the literature about interprofessional team working tends to highlight the difficulties and barriers associated with this approach, but for some professionals in my study the team experience was a positive one:

"I think it's good that now you get the physios, nurses and everything all working together...I think everybody is treated more or less equal as a team." (Nurse)

"Well it's essential that you work as a team member. It's a big team that you are part of. I enjoy working as a team member, I find it an enjoyable experience." (Nurse)

However, other professionals identified that teamwork was important but that it was only a positive experience under certain circumstances, good communication being an important factor in good teamwork:

5.1.2. Communication

Because multidisciplinary teams are, by definition, composed of individuals with a range of professional perspectives and languages good communication is vital if misunderstandings are to be avoided (Cooley 1994). However, in practice good communication can be difficult:

"The first thing that comes to mind is it's hard work. Trying to keep everybody up to date, trying to communicate and sometimes it's quite easy when you're under pressure to feel isolated and like you're not part of the team. Sometimes it's felt like we haven't worked as a team at all." (OT)

"Sometimes I think we think we are more of a team than we actually are. Some are more team orientated than others. I think it is crucial to spinal cord injury because

any one professional doesn't have all the answers...communication between the team is vital." (AHP)

However if it worked it was worth the effort:

"Obviously the multidisciplinary team is very strong; a lot of liaison, a lot of collaboration between parts of the team and I think that definitely comes out in the quality of the rehab that the patient has in the end." (OT)

5.1.3 Tribalism

Professionals within the NHS have been accused of too much "tribalism" with historically drawn boundaries (Beattie 1995). Professional roles and boundaries are perceived as 'baggage' that prevents collaboration within multidisciplinary teams. Professionals may take a protectionist stance that implies power differentials not only between professionals but also between professional and client (Rowe 1996). Team members often work independently with discipline specific patient goals (Proctor-Childs et al 1998).

Nursing, physiotherapy and occupational therapy have been described as semi professions in that their members are predominantly female, are involved in direct patient contact, have a strong emphasis on care giving and require supervision and outside control (Raz et al 1991). All three of these professions are struggling to achieve professional status, but the central attributes that define a profession are drawn from the practice and philosophy of established male dominated professions.

Some of the participants in my study recognised tribalism as an issue:

"I think the most important thing about being a team member is communication. I don't want to sound negative but sometimes we get caught in our own little boundaries or in our own little areas." (AHP)

"If the team is coordinated in its effort to help the patients the whole exercise will become a terrific and rewarding exercise... however if there is polarisation amongst

members of the team, or there is some sort of isolation or protection within team members and if in this sense is unhealthy then it might reflect in a very negative way on the outcome." (Doctor)

5.1.4 Medical dominance of the team

Medical dominance in multidisciplinary teams has been assumed as inevitable however this might not always be the case. A study carried out on an assessment unit for the care of older people found that although in some respects the consultant exercised considerable power in some circumstances he was not so dominant (Gair and Hartery 2001). These consultants were described by team members as 'rehab-minded' in that they valued other professionals' contribution. A physiotherapist in my study also identified the importance of this approach:

"I think until you get a truly interdisciplinary doctor on board, our rehab will always be fragmented as in physio, OT, psychological, nursing and anyone else goals and then the medical management and we touch base whenever we want something from the other and that works both ways. They will call upon us when they think we have something to offer them. That I don't think is a true team."

One nurse felt that some consultants did have this approach:

"My perception is that each member of the team has an equal role but obviously at the end of the day the consultant takes overall responsibility, but that the consultant is willing to listen to ideas, respects other people's professionalism."

Research has suggested that within teams doctors have a position at the top of a hierarchical structure (Long 1996) and favour authoritarian team interactions (McCallin 2001). The accountability and responsibility for a final decision often lie with the doctor because team members are not considered equal in terms of expertise, status or function in the team (Anderson et al 2000). As one nurse said:

"I do feel part of the team definitely but I do feel it is possibly led by the medical staff whereas it could possibly be led by other members of the team."

On the other hand Burke et al (2000) suggest that doctors should not assume they are the natural leaders of a multidisciplinary team but should take on a role that best suits their expertise. The issue of accountability and responsibility is discussed in greater depth in Section 2.4 where doctors discuss their role. Breaking down hierarchical structures was an issue for one participant:

"I felt that as a team there was a cohesive team at (spinal unit) *it was quite structured in a hierarchical sense. I think the other focus is to move away from what's physio doing, what"s OT doing?"* (AHP)

Being listened to and respected as a team member to some extent depended on how long the professional had been involved in spinal injuries:

"It's got better as I've got more experienced I suppose. More people know you so there is more respect and they listen to your opinion." (Nurse)

"I think obviously by being a very old hand at it you do know a lot of people, I know where to go and that makes life easier, there's no two ways about it." (Physio)

However, with regard to hierarchy in professional teams, observation of ward rounds was illuminating, as just as seating arrangements at meetings have social meaning (Fetterman 1989), it was apparent that on ward rounds standing arrangements also had social meaning. For example, when coming into a curtained off area to see a patient it was the consultant who led and the nurse who entered next. If a nursing colleague and I were already in the area we would move out of the way to allow the consultant in. Other professionals stayed outside unless they were specifically called in.

In recent years there has been an increasing emphasis, from both political and professional sources in the UK, on flexible multiprofessional teamworking to meet patients needs and accommodate changing demands of healthcare provision (Wilmot 1995, Scholes and Vaughan 2002). Barnitt and Pomeroy (1995) suggest that to accomplish holistic rehabilitation each member of the team needs to be given equal value. However, in reality the notion is often all rhetoric with little evidence of institutional transformations based on these ideas and practices (Minton and Duffin

2000). Interprofessional collaboration is seen as 'a good thing'; however the experiences of some team members do not reflect the assumption that collaboration leads to improved quality of care for patients and service users (Wells and Nicosea 1993, Leathard 1994, Embling 1995). It has been suggested that the current literature offering evidence of the efficacy of interprofessional teams is poor, with significant weaknesses in terminology and research content. Much of it lacks conceptual rigour (Schofield and Amodeo 1999, McCallin 2001).

It has been suggested that changes in the balance of power between practitioners and patients have affected the way in which practitioners relate to each other. If patients have more power in their interactions with professionals, particularly doctors, this may reduce the power held by those professionals. This may affect power differentials between professionals; the balance of power may be changed with more equality between practitioners (Ovretveit 1997). Coordination and teamwork among professionals are vital to the efficiency of rehabilitation services. However, effective teamwork does not occur automatically and often runs into process related difficulties. Cooley (1994) grouped these difficulties into three categories:

1. Disorganisation,
2. Miscommunication and misunderstanding,
3. Inadequate participation in/procedures for problem solving.

All of these problems can affect the service that is delivered to clients. It may be the case that some of these problems may be linked to the gender relationships within teams.

Historically it has been assumed that women, because of their childbearing ability, are naturally suited to the caring professions (Turner 1987, Wilkes 1995). This may account for the fact that in the United Kingdom about 91% of nurses are women (Evans 1997). British data for gender in physiotherapy and occupational therapy are difficult to find but Pollard and Walsh (2000) call occupational therapy a "feminine profession" and Bradley (1989) identified that in professions allied to medicine such as physiotherapy and occupational therapy where handling patients is important women predominate. Data from other European countries and the USA confirm that occupational therapy and physiotherapy are female dominated professions (Raz et al 1991, Chevan and Chevan 1998, Johansson 1999).

The only area where women are under-represented is in the senior levels of medicine. More than half the entrants to medical school and a third of GPs are women but they account for only a fifth of hospital consultants, only 5% of consultant surgeons are women (Millar 2000). Women tend to be situated in specialities which offer more flexible working patterns or less unsocial hours but which are also seen to be lower status specialities (Brooks 1998). These specialities are usually those, which are considered most suitable for women in that they can use their perceived 'feminine' skills and male doctors do not compete for them (Miles 1991). There is considerable discussion about the "glass ceiling" that traps women doctors and prevents them moving up the professional ladder (Kvaerner et al 1999, Paice 2001, Riska 2001). A number of reasons for this have been cited and include: conflicts between career and family (Wynn 1988, Showalter 1999) and deficiencies in career advice and counselling (Kvaerner et al 1999).

In this study, whereas only one of the five doctors was female, the majority of the other professionals in the team were female. However, for a team to work well together there need to be the following ingredients – flexible and adaptable staff, good channels of communication between staff, and opportunities for the creative development of working frameworks (Molyneux 2001).

Different models of teamwork have been identified from behavioural to cognitive models (Billups 1987, Mullins et al 1994, Proctor-Childs et al 1998, Milward and Jeffries 2001, Strasser et al 2002). Behavioural models either portray a continuum of increasing intensity and complexity of cooperative working relationships from less to more cooperation – from acquaintanceship to joint operating responsibility; or a continuum that is characterised by indecision, crisis and team maintenance with shared acknowledgement of team tasks (Billups 1987). In a cognitive approach teams share a vision of what constitutes a team and have a sense of team motivation (Milward and Jeffries 2001). A study of multidisciplinary teams in Toronto, found that teamwork has different meanings for staff in different structural positions – the structure of the team being alienating for staff in lower structural positions (Cott 1998). The suggestion is that team relationships are not static and the perception of team membership has different meanings for each individual.

5.2. Perceptions of roles within the team

A role is a defined function carried by an individual or group. However, several different types of role may be relevant to the part one is playing in a team (Hornby 1993). These include: personal roles – which are based on individual attributes, professional roles – based on professional competencies and team roles – based on team interaction such as team leader (Ducanis and Golin 1979). Hornby (1993) suggests that recognition of roles is important in achieving a secure and satisfying identity and can influence the way that helping relationships are evaluated.

It has been suggested that patients often perceive the existence of a hierarchy, with medical staff at the pinnacle, and this can have an effect on the relationship and behaviour exhibited toward care-giving professionals and in particular the nurse-patient relationship.

5.2.1. Nurses' and patients' perceptions of the nurse's role

The nurses in my study acknowledged that they have many roles within the rehabilitation setting:

"I've got several roles and they might all be quite different. I mean I have a role as a named nurse, a role as a ward manager and just as a member of the team you have another role don't you? Hard to define the role."

"I've got a multi role I think: education of myself, staff, patients, visitors. I think my main role is just help pass on that knowledge (sic) *and still learning. But I think that my role, I wouldn't even like to begin to define it, definitely not."*

The roles identified by the participants in this study were, giving physical care, providing emotional support, imparting information and knowledge and moving patients on in their rehabilitation.

5.2.1.1. Giving physical care

Few nurses focussed on functional and technical roles and when they did they were seen as only a minor aspect of their role:

"I see it as my role to help them along to achieve these goals really to be as independent as possible. Obviously it's more the nursing goals like the bladder and the bowel and the washing and the dressing, but also helping them to adapt to the spinal cord injury, but also being their advocate."

Nurses are perceived to have a major role in carrying out aspects of physical care such as washing, dressing, movement, elimination, eating and drinking in a range of rehabilitation settings (Long et al 2001). Patients in this study described how nurses in carried out personal care:

"The nurses get me up in the morning, put me to bed at night." (Marina, newly injured patient with tetraplegia)

"Wash me, turn me, feed me, personal care, make sure I go out of here in one piece." (Mark, patient with tetraplegia injured 40 years)

5.2.1.2. Providing emotional support

Pound and Ebrahim (2000) observed nurses on a stroke unit and found that there was very little in the way of emotional labour i.e. the provision of emotional support for patients, the nurses tending to focus on functional and technical aspects. However, with the development of technological medicine emotional work is now more vital than it ever was (Phillips 1996). On the spinal unit in my study nurses and patients perceived giving emotional support as a major feature of the nursing role:

"If they are worried about something, not necessarily as a nurse but just as a pe on they can talk to. So it's like having a friend in a sense...it's not easy to define what you actually do." (Nurse)

Friendship in the nurse-patient relationship is seen to require a deep and affective involvement and the process of befriending can contribute to the empowerment of

patients and clients in sharing control of care management (Bignold et al 1995, McQueen 1997, Hunter 2001).

This befriending for some nurses and patients meant that nurses were also perceived as allies for patients in their dealings with other professionals:

"We have to be the patient"s voice and I think out of the whole professional team we're the person who becomes closest to the patient. Again, it's the intimate care, once you've done somebody's bladder or bowels or a lot of men talk about sexuality or intercourse and once you"ve talked about that most of the barriers are brought down. The patient looks on you as more than a friend." (Nurse)

During a period of observation when working with an older patient and the patient's named nurse the nurse described how the patient's OT had told them that the patient must always push her own wheelchair, build up her strength and transfer from bed to chair independently. The OT was unwilling to provide aids for the patient. The nurse had argued that it was unrealistic for a seventy year old to be expected to do the same things as a young person and had supported the patient so that now the OT had conceded her expectations were unrealistic and had provided aids for the patient. In this situation the nurse had joined with the patient to ensure the patient's views were heard.

A patient also reiterated the point made by the nurse above that nurses can act as allies in their dealings with other professionals:

"They reassure, they're there, their presence is so important. I think they can help identify problems. If it's just me I think the doctor thinks I'm fussing, if it's the nurse as well then you feel stronger with the nurse."

Some rehabilitation research has suggested that hospitalised patients do not consider personalised, supportive care as essential but as secondary to the provision of physical care (Keane et al 1987, Schutz et al 1998). Other research, however, has suggested that patients see nurses' affective activities as more important than nurses' technical activities (Williams 1998, Lucke 1999). In this study participants valued the

emotional facet of the role and identified that because of the 24-hour nature of nurses' work they were in a position to give emotional support at any time:

"At your low points supporting you as well because they're the people who see you most as well."

"The nurse looks after our health issues, is your main point of contact, is the person that probably gets closer to you, (sic) *takes more attention to your mental state and is the person who really knows what is going on with that particular patient and sees them a lot longer than the others."*

However, this 24-hour close relationship may have a down side for patients. It was apparent that nurses wielded a great deal of power over the day-to-day lives of the patients in their care and this was a source of distress to some of the patients:

"I think sometimes the nursing staff forget that you're a grown up human being who"s lived their life for twenty-seven years and all of a sudden you know you get treated like you know I lost my legs (sic) *you know but it didn"t mean I lost my mind, my brain and I think a lot of times they forget that."*

A patient who had been injured twenty-five years put it more forcefully:

"*It* (sic) *don't matter even if you disagree with the way you're being nursed at the end of the day it's her* (the sister's) *word. If you don't like it you have to go home.*""

An ethnographic study of a spinal cord injury unit in Canada found that patients thought of the staff as authority figures who were there to help them and they developed likes and dislikes for staff members. The patients liked staff members who were caring, treated them like adults and were relaxed about rules and regulations. Staff considered rude, bossy, rigid and superior were disliked and patients did not share their fears about being disabled with them (Laskiwski and Morse 1993).
The fact that nurses do have power in their interactions with patients has been recognised (Malin and Teasdale 1991, Vander Henst 1997) but in the nursing literature there has tended to be greater emphasis on the disempowerment of nurses by

other professionals (Fulton 1997, Rankin 2000). It was interesting that only one nurse recognised the power that nurses hold over patients:

"I think that we have a lot of power but it could be used wrongly. I think we are quite powerful with regard to the patient and the family...you could abuse that power."

This presented me with a dilemma during participant observation. I was asked by a nurse to 'set up' a female patient so she could get washed and dressed. I got the bowl and equipment for her and asked her what I needed to do. The patient said she could not reach her back. She had both a bowel movement and was menstruating so I washed her. The nurse then came in and said to the patient "You should be doing that!" then said to me "She should do that herself." The patient said to me "How the ___ am I supposed to do it, other people can do more and they get more" ___ help." I finished cleaning her up, got fresh water for her and she did everything else unaided. I decided to work within Hammell's (1995) definition of independence, which includes directing others in ones care. I had asked the patient what she needed me to do and to not help her would have disregarded her dignity and her ability to decide what help she needed (Nursing and Midwifery Council 2002). I then explained to the nurse what I had done and why and explained to her that once I had helped the patient with what she could not manage unaided, she had then done everything else by herself.

5.2.1.3. Information and knowledge

In a study comparing nurses in an acute care setting and a rehabilitation setting there was little evidence of education and coaching of patients in either setting (Jinks 2000). However, in my study teaching patients was seen as a key feature of the nurses' role in rehabilitation:

"Teaching, encouraging, explaining, helping patients do what they can't do, or helping them with things they need help with. Allowing them to take charge, allowing them sometimes to make mistakes." (Nurse)

Patients also saw teaching as an important facet of the nursing role:

"The nurses while you're here you learn a lot in the ward about your medications, they teach you about Conveens (urinary continence device)."

In Natterlund and Ahlstrom's (1999) study of patients with muscular dystrophy patients emphasised the importance of having trust in the staff's knowledge of them and their disability so they did not have to explain things and this was also identified by a patient who had lived with a complete tetraplegia for forty years:

" They know me (nurses on a certain ward) *and actually this is quite a relief because if I get admitted to another hospital or another ward with staff that aren't familiar with you then it's quite exhausting to go through forty years of history...and go through the whole teaching process again"*

5.2.1.4. 'Moving patients on' in their rehabilitation

Lucke (1998) found that spinal cord injured individuals expected nurses to know when they were ready to take on a task or skill and try different approaches. In my study there was an expectation amongst some participants that nurses would know when the time was right to start withdrawing that personal care and enabling patients to take on that aspect for themselves, as two patients pointed out:

"Really and truly I've got more respect for the nurses here than any other nurses I've met because their job's a little bit harder and they've got to be like parents in that respect they've got to say – Well now it's time to get cracking, watch them do it themselves"

"I think the nurses' role is very difficult to explain – she's there, you are very much dependent on her at first and she encourages you to be independent"

This was observed in practice. Patients would be 'set up' i.e. the nurses would assemble the equipment, wash parts of the patient that they could not reach such as their back and then patients would be positioned so that they could dress themselves, apply their make-up or comb their hair. If a patient was able to make their own bed then the nurses would usually not make it for them.

It has been recognised that rehabilitation nursing requires a different approach from acute care nursing and is a role with which not all nurses feel comfortable (Johnson 1995b). Some of the nurses acknowledged that making the transition from acute nursing to the different philosophy of rehabilitation was difficult:

I'm very acute nursing still, I've been here for three years and I'm still not thinking as a rehab nurse...I find it a lot more satisfying personally to make somebody better and these patients aren't sick."

"You know it's 'I'll solve the problem for you', so there's something in our training that makes us all not think rehab."

The nurses in this study appeared to exhibit tensions between the 'caring' nurse and the rehabilitation role. Hill and Johnson (1999) identified that nurses felt that they may be seen as uncaring if they did not help patients. The nurses in my study recognised that they must encourage self-care but that this may be seen as hard and bullying by patients:

"Sometimes I feel like I'm a bully because you have to make them do things sometimes that they don't want to do."

The approach to caring for a patient with an acute illness is very different from the approach to the care of patients with chronic illness. Acutely ill patients are unable to provide their own care and interventions and will be monitored continually, whereas rehabilitation focuses on working toward goals of independence and self-care management (Neal 2001). In the UK, very little attention is given to rehabilitation, chronic illness and disability in nurse education (Nolan et al 1997)

The participants in my study viewed the nursing role as having several facets. For patients, nurses play an important part in their hospital stay, but whether or not this is seen as rehabilitation is another matter. The nurses appeared to regard their role as one of rehabilitation, although research suggests that nurses are not necessarily perceived as carrying out therapeutic rehabilitation activities (Macduff 1998, Edwards 2002). For some patients the nursing role in rehabilitation was debateable:

"Basically they are giving me nursing care which isn't rehabilitation. Obviously they're trying to help me cope with bladder and bowel problems which is... (rehabilitation)." (Laura, newly injured patient with incomplete paraplegia)

"Bless them (nurses) *I mean they saved my life. They don't play a big part in rehabilitation nowadays I don't think but they're there for you."* (Mack, patient with incomplete tetraplegia, injured 28 years)

In a large study of the role of the nurse in the rehabilitation team, across a range of clinical areas, six, core, nursing roles in rehabilitation were identified (Long et al 2001). These were:

- Assessment,
- Coordination and communication,
- Technical and physical care,
- Therapy integration (monitoring and reporting the effects of therapy)
- Therapy carry-on (carrying on routine therapy when therapists are not around)
- Emotional support and involving the family.

The unique 24-hour presence of nurses in patient care automatically ensures a carry-on role so that the input of other professions is maintained (Johnson 1995b, Nolan et al (1997).

Patients asked to define 'excellent nursing care' have characterised the concept as consisting of professional knowledge, continuity, attentiveness, coordination, partnership, individualisation, rapport and caring (Radwin 2000). Nurses who display these characteristics contribute to patients' achievement of increased fortitude and sense of well-being.

There have, however, been some suggestions that older patients tend to judge rehabilitation nursing in acute care terms and are unaware of the different role of the nurse in rehabilitation (Sheppard 1994, Nolan et al 1997). The issue of nurses' and patients' perceptions of the nursing role are complex, with tensions for nurses about their caring role. Nurses have found it difficult to cross from an acute care mindset of

doing things for ill and helpless patients to a rehabilitation philosophy, where patients are disabled rather than ill and encouraged to do more for themselves (Sheppard 1994, Pellatt 2003b).

In this study the nurses' role is seen as complex, providing a range of interventions and support mechanisms. Unlike the findings of research with older people, patients recognised that nursing care would decrease as they became more able to undertake this for themselves. However, for some patients nursing care was compartmentalised into something different to rehabilitation.

5.2.2 Physiotherapists' and patients' perceptions of the physiotherapists' role

The physiotherapy role has been described as being concerned with restoration of normal function, or assisting patients to achieve their maximum potential by muscle testing, gait training, electrical stimulation and pain management (Brown and Greenwood 1999, Higgs et al 2001). The physiotherapists in my study echoed this perception of the role:

"Trying to put as many tools in the toolbox that people would need and teaching as many skills as they might need now and in the future. So I would see it as just getting them strong, teaching them balance, teaching them how to transfer. I would try and ensure that they could solve any situation they came into. If they couldn't even do it physically for themselves they would know how to ask somebody for help."

"I suppose it's to provide the patient with the skills to live their life a lot of the time from the wheelchair... as well as stretching, lots of functional things, the transfers, the wheelchair skills, getting in and out of cars, in and out of standing frames, up and down kerbs, up and down stairs. Just give them all the skills to get on with life."

So for the physiotherapists there was no difficulty in defining their role in the patient's rehabilitation. Patients in this study seemed to agree with the physiotherapists' perception of their role although for Mack (who called his physiotherapist 'Miss Whiplash'), this was a necessary evil:

"The physios" have been coming in every day you know including weekends and give the stump a stretch. But it's intensely painful...so physios" not something I look forward to at the moment, not this type of physio."

Payton et al (1998) identified that patients saw the physiotherapist's role as providing information about exercise and making decisions about their treatment programme and a newly injured patient in my study confirmed this perception:

"Well, the physiotherapist sets the standard of the exercises she'd like me to do and we talk about it in the first instance- do you think you'll be able to do this? And I say well we don't know until we try. And she started off with easy things."

Whitfield et al (1996) asked a group of design students about their perceptions of physiotherapists and found that they perceived physiotherapists as an intermediate profession i.e. not an established profession in the way that they perceived medicine to be. Physiotherapists were considered to have almost identical levels of education and social standing to nurses. One of the patients in my study who had been injured for more than 25 years was surprised at the amount of knowledge physiotherapists possess:

"I wasn't sitting properly and I went up to the seating clinic and was chatting to the physio who had more knowledge than I ever thought she would have, she really did, she knew a heck of a lot more and pointed out so many things that although I hadn't had problems it made me aware of things to keep an eye out for. They have a great deal of knowledge that they can pass on to you."

Physiotherapists, like nurses, gradually withdraw in an effort to help patients discover their own possibilities and take responsibility (Proot et al 2000). As a physiotherapist in my study pointed out:

"There comes a point when you just like say, time to move on."

However, patients saw physiotherapy as continuing right up until the last minute prior to discharge:

"It's very hard to describe. Mainly at this point until discharge, it's mainly working on transfers and getting my strength; finalise those last bits."(Jemma, newly injured patient with tetraplegia)

Johnson (1993) interviewed patients in the community and found considerable dissatisfaction with physiotherapy- however it has to be noted that the sample was only four people. Lund and Tamm (2001) on the other hand found that patients' considered contributions from physiotherapists as essential to progress. Patients in my study also confirmed this positive view:

"Physiotherapy is the core of the whole hospital."

So, unlike nurses whose role is unclear, both physiotherapists and patients are generally in agreement about what a physiotherapist does in spinal cord injury rehabilitation. It has been suggested that the predominant paradigm of physiotherapy appears to focus on treatment, concepts of assessment, diagnosis and management and is therefore akin to the medical model approach (Santy 1999). Physiotherapists see themselves as having an advanced level of clinical autonomy (Harrison and Williams 2000, Higgs et al 2001), although this has been perceived to be under threat in recent times (Ovretveit 1994).

5.2.3 Occupational Therapists and patients perceptions of the Occupational Therapists role

The occupational therapists role in spinal cord injury rehabilitation has been described as providing adaptive equipment and splints for positioning and function of limbs (Sherburne 1986, Rinehart 1990). However, OTs themselves find defining the role much more difficult (Lycett 1991). The three OTs in my study, however, were quite clear as to their role in spinal cord injury rehabilitation:

"We also cover the activities of daily living and also look into the workplace, look into housing and driving, anything in the persons daily life we need to cover."

It has been suggested that there is considerable overlap between physiotherapy and occupational therapy roles but that occupational therapy is concerned with the upper extremity whereas physiotherapy focuses on the trunk and lower limbs (Brown and Greenwood 1999, Boutin-Lester and Gibson 2002). Both OTs and patients identified this focus on upper limbs:

"Our roles have become very much more of a specialised hand splinting, hand function and all the aids and adaptations for shaving, feeding, teeth cleaning, driving stays very much with us, and computing...assessing for appropriate equipment.'" (OT)

"She spends a lot of time on my hands, you know, cooking, cleaning your teeth, brushing your hair, shaving, all done by the OT." (Shaun, newly injured patient with tetraplegia)

Patients also identified liaison between physio and occupational therapy:

"I think the OT and physio work very closely together...and your OT she does much more of your fine movements in your hands and so you can be doing functional tasks in the home. On top of that they're responsible for what the workplace is like." (Basil, newly injured patient with tetraplegia)

However, an OT recognised that it had been a struggle to leave the historical perceptions of occupational therapy (basket weaving and soft toy making) behind:

" When I first came here...we were not very well looked on, probably that's because of the history before we got here."

For one patient earlier experiences of occupational therapy had coloured his views on what OTs do 28 years later:

"I see the occupational therapist as somebody who walks around with a roll of Velcro in one hand and a lump of Blutak in the other (Laughs). *I think they try and stick Velcro anywhere they can. It's par for the job – Velcro something."*

However, generally there appeared to be congruence in the perceptions of patients and OTs about what the occupational therapy role is in spinal cord injury rehabilitation.

5.2.4. Doctors' and patients' perceptions of the doctors' role

Medicine has been described as having a dominant position in hospitals by having authority over admissions, treatment decisions and discharge of patients (Walby et al 1994). There has been very little research into patients' or doctors' perceptions of the medical role in spinal cord injury rehabilitation. The doctors in my study saw their role as coordinating and supervising the work of the other members of the team, implying a hierarchical structure:

"It's like a ship. A ship needs a captain. Now, the captain as we all know stands on the bridge and does nothing but he brings it all together. So that's how I look at my role in the rehabilitation or treatment of the patient with SCI in the acute stage where it might require more than one specialist, they need an anchoring person and that is me. In the rehabilitation phase it requires a multiplicity of professionals, a nurse, a physio, a psychologist, an OT but these need to be brought together by me." (Doctor)

Young people and children perceive doctors as being the professionals who make all the important decisions (Holyoak 1998). Although an older age group, this was the case with some, but not all of the patients in my study where doctors were seen as at the top of a hierarchy of professionals:

"There's got to be someone in charge of all the nurses and in charge of all the medical side. (Dave, newly injured patient with tetraplegia)

Walby et al (1994) point out that medical consultants have always had legal and organisational responsibility for patient care. Patriarchy has been described as a system of male oppression of women in that men have hierarchical relations between themselves and solidarity among them, which enables them to control women (Carter 1994). Medicine is perceived to be the dominant and most powerful profession within health care and it is suggested that it oppresses all the other professional disciplines. Medicine is a benchmark upon which each profession gauges its status in terms of how close it comes near medicine in relation to power and responsibility (Warelow

1996). The doctors in my study were clear about their role as co-ordinator, however they also acknowledged that with power and responsibility came accountability:

"The doctor has full clinical responsibility: this is enshrined in his job description, in his contract...he has the ultimate clinical responsibility for supervising." (Doctor)

Patients also identified this:

"When things go wrong mate, you shout doctor." (Laura, newly injured patient with incomplete paraplegia).

A study of medical ward rounds identified that patients perceived doctors as being too busy to be questioned and thought that they gave misleading or complicated answers (Busby and Gilchrist 1992).

Patients in my study had similar perceptions:

"I think consultants are inclined to live this life from the next floor up which doesn't wear with me whatever they think." (Laura, newly injured patient with incomplete paraplegia)

"The doctors do what the consultants do which is to be standoffish and give very vague answers to your question in a rather imperial manner." (Mick, newly injured patient with paraplegia)

However, one doctor, while I was carrying out participant observation, demonstrated a sense of humour about the perception of his own importance. A consultant on his ward round noticed one of his patients leaving the bay he was about to enter:

Consultant: *"Hey where are you going?"*
Patient: *"I've got something important to do."*
Consultant: *"What is more important than me?"*
Patient: *"I've got to go to the toilet"*
Consultant: (Laughs) *"So that is more important?"*

Patient; (Laughs) *"Yes it is actually.'"*

A patient who had been injured forty-four years and was having difficulty obtaining services in the community however, was able to harness the perceived power and authority of the consultant:

"If you've got the consultants assistance they can open all sorts of doors can't they?"

Another who had been injured for twenty-five years had found doctors helpful:

"Certainly the doctors I find, the ones I've dealt with, I think explain things very clearly."

Although for the most part, in their relationships with professionals the experiences of patients with chronic illness do not reflect a shift towards an emancipatory model, there are some enlightened professionals (Thorne et al 2000). It could be argued that these patients had encountered doctors who recognised their expertise gained from patients living with a disability for so many years.

The participants in my study saw the doctor as playing an important role when patients were ill but once the acute episode was over the doctor's role was one of supervisor:

"There is a lot of medical input early on but later it becomes more therapy based." (Doctor)

Patients also recognised this changing input from doctors:

The consultant apart from early on...has been the main medical man, but his input is very limited after you become healthy yourself. I think he's a figurehead and that's very much it'" (Shaun, newly injured patient with tetraplegia)

Observation of ward rounds for rehabilitation also suggested that the medical input was much reduced for rehabilitation patients. The doctor's input in some cases was limited to asking patients how they were and if they had any questions.

Some patients perceived not seeing the doctor so often as signifying their improvement:

"At this point I hardly see them which is good...well because you only see them when you don't feel well.e' (Jemma, newly injured patient with tetraplegia)

There appears to be considerable agreement between patients and doctors about what the doctor's role entails and although doctors were viewed by some patients as not being very communicative, they were seen as important in their acute management and as helpful allies.

5.2.5. Allied Health Professionals' and patients' perception of the AHP role

The AHPs in this study were made up of a discharge planning coordinator and two clinical psychologists. Discharge planning coordinators have been introduced into multidisciplinary teams to improve the discharge planning process; their role is to coordinate the discharge planning process, open interagency communication, educate, act as a patient advocate, be an information resource and audit discharges (Summerton 1998). Clinical psychologists are described as teaching coping skills, and as helping with the stages of grieving and adaptation to disability (Sherburne 1986). They see themselves as assessing, ameliorating and preventing psychological distress, disability and dysfunctional behaviour (Huey and Britton 2002). In spinal cord injury care the clinical psychologist has a major role to play in needs assessment and goal planning (Kennedy and Hamilton 1999).

The AHPs in my study had no difficulty in describing their role:

"There's the one-to-one role in terms of helping people to adjust to their injury and supporting them to think about the effect the injury has had on their lives...enabling them to translate the things that are hard in ways that they can problem solve their difficulties and apply that beyond discharge. Part of my job is to enable everyone to

translate that conceptualisation (goal planning) *in a manageable way and be able to apply that to what's important to them, and to give over that problem solving, that control."* (AHP)

"Advocating the clients' voice is a big thing for me...it's making sure that the Unit has put in place all the necessary tools to enable a successful discharge." (AHP)

It is interesting that this AHP used the concept of tools, intimating that a range of healthcare professionals espouses the toolbox definition of rehabilitation. There is a paucity of research on patients' perceptions of the role of clinical psychologists in a spinal cord injury rehabilitation setting. Yet the importance of psychological processes in spinal cord injury has been identified (Laskiwski and Morse 1993, Carpenter 1993, Yoshida 1994). One patient in my study explained how she had found talking to a clinical psychologist of great value:

I've seen (clinical psychologist) *which I find very helpful because not only is my back iffy but mentally it, you know, I can't get through that brick wall of having been made like this without any warning."* (Margaret, newly injured patient with incomplete paraplegia).

Another patient had seen a clinical psychologist in the earlier stage of his injury but had since discontinued:

"I did for a bit (see the clinical psychologist) *but I was told I wasn't clinically depressed so I didn't get my Prozac* (laughs)." (Dave, newly injured patient with tetraplegia).

This group of Allied Care Professionals is very small and plays no part in a patient's physical care, and this may be why there was very little mention of them by the patients.

However, the success of a rehabilitation programme depends on the commitment of the team and the motivation of the patient and their carers, so all have a role to play (Woodhead and Fortey 1997). It has been suggested that there is an imbalance in the relationship between professionals and patients, which is reinforced by the expertise

of those professionals (Johnson 1993). Yet functional outcomes in rehabilitation are more successful if the expectations of professionals match those of patients and this requires collaboration between them (Schonherr et al 2000).

It has been suggested that for a profession to be understood by others it is essential that a core professional identity be established. Lack of understanding of differences between practitioners can lead to mutual irritation and devaluation of each other's contribution (Hornby 1993). Practitioners need to establish an adequate professional language to establish a strong professional identity but for some professional groups this has been an ongoing problem. Nurses and OTs appear to have the most difficulty in establishing a professional identity as there is considerable nursing and occupational therapy literature that addresses the questions of what the two occupations are, or what nurses and OTs do (Lycett 1991, Santy 1999, Finlay 2000, Dalley and Sim 2001).

It has been suggested that professional identity comes from the character role based on the possession of specialised skills and a particular role relationship with those who need them (Hornby1993). If a profession does not have a strong and cohesive image it's perceived identity will be varied and confused and the role identity of its practitioners will be insecure, making collaboration with other professions difficult. Hornby goes on to suggest that the perceived identity of a profession is based on the professional stereotype, which serves to enable people on first meeting to have some idea what can be expected of the practitioner. However, stereotypes can also hinder collaboration. Hugman (1995) suggests that boundaries between professional groups are developed and maintained through claims to competence in dealing with specific problems. However, it has long been recognised that there is great potential for misperceptions and misunderstanding between professionals because they are often not aware of each other's competencies and roles (Ducanis and Golin 1979, Hunter 1992, Miller et al 1999). A Swedish study of patients with muscular dystrophy undergoing rehabilitation identified that participants received help, support and information from staff. They also appreciated that different disciplines had different areas of expertise and that this enhanced the experience (Natterlund and Ahlstrom 1999). Professionals in my study were asked how they thought other professionals

perceived their role and also professionals were asked to say what activities they thought their colleagues undertook.

5.3. Professionals' perception of how other professionals view their role

5.3.1 Nurses

The nurses in my study felt that generally the other professionals had little idea of what nurses do in their day-to-day work. As one of them pointed out:

"They (other professionals) *haven't got a clue."*

Rehabilitation has traditionally been seen as the domain of therapists with the nurse mainly responsible for keeping the patient clean, comfortable and ready for their therapy appointments – what Johnson (1995b) calls a "24-hour hotel service with expertise in the less attractive aspects of human functioning." This aspect of care has led to nurses sensing that their work is of a lesser status than that performed by therapists (Miller et al 1999). Nurses in my study certainly perceived that this was how they were regarded by some of their colleagues:

"I think the other professionals understand that when a patient has a bowel accident let's bring him back to the ward and the nurse will deal with it."

This perception was reinforced by my observation of similar situations in practice. When patients had attended hydrotherapy they returned to the ward to be showered and dressed by the nursing staff, although there was a shower at the pool.

On the other hand nurses are also seen as carrying on with therapy when the therapists are not available i.e. evenings and weekends (Nolan et al 1997, Long et al 2001). There is a fear amongst rehabilitation nurses that they are regarded as 'jacks of all trades – masters of none,' and that this devalues their role (Walker 1995, Booth and Waters 1995). Nurses in my study articulated this perception:

"I think they think we're everywhere. You're expected to be able to do everything because out of hours...we do as much assisted coughing and heaven knows what as the physios' do. And we're supposed to be OTs as well putting on splints, and this that and the other."

Much of a nurse's time is spent in informal counselling (Hill and Johnson 1999) and providing emotional support (Kirkevold 1997). This was true of my participants, but their perception was that this aspect of their role was not recognised by other professionals:

"I don't know if they know how much time we spend listening and talking to patients and actually helping them...You actually get a real overall picture of the patient and their situation but I think sometimes some other professionals may think all we do is wash them and get them up to departments."

It has been identified that the rehabilitation nurse needs to use many skills and techniques in order to deliver effective care. These comprise:

- Skills and techniques that enable the maintenance of physical activities of daily living such as elimination and personal cleansing and dressing
- Supporting patients with the emotional and psychological aspects of spinal cord injury
- Co-ordination, communication and collaboration skills to enable them to work as team members

(Pearson 1999, Seaman 1999, Smith 1999b, Bonney 1999)

It has also been recognised that nurses enable a continuity of approach over the 24-hour-a-day, 7-day-a-week period (Whitelock 1999)

For some time nurses have been attempting to escape the legacy of nursing history that casts them as doctors' handmaidens (Kramer 1968). They are challenging the sex-role stereotyped traditional role of the nurse, that nursing is a feminine occupation (Benson and Ducanis 1995). However, other health care professionals may be confused in their role expectations of nurses because they are based on an outdated framework. This handmaiden perception may have been perpetuated by Florence

Nightingale (1974, p4) who suggested that: "Every woman is a nurse." This statement seems to suggest that because caring comes 'naturally' to women nursing is an occupation that requires little in the way of education and training. Florence Nightingale reinforced this notion by suggesting that nursing knowledge is common sense as distinct from medical knowledge, which only a profession can have.

The perception of the nurses in this study was that the range of nursing skills was neither understood nor valued by other professionals in the team. Other professionals were seen to focus on the physical aspects of a nurse's role.

5.3.2. Occupational Therapists

Occupational therapists appeared to have similar perceptions as nurses about colleagues understanding of their role:

"They don't have a clue where we're coming from and I know from experience that they quite often are like, they'll see things as, 'oh I didn't realise that was you.' Or you sometimes get stuff like, 'OT should be doing that."

"Even one of the sisters on the ward said, 'Oh I didn't realise you did that."

A study of occupational therapists in Australia found that where colleagues did not understand the role of an OT there were relational difficulties (Griffin 1994) and my study appears to reinforce those findings.

Occupational therapy has its historical roots in the notion of 'worthy work' where middle class female values were promoted through activities of daily living (Pollard and Walsh 2000). Over the last two decades occupational therapy has been accused of losing sight of its core domestic activities and traditional caring roles. It has attempted to define its status and role in a way that fits into structures defined by the medical profession (Pollard and Walsh 2000). Occupational therapists appear to share nurses' difficulties, in that they too are struggling for professional recognition by their professional colleagues. They feel they lack respect because of the discipline's 'global thinking', little scientific value and apparent use of common sense (Barnitt and

Pomeroy 1995). In a small study of occupational therapists participants were seen to be searching for an identity that was both understood and valued by others (Finlay 2000).

5.3.3. Physiotherapists

Physiotherapists perceive themselves as having higher status and being less dependent on team processes than other team members (Strasser et al 1994). One of the physiotherapists in my study said:

"As a general rule physios do lead the rehab and I think that my expectation would be that the patients would agree with that."

Physiotherapy has a high status because it is reductionist in that it breaks patients problems down into treatable units and therefore does not conflict with medicine (Barnitt and Pomeroy 1995). One of the physiotherapists in my study identified that within the rehabilitation team they had a high profile, and that this might be an issue for other professional colleagues:

"I do think we've got a fairly high profile. The patient sees us as a very central part of rehabilitation, probably to a lot of other professionals' annoyance – overly so."

Physiotherapists in this study therefore identified that they may be perceived as having a high profile in rehabilitation. Physiotherapy lacks a philosophy based on female virtues because in the early days it was a male-dominated occupation. Only in the 1930s did women take over physiotherapy in response to the medical professions requirement for obedient assistants (Johansson 1999). This may influence how the physiotherapists thought the other members of the team perceived them. Physiotherapists have high status and power in multiprofessional teams and may be perceived as being bossy and domineering (Miller et al 1999).

5.3.4. Doctors

In the professional literature both doctors and other professionals have identified that doctors are perceived as having considerable status and authority (Adamson and Kenny 1993, Adamson et al 1995, Lupton 1997). As discussed earlier doctors were

very clear about their responsibilities and accountability as leaders and coordinators of the team. However, on the other hand some were concerned that they were perceived as being as one doctor put it:

"All things to all people"

Another doctor in my study acknowledged this perception but felt that this was a misconception:

"I am a medic and for all they think I am all powerful and all knowledgeable I'm not and I have a limited amount of knowledge and a limited ability and I work within that."

There appears to be a tension here for the doctors in that they see themselves at the front of the team, taking responsibility for team decisions, but on the other hand they acknowledge that their knowledge has its limitations.

5.4. Professionals' perceptions of other professionals' roles

Barnitt and Pomeroy (1995) point out that not only should each practitioner be aware of the core skills knowledge base and philosophy of their own profession, but also of other rehabilitation professions. This will prevent misinterpretation of other professionals' actions. It has been suggested that collaborative education can increase postgraduate students knowledge of each other's roles (Stubblefield et al 1994). However, health care professionals know surprisingly little about each other's professional roles, even when they deal with similar client groups and have some shared learning in their education programmes (Perkins and Tryssenaar 1994). A commitment to working together and sharing expertise is dependent upon the individuals involved having a clear understanding of both their own role and those of other professionals (Bliss 1998). In any multidisciplinary team there will be overlap of many roles but lack of role definition can affect the team's functioning and organisation (Fountain 1993). Although it has been noted that the culture of the

organisation in which the team operates has a significant impact on it's functioning (Strasser et al 2002).

In my research occupational therapy and physiotherapy are the two professions perceived to have the greatest overlap:

"Here physios do a lot of the manual wheelchair prescription and in other units that would be an OT role. Equally we do a lot of seating assessment here that would be OT. There are OTs in the seating clinic as well so we do work together." (Physio)

"If you think what an OT did, she used to come round and make them make mosaic ash trays and fluffy toys and things, but it seems to me now that the OT and the physio roles are merging a bit as far as posture and seating is concerned and certain exercises and equipment for the home and things." (Nurse)

Research that has been undertaken on professionals' understanding of each other's roles is sparse and in some cases has methodological limitations. What is available reinforces the perception that professionals do not understand each other's roles and functions. As Ducanis and Golin (1979) pointed out in an early study the way that members of a profession perceive themselves may be very different from the way they are seen by other professionals. Another early study found there was also confusion about roles between physiotherapists and occupational therapists and between nurses and social workers (Lister 1980).

Attempts have been made to define what team members do in rehabilitation settings. Whitelock (1999, p 62) identifies team members' roles thus:

- Medical staff – leads the team; explain diagnosis and prognosis to the patient, chair case conferences and other meetings, are responsible for service development, audit, staff education and research. They are also involved in budgeting and management of allocated resources.
- Nurses – assess clients needs, plan implement and evaluate care; maintain clients right to privacy and dignity, offer counselling and support to clients

and their relatives, act as experts in bladder and bowel management, skin care, wound care, pain management, nutrition, hydration and health promotion.

- Occupational Therapists – the main aims of therapy are to assess the difficulties a person has with the activities of daily living; facilitate maximum independence, encourage return to function and determine functional ability, or adapt to new difficulties, prevent deformity, arrange pre-discharge home visits, provides aids and equipment to encourage independence.
- Physiotherapist – is concerned with improvement of function; strengthen muscle power, improve joint range, correct positioning and functional movement training, improve neuromuscular coordination, improve cardiovascular efficiency and fitness, re-educate functional activity, relieve pain or muscle spasm
- Clinical Psychologist – is concerned with the assessment and management of cognitive problems; offer counselling to patients and relatives, assessment of anxiety and depression, support staff.

Nurses and podiatrists have been asked about their knowledge of each other's work roles (McGee and Ashford 1996). Both groups were found to have a reasonable view of each other's roles although a high percentage of both groups did not know the types of procedures each carried out. In a rehabilitation of older people setting nurses saw it as the OT's role to provide patients with opportunities for purposeful activities (Walker 1995). In Dalley and Sim's (2001) study of a variety of rehabilitation settings nurses saw physiotherapists as being involved with mobility and movement. These studies highlight that there is some understanding of other professionals' roles, but the full complexity of the skills required is not appreciated.

The roles of professionals in rehabilitation have been described in the terms of a jigsaw puzzle, where all the pieces i.e. roles and functions interlock (Bowie 1999). Different disciplines may be dealing with the same area but from their specialist perspective. Most participants in this study saw their roles as similar but different in that they focussed on specific aspects of the same area of rehabilitation. There might be some overlap but this was a strength rather than a weakness in achieving the goal:

"It tends to be nurses do all the washing and showering now... often, OT, there's a lot of overlap between different professions. If you think about spinal injury patients there's emptying your bowels, there"s getting yourself washed, getting back on the bed, all your transfers, the equipment you need, that the house is adapted...that's where we need the other disciplines as well." (OT)

In my study nurses' and OTs' roles were sometimes seen to overlap:

"There are things that the OT's teach them that we kind of teach them regarding hygiene and dressing needs and all that so they do overlap sometimes." (Nurse)

However, there was a perception that the different perspectives of the professional groups complemented each others input:

"I'd say the OT, the physio, the doctor and the nurse; they should complement each other. We all have our roles and they aren't the same in the fact that physio will look at the mobility side and the OT will look at ways of dressing, cooking and everything like that. So the roles aren't the same, we are all tying to end up achieving the same thing in the end." (Nurse)

As discussed earlier, some of the nurses felt that the other professionals had very little idea about what nurses do in relation to spinal cord injury rehabilitation. It was interesting that two of the physiotherapists (both of whom had worked in the unit for many years) had considerable insight into nursing work:

"Nurses do far more than you could ever picture from just observing them in terms of their reasoning and their background. I'm working with a nurse at the moment, something like getting patients up to the shower, I thought it was just getting up to the shower but now I see how they think about it, how they structure it." (Physio)

This physiotherapist appeared to have seen beyond the purely physical nature of the task she was describing. She had become aware of the cognitive and educational background needed by nurses to provide competent care. Competency includes not

only the observable performance of skills, but also the intentions, judgements and choices that underlie that performance (Smith 1999b).

Another physiotherapist had worked as a health care assistant prior to entering physiotherapy and had considerable insight into how long it could take to carry out certain nursing tasks:

"It sometimes surprises me that physios can go in and expect things without realising the absolute nightmare of trying to organise people first thing in the morning, and how long it actually takes to get someone ready. That's not a five-minute job. That is quite difficult to get across because you can tell people but I think unless you've actually done it and realised that it's taken you an hour to get a tetra (plegic) *dressed, ready and up in the chair I don't think they would truly believe you."* (Physio)

Generally the participants felt that they had some understanding of each other's roles, if not the fine detail and did not seem to see understanding of each other's role as a major issue. As an OT said:

"We all know what the other members of the staff do. Whether we know the nitty-gritty, day-to-day work goes on..."

This is noteworthy, bearing in mind that a large number of participants were quite forthright about the fact that they felt that the other professionals did not understand what they did.

This is a finding that has not been identified in the professional literature. There is some evidence about the lack of congruence between the way a profession defines its own roles and the way others define them (Embling 1995). However my findings suggest another dimension: one of self- awareness in relation to professional identity. The concept of 'Othering' may be appropriate to the way the professionals were engaging with other groups of professionals who they perceive to be different from themselves. Canales (2000) suggests that the self is only known through 'Others' and how 'Others' are 'marked' and 'named' depends on the role taking of the self. When people fail to take the role of others, or resist role-taking opportunities they are unable

to interact or they interact on misconceptions or stereotypes. Davies (2002a) argues that when describing identities there must be an understanding of their relational character. The question that needs to be asked is who is the 'Other' in constructing this identity? She goes on to say that classic professional identity calls for either an 'Incompetent Other' (usually the patient or client) or an 'Invisible Other' (often informal carers).

It could be argued that for my participants when it comes to professional identity the other professionals have become either 'Incompetent Others' or 'Invisible Others.' This binary thinking is problematic in that it stresses differences between people rather than their similarities. There is always an 'Other' symbolically located outside the boundary of a specific identity but in practice giving meaning to it, the 'Other' being devalued (Davies 2002b). Exclusionary Othering uses the power within relationships for domination and subordination (Canales 2000). Classic professional identity involves seeing oneself as an autonomous and independent expert, which leaves little room for valuing the contribution of other professions (Davies 2002a). Professional self-awareness is seen as a necessary condition for competent practice (Kondrat 1999). However, my findings suggest that for some of the professionals there was a focus on their sense of professional identity without looking objectively at themselves or their experience in relation to others. It could also be argued that if some professionals are still struggling to define their own identity – particularly nurses and OTs then it might not be so surprising that they perceive others as having similar difficulties. It might reflect the ongoing relational experience of some groups- Canales (2000) suggests that people from subordinate groups may experience Self-Othering where they internalise the Exclusionary Othering perpetuated against them.

If professionals understand each other's roles this avoids stereotyping and incongruent role expectations, which are likely to cause conflict in a team (Rowe 1996). There appear to be tensions here, and if the professionals in my study have a stereotypical idea of what the others do, yet feel aggrieved that their role and contribution is not recognised or valued this could go some way to explaining why conflict occurs within the team.

5.5. Conflict between team members

When interviewing the professionals I did not ask about conflict in the team, it was however raised by several of them. Conflict in occupational groups arises from interdependence among or between groups, from specialisation of tasks and from workforce heterogeneity. Specifically this conflict tends to be rooted in differing role expectations among various professional groups (Fried and Leatt 1986). Conflict occurs when an individual or group feels negatively affected by another individual or group (Skjorshammer 2001).

One patient had identified how nurses were perceived by some professionals and the impact this might have on the nurses:

"I think sometimes their (nurses) *skills and experience are overlooked. I've seen doctors almost ignore them as if they're not there and yet the work wouldn't be done...their self esteem must be very low and I can see people leaving for that reason."*

A study of multidisciplinary teams concluded that a 'blame culture' develops between team members when things go wrong because they do not know how to work co-operatively (Minton and Duffin 2000). There was a hint of this from some participants in my study:

"I think they feel sometimes we're just there to get the patients up on time. If it's not on time you know – why isn't the patient down in physio?" (Nurse)

"It is important that individuals within a team have responsibility for their own actions. So for example if you decide a car transfer (transfer from wheelchair to car) *has to be learnt somebody has to make sure that the patient can carry that out safely and that would normally be the physiotherapist. And the patient would then be aware the physiotherapist is responsible for that. If they don't achieve car transfers the patient and the rest of the team can look at the physiotherapist and ask the question, why has that not been achieved?"* (Doctor)

Long (1996) studied perceptions of teamwork in two primary health care teams and found that examples of conflict in these teams were mostly concerned with communication and interpersonal conflicts. This was an issue for a doctor in my study:

"The appropriate function of the multidisciplinary team is to have good communication. If you're unhappy about certain aspects of my prescription for example you come to me. You cannot use the vehicle – the ward round for example to criticise that aspect however right you are...We need to be taught how to communicate, how to express ourselves and how to present our opinions in a positive way."

In the last decade there has been a growing perception that traditional boundaries between professional groups in health care are under attack with a move towards a more generic health worker who is able to undertake a wide range of roles (Hunter 1992, Beattie 1995, Barnes and Ward 2000). This may have led to a certain amount of protectionism within the spinal unit team:

"I do think everyone's got this, a lot of people have this professional jealousy around. You've got to protect your job role." (Nurse)

It has been suggested that the inclusion of clinical psychologists in hospital settings such as spinal cord injury units has not been an unproblematic process. There have been problems with interprofessional power relationships, with psychologists reinforcing the power hierarchy in relation to professionals with lower social status such as nurses (Miller and Swartz 1990). In my study this type of conflict was not an issue although one nurse felt there could be differences in perception of outcomes:

"I suppose the person we come most into disagreement with is I would say is probably the psychologist in a lot of ways. They're solely looking at one thing and we're trying to look at the whole thing so I think you can come into conflict with them more than any other member of the team. Certainly nurses seem to."

On the other hand one OT saw the psychologist more as an ally:

"I suppose that's where OTs and psychologists are fighting a bit against some of the other disciplines."

Interdisciplinary role conflict may occur when professionals – in particular nurses - are unwilling to take on activities which other disciplines expect of them and have changing ideas about the boundaries between professions which result in role confusion (Walker 1995). As a nurse pointed out:

"There"s conflict sometimes between physios" and nurses" because that"s (moving patients onto tilting beds which enable them to stand upright) *not really part of our job."'*

Conflict between nurses and physiotherapists are seen to arise because of the differences in the work patterns of the two professions. It may also occur because nurses perceive physiotherapists to have a poor understanding of the pressures emanating from high workload and shortage of staff, which are placed on them. Nurses have also indicated that physiotherapists are condescending and lack respect for their knowledge and expertise (Dalley and Sim 2001). In my study one nurse highlighted a perception that therapists sometimes had a cavalier attitude towards nurses' work:

"I think it's easy for them sometimes to come on the ward...the physio says I'm going to come at 10 o' clock and do so-and-so in physiotherapy, they should be up and washed – sure. I think they forget that we've got 19 other patients. So you've gone like a mad thing, trying to get this patient ready and at five to ten they go, 'sorry I can't make the appointment" and you want to punch their lights out."

I experienced this when working with a health care assistant (HCA) during a period of participant observation; we raced to get a patient with tetraplegia ready by 9 o' clock when his OT was due to come and work with him on perfecting his bed to chair transfers. All three of us were not very happy to receive a message at 9 o' clock that the OT was not coming, particularly the patient who could have had longer in bed. So

it was the HCA and I in the place of the OT that coached him and supported him as he used a sliding board to transfer into his chair. This scenario highlights two issues. Firstly, the attitude described above towards nursing work: we did not know the reason why the OT had missed the appointment but our perception was that that she had decided to do something else thus reinforcing the feelings described above. Secondly, the concept of therapy 'carry on' where nurses take on a therapy role in the absence of therapists was reinforced.

One of the few male participants in my study had a direct approach to conflict management:

"I'm always sticking my five eggs in, and butting in, stepping on toes occasionally." (Physio)

This male physio felt able to speak directly to colleagues regardless of whether his opinion had actually been asked for and whether he was upsetting others.

Women are perceived to bring different approaches to the workplace than men (Bolden 1996, Valentine 2001). Nurses have been seen to use gender specific strategies to manage conflict situations. Because nurses work in a patriarchal environment where men occupy the most powerful positions, their choice of conflict management strategy may be to some extent based on the powerlessness of their position. Lack of recognition, trivialising or undervaluing of nurses' contributions by other professionals results in low self-esteem. This can have a negative effect for both nurses and patients as the concerns of other professionals may take precedence over those of nurses and patients (Valentine 2001). However, it was not only nurses that conceded to others in conflict situations and did not stand their ground:

"You do end up coming in on your days off (to attend goal planning meetings that are arranged to suit other team members) *as well sometimes"*. (Nurse)

"You feel you have to fit in with people and we try to say we are part of this team...all speak nice and stuff, we have to get respect from other people in the first place." (OT)

Therefore, conflict was an issue for participants but it was handled using the range of three conflict management styles as identified by Skjorshammer (2001): avoidance, forcing and negotiation. Avoidance means not talking about an issue publicly, forcing means using formal or informal positional power and negotiation requires both parties in the conflict moving their position in some way towards a compromise. However, generally the team managed to show a united front in their dealings with patients. Teams require a shared vision and an ability to act in a coordinated manner to provide quality care and work in a coordinated manner with patients (Enderby 2002, Gibbon et al 2002). For some patients in my study this was the case:

"Each one links with the next one in the team...everyone just all works together."

However, some patients had noticed that this was not always the case in interprofessional relationships:

"Everybody's got such strict guidelines to everybody's job, which they can't step outside or even deviate from."

This could lead to conflict between different teams. One patient felt that she was in the middle of a conflict between two consultants, acting as a go-between:

"The only thing I find frustrating is because I have a spinal consultant and an orthopaedic consultant, they don't speak to each other. They make little jibes about each other, quite petty."

This had had a significant effect on her:

"I don"t feel confident about- it"s one half doesn"t know what the other half is doing and it"s all about me."

Therefore, when professional territorial disputes occur, with accompanying breakdown in communication, the patient can fall helplessly in between the cracks.

5.6. Conclusion

There is evidence that the professionals in my study felt that a multidisciplinary approach is both the right approach and for the most part an enjoyable way of working. Professionals felt that although their input might overlap in some areas they were dealing with different aspects of a particular area of care. The professionals and patients identified that the members of the team were working toward a common goal. Participants recognised that each had a specific area of expertise and no one person could cover every area of management. However there were considerable misperceptions about the roles of others within the team. Some team members felt undervalued and experience conflict in their relationships with other team members.

Nurses exhibit tensions with regard to their role in rehabilitation in that they perceive that they will be considered uncaring if they encourage patients to do things for themselves. They identify difficulties with changing from an acute care philosophy to a rehabilitation philosophy. Patients conversely, see the nurse's role as moving them on in their rehabilitation and expect to do more for themselves, but they do not consider nursing input as rehabilitation.

Doctors also appear to experience tensions in their role. On the one hand they see their role as team leadership and being responsible for decision -making, yet on the other hand acknowledge that their knowledge about all aspects of spinal cord injury management is limited. Patients expect doctors to have a greater input when they are acutely ill. They do not expect doctors to have a great deal of input into the rehabilitation phase and this concurs with the doctors' perception that they have an emphasis on acute care rather than rehabilitation.

5.6.1. A "knowing paradox"

This research appears to have identified an issue that has not previously been recognised in the literature. This is that professionals feel that they know what their colleagues' roles are but that their colleagues have little understanding of their role. This paradox appears to have a considerable impact on team relationships. The literature that is available has tended to focus solely on misperceptions that

professional groups have about other groups' roles and professional identity (Billups 1987,Wilmot 1995, McCallin 2001,Hudson 2002). My study therefore offers a new perspective on relationships within the interprofessional team. I have suggested that the concept of 'Othering' may offer some insight into this phenomenon. If classical professional identity calls for an 'Incompetent Other' i.e. someone with less knowledge and expertise and an 'Invisible Other' i.e. someone who's work goes unrecognised then for the professionals in this study it could be that other professionals are 'Incompetent Others' or 'Invisible Others'. I have also suggested that subordinate groups such as nurses and occupational therapists may internalise the 'Exclusionary Othering' perpetuated against them by more dominant groups. This may account for the feelings that these two groups have about being misunderstood by other professionals.

In the next chapter I will discuss the patient's role as a member of this team as it could be argued that relationships between professionals are likely to have an impact on the experience of team membership for the patient.

CHAPTER 6 – PATIENTS AS PARTNERS AND TEAM MEMBERS: PATIENT PARTICIPATION IN DECISION-MAKING

PATIENTS AS PARTNERS AND TEAM MEMBERS: PATIENT PARTICIPATION IN DECISION-MAKING

This study aimed to identify patient and professionals construction of patient participation, the perceptions of patients and professionals of the patient's role in the team, what supports or constrains patient membership of the team and develop a model of patient participation. The objectives being to explore how patients and professionals construct the concept of patient participation and to identify to what extent the patient was an active member of the team. This chapter will discuss the following findings related to patient participation.

- The patient's role in spinal cord injury rehabilitation
- Patient participation in the decision-making process
- Environment of care – limiting choices
- The patient as a team member
- Team leadership

A model of the patient's role in rehabilitation will be identified, levels of patient participation will be presented and team leadership will be discussed.

6.1. The patient's role in spinal cord injury rehabilitation

In the previous chapter some health care professionals pointed out that their role was multifaceted so it would seem illogical to view the patient's role as one-dimensional.

The following themes emerged from the data analysis to form a model of the patient's role:

- Take 'control' of rehabilitation
- 'No gain without pain'
- Cooperate with professionals
- 'Doing as you are told'

- Use the professionals as a resource for knowledge and information
- Be motivated
- Work in partnership as an equal team member

6.1.1. Take 'control' of rehabilitation

Participants in my study articulated that the patient's role was to take control of rehabilitation:

"You've got to be willing to sort of ask questions and not let people take control of your life." (Mark, patient with tetraplegia injured forty years)

"They've got to be the ones pushing us to do things...their key role actually is to challenge us." (Nurse)

Patients have been found to use the following strategies to facilitate their autonomy (Proot et al 2000): Taking responsibility and initiative, which encompasses

- Co-operation;
- Anticipating;
- Problem solving
- Taking stock of the situation
- Own effort
- Refusing

Spinal cord injured patients also see being able to take charge of rehabilitation as an outcome of good relationships between themselves and rehabilitation team members (Lucke 1999).

During rehabilitation the strategies care providers use to enhance this control are: information giving; training in activities of daily living (ADL); mobility; communication; decreasing paternalism; enhancing patient choice; and cooperation with patients and their families. Gradually care providers challenge patients to solve their own problems and act more in a consultative role (Proot et al 2000). This was also the case in my study:

"I would like to say be good and compliant and do whatever, but I think patients that are good and compliant aren't necessarily the ones that are successful. I think the ones that take control of their situations are the good patients so the patient"s role is to use the other members of the team." (Physio)

"My role is to recognise when I need help and work at it and not wait for a crisis, actually try and prevent it." (Martha, patient with paraplegia injured thirty years)

For most this meant taking the lead in the setting of goals that were meaningful to them rather than working to someone else's agenda:

"Well I'm the one being rehabilitated so I'm the subject so I'm the one who's working with everyone who's working with me. So OK I'm the one who says what I want to achieve to the people who are the physio, the occupational therapist, this is what's really important to me." (Basil, newly injured patient with tetraplegia)

"My job is to tell the physios" what I could do and how I could do it so they can help me adapt what I could do. I'm hoping it's going to work like that." (Mack, patient with tetraplegia, injured twenty-eight years)

As discussed earlier the spinal unit places a considerable emphasis on goal planning to enable patient participation in the rehabilitation process (Kennedy et al 1996, Duff et al 1999) so it is perhaps not surprising that the word 'goal' featured heavily in the comments from health care professionals:

"Their role is to know what they want, what their expectations are...hopefully they will shake off 'we will tell you what to do and do it to you.' Learning to take control and learning to set realistic goals." (Nurse)

"Their role is central. They have to define what their goals are and where they want to go, what they want to be; they are absolutely key." (Doctor)

However the achievement of those goals required considerable effort from patients.

6.1.2. 'No gain without pain'

A theme that was much more apparent in the patient responses than it was from professionals was that there was, 'no gain without pain'. The patients in my study recognised that rehabilitation was hard work and that this would impact on their role in the process:

"I've got to work hard, it can't happen without effort from me and on a good day that"s fairly easy, but on a bad day it"s horrible." (Laura, newly injured patient with incomplete paraplegia)

The concept of 'good days' and 'bad days' has been identified by Canadian spinal cord injury patients (Laskiwski and Morse 1993). On 'good days' they felt energetic, mastered new skills and found new activities to participate in. On 'bad days' everything was a struggle, they were bored and time dragged. However, for my participants hard work was seen as a means to an end:

"A lot of hard work (Laughs). *Just give it 110% and get on with it. The harder I work the quicker I get out is the way I look at it."* (Clive, newly injured patient with paraplegia)

Participants expected that there would be pain but that this was part of the process and was something to be overcome with hard work. This attitude spanned the age groups – Lillian was retired, newly inured with paraplegia:

"My job is to put it bluntly do as I'm told and do my best. If it's painful you've got to have a certain amount of pain because you use things you haven't used before, you've got to tolerate that and treat it as a challenge."

Lillian had also recently undergone a mastectomy, which made transfers out of bed a struggle, and could be painful. However I worked with her on several occasions during periods of participant observation. I would set her up with a lateral transfer board (sliding board) and a glide sheet and stay with her for moral support while she transferred in and out of bed. She was determined not to use my help unless she really could not manage. Over the period of my research she became stronger and did

master the transfers. Lillian therefore demonstrated that she was indeed willing to accept a certain amount of pain. She did tolerate it and treat it as a challenge because her ultimate goal was to return home and be as independent as possible.

Shaun was in his twenties, newly injured with tetraplegia:

"It entails pushing yourself I think. It means accepting a bit of pain here and there...having to accept things you don't want to do sometimes."

This is an issue that has been identified by stroke patients (Woodhead and Fortey 1997, Maclean et al 2000) who see rehabilitation as both a mental and physical struggle. Patients recovering from strokes and amputations have defined rehabilitation as an active struggle where success depends on their own efforts (Sheppard 1994). Canadian spinal cord injured patients have compared rehabilitation to doing hard labour in jail (Carpenter 1994).

Two of the physiotherapists recognised that the rehabilitation role for patients was one of very hard work:

"Take it on board and get it all gelled...there is a strict routine that they would have (sic) *to follow to very successfully do that which I suppose is actually hard graft."*

"So much of it is learning things that they have probably never had any experience of in any shape or form and they are expected to take it on board very quickly and learn it first time round. So I don't think it's an easy ride."

Lucke (1998) proposes that the special relationship between a nurse or therapist and patient centres on viewing the world from the other's perspective. However my findings suggest that in this respect most of the professionals do not. Although some professionals recognised the life changing impact of a spinal cord injury only two physiotherapists identified the pain and hard work of rehabilitation. The professionals in this study were concerned about recognition of the difficulties related to their work. If as Lucke suggests the patient/professional relationship is vital to enable professionals to give authenticity and authority to the patient's voice then these

findings have implications for practice. By denying the lengths to which patients are willing to go (enduring pain and discomfort) to achieve their goals I would argue this reinforces professional power and authority rather than caring.

Another interesting finding was that the patients in my research were much more positive, one could say stoical about accepting pain and hard work during rehabilitation than the patients in the limited amount of work that has been carried out in spinal cord injury care. It is perhaps linked to the fact that the other research was conducted in other countries – the USA (Cooper 1994) and Canada (Laskiwski and Morse 1993, Yoshida 1994, Carpenter 1994). Obviously one has to take care not to perpetuate the stereotype of the British 'stiff upper lip,' but cultural differences may impact on patients' perceptions of the pain and effort they are prepared to tolerate to achieve their goal.

6.1.3. Cooperate with professionals

Cooperation is seen as a strategy used by patients to anticipate care routines and solve problems (Lucke 1999, Proot et al 2000). Cooperation with health care professionals was recognised by my participants as important, however it appears to take place on several levels as outlined in Figure 4:

Level of cooperation with professionals	**Patient role**
Comply with professionals instructions	Do as you are told
Listen to and learn from professionals	Use professionals as a resource for knowledge and information
Comply with professionals instructions, listen and learn from professionals	Be motivated
Contribute to a therapeutic alliance	Work in partnership as an equal member of the team

Figure 4- Levels of cooperation with professionals

6.1.3.1. 'Doing as you are told'

An earlier study of spinal cord injury patients suggested that patients felt that they were expected to do as they were told and to fit into the rehabilitation regime (Oliver et al 1988). Two decades later some participants in my study had similar perceptions:

"Be as prompt and compliant as possible." (Mick, newly injured patient with paraplegia)

"Well I think they should respect themselves and respect the staff enough to make the effort and get up and go to physio on time, because that shows respect for the people who are helping them, but also shows their own self respect." (Nurse)

This perception of cooperation suggests that patients and staff expect compliance by patients. Compliance has been defined as adherence to health care advice (Wilkinson 1996), or the willingness to follow the wishes of another person (Buchmann 1997). However, for some time it has been suggested that compliance is not an appropriate term to use in rehabilitation as rehabilitation should be a collaborative process between patients and professionals (Quigley and Giovinco 1988, French 1997).

6.1.3.2. Use the professionals as a resource for knowledge and information

Harry, who had managed his life with tetraplegia for 40 years, commented on a need for knowledge:

> *"Try and learn and understand by talking to the nursing staff, physios and doctors. Learn as much about yourself and what has happened to you and how to recognise when things are going to go wrong."*

This emphasis on learning was echoed by other participants:

"Be as flexible and not too rigid in what you think...and certainly willing to listen to whatever knowledge is passed on." (Gordon, patient injured twenty-five years with paraplegia)

"Be a sponge...absorb as much information as they can." (Nurse)

Patients with chronic illness often learn to self-manage their own condition by taking control of everyday problems (Braden 1993). The concept of patient expertise in chronic illness which leads to self help behaviour is one that has been promoted in the professional literature (Braden 1993,McGauran 2001). However, it has been suggested that patient expertise is not always recognised by health care professionals (Thorne et al 2000). For a participatory relationship patients need knowledge and a supportive environment and professionals need to be able to conceptualise the self-care decision -making process of people with chronic illness (Paterson et al 2001).

6.1.3.3. Be motivated

It was recognised by both patients and staff that motivation is a factor in success. Patients perceived motivation as important in achievement of their goals:

"There's only so much the rehabilitation staff can do without me participating and getting up in the morning and doing as much as I can." (Sam, newly injured patient with incomplete paraplegia)

"I'm the person who's got to put quite a lot of the effort as well. I have to be there; if it"s a weight session I actually have to pull the weights." (Dave, newly injured patient with tetraplegia)

Rehabilitation professionals have long suspected that a patient's motivation plays an important role in determining the outcome of therapy (Sheppard 1994,Maclean and Pound 2000, Proot et al 2002). Maclean et al (2000) in a study of stroke patients found that highly motivated patients take an active role in rehabilitation. The professionals in my study also expected motivation and felt that those with a positive attitude would be successful:

"I think to be focussed and have a positive attitude and I think to believe in themselves as well...patients that start out on a positive note seem to do a lot better." (Nurse)

Another nurse echoed this perception that motivation was an internal issue linked to self worth:

"If they feel that they are not worth anything and are just dossing around in bed all day and thinking they are not going to get anywhere then they are not going to get anywhere."

Another participant acknowledged that working with a motivated patient is more rewarding than working with someone who is not:

"Some of the patients are really enthusiastic, really driven in their rehab and they're great to work with. Some of them are very apathetic, constantly having to motivate them and drive them to do things. (Physio)

Maclean et al (2000) have suggested that patients who appear to be motivated and thus share health care professionals ideology of rehabilitation are likely to receive more attention from professionals than those who do not. It could be argued that patients who are perceived by professionals to be 'good' patients are more likely to have greater rehabilitation input than patients who are considered to be apathetic and unmotivated.

There are many theories that attempt to explain motivation that range from internal personality trait explanations, to 'carrot and stick' psychological and sociological theories (Wilkinson 1997, Maclean and Pound 2000). These explanations include the patient's health belief model-attitudes and perceptions of health. The health locus of control will determine to what extent patients are likely to assume responsibility for their own care. The self-efficacy model maintains that perceived control of a situation is determined by the patient's outcome expectancy and self-efficacy expectancy (Graham 1997). The carrot and stick approach describes stimuli that drive or goals that pull a patient's behaviour in a certain way (Wilkinson 1997). However, the youngest participant in my study (Clive) may have summed up the driving force behind motivation when he said:

"My role is to get back to normal society, be an active member of the general public."

6.1.3.4 Work in partnership as an equal team member

The concept of a therapeutic alliance as opposed to compliance in patient/ professional relationships has been around for some time (Moughton 1982). Patients are more likely to expect an equal relationship (McQueen 2000, Roberts 2002) due to a range of initiatives such as The Patient's Charter (Department of Health 1992) and Involving Patients and the Public in Healthcare (Department of Health 2001). Participants in my study articulated this expectation:

"I've got a team with a named nurse, my physio, my OT, my key worker and myself and you know we all work together to get to a certain goal, but it's like they work for me, help me to get to that point." (Jemma, newly injured patient with tetraplegia)

"They're very active in their rehabilitation and they're very good at identifying their needs and trying to sort things out...to be as verbally independent as they can." (Nurse)

So for my participants working hard, bearing some pain and working closely with professionals while simultaneously taking control of their lives were the key facets of the patient role in rehabilitation. As discussed earlier, patient motivation is a complex phenomenon and may be grounded in personality traits, social factors or clinical characteristics (Maclean and Pound 2000). The patients in my study appeared to be highly motivated. It could be argued that the ethos of the spinal unit is one of positive thinking and that this has been the case since it was founded. Some of my participants remembered the unit's founder and how the emphasis had been on hard work and learning as much as possible about their condition and its implications. One patient who had her initial rehabilitation in the unit as a child thirty years ago remembered:

"I remember being in tears at the time and just being told to get on with it, and if you didn't do it you were considered a failure. And you know maybe it did work and I did achieve it – it was a bit like a boot camp."

So the emphasis was and still is on what a person can achieve, not on what they cannot do. However, this comment also reinforces the notion of patients doing as they are told. The historical background of the spinal unit may then to some extent go

some way to explaining contradictions between the espoused philosophy of participation by professionals and the reality that the patients experience.

It is interesting that there was a considerable amount of agreement between patients and staff about the role of the patient in rehabilitation. Goffman (1961) suggested that some of the most effective agencies of socialisation are those which shut people away from the wider world such as long stay hospitals. Goffman called these places 'total institutions.' The spinal unit may or may not be a 'total institution', it is somewhat separate from the rest of the hospital but patients are not shut away from the wider world. Patients may undergo a socialisation process but it may be more akin to the process that students of many occupations experience when they are in training. Students are seen to undergo a process of organisational or occupational socialisation where they undergo a process of 'learning the ropes' of a particular organisational role as they develop a professional career. They learn the correct way to perceive, think and feel (Parry 1990, Rickard and Knight 1997, Curtner-Smith 2001). In particular student nurses have to learn unwritten rules and learn to 'fit in' with the culture of the clinical area (Melia 1987). Negative sanctions may be used to may be used to ensure compliance to a ward culture (Philpin 1999). It could be argued that patients entering the spinal unit are embarking on a career – as a person with a spinal cord injury and are therefore undergoing a similar process. If this is the case it would not be surprising to find congruence among patients and professionals.

A philosophy of emphasising what a patient is able to achieve has been identified by spinal cord injured patients in other studies as vital to their self-esteem and re-integration into the community (Carpenter 1994, Lucke 1998, Lucke 1999). As Wade (2002) points out rehabilitation is a way of thinking, not doing and rehabilitation works not by life-saving interventions but because it focuses on helping patients achieve their own goals, thinking how each obstacle can be overcome. Patients as active participants in the rehabilitation process was a recurrent issue in the defining of the patient's role. There is very little research into perceptions of professionals' and patients' of the role of the latter in their rehabilitation. However, some of the work available seems to suggest that rehabilitation is something that is 'done to' the patient who is a passive receptacle of treatment (Cooper 1994, Lu and Yarkony 1996, Beck et al 1999). The focus of work on the patient role in spinal cord injury rehabilitation has

been on goal planning (Kennedy et al 1991, McGrath et al 1995, Kennedy et al 1996, McLeod and McLeod 1996, Foley 1998, Duff et al 1999, Playford et al 2000). This is seen to enable patients to take part in rehabilitation planning, but goals may not necessarily be patient directed (Wade 1998, Playford et al 2000). It could be argued that goal setting is only one facet of a much more complex issue of what constitutes the patient's role. What limited work has been done on patients' perceptions of their roles has produced conflicting results, although this may relate to the type of rehabilitation studied; mostly stroke rehabilitation and the care of older people. Some findings suggest that patients do not expect to be actively involved in the planning and implementation of rehabilitation (Sheppard 1994, Abbott 1999). Other work however, suggests that patients do wish to be actively involved and that they recognise the importance of their role in rehabilitation (David 1995, Brillhart and Johnson 1997). This chapter will now discuss patient participation in decision-making processes, their membership of the team and perceptions of team leadership.

6.2. Patient participation in the decision –making process

6.2.1 'Why Grandma, what big teeth you've got!': paternalism

When analysing my data it was found that while the concept of participation was acknowledged by the professionals as implicit to their practice (and most of the professionals felt they involved patients in decisions), in practice there was inconsistency in using a partnership approach to care. Only a few participants in my study appeared to notice that participation was not quite how it appeared. Patients and professionals appeared to articulate different levels of participation ranging from open paternalism to active participation, as outlined in Figure 5:

Level of paternalism	
Open paternalism	Power and control lies with professionals
They tell me what they are doing	Patients are told about the decisions
They can always say no	Patients can agree or disagree
Making the 'right choice'	Patients steered towards the 'right' choice
Active participation	Patient chooses the course of action

Figure 5- Levels of participation

Partnership in care is derived almost solely from the perspective of health care professionals (Wade 1995). In a Canadian study of adults with longstanding type 1 diabetes participants identified the covert and subtle ways in which practitioners contradicted their stated goal of participatory decision making (Paterson 2001). Ikonomides and Singer (1999) have distinguished between "hard paternalism" which justifies the imposition of values and judgements on people "for their own good", and "soft paternalism" which permits interference when individuals are unable to give voluntary consent. The responses of some of my participants suggested there is open and obvious paternalism, mostly of the "hard" category. However, paternalism may be dressed up like a wolf in sheep's clothing. In this type of paternalism both professionals and patients think that they are involved in a partnership and that patients are making the decisions

6.2.1.2. Open paternalism

In a paternalistic model of provider-patient relationships the locus of control is with the provider. The professional is seen as holding the knowledge of what is in the patient's best interest. The professional takes responsibility for care decisions and the patient will accept the recommendations of the professional and follow the orders they are given (Fosnaught 1997). The relationship is a parent-child approach with the professional taking on the role of guardian (Sabatini 1998). As an OT in my study pointed out:

"The medical model says that we're in control, we're the ones with the power and patients come to us and we're the ones with the knowledge."

Cancer patients have identified that one obstacle to participation in decision-making is being treated as an object (Sainio et al 2001). Patients in a community setting receiving rehabilitation services felt that they were not consulted during assessment, few being given choices or even explanations relating to their rehabilitation needs (Abbott 1999). Patients have also stated that they did not feel they were involved in decisions; they perceived that they were not asked about or listened to with regard to

their wishes before treatment decisions were made (Nordgren 2001). In my study some patients were not informed of decisions:

"Sometimes it might be a change of medication, sometimes an investigation or something but the first the patient knows is when they're given a different dose and they say 'that"s not what I normally have.' 'Oh well' I say 'haven't they discussed it with you?" 'Well no"'" (Nurse)

This paternalistic ethic has been accused of denying patients the right of self-determination (Maier 1993). This approach was a cause of annoyance to some patients:

"A lot of times that"s really frustrating, you don't have input on your own life." (Jemma, newly injured patient with tetraplegia)

Another patient was unable to contribute to decision making because of the position he was being nursed in and the fact that no one on the ward round attempted to speak to him face to face:

" Oh if they came in here and discussed it with me and I didn't agree I'd put my input in and perhaps persuade them otherwise. On ward round yesterday I'm laying practically on my face because the doctors have got to look at my wound and I hear them mumbling behind me and I can't hear them talking. It would be better if they would talk louder so you could hear exactly what they were saying...I think it's important for patients to know then they're not sitting there thinking is it x or y or z?"" (Mark, patient with tetraplegia injured 40+years).

This approach was also seen during observation when the ward round reached the bed of an older patient who was hard of hearing and the consultant stood at the foot of the bed but the patient could not hear so the ward round moved on without including the patient in the conversation. So in these instances the patients were not involved at all and therefore the power and control on these occasions rested with the professionals.

6.2.1.3. They tell me what they are doing

Some patients in my study did feel that they were told about the decisions:

"Yes they're quite communicative, explaining what to do, why you're doing it."(Phil, newly injured patient with tetraplegia)

"I don't think that you necessarily feel it's being done behind your back." (Mick, newly injured patient with paraplegia)

One felt she was told but only if she asked for information:

"I check things now, whereas before I used to take it that's what I was given, take it, but I'm more likely to ask now." (Laura, newly injured patient with paraplegia)

The extent of involvement of patients may depend on factors such as the patient's age, social class, and the professionals' perception of the patient's level of understanding (Wade 1995,Thistlethwaite 2002). It will also depend on the professional's perception of their own professional knowledge and their perception of the amount of knowledge patients possess – the approach that "I'm a professional therefore I know best," will mitigate against partnerships with patients (Mead 2000). The extent to which patients are listened to may vary:

"Yeah well they do listen to me, some of what I say does seem to sink in." (Phil, newly injured patient with tetraplegia)

"I think they are list...some are listened to more than others." (Nurse)

The paternalistic approach may also be taken because patients are perceived as not being ready or able to take on a decision-making role:

"I think it's difficult initially because they don't know what they need and they don't know what they want." (Nurse)

In this case professionals may be making decisions for patients until they are able to take on this role.

A patient who had been injured a very long time highlighted this as a factor:

"People are asking me what I feel about something and I can't always say what I think because I don't always know. There are things they can tell me, lots of things they can tell me." (Peggy patient with incomplete tetraplegia injured 44 years)

6.2.1.4. They can always say no

Some participants saw patient participation as being able to either agree or disagree with a decision:

"At the end of the day it's the patient and they fully have the right to refuse things." (Nurse)

"Well they always ask and you know it's not you have this and you have that. They always ask if that's what you'd like. (Margaret newly injured patient with paraplegia)

This could be construed as some degree of participation, however Ozer (1999) suggests this is the lowest level of patient participation with only 20% patient contribution.

Savulescu (1995) has argued that doctors should make value judgements about what is best for their patients calling this "rational non-interventional paternalism". This differs from old-style paternalism in that patients should not be compelled to take that course.

Patients who did say no felt that they had to be assertive to overturn a decision:

"You are told what you are going to do... I'm quite forceful so if I don't want to have anything I don"t have it. Where I can make decisions I'll make them. I won"t do it; I'm too stubborn for that.

"I'm a little bit assertive. I hate not being in control so whether they like it or not I keep asking them enough questions that I understand what they are doing. And I make as much of a decision I think as I can. I think if a patient says no I think they often do take the answer as no."

Professionals may find it very difficult to 'let go' and grant patients autonomy especially when they do not conform to what the professionals see as the correct course of action (Pill et al 1999). In my study professionals did not always perceive patients who say no in a positive light:

" When a patient says they don't want this, the first thing we do is make judgements upon them. We don"t say, 'fine that"s their life.' We have no law to make this person do what we want." (AHP)

"Some people feel very intimidated by a team ...you sometimes get the feeling that people will agree; they probably feel it's in their best interests to agree. Then they'll not necessarily agree with what's happening and I suppose we're not too pleased with the other variety where we just see people as being bloody-minded when they say what they want." (Physio)

However there appears to be a contradiction in that professionals perceive that their role is to encourage patients to be assertive particularly in readiness for the outside world. One professional commented on a perception by professionals in the community that patients from the unit are aggressive in their pursuit of their requirements:

"Our patients are renowned for being very assertive when they've left hospital and they (community professionals) *think we train them to be very aggressive. They are not, they are quite assertive because we teach them to be in charge of their care."* (AHP)

So perhaps for the professionals in my study assertiveness in patients is something that is encouraged when they leave hospital but is not necessarily appreciated by them

during the hospitalisation phase. Similarly, when they enter the community with assertiveness skills they are perceived as aggressive by the professionals they meet.

6.2.1.5. Making decisions: making the 'right choice'

Being able to make choices about ones care has been identified by nurses as important to a patient's quality of life (Draper 1996).

There is a great deal in the literature about giving patients the facts and the possible options and then letting them make up their own minds (Ovretveit 1997,Guadagnoli and Ward 1998). Some of the professionals in my study felt that they enabled patients to do this:

"Give them all the facts in an understandable way then leave it finally to the person to make the decision." (Doctor)

Although an OT acknowledged that enabling patients to make decisions was something professionals espoused as an ideal:

" We like to think we enable the patients to make as many decisions as they can in their rehab and give them the opportunities. We're like facilitators to say this is available to you if you'd like to take that up in your rehab, it's whether the patient actually takes it on board or not really." (OT)

However, when giving patients information on which to make a decision there is a danger that all the alternatives might not be presented or it may be biased towards a particular option (Holmes-Rovner et al 2001). In Jewell's (1996) study of older patients participation in discharge decision-making nurses assumed that they would guide the decision making by controlling and structuring how and when advice and information was given. Health care professionals may overtly or covertly exert pressure on patients for the professionals' best interests (Wade 1995). Doctors have acknowledged that they normally biased their presentation of facts in order to 'steer' patients into making the decision the doctor thought they ought to make (Elwyn et al 1999). It appeared that in my study some patients were steered toward what the professionals thought was the 'right' choice:

"I'll give a little example where it's decisions are made with my input but sometimes they're steered. For example my doctor looked at my pressure sore and said there might be a few complications in trying to close it surgically and it would be better to let nature take its course. I said fine, good, you're the doctor, you know, you've got years of experience with this. Then on the following visit while consulting with his fellow doctors he said "we're not going to close this surgically because I know Mack's very keen, very, very keen to let nature take its course." (Mack patient with incomplete tetraplegia injured twenty-eight years)

Mack was the only patient who identified that professionals used this strategy. Although it has been identified in the professional literature – Bottorff et al (2000) call this psuedochoices or 'leading choices'- choices being phrased or offered in such a way that support's the professional's agenda or what they think is best

However several professionals recognised that patients might be steered towards certain options:

" I'd hope by the end of their rehab they'd feel that they were involved in the majority of their decisions. I think...we have to steer them in a direction." (Physio)

"Well they have to be fully involved; they have to define what their goals are. It's up to the team to enlighten them whether that's possible or not and what they need to do to achieve it." (Doctor)

Only one professional acknowledged the tensions between patient participation and professionals' wishes, and how professionals might steer patients towards what they see as the 'right' choice:

"They tend to be given options and then I suspect it"s like a lot of things, we"d like to think we truly give them options. Now whether they feel that they truly have a choice or whether the way that we present the options to them is actually signalling what we would like them to choose I'm not sure." (Physio)

The steering of choices may therefore be overt or covert and may occur for a number of reasons. It may be because there is no choice as the professionals see it:

"Patients should be involved in all things, should be given a choice in a given situation and when there is no choice, be made to understand why there's no choice and even so should be able to refuse the treatment if they do not like it." (Doctor)

However, steering of choices can occur with regard to more basic decisions: during a period of participant observation I observed a patient being offered a wash by a nurse. The patient asked if he could have a shower. The ward was very busy and the nurse had all the equipment ready on a trolley to wash the patient. The patient was told that as his bay was being tested for MRSA he would have to wait until all the other showers had been done to use the shower trolley, so he might not be able to get up until after lunch. As the patient wanted to get up before lunch he agreed to have a wash. This could therefore be seen as a way of manipulating the patient to make a decision that fitted in to the nurses work plan for the morning.

6.2.1.6. Active participation

Two of the patients felt that they had been fully involved in choosing the course of action to take:

"I was involved every step of the way, I was involved in it. I was involved in the decision-taking as to what would happen and I made the choice there." (Lillian, newly injured patient with paraplegia)

"It was a matter of 'well these are the choices; you don't have to decide today, let me know what you think'" (Gordon, patient with paraplegia injured twenty-five years)

Bottorff et al (2000) describe this approach as letting the patient 'set the pace;" this gives the patient time to think about the alternatives and to determine priorities in relation to their individual situation. I observed a doctor in out patients setting out all the options, (including an anterior sacral nerve root stimulator which involves major surgery) to a young woman and her partner for the management of her neurogenic bladder. All the advantages and disadvantages for each option were presented, but the

patient was unsure about which option to take. The patient was advised by the doctor to go home, think about it, discuss it with her partner, come back and talk to the doctor again if she wished, before she made her final decision.

Braddock et al (1997) outline six criteria for informed decision-making:

- Description of the nature of the decision;
- Discussion of alternatives;
- Discussion of risks and benefits;
- Discussion of related uncertainties;
- Assessment of the patients understanding and
- Elicitation of the patient's preference.

Although this approach was used in the scenarios cited above it was rare.

Therefore, for some participants there was active participation, with patients and staff playing an equal role in the decision-making process. However, active participation can depend on how well or physically fit the patient is. Being too ill is a reason cited by patients for not participating in decision-making (Biley 1992). An OT recognised that some patients needed to build up to that stage whereas others were ready earlier:

"For various reasons it might be that a patient is just not ready to take on that role and need a lot more support and pushing and some people just take it on automatically...they want to be in control and they want to be in charge".

So for some patients full participation may be something that happened immediately, for others it might be a more gradual process.

A nurse, however recognised that active patient participation was inevitable:

"With people having more knowledge and more autonomy a lot of it is patient led. You find a lot more patients are wanting to take over their own care, their aims, they indicate whether they're right or wrong, whether we're right or wrong. They want to get much more involved and that's really developing."

There has in recent years been a growing acceptance by the government and some health care professionals that some patients might know as much, if not more, about their conditions as the professionals. The concept of the 'expert patient' teaching professionals has been discussed in the professional literature (Gaze 2000, Smith 2000, McGauran 2001, Department of Health 2001b). A patient who had been injured for forty years felt that staff recognised his expertise and were eager to learn from him:

"They (the ward staff) *are keen to be taught or learn. It's a feather in my cap to have been told afterwards by the ward staff that they enjoyed having me in there because they were able to learn so much from me."*

During a period of participant observation a ward round was observed where a patient, injured for several years with a pressure sore told the consultant that he was going home and his family would look after him. The consultant concurred with the patient that he and his family had the knowledge and ability to look after him and agreed to his discharge home. In this scenario the consultant recognised the expertise of the patient and his family.

It has been suggested that some patients do not want to be active participants in their care and therefore do not wish to be fully involved in decision-making (Waterworth and Luker 1990,Caress et al 1998). In my study patients wished to have some input into the decision-making process. Not all were being fully involved although they may have perceived that this was the case. Likewise, professionals perceived that they were involving patients in the decision-making process. The reality of what was happening in practice was much more complex and suggests that the power imbalance between patients and professionals enables professionals to maintain control of the decision-making process.

6.3. **Environment of Care: limiting choices**

A patient in my study pointed out:

"There are times when you think, I want, I would love to say I'd like a shower every day but you know that's impossible because of the understaffing and so you think no I can't push for that. You know I have to rely on them to make the decision when they"ve got the time." (Martha patient with paraplegia injured thirty years)

Draper (1996) warns that there needs to be recognition of the distinction between altruistic and sociological arguments in defence of choice limiting action. The altruistic justification appeals to the greater good of the patient, whereas the sociological argument suggests that choice limitation is necessary to ensure the smooth running of the institution. He suggests that it is possible to construct an argument of the functionalist type to claim that patients who adopt the sick role on entering hospital implicitly hand over control and responsibility for their lives to professionals.

A study of medical patients found that patients tend to 'toe the line' by complying and doing as they were told either because they felt they might be penalised or to fit in with routines (Waterworth and Luker 1990). Medical and surgical patients in a Swedish study tended to accept staff decisions in order not to be seen as being difficult (Nordgren 2001).

It has been suggested that patients should be recognised as honorary members of the health care team to enable the development of a framework within which the potential contribution of patients to their own care could be valued and effectively supported (Edwards 2002). This concept of patient as team member is an aspect of patient participation that will now be discussed in relation to my study.

6.4. The patient as team member

As in the case of patient participation in decision-making for the most part both patients and staff articulated a discourse of patients being team members.
Some patients who had been injured for many years felt that their participation as team members had changed for two reasons:

- The concept of patient involvement in team processes had evolved over time

- They had gained confidence due to their experience of living with a spinal cord injury:

"The whole system seems to have changed and involve the patient much more." (Peggy patient with incomplete tetraplegia injured forty-four years)

" I do this time, (feel part of the team) *much more this time. I don't feel angry whereas last time I felt angry a lot of the time."* (Martha patient with paraplegia injured thirty years)

"I do feel part of the team. I do feel if I make a suggestion it"s heeded. When I had the original injury I was a bit too gob-smacked to, but I've had twenty-eight years of experience of it now. So I feel I am qualified enough to give some input." (Mack, patient with tetraplegia)

Being newly injured or being unwell has already been discussed in relation to participation and it was also identified as a factor that inhibited team membership:

"Loosely yes, if you're unwell then you can't partake as actively as you'd like to be. But once you"ve got over the hurdle then to be part of the team helps them to help you to get out again." (Harry, patient with tetraplegia injured forty years)

"When patients are first injured they haven't got an idea of what it's like so they're always guided by us. But I think when they're old lesions and they come back in again it"s very much the other way." (Nurse)

Both patients and staff recognised that without the patient there would be no need for the team and therefore assumed that this was evidence for the notion of patient membership:

"Well an integral part I suppose because if they weren"t there I don"t suppose there"d be any point in us being here. I think they"ve got as much to offer as we have to offer.'" (Nurse)

"Oh yes, well if I wasn't here they wouldn't have much to do would they?" (Laura, newly injured patient with paraplegia)

Interdisciplinary teamwork has been described as a cornerstone of rehabilitation therapy (Whelan and Hochberger 1996). Effective teams have shared leadership roles and individual and collective accountability. However, the value of multidisciplinary team care for patients with spinal cord injury is not clear (Wells and Nicosea 1992). A team has been described as a collection of people who share a common purpose requiring the unified efforts of all the members to achieve that purpose. An effective team leader develops the leadership qualities of team members. Additionally team members are able to support and buffer one another against the stresses of the workplace (Richardson 1992). However, the notion that all employees are members of a team devoted to meeting organisational goals is not always observable (Lenkman and Gribbins 1994). Interdisciplinary collaboration may be more attractive in theory than it is in practice as team effectiveness can be affected by both personal and professional disagreements (Gibbon 1999).

Unsworth (1996), an occupational therapist suggests that the rehabilitation team consists of a wide range of health care professionals who share assessment findings, treatment outcomes and provide information. Unsworth adds that the team may also include the patient and their family but in her study of rehabilitation team decision making patient participation in decision-making was not discussed.

There is a great deal in the professional literature about patient-centred care models (Ellis 1999) effective team interventions (Sherburne 1986,Rinehart 1990, Scott and Cowen 1997,Watkins et al 2001) and team relationships (Cott 1998). Much work has gone into analysing how teams function, why they function and where they function. However, in all this literature one thing that does not appear to have been recognised is that if the patients were not there then the team would not be required. I would suggest that this might be because this fact is so obvious but at the same time the disability movement is questioning whether there is a role for professionals in the management of disability (Oliver 1999). The implications of this reliance on patients for their existence therefore tends not to be contemplated by professionals. It is interesting therefore that in my study both patients and professionals quite bluntly

articulated this fact. There is then a paradox in that patients and professionals on the one hand are aware of the power that patients have in that professionals rely on them for their livelihood. On the other hand professionals exercise considerable power over patients with regard to how much input they are able to have in team decisions. Patients have been described as co-workers in health care (McLeod 1995) and there is a great deal about patient partnership and patient participation in the professional literature (Cahill 1998, McQueen 2000). Mackay (1995) however suggests that far from encouraging patient participation, professionals actually use patients as pawns in their interprofessional relationships.

It could be argued that if patients were empowered then they would be seen as the leaders of the rehabilitation team. A democratisation approach involves decision making between front line staff and service users and puts user control on the end of a continuum (Hickey and Kipping 1998):

Information/explanation consultation partnership user control

The first two positions information/explanation and consultation do not transfer decision-making power to the user. The partnership and user control positions redistribute power so that the user makes the decision and it is the user that decides whether or not to involve other people in the decision-making process.

However, the findings in my study suggest that although patients may see themselves as part of the team, and may be involved to some extent in the decision-making they are not team leaders. The professional literature reflects this viewpoint, identifying that each team must have a leader or a set of leaders. However, the leader is the doctor and goals of care are based on the patient's assessed needs (Mullins et al 1994). There is very little in the professional literature that suggests that patients are or should be the leaders of the multiprofessional rehabilitation team. A true 'client led' approach would mean that the patient would coordinate goal-planning meetings his or her self (Foley 1998).

6.5. Team Leadership

In my study four perceptions of leadership have emerged from the data:

- There is no one leader;
- The doctor is the leader;
- Other professionals lead the team and
- The patient is the team leader.

6.5.1. There is no single team leader

Martin (2000) suggests that in some health care situations teams are self managed with no one individual having a leadership role. Some of the participants in my study were unable to identify one leader of the multiprofessional team. For some this was because they saw all the team members as working together:

"Any one person is difficult. I would, you just said it, the team. I don't think there is any one person, you just said it yourself it's the team." (Mack patient with tetraplegia injured 27 years)

Some saw this joint approach as being as strong as the weakest link:

"Well there"s no real leader. I mean everyone works, you're all working toward the common goal and everyone does their bit. If one person doesn't do it then it doesn't work." (Clive, newly injured patient with paraplegia)

Or by others as being as strong as its strongest links:

"In my case it"s a joint effort starting from Mr... (Consultant*), the named nurse, the physiotherapist who sees me every day. I have a lot of encouragement from both those two and the three of us have an essential rapport which I suppose is essential."* (Lillian, newly injured patient with paraplegia)

For one patient having no discernable leader was a problem:

"There doesn't seem to be one. There's no one person I can go to." (Phil newly injured patient with tetraplegia.

6.5.2. The doctor is the team leader

The doctors in this study identified that they were the team leader and quoted their legal and professional responsibilities to support that view:

"I think in the current environment of the NHS the legal team leader is the consultant.""(Doctor)

Other members of the multiprofessional team also saw the doctor as taking the leadership role:

"Well I think the doctor does lead the team, but they lead it in their direction." (Physio)

"I think it varies but the base line is it feels like the consultant at the end of the day have the say or have the authority to make decisions basically and go above us but I don't always feel like they are the ones with their finger on the pulse." (OT)

It was interesting that only two patients identified doctors as being team leaders. However, Gair and Hartery (2001) in an observational study of discharge case review meetings found that although the senior doctor exercised considerable power in some areas such as chairing meetings, and the initiation of discharge, this was not the case in other areas and all team members were part of the decision making process.

6.5.3. Other professionals lead the team

Martin (2000) suggests that different people can undertake team leadership at different times rather than one person all the time. In a study of stroke rehabilitation team conferences the core professionals, i.e. those who made the decisions, were the physiotherapist and the occupational therapist (Gibbon 1999). On the other hand in a case study of a neurorehabilitation unit the clinical nurse specialist was the person who drove the culture and philosophy of the unit (Proctor-Childs et al 1998).

Some participants – mainly professionals - felt that the leadership role was taken by the key worker (key workers come from all professions).

"I'd like to think it"s a team effort...goal planning... the actual key worker leads that team. Some decisions get made for you and some doctors think they are team leaders. I think we"ve moved on. Whether they have is a different matter." (OT)

There appears to be a difference between the professionals with regard to leadership in that doctors perceive themselves to be the leaders of the team. However, other professionals and some patients see the leadership role as much more flexible depending on the decision being made at the time.

6.5.4. The patient is the team leader

Some patients did see themselves as having that role:

"I don't know probably the conductor of the team almost as long as I make myself." (Basil, newly injured patient with tetraplegia)

Some professionals also saw the patient as the leader of the team:

"I think the patient's in charge of rehabilitation and I feel that's what it should be"" (AHP)

Partnership has been described as a co-operation or an alliance where people work together in mutual respect. If the patient is a partner, a co-worker and a team-mate, for the health professional this means giving up control (Enehaug 2000). It could be argued that true partnership means that patients take on the team leadership role. My research appears to highlight a contradiction in that patient participation in team decision-making processes is seen to be desirable but on the other hand rarely happens as part of an equal partnership. However, under current legal and ethical principles beneficence is no longer adequate; respect for autonomy is seen as vital and this requires patient participation (Deber 1994a). Research undertaken across the Western world suggests that patients want to be given as much information about

their condition as possible to enable them to express informed preferences about their care (Deber 1994a, Adams et al 20001,Snowden et al 2001).

My research does not concur with that of others that suggests that many patients, while seeking information do not want to be involved in decision-making. However, researchers have found that younger patients are more likely to want to be involved in decisions (Robinson and Thomson 2001). As spinal cord injury tends to happen to people in a younger age group these findings are not surprising.

6.6. Conclusion

There is some evidence that well-informed patients who actively participate in decisions about treatment have a more favourable health outcome (Cooper et al 2002, Holmes-Rovner and Rovner 2000). Giving patients more information has been associated with greater patient satisfaction. Yet there are a number of reasons why participation in decision-making does not happen; professionals may think that sharing information may encourage patients to make more demands thus increasing their workload. Some are afraid that knowledgeable patients might be in a better position to criticise their performance. There may also be a mismatch between what information professionals deem to be important and what patients think. Time constraints have also been identified as a barrier to implementing measures to improve patient participation (Snowden et al 2001). There is also the problem that there are few incentives to encourage professionals to actively involve patients and no sanctions for failing to do so (Ovretveit 1997). Ovretveit also suggests that increased power for patients affects how professionals work together and depends on how closely practitioners work together. Increasing patient power may impact on team members' relationships. Patients in spinal cord injury rehabilitation are becoming more aware of the power they could have in the rehabilitation process but there are restraints on their ability to exercise that power.

In the next chapter the implications of the findings of this study will be discussed. Suggestions for improving practice will be made

CHAPTER 7- CONCLUSION

CONCLUSION

Clients and carers must be major partners, at the centre of care and needs assessment. (Long et al 2001)

This study has attempted to fill a gap in knowledge about team relationships and partnerships in spinal cord injury care in the context of a British health care setting. There has been very little research in the UK that has examined the issue of patient participation and partnership in spinal cord injury rehabilitation from both the patient and professional perspective. The study utilised a qualitative design with ethnographic techniques to collect data. Male and female patients and health care professionals participated. The research was conducted in one spinal cord injury centre, with a catchment area that enabled access to a wide range of participants. Using a qualitative approach allowed the phenomena being researched to be viewed in the context in which they occurred. I was able to understand the issues under study from the participants' perspective and within their natural environment.

7.1. Contribution to theory

This research has used an inductive approach in that I have sought to generate theoretical propositions from the data. The research can contribute to the work that has already been carried out on patient participation in decision-making by placing it in a spinal cord injury rehabilitation context. It has been suggested that the ability to explain and understand the findings of research within a conceptual framework, which makes 'sense' of the data, is the mark of a mature discipline (May 1997). As a social researcher the phenomena were the dynamics, content and context of social relations. I aimed with my experiences and perspectives in mind to understand the social world. This required the development and application of social theory. Classic nursing theory has been accused of dividing people up into component parts and social science theory of determining where people are rather than where they are going (Purkis

2003). This research however, contributes both to social theory and to nursing theory by offering a dynamic conceptualisation of how and why the members of a culture think and behave as they do.

This research provides new insights into the impact of power and power relationships on the lived experience of patients and professionals in their interactions with regard to patient participation in decision-making processes.

It has identified that rehabilitation is perceived as both a process and an outcome by patients and professionals. Previous work has suggested rehabilitation is either a process or an outcome with structure implicit in the definitions. The concept of rehabilitation as a structure was not identified by the participants of this study. The definitions articulated by participants are not seen to be mutually exclusive, rather they are complementary and patients may move backwards and forwards as they progress through their disability career. This is a finding that can enhance the understanding of the disability career concept.

7.2. Implications of this research for professional practice

If research-based practice is to become a reality then research must become embedded within the culture of health care practitioners. Researchers have been accused of not representing the practitioners' world (Mulhall 1997). Practitioners need answers to questions that arise when they care for clients. This work contributes to the qualitative knowledge about spinal cord injury rehabilitation. There is already a growing body of research within the quantitative paradigm but this research has identified aspects of the patient and professional experience that cannot be quantified. The research has enabled participants to tell their story and describe their experiences. Latimer (2003) suggests that a field researchers capacity to represent or evoke a field depends on their methodology. Further, the epistemological and ontological assumptions drawn on when interpreting the data will influence the contribution made to nursing knowledge. Consequently it has to be recognised that different approaches to methodology will yield different understandings of the field. There are ways in which with more time and resources this study could have been strengthened. For example a longitudinal

study, following more patients through their rehabilitation careers, with several interviews over a prolonged period of time would have enabled greater identification of the moving back and forth between the different definitions of rehabilitation.

However, this study has raised a number of issues and revealed some tensions around patient participation in the decision-making process. These have important implications for professional practice:

7.3. Linking the research to theory and professional practice

Research plays an important role in theory building. Theory plays a vital role in expanding knowledge, which informs professional practice (Polit and Hungler 1991). The following discussion will draw together conclusions that link my research both to theory and professional practice.
The research addressed the following aims:

7.3.1. Identify differences between patient and professional definitions of rehabilitation.

Rehabilitation medicine has been described as being as much a concept or philosophy as an exact science and this is why it has been difficult to describe and various definitions have emerged over time (Marks 1997). The definitions that are available have tended to define rehabilitation as either a process or an outcome. However, in this study the definitions of rehabilitation articulated by participants formed a model of rehabilitation. This model suggests that participants perceived rehabilitation as both a process and an outcome. This is a finding that has not necessarily been recognised by other research, particularly in the field of spinal cord injury. The model encompasses three definitions:

- The 'toolbox' definition was one of providing the physical and psychosocial skills that enable patients to deal with a range of problems both now and in the future. The 'toolbox' could be added to as the person progressed through their disability career.
- 'Picking up ones life again' was about getting back to the real world and picking up their lives where they left off.

- In the empowerment definition participants perceived that rehabilitation was about being in control and being able to make decisions.

However, although three clear themes have emerged in the model of rehabilitation they are neither hierarchical nor mutually exclusive in that the process of learning and developing skills enables people to pick up their lives again which in turn allows control and autonomy or vice versa. It could be argued that empowering practice in the process of rehabilitation by professionals is more likely to enable patients to develop skills in problem solving by using those skills flexibly. If health professionals use a paternalistic, rigid approach to rehabilitation then it may be the case that patients find it difficult to adapt to changing situations such as the ageing process as they are unaccustomed to making decisions for themselves.

The model is not necessarily a continuum in that patients may move backwards and forwards throughout their lives. As patients' lives change they may need new skills in their 'toolbox.' They may need to relearn old skills to continue to lead their lives autonomously. For some participants rehabilitation was something that ended when patients were able to pick up their lives again and make their own decisions. For others rehabilitation was ongoing in the form of physical skills or as a lifelong support mechanism. Oliver et al (1988) have described an 'accident to grave' spinal injuries service but not everyone with a spinal cord injury is admitted to a specialist unit and many of those who do may never return after discharge. There was little difference between professionals and patients in their perception of rehabilitation and this may have been influenced by their recognition that even in the twenty-first century life is not easy for disabled people in the community. While patients are in hospital they need to be equipped with as many skills as possible because they may not be able to return to learn new skills or develop old ones.

7.3.2.Patient and professional constructions of patient participation –levels of patient participation

There is very little work available in the UK on the patient's role in the rehabilitation process after spinal cord injury. In this research both professionals and patients articulated that the patient's role was to take control of rehabilitation and to do that patients recognised that there was 'no gain without pain' as rehabilitation is hard

work. Cooperation with professionals was identified by participants as being important for successful rehabilitation, however this appeared to take place on a hierarchy of levels:

- Open paternalism, where the patient has no input at all
- 'They tell me what they are doing', where the patient is told what is happening but has limited input
- They can always say no, which can open up issues of non-compliance
- Making the 'right choice,' being guided or steered into the professionals choice
- Active participation based on a partnership approach.

Paterson (2001) has identified a type of paternalism where professionals think that patients are making the decisions. In my study both patients and professionals seemed to think that patients were making the decisions without noticing that all might not be quite as it appeared. This study appears to highlight a paradox in that patient participation in team processes is seen to be desirable by both patients and professionals but does not occur in the context of a relationship that could be considered an equal partnership where both parties have the same rights and status. In acute spinal injury care professionals have more experience and knowledge of rehabilitation and true equality may be difficult to achieve. However, even when patients had many years of experience of living with a spinal cord injury and could be considered as expert patients there was limited evidence of equal input from professionals and patients into the decision-making process. It could be argued that the pressure for change with regard to patient participation that is coming from government and patients requires health care professionals to carefully consider how they are addressing those pressures.

7.3.3. Perceptions of patients and professionals of their roles and relationships within the team

It has been suggested that changes in the balance of power between patients and practitioners may have affected the way in which practitioners relate to each other (Ovretveit 1997). In this study the professional team members identified that a multidisciplinary approach was the most appropriate way of organising rehabilitation and for most of them was a positive experience. Yet there appeared to be a number of

underlying tensions related to team membership. Some team members' felt that they were not valued by their colleagues and experienced conflict in their relationships with other team members. There was lack of congruence in that professionals felt that they knew what their colleagues in other professions did but that this understanding was not reciprocated and their colleagues had little comprehension of their roles. The concept of 'Othering' (Canales 2000) may describe how the professionals were engaging with other professionals who they perceive to be different from them.

Although generally, despite these tensions, team members seemed to be able to present a united front to patients, it could be argued that the implications of 'Othering' may spill over from professional relationships into the professional/patient relationship, with patients being perceived as 'incompetent others' or 'invisible others' (Davies 2002b). This could reinforce the unequal power relationship between professional and patient leading to domination and subordination of patients by professionals.

Most participants felt that patients were members of the team, although who led the team was a contested issue. Some patients pointed out that if they were not there the team would have no purpose. Medical dominance of the team was an issue for many of the participants. Doctors however identified that although they had the responsibility for team decisions, they had gaps in their knowledge and were not as powerful as they felt they were perceived to be.

Both doctors and nurses appeared to have difficulties with crossing an acute/rehabilitation divide, nurses in particular recognised that their education and training was more acute orientated. This may have implications for the rehabilitation process in that acute care is concerned with doing things for patients, as they are ill and often in life threatening situations. In a rehabilitation context patients are not ill, they are disabled and the philosophy is one of supporting patients to do things for themselves. This may entail physically doing things or if they are not able, having the knowledge and skills to direct others to do things for them. Professionals with an acute care orientation may be tempted to take over and do for patients and find it difficult to step back, let patients make decisions and solve their own problems.

7.3.4. Supports and constraints to patient membership of the team

When a patient is admitted to the spinal cord injuries unit they are entering an environment of unequal power relationships between patients and professionals and between groups of professionals. These power relationships have an impact on the rehabilitation that patients receive. Generally patients were very positive about the quality of the care and rehabilitation they received and most were determined to utilise the facilities offered by the Unit so that they could achieve their goals. Several patients expressed the relief they felt when they were admitted from a general hospital to the specialist unit where it was apparent that the staff had the expertise to treat their injury and provide rehabilitation. It is clear that rehabilitation can mean different things to different people. In an earlier study of ex-patients of the Unit the rehabilitation programme was seen to be too physicalist and inflexible (Oliver et al 1988). This has clearly changed in that patients and professionals articulated the concept of goal setting and of a rehabilitation programme geared to patients' goals. Despite this for some patients in my study there still appeared to be issues surrounding the extent to which they were actually involved in decision-making processes, which ranged from no participation to full participation.

A spinal injuries unit is a small closely-knit community, whereas for most other specialities patients are in hospital for increasingly shorter lengths of time a spinal cord injured patient's stay in hospital will be several months. It is possible that because of this patients undergo a similar socialisation process to students or new members of staff. This could explain why in several areas of this research there was congruence between patients' and professionals' responses'. Relationships between staff and patients are therefore likely to be much more intense. This has both costs and benefits to patients. They are able to build up a rapport with their consultant, named nurse, key worker, physiotherapist, occupational therapist, clinical psychologist and discharge planning coordinator. The intensity of the relationship can be a source of power imbalance to patients, a particular issue with nurses who are with patients 24-hours-a-day, 7-days-a-week. Professionals may use that power in ways that disempower patients and prevents them from being equal partners in the professional/patient relationship. By the same token the working relationship between professionals is equally intense and can lead to conflict and misunderstanding about the nature of each other's contribution to the patient's rehabilitation. This can have

repercussions on the patient who may be at the centre of power relationships between professionals. Professionals therefore need to be aware of how their relationships with other professionals may impact on the quality of the rehabilitation experienced by patients.

7.4. Reflexivitye- Where am I now?

Throughout this study I have attempted to undertake on going self-critique and self-appraisal to increase the rigour of this ethnographic research. Therefore I have included a reflexive account in this thesis of the conduct of the research. This will enable readers of the thesis to decide whether the text is believable (Koch and Harrington 1998). My own philosophy and values and context of the research may have affected the chosen methodology and ultimately the interpretation of the findings. Williams (1995) suggests that self is not necessarily analogous with ethnographer and in my case self also meant self as a woman and as a health care professional by which I shared aspects of the experiences of the people in the field. The text has incorporated many voices i.e. voices other than the 'lone introspective researcher' (Koch and Harrington 1998) thus demonstrating the co-constitution in the making of the text between researcher and participants. The research gave participants an opportunity to tell their story and the reaction, particularly from patients was very positive about this with some actually thanking me for listening.

Researching in ones own culture can cause tensions between strangeness and over-identification and I have to acknowledge that I cannot stand back from my knowledge and experience. I have similar perspectives to the host culture and was likely to face analytic problems. This thesis has been written in a way that encourages the reader to challenge, dispute and reconstruct and by doing so will complete the reflexive cycle (Freshwater and Rolfe 2000). Perhaps the most important issue related to the rigour of this research is that it is a step towards bridging the academic/practice gap by making my research transparent to reveal the workings of my world.

I came to this study from an assumed position of 'knowing'. I am an ex-member of the multidisciplinary team in spinal cord injury and a member of the nursing profession. These biographical characteristics helped me to gain acceptance in the field, both by the health care professionals and the patients and influenced my choice of research field. Having considerable experience of spinal cord injury nursing helped me to understand what I was hearing and observing. However, that experience inevitably influenced my interpretation of the team's practice. My background will therefore, have affected why the research was carried out and the role I assumed in the data collection.

I had to confront the tensions between being a nurse and a researcher. This encompassed the possible conflict between objectively collecting data but at the same time being accountable for my practice. The Nursing and Midwifery Code of Conduct (2002) points out that I have a duty of care to my patients and clients to provide safe and competent care. On the one occasion when conflict did occur when I assisted a patient who had been told by another nurse that she should manage unaided my nursing accountability took precedent. As the Code states:

> When facing professional dilemmas, your first consideration in all activities must be the interests and safety of patients and clients.

As I was making explicit use of my professional background to as a medium to facilitate data collection I was professionally accountable for both my nursing as well as my research conduct. My nursing expertise was used effectively throughout the fieldwork. Coffey (1999) describes the experience of fieldwork as a personal journey of self- discovery and I was surprised at the strength of emotions that I felt when listening to patients. As a researcher this was the first time I had the opportunity to confront what patients are feeling and to experience those feelings myself.

I began the research with biases and pre-conceived notions about how people behave and what they think. To mitigate the negative effect of bias I have attempted to make biases explicit and have an open mind. As a lecturer who is also a practitioner in spinal cord injury I have recognised my own preconceptions. However some of my findings have surprised me and caused me to look into areas I had not thought of prior

to data collection. For example, as I analysed the data they revealed the amount of power that nurses have over the day-to-day lives of patients. This finding led me to examine my own practice and reflect on whether when I was a ward sister I had been aware of the power I had. This new insight is influencing my teaching role as I encourage students to think about power relationships between nurses and patients.

I have also found that I have identified with nurses in the study for example in their interactions with other health care professionals. I could remember being in similar situations myself in the past. However, I found that my own experience of similar situations both informed and provided further questions for the research.

Reflexivity has been identified as having relevance to research focussing on disability. Critical reflection on personal and professional values, and professional and research practice, requires that nurse researchers examine their understanding of disability. They should recognise that they may be viewed as part of a system that oppresses disabled people and question whose interests are being served by the research (Northway 2000). It has been suggested that as far as many disabled people are concerned, most disability research is a waste of time (Moore et al 1998), and that good disability research requires critical reflection and commitment to making human rights explicit. Although it is not necessary to have an impairment to produce good quality research (Barnes 1992) I have to face the fact that I am an able-bodied health care practitioner and as such could be criticised. In reality I found that I established a rapport with participants who have been open and honest and do not seem to have been inhibited by the fact that I am a nurse. There is a considerable lack of spinal cord injury rehabilitation nursing research and this inhibits research-based practice. There is a need for quality research (Thorn 1999) and this study will add to the knowledge base of spinal cord injury rehabilitation and contribute to improved practice.

It has been suggested that transition to a more subjective, reflexive approach to nursing research may be painful (Schutz 1994). At the same time it brings benefits in that the researcher becomes a partner with the informants and I have been able to use my own experiences and reflections to uncover valuable meaning. Examining the issues that have arisen from this research in relation to my own experience as a nurse has at times been uncomfortable. However, the boundaries between reflexivity and

self-indulgence are fragile (Coffey 1999), and as a researcher one has to balance self-absorption with recognition of the intensely personal nature of the research and the potential benefits of utilising subjectivity. In this study, subjectivity was objectified by recreating the experiences of others, thus creating new meaning (Schutz 1994). In this way I was able to avoid self-indulgent 'navel-gazing' and therefore understand more clearly the deeper meanings of the phenomenon being studied (Carolan 2003).

7.5. Future initiative in response to the findings of this research

The findings from this study suggest that there is a need for practitioners to examine their own practice, to ascertain if they are working in an empowering way. This will involve careful examination of values and beliefs and may be painful for the professionals. Certainly while undertaking this research I have been forced to confront my own practice, it has made me much more aware of how I deal with patients and how I may exercise my power as a nurse in a way that could disempower patients. Professionals also need to develop an awareness of the power relationships internally between themselves as a team. Professionals rarely have the opportunity to meet and communicate in situations that are not patient focussed. Although professionals are often stretched because of staff shortages and pressure of work it may be useful to provide self-awareness workshops and team-building sessions where misconceptions and misunderstandings can be discussed openly in the presence of an experienced and impartial facilitator. This would provide the opportunity for professionals to agree on a common goal, related objectives and the appropriate distribution of tasks. Unless professionals feel confident that they are experts in their own field and are regarded as such by their peers they are unlikely to be willing to negotiate the distribution of tasks within the team (Engel 1994). My research has identified tension between professionals on this issue. A forum where these feelings could be aired and resolved could help with interprofessional relationships. A team that is truly working together collaboratively should provide more cohesive and supportive care for patients. Patients require a more equal relationship with health care professionals. It could be argued that a professional team that supports mutual respect and equality for each other is more likely to provide a climate for patient participation in equal partnership. The research reported in this thesis has identified that patient participation in decision-

making in spinal cord injury rehabilitation is limited. These findings therefore identify an issue that needs to be responded to and a problem that needs to be solved.

7.5.1. Further research

To address this problem there is scope for research in the form of an action research study. Action research uses spiralling reflective cycles to identify a problem in practice and implement a research based change. Action research requires co-operation and collaboration (Cerinus 1999). Brooks and Gillam (2001) identified that there was a need for more research on professional and user relationships. This research has provided insights into that relationship. It could be argued therefore that the first phase of an action research cycle has been addressed by this research in that the problem has been identified. The research could be taken forward by the development of action groups comprising patients and practitioners who could jointly identify ways of improving patient participation in the decision-making process. This would lead to the implementation of a change in practice. Patients and professionals would then be able to evaluate the outcome of this change. The action research cycle might then need to be repeated as patients and professionals work towards a model of patient participation that is acceptable to all team members.

Finally, this thesis suggests that the impact of power and paternalism can have a considerable impact on the experience that patients have during their rehabilitation. When the patient-professional relationship is supportive and empowering, it can be a positive experience. One patient remembered when he was first admitted many years ago:

"You felt as though you"d suddenly become part of another family. Staff and the other patients were part of that family and everybody helped each other."

Where the relationship does not nurture partnership and equality it can have a negative effect on the rehabilitation experience for patients. They need the expertise of the staff on the unit but may be aware that the ultimate sanction for rebelling or disagreeing with professionals may be the loss of that expertise, as another patient said:

"You've got to do what they say, you don't get the final decision even as far as going home. If you've had enough you can't just up and go because you don't know if they'll take you back again."

By exploring the experiences of patients and professionals this research has provided valuable insights into current practice to enable values and preconceptions to be questioned. It has gone some way towards highlighting issues for professionals to consider when caring for patients with spinal cord injury. Spinal cord injury rehabilitation is designed to prepare individuals to live in the community where they will need to make decisions about their health and welfare on a regular basis. If professionals take a paternalistic approach to rehabilitation, patients may not be able to develop the problem-solving, decision-making skills they will need in the community.

APPENDICES

APPENDIX 1A.

UNIVERSITY OF LUTON

Faculty of Health Care and Social Studies

DEAN and Pro-Vice Chancellor : Professor Kate Robinson

[redacted]
Education Centr
[redacted]

Telephone:
01296 315554

Facsimile:
01296 315567

formerly
[redacted]
College of Nursing
and Midwifery

Dear

I am a nurse lecturer who teaches both student nurses and qualified nurses about spinal injury nursing. I am carrying out a research project to investigate how patients and health care staff define rehabilitation and the roles that both patients and staff play in the rehabilitation process.

I feel that it is important to discover the views of patients about their experiences of rehabilitation, as a result I would like to talk to you about your views and experiences of rehabilitation.

. The discussion will take about an hour and if agreeable to you will be recorded on a tape recorder. The tape will only be accessible to my examiners and me. Your name will not be used on any written transcripts of the interview or on any written report. During the project tapes will be secured in a locked drawer and they will be erased when the project is complete.

You may withdraw from the study at any time if you wish and the recording of your conversation will be erased.

Participation, non participation or withdrawal from the study will not affect your treatment in any way.

If you have any questions and would like to speak to me further I can be contacted on extension 5480. Alternatively my supervisor Dr. Fiona Brooks can be contacted on 01580 743773.

Yours sincerely

Glynis Pellatt (Mrs)

APPENDIX 1B

Faculty of Healthcare and Social Studies

SENIOR PRO-VICE CHANCELLOR and DEAN of FACULTY
Professor Kate Robinson

Education Centre
[redacted] Hospital
[redacted]
England

Telephone:
01296 315554

Facsimile:
01296 315567

Email:
jackie.coates-@luton.ac.uk

23rd March 2000

Dear Colleague

I am undertaking a research study on professional and patient perceptions of rehabilitation and their role in the spinal cord injury rehabilitation process.

I would like to talk to you about your perception of rehabilitation and your views about the rehabilitation process. The discussion would take about 40-45 minutes.

I realise that you are very busy but I would be very grateful if you would be willing to participate. The discussion will be taped, tapes will only be accessed by my examiners and myself. You can be assured of confidentiality and no names will be used in the final report.

If you would like any further information please contact me on extension 5480 or 5363 where a message can be left.

If you would be willing to participate in the study would you be kind enough to complete the form below and return to me in the envelope provided by 3rd April 2000.

Yours Sincerely

Glynis Pellatt (Senior Lecturer)

.....

I am willing to participate in your research study

Name.....e.....e..... Job Title.....e.....

Signature.....e..... Contact Phone number.....e.e.....

Appendix 1c

I……..
Of…..”……”……”……..
……..

Hereby fully and freely consent to participate in a study entitled:

A qualitative study into patient participation in decision-making in spinal cord injury rehabilitation.

I have read and understood the above information.

I understand that I may withdraw my consent at any stage in the study and that the nature and purpose of the study has been explained to me by Mrs Glynis Pellatt and I have discussed matters with her.

Signed……..
Name in capitals……
Witness to verbal consent
Signature of witness……”……
Name……”……”……

Date……”…….

Declaration by the researcher
I confirm that I have explained the nature and effect of the study to the patient and that his/her consent has been freely and voluntarily given.

Signed……”…..”…….

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